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Select Committee on Developmental Services

Developmental services strategy

Chair: Laura Albanese
Clerk: Trevor Day

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aux personnes ayant
une déficience intellectuelle

Présidente : Laura Albanese
Greffier : Trevor Day

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ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

SELECT COMMITTEE ON DEVELOPMENTAL SERVICES

COMITÉ SPÉCIAL SUR LES SERVICES AUX PERSONNES AYANT UNE DÉFICIENCE INTELLECTUELLE

Monday 20 January 2014

Lundi 20 janvier 2014

The committee met at 0902 in committee room 1.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Good morning. I call the Select Committee on Developmental Services to order. We are back in Toronto after a week of travel across Ontario, and we're back to the urban setting with the congestion, getting started a couple of minutes late.

DEVELOPING AND NURTURING INDEPENDENCE

The Chair (Mrs. Laura Albanese): In any case, we want to call up our first presenter this morning from Developing and Nurturing Independence, DANI for short. Please come forward and take a seat. You will have up to 20 minutes for your presentation. If time permits and it should be less than that, that will allow for questions and comments on behalf of the members of the committee. Please start by stating your name and title, and you may begin at any time.

Mr. Rudy Barell: My name is Rudy Barell. I'm part of the junior board at DANI.

Ms. Kathy Laszlo: Hi. My name is Kathy Laszlo. I'm the founder and co-director of DANI.

The Chair (Mrs. Laura Albanese): Welcome.

Mr. Rudy Barell: Thank you. First of all, we'd like to say a quick thank you for allowing us to present. We understand the time constraints, as you mentioned, so in an effort to be brief, what we will do is provide a general overview of what DANI does and then hopefully accept some questions from you. For a more in-depth understanding of us, we've provided a little briefing. As well, we're making ourselves available to you guys should you feel the need to get more information from us on a personal or one-on-one kind of individual basis.

You'll excuse me; just in order to get all my points to you in the brevity of the presentation, I'm going to be checking my notes occasionally.

DANI was created with an understanding of the current fiscal constraints facing the province of Ontario and the need for the province to create a sustainable option for this sector—i.e. individuals with developmental disabilities and/or cognitive disabilities, as well as physical challenges. Our goal today is to present what we feel are some suggestions for a sustainable option. It's a model that we're currently using, and it's successful.

Essentially, the way DANI runs is that we train and employ individuals with developmental and/or physical disabilities towards long-term employment within a social enterprise setting. Our individuals are constantly being trained within viable businesses where the businesses are actually earning. They're being trained, the businesses are earning, and then that money gets funnelled right back into the program.

The model is based on something that exists in South Africa, which was researched and visited by Kathy. Kathy took that model and brought it here. That model has actually been in existence for almost 20 years. It's very successful and it continues to grow.

Basically, our long-term goal is to become fully sustainable. Currently, we get a lot of support from donations while the social enterprise dollars continue to increase as the businesses grow. We have received some funding from government for capital costs and renovations on the municipal level, as well as on the provincial level from Trillium—which is a nice thank you we'd like to say, anyway.

The short-term goal is to continue to expand the social enterprise arm of the organization. For that, I'm going to let Kathy go into a little bit more detail on that.

Ms. Kathy Laszlo: There are many unique sides of this organization, and some of them Rudy pointed out: that we are looking to sustain ourselves in the long run. You will see it in our write-up. There are six arms for that social enterprise, as we speak; currently, three of them are working. We are putting them in place in a levelled way, not just because as a business you have to be careful how you plan your business, but also because we have to make sure that the young adults are trained and able to functionally work in these places.

Our goal is not that we put them in just for the sake of being in, but that they are absolutely part of the whole business. We train them in soft skills as well as vocational skills, and then they are part of the whole organization.

The most successful arm right now is our catering arm. We actually just, in the last three days, hosted 600 people in our facility over three functions. Thank God we also made some money, as well as gave the opportunity for these young adults to show what they can do.

The other uniqueness of the organization is that it's community-based. We have many, many volunteers helping us out, which helps to lower the payroll; we don't have that many paid employees. The community comes in, and they support us by taking part and ordering from us. As well, they help us to run the whole organization, so it's a win-win situation on many levels.

We involve different groups: senior groups, who are also somewhat in need of a bit of help, and they come and they help us out. In return, they have a place to be when they feel very much needed. We work with schools and university groups, so it's really a very nice community organization.

We're looking at this as a pilot project that we have brought back from South Africa. We are also documenting everything, because we really believe that it can be used all over the city, Ontario and even Canada. The model is really working. We already see returns financially, which we can turn back into our organizational budget. In the long run, that can be even more successful as the business will grow.

The other arm to the social enterprise is an open-to-the-public retail store. We are located in a community centre; we are very lucky that, inside the community centre, there is a concession store, which we also manage. That gives an opportunity to different groups of young adults who are able to interact with the clientele. Through that interaction, in the long run, they are able to take outside, open-market jobs. We successfully have three individuals right now, as we speak, who are paid and employed in the open market. By the way, the social enterprise also pays the young adults who work there, because we believe that if they do the day's work, they should be compensated. We also teach them budgeting skills; it's very difficult to teach budgeting skills if you don't own any money, so it's a very important part of the organization.

The third arm working right now is a gift store. Again, it's a different group of young adults who are able to package some of the big goods going into gifts, and then they are also helping us with marketing. We have some kids who are very good on the computer, so they make up flyers. They're really part of the whole business, not just the manual work.

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It is extremely successful on many levels, but there are limitations. The major limitation is in terms of the speed of how we can put in the additional arms of the social enterprise. Especially the limitation is how many young adults we are able to train in any given minute.

I'm sure you can appreciate that even the highest-functioning person with difficulties needs bigger support if you want to train them in a new area, especially vocational training. Therefore, the ratio has to be really high. Job coaches have to be higher. Social workers are needed. We take on young adults who have mental health issues. Social work is a very, very big component.

There is a financial limitation on what we can do and how fast we can enrol these young adults. We researched that there are many, many more out there who would benefit from being part of DANI. It's a struggle. We'd like to see how the system would work if we would be able to grow a bit faster. Regardless, we are growing, thank God. We've existed for seven years, so I think we've done really great growth in these seven years.

We are serving about 100 families in different ways, not all of them part of the social enterprise. Some of them are younger, and they come from high schools. They stay with us in the transition years. It has proven that those adults who were with us through high school transition into our day program much easier because they are already known to us and they feel much more comfortable. So we also work on the transition part, as well as providing them with co-op placements in our social enterprise.

I can talk about this until tomorrow morning, but the time is limited. So I really would like, if you have any questions—and we brought some numbers here, so that probably needs a bit more studying, but I'm an accountant, so go for it, please.

The Chair (Mrs. Laura Albanese): We will start with Ms. Jones. It's roughly three minutes per party.

Ms. Sylvia Jones: Thanks so much for appearing before the committee. You sound like you are serving a lot of people in a relatively small area. I see, back on page 1, where you talk about your income and stuff—I'm curious as to: What was the trigger that allowed you to start up? You've tapped into a number of programs. You've been blessed with some Trillium money and, obviously, donations. Is the rent being covered in the community centre by the municipality? Are you charged rent?

Ms. Kathy Laszlo: We are charged a lower rent, but we do pay that.

Ms. Sylvia Jones: Who put the initial commitment in, or where did the initial funds come in, to get you started?

Ms. Kathy Laszlo: There is a user fee to every program we run. The parents pay. Every single person is subsidized. We don't have the traditional subsidy format. Everybody is subsidized. Currently, about 33% of the budget is covered by user fees from the parents; 77% has to be somehow brought in. As we speak, right now, it's all brought in through fundraising and some of the money coming from the social enterprise already. The catering arm is already making a profit.

Ms. Sylvia Jones: In year one, it looks like there was seed money of $250,000.

Ms. Kathy Laszlo: No. The yellow highlighted item is really what we would need to have the growth of the social enterprise really working, the seed money we're actually looking for.

Mr. Rudy Barell: I think the concept here is that, as we were saying, we're growing slowly, but—

Ms. Sylvia Jones: Oh, so the seed money is your ask.

Mr. Rudy Barell: This budget was made for an ask, yes. But the concept here—we're not coming here to ask for anything. We're showing what could happen with seed money, i.e., we know that the government is looking to make intelligent investment in—you guys are already spending tons of money. So rather than spending it on—I refer to it as a black hole, and I apologize, because the truth is, more and more people are being identified as with needs, and that just means more money that needs to be spent. This way, we're seeing—

Ms. Sylvia Jones: Well, actually, right now, it just means more waiting lists.

Mr. Rudy Barell: Sure.

Ms. Kathy Laszlo: Exactly.

Mr. Rudy Barell: So either it's more money, or people aren't being serviced in the way that they need to be. Essentially what we're saying is that we're going to continue to grow at our incremental level, but in order to service more people, as you were saying, a smart investment—that's sort of what that shows.

Ms. Kathy Laszlo: What the yellow highlighted area shows is really a decrease of the need of money in the upcoming five years, because the social enterprise will replace this amount. Initially, any business you run needs a start-up, so when we call it "seed money," it's really a start-up cost to the business to run as it should, service as many young adults as it should, and start to make money so that in five years it can be phased out. We can call it government support; we called it seed money. Basically what we show here is that in five years, the government support can actually be lower and lower and lower and disappear, as opposed to today's traditional funding, where it's ongoing and needs to be increased to keep up with services. What we show here is a decrease.

Ms. Sylvia Jones: Thank you.

The Chair (Mrs. Laura Albanese): Thank you.

Ms. DiNovo.

Ms. Cheri DiNovo: Yes, thank you, and thank you for the presentation. It sounds amazing. Thank you for all the hard work that you've put into it, I'm sure with little recompense.

I had some of the same questions that Ms. Jones had, so now that you've explained some of the figures, what is the user fee that you charge parents per participant?

Ms. Kathy Laszlo: In dollar amounts?

Ms. Cheri DiNovo: Yes.

Ms. Kathy Laszlo: It's depending on how many days somebody is in the program and which stream they are taking. There are three different streams at DANI. One is the vocational stream, where we teach them the skills and then they eventually work inside internally. Then there is a stream which is called Bridges to Transition. These are young adults who are candidates for independent living. We can call them the highest-functioning ones. They are the ones who start to work in the open market. Then we have the life skills groups: those young adults who somewhat take part in the vocational training, but very limitedly because of either their needs or the family's needs. We do not refuse somebody just because they're not going to be the best-ever worker in the catering business. The fee is dependent on which stream somebody is in.

The highest fee a family would pay is $1,500 a month for full-time, five days a week. Keep in mind that we provide all food, from snacks to lunches to anything—to drinks or transportation, and all the training and anything needed—any device, any modification to any work environment.

Ms. Cheri DiNovo: And what is the lowest? What is the range then?

Ms. Kathy Laszlo: The lowest range would be the young adults who are fully working. They pay $20 per day—it's really for their upkeep—but they get paid by us, according to how much they work and which arm of the social enterprise they work in.

Ms. Cheri DiNovo: Right. So when I'm looking at schedule A, when you're looking ahead: If the seed money—the $252,000—doesn't come from government, you're planning on fundraising all of that?

Ms. Kathy Laszlo: We will fundraise some of that. We just had a very successful gala event yesterday honouring the mayor of Vaughan. We come up with ideas. But I also have to tell you: What happens is that the growth is going to be slower and we're going to take fewer kids than we could. We consider this as really a last option because right now we accommodate anybody who comes to us and we are able to support them.

You should also know that I'm a parent of a special needs child. My son was the first person at DANI. DANI is named after him; he is Dani. If I wear the hat of a parent—it's the most horrible thing ever when you find a program which you absolutely love and you know it's great for your kid and then they turn around and tell you, "I'm sorry; it's full." As a parent, nothing worse can happen to you. We tried to stay away from that. As long as we can support the young adults, we would like to take them, but unfortunately, there is a limit, financially speaking.

Ms. Cheri DiNovo: Thank you.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair. Thank you so much for your presentation. I'm just looking at the Bridges to Transition program. You also mentioned, Mr. Barell, that investments are required. What types of investments would you say would assist the social enterprise?

Mr. Rudy Barell: I'm going to let you handle that one, if you don't mind.

Ms. Kathy Laszlo: Right now, we're not really looking into capital dollars. We are very happy that Trillium helped us. In about a month, we're going to open our next social enterprise arm, which is going to be a year-around heated greenhouse. That's with the help of Trillium.

What we need is really operational dollars to be able to hire additional job coaches, and we desperately need a full-time social worker.

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Ms. Mitzie Hunter: In terms of the participants gaining employment out in the marketplace, can you talk about your experiences there and what you're seeing in terms of the uptake—

Ms. Kathy Laszlo: Absolutely.

Ms. Mitzie Hunter: —as well as the retention of those jobs?

Ms. Kathy Laszlo: We do have a very good relationship with businesses in our area. Two of the young adults work at Red Lobster. One of them working there started out as a co-op student from high school. When he ended up at DANI, we kept this workplace and they kept him on, so this is his third year there. I would say that's quite sustained. We added another young girl to that same workplace, and then there's another individual working in a different restaurant.

Sustainability: I tell you, I really believe it's sustainable as long as there is—there has to be support. Even down the road, if somebody can work fully, trained in any given way, there has to be a buffer zone. If you want to be successful, there has to be a buffer zone.

These individuals have their issues. It's never going to go away; it's never, ever going to go away. If we want them to be successful, we have to be there for them. If there is an issue coming—and let's face it, they work in the lower end of the spectrum, right? They usually have very, very start-up positions. The person who supervises them is also not a very high-up management position. They're usually not overly trained on how to deal with these individuals. There arises an issue when something is not done properly. The manager yells at the kid. The kid is not going to go back, because they don't understand that this is the boss and they have to do it. So we have to be there for them—and for the employers as well, to have sensitivity training, to teach them that these kids are fantastic but they might be a little bit different.

We have to be there to modify the work stations. We have kids working in packaging plants, where they package socks. We have my own son, who is visually impaired. He can work there, but he needs different lighting, so we had to make sure that we can provide that. The workplace was amazing; they never even let us pay for it. They put it in, and he's fantastically successful. It's the second year he's working there—amazing. It's not just the fact that he's really doing the job, but can you imagine, when he's coming home, how proud he is of himself that he went to work like his siblings? He is just like anybody else. The satisfaction is fantastic.

We have young adults who, until now, were sitting at home doing absolutely nothing, and they work in a restaurant. They come up to me and they say it's the first time ever that somebody looked up at them instead of down at them. Can you imagine? You can't put dollar figures on this; you really can't.

This boy is very high-functioning. He comes and goes on his own. He is TTC-trained. He's a fantastic guy. You just have to give him the opportunity to be there. Then he gets a tip, and it's like $2, and it's the world to him that he got $2 on his own. It's not like they paid him; it's that the customer was happy and they tell him how good he's doing. It's amazing. He wants to come back, and I put him only for four hours and he wants six hours. It's amazing, what happens there.

I really think that they have a rightful place. Yesterday, we had 300 people there, all walks of life, at that gala—all walks of life; different communities; all kinds of people. The tears in their eyes—we showed a video presentation about what the kids are doing. You can't really put a price tag on it. It's really successful, and this is something which is proven.

I don't believe, by the way, that government should just give the money year after year and year after year, regardless of what you're doing. We've seen, as a parent again—believe me, my son went through many, many places throughout his 27 years. You can't have a place where you get the government money every single year, regardless of what you do. I really don't believe in this.

I think that, including ourselves, we have to prove ourselves. It's not like we're asking for the money and you should never return to see what happened with the money. I want you to come. I want you to see that this money is working, because that's the only way you would see the value of supporting us in our next adventure. I'm a dreamer, right? I already have other ideas.

The Chair (Mrs. Laura Albanese): Thank you—

Ms. Kathy Laszlo: But if I want to come back to you, I have to prove that I can do it, that we can do it. It's a team, and I believe in this. We all have to show that we can actually do it, and what happens with every single dollar. Again, I'm an accountant, so every single dollar is accounted for, and it's very important.

I would love you to come and visit us, by the way.; you're very welcome. We make a very good cappuccino.

The Chair (Mrs. Laura Albanese): Thank you very much for the invitation.

Interjection: Send us your address.

Ms. Kathy Laszlo: It's right here. The address is on.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation this morning.

Ms. Kathy Laszlo: Thank you very much for your time.

The Chair (Mrs. Laura Albanese): We really appreciate learning more about DANI. Keep up the good work.

Ms. Kathy Laszlo: Thank you. Sorry if it maybe took too much time.

The Chair (Mrs. Laura Albanese): Thank you.

MS. LAURIE WATT

The Chair (Mrs. Laura Albanese): We'll now call on our next witness: Laurie Watt. Good morning to you.

Ms. Laurie Watt: Good morning, Madam Chair and members of the committee. My name is Laurie Watt. By profession, I'm a newspaper reporter. I'm here to share my daughter's story. This is my daughter Rachel.

The Chair (Mrs. Laura Albanese): Wonderful to meet her.

Ms. Laurie Watt: You won't be able to see her picture, but anyway, here she is. That's her high school graduation picture.

Anyway, by the time Rachel was two, she didn't speak—not a word. I went with Rachel to the Barrie Parents Club, a drop-in play program run by our local Community Living agency and a precursor to what's now our Ontario Early Years Centre. I hoped that through interacting with other children, Rachel might begin to speak. That winter morning on which I dared to venture out was pivotal. Rachel darted around the centre and didn't really interact with anyone or focus on play. But a staff member there said, "Bring her back. She belongs, just as much as anyone." Every day, I hear that staff member's voice.

I went home and began fighting for speech therapy. I made a call to the Royal Victoria Hospital's speech therapy department and begged for someone to call me. We had been on a waiting list for months. I asked for a recommendation for a book or a course to take, anything to help me help my daughter talk.

Someone called me back. She was Mary Riggin Springstead. Mary is a speech-language pathologist. She was instrumental in getting Rachel placed into the preschool system. Through the preschool system and into the elementary system, through the transition to high school and now the adult developmental services system, I've had the good fortune of encountering real stars like Mary—wise people who cared, who believed in Rachel and who fought for her. If it wasn't for these people, I don't know where Rachel would be today.

As I endeavoured to get Rachel the help and care she has needed throughout her life, I have found there are a series of cliffs off of which people fall. The preschool system is critical. Mary got us in. I worked with resource teachers in an integrated preschool to implement a speech therapy plan, and together we got Rachel talking by the time she was five.

We looked at her sensory issues and implemented an occupational therapy program to help her even more. The benefits Rachel received during these formative years were immense. It's my understanding that resources are tight in Simcoe county and there are waiting lists for infant development and resource teacher programs. Early intervention is key, as Rachel's brain shows that their brains are most malleable in those early years.

However, going from the preschool system to the school system—that's a cliff. Services and supports drop dramatically. At the time, Ontario didn't have the ABA program. It took us six and a half years to get her diagnosis. Had that program existed then, Rachel would have aged out. We were lucky to get her diagnosis at the Hospital for Sick Children.

Thanks to Patricia O'Connor, an integration resource teacher, I got Rachel settled in kindergarten and later into a specialized autism pilot program. Unfortunately, the Simcoe County District School Board deemed it too expensive and cancelled it after two years despite having $10 million in unspent special education reserves. The school board went on to discourage and scatter some of the best-trained teachers and support workers, like Pat O'Connor.

Keeping the school board focused on my daughter's needs was a battle for years. I had to keep a vigilant eye on her IEPs and how they were being implemented. But after I had another child and was unable to keep as keen an eye on the school, I soon suspected Rachel's seizure medications were being inappropriately administered. She was sleeping her school days away in her later elementary years, and I knew it was time to change school systems.

Then I met another star, Erin O'Brien, a special education resource teacher at St. Peter's Catholic high school in Barrie. Rachel calls Erin her best friend. St. Peter's took Rachel in and for six years Rachel thrived and developed. This was an incredible blessing for us, as Rachel's father and I had decided just a few years earlier to place Rachel into Daffodil House Children's Residence, a private group home just down the street from St. Peter's, in hopes that routine and treatment would build her skills and keep our toddler son safe—Rachel's seizures and sometimes violent behaviour were a threat to his safety. We did this with the help of individualized funding.

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While on a visit to St. Peter's with her Grade 8 EA, a passer-by called police to express concern about the way Rachel was being treated by her EA. Days later, just days before Rachel was leaving her elementary school, an officer called me to ask whether I'd like to lay charges. I opted not to, because I felt had to focus on the next phase of Rachel's life, the seven years in high school which would get her ready for the adult world.

I am grateful for these stars like Mary, Patricia and Erin. They kept Rachel out of real harm in the Simcoe County public education system that has made headlines around the world with its inappropriate use of rugby blocker shields in a specialized autism class—which is, by the way, where the board suggested that Rachel be placed.

The health care system is another story. Getting appropriate care for Rachel has been a struggle from the get-go. She has had complex seizures, sparked by her immunizations as a baby. According to SickKids, they played a major role in the development of her seizures and her autism.

Memories of Christmases past include being sent home from the Royal Victoria Regional Healthcare Centre because a one-to-one nurse couldn't be found and the hospital didn't want to accept the liability of admitting her. So, instead, I—her journalist mother, armed with needles and Ativan—would be the neurology nurse.

Hospitals never like admitting Rachel, because of her behaviours. She is difficult. Getting her autism diagnosis—which helped and sometimes harmed her—was a struggle too; as I mentioned, it took until she was six and a half.

Getting in on research at SickKids was our ticket to better care, but through the years, this has been stressful and expensive and was indeed a factor in killing my marriage, as time demands ate away at our finances and our relationship. But Rachel benefited, and that's all that really matters.

At our local hospital, Rachel had become "the girl who always seizures"—at least, that's what the emergency nurses called her. I remember a day in 2011 when Rachel broke her nose after falling face-first during a seizure onto a cold-air vent at the Daffodil home during a seizure. Rachel was just turning 18. I can still hear the emergency doctor saying, "For people like your daughter, it would be pointless to fix her nose. It'll heal eventually."

"People like my daughter"? An 18-year-old woman with her whole life ahead of her? An 18-year-old woman who has already encountered more than her fair share of barriers? I demanded to see a plastic surgeon, who said, "Oh, yes, I can fix that." Thankfully, she has a better nose now, because she had broken her nose during a severe head-banging phase when she was about five.

We discovered through that nose incident that oversight in the children's system isn't sufficient. A year later, the group home's licence was suspended, and I don't have details as to all the reasons why. The need to get Rachel moved out of that home was both good and bad. It made Rachel a priority at the DSO's regional table. It got her a placement at Camphill Communities in Angus, but it opened our eyes to the lack of quality and accountability in the adult system.

Within months of Rachel getting her placement at Camphill, her cellphone was taken away, the land line in her apartment was removed, and the agency began picking fights with school staff. One day the school called me at work to tell me they'd received a call that Rachel wouldn't be returning to school. When her father and I fought that, allegations of bullying by school staff emerged. Although details were scanty, it was an issue of control. Camphill's executive director told me to be grateful and to basically stop advocating for my daughter, whom I could not drop out to see nor whom I could call.

Rachel's ability to carry on conversations diminished dramatically. Her obsessive behaviours became more intense. Then, one day, I'm asked to talk to a psychiatrist about adding more drugs to Rachel's handful—literally a handful—of anticonvulsants and antipsychotics. I said no. I recommended that group home staff follow the OT and speech programs that had been so successful in the past.

More than a year and a half after being admitted to this agency's care, her father and I still don't have an individual support plan, and such a plan shouldn't have been too difficult to create, since we'd given Camphill several of Rachel's IEPs and occupational therapy reports. And, I might add, her father and I don't know what her days look like, what activities she's enjoying most or making the most progress in. That not only hampers our ability to have meaningful conversations with her; it prevents us from supporting or encouraging her on her ISP goals. At Camphill, parents are definitely not partners.

Meanwhile, the skills that many of us—Mary, Patricia and Erin—worked so hard to build are diminishing. My daughter's quality of life is diminishing. It feels like I'm losing Rachel to a cult. Not only that, Camphill has the right to remove Rachel from care should they deem her too much of a burden, with no recourse and no alternate placement, with only six months' notice. I am told I should be grateful.

What do we learn from all this? What wisdom can I offer you? What recommendations would I like to see in your report?

(1) Ontario's quality assurance standards—and they are wonderful; I've read them—aren't being respected or enforced in schools, hospitals and group homes. They need to be enforced, and compliance should be mandatory.

(2) Institutions that Ontario had the vision to close, such as the Huronia Regional Centre, never reopen, that the abuses in them are never repeated and that institutional segregation and treatment—which doesn't have to happen in a building; it can happen in other places—should never be allowed to take root and grow again.

(3) We have a developing developmental services system. Agency leaders and workers need clear direction in terms of the transition from the IEP to the ISP.

(4) For young adults with autism, like Rachel, ensure that they're engaged in meaningful work, work that embraces their interests and abilities, and not slotted into spots for the convenience of the organization.

(5) Insist that all ministries work together during and after transition of young people like Rachel from one level of education and care to another to create a seamless transition at a very challenging time.

(6) Develop a case management system that supports individuals and values family input.

(7) Create structured days for individuals like Rachel, days that include proven therapies and strategies and the teaching of independent living skills and activities that are meaningful, whether paid or volunteer. Enhanced investment is needed, not an additional red-tape process such as a DSO, which can keep families away from services, which, when they get them, can be limited.

Ontario has the idea and the ideals. Through years of volunteering with Simcoe Community Services, I've been to Community Living Ontario and even the national community living conferences, where I've seen people with special needs gain their voices. Our communities have become more accepting.

I'll leave you with a documentary made last fall—I gave it to your Clerk—that shows how some Barrie-area adults tell their stories. They show why the commitment to inclusion, rather than institutionalization, is worth it.

We need to find ways to ensure that Ontario's quality assurance standards are not only respected but enforced. Much more oversight is needed. Otherwise, it's just a matter of time—months, not years—when we will see the era of the institutions we have just closed re-opening. We must be diligent in ensuring that institutional thinking and treatment never be allowed to recur. That's not the way we live in Ontario, where everyone belongs and where we are better together.

Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you for your passionate presentation. About two minutes each. Miss Taylor?

Miss Monique Taylor: Thank you so much for being here with us today and for the efforts that you put into this presentation. It's appreciated.

I could be wrong, but I don't recall hearing at this table the request for quality assurance.

0940

Ms. Laurie Watt: You do have quality assurance standards; they just aren't respected.

Miss Monique Taylor: Like I said, I'm pretty sure that you're the first person who has brought it up, saying that we need further oversight on that because it's just not happening in the homes. That was a really good point that I'm happy you brought forward.

You mentioned transition and better transition. What was your experience when your daughter was transitioning out of high school?

Ms. Laurie Watt: It was rather rushed because of the group home licence—the children's licence suspension.

Rachel went to the DSO table, and she quickly got a placement; she was a high priority. But then, it seemed, they moved her in and they put her in the home and thought, "No, this really isn't where she belongs." They suspended her for two months.

My husband and I—well, he's my ex—basically managed her between our two places, with complex care funding. They moved her into a different home within Camphill Communities. They said, basically, that her anxiety was too much. They took away her cellphone; they took away her land line. They restricted our visits. They said that visiting her family was too stressful. We basically lost touch with her.

Miss Monique Taylor: So it was a decline, once you put her into that home.

Ms. Laurie Watt: It was a dramatic decline, and the decline continues.

Miss Monique Taylor: Have you filed any complaints or anything—

Ms. Laurie Watt: I've spoken to the Ombudsman. The Ombudsman is preparing a report on services for people with autism. I'm hoping that they'll be able to use some of my feedback.

The Ombudsman has suggested that I speak directly to my regional office of the Ministry of Community and Social Services, but I hesitate in doing that because I'm really afraid that Camphill will pull out the six-month clause, and then where will Rachel be?

Miss Monique Taylor: So you're afraid to make—

The Chair (Mrs. Laura Albanese): This is the last question. Sorry.

Miss Monique Taylor: I'm really sorry to hear that.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Hunter.

Ms. Mitzie Hunter: Ms. Watt, thank you for being here today and sharing your story as well as Rachel's story over these many years. It clearly highlights the need for better transition, and also coordination amongst ministry areas. It's something that we have heard, during the course of our listening, right across the province. We are definitely receiving that information and taking it into consideration as we prepare our recommendations to improve the system and to strengthen the system. It's meant to be across a lifetime for people with developmental disabilities.

I do want to assure you, because you raised it a couple of times in your presentation, regarding the past and the institutional era, that that is behind us. I know that our Premier has stood in this House and offered an apology on behalf of the government, and all party leaders did the same.

Our focus moving forward is on inclusion and better integration within communities. That's something you also refer to here in terms of: Are communities becoming more accepting? That's something that we believe as well, and want to see that happen. There are some good examples that are happening, but we need to see more of that.

I don't know if you have any further recommendations along those lines in terms of improving inclusion.

Ms. Laurie Watt: Institutional thinking doesn't just happen in buildings; it can happen within organizations. Camphill does receive government funding, and therefore it is a placement that is given out at the DSO table. But clearly, it is an institution, and I think that there desperately need to be quality standards that are met, as well as much closer oversight by the Ministry of Community and Social Services. I know that the executive director of Camphill talks with the regional office.

Rachel does require a lot more money than your typical resident, but I don't think the money is necessarily being used appropriately or well.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Elliott.

Mrs. Christine Elliott: Thank you, Chair, and thank you very much, Ms. Watt, for being here today and sharing Rachel's story. You've had many bumps in the road over the years, and it's quite unfortunate. Your story is very similar to what we've heard from other people, that the transitions are very difficult.

One thing I did want to follow up on with you is the education system for your daughter. Is she still in school? How old is she now?

Ms. Laurie Watt: Rachel is 20. She could have spent this last year in high school, and we had hoped that she would spend the year in high school. But Camphill made the previous year of school so difficult that we had to pull her out. We tried to transition Rachel out by creating a co-op placement for Rachel, but Camphill didn't abide by or respect that agreement either.

Mrs. Christine Elliott: So what is she doing now? Is she just at Camphill?

Ms. Laurie Watt: I don't know what she does. The great irony of all this—and I told Camphill's executive director—is that my parents knew more about what I did when I went to journalism school in Ottawa, which was six hours away from where I grew up, than I know about what Rachel does half an hour away, and Rachel is a vulnerable adult.

Mrs. Christine Elliott: Well, that definitely should not be. We will certainly be taking all of that into consideration for our deliberations. Thank you very much for being here.

The Chair (Mrs. Laura Albanese): We want to thank you for your presentation this morning. You've brought forward some important recommendations. We hope that through our work here, we will be able to improve Rachel's life and the lives of others like her. Thank you very much.

Ms. Laurie Watt: Thank you so much.

PEEL PLANNING GROUP

The Chair (Mrs. Laura Albanese): I just want to advise the committee that our 9:40 has cancelled—Prince Edward Learning Centre—but our 11 o'clock is here, and they're ready to go.

Interjection.

The Chair (Mrs. Laura Albanese): Yes. Okay.

Ms. Leanne Baldwin: Thank you. We appreciate it.

The Chair (Mrs. Laura Albanese): Thank you. We appreciate the fact that you're willing to go earlier.

Ms. Leanne Baldwin: No problem.

The Chair (Mrs. Laura Albanese): So just settle yourself in. You're from the Peel Planning Group; is that correct?

Ms. Leanne Baldwin: Correct.

The Chair (Mrs. Laura Albanese): Welcome to our committee this morning. You'll have up to 20 minutes to make your presentation. Should it be any shorter, we will have time for questions and comments from members of the committee.

Ms. Leanne Baldwin: Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you. Whenever you're ready, you can start by introducing yourself, by stating your name and your title.

Ms. Leanne Baldwin: Okay. My name is Leanne Baldwin, and I'm the chair of the Peel Planning Group. Actually, in the 22 years of its existence, I've been the chair for 14 of those 22 years, but not consecutively. In my sort of more full-time role, I have been the manager—different titles over the years—of Peel Behavioural Services since 1979.

I feel that this is very much an honour, to have an opportunity to present to you, and I really appreciate you giving me this opportunity.

The Peel Planning Group provides leadership in a systemic and strategic evolution of developmental services in the region of Peel. Comprised of representatives from a number of ministry-funded community-based service providers, it has an established track record of serving an advisory function to the central west regional office of the Ministry of Community and Social Services. In addition to representation from the developmental service sector, the group includes representation from the child welfare and mental health sectors and also family groups.

Peel region's population continues to mushroom at a rate over double that of the province of Ontario. If the growth rate continues at 11.8%, Peel's population will grow by 150,000 between 2011 and 2016, which is the equivalent of adding the city of Oshawa to the region of Peel—or the city of Kingston; take your pick.

It is important to understand that the incidence of developmental disabilities is 2% of the population or thereabouts. That means that as population increases, more and more people are in need of services. Presently, there are approximately 26,000 individuals with a developmental disability in Peel. Approximately 21,000 are over the age of 15, and 14%, or 2,869 people in Peel, are now registered with the DSO for the central west region.

0950

For decades, Peel was receiving approximately $140 million less, almost half the per capita funding for developmental services, than other Ontarians, and I believe that's very well documented through the Fair Share for Peel initiatives.

While Peel has a broad continuum of services, we have very little depth to them, and we have been creative and efficient with the limited resources we have. These services, however, are woefully inadequate to keep pace with the growing needs and mounting pressures in our region.

It is important to recognize that individuals with a developmental disability face a lifetime of challenge, marked by periods of fragile calm but continuously punctuated with anxiety associated with, "What if or what about when circumstances change?" More and more families are in crisis. Families and individuals languish on waiting lists, and we have even seen desperate families relinquish care of their children in hospitals, at respite homes and at agencies.

We also see young adults being placed in long-term-care centres because the developmental service sector cannot respond. The inadvertent message to families is becoming, "Drop your children or adult children off at an agency or hospital and you will get service." This has caused much frustration amongst families who are playing by the rules by remaining on the waiting lists. Right now, we know that there are 363 people in Peel who would accept residential support if it was offered yesterday.

I've included in your documentation the latest preliminary findings of the DSO for Peel region specifically. Also, I believe the Ending the Wait report documents the extent of the issue.

There are a number of examples in Peel of families organizing themselves and pooling their own resources to respond to the needs of their family members with a developmental disability, but they can't do this alone. They need ongoing, predictable support.

It is unacceptable that young adults with a developmental disability graduate from the school system with nothing to do and nowhere to go. Parents have had to quit work to stay home with their adult children. Most often, this increases family stress, which can then lead to family breakdowns.

Some 72% of the people seeking services through the DSO were between the ages of 16 and 24 in 2012-13. I asked our executive director of the DSO if the figures were different for 2011-12, when it first opened, because of course a number of people were grandfathered. Unfortunately, the bulk was still in that age group, so it's obviously a pattern.

Parents in Peel and across this province are at a loss as to what will happen to their son or daughter when they're gone. We know of parents in their 60s, 70s and even 80s, some of whom are infirm, who understandably fear for the future of their children. There have been situations where elderly parents have passed away and their adult children now have no one to care for them.

In another role, I'm also the chair of service resolution in Peel. One only has to attend a meeting to hear the heartbreaking stories. We listen to presentations at every adult service resolution meeting that exemplify the crisis mode we now assume is the norm.

Over half of all of the applicants for services through the DSO have only their parents, and possibly one other person in their life, that they can count on for regular support. Individuals with a developmental disability are living increasingly isolated lives. This isolation is also referenced in the Ending the Wait report.

Based on the above, the Peel Planning Group prioritized the development of an advocacy framework in the hopes of raising awareness of the need for new resources and public policy to support adults with a developmental disability to live and participate fully in their community, and to help families care for their family member with a developmental disability. The preliminary report of the DSO relevant to the region of Peel describes the dreams of the individuals we serve, and here we are unable to meet basic needs. This report, as I said before, is in your package.

The relinquishment of care alluded to above was another priority identified. Peel Crisis Capacity Network, which is really a network of agencies providing services to this population from age 11 and up, indicated that, between January 2011 and August 2013, 44 individuals were abandoned; 26 of the 44 were described as having high behavioural needs, and 17 of the individuals were abandoned at a health care facility. The Peel child and youth planning table concurred that this was a significant problem.

Kerry's Place Autism Services took the initiative to examine the issue more closely, and a guide was developed with the intention of assisting professionals who may have a direct or indirect role in addressing the immediate and longer-term needs of complex youth and young adults who are in crisis due to the absence of a participating primary caregiver, all in an effort to reduce the frequency of abandonment.

Currently in Peel, there are 14 individuals who have been placed on a "pressures" list since April. Of these 14, seven have been confirmed on the ministry's at-risk list. The "pressures" list is made up of individuals who are at risk for homelessness or who may already be homeless and may have aging or infirm caregivers or be experiencing significantly changing needs.

The need for day programs has also been prioritized. We currently have 1,443 people who reside in Peel receiving support from the Passport Program. Unfortunately, there are another 596 on the waiting list, either waiting for more needed hours or simply waiting for hours, period.

What has become really clear is that students leaving the educational system have nothing to do and nowhere to go. They remain at home, and key skills that have been previously mastered begin to disappear. They remain at home, and their behaviours begin to escalate, and families have to alter their lives drastically to provide support in the hopes of averting a more urgent crisis.

Finally, the Peel Planning Group prioritized individuals with a dual diagnosis and the need for a system-level response. You've already heard the data and suggestions provided by Dr. Yona Lunsky, Cathy White from the autism society in Ontario, Dr. Szatmari and others indicating the need for a comprehensive, systemic response across the lifespan for individuals with complex needs.

In reflecting on the above, one is struck by the urgent nature of the needs identified. As a planning group, Peel Planning Group does work well together. We have a high degree of trust and a deep respect for the individuals we serve. We've developed some very creative solutions over the years, but we feel we are now facing a wall and that it has become a humanitarian crisis. The system of supports is so fragile that when one variable is altered, the support system falls like a stack of cards and individuals go into crisis.

As a social service system, we have reduced flexibility. We've been forced to be reactionary versus proactive. We are incapable of meeting the basic needs of individuals. We are constantly dealing with a skewed distribution of the population, and by that I mean the most complex individuals with the highest needs. Where is the preventive component? Essentially the bottleneck in the system is moving down into community supports, and the waiting lists are growing.

What do we need? We need a comprehensive service system that supports individuals across a lifespan. We need better collaboration across ministries and increased flexibility—housing, health, education and social services. We need an integrated response that views the individual as a whole and is proactive: for example, comprehensive health care which is consistently supportive but also responsive when needs change. We need integrated data. Everybody is collecting their data here, there and everywhere, but I believe we really need a solid database so that we can really engage in some thoughtful, strategic planning to ensure that both ends of the spectrum of needs are addressed. We need to be able to project needs of individuals as they're coming up through the system and develop responsive supports accordingly. We need to focus on prevention as well as responding to crisis situations. When you're always serving the pressures on the system, it has to come at the cost of serving more, but less severe, individuals. Finally, we really need a commitment of multi-year funding to enable the evolution of sustainable supports for our vulnerable citizens.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your comprehensive presentation this morning. We will have about three minutes for each party. Ms. Hunter, you may start.

Ms. Mitzie Hunter: Thank you, Madam Chair. Ms. Baldwin, thank you so much for just the details you've provided and the research to support your presentation. I do want to assure you that the recommendations you've provided are very consistent with the mandate of this committee. It is being well received.

A couple of questions that I have: You mentioned that a database is needed, and a comprehensive one, that could feed into the strategies. Do you see a role for the DSO in helping to coordinate that?

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Ms. Leanne Baldwin: I think they're beginning to have a good database. I guess it's just scratching the surface.

We have a very good executive director in our area, Gary Whetung. He has set up an advisory committee to his work. It's a difficult task and he has gone about it the best he can, following the guidelines.

Whether it's a DSO—obviously, they would have a good start on it—but I just feel that being part of a planning body for so long, it would be really great to be able to know the kind of diagnoses we're faced with across a lifespan. How can we plan and be very strategic—we're never going to have enough resources, so we need to come up with shared-care models. We need to come up with different kinds of models of service that are going to support our clients and our individuals that we're serving. However, if we don't know what's coming up through the school system into the next period of their life, then we have no way of being proactive.

We know, for example, that as individuals with developmental disabilities age, there tends to be more comorbid conditions. What are you going to do with that? If we know that there's X number of individuals who have, perhaps, Down syndrome—while it's not one-to-one correlation, many do go on to develop Alzheimer's; what does that mean for the system? What does that mean for health services? What does that mean for planning better supports before they're in crisis for those supports?

Could the DSO do it? I don't really know. I think it's early days. I think the DSO and the report that you've been provided with is a good stab at some preliminary information. Does it take into consideration health care usage? No. There's a need to have information from the emergency visits, from the visits to psychiatry, from education. That's where I feel that we need to have some kind of integrated pool of information to say, "Let's get a handle on this. What are our priorities? How can we best address this going forward?"

Ms. Mitzie Hunter: That's excellent.

The Chair (Mrs. Laura Albanese): Thank you. Sorry; we have to move on to Ms. Jones.

Ms. Sylvia Jones: Thank you. There's a lot of excellent detail in here. The numbers concern me greatly. We all hear about waiting lists, but now we've got at-risk lists and we've got abandonment lists and we've got—what was the other one you said?—pressures lists. When does it stop?

You made reference, at the front of your presentation, to 363 people in Peel who would accept residential support if it was offered yesterday. You also talked about some innovation that's happening with parents who, quite frankly, have got tired of waiting. Can you share with the committee a few examples of those innovations, and more importantly, why they're getting blocked or where the block is happening?

Ms. Leanne Baldwin: I think that parents have come up with, I suppose, cost-sharing methods of pooling their resources together to come up with a day program, for example, or pooling their resources together to make a plan for taking over a house. I think the barriers that arise out of that is, you still need to operate it. You might have capital; you might have a place for people to live; but you may not have any money to staff that situation. So you need to partner with social services or you need to find somebody to partner with that's going to have some injection of ongoing funding to do the human resource support aspect of it. That's it in a nutshell.

In terms of the number of clients that are waiting, that was provided to me this week. The DSO doesn't track how many clients are on a waiting list that have been on a waiting list forever. One of their questions, I believe, is that, "If you were offered residential services or some residential supports tomorrow, would you take it?" It's kind of like the long-term-care situation, isn't it? You've got a bed in a nursing home: "Do you want it now or not?" Game over.

They have asked that question, and 364 people have said—or whatever it is, sorry. I'm not looking at my document.

Ms. Sylvia Jones: It's 363.

Ms. Leanne Baldwin: So 353—

Ms. Sylvia Jones: Sixty-three—363.

Ms. Leanne Baldwin: —363 have said, "Yes, I want it yesterday. I want it. I'll take it."

Ms. Sylvia Jones: Yes, although I have spoken to some of those—

Ms. Leanne Baldwin: Now, part of that, they may be saying they're taking it because they feel they have no choice, too.

Ms. Sylvia Jones: Right, so they feel like they're in a bit of a box—

Ms. Leanne Baldwin: Right.

Ms. Sylvia Jones: —because then I get the phone call, saying, "That's not really what I want right now. I know that I will need it eventually, along the continuum." But you don't want to say no.

Ms. Leanne Baldwin: But I sat on a residential services management committee as well, before the DSO ever got into play, and I believe we had over 700 names on the list. That was people trying to be—"I want to be on the list, because I know sooner or later I'm going to need it." But nonetheless, that still is a prodigious number of people who are going to need something sometime.

Ms. Sylvia Jones: Right. Thank you.

The Chair (Mrs. Laura Albanese): Thank you, Ms. Jones. I will move on to Ms. DiNovo.

Ms. Cheri DiNovo: Thank you very much for this presentation. It was wonderful and packed with detail and packed with figures, which I, in particular, love.

First of all, I have a question to research. I'm sure we've asked this before, but I'm not sure we've had an answer yet from the ministry or whomever. The numbers of abandonment cases: We really need to know that. If Peel region is able to produce that, surely the ministry, or somebody, can produce those figures. That really tells us the nature of the humanitarian crisis we're dealing with here, which is absolutely what we think it is.

Your suggestions are excellent. We know that there are many jurisdictions in Europe and here that don't have any waiting lists at all for their services for developmental disabilities. My question is, really, do you know of or have you researched a jurisdiction that you think really has the best answer for the crisis we're facing here?

Ms. Leanne Baldwin: You know, I'll be honest with you and say no, I haven't, personally. I did go through a lot of the select committee presentations and did hear that there are models in England and there are models in Australia. But I'm not personally familiar with them enough to speak articulately or to—

Ms. Cheri DiNovo: No problem. You've done due diligence. You've done excellent work.

The other thing that jumped out at me, too, was the discrepancy in per capita funding, which clearly is unfair. If some regions are getting more per capita funding than others, then that's something that we really need to look at. So I just want to thank you for that.

Ms. Leanne Baldwin: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very—

Ms. Leanne Baldwin: Sorry. I believe the Fair Share for Peel process has been around for about 20 years as well, and I've participated in that for a very long time as well. I think that speaks to the age of me. They, too, have well-documented figures.

I do want to say that the central west region of the Ministry of Community and Social Services has always been extremely great to work with and very willing to help us try to address areas and be creative and come up with different kinds of solutions. We're just facing a wall.

The Chair (Mrs. Laura Albanese): Thank you very much. We've reached our time limit.

Ms. Leanne Baldwin: Okay. Well, thank you very much.

The Chair (Mrs. Laura Albanese): Thank you for presenting to the committee and bringing forward all of this information. It's very useful.

RYGIEL SUPPORTS FOR COMMUNITY LIVING

The Chair (Mrs. Laura Albanese): Our next presenter is—I don't know if I'm pronouncing this right—Rygiel Supports for Community Living. I will ask you to come forward. We welcome the executive director, Donna Marcaccio. Please make yourself comfortable. You will have up to 20 minutes for your presentation. If it's any shorter, then we'll divide the time equally for questions.

Ms. Donna Marcaccio: Thank you very much. My presentation is short, and it's somewhat informal. I'm well aware that the committee has received numerous presentations with lots of facts. Mine is a little bit different.

Just to further introduce myself, I am the executive director of Rygiel Supports for Community Living in Hamilton. We have been providing service in our community—we're in our 46th year—particularly focusing on the individuals with the most significant cognitive disability and multiple physical handicaps.

Many of these young people—well, they're not so young now. Many of these people were abandoned in their childhood, and others along the way. Of the 180 people we support, about half of them do not have any family—any significant relationship that you and I would consider important in our lives.

So my message today—the handout really is just a summary of my two key points.

1010

Our agency's history is that we were a schedule 2 facility, so in the province of Ontario we had our government-operated facilities. We were one of the first community transfer payment institutions and we were the first to self-deinstitutionalize throughout the early 1970s up until 1980. That was all driven by the principles of normalization. We take great pride in having those principles that lie in that philosophical and social structure as the roots of our organization, which have driven us over the years.

It is those principles that helped us be one of the first agencies to pilot respite care and shared care in Ontario. As we all know, respite has become a very popular service structure and a least-intrusive service structure, and, for a family, one of the most critical supports we can offer to them. As a service provider as well as—I'll declare I'm also a family member not using service. In both roles I'm well aware that as a province we've been able to provide more and more respite, but one of the key messages I bring to you today is that services such as respite have become so regimented that it undermines the intention of what respite is.

As an organization we, like all others, have striven to do the best we can and to live according to our mandate and mission. When it comes to resources—and we're grateful for the ongoing recognition of our province of the service needs and providing more and more resources—the reality is, what comes from the province is only a fraction of what it truly costs to support a person with a basic lifestyle.

One of my concerns whenever we talk about developmental services is that we only look to the province and to our government and we don't talk about our community. We don't talk about what it really costs and how our communities have contributed significantly. Just as an example, in our organization it has been wonderful that we've received operational dollars to care for people, but we're serving a population who can't go and rent a house or an apartment. They need barrier-free design. Yes, there are lots of non-profit, barrier-free townhouses; only two people can live there, but if you have an extended wheelchair, maybe only one can fit. We have lots of those.

We have created, over the last many years, our own non-profit housing corporation, and it's through the goodwill of our community, lots of volunteers and wise financial management that we've been able to provide 15 completely accessible houses to our community and to continue with that commitment of providing more. That needs to be recognized. We're one of many, many organizations and many communities where it's a partnership between the community and our government. I think that needs to be talked about more as we face this crisis.

Just a couple of operational challenges that really impact our ability to be more flexible and responsive—again, I'm not going into a lot of detail because I know you've heard about this. For example, as an organization where we're having to respond to conflicting legislation. For example, pay equity is a very serious issue. In our organization alone we are faced with not reaching pay equity until at least 2021. By the time we're finished, it will have used the resources equivalent to 66 full-time employees. That affects a significant number of people with disabilities. The conflict in meeting that legislation is that we're in conflict with our own legislation, which says, and rightly so, "You cannot affect the service targets that you provide."

Fire code: I'm sure you've heard about that. That is another conflicting—we have a philosophical issue where we're turning houses into institutions. We have legislation that's not clear for our sector. The legislation says that if the occupancy is more than 10 residents and more than three storeys—this is a requirement. We provide bungalow care for three to four to five people, and no one knows where we fit. We're having to spend an enormous amount of money to retrofit to a standard, and nobody is really clear what that standard should be. In the midst of that, where we have capacity to welcome one or two more people into a house, we're not allowed to do that because we can't change occupancy until the fire code issue gets resolved. So we have spent an enormous amount of hours—not alone—and these conflicts really affect our ability and your ability to respond to our vulnerable citizens.

Then, of course, the whole issue of mandatory requirements on agencies and just a small example of that: Understandably, our ministry, several years ago, mandated all residential services to train their staff within 30 days of employment in non-violent crisis intervention or some form of restraint training. In an organization like ours, we have always had a no-restraint policy from a philosophical and research perspective, where it's clearly research that restraining somebody only adds to the agitation. We have a no-restraint policy, and more importantly, 90% of the people we support can't move their own limbs. But every year, we have to spend an inordinate amount of money, at least $25,000 and up, to train people in something that they will not use within our organization.

Equally as important, having to do that is bringing back into our culture in our province the ancient stereotypes that we've spent decades trying to eradicate: that anybody with a disability is going to be violent, is going to be aggressive etc. There are people; it's a small population. I ask: Why isn't it mandated that I have to teach everybody sign language or alternatives to communication within their first 30 days of employment? I have to teach them something that suggests that the people on the other side of the door may harm you. So I bring that forward and ask the committee to seriously look at some of these issues that put organizations and families—more so, the people we're here to serve—in this very difficult situation where, while there was good intention on one part, quick and blanket decisions are actually causing a lot of difficulties.

My second key point is actually responding to some of the issues of the previous speaker, and that is for families. While it's very understandable why the structure of DSO came into existence and how helpful it is in many ways, it also becomes a challenge because it has created a very, very highly structured service system, again, with a degree of understanding. However, I bring forward and ask you to consider: Is there a way for us to bring back some of the grassroots flexibility in our system?

Developmental services, like many other non-profit sectors, started with families coming together, helping one another, and community members helping them. That's the root of our agency and it's the root of many. Families today do want to be planful—many families. Many families do put resources aside for the future, but clearly a lifetime of resourcing is not anything that any family—there may be a couple of families, but most families—would ever be able to achieve. So families coming together and planning and sharing resources have great limitations, yet we say we want families to do more. But we have no mechanism to support that. Respite is a little bit of a mechanism, but again, highly structured programs that we've put in place sometimes undermine that. Families need responsive respite. They need it with more flexibility. Yes, they need some predictability, but if something comes up in a family—a family member dies—they need some care while they deal with that. How do you get that quickly? You don't anymore.

Families who are planning for the lifetime future of their family member used to be able to partner with agencies. They used to be able to come together and say, "Today I only need a respite, a weekend a month, but down the road I'm going to need this." And you worked and planned together and you knew each other and you knew the family member and there was security: emotional security, knowledge security, etc. All that is gone. A family for whom we provide respite now says, "I have these ideas. I'd really like you to work with us and develop them. Where do you think I might be able to get some resources in five years?" That's what my budget tells me.

1020

I legitimately, as agency staff, can't be helping them, because they're not referred to us through the DSO, and our resources have to go to people referred to us through DSO. I'd gladly do it as a volunteer, but I have no answers for them.

We need to build in some way of helping families who are willing to do things and plan for their family member, but if two or three families come together and they look at being able to sustain some kind of support, whether it's respite, day supports, accommodations down the road, the reality is that the day will come when they need some help from the system. Who is to say that they will be at the top of the list—all three, or all two? The chances are very slim. So those families become broken; the arrangement they've made has become broken.

My real message today is that we need to look at how we back up families. We'd have families who received respite who would say, "If my son or daughter is in their day program and they get sick, can you be a backup if I can't get away from work?", and we would do that. Do you know how often we got called upon? Almost nil. The security that that gave families was beyond what we could put dollars to.

We can't do those kinds of flexible services and supports to families anymore. We need to find a way, because we can't afford to provide—nor should we—very intrusive service to people. We need to provide what they need, and a lot of people only need minimal support and backup. They need to know someone is there if there's going to be a crisis. They need to know they can be planned for, and that they've got somebody and some organization behind them for that planning.

We've created a very comprehensive service system, but it's quite fragmented. It has become very structured. We have wonderful legislation that talks about people being members of their community—a person-centred, person-directed service system—but the actual fact is that it's very fragmented and structured, and it's taking away from people really being part of family and community.

So I encourage this process to consider ways of building flexibility into the structures and funding models, as well as regulations that will help families build a more normative lifestyle with adequate supports for their family member, a lifestyle that's rooted in community, not in agency; a lifestyle that's rooted in meaningful relationships. There's a role for agencies to provide this flexible soft service, to partner with families, and I suggest that this will really be a significant contribution to the transformation agenda.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation. That brings forward points that are a bit different and highlights different aspects of the issue.

We have about two minutes per party, so we'll begin with Ms. Elliott.

Mrs. Christine Elliott: Ms. Marcaccio, thank you very much for your very thoughtful presentation. You have certainly raised a number of the issues that we have heard about, but you have some innovative solutions, by the sounds of things.

I wanted to ask you: I took a note that you had created a non-profit housing corporation that was working with the community and with government. Could you provide us with a few more details of how that was set up, please?

Ms. Donna Marcaccio: Basically, we learned from other non-profit groups. We incorporated a group of volunteers to become a founding body and registered it. Basically, it took some volunteer dollars, donated dollars, bought a house and used that as equity and continued to build on that equity. The individuals rent from that corporation.

Mrs. Christine Elliott: So you were able to do that through private donations, basically.

Ms. Donna Marcaccio: Yes.

Mrs. Christine Elliott: And you were able to actually purchase the residences.

Ms. Donna Marcaccio: The original houses, and then the individuals pay rent to pay off the mortgage now.

Mrs. Christine Elliott: Okay. Do you think that's something that we could replicate across the province?

Ms. Donna Marcaccio: There are many good examples of it throughout the province. Some call it a foundation, some not. There are quite a few examples in our sector. It's not well understood. It's a model that really works and builds equity for our system, as well as providing immediate appropriate housing.

Mrs. Christine Elliott: That's great. I think it's happening—

Ms. Donna Marcaccio: I'm happy to share whatever—

Mrs. Christine Elliott: That would be helpful. I believe it's happening in Peterborough as well, with their Community Living, and it may be happening elsewhere.

We're just not that familiar with it. But if you could provide us with more information, that would be great.

Ms. Donna Marcaccio: I will do so.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): Thank you, Ms. Elliott. Miss Taylor.

Miss Monique Taylor: Thank you so much. Thanks, Donna, for being here today. We've met several times; we've had many conversations. I know the great work that you do in this sector and the hard times that you find this sector falling through.

I would hope that you could share with the committee some of the problems that you find within your facilities for the lack of funds, and the troubles that that's putting you in, and what's happening to our resources because of that lack of funds.

Ms. Donna Marcaccio: I could spend a day, so I'll just pick a couple of examples. In order to meet our pay equity legislation, we actually had to sell a house. Fortunately, we were able to put more people into a house and relocate, just prior to all the hype around the fire code. If we wanted to do that today, we wouldn't be able to do that, because we can't change occupancy.

There's a fine line, and there is a lot of research out there—we're doing it, as an agency—of what the impact is on groupings.

We've had a very interesting experience as a result of recent financial pressures. We added capacity, so we went from a four-person to a five-person residence. One of the individuals who originally lived there had a history of some very traumatic times in her life, emotionally. Her last 10 years have been amazing. She goes to the gym. She does all kinds of things with her support and with volunteers, and she actually has some real friends now.

It just came to my attention within the last few weeks that as a result of the increased number in the house—therefore, greater chaos, and so on and so forth—some of what was exhibited prior to 10 years ago is starting to happen again, which means she now needs to be referred to the behaviour management team in our community, and we need to do other training for our staff, and so on and so forth. Her home—a place of security and a place where you're supposed to be comfortable and trusting and be able to be yourself—is changing.

It is a balance. I understand that our group homes, our residences, are part of the system and not home like my home, but we have to find a balance. We had a balance in that home, and we don't now.

Resources, on the one hand—because of increased costs and no change to resources coming in, we've had to take some measures to meet all these obligations. The impact on the individuals isn't always for the best, and in the end, it's not cost savings, because now there are other costs being incurred to the system.

For time, I'll just leave that as an example. I'm happy to answer and provide more, if you'd like.

Miss Monique Taylor: Thanks, Donna.

The Chair (Mrs. Laura Albanese): It's a good example. Ms. Hunter?

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you so much for your presentation and the work that you and your organization are doing for people with developmental disabilities.

I was very interested in your support to families. We've heard a lot about that in terms of families really wanting to provide that natural support, but they need to be backed up. Can you talk a little bit more about what you see families are most in need of, in terms of getting that backup support so that they can provide the natural supports?

Ms. Donna Marcaccio: What I hear over and over again, and I can personally appreciate, is the importance for some spontaneity. I use that example of, let's say there's a family of four: a person with a disability, a sibling, Mom and Dad, and one of the parents gets very ill. They haven't got any respite dollars other than maybe a weekend every seven or eight weeks. What do they do? They don't have extended family; they don't have any support. There needs to be some flexibility. The system has become so rigid that that flexibility—it's a crisis, and somewhere, somehow, we always seem to manage a crisis, but is that in the best interest of that family?

When that happens, it might be the agency that's providing the ongoing respite, but because it's a crisis, it may have to be somebody completely new. That does not give families a lot of security. They live in anxiety: "Who will know my family member? How will they adjust to a foreign environment and different people in a crisis?" It's already traumatic, having to be removed from your home, or bringing somebody new into your home.

1030

The other thing is that, as the world becomes more refined, or fragmented, as I call it, as well as tight rules—regimented—families are overwhelmed with the responsibility that comes from hiring workers, paying workers, considering WSIB, and all those issues. That administrative piece needs to be simplified. As an agency, we do a lot of that for families. How much longer can we do it without any resources to cover that? I don't know. We use a lot of donated funds to help offset that. Communities are amazing, but it's getting to a point where that's really becoming very difficult for an agency like ours. We raise money to buy houses, and we raise money for vehicles and then daily supports, so it's very challenging.

For families, it's the backup of, "I need to go somewhere today with my other sibling. Can I bring my child to the residence where they have respite, because they're their friends, just for an hour or two?" I used to be able to do that. Now I have to say no, because it's not part of their approved service.

The Chair (Mrs. Laura Albanese): Thank you. Unfortunately, the time has expired. But at the same time, we want to thank you for your thoughtful presentation to our committee. We'll take those considerations.

Ms. Donna Marcaccio: Thank you for having me.

HALTON SPECIAL NEEDS FAMILY NETWORK

The Chair (Mrs. Laura Albanese): We now welcome Halton Special Needs Family Network. Good morning.

Mr. Nick Norvack: Good morning.

Mr. Tom Mahoney: Good morning.

The Chair (Mrs. Laura Albanese): I saw that you were sitting in the audience for a while, so I think you know more or less the way the committee works: up to 20 minutes for the presentation. If any time is left over, we'll ask questions. You may begin any time. If you could begin, please, by stating your name and title.

Mr. Nick Norvack: Okay. First of all, my name is Nick Norvack. We wish to thank the committee for allowing us this opportunity to raise our concerns with regard to the present difficulties facing those who are developmentally disabled.

Rather than read directly from our written submission, I will provide you with my experience as a father to a 24-year-old daughter who is developmentally disabled, and as a member of the board of directors for Community Living Oakville.

My daughter Samantha is presently attending a fee-for-service program provided by CLO called STEPP, Skills Training to Enable Personal Progress. The program costs $40 a day, approximately $12,000 a year. At the time of her completion of her life skills program from high school, we were placed on the Passport funding wait-list, and to this day we have incurred the majority of the costs of her STEPP program.

In order to ensure the maintenance and success of the program, I became a member of CLO's board of directors. My initial observation was of a considerable amount of funding provided by MCSS for residential homes—approximately $6 million a year, for 75 individuals; average cost, $80,000—and the total lack of funding for other programs and individuals.

Although 48 adults between the ages of 21 and 26, who presently live with their parents, are presently enrolled in the STEPP program, the program receives absolutely no funding from the ministry. Since the entire costs are borne by the parents, many of whom have limited or no funding, many of the participants can only attend part-time.

Our Best Pack and Speers Place Industries programs, which provide employment and learning skills opportunities for 80 individuals, also receive minimal funding from the ministry. Last year, eight of these individuals were provided with sufficient skills to actually find full-time employment in the community. Unfortunately, the annual shortfall between expenses and income from these enterprises is borne solely by CLO, even though these enterprises provide a positive experience for the individual and community.

However, the most revealing aspect regarding ministry funding is our latest residential home. After CLO purchased the home for five complex-needs young adults, for $630,000, the ministry provided us with $150,000 for renovations and $75,000 for furnishings. Noting the complex needs of these individuals, the ministry provided us with an annual operating budget of $950,000 for staffing.

Assuming an annual 2% cost of living over the next 40 years, since these kids are only in their early 20s, the total operating expense will be $59.2 million. Considering the ministry has informed us that the numerous complex-needs individuals still without homes will be serviced next, this residential home model is almost financially unsustainable for the province.

With regard to DSO and the comments presented to the committee by previous presenters over the length of testing, my concern is more directed to the impact that the scores arrived at from the supports intensity scale testing has on the parents. For instance, my daughter scored at the 86th percentile level, which should correspond to the highest level of Passport funding. However, we were only provided with $2,700, which was the direct transfer amount from her previous SSAH funding, an amount which would not have been available now if she was just turning 18.

In addition, the committee may find it interesting that the American test used actually refers throughout its paper to the 1,500 individuals used in devising the test as "MRs." In addition, the percentage of these individuals who were categorized as autistic was 0.4%; that is, six out of the 1,500 were autistic. There is no way this is a fair representation of those presently taking the test in Ontario, and I would question the validity of any of its findings for these autistic individuals.

I'll pass it over to Tom now.

Mr. Tom Mahoney: Good morning. My name is Tom Mahoney and I'm here with Nick representing the Halton Special Needs Family Network. I'm a single parent. I have three children. My youngest son, Connor, is an autistic 22-year-old who also suffers from seizures.

My comments today are a cumulative reflection of my own and our Halton special needs families' experiences.

I'm going to stray from my context that I've handed you before because I'd like to speak directly to you. You have heard many, many horror stories—the continuity of statistics by region within this province. I'd just like to start right at the very top, or at the very beginning of what life is like as a special needs family.

First of all, we have a diagnosis made. Today, if you're lucky enough that it can be defined that you are eligible for intensive behaviour supports, you will get them. If you're not, you are left on your own on a waiting list. You then must go and find supports for your child to help them with the modelling of behaviour. I want to keep this thought in mind of behaviour modelling throughout this presentation, because that is the overall goal throughout this whole process. By the time our children reach the age of being graduated out of high school, it's the behavioural model that must be reinforced, and hopefully all the resources that we have put into that behavioural model will pay off. If it doesn't, we have thrown away hundreds of thousands of dollars per individual.

During grade school, your child goes into a fully integrated process in the middle and amongst all their age peers and age brackets. They have a wonderful time. They're totally integrated within the community. That continues until they reach high school. In high school—never forgetting, there's an IEP done for every year for each individual. By law, that IEP must be signed. I want you to know that the IEP is this thick. Parents have a terribly difficult time of understanding, "What am I trying to achieve with this IEP? Is it academic or is it behavioural?" What are the points of measurement within that IEP? There are none. Teachers don't have any tools to measure progress through that process.

Let's get to high school. We now put them into programs where they have a central location for special needs, and hopefully they have the behavioural skills at that time to move through the high school. Many times, they don't. When we had the dream of inclusion, we've just pulled back on that inclusion. They move through the school with best programming—once again, it's the IEP process. Do those IEPs support the behavioural modifications that we need? The whole objective in everything that we do is to remove the ideal of a five-to-one ratio at particular times where I need five people to look after my special needs child down to four, down to three, down to two, down to one, and then moving it on the opposite side. They can now be part of a group of five kids to one attendant or 10 individuals to one attendant, and keep moving them in that process. That is our objective.

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After high school, they are graduated out at 21. We have no idea how well they are performing from a functional standpoint, but then they move into the realm of Passport. Before I get to that, the Special Services at Home, hopefully, at one time were supporting them throughout this process. The history of Special Services at Home was that they got an immediate amount—I'll give my own history—of $3,000 a year. That amount was the same until my son reached 19, so from six years old till 19. When he transferred over to Passport, it was still the same amount, and still is the same amount today. This is the only sector within government services that has been based on a zero-based financial model, and that goes completely down to the supports that are given to Community Living, to Christian Horizons. We also ask them to pick up, learn from within, take from within. We'll make changes with fire codes and we'll make changes here, but we will always have to work on a zero-based budget. I work with a zero-based budget of supports.

I'll never forget within school, again—pardon me for moving around a little bit—but school and education for families is 35 weeks a year. What happens with the other 17? My Special Services at Home supports were totally allocated to programming for the summer time, and hopefully I could structure that programming to support the learning and the IEP process that I had within the educational system so that I have continuity.

Once again, with the Passport Program, we move forward to the process of having to qualify. There's no use even asking for support unless I have an IQ below 70. This is ridiculous. Many special needs have an IQ over 70, but they don't have the behaviour adaptations that correlate to that IQ. Their behaviours are of five-year-olds, but we accept that; that's fine.

I'd like to immediately jump right now into establishing recommendations. I went a little longer than I had intended initially and I apologize for that, so I'll quickly try and read these, and hopefully we can have a little bit of discussion about them.

(1) First of all, yes please, establish a single lead agency contact point for all clients and family contact.

(2) Immediately provide bridge supports to all families on waiting lists, allowing for program access. The longer you wait, the more costly it will become. This will allow for service providers to guarantee available programming, which is now at great risk. Please don't throw that money away that has been spent on them throughout their whole education process, by allowing them to sit at home and re-learning all the bad behaviours that they knew previously.

(3) Support funding should be administered using the direct funding method to the family. In many circumstances, even with approval for funding, the families are unable to secure appropriate day services because of their location or lack of services being offered.

(4) Bridge residential supports to families until long-term solutions can be implemented. We also recommend that consideration be given to new non-profit strategies, and there's one I'd like—if you have questions about it, it's the Habitat for Humanity business model. Here, homes are owned by the clients, the special needs themselves. The way it works is that Habitat for Humanity will own the mortgage. It is interest-free. The client then pays back that mortgage over a 30-year time period. It is recognized that there will not be a single solution but a number of best solutions that embrace the unique individuality and personality of each person. Please never forget that the housing—the home—is an individual's choice. We got rid of the institutional model because of the inhumanity of it. An institutional model, even with five people in the home, can be exactly the same thing to the individual.

(5) Initiate a "perfect 10" work strategy, where 10% of all provincial government employees are individuals with special needs. The problem we have with ministries is that they have become more financially challenged on the basis of where does the money go, versus goal-oriented. If we achieve our start point, a goal of jobs for all, then all the behaviours and all the movements that we have from starting in primary school will lead up to that point. We want them prepared to be able to go to work. That's our objective. Their ability to work really, truly is the meaning of being included equally within our society. As it stands right now, every individual who is residing at

home will not have that opportunity. The "perfect 10" sets the goal of 10% higher for people with special needs within the public sector, and this is to be achieved by the year 2020. As an example, the US Senate's subcommittee has a recommendation that there are going to be 600,000 special-needs employees within the federal public service by 2017. They have taken on this challenge, and they have set that goal.

(6) A championing of special needs in the private sector: that an Ontario Chamber of Commerce partnership be initiated, providing examples of the amazing corporate experiences for those companies that have initiated a 10% to 20% special-needs hiring mandate. There are examples of this through Walgreens in the United States, which at every fulfillment centre has a mandate of 20% higher for special needs. They also take these individuals in and train them themselves. The actual cost to Walgreens per employee in additional training costs is $400. Their experience has been phenomenal. They have moved it down now to the next level, where they are looking at every grocery store now having a minimum of 10% special-needs hiring. Individual companies working with Walgreens—Procter and Gamble fulfillment centres—have also set that 20% goal.

(7) Initiate a special-needs public transit strategy which mandates that all ODSP recipients receive 50% transit discounts, and that any attendant who travels with them is not charged for any transit authority that is supported by the province of Ontario. The city of Toronto just announced that attendants will not be charged—I believe a month ago. Previous to that, special needs were penalized. If I had to be at a doctor's appointment and I had to take the TTC and my attendant had to go with me, I have to pay two fees. If a person with a seeing-eye dog gets on for free, it's not equitably fair. The other part is that, given that ODSP is their major income source, a Metropass or any regional pass right now is in the neighbourhood of $200 a month. How do they get to and from work when 25% of their monthly budget allowance without income is utilized just in transportation?

In closing, one Saturday morning I opened up the Hamilton Spectator. On the front page were three individuals in their 60s. They live on ODSP, and they're living in absolute squalor. The toilet is frozen. One woman living there killed a rat the night before with a toaster. I looked at that picture, and what I saw coming back to me was my son.

With the systems that we have in place now, we lose these individuals as time progresses. This, ladies and gentlemen, is no longer acceptable. The challenge to you as a panel is probably the most important challenge you will ever have in your lives. I ask you to bring party consistencies and objectives all focused forward to support these marginalized individuals.

We live in the greatest province in the world, but as long as we marginalize these individuals, we're fooling ourselves; we're not. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much. We just have time for a comment for about a minute. We could use it for a quick question or a comment, and it would be the NDP's turn to start.

Ms. Cheri DiNovo: Thank you very much for this presentation. Of course, we've heard similar themes throughout our days of hearings on this issue, so you're not alone. I want to tell you that, first of all, and say that we are all here charged with exactly what you have just charged us with: that we do something, that we recommend something, that we make change. That's what we're all here to do.

I particularly liked your idea of the public service setting targets for those with special needs in terms of hires. I thought that was excellent. I think that's the first time I've heard that, so that definitely goes into the roster. Thank you very much.

The Chair (Mrs. Laura Albanese): Mr. Balkissoon?

Mr. Bas Balkissoon: Thank you, Madam Chair. Let me say thank you for being here and sharing your thoughts with us. Just to echo the same thoughts of my colleague, the committee was struck so that we could go out and get this kind of data, so that we would make recommendations to the government. I can assure you we're working as a team here.

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Based on previous experience of doing similar work in mental health, hopefully, the report that will come out will be very positive, and it's up to the government to implement it.

But thank you very much for taking the time.

Mr. Tom Mahoney: Thank you.

The Chair (Mrs. Laura Albanese): Ms. Elliott.

Mrs. Christine Elliott: I also would like to thank you very much for your presentation and, again, to assure you that we are working together here—we want to set up a framework that can be followed by anyone—and that we are going to see this through. This is not something that we're just sitting around here listening to people and then we'll write a report and nothing will come of it. We're all personally committed to making sure that change happens. I hope that you feel assured by that.

I just wanted to make one comment. I'm also very strongly in favour of having a champion in the private sector to bring employment and opportunities for young people. You may be aware of the Rotary at Work initiative. I think they're doing some really groundbreaking work. Some of the private sector employers have made it their business to hire people with special needs, not as an act of charity but as a good business practice. As you've indicated with the Walgreens example, it's very little that needs to be done by the employer, and the benefits that come back are huge. So thank you very much for bringing that forward.

Mr. Tom Mahoney: Thank you.

The Chair (Mrs. Laura Albanese): I, too, want to thank you again for your presentation and assure you that we're trying to work in a very non-partisan way. We're looking at issues, at the needs, that we're hearing, and we hope to put together a good, comprehensive report that will bring some results to the people who need it: the most vulnerable. Thank you very much.

Mr. Tom Mahoney: Thank you.

FAMILY SERVICE TORONTO

The Chair (Mrs. Laura Albanese): We'll now welcome Family Service Toronto. Good morning.

Ms. Janet McCrimmon: Good morning.

The Chair (Mrs. Laura Albanese): Please make yourself comfortable.

Ms. Janet McCrimmon: Thank you.

The Chair (Mrs. Laura Albanese): If you could kindly introduce yourselves before you start. You'll have up to 20 minutes for your presentation.

Ms. Janet McCrimmon: Good morning. My name is Janet McCrimmon, and I work at Family Service Toronto as the director of Building Inclusive Communities, which is the part of our organization that serves children and adults with developmental disabilities. I'm here with a couple of our staff and with a parent of one of the clients in our program. We really appreciate this opportunity to talk to you about some of the challenges that people with developmental disabilities are facing in our communities.

FST is a proud United Way agency. We've been serving individuals in Toronto for 100 years this year. It's our anniversary, and we're very proud of that. We provide counselling, community development, public education and advocacy. We have 13 locations in Toronto, and we served 65,000 people last year in 20 different languages.

We provide several programs that partner with individuals with developmental disabilities, and their families, to promote inclusion and improve the quality of their lives. Our Options program supports more than 450 children and adults with developmental disabilities, and their families, to achieve their potential through person-directed planning, service coordination, individualized funding, circles of support, supportive counselling, self-advocacy and mutual support groups. We connect people to opportunities for employment, inclusive education, recreation, living arrangements and opportunities to develop new relationships in the community.

FST also administers the MCSS-funded Passport Program in Toronto, providing individualized funding to more than 2,500 adults with developmental disabilities to access community participation supports and to enable respite for caregivers.

We are the lead agency for person-directed planning in Toronto, partnering with seven other developmental service organizations to deliver this important service and build system capacity for person-directed planning.

We also have a dedicated counsellor in our Violence Against Women program who works with women with developmental disabilities who have experienced abuse.

Our 23 years of experience in delivering these programs, and in listening to the individuals we support, form the basis for our presentation today.

The key messages we want to convey are:

(1) Individualized funding that's flexible and can change as individuals' needs change is a critical part of the developmental service system. Such funding has the potential to transform people's lives, and we encourage the government to expand its support of this approach to service.

(2) The current level of support for our community members with developmental disabilities is inadequate, and lengthy waiting lists for individualized funding and services are creating crisis situations for many.

(3) Individuals who are experiencing life transitions—for example, young people transitioning into adulthood and individuals who are aging—are particularly at risk of destabilization and crisis due to the interruptions of service and funding that they experience. We need better strategies that will enable a continuum of support and service for these individuals and their families.

(4) The lack of affordable and supportive housing options for individuals with developmental disabilities is a significant barrier to improving the quality of people's lives.

To help elaborate on some of these points, we've invited Patricia Parker to share her experiences with you as the parent of Victoria, an individual receiving service through our Options program.

Ms. Patricia Parker: Good morning. I'm Patricia Parker and I am here presenting to the Select Committee on Developmental Services this morning as a parent.

My 41-year-old daughter Victoria has Prader-Willi syndrome. We're really grateful to have been receiving individualized funding, since 1998 actually, from the Options program of the Ministry of Community and Social Services. The flexible and family-focused nature of this kind of funding has made it possible for Victoria to live independently, safely and with a high quality of life in her own apartment in the community of her choice, the neighbourhood of her choice, for the past 16 years.

What works so powerfully for us is that with individualized support, Victoria and her family are the true authors of her support model. Options capitalizes on the knowledge and strengths of Victoria, her family, her support workers and others who are part of her caring community. Victoria's supporters are resourceful, experienced and talented. In a more conventional funding environment, where we would only be consulted at an annual review meeting, our contribution would be lost and Victoria's needs would not be as well served as they are.

My understanding of the individualized funding program of Options, from its inception in 1998 as a pilot initiative of MCSS, is that the ministry wanted to develop an innovative and participatory model of individualized funding. Our family's partnership with Options has created, at a relatively low cost, a safe, secure and meaningful life for Victoria that is almost miraculous. All the medical, behavioural and research literature about Prader-Willi syndrome emphasizes that those affected cannot live safely without around-the-clock supervision.

And yet, together, as partners, we have successfully supported Victoria in defying those odds.

For MCSS, Victoria's life, I believe, is the best possible illustration of the effectiveness of individualized funding and also the power of partnerships with families. This collaboration has been life-altering for our whole family and, I actually believe, life-saving for Victoria.

While our experience over the past 16 years has been rewarding and gratifying, there are two concerns that I do want to speak about this morning. Actually, there are a whole lot more concerns, but I'll speak about two.

First, our family's success story with individualized funding is far too rare. The more common reality is that many of our most vulnerable citizens are not adequately supported, are often in medical, psychiatric and behavioural crisis, and, in fact, are at high risk of dying prematurely as well as unnecessarily.

While the Options model is innovative and successful, it's very limited in scope with respect to individualized funding, and there is currently no expectation that the ministry will allocate more funding to it. This means that other families who would so clearly benefit from inclusion in this program have no realistic hope of gaining access to it.

This is relevant to my second equally significant concern. Many people with developmental and mental health challenges are living longer than ever before, and there is no provision within Options for responding to the changing needs of its aging participants or to compensate for the increasing frailty and ultimate mortality of the parents and other family members who have been crucial to the program's success so far.

The MCSS's Options partnership with families has been a successful collaborative model for over 16 years. Now we're at the point where we have both the opportunity and the responsibility to be innovative in our approach to the next stage of planning. It's time to think differently about the delivery of developmental programs and services, and also to think differently about the role of government ministries, families, communities, corporations and the non-profit sector. I used to think that there was a crisis looming in the developmental and mental health services sector. In fact, we are in full-fledged crisis right now.

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When elderly parents are afraid of dying, when they say, "I just need to live one day longer than my son or daughter," there is something really wrong going on here. I can't tell you how many times I've heard that articulated. I can't tell you how many times I've thought that at 3 o'clock in the morning when I wasn't sleeping.

I'd like to make two specific recommendations to the select committee: first, that MCSS reaffirm its commitment to the model it implemented in 1998, so that individualized funding actually becomes a core component of our provincial funding strategy for developmental services, not a one-time closed shop; second, that there be a commitment across government ministries to be proactive, innovative and visionary with respect to the changing needs of the aging population of our most vulnerable citizens. We must find ways of moving away from being crisis-driven.

I would like to have been able to tell you in more detail why the Options partnership works so well, particularly for Victoria, but also how our family is addressing the question, "What happens to the partnership necessary for individualized funding when the parents are no longer involved?"

Our family, and many families that I know, are not passive recipients of government assistance, nor do they want to be. They want to be full partners in moving ahead and planning for the future.

I have prepared some additional comments in the handout that I've given you for your consideration, with the hope that these thoughts also could be incorporated into your submission.

Thank you for giving me the opportunity to share some of our family's personal experiences and successes and for your consideration of my recommendations. Thank you.

Ms. Janet McCrimmon: Thank you, Patricia. The story that Patricia shared is one of many that demonstrates the tremendous difference that individualized funding programs, such as Options and Passport, can make. Such funding can promote choice, inclusion and independence—the independence that individuals seek and that the government envisioned in its SIPDDA legislation.

In expanding individualized funding, we urge the government to ensure that funding is as flexible as possible and is linked to person-directed supports that encourage individuals to plan for and build meaningful lives in their communities, building on their strengths and interests.

Our Options program, an individualized funding pilot program funded by MCSS in 1997, continues to provide 89 individuals with supports to develop visions for their lives and plans to realize those visions. Individualized funding removes barriers to these individuals achieving their potential and being active, valued, contributing members of their communities. Each individual's plan and budget is unique and can include different types of supportive housing arrangements, community activities, educational courses, support for volunteering, respite, therapies etc. This is a broader array of activities, services and supports than is currently available through the Passport Program.

In addition, the individualized funding system needs to be able to accommodate changing needs that individuals and families experience without long delays. An individual's funding level should be able to go up and down based on their priorities and their needs, as well as other services and supports received. It should also be possible to reallocate unused individualized funding to people who are waiting for funding in a timely fashion.

Unfortunately, the demand for individualized funding is far greater than available resources. Ministry data shows that there are more than 5,000 adults with developmental disabilities waiting for Passport, and there are 3,500 people who are in receipt of Passport funding but have asked for more because their needs have changed or the amount isn't meeting their needs. There hasn't been, as Patricia said, an increase in the amount of individualized funding available through Options for years.

I know you've heard a lot about waiting, and I don't want to talk too much about it, but you know that people are waiting for 18 months just to get an assessment at Developmental Services Ontario to determine whether they're eligible, and then they're put on waiting lists for service or for funding.

We hear regularly from people whose personal situations are heartbreaking, who have been waiting years for services or funding with no end to their wait in sight. We can't help but think that addressing their needs more proactively could have avoided some of these crisis situations. Historically, individuals have been able to access supports while they waited for funding or service from lead agencies; however, this level of support is not possible through the DSO, which is problematic.

Individuals experiencing life transitions are particularly impacted by systemic issues. Young adults who have benefited from participation in school, who have received Special Services at Home funding and other services, often suddenly find themselves isolated at home upon the completion of secondary school. These individuals must apply for an assessment with the DSO and then wait for funding or services. They are encouraged to apply for the ODSP benefit, but this doesn't provide sufficient income to meet basic needs, much less provide for community participation. This situation is incredibly destabilizing for individuals and families and has many ripple effects for the quality of life of these individuals, including negatively impacting caregivers' ability to engage in paid employment. Ensuring continuity of services and supports for young people as they become adults has to be a priority and would go a long way to preventing some of the crises that are currently occurring.

Patricia spoke about parents who are aging and individuals who are aging. There is a DSO council paper called The Crisis of Aging with a Developmental Disability in Toronto. We really encourage you to look at that document. Their recommendations are very good and a couple in particular that we're wanting you to look at are the idea of developing a cross-ministerial strategy for addressing the money issues associated with aging with developmental disabilities, and enabling age-adjusted funding.

Finding suitable housing that is affordable is another challenge for people with disabilities. There's not enough affordable housing, and this needs to be addressed by all three levels of government. There just aren't enough supportive housing options as well for people.

In summary, we acknowledge that the challenges facing individuals with developmental disabilities and their families are numerous and complex. We urge you to strive for a flexible, seamless continuum of services and supports for people with disabilities as they navigate life transitions and age. We encourage you to be bold in order to enhance equity and fairness in the province. Ensure individuals have real options for creating a meaningful life in the community and for receiving the services they require through individualized funding and through responsive, person-directed services. Capitalize on the experience and the will to find solutions that exists amongst self-advocates, family members and agency staff. Together, we can create the future that we all seek.

Thank you for considering our recommendations.

The Chair (Mrs. Laura Albanese): Thank you very much. We have about a minute and a half for each party to comment or ask questions. We're starting with the government side. Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you so much for the work that you do. I know that you are a fairly large multi-service organization across Toronto, and you've really articulated the supports that you're providing specifically to individuals and families in this sector.

I want to thank you for sharing Victoria's story, as well. It really does help to put a face on the work that we're doing, which really is intended to strengthen our supports across a person's lifetime. I actually appreciate the fact that you focused on the aging side of things. That's something that we've touched on as we've conducted hearings, but it hasn't been, I think, as strongly articulated as you've done here today in terms of the complex needs and that report as well. I agree. I think we need to ensure that copies are shared with this committee and those recommendations factored in as we do our deliberations.

I just want to thank you for the work that you do, in particular the specialized work, such as women with development disabilities that have experienced abuse. You're focusing your resources on some of those areas that perhaps are overlooked, so I want to say thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Jones.

Ms. Sylvia Jones: Thank you for your presentation, ladies. I am not familiar with the DSO council's paper The Crisis of Aging with a Developmental Disability in Toronto, so perhaps we could get a copy of that for the members, because that's something that sort of comes up peripherally, but nobody is talking enough about it, and we should probably delve into it a little further.

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A hundred years—congratulations on your centennial.

Ms. Janet McCrimmon: Thank you.

Ms. Sylvia Jones: We're going to try to put together this combination of supportive family members and individuals who do not have that advocacy. That, I think is one of the challenges as we look at recommendations: How do they match both sides? I think what your agency is doing is a good example of that, so we have to figure out how we can take that model further afield. Thanks.

The Chair (Mrs. Laura Albanese): Ms. DiNovo?

Ms. Cheri DiNovo: Thank you very much for the presentation. Congratulations, and thank you very much, Ms. Parker, for Victoria's story. That really hit home.

Thank you for providing the figures, too. We're having a devil of a time getting figures out of ministries, so thank you for doing that. I understand that it's about 9,000 on the wait-list, which I think is what we're hearing from other agencies as well.

One of the figures that we haven't received and have asked research for is the number of folks with developmental disabilities who are in long-term care, where they shouldn't be. We've heard the figure of 4,500. We don't know if that's accurate or not. They're also in alternative levels of care, i.e. in hospitals, just sitting there, where they shouldn't be either. So that's something that we're looking for.

I have a question for you about Victoria. What will happen to Victoria once she's on her own completely? I'm just asking a question about the self-directed funding model and then how that will segue when she's on her own.

Ms. Patricia Parker: That's actually one of the things I would have loved to have been able to speak to and didn't have time for. In my submission, I have addressed that; the page is "Securing the Future of the Partnership." There I've spoken more specifically about what we're doing as a family rather than assuming or hoping that something will happen when we're no longer here.

As her parents and some other supporters, we're putting a number of things into place. Some things that people know about, like an RDSP and a Henson trust, are in place. We mortgaged our souls and bought her a little condo. It's paid for for her, so that guarantees her housing for a lifetime, as long as it's appropriate for her; nobody can boot her out.

We're working very closely with a disability lawyer, as well as working with Options and FST. We're working with PLAN Toronto in terms of looking at how we put together that next generation, and we're fairly far down the line, actually, in having identified people of Victoria's age or younger who are going to be trustees for her trust, people who know her personally and love her, who are agreeing to—I need me, you know? I can't find me. Some days I can't find me at all.

There are a number of people who know her well and who care about her, both family and not, and who love her and are stepping up to the plate, because we're asking them in terms of creating a circle of support, a network for her. That's what we're doing.

Ms. Cheri DiNovo: Thank you.

The Chair (Mrs. Laura Albanese): Thank you for adding that to your submission. That really helps us better understand what you are securing for the future.

Thank you for your presentation, once again.

Ms. Janet McCrimmon: Thank you for your time.

MS. NICOLE FLYNN

The Chair (Mrs. Laura Albanese): We now welcome Nicole Flynn, and we ask her to come forward. Good morning, Nicole. Please make yourself comfortable and start your presentation anytime you feel ready.

Ms. Nicole Flynn: Thanks. Good morning, members of the select committee. My name is Nicole Flynn. Thank you for permitting me to speak today.

Have any of you been told that you are not allowed to play on a team? I was.

Have any of you been told that you are not allowed to earn credits in high school? I was.

Have any of you been told that you were not allowed to enter a race? I was.

I was not allowed to do these things because I have Down syndrome.

Having Down syndrome doesn't stop me; society does.

When I was little I wanted to play t-ball like my brothers. I joined the same league as them. I needed extra help, and the coach looked right at me and said, "If she needs help, she can't be on the team." My parents were astonished to hear this, but they did not give up. They found other places where I was accepted.

I was eight years old when I learned about synchronized swimming. My life changed. At first, I trained three times a week. I worked hard. I had to learn to handle transitions and corrections, as well as the figures and elements, and put it all to music with a smile on my face.

My coach used to sign my routine to me as I swam because I couldn't remember my routine. I competed against athletes with a disability. Eventually, I was integrated onto a team of "normal" swimmers. For two years I competed against "normal" 16- to 20-year-old athletes. I did not win, but I had the challenge of competing against others closer to my ability.

In 2012, I was getting ready to go to Italy for the Down syndrome world swimming championships, but I had a problem. I did not have a coach to help me get ready. Imagine training for the biggest event of your life and not having a coach.

Another problem I had was money. I had to find a way to pay for my coach and for me to travel to Italy. I did not qualify for any funding because my international competition was not a sanctioned event. I guess for some people the world Down syndrome championships aren't important. But for me they are the Olympics. I swam on my own to get ready, and I fundraised by selling my wildlife photography. I held a draw for some of my framed photography. I also saved every dime I could to pay for my coach and me to get to Italy. That was hard work and stressful.

I represented Canada in the solo synchronized swimming event and Ontario in the speed swimming events. I was the only athlete in the world to compete in both synchro and speed swimming.

I won a world gold medal for Canada with my solo and two silver and three bronze international medals for speed swimming. The next competition will be held in Mexico in November 2014. Hopefully I will defend my gold medal. I'm up for the challenge.

My parents homeschooled my brothers and me because they wanted us to have a strong education. When I was 13, I wanted to go to high school. I went to an all-girl school in the TDSB. It did not work out well. I was bullied and I was not allowed to take credit courses because I have Down syndrome.

I wanted to take courses that were interesting to me and earn credits as well. I left high school and completed the Duke of Edinburgh challenge. I learned to set goals for myself. I believe the more I achieve, the more I succeed. I enrolled at the Quinte Adult School when I turned 18 years old. This works well for me because I can move through the courses at my own pace. I have earned 20 credits so far.

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In the past I have done two triathlons. My coach wanted me to do the Welland Sprint triathlon because the course is flat. A flat course would be easier for me on my recumbent bike. I was not able to do the triathlon because they wouldn't accept my recumbent bike. It is hard for me to ride a two-wheeled bike because I don't have good balance and I have to be careful about my neck. This summer I started riding a two-wheeled bike with adult stability wheels.

I hope people in charge of the races will learn to accept people who require different equipment and permit them to enjoy the same privileges as everyone else. People of all abilities like to race and push the limits.

I hope to have a job one day. I would like to work at something that I enjoy, am good at and will support me. I know it will take time to learn to do a job well, but I have a lot of practice at hard work. I have volunteered for many years, and I am ready to be paid for my work.

I would like to live on my own one day. Right now I have to live with my parents because I don't have enough money to live in my own place, buy groceries and participate in society. I am also worried about being safe. People try to trick me and sometimes they make fun of me. I don't like that. I am careful with my money, but sometimes I need help counting the right amount. Sometimes people rush me and I make mistakes. I need extra time. It is not fair to rush people.

I have an extra chromosome but I have a lot of ability too. I have overcome many obstacles that people said I never would. It hasn't always been easy. I do not give up. I keep on trying. I have done many things in my life, and there are more things that I want to try.

The greatest challenge for me is that people think I am not able to do things. When people take the time to work with me, they get to know me and are able to see what I can do. I am a human being and I am capable of living a full life.

Now, I'd like to read my poem. It's called I Am Not Invisible. It was published by the city of Toronto in 2010.

People talk to me as if I am a child
I am an adult,
Look at my eyes and talk to me as an adult.
People treat me as if my feelings don't matter
I feel things,
I hurt inside when things happen.
People won't even let me try
I want the chance to try,
I might make mistakes; I will keep trying.
People do not see me; they treat me like I am invisible
I am here,
I want people to look at me.
People tell me what to do all the time
I can make decisions,
I am able to think for myself.
People treat me like I'm a non-person
I am a human being,
I am not a mistake.

Thank you.

Applause.

The Chair (Mrs. Laura Albanese): Thank you, Nicole, for your story of incredible success against all obstacles. I want to commend you for your determination, for your courage, and congratulate you for all your achievements—your medals and your achievements in education. But I have to go on to allow for questions. We'll have about three minutes for each party to talk to you.

Ms. Elliott.

Mrs. Christine Elliott: Thank you so much for being here, today. Nicole, you are awesome. It's unbelievable what you've been able to do. You've got a brilliant future ahead of you, I'm sure. It also sounds like you've got a pretty special family that has been supportive of you, too, and helped you every step along the way. You know, there are lots of people who do not even think about coming to sit up there by themselves and be as composed as you are, so it's wonderful of you to be here. You've given us a whole new opportunity, a new way of looking at things, that you're really going to make a difference for us in our presentations and in our decision-making at the end of it to create a report that's going to make sure that everybody has an opportunity to be the person they want to be and to do their very best.

Can you just tell me: What's your plan for the future? Where do you go from here?

Ms. Nicole Flynn: I'm hoping to be with my parents somewhere that it can be more supportive in respect for a different atmosphere that I can be most productive for myself and to society.

Mrs. Christine Elliott: Wonderful. Thank you very much for being here.

Ms. Nicole Flynn: You're welcome.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Nicole, you are truly a champion. I just want to thank you so much for coming here and talking to us. I couldn't synchronize-swim if my life depended on it, and I've never entered a triathlon. I don't think many people here around this table have. So you're our hero. Thank you for sharing those incredible accomplishments. You're an amazing young woman.

I just want to ask something of research. That is: We have, in Ontario, an act that is supposed to gain accessibility for people with developmental disabilities. I know that the date for doing that is way off in the future—I think it's 2025—but I want to know if that act covers sporting events and athletic events, because I was very shocked to hear what you had to face when you just wanted to enter those sporting events. We need to make sure that sporting events, especially if they get public money, are open to everyone. That's something that I pledge that our committee will look at and take action on—because of you. So thank you.

Ms. Nicole Flynn: You're welcome.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you, Ms. Flynn, for your very powerful and excellent presentation. I think that what you're doing is absolutely amazing. You're a wonderful ambassador and inspiration to all of us. I really want to commend you on all of the achievements that you've had in your life and those that are ahead. I know that there are many great things ahead of you.

I notice here that you are interested in getting into the labour market and to find paid work. Are you participating in any of the social enterprise programs or in any way connected to organizations that could help you do that, and to achieve that goal that you've set for yourself?

Ms. Nicole Flynn: Well—

Ms. Kathryn Primrose: Can I step in?

The Chair (Mrs. Laura Albanese): Sure. Please come forward.

Ms. Kathryn Primrose: I'm her mom.

Ms. Nicole Flynn: Kathryn Primrose is my mother.

Ms. Kathryn Primrose: You lost her at "social enterprise."

The Chair (Mrs. Laura Albanese): You can have a seat.

Ms. Kathryn Primrose: What do you want to do for work?

Ms. Nicole Flynn: I want to work. There's a lot of stuff that I want to work at. One of them is speaking to you guys, which is my strength—

Ms. Kathryn Primrose: Being a speaker.

Ms. Nicole Flynn: —being a speaker, and—I don't know what else to think of.

Ms. Kathryn Primrose: You've been talking about Pet Valu.

Ms. Nicole Flynn: Yes, I was thinking about doing Pet Valu and maybe work in their shops.

Ms. Kathryn Primrose: And your photography business?

Ms. Nicole Flynn: Yes. I do photography at Madoc market up in northeast—

Ms. Kathryn Primrose: She has her own photography business where she sells her wildlife pictures.

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Ms. Nicole Flynn: And it's actually called Flynnster's Pictures.

Ms. Kathryn Primrose: Flynnster's Pictures.

Ms. Mitzie Hunter: That's wonderful. So you actually are creating your own employment and are an entrepreneur. That's wonderful. So good.

Ms. Nicole Flynn: Thanks.

Ms. Mitzie Hunter: Thank you so much.

The Chair (Mrs. Laura Albanese): I want to thank you once again for coming to speak to us today and I also want to wish you all the best for the next competition in Mexico in November of this year to defend your gold medal. All the best. We'll be rooting for you; we'll be cheering for you. We hope you defend Canada and defend with determination all you have earned. Good luck.

Ms. Nicole Flynn: Thanks.

Miss Monique Taylor: Let us know how you do. We'll be rooting for you.

Ms. Nicole Flynn: Will do.

The Chair (Mrs. Laura Albanese): Yes, we'll be in touch.

Ms. Nicole Flynn: Thanks.

ONTARIO AGENCIES SUPPORTING INDIVIDUALS WITH SPECIAL NEEDS

The Chair (Mrs. Laura Albanese): We'll now ask the Ontario Agencies Supporting Individuals with Special Needs—OASIS—to come forward and make their presentation. Good morning.

Ms. Jane Joris: Good morning.

The Chair (Mrs. Laura Albanese): You will have up to 20 minutes to make your presentation, and if it should be any shorter than that, that would allow for comments and questions from the members of the committee. You may begin at any time.

Ms. Jane Joris: Thank you very much for the opportunity to address the committee today. My name is Jane Joris and I'm the president of Ontario Agencies Supporting Individuals with Special Needs, or OASIS. I'm joined by our vice-president, volunteer, David Barber, and vice-president and executive director, Allan Mills.

OASIS is a volunteer-run, member-driven organization. Our member agencies serve over 65,000 of Ontario's most vulnerable citizens and employ 25,000 full- and part-time staff. Our 172 member agencies currently provide more than 85% of all developmental services funded by the Ministry of Community and Social Services and receive approximately $1.4 billion in operating funding annually from the Ontario government.

In addition to our work with OASIS, each of us is involved in other roles in a different part of this province. I work as an administrator of a long-term-care home in Lambton county and as a volunteer with Lambton County Developmental Services. Both David and I have family members who have intellectual disabilities. David Barber serves as president of Simcoe Community Services, and is also a business owner. For his part, Allan Mills serves as vice-president, Ontario, of Christian Horizons, Ontario's largest provider of developmental services.

I mention this in the interest of full disclosure, but also by way of highlighting the hard work and double volunteering duty that so many in the developmental services sector are known for.

Perhaps most importantly, these multiple hats give each of us the ability to understand the challenges facing developmental services both in our communities and at a provincial level.

We have seen first-hand countless families struggling to make ends meet and having to make decisions that most Ontarians would never have to contemplate. We have seen families languishing on wait-lists forced to leave their jobs in order to care for a loved one. We regularly encounter adults with developmental disabilities living with aging parents whose own health challenges are exacerbated because their retirement savings have been depleted and they are no longer able to support the daily needs of their child or themselves. Worst of all, we have seen many declare themselves broken and make the heart-wrenching decision to leave their child on the doorstep of a service provider.

We are deeply embedded in the economy of the province, and we see first-hand every day how the level of unmet investment in services for Ontarians with developmental disabilities results in a loss for every taxpayer. This economic loss is not only felt at the front end when family members are forced to quit their jobs to care for loved ones on wait-lists; ultimately, unmet needs of this nature evolve into crisis scenarios and end up costing taxpayers even more on the back end in costly band-aid solutions. A lack of preventive services is inextricably linked to more crisis situations, which ultimately drives up the cost to taxpayers.

It’s clear that the needs are great and the resources are limited. We are now at a breaking point. Existing services alone face a funding shortfall of $100 million by 2015-16. That figure does not take into account the 12,000 to 20,000 Ontarians with developmental disabilities currently on wait-lists.

Ontario’s approach needs to be one that engages a village in an integrated strategy. A holistic solution must reach beyond the parameters of services provided solely through the Ministry of Community and Social Services, in a way that follows the path set out by the principles of the Accessibility for Ontarians with Disabilities Act, the transformation agenda and the service improvement recommendations outlined in the 2012 report commissioned by the Ministry of Community and Social Services, Brighter Prospects, which reviewed social assistance in Ontario.

Today we would like to touch upon some of the presentations that have already been delivered to this committee, and, in doing so, help to demonstrate that solutions for the developmental services sector are within reach. With proper planning, people in need of support can transition into less expensive situations, connect to more informal supports and take control of their lives.

Mr. David Barber: Many of our member agencies have appeared before you, outlining the ways they have stretched limited resources cost-effectively and responsibly to build more capacity in their local communities and modernize service delivery. Our members have been responsive and responsible in doing their part to help mitigate the financial challenges of the province, while continuing to honour commitments to our most vulnerable citizens.

As a sector, we have championed the challenges in many creative ways—ways that have built partnerships and collaborative approaches, forging inroads to access in five critical developmental services success areas: providing housing, employment, respite care, knowledge sharing and leadership development.

I want to reiterate just a few examples you have heard of our member agencies and their long record of great care, service quality and ensuring bang for taxpayers’ buck:

Community Living Toronto has the Lights alternative housing model;

Community Living Essex County has partnered with the city of Windsor and the Ministry of Municipal Affairs and Housing to provide affordable housing;

Community Living Tillsonburg has partnered with the Ontario Disability Employment Network to promote and find employment opportunities for individuals with disabilities;

Christian Horizons has created a family retreat through fundraising and through volunteerism;

Kerry’s Place Autism Services has provided specialized services for individuals with autism in collaboration with schools and families, while Ottawa Rotary Home has provided leadership in development of an agency collaborative to provide a community nurse consultant;

Participation House Project (Durham Region) has developed models of transparency and accountability that engage all employees in financial decisions;

Community Living Owen Sound and Community Living Walkerton and District have created a model to share the expertise and oversight of one executive director.

Mr. Allan Mills: In an environment where urgent problems consistently trump important structural issues, little money is allocated for preventive and proactive services. Funding based on crisis alone will ensure that waiting lists continue to grow, that we fall further and further behind, and the burden to taxpayers continues to skyrocket. Continued referral of our families to other public support models, the costs of which are far greater than what could have been provided through developmental services, is unsustainable.

Perhaps most unjustly, many of those on waiting lists and facing crisis are people who have kept their kids at home, founded agencies and services for others, and now find that there is no support available for them. The positive news is that we can stem the negative tide immediately, using a two-pronged approach that addresses a growing backlog of crisis care while also proactively investing in preventive solutions to stop crisis situations from germinating in the first place.

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First, we must commit to proactive systems changes. For example, many of our member agencies have legislated pay-equity commitments to their staff. In a frozen funding environment, services will continue to be eroded as agencies struggle to meet these legal requirements. At no cost to the government, the province should delay this pressure to ensure that services are not compromised.

Additionally, many of our member agencies deliver services on an ad hoc basis with no government commitment to fund the services beyond the current fiscal year. An inability to plan more than one year ahead means that agencies lack the ability to fully apply localized expertise to ensure cost-effective service delivery.

Because our members have proven their worth in terms of stretching every dollar, it is time to repay that faith by giving them more responsibility and opportunity. The budget process must allow for the creation of reserves, similar to community counterparts funded by the Ministry of Health. Transfer payment agencies should have four-year rolling budgets, with appropriate accountability measures, for the purposes of establishing reserve funds to fund capital projects and major repairs, and to develop innovative, cost-effective programs in a planned manner.

Second, additional investments are needed to ensure that critical and immediate needs are balanced with the imperative for preventive and proactive services. The province must commit to a one-time investment to stop the mounting crisis situation created by four consecutive years of no additional funding to sustain existing services or even to provide an annual cost-of-living increase.

Third, we must prioritize inter-ministerial and cross-sector collaboration. Prioritizing collaboration across ministries such as the Ministry of Training, Colleges and Universities, the Ministry of Health and Long-Term Care, the Ministry of Labour and others is the only way to develop an integrated strategy to address poverty and the need for accessible and affordable housing, and to ensure that every person who has a developmental disability and their family has access to the support they need. The Ontario Partnership on Aging and Developmental Disabilities and the Ontario developmental services human resource strategy are but two successful examples of a type of inter-ministry programming that we desperately need more of.

Ms. Jane Joris: On behalf of OASIS's 172 member agencies and the thousands of Ontarians that we support, I want to thank the members of the committee for your time today. We are happy to delve into further detail in the question-and-answer time and elaborate on the three solutions we've briefly outlined, solutions that will allow volunteers in our member agencies, who are experts in the field and who have already demonstrated to you over and over again a capacity for stretching every dollar to deliver high-quality services, the opportunity to address both critical and preventive service needs. Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you. We have about two and a half minutes each for questions. Ms. DiNovo?

Ms. Cheri DiNovo: Thank you very much for your input here. Of course, it just builds on everything that we've heard from every other person who has come forward as a witness, so there is a wonderful—sad, but wonderful—congruence between it all.

The multi-year commitment model, we've certainly heard before, and it makes some sense. You don't spend all your time reinventing the wheel. In terms of the pay equity, we've certainly heard that before, that legislation.

Again, the wait-lists seem all over the map. We don't seem to have concrete data. We are saying 12,000 to 20,000; that's a gap of 8,000, so we don't even—this is a great shortfall of the ministries, I think, if we don't even have accurate figures to work with on that.

You perhaps heard me say earlier that we would really need figures on how many people are in alternative levels of care, waiting in hospitals and in long-term-care homes, where they shouldn't be—that whole sector, because essentially what that helps us to do is make an economic argument for proactive planning, which is what you're calling for, because we are crisis-funding now. By doing so, we've created a crisis; that's very, very clear. So we have to get away from that, and to do that, just to find even the figures that we need is difficult. That shows how far behind we are.

I want to thank you for all the good work you do, and your member agencies are phenomenal. We've heard from many of them. I particularly made notes of some of those special—like Lights and others, some incredible creativity when families get together and start to think and plan. Thank you.

Ms. Jane Joris: Thank you.

The Chair (Mrs. Laura Albanese): We'll pass it to Mr. Balkissoon.

Mr. Bas Balkissoon: Thank you for being here and for all the work that you do in the communities.

There's something I heard you say, and I'm not sure I heard it exactly correctly, but a lot of your member agencies have been here presenting, and you're here. Has there been a collective report with some major recommendations that the government can look at, rather than us going through all of it and having to put it together? Because you're the experts.

Ms. Jane Joris: We have not done that. I believe that the provincial network has done a little bit of work on that, so we can speak with them and see if they've got something together. But we have not done that.

Mr. Bas Balkissoon: Is there any possibility of something collaborative being done before the committee finishes its work?

Ms. Jane Joris: The provincial network meets on Thursday, so we could speak with them then, for sure.

Mr. Bas Balkissoon: Thank you. I'd really appreciate that, because we've gone through piles of documentation. I think yours would be more focused, because you've basically made some comments that some of the changes necessary can accomplish a lot. I'd love to make sure that we consider them.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Jones.

Ms. Sylvia Jones: It's good to see you again. Thank you for your presentation.

I have to say, I really am glad that you raised the fact that we almost are punishing families who were willing and able to support their children in a family environment by the situation we're faced with right now with the wait-lists and the "Come back later" concept.

I have a question for you. You were very diplomatically silent on any comment about the DSOs. I wonder if you could share with the committee your thoughts.

Ms. Jane Joris: A number of our members are DSOs, so we're working with them to help them with the struggles they are facing. We do recognize that we don't have the informal contacts with the people who are waiting for services that we used to have, and I think you've already heard about that in a number of presentations. We recognize the struggles and we recognize it's a huge change in how the sector works. There are definitely some problems, and we're trying to work with the DSOs to help them work on that. We meet regularly with the network of the DSOs as well.

Ms. Sylvia Jones: Are you finding that the DSO rules are being applied consistently province-wide?

Ms. Jane Joris: Probably Allan can speak to that better, since their organization is provincial.

Mr. Allan Mills: Sure. I work with Christian Horizons, and we work with all nine ministry regions—I guess it's five now, but there are nine Developmental Services Ontario organizations, and my organization works with all of them. There is a fairly vast range of how they do their work, considering that the intent of the system has been to standardize access across the province. In some regions it works quite well, and where it works best, there's a collaborative approach that involves the developmental services organization along with the service provider agencies, working strongly together. We see that in several of the regions.

In some, there seems to be more of a sense of barrier and isolation between the families that need services and the service provider organizations. Like Jane mentioned, historically, there would be some informal relationships developed over a period of time, maybe informal supports provided while waiting for the more formal supports, but it's harder to do when there's a step in between the families that need the services and the service provider. Things are much more tightly monitored in terms of services. We serve a certain number of people according to our service contract agreement with the ministry, and for us to essentially informally serve more people kind of takes away from the people that we're officially funded to serve. So it helps if there's some creativity and flexibility in that process.

Ms. Sylvia Jones: Thank you.

The Chair (Mrs. Laura Albanese): Well, thank you once again for presenting to our committee. I guess we'll look forward to that more comprehensive presentation that will sort of summarize all of your suggestions and recommendations.

Ms. Jane Joris: Okay. Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you so much.

We are recessed until 1 p.m.

The committee recessed from 1150 to 1304.

CUPE ONTARIO

The Chair (Mrs. Laura Albanese): Our committee is back in session, and we are calling on our first presenter of the afternoon, CUPE Ontario. President Fred Hahn, how are you? Good afternoon. You can start any time you're ready. You will have up to 20 minutes for the presentation.

Mr. Fred Hahn: Perfect. Good afternoon. My name is Fred Hahn, and I'm the president of CUPE Ontario. With me today is Sarah Declerck, who is the coordinator for our social services in Ontario for our union.

I should also tell you that a number of CUPE members who work in developmental services will be appearing before the committee to bring you a more in-depth examination of the experience that they have in different community agencies.

Let me begin by saying that CUPE welcomed the establishment of the all-party select committee and its mandate to develop a comprehensive developmental services strategy to address the needs of children, youth and adults in Ontario with an intellectual disability. We very much appreciate the opportunity to appear before you today and to deliver a submission on the state of the sector and our proposals on a way forward.

I want to stress that this analysis and the recommendations contained in our written submission, which is on the way—sorry, it got caught in traffic—is based on the broad experience of our many years in the developmental services sector across Ontario.

CUPE has the privilege of representing 8,000 members who work in developmental services in 55 different community agencies. In fact, prior to becoming CUPE Ontario president, I also had the privilege of working in this sector for well over a decade.

The sector has evolved and changed dramatically over the years, and our union's members have been there at every step. CUPE members working in developmental services care passionately about the work they do with the individuals and families they work with every day, and they are looking to you, the members of the select committee, for leadership in this sector, which desperately is searching for a champion. All of us look forward to your report and hope that it reflects our combined efforts and that our efforts will make a contribution to that.

Overall, the developmental services sector, from our view, seems to face two big challenges, the answers to which will be the core components of the comprehensive developmental services strategy that you have been tasked to find.

The first is about funding and the second is about ensuring that the design of a support system that we provide is shaped by the needs of individuals, families and service providers and not by the dictates of any one or other political or fiscal agenda.

Let's start by talking about funding. Although it suffers from overuse in some discussions like this, the word "crisis" seems appropriate to describe the facts in developmental services in Ontario today. There are at least 24,000 families on wait-lists for residential care, respite care and day programs—24,000. Is that a crisis? For the families on those wait-lists, I suspect it is. And it does get worse. According to a recent survey done by OASIS, an association representing agency employers, 62% of responding organizations have cut staff hours, 51% are eliminating staff positions, 58% are not filling open positions like maternity leaves, 18% are reducing program hours of operation, 7% are permanently closing programs, 16% are shutting down programs for a specified period of time, 28,000 staff hours per week and 665 program hours per week have been eliminated, and 42 programs have been temporarily closed. Some 65% of agencies surveyed reported that as a result, they're able to provide less individualized care, fewer specialized services, a decreased prevention service ability, elimination of recreation activities and community outings, elimination of quality-of-life activities, and being forced to introduce new user fees for transportation and day programs.

What conclusions can we draw from this information? Remembering that we have a steadily growing and aging population, the most logical conclusion would be that provincial funding supports for Ontarians with developmental disabilities have obviously not been sufficient to prevent reduction in service levels. Even when we take into account one-time injections of $220 million in 2007 and $42 million last year, what we see is simply a failure to keep pace with growing demand. We see an actual reduction in services.

Let's be frank: Reduced services mean cuts. I'm sorry; there's no better way to describe it than to say "cuts" when we talk about reduced hours, eliminated staff positions and closed programs. I stress this because in our experience with the ministry, we've been repeatedly told that there are no cuts because government has delivered funding increases. The facts would say that whatever increases may have been delivered have not been sufficient to prevent cuts in service levels and programs, and we have an obligation to do better. That's what adults and children with developmental disabilities and their families need to hear in your report, and it's also what CUPE members and everyone else involved in providing these supports is looking for you to say. They need this all-party select committee to be unequivocal in its report, that when it comes to supports for children and adults with developmental disabilities in the province of Ontario, reduced hours, eliminating staff positions and closed programs are not something that we're prepared to live with, nor should it be accepted by any government of any political stripe in Ontario in 2014.

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The second major issue facing this committee is about strategic design. What model of support system is best for persons with developmental disabilities and their families? We all know that in Ontario, the model has changed and evolved over decades, and it's still evolving. While the move away from old institutional models was necessary and overdue, there is today a pressure that threatens to go too far in another direction. Driven more by political dictates than by the needs of Ontarians, there is now a pressure to undervalue the degree to which individuals and families need the organizationally structured support that only an agency model can provide.

The number of individuals who need agency and residential supports is increasing, not just because our population is growing, but because the parents of developmentally disabled children and adults are themselves growing older and, as such, are less able at home to provide those supports even when they have accessed Passport funding or by accessing a measure of respite care. Just looking at the relative size of the wait-list leads us to the same conclusion. The number of people waiting for agency residential supports is not shrinking, but is, in fact, much larger than the number of people waiting for respite care or individualized direct support that comes through Passport. And it will only ever more so increase in the years to come.

This is even more so true when we look at the numbers and understand that many families, when they've come forward asking for support and put their names on a wait-list for Passport, have done so because they've been told that if they only wait for a residential space, they could wait forever. Facing up to that reality should make it clear that the strategy of the slow starvation of our agencies is wrong-headed and should not be part of the direction this committee charts for the future.

But this is not a discussion about a growing and aging population only; it is about the model that is best suited to deliver services that Ontarians need. Is it just a coincidence that as more agencies are starved to the point of cutting hours and programs, and there are longer waiting lists for residential spaces, the more vulnerable the agency model becomes to the charge that it is no longer the best model for service delivery in the sector?

What I've learned—what thousands of other CUPE members working in the sector have learned over the years—is that residential support cannot be replicated through individualized funding models like Passport. In fact, not only is the agency model capable of providing support based on individual need and program design, it is the best model to do that. Why? Because it brings together the broadest range of talent, experience and resources. It does things that no individual family or service provider could do working alone. It is efficient precisely because it makes possible economies of scale.

Let me be clear: CUPE is not here today to say that Passport should be eliminated or the DSO shut down, but we are here to say that the funding balance is wrong. The emphasis is wrong, and it is past time for a rethink of our model of service delivery in this sector.

It's time to recast the model such that it reflects the reality of developmental services and meets the real needs of Ontarians. Doing that in an honest way, in a way not driven by dictates of a crusade against the provincial deficit, will lead to an appropriate valuing of the organized agency model and, accordingly, an appropriate approach to funding.

In conclusion, I want to be very direct: What CUPE is asking of this committee—and I believe what Ontarians with developmental disabilities and their families and indeed all service providers are looking for from the committee—is for you to find the political courage to say something that has become very difficult to say in Ontario. We need to say that there are times when some priorities in a civilized society must stand above any short-term pressure to achieve a balanced budget. Meeting the needs of our friends and family members with developmental disabilities is one of those times. If you can find your way to that conclusion, you will have done a great thing for Ontario and you will have made a lasting difference for thousands of families.

Thank you, and we'd be pleased to take any questions.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. We have about three minutes for each party. I'm going to continue where we left off, so it's the government's turn to start the questions.

Ms. Mitzie Hunter: Thank you so much for your presentation. I know that the handout that you provided has more detail and background that will help to inform our work. As you know, this Select Committee on Developmental Disabilities was struck to respond to the needs and to ensure that we have the supports across a lifetime for a person with developmental disabilities and dual diagnoses, but also to ensure that there is inter-ministerial coordination and prioritization. That is the mandate. That's what we're here to do. We have been talking to many families, individuals and organizations across the province. Many of your members have provided really valuable input.

I see here that on page 15, you have a number of recommendations in terms of what the sector needs. Is there a particular—I won't ask you for one, but are there any of these that you feel are of greatest importance for us to consider?

Mr. Fred Hahn: Thank you for calling attention to some of the more concrete recommendations. I think, from our perspective, many of these are interrelated. As I said in my presentation, what we try to do is characterize both the challenges around funding, because there seems to us to be a clear need for additional funding in this sector, but also around the model in which that funding is disbursed and utilized.

Some of the other things that we've pulled out here speak to the way in which we can best provide supports for people with developmental disabilities, based on the experience our members are currently seeing, but also the experience they've had over a number of years: for example, having the right staffing ratio to deal with particular challenges and particular individuals to ensure that that ratio allows for community integration and all of the other things that our agencies and that many of us are mandated to provide and to ensure and to facilitate for people with developmental disabilities. In many ways, these are all tied together in some way.

It's good to hear that the work of the select committee has already been important in ensuring some inter-ministerial coordination, because for young people who reach an age where they're no longer able to access certain supports and enter the adult realm, there is a challenge in that transition, and the more focus that we can place there and the preparation for people is quite important.

Again, all of these things in some ways are linked, but in some ways it also goes back to the fundamentals, which are: How will we fund the service and what is the model in which we're funding it? It's why we say that we believe strongly in the ability of agencies to bring together the kind of expertise and support that families truly need.

Ms. Mitzie Hunter: We've heard so much from the families with children and adults with developmental disabilities and there seems to be the need for both, that families want to be able to provide that natural support, but they need the help and the relief to do that. Can you talk about what your members are seeing in terms of what families are asking for the most?

Mr. Fred Hahn: I think it depends on the particulars of a family, naturally, but there are increasing numbers of aging parents who have, for many years, cared for their adult child with a developmental disability. Those supports for those families are in fact more critical. But one of the challenges we have in this sector is that in fact that's where we're at: You have to have a crisis before people can access the kind of supports they need, rather than making a plan that will help people to access these kinds of supports in a way that isn't based on crisis but is actually based on what's best for the individual.

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In the experience that I had in the agency that I worked for, one of the things that we were engaged in at that time, and that was some years ago, was this real work with families to ensure that we were working together for the best interests of the individual with a disability, and that we could be providing the kind of supports necessary. But that was always limited to how many staff we had, how much we could do for that family. Increasingly, people were left with small amounts of respite care, which provide some support to a family but aren't the kind of comprehensive care that's required to plan into the future for anyone with a developmental disability.

The Chair (Mrs. Laura Albanese): Thank you. I'll pass it now to Mrs. Elliott.

Mrs. Christine Elliott: Thank you very much, Mr. Hahn, for coming before us with your presentation and your recommendations. We really appreciate it. We have heard from some of the agencies in some of the travels that we did last week, but I think this is the most comprehensive piece that we've seen so far.

One of the things that you talk about in your recommendations is to let people know the extent to which people are being held in inappropriate locations, like long-term-care facilities, hospitals and jails. I agree with you entirely. That's much more expensive care to begin with, but also, more importantly, it's not appropriate care. We should be making sure that we only use that as an option where there's absolutely nothing else available.

But I think there is no question, at the end of the day, that this is a sector that is under-resourced and that is going to need some assistance across a whole range of activities, from housing to respite to day programs and so on. I think that what you've brought forward makes a lot of sense. I think you'll find that the members of this committee all feel the same way. So we look forward to working with you in the future.

Mr. Fred Hahn: Thank you.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Thank you for the presentation. It's very succinct.

In the recommendations, one of the interesting ones—you say it directly, what so many others have inferred—is that the money that goes to the DSO could be better spent. That was welcome.

Number two: What you've said here, which I've constantly been asking for, are examples of where it's done better. It's interesting that you mention Saskatchewan and Australia, because those are two that have come up again and again. Particularly interesting in a sense, especially because it is, of course, not a left-leaning government in Saskatchewan, is the mandated end of wait-lists. I think if you mandate, the money flows; if it's entitled, the money flows. If it's discretionary, it doesn't, and that's what we're seeing here. So the different systems, the discretionary, i.e. welfare kind of systems we're used to, or entitled, as in health care, are two very different systems. We're not sure that what's working here is the discretionary one, which is what we've got.

So I thank you for all of that as well. Again, I think, like Mrs. Elliott said, we're on the same wavelength here. Thanks.

Mr. Fred Hahn: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much once again for the comprehensive presentation, and we'll leave it at that for now.

Mr. Fred Hahn: Great. Thank you, and thank you for all of your work on this committee.

The Chair (Mrs. Laura Albanese): We appreciate your input.

DEVELOPMENTAL SERVICES TORONTO COUNCIL

The Chair (Mrs. Laura Albanese): Next we're calling on Jasmin Earle and John Mohler. We had a change in the names, and I guess the Clerk would enlighten us. He just made a change on my agenda.

Welcome to our committee. You will have up to 20 minutes to make your presentation. If there is time left over, then we will have some comments and some questions from the members of the committee. You may begin any time you feel ready.

Ms. Jasmin Earle: Okay, thank you. First of all, thank you for giving us the opportunity to come before you. Let me just introduce myself. I'm Jasmin Earle, and I chair the Developmental Services Toronto Council. The DSTO Council is made up of community volunteers, board members from service provider agencies, family members who are using services and self-advocates who are service users who are supported by facilitators to participate on council. We also have representation from the ministry, and we have representation from the service provider committee of the DS Toronto partnership, which is all of the service provider agencies working together in a collaborative.

Council's primary role is to advise the ministry and advise service providers around issues that are related to the delivery of services within Toronto. So what we brought today was something that were really system challenges and pressures which we thought were relevant to the role and mandate of this committee. We didn't bring forward specific challenges that are unique to Toronto because we already have the opportunity to work within that system on service delivery improvement.

Council has representation on standing committees of the DS partnership, such as improving quality information and planning. We also participate in task forces, ad hoc work groups, and we also have our own council working groups, which include members of council, but also external resources and experts, including academics, who work with us on working groups that are linked to the priorities that the council has identified around making improvements to the service system.

Sorry—I just have to now get back to my notes, because that was sort of ad hoc.

Three years ago, DS council struck a working group, and this working group was really in response to much of the community engagement and stakeholder consultation that we had done, because we see part of our role as giving voice to service users and providing a forum and opportunities for them to bring forward their priorities.

A priority that we were hearing over and over again was related to aging caregivers and aging service users, and some of the challenges that people were experiencing as they aged in continuing to provide either complementary services and/or being exclusively the caregivers of their adult children with developmental disabilities who were also aged.

Our working group was struck three years ago, and we developed a report. The report that you have before you is the product of that working group. It was also shared with the Ombudsman during the recent inquiry. It's also a report that has come through support from our collaborative, so that the ministry and our service provider partners are aware that we're bringing this report before you today.

I'm going to let my colleague John Mohler, who is a member of council but also a member of the aging work group, to run through some of the highlights of the report. Then, at the end, we have some recommendations. Those recommendations are contained at the back of your report.

Mr. John Mohler: Thank you. I'll hope my voice holds out. I have an appointment with my surgeon tomorrow at St. Mike's, but we'll soldier on.

I should add that, in addition to being a member of the council on the work group, I'm a parent. My wife and I have four children, three of whom were born blind. Of those, our two eldest sons, 34 and 33, are also nonverbal. They have a dual diagnosis. They both understand the world as someone much, much younger. Their contribution to the community has to be considered in quite a different manner. We also have a 28-year-old daughter, who is blind and has a master's degree from the University of Western Ontario.

Having read some of the transcripts that have been presented, especially those of parents, what we're going to talk about will undoubtedly come as no surprise to you. You've heard heartfelt stories. Families will have the issue of aging to deal with, not only the aging of their children, but their own aging.

It's difficult to establish the prevalence of developmental disabilities within a population, but the best evidence at the time of our report indicated that somewhere between 1% and 3% of Ontarians are developmentally disabled. So that suggests that within Toronto there are between 25,000 and 75,000 people with some level of developmental disability.

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How many of these individuals are receiving service from the 37 agencies within the metropolitan area that are funded by MCSS? Statistics available when we published indicate that there are just over 12,000 individuals receiving services. That leaves, as you can see from the other numbers, a large hidden population of more than half who are unknown to the system, who are unidentified. They will need services at some point, likely when a crisis arises, and likely when their parents can no longer take care of them. Of those 12,000-plus receiving services, 1,920 receive some kind of residential support—that could be a group home, semi-independent living or some other support.

Also, we know that in Toronto there are 2,296 individuals on the waiting list. Caregivers for 207 of these individuals are between the ages of 71 and 80, and 112 are between 81 and 90. And shockingly, for 22 of those individuals, their caregivers are more than 90 years old—these are people living at home with a parent more than 90 years old.

Ontario has made great strides over the past 20 years in the advancement of care for people with developmental disabilities, especially as it relates to living within a community as opposed to living within institutions. However, this also comes at a cost to the family home, exacerbated by existing demographics.

With our aging baby boomers, as well as longer lifespans, comes a two-pronged dilemma. As the parents of individuals with a developmental disability age, their capacity to care for their children diminishes as their own health declines—and as they die. As adults with developmental disabilities get older, the onset of age-related change often occurs earlier than otherwise, and typically would require more extensive—and, therefore, more expensive—care. For example, among people with Down syndrome, the mean age of death rose to 56 by 1993, up from an estimated nine years in the 1920s.

US studies suggest that the total population of people with developmental disabilities age 55 and over will double by the year 2030. Compounding these changes is the fact that there is a higher prevalence of early-onset dementia within this population, including those with Down syndrome.

Additionally, a recent study showed that in Ontario, over 45% of adults with a developmental disability have received a psychiatric diagnosis, a dual diagnosis, during a two-year period.

From the statistics that we've prepared in the report and summarized somewhat here, we can estimate that somewhere between 85% and possibly as much as 95% of the day-to-day care for people with a developmental disability is provided by those individuals' parents and/or families.

Here are some highlights of several cases that are identified within our report.

Ms. Jasmin Earle: Mary is an 84-year-old woman living in a one-bedroom apartment with her 85-year-old developmentally disabled brother. She has been her brother's primary caregiver for almost 30 years. The CCAC provides some support, as well as a day program and some occasional respite service. However, Mary's health is declining, and she worries about her brother, who is very reliant on her. She is also unhappy with their current level of supports, where they rely on a revolving door of workers and support staff coming in and out of their home.

Another story is of Carol, who is 77 years old and has a 57-year-old daughter, Karen, who is developmentally disabled. There is no long-term plan for Karen, who is currently involved in an occasional respite program, as well as a social program once a week. Carol feels trapped as the caregiver, and she herself doesn't want to go into long-term care because she has no place for Karen. She would like to see Karen settled into a group home.

Does long-term care fit into the equation? Well, yes. The Ontario Partnership on Aging and Developmental Disabilities, known as OPADD, is a partnership between the developmental and long-term-care service systems, with the goal of coordinating an approach to supporting people as they age. They've had some success, and we recognize that their focus on bridging the developmental and long-term-care sectors is an essential step in helping people to address the issues surrounding aging within our population.

The sectors must use each other's resources and must coordinate their response so that people can remain in their homes if they wish and are able. And when it is appropriate, the application process for an individual with a developmental disability into a long-term-care facility is no better than the process for the rest of the population.

So with over 20,000 at any given time waiting for a long-term bed in Ontario, the availability of specialized care required for this population remains severely restricted and with very inequitable access.

Mr. John Mohler: To assess the current level of service on the part of the 37 Toronto-based agencies, we conducted an online survey in April 2012; 24 of those agencies replied. You'll see their detailed responses in our report; that's appendix B.

To summarize, the report was based on individuals over the age of 40. Highlights are that 70% of the agencies who responded are providing some level of support to individuals over the age of 40; 16 provide residential support and 20 provide non-residential support. There's some overlap between those two numbers. There are 10 agencies considering or developing new supports to those over 40. Four agencies have a staff committee devoted to aging, and nine agencies in Toronto have made a referral to long-term care in the past year.

The good news is that since presenting this report to the Toronto-based agencies, a task force—a subset of these agencies, along with others representing the DSTO—has been struck to strategize a coordinated approach to the issues of aging within our population. The task force has its first meeting scheduled for later this week.

Ms. Jasmin Earle: In our research into other jurisdictions, both within Canada and elsewhere, we can truthfully say that we didn't uncover any innovative solutions to these issues. What we found was that there was a general consensus that there is a crisis associated with this population's aging and the aging of its caregivers. Even with a wealth of academic studies and discussion papers, there have been no particular solutions that seemed viable that have been presented.

In our opinion, there's an opportunity for Ontario to lead the way. With our universal health care system, there are systems in place to promote a sustainable system of family and community care.

We'd like to make the following recommendations to this committee, which we obviously sincerely hope that you will adopt. We want to develop a strong partnership between the ministries associated with services to the developmentally disabled and to the aging population. We're obviously identifying the Ministry of Health and MCSS as two obvious ones, but really, adults with developmental disabilities are accessing services and are supported by a variety of service systems supported by a variety of ministries.

We also want to see that linkage established with the CCAC. We think that with that level of coordination between funders and between systems, there will be an opportunity to build solutions that will provide the necessary supports that these populations need. We recognize that one change, even a small change, in one service system has a ripple effect on other systems. We are very mindful of the demographics in the general population and the aging of our population as a whole and the cries for fiscal restraint and for other kinds of financial limitations on ministries.

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However, we still feel that a coordinated approach presents the most viable opportunity. An example of this could be using a long-term-care facility to house an aging parent as well as their developmentally disabled adult child. While recognizing that the needs of both within the facility would be different, nonetheless supports around staff training and strategies around managing behaviour could be provided by the DS sector to the long-term-care sector.

We want to ensure that planning for the aging population takes place. At the moment, the ministry has no robust data to quantify the hidden population, and neither is there good data available to support system and service planning around what the existing needs, as well as the emerging needs, are of the people who are served within the service system. Certainly, this data is not shared at the tables that we are at, which is a collaborative between service providers, the ministry and the community.

Even the hidden population who aren't currently availing themselves of services will at some point become frail, aged, face a financial crisis and/or face a health crisis that will force them to access the service system, and, currently, the service system will not be able to respond. The best that can be done is that some intake will take place and they will join a waiting list, which has many thousands waiting for service.

We want to continue, as this committee is currently doing, to engage parents, professionals and agencies in working together around solutions and ideas. We certainly look forward to any recommendations that may come forward from this committee's work, with the hope that you will have heard from many, many stakeholders and that there must be some viable ideas within that consultation.

We want to begin formal discussions about the shared funding responsibilities. As people age, their health needs will grow quickly, and far more quickly than the DS supports that are available. We would like to see a system that develops age-adjusted funding so that the funding needs that provide services can keep abreast of the changing needs as the adults receiving services age and as their primary caregivers age too. And we'd like to reinforce the flexibility in the direct funding model to facilitate alternate models of care for aging at home.

That's the end of our presentation. We look forward to any questions that you might have.

The Chair (Mrs. Laura Albanese): We just have about a minute left in total. I don't know if there are brief comments that the members want to make; otherwise, I will leave it at that.

I want to thank you for appearing before the committee and for all the information that you've brought forward. This is very helpful to us. If we have any more questions, we'll be in contact.

Ms. Jasmin Earle: Thank you very much for your time. We really appreciate it.

DEOHAEKO SUPPORT NETWORK

The Chair (Mrs. Laura Albanese): Next, we will hear from Deohaeko Support Network. Good afternoon.

Ms. Helen Dionne: Good afternoon. We move a little slowly. A few of our members are coming up.

The Chair (Mrs. Laura Albanese): That's okay. Take the time that you need.

Ms. Helen Dionne: Thank you for this opportunity to come here today to present. I am Helen Dionne. I'm here to talk about Deohaeko Support Network. We're a group of families that came together 24 years ago to think about and plan good lives for our young adult sons and daughters who happened to have a developmental disability.

I'm the mother of Caroline, who has just passed her 51st birthday. She happens to be a photographer and a family historian. She loves to travel. She's a proud aunt, and she also is recently engaged to be married.

I'm joined here today by Linda. Linda is at the end of the table here, and Linda is the mother of Tiffany. Tiffany is an artist of some local repute, who is a member of the PineRidge Arts Council, a part of a studio art group and is active in the art world in many ways. She is also a member of the local drum circle, part of her church choir and an active member of her housing co-operative.

Barb Boettcher here on my right is the sister-in-law to Brenda. Brenda is a good neighbour to the people in her co-op, for whom she bakes muffins for a surprise, and she offers gifts for birthdays and has potluck suppers. She's also a crafter, a puzzler and a great host in her home, as her mother was.

Mary Bennett, sitting here to my left, is the mother of Jonathan, who for many years had a small shredding business, J.B. Shredding. He's an active volunteer in his community.

I'm also joined to the left of me here by our coordinator who has been with us for 20 years, and her name is Janet Klees.

Twenty-four years ago, the families of Deohaeko began by thinking about where our sons and daughters would live in the future. What kind of a place would they come to call home and what might it look like? After much research and discussion, we had a good idea of the kind of welcoming, typical place we thought would work best. We took advantage at that time of the federal-provincial cost-sharing arrangement to design and build Rougemount Co-op in Pickering. Rougemount Co-op is a six-storey, 105-unit housing co-operative. Couples, singles, young families and elders of many cultures, abilities and backgrounds live together in a housing co-operative where they contribute to each other in many ways.

For our sons and daughters and for ourselves, Rougemount is not a residential option; it is home. It is where people are hosts in their own homes, co-operative members with rights and responsibilities and good neighbours to one another. There is no support service within the building and no office for Deohaeko Support Network. Supporters work directly with people in their own homes, and our coordinator—we give her a telephone and a second bedroom in someone's home once in a while to use.

If Rougemount is all about where people have chosen to live, then Deohaeko, which is a separate incorporation—we had to incorporate to build Rougemount and then we had to incorporate to form Deohaeko Support Network—is all about the lives of our children. We're a group of families who come together to think about and plan for ways that our sons and daughters might live good, full and contributing lives at the heart of their co-operative and the larger community. After 24 years, we still manage to meet at least once a month, and talk together more often than that. We think about and we plan for supporting our sons and daughters to create a secure and welcoming home, to enter into a range of relationships with many people to keep them safe and to explore a range of typical and valued ways to contribute to their community as citizens.

We do all of this with a range of family support, assistance from our friends and neighbours and some consistent paid support. Our part-time coordinator works for us directly in a unique partnership that provides a layer of resources, support and resiliency to the voluntary efforts of the families. This feature of our group is vital to our sustainability.

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We're not a service model; we're not an agency. Board members are us, the family members. Paid supporters work for each family separately. Each person's life is very unique and is supported as an individual. Families help their sons and daughters hire their own supporters, plan their own schedules and remain in control of their own lives.

Our story is not about the co-operative, although this is a very nice place to live and all are welcome to visit. It is about people with disabilities leading good, ordinary lives at the heart of the community of their own choosing. It's about the capacity of families to be creative and innovative. We have a vision, and we follow it through. It's about intentionally developing community no matter where one lives.

At the same time, right now, we're standing at a crossroads. There's no doubt as to the success of our model, on a budget that's admirable, with plans for succession into the future. But as parents, we're all over 70, some in our 80s, and most of us are experiencing significant health problems. Two sets of our parents and our dear friends have passed on. Yet we remain at only about 60% of the funds required.

This means, as seniors, we are continuing to provide high levels of direct support, that supporters earn as little as $13 an hour—I think our minimum wage is changing, so that's frightening—and that, after all this time, our financial future is not yet secure and we cannot move into our own futures with any peace of mind. I also add that most of our fundraising days are over.

Our message today is that families need the resources and the flexibility to create and innovate. In this way, people will end up with a wide range of places to live within their communities in good ways. Let there be as many options as there are people.

I'll ask Janet to continue.

Ms. Janet Klees: I'm going to continue with some more of the details.

The seven families of Deohaeko Support Network are pioneers and forerunners in supporting their adult sons and daughters to live ordinary, meaningful and contributing lives at the heart of their community and from within homes of their own. We have put the theories of person-centred approaches into practice in Durham region for the past 20 years. For years, the government has been developing policy to move into person-directed practice and individualized planning and funding, lately in the social inclusion policy. We have long been putting these ideas into practice, well before that.

We have also pioneered other significant and complementary ideas: family government and support, a shared coordinator role to support families, community development, innovative social housing, supportive decision-making, customized employment strategies and social role valorization.

When we tell our many stories, we are not only talking about visions, hopes and dreams. We are talking about real lived experiences, achievements, goals met, and a good quality of life sustained over two decades.

Many families, organizations and others from around the world—Ireland, New Zealand, Australia, the United States and more—seek us out and find that our stories and lessons have resonance and truth. People buy our two books, visit us in Durham region, cite us as inspiration for their own models, invite us to speak across Canada and worldwide, and track us down to learn more. This is our track record.

At the start, when no housing was available for our family members, we researched, designed and built the Rougemount Co-operative with federal and provincial funding. When no service agency was even remotely able to provide support in the individualized way we imagined, we incorporated Deohaeko Support Network as a charitable not-for-profit organization so as to manage our own affairs.

When no support was offered at move-in time, families and friends moved in with sons and daughters until some of the support funding came about.

When our detailed individualized budgets and plans for each person 20 years ago were ignored, and instead we received just a chunk of funding, we invented group-based, flexible, individualized funding, which has allowed us to be innovators of this flexible nature of funding and allows us to share a part-time coordinator and to share our funds with each other in times of need, instead of each one just having their own.

When we wanted to ensure that our group had resiliency and flexibility, we designed a role for a shared coordinator. When the available support funding was only 60% of the original request in 1993, the families found ways to make it work, augmented by family support, supportive allies, fundraising and innovative measures. When the local supported employment programs five or six years ago deemed every single person within Deohaeko as unemployable, we went out and started our own customized job development initiative, and now five people are working at seven new paid jobs in our community. Furthermore, we've had enough time to reach out to six people outside of our group to provide the same service.

When all around us there were people with medical conditions and mental health conditions needing to use expensive and difficult emergency rooms, hospitals and in-house mental health services, we intentionally designed highly unique and personalized environments and support that have kept our fragile people safe and out of costly hospitalizations and systems. This includes three of our members who are very much medically fragile, and one has been assessed at the 95th percentile in the DSO SIS assessment system—just to show you the level of complexity we're talking about; not easy people to figure out support for. We designed ways that keep people with ongoing significant mental health issues at home versus in care during crisis—that affects three of our members—and other measures that keep people with very complex issues such as health, mental health, motherhood and social issues all safeguarded and on track.

When other families wanted to learn from Deohaeko, the group kept to their "small is beautiful" principle, and instead of expanding, we wrote two books and invited others to come and learn on study tours at Rougemount.

Finally, when parents began to think about the long-term future, when they would no longer be present, they got their wills and estates in order, put money into RDSPs and imagined friends of Deohaeko, which is the next generation of board members, and Barb would be one of those.

For over 20 years, this has been one innovative example of an effective family group. We have designed, tested, co-funded and constantly adapted to bring about a comprehensive way to support people with a wide-ranging and changing set of needs and gifts. For a time, about 10 years ago, MCSS seemed to recognize and appreciate our work, and we received a number of small funding project extensions to our funding in order to continue our work. However, political parties and systems change, and we have not regained that momentum. As has been pointed out, we have maintained all of this with only 50% to 60% of the funding that we require, and we are just not able to continue this for very much longer.

More clearly focused on this committee's mandate, we want to offer an idea of a good approach, and then, what is needed to sustain it. The question becomes: What will it take for governments to recognize, then support and finally share good ways to help people live good, ordinary lives? First of all, we'd have to agree on what "good" means. "Good" is when people with a very diverse and sometimes complex set of support requirements are living unique lives of their own in the heart of their community in homes of their own where they are kings of their own castle, making decisions about their lives and support on a daily basis etc., in ways that bring richness to their lives and safeguard their lives. In other words, "good" is when people are living lives that are pretty well described in the social inclusion act of this government. Clearly, we agree on this.

"Good" is when a group of families show evidence of being able to sustain quality and stability for individuals over two decades. This is not a flash in the pan. "Good" is when the group is able to encompass people who require more complex supports and do it in a way that's very light on expensive emergency systems. "Good" is when families and other ordinary systems are excited and engaged enough to the point of proactively figuring out housing and creating new ways of support, new ways of employment etc. "Good" is when families are able to demonstrate economical ways of using government money that use innovation. Almost all of our funds go to direct support. "Good" is when there is demonstration of long-term sustainability and succession planned. As we say, we are into the future at this point.

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On all of these levels, we can agree that this is what is offered in this approach, and it's good—not perfect, but good. For individuals, it's good—for families, for communities and for governments elected by citizens in those communities.

The next point is, where does good make it sustainable? Support good efforts and effective projects in the following ways:

Where there is family innovation, energy and proven ability, including countless voluntary hours, the government should provide a way to ensure financial sustainability into the future.

Where there is long-term, hard evidence of people with significant disability being in charge of their lives, holding important contributing roles, finding places of belonging—evidence of people leading the lives outlined in the social inclusion act—the government should financially support the model and make efforts to learn from and share with the families.

Where there is evidence of personal and individualized support for over 20 years which keeps fragile and complex people safe, governments at all levels should recognize, coordinate and support these efforts with resources from several ministries.

Where there is evidence of a comparatively reasonable budget with good outcomes, governments should take notice of support for sustainability and learn from these examples, including reasonable compensation and cost-of-living increases.

Where there is a proven record of effective and affordable housing with good neighbourly relations, the government should learn why it works and offer more.

Where there is evidence of good job support that actually helps people get paid employment based on their interests, the government should find ways to fund this.

The need for an effective and comprehensive set of resources and supports funded by government in many creative ways to help support people with complex needs and dual diagnoses live good lives is clear. Our 20-plus-a-year example has been pieced and cobbled together and made comprehensive by the families. Why not fund it, study it, learn from it and share it? We are clear that our ways will not be suitable or interesting for all other families in Ontario. However, we know there is great interest among many for small, local family groups and individualized and personal community-anchored approaches such as this one. "Comprehensive" should not and will not mean that one size fits all.

As Helen said earlier, let there be as many options as people, and, we would now add, where it is working, make it sustainable.

Ms. Helen Dionne: I just wanted to add, these are our two books. We Come Bearing Gifts is the first book, and our second book is Our Presence Has Roots. Janet Klees is the authoress of our books. I'm sorry I couldn't bring 35. I can't afford it.

The Chair (Mrs. Laura Albanese): Thank you very much for appearing before our committee. There's less than a minute left for comments. But I do want to say, congratulations on such a successful model. It is something that we will definitely take into consideration. It is something that we've heard from other families: that they want to be involved and have more of a say. There are families who are willing to take on more responsibility, such as you have done. But you're right; you do need a partner. You need partners in this, and we will certainly take note of that as we consider our recommendations.

Thank you very much for your time.

Mr. Bas Balkissoon: Chair, can we find out how many clients they have and how many residents live in the co-op?

Ms. Janet Klees: There are seven sons and daughters of the founding families, and the co-op has 105 units and 225 people—just ordinary, typical kinds of people.

The Chair (Mrs. Laura Albanese): Thank you. That's very helpful.

Interjection: She just wants a copy—

Miss Monique Taylor: Yes, just to show us your project and how it works.

Ms. Helen Dionne: Yes, absolutely.

The Chair (Mrs. Laura Albanese): So you will be submitting the copy of the presentation—

Ms. Helen Dionne: We can, yes. We'll send it.

The Chair (Mrs. Laura Albanese): That's fine—in electronic form, and this way all members will get a copy. Thank you.

Ms. Elliott?

Mrs. Christine Elliott: While the next presenter is coming forward, I would just like to state, for the record, that I do have an association with the Abilities Centre. I'm one of the co-founders, and I'm currently the chair of the board of directors.

The Chair (Mrs. Laura Albanese): We'll take note. Thank you for disclosing that.

ABILITIES CENTRE

The Chair (Mrs. Laura Albanese): We now welcome the Abilities Centre. Good afternoon.

Mr. Leo Plue: Good afternoon.

Ms. Melissa Rudan: Good afternoon.

The Chair (Mrs. Laura Albanese): Welcome.

Mr. Leo Plue: Good afternoon, ladies and gentlemen. Thank you so much for the opportunity to present in front of this select committee. My name is Leo Plue. I'm the executive director of the Abilities Centre, and I'm accompanied by Melissa Rudan, who's our manager of programs and educational partnerships.

Abilities Centre is a state-of-the-art facility located in Whitby. It opened in June 2012 after many years of planning and building. The centre is open to the entire community, with special accommodations to meet the needs of anyone with accessibility issues, be they related to mobility, sight impairment, hearing impairment or any other issues.

The centre provides both self-directed and instructor-led programs in fitness, recreation, sports, performing arts, arts, life skills and music. We've established partnerships with:

—sports organizations such as Ontario Basketball, the Canadian Lacrosse Association, the Ontario Lacrosse Association, wheelchair lacrosse and Wheelchair Basketball Canada, as well as the para-sport organizations;

—cultural organizations such as Station Gallery, which is a local art gallery, the Royal Ontario Museum and the Royal Conservatory of Music;

—health care facilities: Lakeridge Health, Rouge Valley, Providence Healthcare and others; and

—many universities and colleges, primarily from Alberta and Ontario.

We deliver programs for all ages, all abilities and all activities, and believe strongly that it is more important to realize what an individual can do rather than what they cannot do.

The centre has been recognized with a variety of awards, locally, provincially, nationally and internationally. Our most recent award was for accessible design and was presented to us in Cologne, Germany by the International Paralympic Committee, represented by Sir Philip Craven, their president, along with its international architectural partner, known as IX. In August 2015, Abilities Centre will be the host site for two Paralympic events, boccia and judo.

While the built environment of Abilities Centre is unique and world-class, it is really the people and programs that make it come to life. Today, we want to talk about two programs that are the focus of this select committee's work. To that end, I will turn it over to Melissa Rudan.

Ms. Melissa Rudan: Thank you. Good afternoon. My name is Melissa Rudan and I am the manager of programs and educational partnerships at Abilities Centre. I am excited to be here this afternoon to speak with you about some of the innovative programming we offer at Abilities Centre for adults with disabilities.

I'm proud to introduce you to Thrive, a signature program at Abilities Centre. Thrive is a fee-for-service adult day program that enables individuals with disabilities age 21 and over the opportunity to spend the day engaged in meaningful, integrated programming in the areas of sports and fitness, life skills, arts and social recreation. The focus of Thrive is to improve the health, well-being, community access and independence of participants through a variety of activities.

Thrive was created in response to feedback from adults in Durham region living with disabilities, as well as their parents and guardians, as part of a needs assessment conducted by Abilities Centre in the fall of 2012. An overwhelming 88% of those surveyed indicated that a quality day program was needed in the Durham area, especially one that was inclusive, accessible and included a variety of meaningful activities.

As you know, individuals with disabilities may remain in the secondary school system until they are 21. However, unless they are continuing on with post-secondary education or have obtained full-time employment, these individuals do not have many options for structured daytime activities in the community. Feedback from our needs assessment indicated that programs for adults with disabilities were few, and less than 18% of those surveyed had participated in existing programs due to barriers such as lack of accessibility and affordability, as well as inappropriate program content.

Using information gathered from this needs assessment, we designed a program model, and the pilot of Thrive was launched one year ago. Since then, we have continued to grow and expand the program, due to the overwhelming response from the community and the success of the program.

Thrive is currently offered three days per week in morning, afternoon or full-day sessions. Participants have the flexibility of registering for as many or as few sessions as fit their own personal schedule and interests. We have partnered with community agencies such as Participation House Durham and Whitby's Station Gallery, among others, to provide specialized instruction.

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The winter program of Thrive currently offers fitness classes, recreational sports, drama, dance, music therapy, visual arts, social media, healthy snacking, customer service and a variety of social-recreational activities.

We have also partnered with several colleges and universities to provide placement opportunities for students enrolled in relevant fields. We currently have students from social work, nursing, recreational sports and leisure, and therapeutic recreation programs assisting in the facilitation of Thrive.

We are in the process of developing a partnership with local high schools to potentially use the Thrive program as a transition step for students with disabilities who are in their final year of secondary school.

We have seen many positive outcomes for participants of Thrive. For example, after completing the 12-week fall program of Thrive, one participant's physical health had improved so much that she was able to gradually stop taking a medication needed for muscle spasms. Another participant, previously very shy and quiet, gained so much confidence that she was able to obtain part-time employment in a restaurant. Another new Thrive member had never felt comfortable attending any program without a family member, but after only a few days of Thrive, wanted to stay in the program on his own. Not only did this do wonders for his own independence, but it provided his family members with some much-needed respite time. There are triumphs and accomplishments for our members every day, and these are just but a few that I've chosen to share with you.

So why has Thrive been so successful? One reason is that there is such an overwhelming need for this type of program in the community. I am continuously receiving telephone calls or visits from parents who tell me that their adult son or daughter with a disability has completed high school, and that their child just stays at home all day with nothing to do. They want, as any parent would, for their child to enjoy life, be engaged within the community and have their own circle of friends outside of the family.

Another reason this model has been successful is the flexible schedule, which allows participants to register for sessions that best fit their schedule and interests.

We have also created this program to be as affordable as possible in an effort to try to maximize the number of individuals in the community who can participate in Thrive.

I believe the most important contributing factor to Thrive's success is that it is truly a community effort. Our team is made up of Thrive participants, their families, our staff, volunteers, placement students, community agencies, specialized instructors from the community and members of Abilities Centre. A program has been created where participants feel that they truly belong and have a place within the community.

What does the future hold for Thrive? Well, since the pilot of Thrive launched one year ago in January, registration has tripled. The winter program of Thrive—which actually did begin this morning—with 60 available spots, is currently full, and we are in the process of immediately expanding the program to increase capacity. We will continue to grow and expand Thrive with feedback from all those involved, especially the participants and their families. Our goal is to eventually provide programming five days per week and offer even more activity options at different times throughout the day, so participants can customize their individual schedule.

The popularity of Thrive is a clear indicator that this type of program is long overdue and has a ready audience. With increased attention of the government towards accessible, inclusive programming, Thrive is a unique, well-designed program that has demonstrated success within the community.

The second program I'd like to speak to you about today is an initiative for adults with autism. This fee-for-service program has been named Achieve and is in the final stages of development. Achieve will ensure a secure and supportive environment for individuals with autism who require one-to-one, or sometimes two-to-one, support. This social-recreational program will provide specialized instruction in the area of life skills, arts, sports and recreation. Utilizing the Abilities Centre facilities and highly qualified staff trained by the Geneva Centre for Autism, participants will focus on improving health, well-being, community access and independence. To encourage self-determined behaviour, participants will be offered choice through flexible program options. Depending upon individual interest, specific activities may include group or individual fitness, dramatic arts, music appreciation with a registered music therapist, life skills and use of our sensory room, just to name a few.

The pilot of Achieve is scheduled to run for 12 weeks beginning in June, and will offer full-day activities from Monday to Friday. Provided with the appropriate level of support according to their individual needs, this pilot initiative will work alongside existing programs at Abilities Centre, such as inclusive group fitness classes or the Thrive adult day program. This is to ensure that each participant is provided with a spectrum of choice regarding the level of social interaction and inclusion. This pilot initiative will be partially supported by a grant from the Unity for Autism foundation and Magna International. We hope that it will be as successful as the Thrive program has proven to be.

Thank you for the opportunity to speak with you today. We welcome any questions that you may have.

The Chair (Mrs. Laura Albanese): Thank you for your presentation.

We have about three minutes per party for questions. It is Ms. Jones's turn.

Ms. Sylvia Jones: As you can imagine, based on who is sitting beside me, we know a little bit about Abilities Centre.

I did have one question. With your Achieve program that you're starting in June, is there an age parameter on that?

Ms. Melissa Rudan: It will be the same as the Thrive program, so for individuals 21 and up.

Ms. Sylvia Jones: Okay. You said that the Thrive program—you have 60 in-programs and you're trying to expand it now?

Ms. Melissa Rudan: We are, yes. The winter program is currently full, and I'm still receiving calls and interest from families who want to sign up for it, so we're looking at ways to immediately expand the program. We're fortunate at Abilities Centre that we have the space and the capacity to do that. We're currently running the program at a break-even. We're covering our costs on the program to keep the fees as minimal as possible for the participants. So with that model, we have the opportunity to expand it.

Ms. Sylvia Jones: Are all of the participants you are currently serving or offering program to—would they all be individuals who live in family-home situations? Or would you have young adults who are in a group home? What's the breakdown?

Ms. Melissa Rudan: It does vary. I would say that 80% to 90% of the individuals do live with their families. But we do have some individuals who live in the group home settings. It's great for the families, as well, because some of the families are still working, so it provides opportunities for their son or daughter to have activities during the day. Some are aging parents, so this provides respite for them. But primarily, it's for the individuals themselves to be engaged in meaningful activities throughout the day.

Ms. Sylvia Jones: How far would individuals be coming for your program? You're obviously based in Whitby—but how far are people coming?

Ms. Melissa Rudan: I would say, on the east side of Whitby, we have individuals as far as Cobourg coming, and on the west side, from Pickering and everything in between.

Ms. Sylvia Jones: That's great. Thank you.

The Chair (Mrs. Laura Albanese): Ms. DiNovo?

Ms. Cheri DiNovo: Thank you so much. It sounds amazing.

I just had some questions about your supporters. You don't have finances in here. In terms of the fees for families, is it completely self-funded by families? I see you do fundraising as well, and I was wondering what the breakdown is, generally speaking, between fundraising, corporate sponsors, or whoever is sponsoring you, and fee for service.

Ms. Melissa Rudan: In terms of the fee for service, the fee that we charge our members for Thrive—if you're currently a member of Abilities Centre, it's $15 for a half-day and $30 for a full-day program. If you're not a member of Abilities Centre, it's $20 for a half day and $40 for a full day.

We also offer, through Abilities Centre, a membership assistance program. Individuals in financial need can apply to that program and receive an Abilities Centre membership at a reduced rate. That is supported through sponsorships and through fundraising.

Ms. Cheri DiNovo: So it really is almost all generated by the funds that folk are paying.

Ms. Melissa Rudan: It is. We also try, though, giving the students from colleges and universities the placement opportunities, in terms of getting the support that way and minimizing our costs. So we do try to minimize our costs as much as possible so that we can keep the rates affordable for the participants.

Ms. Cheri DiNovo: Thank you very much, and thanks for the work you do.

The Chair (Mrs. Laura Albanese): Ms. Hunter?

Ms. Mitzie Hunter: Thank you so much for your presentation. I had an opportunity to visit the Abilities Centre in Scarborough and was incredibly impressed by the work that they're doing within the community and their understanding of the needs. Clearly, you've identified this as a growing need and are responding creatively to meet that need.

I was wondering if you will be sharing your learnings with the network of Abilities Centre that you are in touch with.

Mr. Leo Plue: We probably have four to eight tours a week that will come through Abilities Centre looking at both the facility in terms of accessible design, but also our program offerings. We're wide open. Anybody who wants to come in and speak to us, we're prepared to do that. We're sharing whatever we can. We believe that we are there to provide services for our community individuals, but also for organizations in our community. That's why we've established so many different partnerships with so many different organizations. We work very closely with Variety Village from Scarborough and other organizations throughout the province.

Ms. Mitzie Hunter: Excellent. In terms of the employment outcomes, I noted that that was also the confidence, really, to do more. If you could talk a little bit about how those matching type of connections are made through this type of program.

Ms. Melissa Rudan: Each member is unique. Every day we have minor and major accomplishments that we see within our members. We try to keep the program as small as possible, so we have the quality, and then we can do the individualized programming. Different members have different goals, and when we keep the program small, we can really individualize a participant's goals and their needs, and work with them. Again, we have so many resources within the community that we really are well-equipped to try to meet those goals and needs of the participants.

Mr. Leo Plue: I would also direct you to the back of the handout sheet that we gave you that talks about the program. On the back of that page is a poem written by one of the Thrive participants. I think it captures very well the attitudinal changes that are taking place for people who are in that program.

Ms. Mitzie Hunter: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for being with us today and for making us learn more about the Abilities Centre. We know that some members do know everything there is to know about it, but it's great that, as a committee, we learned to know more about who you are and what you do. Congratulations.

Mr. Leo Plue: Thank you.

Ms. Melissa Rudan: Thank you.

The Chair (Mrs. Laura Albanese): The next presenter, unfortunately, will not be able to make it, but the one right after that is almost here. I would suggest that we have a short recess until 2:30, and we will then resume the committee.

The committee recessed from 1422 to 1430.

MR. RYAN WALKER

MS. SUE WALKER

The Chair (Mrs. Laura Albanese): The committee is back in session. We welcome Ryan Walker and Sue Walker. Good afternoon. You'll have up to 20 minutes for your presentation. If it should be any shorter, that will leave time for questions and comments by the members of the committee. You may start at any time.

Ms. Sue Walker: Okay.

Mr. Ryan Walker: Okay, great. As was said, my name is Ryan Walker. This is my mother, Susan Walker. We're both developmental service workers. We both actually work at the same workplace in Oakville.

A little bit about myself: I've been a developmental service worker for about seven years now. I grew up in the field my entire life, as you can see, with my mom being a DSW as well. I'm not the only developmental service worker she has raised. Also my older brother and my older sister are developmental service workers. I also have family members who work in the field: aunts, cousins. Many neighbours and friends actually work with us at our workplace.

I have personally worked in the field in respite care, residential care, vocational services. I've done treatment and assessment. I've run the whole gamut of the possible services provided in developmental services.

I've had seven years' experience. My mom has had about 32 years' experience. I guess you could say all the exact same things about her as I've just said about myself.

My mother has also been the developmental service sector chair for OPSEU for over 10 years, just coming down from that position recently, in the past year.

As you can see, our family is definitely well invested—we're pretty big stakeholders when it comes to developmental services, where the field's going and how the Ontario government is looking at it today.

Why we're basically here today is to share our experiences with what we see as the current crisis and the critical need for funding for developmental services. From a staff perspective, I can tell you, we definitely do not get into this job for the money. It's something most of us do definitely because we care. Unfortunately, it does seem that this mantra has been misunderstood recently, because developmental service workers have been poorly underpaid for far too long now.

As a result of low wages and increased part-time jobs, we are seeing a high rate of turnover, and staff juggling multiple jobs just to survive. What this translates into and means is a lack of continuity in the services that we provide, the services as workers for the people we support and for our communities.

Unfortunately, some of the words that come to my mind when I think of explaining developmental services today are "inadequate," "improper," "underfunded," "inaccessible" and maybe "nonexistent." For example, we have people with developmental disabilities being placed in psychiatric and long-term-care facilities. They are being placed there either just to get a placement or just to receive care. If I were to put this to a metaphor, it would be like going to your auto mechanic to file your taxes. It's just not right. You're not going to get any good work done with that, and it's not going to help the situation at all either.

I guess I can give it over to my mom now. She can tell you some more stories and experiences of what she's gone through in terms of the lack of funding in developmental services.

Ms. Sue Walker: It's true: I've worked in developmental services for over 32 years, and I've seen complete changes. Today I'm seeing things that they stopped years ago. Individuals are being moved into nursing homes again, where 20 years ago they were all moved out because that was not the proper placement for them, as they are not ill; they're just a little bit different.

The growing waiting list in developmental services in Ontario is just getting larger and larger due to the lack of funding. If you look at facilities across Ontario, they have all kinds of vacancies due to operation budgets being cut, government not giving money to fund these facilities. They've closed most of the government facilities across Ontario; they're in the middle of closing one now. They've basically increased the waiting list because the people that have already had a placement are now taking a second placement, taking away from the people that are waiting in the community. Aging parents are getting more frustrated because they don't have places to put their children.

In my time, I have seen kids abandoned. Their parents can no longer care for them. They're frustrated; they don't know what to do. So you have them in your facility for respite, and they just absolutely refuse to pick them up. Then, it's a mad scramble to find a placement. In my time, when the children were abandoned, they were placed either at the facility they were abandoned at or the CAS took over. Nowadays, they're going to homeless shelters—you hear about them in the paper all the time; you don't hear the results of where they're going.

But these parents cannot do it. We have to increase funding in this sector so that the critical waiting lists are cut. We have—I'm sure you've heard all kinds of numbers—over 20,000 in Ontario alone. To go into the area where I work, their waiting list—to talk about how many thousand are on that list just doesn't cut it. The problem is across Ontario, and we need to fix this problem for the parents and the waiting lists.

Mr. Ryan Walker: As my mom said, in our experiences—just us personally; I'm sure you've heard many stories at this committee as well—we've seen clients abandoned, we've seen families pushed to the limits and we've also witnessed this crisis continue to grow. As this crisis continues to grow, the gap widens between the demand for and the supply of services for people with developmental disabilities and their family.

We could go through so many examples of what we've just said in terms of abandonment. We've seen it personally and we've also heard it, being so connected within the field of developmental services through our own personal union, and being sector chair of developmental services. We've had the stories come to us from all around, all over Ontario as well. So we know it's not just an experience that we're having with our workplace; it's also something that goes province-wide.

What we'd like to leave you with today is that there is an urgent need to address the crisis in developmental services, and to address that crisis, we need more services and more funding. As we know, our place in Ontario right now is that we can afford to care for the most vulnerable people in our society. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for appearing before the committee today. We have about four minutes for each party, and I believe it's the NDP's turn. Miss Taylor.

Miss Monique Taylor: Thank you so much for being here today and for your presentation. It's very much appreciated. We need to hear perspectives of workers, and we've heard them from several areas. I know we've heard quite a few from CUPE, and now you're bringing an OPSEU perspective to it also. It's important to hear, and it's sad to hear that you've seen so many people abandoned. Do you have an approximate number of how many people just alone you've seen abandoned?

Mr. Ryan Walker: I know in my seven years, I've seen three people abandoned completely from their family, given up full custody, and those are personal experiences I've witnessed, yes.

Miss Monique Taylor: Do you know the background history of those families? Do you have an idea? Was it just because they could absolutely not get the services that they needed or were they getting the services and just not able to cut it?

Mr. Ryan Walker: The majority—any time where I've heard it, it's usually upon waiting for placement into group homes, so wait-lists. In certain circumstances, the clients are very young and maybe certain needs are not displayed by that person, so it kind of puts them at the bottom of the wait-list. Then, the perspective of some of those parents is, "My child will probably be an adult before I get them into a permanent placement." And then the other ones I've witnessed, again, are pure desperation. A lot of it goes back to families not knowing what to do or just not having the supports to do what they want to do for their child and what their child deserves at home.

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Unfortunately, sometimes, especially nowadays, the clientele who we're dealing with are a little bit different from back in the day. In terms of behavioural programming, we know what actually can and cannot work today with our clientele a lot of the time. A lot of the time it's just that those supports aren't there for them in their home. In terms of getting into the community, the wait-list is the biggest barrier.

Miss Monique Taylor: So, are you working in residential facilities? Are you working in community homes?

Ms. Sue Walker: Yes. I don't work in a community home. I'm a vocational support worker.

Miss Monique Taylor: Okay.

Ms. Sue Walker: The facility runs the day program, but we do work out of the homes in there. Ryan does work in residential.

Some of the clients I have seen abandoned have been ones whose parents were receiving care, but it was all over the place. It wasn't in one area. One week they were here, two weeks they were here and three weeks they were here, not waiting for a permanent placement. So the stress was on the parents, because when an individual is moved and not knowing what's going on, they go home for a few days and they take it out on the families.

They just can't deal with it. When you have younger children at home and you have somebody who can potentially hurt your younger child, plus not knowing if they're ever going to get a placement, I think they've hit the wall. One parent I know, we talked to her and she just phoned and said, "I can't do it. I'm not coming to get him. I just cannot do it. You have to do what you have to do, because I can't do it."

Miss Monique Taylor: So sad.

Ms. Sue Walker: And then, any time you try to contact them, you don't hear from them until they know that their individual has a permanent placement. Then a lot of them can become involved again, but a lot won't, because they're scared that, if they do become involved back in their child's life, they're going to eventually wind up with them again.

Miss Monique Taylor: So they're just walking away and never coming back?

Ms. Sue Walker: Completely walking away—

Miss Monique Taylor: Out of fear.

Ms. Sue Walker: —and having absolutely nothing to do with them.

One individual parent called me, being also the president of the local in the sector, about how she could get her child into our facility, because we do have the supports in place. We're a facility that's really lucky that we offer a lot more than a community agency does, so they want to come to our facility, but we have a no-admittance policy. We only take special cases.

You feel sorry for the parents. I mean, I've sat and cried with parents—

Miss Monique Taylor: Oh, no doubt.

Ms. Sue Walker: —because they just don't know what to do.

Interjection.

The Chair (Mrs. Laura Albanese): One more—

Miss Monique Taylor: You work in a residential facility. I'm curious about if the people who live in the facility are getting day support programs, because we're hearing a lot of that too, that people who are living in residential are not getting the priorities for the day programming. How are you finding your individuals?

Ms. Sue Walker: We get full—I'm a vocational support worker. All of the individuals who live at our facility have a full day program. Some run from 9 until 4; some run from—

Miss Monique Taylor: So you're not finding a problem with them not getting it?

Ms. Sue Walker: We have no problem whatsoever.

Mr. Ryan Walker: That being said, though, again, we understand that our workplace is a workplace that is well-funded. We do get the supports that we need as developmental service workers, but again, being so invested in the field, and we being so connected to developmental services, we understand that that's not the norm at other places.

Again, a lot of the barriers are the aggression of the clients; day programs won't accept them into their programming.

Miss Monique Taylor: Thank you. Thanks, Chair.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Hunter?

Ms. Mitzie Hunter: So, your comment was that you're seeing some of the cycles of 20 years ago come back. I'm wondering if you could talk a little bit, with your tremendous experience base combined, about what you would see as an ideal model for us to aspire to, and any steps to get there.

Ms. Sue Walker: I think the first thing is that you do have to increase funding to open more community group homes and either give them a job or have a vocational or an activity. Nowadays, a lot of facilities are using the daily activities, which is a wonderful opportunity for clients, because they're doing what they want to do. They're out in the community, they're going swimming, they're on computers—they have laptops; there are special programs out there for them. Some of them are taking college courses at the community colleges.

That needs to be offered to everybody. It's a start. Start building on the day programs for them and a placement for them, because even the people—the parents who are at home, they have no day programs or a placement, so they're with them 24 hours a day. They don't have special needs allowance to pay for a worker to come in to give them respite for a couple of hours, or they don't come into a facility that offers respite because the waiting lists are so long. They're always on duty. I think you have to increase funding to offer supports for the people that need them.

Mr. Ryan Walker: Yes, there's no joke around what our top, number one priority would be, and it would be increased funding. To touch on that, we've seen recently a lot of the older institutions closing down, closing up shop. The clients that lived there still exist. They've gone to group homes and they've gone to other facilities. Our biggest worry, again, is facilities like ours getting closed like those. We're not in a time where clients with epilepsy were thought to be possessed by the devil. We understand a lot more in the field. There are much better-educated workers. We would say to continue to fund those existing programs and to beef them up and strengthen their purpose instead of closing down programs and just shifting the need of those clients onto other programs.

Ms. Mitzie Hunter: Do you see the needs of the clients changing?

Mr. Ryan Walker: I've done treatment and respite, so I see a lot of the younger clientele as opposed to the vocational. It's definitely a much higher prevalence in autism. I've said it a couple of times, and the clientele is changing in terms of some—I guess you could say, risks or fears are elevated a little bit in terms of aggression. If you're a single parent and you live at home with your teenage child with autism and they are bigger than you and more violent—even if they're not bigger, nobody wants to have to physically hold down their 18-year-old child because they're trying to aggress towards them because they didn't get Cheerios. So it's definitely a higher prevalence in autism, and the clientele that we're dealing with are a little bit higher-functioning than we could say in the past 30 years. It's just a different style of working with the clients as well.

The Chair (Mrs. Laura Albanese): Ms. Elliott.

Mrs. Christine Elliott: Thank you both very much for coming today and for sharing your expertise and experience in this field. Certainly a lot of the issues that you've raised are things that have been told to us by previous presenters. As a matter of fact, we had a presenter this afternoon who talked to us about the hidden number of people who need service. We heard the number of 12,000 people who are on lists right now, but I think you mentioned something like 20,000 people who are really needing service. Is that including that sort of so-called hidden population that aren't there now?

Ms. Sue Walker: Yes. With the research I've done, it's 23,000 across Ontario, and I think OASIS has the same number. That's what we've been able to come up with. I think they go to the resolution committees and they get the waiting list from each resolution committee and then they talk to parents and groups and everything, and that's how they come up with the terms of 23,000.

Mrs. Christine Elliott: Well, it's really frightening when you think that we're barely coping with what we have now. In fact, we're not coping. The system is in crisis, so we really need some urgent action on that, and certainly we are well aware of that on this committee.

If I could ask one question about the vocational work that you're doing: Are you finding that it's getting any easier to place people with prospective employers? Are they starting to get the message about the benefits of hiring people with disabilities or not?

Ms. Sue Walker: The community I live in is very good at hiring. In Oakville they're very good at hiring our people. Oakville has a wide range: Christian Horizons, Community Living Oakville and Central West. They're pretty good at hiring them in the communities, but it's in the smaller-paying jobs, like McDonald's restaurants, the guys are hidden in the back. They're not out front to be exposed.

I went to Orangeville, and I happened to stop into Home Hardware and there was a developmental services person running the cash register. You could definitely tell he was DS, and he was doing a fantastic job. He was out in the public, he was talking to us, plus he ran the cash register, and I wouldn't say he's as high-functioning as a client I have placed in back rooms.

Mrs. Christine Elliott: It's great to hear.

Ms. Sue Walker: It seems that the little communities do more.

Mrs. Christine Elliott: I think my colleague, who's from that area, has a question as well. Thank you.

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Ms. Sylvia Jones: I'm just glad you plugged Orangeville. Thank you. We'd like to think we're very inclusive.

I had one question that tied into the hiring. You mentioned that the community you work in, Oakville, has been doing a good job. What was the trigger? What unlocked that potential, that understanding between value and inclusiveness and participation?

Ms. Sue Walker: I can just talk from our experience. We go in and offer our clients to volunteer for a few hours. We start them at volunteering, and that's why they've progressed to a hired position. There's also a factory in Oakville that came out of Community Living Oakville, Best Pack, and you have to be DS to work there. It's amazing to see. I mean, they're foremen; they run that place—unbelievable.

Ms. Sylvia Jones: So the volunteering is really more about educating the employers.

Ms. Sue Walker: Yes, to find out that they can go in and they can do the job. They're not going to disrupt their business, because you're certainly not going to place somebody in there that would disrupt their business. We have placed people in community jobs that their parents said they could never do, it would never happen, and they've done wonderful jobs.

We also have the seeing—the blind, for the dogs, and they also will take some of our clients.

Mr. Ryan Walker: Yes, in Oakville, at our workplace, we're a big part of our community. It's kind of like a community centre in a sense, when you think about it. We open up our services for renting the pool, gym, other services like that. There are always areas. There's a daycare on grounds, other services which aren't directly tied to us—

Ms. Sue Walker: Brain injury.

Mr. Ryan Walker: —for brain injury services, so really kind of getting out there. In Oakville, everybody knows our workplace. It's been around for 30 years. The grounds have been there, obviously, a lot longer in terms of the history, with an air force base and that. The connection to the city is huge because of that, and the history with it. Unfortunately, that's what we don't want to see lost with workplaces like ours and other ones which we've recently seen get closed down in the past.

Ms. Sylvia Jones: Thank you.

The Chair (Mrs. Laura Albanese): Thank you again for participating in the hearings today. We appreciate your testimony.

Mr. Ryan Walker: Great; thank you.

Ms. Sue Walker: Thank you.

MCSS PARTNERSHIP TABLE'S HOUSING STUDY GROUP

The Chair (Mrs. Laura Albanese): Now we'll call on the MCSS partnership table's Housing Study Group. Good afternoon.

If you could kindly start by stating your name and your title before you begin the presentation, we would appreciate it.

Ms. Margaret Spoelstra: I'm Margaret Spoelstra. I'm the executive director of Autism Ontario.

Mr. Ronald Pruessen: I'm Ron Pruessen. I'm the board member for Opportunities Mississauga, and I've also been involved with this Housing Study Group.

Mr. Gordon Kyle: I'm Gordon Kyle. I'm the director of policy at Community Living Ontario and a member of the housing group.

The Chair (Mrs. Laura Albanese): Thank you. You may begin any time you feel ready.

Ms. Margaret Spoelstra: Okay. Thank you so much for your time. We appreciate the opportunity to speak with the committee again and are grateful for the opportunity for you to also take a look at what was handed out to you, which is our report.

About a year ago, a group of us who are members of the MCSS partnership table felt that there was a need for us to become more specifically focused on one of the many needs that people with developmental disabilities in Ontario face. A small subcommittee said, "Okay, we'll do this," and a group of us together, representing organizations, volunteers and the ministry, said it would be important for us to focus on housing because there is a significant crisis. We don't even need to rehash the nature of that crisis or the numbers. It's all laid out in the report. But we felt it was also extremely important for us to say, "What could actually be done in a practical way?"

So we conducted a study, and we got ideas from people around the province—45 of them, actually, who responded in a very short period of time—who said there are some really practical things we can do that we've already started, that have been successful, but that could really use additional supports. Out of that, then, emerged further information in our study, and today, as you know, I'm here with three other representatives from this group. We represent 11 organizations supporting thousands of families and individuals with developmental disabilities in the province.

The other members of this committee are listed on page 6, and you can see who they are for yourself on your own time, but we're very proud to be representing them.

We're going to be brief in our presentation because you have the report and we really want to save as much time as possible for questions.

Mr. Gordon Kyle: You will notice that the subtitle of our document is An Action Agenda to Address the Housing Crisis Confronting Ontario Adults with Developmental Disabilities. We really want to focus your attention on the crisis that does exist. You just heard in the last presentation some good examples of the type of crisis that we see at the community level and the numbers of people who are waiting for support. We've identified that there are at least 12,000 people who are looking for residential support. To put that in a bit of context, right now, the ministry tells us they provide residential support for 16,000 people. It's taken us more than 50 years to develop those residential options, so the fact that we have 12,000 still waiting for some form of support means that we have to figure out some new and creative ways to address this issue. It really is time to get on board with this to figure out how we avoid the traumatic experience that far too many individuals and families are facing right now.

We've outlined in this document an action agenda which we want to talk to you about a little bit today, and we really see that this aligns very closely with the idea of a comprehensive plan that this committee is working to develop. So we're hoping very much that you'll see some close alignment with some of what we've proposed here today.

Mr. Ronald Pruessen: One of the emphases in the report is also captured in the title, as Gord has just mentioned. We really do put some strong emphasis on the notion of an action agenda. It is time to act at this point. We're talking, to some degree, to the choir here; you're obviously on the same page. This committee wouldn't exist if most of you didn't agree that it is indeed long past time to undertake this.

We do believe that this is going to be a long-term process. No one is imagining flipping a switch and having everything look good by the end of 2014. But as we put on page 13 in the report, we must begin, and the beginning must be energetic, and earnest as well.

One of the other emphases in the report is on partnerships. We don't believe, after extensive discussions both within the ministry's partnership table and within the Housing Study Group, that it is either practical or even smart to rely exclusively on the Ministry of Community and Social Services for solutions. It is too big a problem. It is too complicated a set of tasks confronting us, given the scale of the waiting list and given the nature of the problem, to some degree. Instead, what we are suggesting is that the government tap the creativity and the resources of other players, as well as the ministry and the government itself: families themselves, agencies, communities and the various organizations within communities, and the private sector as well—developers and tech companies and the financial institutions, for instance, as well as other government ministries beyond MCSS, and indeed other layers of government.

Ms. Margaret Spoelstra: So, as Ron talked about partnerships, we know that they are crucial, but they do not mean that government can play a minimal role. The Ontario provincial government, in particular, can make or break efforts to genuinely solve the current crisis. The action agenda outlined by the Housing Study Group highlights key steps that would provide the government leadership resources needed to energize partnerships and truly transform the environment within which adults with developmental disabilities and their families are struggling.

There are a few examples, and if you turn to page 16, you'll see our three-year action agenda overview. It looks like this page. This really is the heart of the document, so it's the Coles Notes for the reports. If you turn to that, we're going to focus for a few more moments yet on a couple of the items that we think are really wise steps to go forward.

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The first one is the creation of a capacity-building task force. We think that this group can be tasked with developing a framework for capacity-building projects.

We recommend that five—at a minimum—initiative projects should begin in 2014 to create opportunities across the spectrum, but paying particular attention to adults with developmental disabilities whose parents, parental caregivers, are over the age of 80, and also to create a baseline and scorecard measure for ongoing evaluation of progress and planning.

Mr. Gordon Kyle: Another recommendation within the action agenda is to deal with the role that government plays in carrying this out. As Ron pointed out, the response to this issue really will require bringing to the table all of the various players who can play a role, both in government and in the public.

Within government, however, we really want to emphasize that we don't see this as a responsibility of the Ministry of Community and Social Services exclusively, but there needs to be other ministries and other departments of the government brought to the table. So we're recommending that a process, a committee process, be struck to bring together the appropriate parts of government and to charge them with responding to these issues. These will obviously involve bodies such as the ministries of health, housing, education and the bodies responsible for senior citizens.

We also want to point to the focus—Margaret mentioned it just briefly here—about senior parents and as a mechanism for prioritizing where we make our investments early on. We want to identify the aging caregivers who are out there across the province right now. We've made recommendations for particular investments in the early stages of this for people who are living with parents who are over the age of 70 so we can address those needs before they turn into crisis.

Mr. Ronald Pruessen: Just to wrap up, prior to some questions that you may have, we believe that your committee, this committee, can play a special and significant role in turning around a tragic story—or thousands of tragic stories, to put it more accurately. We hope you will be bold and demanding in your recommendations, knowing how great the need is for far-sighted leadership from the government, as well as other players, at this particular point, and knowing, as well, given the quantity and passion of the testimony you have heard over the weeks now passed, how many people are waiting for you to do the right thing and how many people are ready to work with you in going forward in the months and years ahead. If I could put it bluntly, we are ready to do our part if you do yours. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for this presentation. I will now turn it over to my colleagues. We have about three minutes each to respond and ask questions. Ms. Hunter?

Ms. Mitzie Hunter: Thank you for appearing again. I know that this was circulated on two separate occasions to the committee. I'm wondering about your recommendations where you've identified funding, specifically on your page 16. I'm just wondering: Are these funds that the committee will seek proposals for initiatives, and then grant? Is that what your vision is for that funding?

Mr. Ronald Pruessen: Yes, that there would be a consultative process, an interactive process, both for the initial capacity-building task force, and then, in year two and three, we talk about the creation of an opportunities fund with resources that proposals from various community organizations, agencies and the like can apply for. For us, that seems to be a way to be able to tap grassroots creativity here, I think.

Ms. Mitzie Hunter: And is it one-time?

Mr. Ronald Pruessen: No, it would be—I mean, in some cases, it would be one-time. I think what we would envision is that the capacity-building task force, or the ministry itself, by creating some sort of mechanism, would make decisions about the pilot projects and the various proposals that come forward to see if they're working, if they are delivering the results that were promised, and provide ongoing funding for those that are clearly making a difference as far as community, family and individual needs are concerned.

Ms. Mitzie Hunter: In the body of the report, you talk about how the needs vary, and that there need to be different housing types. Are you seeing, in terms of the spectrum of housing that's out there, any sort of best-fit model? Have you seen that?

Ms. Margaret Spoelstra: I can begin to speak, and others can join in too. Really, it is so individualized. It isn't a matter of one size fits all. It's very much driven by an individualized process that keeps in mind the family's commitment to working through such a process.

There are actually a couple of points that speak to this—folks in the community who are on board, and other support mechanisms, but ones that really meet the needs of that individual. Particularly when they're adults, we have a better sense of what their needs are, and that needs to be conducted through a process that is related to that person.

Mr. Gordon Kyle: Yes, I would agree. I think that the important factor is the individualization of the plan that you put in place, to just sort out what exactly a person needs. In fact, we've traditionally had in the past an attitude that, if a person had very extensive support needs—perhaps some of the more intensive, traditional types of group living supports—that those are necessary for those.

I've seen some of the transcripts of this committee, and your committee has heard examples from groups around the province who have recognized that the more specific and intensive the need for support, the more individualized it needs to be. In fact, it often requires that the person have something developed that's very unique to them. So we really are looking at a range of options.

The Chair (Mrs. Laura Albanese): Ms. Jones?

Ms. Sylvia Jones: Thank you for your presentation. I obviously have not had a chance to read all of it. I very much appreciate the time you've put into the three-year action agenda.

I've got to tell you that saying that we're going to deal, in the first year, with caregivers over the age of 80 doesn't sound particularly bold to me. To me, that's as close to a crisis as you can get. But maybe you guys have all been in the sector, working so hard and talking to the government for so long, that that is bold. I don't know.

Mr. Ronald Pruessen: Everything is relative.

Ms. Sylvia Jones: That's very kind of you.

Mr. Ronald Pruessen: You're absolutely right. We've been experienced enough to know that there are hundreds of caregivers over the age of 80 who have been waiting, in some cases for 30 or more years, for the provision of such services. They don't have those yet.

We do, over a three-year period of time, certainly talk about all of the caregivers over the age of 70, at least those who've made it clear that they need these kinds of services.

But you feel free to recommend—

Ms. Sylvia Jones: Okay; point taken.

I'm sure you have been following and reading the presentations. We have had some pretty creative ideas and suggestions coming forward. I would be interested in learning from you whether there are governmental barriers that are standing in the way of some of those innovations, where we as a committee could say that even with this investment, we as a government are going to have to make some decisions—to your point that one size doesn't fit all—and open up the ideas and creativity to let some different models flow. Are you seeing that? Are you hearing that?

Mr. Gordon Kyle: There are several barriers to the kind of creativity and flexibility that I think is demanded here. I've heard of lots of issues with the Developmental Services Ontario, DSO, system. It's very much focused on identifying vacancies in existing services and placement. I would like to see, very much, that that system become much more flexible in identifying funding resources that are available to people, but not necessarily tying them to a bed that exists someplace in some community we might peg people into. This demands a lot more flexibility and creativity than we've got within the system or we're able to do with existing resources now.

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Ms. Sylvia Jones: And the reality is that even with coordination of DSOs, you can look for vacancies all you want, but clearly there are not enough of them.

Mr. Gordon Kyle: No, that's clear.

Ms. Sylvia Jones: Okay.

Mr. Ronald Pruessen: Just a variation on that: I think one of the things we would like to see emerge in this capacity-building task force is exactly that ability to say, by bringing other players to the table and not just Queen's Park players, "This is a really interesting idea, and we need to put our money into this to try it out at least for a few years."

Ms. Sylvia Jones: Well, even today we had the Habitat for Humanity model, which to me makes a lot of sense.

Mr. Ronald Pruessen: Right. The extension of that, though, the flip side of the coin, is that at some point, whatever the flexibility and creativity about various models of service are concerned, there is a bottom-line component to this. The Habitat for Humanity example is an excellent one. Capital expenses as opposed to operating expenses is a key variable here. As wonderful as Habitat for Humanity's work will be in my home region of Peel, for instance, in the years ahead, they are not going to be able to provide the support staff for the people who will go to live in those houses. That is a crucial government role that needs to stay in place and be dramatically expanded.

The Chair (Mrs. Laura Albanese): Thank you. Ms. DiNovo?

Ms. Cheri DiNovo: Yes, thank you. I'm going to start off where Ms. Jones left off. It sounds good. Is it happening?

Mr. Ronald Pruessen: Should we let silence speak?

Ms. Margaret Spoelstra: Not yet.

Mr. Ronald Pruessen: It isn't yet. We've had a meeting with the minister, who has been positive and encouraging but has made it clear in any number of cases that some of these steps are clearly going to await current budget deliberations. There is, I think, a clear commitment already expressed by the ministry and the minister to create the capacity-building task force. The key step for us is going to be: Will that capacity-building task force have some money to invest, as opposed to study?

Ms. Cheri DiNovo: As many parents have said, if you've read some of the witnesses, "No more task force. No more checking it out. We need help now." That's the crisis of the situation. Essentially, we're a year behind already on your action plan. That was the number one question.

Number two was that I was wondering if your committee had looked at some legislative shifts; for example, inclusionary zoning. It has been one of the Wellesley Institute's asks. It doesn't cost a dime but does require a change in the Planning Act so that, for example, municipalities that want it can require of developers that they set aside certain numbers of housing units to be used for those with developmental disabilities or others, say in lieu of section 37 dollars in Toronto, for example, or something. It could look very, very different depending on the municipality, but it requires a legislative change at the provincial level. Did you look at those kinds of things as an option?

Mr. Gordon Kyle: Yes, we discussed various options that might be there, but the focus so far hasn't been that depth of analysis as to what those kinds of barriers are. We've really looked at the mechanisms we think would actually create movement to develop this. I really would expect that those recommendations will emerge from the groups that we've identified.

Mr. Ronald Pruessen: I think that capacity-building task force, for instance—we very much recommend that it include developers, municipal authorities and the like to help identify exactly those kinds of needs where the provincial government could be facilitated.

Ms. Cheri DiNovo: The reason I raise that is that it doesn't cost a dime, so it could happen now.

Mr. Ronald Pruessen: Exactly.

Ms. Cheri DiNovo: And in fact the same bill passed second reading already. It just never got to committee stage. So any help on that front would be very helpful, because there's no budgetary consideration but simply a Planning Act change.

Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you very much, again, for presenting to the committee.

Ms. Mitzie Hunter: I just have a question for the researcher.

The Chair (Mrs. Laura Albanese): Yes, Ms. Hunter?

Ms. Mitzie Hunter: I wanted to see what the process is for vacancy management within this sector. If we could get some information on that, that would be great.

Ms. Karen Hindle: Sorry. Could you repeat that?

Ms. Mitzie Hunter: What is the process for vacancy management of the existing housing units?

The Chair (Mrs. Laura Albanese): Thank you.

MRS. ORLENA BROOMES

MR. JEFFERSON BROOMES

The Chair (Mrs. Laura Albanese): Now we'll hear from Orlena Broomes and Jefferson Broomes. Please come forward. Good afternoon, and welcome to our committee.

Mrs. Orlena Broomes: Good afternoon, and thank you for having us. As you heard, my name is Orlena Broomes, and I come as a parent of a son with developmental needs. Jefferson here is my son.

What we want to talk to you today about are the post-secondary needs of students with disabilities and also the employment needs of students with disabilities.

What I'm going to do, because I believe that to hear Jefferson's voice is more important than to hear my voice: I am going to go through quickly some of the situations that we've seen and some of the recommendations, and Jefferson then can talk about some of his experiences. He might just butt in while I'm talking, and that's fine. Then, afterwards, the floor is open for questions.

I've started by giving a profile of Jefferson. I think that's important because we need to know who we're talking about when we're talking about youth. I keep saying "students" because he's been a student for so long. When we are talking about youth with developmental needs, we are not talking about an aggregate set of people. We are talking about individuals, individuals who have needs that are separate one from each other.

Jefferson comes to you as an individual. His developmental needs stem from the fact that he was born prematurely. He was 600 grams, 14 weeks early. It is amazing at that point in time how people applauded him, how people encouraged him, how people wanted to see him succeed.

That changed as he progressed out of the hospital and into school, but he persevered and overcame many challenges, and that's another story altogether. Four years ago, he entered the post-secondary program at Sault College, doing the CICE program, which is a community integrated cooperative program—I think I've got that correct; the "E" is missing somewhere in there—which is a supported program, very similar to what you would find in secondary school in terms of support, one of the few programs available to students with special needs.

Jefferson completed that program in heavy equipment/automotive because his passion is cars. If you got to know Jefferson, you would know that all he talks about are cars. When he was five years old, I took him to the library. He was a regular at the library, but what he wanted to do—he said to the librarian: "Can you give me the video of the Backstreet Boys? And what do you have in here on cars?" That has continued all through.

He wants to own his own business, and so after completing that heavy equipment, he went on to the CICE program at Durham College. He now holds a diploma. Sault offers a diploma and Durham offers a certificate.

I will let you go through at your leisure some of the strengths of Jefferson, because they're going to come out as we go through the presentation. But suffice to say, he's at the point now where he has left college and he's in the market for a job, and we have found that the barriers there are still fairly enormous.

Because Jefferson is one of the few people in a program who have actually attended post-secondary education, we thought it also fitting that we should talk about some of the barriers in post-secondary for students with disabilities.

1520

Jefferson, you can pop in whenever.

I've got a daughter as well; Anna-Maria is 17 months younger than Jefferson. She doesn't have any developmental needs; in fact, she's at the higher end of the spectrum and was identified as gifted. So I didn't have any child who fit what we term "normal."

Every year, high school students all over wait in March, looking for the mail. They're looking for acceptances to college or to university. Every year, graduate students all over this province—July approaches, and they are looking to enter the job market after completing university or college. Every year in almost every household, they start the excitement of moving on to a different milestone in their lives. The exception would be households with students with developmental needs. Those students finish high school, and then there's a block. Where do they go? If, like Jefferson, you happen to be moderately functioning, then it is even more difficult. You cannot go into a group home—you'd better not be going into a group home—because you are too high-functioning. You need to get into a program to contribute meaningfully to your life and to society, but where do you go?

We were fortunate that we found out about the CICE program. They're not well known. When Jefferson started in 2009, there were only three: Sault Ste. Marie, Lambton and Sarnia—and Durham was just opening a college. We live in Barrie. It meant that he had to travel. We decided on Sault Ste. Marie because it offered a diploma program and it offered him the flexibility of doing the automotive course with heavy equipment. Seven hours away from home—that is a hardship, even for kids without special needs, never mind kids with special needs who don't even like to go to camp.

For the academic year 2012-13, when I did rough research on what was available—they have now moved from three to seven colleges. It's still scattered, but now we've got one at Georgian College in Barrie, and Jefferson and his school, St. Joan of Arc, were very vocal in pushing for that. We've got Confederation College—and I have listed the others here.

What we also found in his time both at Sault Ste. Marie and Durham College—and he graduated from Durham in April of this year—was financial barriers. If you do not qualify for OSAP, you do not qualify for the disability grant. If you do not qualify for OSAP, you do not qualify for the $10,000 grant that would help you to buy the equipment you need for special needs. It is no use saying, "Go to the accessibility department and use those," because these students need additional support that the accessibility departments in these colleges cannot supply.

We also found that the privacy laws—and this came out much more at Durham than at Sault College—create a barrier. These are students who have gone into the CICE program because they need support, yet the privacy laws—I know they are there for a reason, and I respect those laws, but they prevent the parents or caregivers from communicating with the college about the student. So when Jefferson, who lived at college and came home on the weekend, came home and I saw he had some notes on the table and I looked and I saw not one promissory note but two promissory notes for $3,000, I just blew my top. I called the school, and what was I told? "I'm sorry, Mrs. Broomes. We can't discuss that with you."

We need some amendments to those laws, particularly where they impact on vulnerable students. Do you know what the school said to me? "If you go and you take out trusteeship for him, then we can talk to you." When I told Jefferson that, I wouldn't tell you what his reply was, but obviously he was quite capable of taking care of himself.

Quickly, coming out of college now, he's ready for work. He's got a $7,000 student loan. That needs to be paid. He also needs—he was very excited about school. He left St. Joan of Arc in a leadership position, organizing the ball hockey tournament there, which has been going on now for about eight years. He co-founded that. Rogers TV named him athlete of the week. He's got good salesmanship skills. He's a beautiful writer. I forgot to attach a letter he wrote to St. Joan of Arc teachers when he was leaving school. They cried. I cried, and I don't cry that much. But now he has got this, and his enthusiasm knows no bounds. He wants to go out there and be a contributing member to society, but what is he finding? Jefferson, what are you finding?

Mr. Jefferson Broomes: I can't get a job.

Mrs. Orlena Broomes: Now, his voice is low because he had a trach in and he had multiple surgeries.

The Chair (Mrs. Laura Albanese): Can you place the microphone closer? You can bring it forward towards you so that it's easier. There you go.

Mr. Jefferson Broomes: I can't find a job.

The Chair (Mrs. Laura Albanese): We can hear you now.

Mrs. Orlena Broomes: And some of the reasons for that being?

Mr. Jefferson Broomes: I'm either underqualified or they don't want to hire me for some reason or the other.

Mrs. Orlena Broomes: And part of the reason that employers don't want to hire students with disabilities, youth with disabilities, is because the stigma still exists out there. They don't know the capabilities. They underestimate the capabilities of these students. There's also a disconnect between post-secondary education for students with disabilities and the workplace. Even though you've got co-op placements, there's that disconnect in the wider workplace once they leave the safe environment of school. We need to educate employers about what these students are capable of doing.

Mr. Jefferson Broomes: I just think that if there was more education for employers, they'd be more likely to hire people like me. For example, I don't know if you guys watch the show Undercover Boss on TV. I think that's a great show, even though I don't really watch it. But I think companies should go undercover and see the policies and what they're doing to the company so they know more information about the company and they would educate their staff and people who work for them more.

I've applied to a couple of car dealerships in Barrie, some of the big-name car dealerships in Barrie. I brought in all my resumés, and they don't even bother to even call me back.

1530

You look at some of these ads, and they say, "We'll train you. We'll train you. We'll train you." But I don't think they have enough training themselves to train people like me, or people in general.

My goal is to become a car salesman—well, it was; I don't know what it is now. But I look at some of those ads, and they say, "We'll train you," but you need an OMVIC licence, and they will train you. I apply for those jobs. They don't call me back. I don't think they even bother to look at my resumé.

Mrs. Orlena Broomes: I think, too, what has happened, because he is part of the Ontario Youth Employment Fund—he's part of that, and what we have found as well is that those employment consultants themselves underestimate what these students, what these youth can do. When Jefferson, from the time he's been registered—and they've got his resumé and they've heard his background, and you've seen that he's a leader. He likes writing; he writes beautifully. His car ads that he has done were part of the Summer Company—he got a grant from the Ontario government Summer Company and he ran his own company. But yet the jobs that they offer him: "There's a cleaner needed here." "We need somebody to stock shelves there."

These students, these youth, are capable of more than being Walmart greeters. I said before: They are individuals. You cannot look at them as a collective. You cannot say that Walmart is really good for hiring special needs students—they are; Walmart is good for doing that. So are McDonald's, Tim Hortons—but we need to rise above the thinking that these young people are only good for menial jobs. We need to recognize what their capabilities are. We need to know that they want to contribute to the tax base. I need to know that somebody's going to be supplying me my CPP pension when I get old, and if we let these young people off the hook by not giving them the training and the employment that they need, we have less in that tax base, haven't we? They don't want to be taking. They will use what you give to them to build on that.

Mr. Jefferson Broomes: I think society today only sees us as entry-level jobs. They want to leave us at the entry-level jobs. I don't think they really want to take a chance on us.

Any questions?

The Chair (Mrs. Laura Albanese): Yes, there will be questions, I am sure. We're starting with Ms. Jones.

Ms. Sylvia Jones: Jefferson, very briefly, because I see my colleague would also like to ask you a question: You mentioned that employers need to be educated. So give your two-minute pitch on what employers need to know so that they understand that you're a great asset to them.

Mr. Jefferson Broomes: Can you explain what you mean, please?

Ms. Sylvia Jones: Yes, what would you like employers to know when they are interviewing you?

Mr. Jefferson Broomes: I'm a great salesman—a huge salesman. I had a fundraiser at my old school. We had to raise money for the end-of-the-year dance, and we had to sell chocolate bars. By myself, I sold almost $800. But that's not really the point.

I think, towards my goal, I can sell cars. Give me a car; I can sell it. I've sold a car within eight hours, alone, by myself. I think, honestly, I know cars, so I could sell myself. I think that if people gave me a chance, I would be able to get a job. I think people—it's very hard for me to sell myself, because people don't give me the opportunities to sell myself. I find it hard to sell myself. So if I got a job, I could bring a lot to the table. I could wash cars; I can do all that stuff. I don't want to wash cars. But I think that I have a chance to do jobs more than—I want to be CEO, one day, of a company. I want to do this and that. But I'll never get there if people don't give me a chance.

The Chair (Mrs. Laura Albanese): Thank you. I have two minutes each. Miss Taylor?

Miss Monique Taylor: Thank you so much for being here with us today. I'm curious to know if you're involved in any organizations to help you find a job.

Mr. Jefferson Broomes: I've been in the Ontario disability program to help me find a job.

Miss Monique Taylor: But no other work-connect organizations?

Mr. Jefferson Broomes: No.

Miss Monique Taylor: So when you go to find a job, do you tell them, "You let me wash your cars"—I'm just saying—"and then I'll show you the job that I can do," and work your way up? Do you think maybe that's a possibility? You have to prove to them, right?

Mr. Jefferson Broomes: The biggest thing is that I don't even get to the interview process.

Miss Monique Taylor: This one is to your mom. Have you spoken with your MPP in your area to see if there are any organizations out there that are working with young people to help them find work experience?

Mrs. Orlena Broomes: I haven't spoken to the MPP, but that is something that perhaps we can do. What we have tried to do is exhaust all the connections that we've got, and we've gone into employment agencies—Northern Lights, inclusive employment, those agencies that are there to help people like Jefferson get jobs.

Now, we can say that the economy is going through a rough time, but it's always a rough time for these students. I take your point that, again, going to the MPP might be another area, but we've done extensive searches through the programs available on the website, going through the government's website—

Miss Monique Taylor: So you've been looking into the resources, and that's why I was pushing you towards the MPP—not that the MPP would be able to help him get a job, but to provide resources that possibly you might not have known about.

Mrs. Orlena Broomes: Right. We've gone through that—myself, and he's done some of that himself—where we've gone through the paper and we've looked at resources.

Also, one of the things we have started thinking about would be going to conferences as well where they talk about employment for people with disabilities, and hoping there to learn more about what's going on.

Miss Monique Taylor: And that's something that we've been working on here, is transitions—

The Chair (Mrs. Laura Albanese): Sorry. I have to interrupt. I have to go to Ms. Hunter to continue.

Ms. Mitzie Hunter: Thank you, Madam Chair. Thank you, Mrs. Broomes, for all that you do on behalf of both of your children.

Jefferson, it's so nice to meet you. I think you've achieved an incredible amount in your life so far, and I have no doubt that you will continue to persist until you achieve your goals.

I do want to say that actually getting a first job for any young person is one of the most challenging things to do, but once you have your first job, you can build on that, and you don't know how far it's going to take you.

I am aware that Goodwill Employment Services has operations in Barrie. They do provide transitional employment programs for people with disabilities. I highly encourage you to get connected with your Goodwill locally in Barrie, specifically with a career plan of getting into one of the car dealerships so that you can eventually contribute to that local economy by selling those cars, because I am confident that you're going to be able to do that. Sometimes you have to work your way up to get to your ideal job. I know that that employment program is designed to create transitional employment opportunities for people with special needs and disabilities.

1540

There's also the youth employment fund, which Goodwill is part of, which is subsidizing employment placements for young people with disabilities up to the age of 29. They will pay for any accommodations that you need, as well as the wages and salaries for the employer—so it just reduces their risk while you're trialling work.

Mrs. Orlena Broomes: He's not part of that youth employment fund initiative.

The Chair (Mrs. Laura Albanese): Your MPP may be able to give you more information in regard to that, locally—what agencies would be involved.

Mrs. Orlena Broomes: We will do that.

The Chair (Mrs. Laura Albanese): Thank you so much for your presentation.

Mr. Jefferson Broomes: You're welcome.

The Chair (Mrs. Laura Albanese): Good luck.

Miss Monique Taylor: Write us a letter and let us know how well you did, okay?

The Chair (Mrs. Laura Albanese): Yes.

MS. JUDY PAKOZDY

The Chair (Mrs. Laura Albanese): Now we'll hear from Ms. Judy Pakozdy. Good afternoon.

Ms. Judy Pakozdy: Good afternoon.

The Chair (Mrs. Laura Albanese): Thank you for coming to Toronto on such short notice.

Ms. Judy Pakozdy: FASD is my life, and I will talk about it 24 hours a day.

The Chair (Mrs. Laura Albanese): You may start any time.

Ms. Judy Pakozdy: My name is Judy Pakozdy. I used to be a pediatric nurse and a nurse manager for 33 years. Then, I was the executive director of the Fetal Alcohol Syndrome Society Yukon for 12 years and the inclusion coordinator for the Yukon Association for Community Living. And now, since I retired to Ontario, I'm an FASD consultant and advocate and co-facilitator of the Halton FASD parent support group. But my primary role in life is being the mother of a very successful young man living with FASD.

I've given Trevor the photographs of a bunch of the kids from our parent support group, because I want you to know that when you look at these kids, you do not see disability, and for them, that's a disaster.

You've had lots of presentations about FASD—I've been following the news—and certainly you got all the info you need, so I'm hoping that you'll be able to incorporate that information into decisions that you're possibly going to make.

As a pediatric nurse, I know that this disability is one of the most difficult for the children, youth and adults who live with it, because they look so normal and sometimes can act normal, so people think they should be normal all the time, and they can't. The prenatal brain damage that they live with is so devastating that it destroys every opportunity that they have for success as individuals.

The hope lies in providing appropriate supports, and those supports have to be family-driven, because no matter how many of these kids go through the foster care system—and I've seen many of them over the last 40 years—they all eventually go back to their families. Whether those families are good families or families who are still struggling or families who finally become sober and can take something on, nobody can take on a kid with FASD without supports. Love is definitely not enough, and sometimes love hurts them.

I want to tell you about my son Matthew. My son Matthew is the shining star in the photograph who looks like a hip hop dance teacher, because that's what he is. He's 34. He was adopted from Yellowknife when he was one. I knew he had FAS when I adopted him—but of course, I was a pediatric nurse; I could fix this. We've all learned over the last 33 years that I can't fix it, but I sure can make it a lot better life for him than the lives that he sees around him from all his friends and classmates. He presently lives in BC with a full-time caregiver. We receive individualized funding from the BC government, managed by a small non-profit group that I formed that's comprised only of people who love him and people who recognize that he is disabled. If they don't want to face the disability, we don't want them around. We don't want to try harder anymore, because trying harder is what kills the kids.

These kids live on the streets; they live in the jails. You all know them. You know the Ashley Smiths; you know the Sheppard boy who died in the bike and car accident. All those kids have FASDs, and they were not diagnosed appropriately, or if they were diagnosed, it was put on as a label in addition to multiple other diagnoses that they had. It was not seen as an overarching brain damage that affected everything that they do in their lives.

So Matthew receives a disability payment, equal to welfare, to pay his rent, but we also get from that small non-profit the equivalent amount of money from the BC government that they would pay for 31 hours of support a week. That's all he qualifies for—this severely disabled child. But 31 hours of government money is pretty good money, so with that money, we're able to hire four different support people to keep him alive, happy, having a good life and safe.

In BC, he's also allowed to make up to $500 a month before they touch a cent of his disability money, which is a real bonus.

His caregiver—he has lived with her for 13 years. I found her in a locker room at the Queen Alexandra hospital. She keeps him safe and comfortable at home. They live in a two-bedroom townhouse. They share it. He lives with a commitment to call her every three hours when he's out and about, and if he doesn't, she calls the local police. She has already trained the police, so they know about his disability. She has trained the EMTs that service his area in Victoria, so they know, when he calls, what it's all about when they get there. These police find him wherever he is—in a nightclub, you name it. They find him and they just go up to him and say, "Phone Carey right now." And it's amazing how just that keeps him safe.

It's not that he has always been safe. Between the years of 25 and 30, he started using alcohol and drugs, introduced by his lovely little dance students, and he became suicidal. He tried to jump off a bridge once. He tried to—oh, he overdosed on all sorts of drugs and ended up on a ventilator for three days. But out of that we were able to convince the government to give us more money to increase his safety, so we could increase the supports he got. So that was a big benefit.

We also found that AA doesn't work, and everybody knows that AA doesn't work for people with FASD, because if you have to go back over your mistakes in life over and over and over, they perseverate on that and they can't get past thinking about that again, so they never move forward. So my son found a group called LifeRing, which is organized through California and BC—you know, all those socks-with-sandals people. They do only forward planning for your life, and he loves it. He goes once a week. He just thrives in that environment, and it's a social activity for him, which is really hard to find for our kids who have brain damage and don't quite act socially appropriate a lot of the time.

He also has three part-time support workers who work six hours each. One coordinates his life, his work, his recreation and other activities. She works with his job managers to ensure understanding between him and others in relation to his tasks and responsibilities and how to deal with stressful situations at work. He works as the admin support, a person in an office for low-cost housing. He gets a lot of phone calls where people are really stressed. She goes in and works with him to try to figure out how to not take that stress home and worry about them not being able to pay the rent or buy their kids Christmas presents and all that kind of stuff that they tell him.

1550

Another one participates with him in shopping, cooking and relaxation classes. He goes to yoga, Zumba and exercise class. He's studying now to become a Zumba instructor. The other one helps him with money and time management, and to be on schedule. These kids really only need an executive assistant, as we all do in life. It works like a charm. You know, we don't need to be spending tons of money, and all sorts of professionals, and locking these kids up in group homes. We need to be treating them with respect and believing that they can succeed, because they sure can, but they're going to need that help all their lives—all their lives. Never take it away; you take it away, and they die.

All of his caregivers are committed to each other and to Matthew. He considers his caregivers to be his best friends. He has great difficulty with relationships and making friends, and these guys are his best friends. I tell the parents that come to my parent support group, "What you need to do—it sounds awful—is buy friends for your kids. Find the most responsible kid in their classroom, talk to them about FASD, introduce them to your child and ask them if they'd like to participate in a project for all of their school years in being this child's friend"—teaching other people about their disability, helping them to fit in more in social activities.

Parents get shocked when I say, "Buy friends," but you know, that's what we're buying here: We bought his best friends; they're his support workers. It's a great life for him. It's not isolated; it's not locked out of the community. It's not what I would have chosen, but it's a damn sight better than dying on the streets.

So I've worked in this field for the past 40 years. I thought I was retired, but it seems I'm not, so I'll be going on doing this work until I die. It's kind of boring being retired anyway.

So what I want to tell you about what Ontario's specific priorities should be—funded diagnostic teams. I've talked to five so-called diagnostic teams throughout Ontario. They're in all the books: "Here's our five teams." And you know what? They assess one or two people a month. When we're talking about a disability that affects 2% to 5% of school-aged children; we are not talking about one or two kids a month. Most of them do not provide training for the parents and support afterwards. It's just, "Here you are. Here's your diagnosis. Good luck with that." It doesn't cut it.

The other thing they need is FASD navigators for families. I was listening to the last young man who presented. His family needs a navigator to get him into all of this stuff. I'm not saying we're supposed to baby people, but I'm saying we have to recognize they're different. We are all different, believe me. None of you are like me, and I'm not like you. We are all very different individuals. Children with FASD came into this world to teach all of us, and by God, they are, in dribs and drabs at the moment, but this is an opportunity for all of us to learn how to be nicer to each other and more tolerant.

I guess that's all I have to say. Look at my pictures and recognize how wonderful these kids are.

The Chair (Mrs. Laura Albanese): Thank you. We have a couple of minutes for each party. Sorry, I lost count here; I believe it is Ms. Taylor.

Miss Monique Taylor: Thank you so much for the work that you're doing, and for bringing your son's story to our table, to let us know how his life is working and what you had to do to make sure that he was living a fulfilling life. I think it's a great picture of what could be happening.

When I listen to these stories of people with FASD—I have to be honest—I'm still so confused as to what their life really looks like, hearing that they need supports every step of the way and yet people would think that they're "normal."

Ms. Judy Pakozdy: And they want to pass as normal, so they're not going to tell you.

Miss Monique Taylor: Yes. I know for myself that it's really hard to absorb. What do we do to make sure that we're keeping these people safe? I'm also hearing that it doesn't matter what we implement at young ages; it's not going to change as they grow older, and those supports need to be continuous.

The picture that you have painted with your son and the supports that are around him—how does he feel about those supports?

Ms. Judy Pakozdy: He's in charge of them. In the beginning, he phoned me one day and said, "Mom, Lisa is not working out." She's one of the caregivers. I asked, "What's the problem?" "Well, I phoned her because I needed someone to come to lunch with me, and she couldn't come. She was busy. We can't have that kind of support worker, who isn't available when I need them."

Miss Monique Taylor: Does he understand what his support workers are for?

Ms. Judy Pakozdy: They're there to keep him safe and to make his life happy.

Miss Monique Taylor: That's his understanding of it?

Ms. Judy Pakozdy: That's his understanding, and that's their understanding of it. It's amazing how wonderful they are.

Miss Monique Taylor: Does he realize that he has a disability?

Ms. Judy Pakozdy: Very much so. He speaks at national and international conferences. In fact, he's presenting in Vancouver, in April, at the national FAS conference. His topic is "Finally, I Am an Adult."

The Chair (Mrs. Laura Albanese): Sorry, I have to move it forward.

Miss Monique Taylor: Thank you very much.

The Chair (Mrs. Laura Albanese): Ms. Hunter?

Ms. Mitzie Hunter: You mentioned the 31 hours per week—it's there; it's committed. I wondered if you could talk a little bit about having a society or community that is inclusive of people with disabilities. It's not about being hidden away; it's actually where it's an acceptable part of our everyday lives, whether at school, at work or in the community.

Ms. Judy Pakozdy: Matthew was bullied all through school. I didn't know that until he got older and told me that kids called him names. Matthew is also gay. He's aboriginal, he's gay and he's disabled—a triple threat, and he was seen as such by the kids at school.

Although I work a lot with disabled people of all disabilities, I rarely see total acceptance of the kids in school. My other son has a chromosomal abnormality. He's 21. It has been a 100 times easier to raise him, because he looks physically different and he's sweet. "Sweet" goes a long way. He was always in a separate classroom with the same five kids, all through school, right through high school, and now they're in the same day program. To me, that's inclusion, even though it doesn't look like it. He has real friends who he grew up with, who he knows and loves.

The Chair (Mrs. Laura Albanese): Ms. Elliott?

Mrs. Christine Elliott: Thank you very much for coming to speak with us about your experience and Matthew's experiences. I'm really interested in your views on the BC model and how you think it compares, relative to what Ontario is doing right now. Is that something that we should be taking a look at—to follow what they're doing there?

Ms. Judy Pakozdy: I didn't know that Ontario had a model for kids with FASD. Our kids here don't seem to fit into any programming until they break the law, and by then it's a lot too late—not too late in the long run, but it's too late for what should've been happening all along.

Without diagnosis, the kids get labelled as something else, so they often get serviced by the mental health groups, but it's not a mental health issue; it's an actual, physical brain damage. You can't fix that with medication or with counselling. Although Matthew does once a month go to a psychologist for counselling: "It's private, Mom." But he just goes so he can destress, and he probably could do the same thing with some yoga counsellor or something. It's just that he has connected with this woman, so he stuck with her.

But BC, Alberta and Manitoba have major commitments of funds specifically for FASD supports, and that's where the difference is. Ontario does not yet recognize FASD as a major disability, and it doesn't commit any kind of programming or funding supports to them.

Now, I don't think we need a whole bunch of programming per se, because most of what's out there can be modified for our kids, as long as there's somebody knowledgeable about the disability to work with the provider. But I think there needs to be—without diagnosis, we're all lost, and all these kids are lost. So the money has to go upfront into a diagnostic process.

In BC, they have 26 diagnostic areas, like LHINs, or whatever they're called here—health care provider groups—and each one of them has developed a diagnostic team that parents do not have to pay for. Here, parents have to pay for this. This is unbelievable, that if someone has a disability, they have to pay to find out about it.

Mrs. Christine Elliott: Thank you very much.

The Chair (Mrs. Laura Albanese): And thank you again for coming to speak to us and for sharing your experiences with us. We will definitely keep all your recommendations in consideration.

Ms. Judy Pakozdy: Thank you, and I'll be back.

The Chair (Mrs. Laura Albanese): This concludes our day.

Ms. Sylvia Jones: One quick question for research: Have we asked—and if we haven't, can we?—what the annualized funding is for the DSOs across Ontario? I know we've seen a few numbers in the packages, but I don't think we've seen anything from the ministry. Thanks.

Mr. Bas Balkissoon: One of the groups said $1.4 billion.

Interjection.

The Chair (Mrs. Laura Albanese): We're adjourned until tomorrow morning at 9 a.m.

The committee adjourned at 1603.

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