



Legislative Assembly
of Ontario
Second Session, 40th Parliament

Assemblée législative
de l'Ontario
Deuxième session, 40^e législature

Official Report of Debates (Hansard)

Tuesday 14 January 2014

Journal des débats (Hansard)

Mardi 14 janvier 2014

**Select Committee on
Developmental Services**

Developmental services strategy

**Comité spécial sur les
services aux personnes ayant
une déficience intellectuelle**

Stratégie de services
aux personnes ayant
une déficience intellectuelle

Hansard on the Internet

Hansard and other documents of the Legislative Assembly can be on your personal computer within hours after each sitting. The address is:

<http://www.ontla.on.ca/>

Index inquiries

Reference to a cumulative index of previous issues may be obtained by calling the Hansard Reporting Service indexing staff at 416-325-7410 or 325-3708.

Le Journal des débats sur Internet

L'adresse pour faire paraître sur votre ordinateur personnel le Journal et d'autres documents de l'Assemblée législative en quelques heures seulement après la séance est :

Renseignements sur l'index

Adressez vos questions portant sur des numéros précédents du Journal des débats au personnel de l'index, qui vous fourniront des références aux pages dans l'index cumulatif, en composant le 416-325-7410 ou le 325-3708.

Hansard Reporting and Interpretation Services
Room 500, West Wing, Legislative Building
111 Wellesley Street West, Queen's Park
Toronto ON M7A 1A2
Telephone 416-325-7400; fax 416-325-7430
Published by the Legislative Assembly of Ontario



Service du Journal des débats et d'interprétation
Salle 500, aile ouest, Édifice du Parlement
111, rue Wellesley ouest, Queen's Park
Toronto ON M7A 1A2
Téléphone, 416-325-7400; télécopieur, 416-325-7430
Publié par l'Assemblée législative de l'Ontario

LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**SELECT COMMITTEE ON
DEVELOPMENTAL SERVICES**

**COMITÉ SPÉCIAL SUR LES
SERVICES AUX PERSONNES AYANT
UNE DÉFICIENCE INTELLECTUELLE**

Tuesday 14 January 2014

Mardi 14 janvier 2014

The committee met at 0901 in the Valhalla Inn, Thunder Bay.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Good morning. The Select Committee on Developmental Services is now in session here in beautiful Thunder Bay. Welcome to all the committee members.

MS. CARRIE GROULX

The Chair (Mrs. Laura Albanese): I believe we have our first deputant already on the phone, Ms. Carrie Groulx.

Ms. Carrie Groulx: That's correct.

The Chair (Mrs. Laura Albanese): Good morning. I am Laura Albanese; I am the Chair of the committee. Where are you calling from?

Ms. Carrie Groulx: I'm calling from Ottawa.

The Chair (Mrs. Laura Albanese): You can begin your presentation. You will have up to 20 minutes to do so. If it is any shorter than that, that will allow time for questions from committee members. You may begin any time you feel ready.

Ms. Carrie Groulx: Thank you. Good morning, everyone. Thank you for all your combined efforts to make this committee happen. My name is Carrie Groulx; I'm a parent-advocate and currently have a postgraduate certificate in autism behavioural science with honours. The purpose of my presentation is to address the part of the committee's mandate to develop strategies and recommendations around the elementary and secondary school education needs of children and youth. Specifically, I will be discussing the effective use of educational assistants in Ontario schools and why the Ministry of Education needs to set standards for EAs—educational assistants—and force the school boards to follow Ministry of Education policies.

All of you should have a copy of the PowerPoint presentation. I'm happy to answer any questions at the end. On page 2 is my beautiful Melanie. I'll start on page 3 with Melanie's story.

Melanie was diagnosed two weeks before her second birthday. Devastated, as most, I panicked. I knew nothing about autism or what to do with her. Melanie was a flight

risk; sometimes aggressive; had pica, which is the ingestion of non-edible items; and tolerated very little. We went on a wait-list for services and were told early intervention was the key to her success. It was then I went back to school and received a postgraduate certificate in autism behavioural science.

Melanie received intense behavioural intervention, IBI, through the Autism Intervention Program. She received a secondary diagnosis of moderate mental retardation. Devastated but realistic, I concurred with her tardiness in learning—capable but tardy.

She then transitioned to the Ottawa Catholic School Board, where she was given an individual education plan, IEP, and a full-time educational assistant, EA. We saw some progress over the first five years of school and came across a variety of staff who were employed by the board, who sat in meetings and took notes but came up short on providing specific teaching strategies.

During this time, the ministry required them to use applied behavioural analysis, ABA, but they did not. Why, you might ask? I was told by my school board they do the minimum required by the ministry for special needs. The ministry has no standards for qualifications of an EA. The Ottawa Catholic School Board has no specific special qualifications required for an EA, and let's face it, the EAs are with the students most.

Despite my education and experience working with children using ABA strategies and my in-depth knowledge of Melanie, the school did not take any of the specific strategies I provided to achieve goals in her IEP.

On occasion, when one of the EAs in the schoolyard saw Melanie and me, they would witness something new. I would get Melanie to do something using ABA strategies we were working on at home. The response was amazing from the EAs. They would say, "Oh, wow. How did you get her to do that?" or "I didn't know she could do that." The EAs were thirsty for knowledge.

In September 2013, the start of the school year, she was assigned an EA who had been trained to use ABA strategies. The principal knew this would benefit Melanie and was thrilled to tell me. The team at the school was so excited, and I believe they were relieved to have someone with this experience. She was who we'd all been waiting for.

Six weeks into this fabulous year of achievement, this EA was declared surplus and had to leave. We saw more

progress in six weeks than we did in two years, so I decided to do what I could to get her to come back.

EA assignment, slide 4: The Ottawa Catholic School Board groups all special-needs students into one category and hires EA staff as generalists, requiring no specific skill set for the special needs of the children they work with. How could this be? Why shouldn't EAs be hired to work with specific groups of students and required to have specific training? Because they don't have to.

On November 13, Miss Monique Taylor told the committee—and if I may, I'll quote from the transcript, page DS-41—“My concern and what I'm hearing from many parents is that there's no consistency with their EAs.” Well, Miss Taylor, that's true. Not only are some children sharing EAs when they need full-time ones, but EAs get yanked, even if they have special qualifications that meet the needs of the children they were assigned to help.

I quote Mr. Clarke, on page DS-42: “About \$11 million a year is provided to school boards particularly for training around applied behaviour analysis so that there are people who have a more advanced understanding of how to support teachers in the principles of applied behaviour analysis and that those classroom teachers can, in fact, be supportive of those children.” This is very disturbing. Mr. Clarke is saying there's \$11 million a year to have a more advanced understanding. Where is the EA, the one who is one-on-one with the students in that \$11 million?

I contacted the board where my daughter's first EA was originally trained. They told me that they provide training to the staff two weeks into the school year for those who work with children with ASD, autism spectrum disorder. They let me know that the Geneva Centre offered free online courses. I told my superintendent of special needs what I had learned. I know from this forum that the Ministry of Education gives the Geneva Centre money annually, so it's not really free but is widely available for those who know about it. I was told by my superintendent of special needs that they needed money to provide EAs with the time off to get trained—no mention of giving them this information or suggesting professional development days would be dedicated to this.

There has to be an incentive for educational assistants. They're often the lowest-paid employees at the board. The EAs who work with the students with ASD are the ones who need the ABA training. They deal with constant opportunities all day long to provide strategies if they have the knowledge.

One of Melanie's teachers received two-day training in ABA in the past. None of the goals in her IEP were ever executed using specific ABA strategies outlined in policy/program memorandum 140, PPM 140.

Perhaps this money could be better spent training EAs who spend more time away from the classroom and away from a teacher, in the resource room, recess, assemblies, in our board church, body breaks, news shows, and outings such as track and field and Special Olympics.

The Ottawa Catholic School Board's reassignment of EAs is based on seniority, with a clause in the current union contract agreement—page 24, section 2, “Surplus to Schoo: Where there is a reduction in the total education assistants positions in the school, education assistants will be declared surplus, subject to ‘special qualifications’ (e.g. Braille, ASL)”—American Sign Language—“based on FTE”—full-time employment—“status and seniority date as per article 18.”

Even though there's a clause in the current union contract, the Ottawa Catholic School Board does not acknowledge ABA as a special qualification. They don't have to because the ministry doesn't force them to. They do say they acknowledge ABA as a scientifically proven way to teach these children. Unfortunately, they lack the qualified, trained staff to implement student-specific strategies. I've seen this first-hand.

0910

Slide 5, ABA in the classroom: The Ministry of Education issued PPM 140 in 2007. It states, “School boards must offer students with ASD special education programs and services, including, where appropriate, special education.” “Principals are required to ensure that ABA methods are incorporated into the IEP of students ... where appropriate.”

PPM 140 provides, under “Principles of ABA Programming,” that some students may require more intense programming. Let's stop and take a look here. Your committee is looking for recommendations with respect to the urgent need for comprehensive development strategies. The Ministry of Education's strategy as of now is, they have PPM 140 and \$11 million spent. The problem lies with no “standard of qualifications” from the Ministry of Education—therefore, not at the board level—for special qualifications of an EA. That means an EA requires no skill set to work one-on-one with special-needs students, and let's throw in not training them so they are not set up to succeed.

PPM 140 came out with a resource guide entitled *Effective Educational Practices for Students with Autism Spectrum Disorders*, which has been proven to provide information but not the how-to teaching using ABA strategies. This is what the ministry gave them to support children on the spectrum.

On page 176 of the guide, there's an ABC data sheet: just the sheet; no explanation on how to use it or what to do with the information collected. What it does show, on the next page, is a list of examples of what to teach. One of them is “I want.” Unfortunately, it does not provide specific ABA strategies on how to teach the “I want,” instead of a behaviour like biting. This key element is missing from the ministry-published guide on how to teach the “I want.”

The principal consulted me the first week of school on what to do about a problem behaviour with my daughter. I gave her a specific ABA strategy and told her to do exactly what I said and exactly how I told her to do it. She did, and the behaviour disappeared immediately. How powerful.

It's easy to get them to listen to me or anyone when it comes to problem behaviour, but when it came to consulting on an ABA strategy in order to help her to achieve her goals in her IEP when it came to education, it has been a real challenge.

My daughter bit her new EA in a "moment of silence" on November 11 because a well-known trigger was present. The well-known trigger was in her file somewhere for the last five years. She was away from her teacher who had had that two-day training in ABA. She was rewarded for this behaviour by getting to leave the gym. The reinforcement of this bad behaviour is now learned: All she has to do is bite and she gets to leave.

We have to stop this by using ABA strategies to teach functional communication training, the "I want"—"I want to leave" or "I want to go"—instead of biting. The EA spends more time with that child than anyone else. Shouldn't she be trained to succeed instead of being set up to fail?

Educators know that not all children learn the same. Children on the spectrum, we do know, benefit from using ABA strategies. The opportunity we have to make a difference is right now. The children in our school system are there for 16 years. We can do it right, teach them how to ask for something, or teach them that biting gets exactly what they want effectively and immediately.

From DS-195, Mr. Steve Levac from the Peel Children's Aid Society—and I only quote parts of what he said because I'm short for time—just to reiterate the point that so many people are looking for the answer and it's right here: "We need to figure out what help our education sector needs to be able to provide safe and practical education to special-needs children and to children with developmental disabilities." This is a real challenge.

The benefits of ABA is slide 6. For more than 30 years, ABA strategies have been scientifically proven to teach autistic children appropriate behaviour when it comes to their triad of impairment: socialization, communication and behaviour. The Ministry of Education recognizes and requires the use of ABA, but they do not tell the school boards how to spend their money and who to train. ABA strategies are simple and provide a step-by-step instruction on how to teach a specific skill.

ABA reinforces positive behaviour. For example, I used an ABA strategy to teach my daughter to count six squares of toilet paper so that she would stop flooding the toilet. This was a terrible problem causing damage and extensive cleanup. Having this skill will benefit her for her entire life, several times a day, everywhere she goes, even after I'm gone. Using these scientifically proven ways to teach, they are learned. The applied behaviour steps help children reach their potential, diagnosis or not.

Teaching children skills using ABA when they're young provides them with a lifetime of tools that contribute to being better integrated into schools and community where we all live. Each child can reach their full potential. It would be cost-efficient and more effective to train EAs to use ABA, even giving them time

off instead of paying higher-paid people who are not one on one with the students.

Slide 7, this is the conclusion: We all recognize that early intervention is the key to a child's success. Funded by the Ministry of Community and Social Services, the autism program is in place. Great, if you can get it, but it's only for two or three years. Then you transition to the next step, leaving behind trained staff and a curriculum essential for success.

The next step is the school system. This is so critical to a child's ongoing success. It's a 16-year opportunity. All children get to go to school, and it's funded by the Ministry of Education. We have principals, teachers, resource teachers and EAs in the schools constantly and every day. Then there are the specialized people: autism spectrum disorder consultants—ASD consultants—speech and language pathologists, behaviour consultants, itinerate resource teachers, school psychologists and occupational therapists. They consult, often leaving a report behind that ends up in a file in a filing cabinet in an office, nowhere near an EA who can refer to it. This system is expensive and not utilized to its potential.

I've seen first-hand how an ASD consultant was unable to provide a specific ABA strategy and used verbal prompts, which are the hardest to fade, when asked to contribute. This is where part of that \$11 million is going? Oh my, we have a serious problem.

Get all the EAs trained to use ABA strategies that work with children so that in the 16 years we can see an increase in skill acquisition. Properly trained EAs could prevent, for example, a behaviour consultation by not reinforcing bad behaviour, like rewarding a child when they bite by removing them from an undesirable situation. This is why we have young adults with ASD leaving the Ministry of Education and ending up no further ahead after 16 years because they didn't have properly trained EAs using principles of ABA.

We can serve these children better by having funds put into the training of front-line workers. They would work with the highest number of special needs children entering the school system today. The cost of lost opportunity is beyond my comprehension.

The public board plumbers in Ottawa are changing all the toilets in the special needs' classrooms because they're getting plugged up and flooding. Use a simple ABA strategy, as I did with my daughter, and they wouldn't have to solve this situation with a band-aid solution. They would take this opportunity and turn it into a lifelong learning opportunity. All it takes is for the EAs to be trained using ABA strategies.

Autism isn't going away. We can't ignore the fact that there is a scientifically proven way to teach these children, and we have 16 years to do so. ABA training is clearly not reaching all the EAs who are providing support to children with ASD. The Ministry of Education strategy on how to deal with this is not working.

What has happened to that \$11-million annual investment? It may be with those specialized staff who left the report in a file at the school. It is definitely not with the

EAs working with a child on the autism spectrum who could benefit from ABA. In five years, I've not seen any benefit to this \$11 million.

One thing I know for sure is that the EAs are the ones with the kids the most. We have a 16-year opportunity; we need EAs trained to use ABA strategies to make the most of this time.

The Ministry of Education needs to set standards for EAs and force the boards to follow the ministry guidelines. The Ontario government, over a lifetime of a person with autism, will pay for them through several different ministries. The opportunity to have educators and one-on-one support is during those 16 years. It's time for a change to get first-hand knowledge of ABA to the EAs who are the front-line workers. They're not going to let that knowledge sit in a file; they will use it all day long.

I thank you for this opportunity to be able to discuss with you the essential use of ABA strategies by properly trained EAs for the development of lifelong skills for children with autism spectrum disorders. I tell everyone, "It's behavioural science, not rocket science. You can do it; you just need to know how."

Thank you for investing in the future. Oh yes, the children thank you also.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation. We have less than a minute for each party to ask a question, so maybe just a comment on that. Ms. Elliott?

0920

Mrs. Christine Elliott: Well, thank you very much, Ms. Groulx, for your presentation today. I entirely agree with you that we do need training for EAs working with students and the ABA principles. Though I don't know that much about them, I do know that they're very effective teaching tools, and you've really illustrated that very well today. We will certainly take that into consideration. Thank you very much again for joining us.

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

Miss Monique Taylor: Hi. Good morning, Ms. Groulx. Thank you so much for joining us. You're absolutely right. You brought a very important piece to this table in speaking about PPM 140. I know that that will be a conversation going forward here and something that seriously needs to be looked at. Thank you so much for everything that you're doing and for bringing this to the table this morning.

Ms. Carrie Groulx: Well, I just wanted to make sure that you guys were aware that the ministry does not make school boards implement anything. Mr. Clark talked about giving the school boards money, but they don't have any say in what they do with that money. By not enforcing any policies, the school boards can do what they want with that money. Right now, because the standards are so low for hiring EAs, when I tried to get my daughter's EA back because we had sought more progress, we weren't able to do so because they don't require them to have specific qualifications. It didn't make sense. It needs to change.

The Chair (Mrs. Laura Albanese): I have Ms. Hunter who wants to make a final comment.

Ms. Mitzie Hunter: Thank you very much for sharing Melanie's story with us this morning. I'm just noting here that you've given us some advice, such as needing to ensure that all of the good work that is being done with students doesn't just sit in files, that it's actually brought into the classroom and is applied. I think that that's something that we can certainly take back. We share your sentiment that no skill set that is being utilized should go unused, and should be for the success of our children in our classroom. I want to thank you for sharing Melanie's story.

Ms. Carrie Groulx: You're welcome. I think that it's an important key to understand that the front-line workers, the ones that are with them all the time, that know them the best, are the ones that need to be trained, and it's not happening, because the board doesn't have to, because the ministry doesn't make them. If the Ministry of Education has this wonderful strategy and the PPM 140 in place—it's not happening. I've been in the school board for almost six years now, and I have not seen any of it. It was through my efforts in finding out how I could get that specifically trained EA back that I came across all this information. So it's very new knowledge to me, and I'm taking it as far as I can to make sure my daughter and everybody else who is in the system has that same opportunity. Sixteen years of one-on-one in educators, and we can't do better than this?

The Chair (Mrs. Laura Albanese): Thank you, Ms. Groulx. We really will take your suggestions into consideration here at the committee.

Ms. Carrie Groulx: Very good.

The Chair (Mrs. Laura Albanese): We really thank you for presenting to us this morning. We'll have to move on to the next presenter. We're on a very tight timeline.

Ms. Carrie Groulx: Absolutely. Thank you for your time. I appreciate you listening and understanding the need in this particular situation. Good luck.

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

MR. GREG BONNAH

The Chair (Mrs. Laura Albanese): We'll now move on to Mr. Greg Bonnah.

Mr. Greg Bonnah: Yes.

The Chair (Mrs. Laura Albanese): Good morning.

Mr. Greg Bonnah: Good morning.

The Chair (Mrs. Laura Albanese): Where are you calling from?

Mr. Greg Bonnah: Ottawa.

The Chair (Mrs. Laura Albanese): Ottawa. The committee members are all here and we are eager to hear your deputation. Please go ahead.

Mr. Greg Bonnah: Okay. Good morning. The subject being covered today is one that I've advocated for years. However, before this laudable goal has a chance of realization, you will have to make the individual minis-

tries accountable for what they do right now. Let me clarify this with a personal account of how, currently, the individual ministries do the minimum until the person with the disability is another ministry's problem.

The Ontario Ministry of Health knows that one child in 50,000 will suffer what they call an adverse event to their vaccines. In 1986, MPP Cam Jackson introduced a bill that would have mandated the ministry to test all children who suffered a reaction to their first vaccination. This bill was defeated, so in 1991 we were compelled by law to sacrifice our child.

His adverse event was Lennox-Gastaut syndrome. His brain was seizing every four seconds, and we were seeing between 60 and 100 myoclonic and/or atonic "drop attack" seizures per day. My research indicated that 70% of the children with this syndrome die within the first year and that if he had the misfortune to survive, he would be a vegetable.

The experts at the Children's Hospital of Eastern Ontario confirmed this by indicating that our child would never walk or talk, and advised us to give up our child—at a cost to the Ministry of Community and Social Services in 1992 of \$250,000 per year—and get on with our lives.

From my perspective, the costs involved in taking care of the few children harmed by the vaccines far outweigh the costs to the Ministry of Health for testing all children for adverse events, but to this day, they continue to refuse to do that because of the costs involved to their ministries. This, in my view, is a perfect example of how, currently, the individual ministries do the minimum until the person with the disability is another ministry's problem.

Now on to the Ministry of Education: Despite what section 8(3) of the Education Act states about the minister ensuring that exceptional children will have the appropriate special education programming, and services without payment, in 2003 I was required to spend \$40,000 of my own money, for which I've never been compensated, and forced to go to the Ontario Court of Appeal in order to have my child educated.

Until that time, special education students were not considered to be "persons" under the Education Act, which thereby allowed school boards such as the Ottawa-Carleton District School Board to legally place special education students in non-academic environments and do the minimum for them until they were another ministry's problem.

Unfortunately, making special education students "persons" under the Education Act did nothing for students who were labelled as developmentally delayed or mildly intellectually delayed, because the Education Act, in its regulations, still states that they have "an inability to profit educationally within a regular class because of slow intellectual development." My child has demonstrably proven this declaration to be false, because his IQ, as determined by the OCDSB's expert witness, their psychologist, at his education tribunal was reported to be at the 0.01 percentile.

Nonetheless, in the six years that the OCDSB chose to obey the court order and provide him with the resources required to access the curriculum, he successfully completed the grade 3 EQAO testing.

Imagine where, academically, my child would be today, had the OCDSB chosen to save the million taxpayer dollars that they squandered in their inane attempt to maintain the status quo, and had provided him with the resources required to access the curriculum for the full 15 years that the Education Act, in its regulations, says he was entitled to.

Finally, from my perspective, the Ministry of Community and Social Services is the textbook example of homeostasis. The government of Ontario, in Auton, stated that they would take care of any person that they knowingly harmed, yet here in Ottawa, this ministry has a one-size-fits-all policy. This ministry is quite willing to pay hundreds of thousands of dollars a year to segregate a person who has a developmental disability, but they are unwilling to provide the resources necessary for them to reach their full potential in the regular environment.

I have written countless times to the Premier, inquiring as to whether the bureaucrats were there to meet my child's needs or whether he was there to guarantee a few bureaucrats lifetime employment. For reasons that I am unable to fathom, the Premier and her predecessor have refused to answer this simple question.

I could go on endlessly with the difficulties I've encountered with this ministry, but I have a limited amount of time.

So, to conclude, if the government of Ontario had been thinking of my child as a whole instead of just components of what its individual ministries were allegedly mandated to do, then my child would not have been incapacitated or, at the very least, would have had the opportunity to reach his full potential in a regular environment.

Until the government of Ontario makes the individual ministries accountable for what they purportedly do, then they will continue to do the minimum for persons with developmental disabilities until these unfortunate souls are another ministry's problem.

Thank you.

The Chair (Mrs. Laura Albanese): We thank you for your presentation. We have about four and a half minutes for each party for questions, so I would ask Ms. DiNovo or Miss Taylor to begin. Miss Taylor.

0930

Miss Monique Taylor: Thank you very much, Mr. Bonnah, for being here with us this morning. We really appreciate your time. You've brought up some interesting topics. Something that we've definitely been focusing on and hearing from many presenters is the fact that we need to have one ministry taking care of people with developmental disabilities, because crossing ministries makes things confusing, makes things harder for families, and it's so important that we get things under one umbrella.

Mr. Greg Bonnah: I agree and disagree with you, because the Ministry of Community and Social Services

recently rolled out Developmental Services Ontario, which is supposed to be one-stop shopping. But we're finding, those of us who want inclusion here in Ottawa, that we're just put on waiting lists and nothing's being done, while the segregationists are getting everything. So one ministry is great, but it's all going to be in the details on how it's rolled out.

Miss Monique Taylor: You're absolutely correct, and wait-lists are definitely something that we're hearing about more than often. We all know that that's the reality of what's happening right now and it's not acceptable. We need to make sure that we have smooth transitions for families to be able to deal with their daily lives.

Mr. Greg Bonnah: Yes.

The Chair (Mrs. Laura Albanese): Thank you. I will now move on to the government side. Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you, Mr. Bonnah, for joining us at the hearing today and for sharing the experiences that you've had. We've certainly noted those concerns. I have, in particular, noted that we cannot expect that we would do the minimum for students with special needs by having them participate in non-academic settings. I think that we have to ensure that the curriculum is being applied to the fullest possible potential and—

Mr. Greg Bonnah: Then explain to me how come there are six schools for developmental disability left in Ontario? I think it's McCordic in Toronto, one in Thunder Bay where you are, and the other four are here in eastern Ontario.

Ms. Mitzie Hunter: Yes, and I think that's what the purpose of these hearings is. It's to hear all sides and a range of issues and concerns. We've certainly heard from some of the presenters that they see value and benefit in some of those specialized settings, and others far prefer the integrated classrooms. I think that we're listening and ensuring that we take in the feedback and the input from all sides, as the focus of our report is to look at how do we address the needs of children and youth and adults in Ontario with intellectual disabilities and those who are dually diagnosed, as well, and how do we coordinate the delivery of developmental programs and services across many provincial ministries in addition to the Ministry of Community and Social Services, so that—

Mr. Greg Bonnah: Well, my child has proven that with the right resources, you can go places. The OCDSB stopped educating him once he successfully completed grade 3 EQAO testing because they don't want people to know that these kids can go far.

Ms. Mitzie Hunter: Yes, and I think that's why we're here, to actually ensure that these children and adults do go far and really achieve their goals and their aspirations, so thank you.

The Chair (Mrs. Laura Albanese): Thank you, and I will now turn it over to Ms. Jones.

Ms. Sylvia Jones: Thank you for your presentation, Greg. You are not the first parent who has talked about the frustration between transitions from various ministries, so I want you to be assured that your voice is not

alone. We're hearing it consistently province-wide, and I'm sure it's one of the many things that we will try to grapple with as we prepare our recommendations. So thanks for your input.

Mr. Greg Bonnah: Well, I was hoping that I could speak to you on Friday when you are here in Ottawa, but again, the selection committee decided who they were going to allow to speak and not speak, so I'm thankful that you guys allowed me to speak to you today.

Ms. Sylvia Jones: Not a problem. As you can imagine, there are many, many families and individuals who are passionate about this issue, and we're very thankful that they're taking the time to put together the presentations.

Mr. Greg Bonnah: Okay.

The Chair (Mrs. Laura Albanese): Yes, we had many people who wanted to speak to us in Ottawa, but there were difficult decisions to make; it was hard to accommodate everybody. We welcome the opportunity to speak to you via teleconference today.

Thank you very much for your presentation. It was really helpful to the committee, and we will take your suggestions going forward.

Mr. Greg Bonnah: Thank you very much.

The Chair (Mrs. Laura Albanese): Have a great day.

MS. HELEN LEASK

The Chair (Mrs. Laura Albanese): We will now move on to our next presenter, Ms. Helen Leask. Hello?

Ms. Helen Leask: Yes, hello. I'm here.

The Chair (Mrs. Laura Albanese): Hello. Good morning. This is Laura Albanese; I'm the Chair of the committee. How are you today?

Ms. Helen Leask: Pretty good, although I will have a bit of a scratchy throat in my presentation, for which I apologize.

The Chair (Mrs. Laura Albanese): That's no problem. Where are you calling us from?

Ms. Helen Leask: I'm calling you from downtown Toronto.

The Chair (Mrs. Laura Albanese): Okay. I guess you're enjoying probably warmer weather compared to us here in Thunder Bay, but it's a nice day here as well.

I would ask that you start your presentation by stating your name and what you do. You will have up to 20 minutes to present. If the presentation is any shorter, that will leave some time for questions from the committee members. You may start any time.

Ms. Helen Leask: Thank you, yes. I understand. Because I have virus brain, I've written all this down. Please bear with me as I go through it.

Members of the select committee and Ms. Albanese, thank you very much for inviting me. I will give you a bit of detail about myself before I start, if I may. Actually, I should just let you know there was a bit of an echo going on—I think somebody got rid of it; that's great.

I was a science researcher and then a science journalist in the UK, but for the last 15 years I've been the partner

in a medical communications company here in Toronto. I actually spend my time facilitating groups of top doctors to figure out how to improve the health care system, so let's just say I do understand a little bit about trying to fix complex systems.

However, of course, today I'll be using my 15 minutes to share some personal experiences, in this case with developmental services, and also some of the conclusions that I've drawn from these experiences. I realize that you'll be hearing from many people and all of us hold a different piece of the puzzle. My piece involves the care of developmentally delayed folks with complex medical needs: in short, my 22-year-old daughter.

I don't have to tell you that developmental delay is a challenge by itself. If you add into that difficult behaviours, you have another layer. Turn up the heat a little and add psychosis, delusions and violence, and then add to that life-threatening seizures, and for a single self-employed parent, this is a torpedo through everything: your family, your other children, your financial stability, your business relationships—everything. You're in survival mode for years and years and years.

Let's start in the proper place, with my daughter. As this is a public record, I've glossed over some of the details for her protection, but I have included some because I think it's in the details that we're going to understand all this.

My daughter was born apparently normal; her developmental delay first appeared as a slight learning difficulty in kindergarten. By nine, she started having seizures, and by the age of 11 she was classified as having intellectual disability.

Her cognitive abilities actually went backwards throughout her teenage years. She seemed to forget everything she learned as fast as she learned it. Our bright little daughter gradually disappeared. From a five-year-old who spoke like a BBC announcer, now, at 22, she can barely form a complete sentence.

We now know that she has a rare genetic disease that affects how the brain forms its neural connections. As her brain grew, it simply got more and more chaotic.

High school was a huge challenge with increasing behavioural problems. She went to a public school here in Toronto for developmentally delayed girls which should have been absolutely perfect. Unfortunately, she hated it. She was bullied incessantly. She learned to fight and to swear and be violent and abusive. On one occasion, a group of girls tried to set her on fire, and the staff did nothing. Not surprisingly, she started to refuse to go to school. This was a logistical nightmare.

I heard other parents complain about PA days. Well, we endured 18 months of school refusal—off again, on again, off again, on again. I didn't dare leave her all day because of her seizures, so it created huge practical difficulties.

0940

I was a single, self-employed parent who had just started working outside the home. I definitely couldn't afford full-time child care, but I paid for it anyway.

In the end, my family helped out, and we found a private school that specialized in brain-injured children, and her attendance gradually increased. Then the behaviour started to come back, so we had aggression, repetitive speech, frustration, separation anxiety, you name it. It's impossible to describe what it's like living with such an individual. Let's just say, try to run a business when your anxious child is calling you 10 times an hour.

In 2011, a series of seizures over 24 hours led to several days in intensive care. When she emerged, her brain was deeply injured and she became even more difficult to manage. Two months later, she was admitted to the Sunnybrook psych ward with psychosis. At this point, I first made contact with developmental services. It was clear that the world had changed permanently. This was no longer curable with camps and special schools and counsellors. As her mother, I could no longer save my daughter if I just tried a little harder. This was deep, enduring and very, very complex. We were scared for her and scared of her.

The first thing that struck me about developmental services was how kind everyone was. I was so used to battling through on my own that it was a shock to be offered a helping hand and be told, "It's okay to feel like this. It's normal." However, it was rapidly obvious that all these kind people were doing their best despite the system, not because of it.

There was a huge amount of duplication. Each agency had its own forms in triplicate, all filled out laboriously by hand. One case manager confided to me that she stayed at home one week in four just to get through the paperwork. They all asked the same questions, needed the same medical and psychological forms signed and the same permissions. They all had to visit me and my daughter several times. This was very comforting, but what a cost to the system. Surely they could all work off the same software, I thought. How much are laptops these days—\$400, \$500? That's much cheaper than a case manager staying home one week in four. And couldn't they all pool their intake system and send just one or two people on a preplanned assessment schedule and circulate the results?

The next thing that struck me was how little actual cash there was for services—for respite, for day programs, for residential care, even in a crisis situation. On a bad day, it seemed as though all the money was going on the army of interviewers and mountains of forms and that there was none left over for actual services.

The funding became most acute during our numerous crises. For example, one day our caregiver quit on the spot because my daughter pushed her head into the floor again. Both myself and my ex-husband were working full-time. We could take a few days off but no more—remembering this is a 22-year-old adult we're talking about, not a child. Even if we could have found someone on short notice, there was no way a regular caregiver could cope. It needed somebody with specialized skills. We applied for crisis funding as a short-term band-aid, to be told there was no further funding until April, which

was three months away. So we were left with a violent, seizure-prone, developmentally delayed young woman with no one to care for her. In the end, all we could afford was a specialized agency caregiver in the afternoons, and we had to keep our fingers crossed in the mornings.

The point of sharing this story with the committee is to illustrate what can happen when a person with developmental delay is medically complex—in this case, has life-threatening seizures and mental illness. She needed 24-hour care because of her seizures, but in this case, because she was also violent and needed expensive specialized care, which we couldn't afford, we had to risk her life by leaving her unattended.

This kind of scenario also means that we've had frequent interactions with the health care system and with the police. When there's no crisis funding, we're told to dial 911 if she gets violent. Needless to say, these are extremely hazardous and complicated experiences. On one occasion, after she had attacked me, the police asked me if I wanted them to arrest her—a question no parent ever should be asked. I couldn't bear to imagine the danger this would put her in, this medically frail young girl, so I told them I could manage. We all remember Ashley Smith. In effect, I had to choose between the safety of myself and the safety of my daughter.

The emergency room is little better. Both times my daughter was admitted to the psychiatric ward, my ex-husband and I had to battle for hours and hours to get her in. Both times they told us that the psych ward couldn't admit her because of her seizures and the neurology ward couldn't admit her because of her psychiatric symptoms. So a tertiary level teaching hospital couldn't cope with someone like my daughter, but the families could—or the families were supposed to, I should say.

While encounters with the emergency services are always bruising and discouraging, the long-term prospects seem even bleaker. Thanks to the efforts of our case manager, last year my daughter came up twice for a residential place. In both cases, they turned her down in the end, saying they couldn't meet her needs. Surely there has to be a better way of caring for people as complex as my daughter.

In the end, we simply couldn't cope with her anymore and I decided not to wait for the system. Last summer, I sold my house and used the proceeds to move my daughter into a small condo with a full-time caregiver. This was expensive and complicated but has been astonishingly successful. Although she's still very unwell, my daughter now is in a much better mental state with her new-found independence. She is well integrated into the community and has just started a full-time job in a sheltered workshop. Needless to say, the rest of her family are also in a much better mental state.

I realize many families are not in a position to move their child out like this, but I would ask the committee to consider how they can help families that are thinking about it. I don't have to tell this committee that caring for my daughter in the justice system, a group home or the

mental health system would cost upwards of \$200,000 a year. Caring for her in her own condo costs one fifth of that: \$45,000 a year. Unfortunately, there's no official funding for this kind of arrangement.

I would strongly urge the committee to consider better ways of providing more support for families like us who are thinking of making their own residential arrangements for their children, perhaps by direct funding for caregiver costs or as a tax break on all disability-related expenses. Most families want to help their own children. This, I believe, is a great use of taxpayer dollars for these complicated, vulnerable people and provides a much better quality of life for them than the prisons, the homeless shelters and the psychiatric wards of this province.

I hope that my experiences are helpful to the committee and to all special families in Ontario. Thank you for listening.

The Chair (Mrs. Laura Albanese): Thank you very much for illustrating so well the situation you had found yourself in and for your suggestions to the committee, which we find very valuable. We have about two minutes for each party to ask questions. We will start with the government side. Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair.

Thank you so much for sharing your experiences. I wonder if you could expand on your daughter's experience in the full-time job that she has in a sheltered workshop, how that came about and what her experience has been like.

Ms. Helen Leask: Yes, absolutely. This is hot off the press because she has only been there since before Christmas. This was the end result of a lot of hard work by her case managers and us, but also an element of luck. A place came up in an organization called Corbrook here in Toronto. My understanding is it's pretty much the top of the tree for adult services. We feel very fortunate. It's a sheltered workshop for people with developmental delay, so they start with the simplest of tasks, with contracts for people like Shoppers Drug Mart, like packing boxes, that sort of thing. It's run on a commercial basis, and the folks are paid to the limits of the ODSP allowance. They coordinate the whole disability allowance for how much they can earn before their disability is affected. So that's all very well coordinated.

But the really smart part about Corbrook is that if the individual says, "You know what? I want to do something different"—for example, if my daughter wants to work in a pet shop; she loves animals—they would find an employer willing to take the person on. They would train the staff and they would shadow the individual until they were well established in that job. So it's a very, very high-value and wonderful organization.

0950

Ms. Mitzie Hunter: That's excellent. Thank you so much for sharing that.

The Chair (Mrs. Laura Albanese): Thank you. This is Laura Albanese, the Chair. I know of Corbrook. It is a wonderful organization, and I'm fortunate to have it located within my riding.

I will turn the microphone over to Ms. Elliott now.

Mrs. Christine Elliott: Thank you very much, Ms. Leask, for sharing your daughter's story with us.

I think you've raised a number of very important points. One is that for people with a dual diagnosis, there is really a dearth of services in terms of residential placement, in terms of how medical personnel are able to interact with them. Too often, people get caught up in the criminal justice system unnecessarily. So thank you for sharing that. That is a theme that we have heard about, and we are turning our attention to that particularly.

Secondarily, I'm so happy that your daughter has what seems to be a very happy landing for her, but I think it shows that everybody wants the same thing. I mean, she is a person. She's a 22-year-old young person who wants to have her own place, and I imagine that some of her behaviours are subsiding, too, because she's happy where she is. So that is something we should be striving for, and then, also, taking a look at what's best for her and is also cost-effective. That's a very important point: that we need to look for more innovative housing opportunities for people because one size doesn't fit all. A group home isn't the answer for everyone. Staying with parents isn't always a good suggestion for people because, again, they are striving for that independence.

You've got us thinking here today with your presentation, and I thank you very much for that.

Ms. Helen Leask: You're welcome.

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

Ms. Cheri DiNovo: Thank you, Ms. Leask, for your presentation. I think we all ring with your experience in the sense that you have not been served well by the system. Clearly, the system isn't working. I think we're coming to that conclusion. We've heard nothing different from any of those who've come forward, so you're not alone. That's one thing I want to make sure that you hear: Your experience may seem unique, but it is not unique in the sense that others have had that same runaround.

I was interested to hear about the assessment again. It's a theme we've picked up on, that we've got places like the DSO that spend all their time assessing and very little of their time actually delivering. That's not the way a system should work to help you.

I was very interested in your suggestion—I think it's the first time I've heard it—for a tax break on disability expenses, because, as you can imagine, it's very difficult with the direct-funding models to get up to that \$45,000 a year that you're spending. But, on the other hand, the tax-break system might be the answer.

I've left you only a few seconds, but could you say a little bit more about how you came to that?

Ms. Helen Leask: The idea of a tax break? Yes. Direct funding, as you say, doesn't even touch on as much as \$45,000, as cost-effective as that is in comparison to other options. Of course, we have Passport funding down here, but some people don't even have it, and it really doesn't even scratch the surface. So we're all scratching our heads a little about what can a system do. It just seems to me that that's a great way of helping

people out because the \$45,000 is after tax. So families are finding, if they are indeed able to find \$45,000 to support a set-up like this—this is after they've paid tax on the money. So, really, if you're middle-class kind of folk, you're earning \$70,000 to pay that \$45,000. So a tax break would really help out.

Ms. Cheri DiNovo: Thank you very much.

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

Ms. Helen Leask: Well, thank you very much for listening to me, and if I can assist in any other way, please let me know.

The Chair (Mrs. Laura Albanese): Thank you. Have a great day.

Ms. Helen Leask: You, too. Bye-bye.

TIPES

The Chair (Mrs. Laura Albanese): We'll now welcome Jennifer Wyatt, executive director of TIPES, who is also joining us via teleconference.

Ms. Jennifer Wyatt: Yes. Can you hear us okay? I'm actually here with Dr. Sherman and Deborah Wyatt. All names were supposed to be on there. I don't know what you have in front of you. Can you hear me?

The Chair (Mrs. Laura Albanese): We can hear you, but we hear a bit of an echo. It's a bit—

Ms. Jennifer Wyatt: I'll move closer.

The Chair (Mrs. Laura Albanese): Are you closer now? Can you try again? Just a "testing 1,2,3"?

Ms. Jennifer Wyatt: Is this better? Can you hear me better now?

The Chair (Mrs. Laura Albanese): Oh, yes, much better. Thank you and good morning.

Ms. Jennifer Wyatt: Good morning.

The Chair (Mrs. Laura Albanese): Where are you calling us from?

Ms. Jennifer Wyatt: We're calling from Ottawa. We're—well, you know we're from TIPES. We have two locations: one in the Kanata area and one in midtown, toward downtown, I guess.

The Chair (Mrs. Laura Albanese): And you said you are with a doctor?

Ms. Jennifer Wyatt: Yes, Dr. Jeff Sherman. He was also on the list, and we said we would go together to make it easier on you guys.

The Chair (Mrs. Laura Albanese): Oh, okay. Thank you.

Ms. Jennifer Wyatt: We work with him. He's our supervising psychologist, so we were going to let him do much of the talking today. I already have a written document that I'd be able to send to you guys, so it kind of takes care of what I really want to say. If you're okay with it, we'll let Dr. Sherman do most of the talking.

The Chair (Mrs. Laura Albanese): Absolutely. He may start at any time. We'll have up to 20 minutes for the presentation. If it is any shorter than that, we will have

some comments and questions from the committee members.

Ms. Jennifer Wyatt: Right. Thank you.

The Chair (Mrs. Laura Albanese): You may start. Thank you.

Dr. Jeff Sherman: Hi. It's Dr. Jeff Sherman speaking. I should identify myself. I've been involved since the mid-1970s in bringing intensive behaviour intervention and applied behaviour analysis to Canada. I was involved in some research into the effectiveness of doing that in community settings, and in establishing comprehensive programs to offer this to the community at Thistletown Regional Centre. I was instrumental in creating a program called TRE-ADD.

I'm going to be speaking about the provincial Autism Intervention Program initiative that was launched around 2000. Since that time, I've been involved in both the DFO and the DSO side of things. I understand that you're aware of what those acronyms mean?

The Chair (Mrs. Laura Albanese): Yes, we are.

Dr. Jeff Sherman: Sorry. I'm just not sure of whether I should be explaining myself more as I go along.

Thank you for the opportunity to address your committee. I think that, in general, the program as it was intended—the initiative is very well-intended. I think it's helped many children across the province, however it's been delivered, but I think that the pressure to treat the many who need it, and the fact that it does take a long time, have resulted in a lot of children losing it prematurely.

I think that the problem with this is that a lot of families of children with autism need hope. The program initially raises hope, but because the pressure to treat a lot of children has caused an issue with discharge criteria, and also an issue with the number of hours and the length of the treatment provided, it's not always consistent with what the research literature says is needed in terms of some of the most recent reviews.

The macro reviews of research indicate that the number of hours and the length of time—the frequency and intensity—are not always there. Because of that, there are a number of children who are discharged, I think, before they have the opportunity to show that they can benefit from the treatment.

I'd like to address for a little while the discharge criteria as they are being presented. I think you're aware—nobody likes the term “benchmarks,” but that's kind of what they are. We're being told that, in terms of assessing—I think that if you want to look at the principles that the program is founded on, the idea that we're getting is that a child, within a short period of time—for example, two years—has to make progress in some behavioural objectives using the ABLLS; I'm assuming that your committee knows what that is. They have to make progress of two thirds of a standard deviation in standardized testing, meaning an intelligence test of some sort.

The problem with this, of course, is that, within a short period of time, we're expecting children who have

developmental disabilities to approximate the normal range of functioning. That's not always possible, but that doesn't mean that children don't make progress.

The words “developmental trajectory” are used a lot, and it's very poorly defined within the program. I've looked at the research available on developmental trajectory, and there are some very good statistical methods for predicting developmental trajectory in other populations, but these don't seem to be applied. The problem is that the discharge criteria, as they are now constructed, are kind of quasi-scientific. They're presented as scientific, but when you look at them in more detail they don't seem to address some of the problems in the literature with developmental trajectory. One of the more recent studies in 2008, for example, found that it's very difficult and troublesome to use overall IQ as a measure of predicting developmental trajectory because children with autism have very specific neurocognitive deficits that you must address, and you must individualize the program.

We're now being given these benchmark criteria: level 1, level 2, level 3, level 4; they're called foundational skills, and they seem to be the same for all children to need to progress through. They don't take into account individual differences in the children, and the problem is, we've also seen children who meet all of those and yet who are discharged because their IQs haven't improved to the normal range in a very short period of time. What I'm saying is, it's premature to look at a scientific method or a quasi-scientific method to base this charge on when the hopes of families are so invested in their children receiving this treatment.

1000

Some of the only research that has been done on developmental trajectories with autistic children comes from a person named April Sullivan at York University, who tried to plot the trajectories as children learn, and there are tremendous individual differences.

I've tried to get the program to say, “How do you calculate developmental trajectories?” and no one can give me an accurate definition of what that is or where exactly the cut-off is. So what it comes down to is a clinical judgment by the DSO or by the AIP provider in the region. I'm the clinical psychologist, as a DFO, who knows these children and knows what the clinical progress has been. I'm being asked to agree with the decision of the AIP psychologists, but I have a responsibility to my patients, through the college, to go with my own clinical judgment. So disagreements often arise, and it causes a lot of conflict and a lot of animosity amongst service providers, and I don't think that's very beneficial in the spirit of working together. It comes back to the idea of providing appropriate ways to judge progress.

At Thistletown, the way we tended to judge progress was through something called goal-attainment scaling, in which we would, as a team, sit down with various professionals and use our clinical judgment and what quantitative measures were available to establish actual objectives for which we would say, “Yes, the child is progressing.”

So it's just premature to use the criteria that are now being offered to us.

The other criteria that's being used is the Vineland. In this 2008 study that I'm talking about, the authors themselves used the Vineland and said this is not adequate to judge functioning. They also point out that having IQ as one of the important measures of the child's functioning doesn't actually say what their adaptive functioning is like.

The other problem with using the Vineland—and I'm sorry if I'm all over the place here—as an adaptive measure is it's only based on the parent report and it's not based on the report of the treatment personnel, who see the child within the context of treatment. So you can get very skewed gains if you don't do a comprehensive evaluation of the child's actual progress.

Going back to the developmental trajectories, when the child is discharged because he hasn't gained, say, two thirds of standard deviation or because he hasn't finished the ABLLS within a certain period of time, in a sense he's penalized for being a slower learner.

Our methods aren't that good yet. It would be presumptuous of me and, I think, a little arrogant to say that we can take every child presented to us and improve their learning in that short a period of time such that they can function within the normal range. But it's not black and white. Just because a child doesn't have the developmental trajectory of a typical child after two years doesn't mean they haven't learned and doesn't mean that they haven't learned a lot and that their functioning is much better off.

The other problem you have with IQ—and I've seen this actually happen—is, if the child has met their behavioural objectives and learning objectives, but if the standardized measures don't point to an actual gain of what's expected in that period of time, the child is discharged. There are two problems with that. The first problem with it is that it is relying on one intelligence test as a decision-making procedure. The Alberta Supreme Court just overturned a diagnosis that was made because one intelligence test was used as the measure. The other thing is, we don't know in the absolute long term what happens to the IQ over time, if you use that as the sole measure. Yes, the IQ can increase for a substantial number of children. But if you look at most of the research on IQ, you see it's stable over time. If you look at all the literature on early intervention programs in education, you sometimes get increases in IQ, but if you don't keep it up, then the IQ can return to what it was pre-intervention. That says something about the nature of learning and the nature of supports that children with autism and other developmental disabilities continue to need.

The other thing is that this program may be intended for children with autism, but it's very difficult to sort out—if you don't provide it for children with autism and developmental disabilities, then that's kind of prejudicial and discriminatory. There's a recent study from Denmark that shows that if you take IBI and apply it to children

who have a developmental disability but not autism, their rate of improvement is even greater than the rates of improvement of some of the autistic children.

If you look back at the initial study that Lovaas did in the 1960s and in the 1980s, you'll find that he did use the measure of IQ to denote success with the program, but that was only in one research study, and he needed a dependent measure to show gains. He didn't intend that to be the hallmark of whether children should get funding or not get funding over a period of time.

The other problem is—and I've seen this in my own practice—I've seen children who are discharged for apparent lack of progress, and then we have provided service for them on a private basis, and those children continue—if the program is adequate, the children are now making gains after two, three or four years of IBI and direct instruction treatment.

So I think the predictive measures we have right now are just premature in terms of saying, over the long run, what happens in giving children IBI over a shorter period of time.

There seem to be irregularities in the distribution of funds.

I'm going to leave this area now and talk about how service is provided. I have been aware that sometimes the DSO provider will try to convince the family to go with the DSO program and not the DFO program. We've certainly been—said, “Well, we base our decisions to continue treatment on the fact that we need clients,” which would be totally unethical of us to do. We try to make decisions that are in the best interests of the child. But I would also say that some of the DSO programs also need clients in order to justify their existence. So to me, having the power to distribute the hours and who gets the hours—private providers and provincial providers—and investing that in the same agency is a little bit of a conflict of interest. It's like giving Coca-Cola millions and millions of dollars and saying, “You give out Pepsi and you give out Coke now, and whoever uses the majority of the products in the future—well, we'll continue to give that manufacturer the money.” Well, there's an inherent bias in there to give out Pepsi, I think. I'm not talking about the intentions of any individual—I'm just saying how the current environment provides a predisposition to do those kinds of things. I've had a parent say to me recently in a program that we've provided privately that they were offered the service but they were encouraged to take the DSO service even though they were with a DFO provider.

We jump to the IRM, or the appeal mechanism. I've been told that I must accept the opinions of the AIP psychologist about my patients in terms of whether they're ready for school or not ready for school, and that if the parent doesn't like that, they can always appeal to the independent review mechanism. But in practice—and it was a good idea in principle—it has turned out that the independent review mechanism is not so independent because it simply reviews the paperwork and it doesn't take an independent look at whether that child has actual-

ly benefited from treatment and should have been discharged or not.

1010

In fact, in one instance I was misquoted about something I said which, if I had said it, would have been totally unethical. I didn't say it; it was put into the independent review mechanism and then written in a letter. I don't know if it's been corrected after that, but I didn't even know that it was going in.

I don't know how long I've been talking. I have a lot of other information that I would like to—

The Chair (Mrs. Laura Albanese): You've been talking for about 15 minutes.

Dr. Jeff Sherman: Okay. I should probably stop and give Jennifer and Deborah a chance to say something.

But what I'd like to say is that the treatment of children with autism and other kids with developmental disabilities is too important a decision for families and children to rely on a quasi-scientific way of trying to determine funding. We need a different way to do this. We need to do individual goal-setting, individual programming, and we need to involve a broader range, an independent way of viewing—people who are independent of the funding agency to decide whether the kids should continue treatment or not.

That's what I have to say. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. I guess this leaves about four minutes or so for others to say something.

Ms. Jennifer Wyatt: Okay. I'm Jen Wyatt. I'm the executive director. I was the person you initially—

The Chair (Mrs. Laura Albanese): Yes.

Ms. Jennifer Wyatt: I have a master's in counselling and psychology and I also have other education through the States for applied behaviour analysis. While I'm the executive director, I also do a lot of the clinical work, like supervising therapists and providing treatment.

I don't want to get too much into the issues. I've read the Auditor General's report and I can tell you, as a service provider—and I should mention we're a children's charity. With all the families we have served over the years, I can definitely support much of the issues that were brought up in the Auditor General's report. We've definitely witnessed many of them. But what I really want to focus on is maybe coming up with some suggestions or ideas on how some of it could be fixed.

I know that the government has to support both public and private, so is there an opportunity for government to reconsider allocating funds? I know that unions drive the price up at government programs significantly, which was also highlighted in the Auditor General's report, that the DSO program is significantly more expensive than the DFO. I am not suggesting that you cancel the program; I'm just wondering if there's a way to make them compete so maybe the money goes to the parents, and if they want to go to a DSO program, they can then go to a DSO program, but they get the same amount of money as everybody else.

I also wonder if government could be doing something more in the area of emergency care for families who have a child who is having severe, severe behaviours. At this point, in Ottawa, there is nowhere to really send them. They are taking up hospital beds and they're being medicated because they don't really know what else to do with them, so if they can do more of an awareness.

I was at a hospital yesterday speaking with the vice-president of a program that works with children with autism, and they didn't even have stuff to give to the families on places to go while the families are sitting on the wait-list. So I said, "You should probably contact all the service providers and we can send stuff in and at least the families have something to do while they're sitting on the wait-list." Obviously, in a perfect world that wait-list would actually go away.

And then, is there something that the government can do on the idea of education or counselling and coordinating? While the IBI is really important, there's a lot that goes into it between dealing with service providers, pediatricians, schools and that sort of thing.

That actually brings up my next point. There is a program through the government agency; I believe it's the Connections program. I can tell you, as a service provider, I've gone to a few meetings and there are so many people sitting around the table, I can't imagine how expensive it is for taxpayers. On average, there are probably about 16 people sitting at that table, and they're all paid either through the school board or through government for the autism program. I just think, as a taxpayer and a service provider, there are probably different ways of allocating funds that would be more beneficial and efficient. Then you would also see the children get the funds earlier and hopefully end up with better results—do the ultimate goal of the money and get into classrooms with typical peers.

The Chair (Mrs. Laura Albanese): Thank you very much to both of you for your presentation this morning, for your suggestions and for providing us with an insight on your point of view on the issues. We thank you very much. Our time is unfortunately up and I have to move on to the next presenter. We're on a very tight schedule this morning, but we want to thank you for participating in this discussion.

Ms. Jennifer Wyatt: Thank you.

Dr. Jeff Sherman: Thank you for listening.

The Chair (Mrs. Laura Albanese): Thank you. Bye-bye. Have a good day.

MR. MICK KITOR

The Chair (Mrs. Laura Albanese): We'll now hear from Mick Kitor. Hello?

Mr. Mick Kitor: Good morning.

The Chair (Mrs. Laura Albanese): Good morning. How are you today?

Mr. Mick Kitor: Outstanding. Yourself?

The Chair (Mrs. Laura Albanese): We're good. We're here in Thunder Bay and enjoying our day. Where are you calling from?

Mr. Mick Kitor: Ottawa. I wasn't able to get on the agenda for Friday. There was a space available to phone in and I figured being heard is better than sitting in the shadows. I still plan on attending on Friday.

The Chair (Mrs. Laura Albanese): Excellent. Yes, and we want to hear from as many people as possible, so the fact that you are able to call in today is really wonderful for us. You will have up to 20 minutes for your presentation. If the presentation is not that long, then that will leave some room for questions from the members of the committee. You may start at any time.

Mr. Mick Kitor: Sure. I'm going to assume everybody loves to add some figures and wants everybody to rehash the Auditor General's report—I'm kidding.

The reason I took the time and stayed up until five in the morning putting this presentation together last night is that I need something from you as MPPs. Some 30,000 children in Ontario need something from you. What do they need? Well, equality and fairness. They need the same quality of autism services regardless of where they live. They need value for the money being spent.

Timing is everything. We invest over \$150 million in IBI therapy. I'm assuming everybody knows IBI therapy and I don't have to explain it?

The Chair (Mrs. Laura Albanese): Yes, we know what IBI stands for.

Mr. Mick Kitor: According to the Auditor General's report, we invested three years too late. We also don't invest in IBI therapy for the kids who benefit from it the most, those kids with milder forms of autism.

Then, the last thing that we need is oversight and ownership. You're born with autism. It's a lifelong condition. It goes from baby to student to adult. When we look at the ministries that it touches, it's the Ministries of Health and Long-Term Care, Children and Youth Services, Education, Community and Social Services. This year, if we look at—and there are stats that range all over the place: Hard stats are one in 77, but it could be as high as one in 50 for children being born with autism. That means 1,600 children will be born this year who have autism. They need somebody to ensure that they don't fall through the cracks between the ministries.

So, digging into equality and fairness—by the way, is my voice okay? Everybody can hear me fine?

The Chair (Mrs. Laura Albanese): Yes, we can hear you very well.

Mr. Mick Kitor: I'm not—

The Chair (Mrs. Laura Albanese): And we're following your presentation. We have a copy of it.

Mr. Mick Kitor: Perfect; I didn't know. So, if you have a child with autism, one of nine people has god-like powers over your family. When I say "god-like powers," it sounds like total hyperbole, but it's not, and I'll explain. Their decisions will determine, quite possibly and very seriously, if your family can keep their home, if you can afford to have more children, when and if you might be able to retire—sorry; it's kind of emotional—and what type of life our children could expect. These people are the regional clinical directors of the Autism

Intervention Program. They're not even government employees; they're contracted, and they've been given this power by the Ministry of Children and Youth Services.

Clinical directors—it seems like, as a parent who has gone through the system—are free to interpret the autism intervention guidelines however they see fit, implement their own agendas and discriminate against the very children they're being engaged to serve.

1020

These people can revoke eligibility. A child can be deemed eligible, go on the wait-list and then hit the top of the wait-list, and some agencies, Ottawa or the CHEO eastern region in particular, can retest that child when they hit the top of the list and then say, "Oh, they no longer qualify." Nowhere is that actually said in the guidelines. They can cut the hours your child receives or stop therapy completely. They determine who receives therapy, how many hours a week they get and how long it lasts. This ranges wildly by region. The Auditor General's report has a great graphic that actually shows the length of service either with the direct funding option or with the direct service option.

These nine regional service providers, at least to a layman like myself, operate with little or no oversight by the Ministry of Children and Youth Services. Instead of holding the regional providers accountable, it seems to me that parents are abandoned by the Ministry of Children and Youth Services. They know that families are going to be forced to choose between paying for private therapy or paying for legal services if they want to hold the regional providers accountable. Parents are frightened to come forward. They live in fear of the power and reprisals that could take place from the nine regional clinical directors.

I got an email last night, and the reason I got the email is that I'm looking to pitch a story to the CBC about the disparity between length of service in Ottawa versus the rest of the province. I had a parent come back to me with the following: "I'm not able to speak to the reporter about my experiences because my child has not been discharged yet and I'm worried about retaliation from Lise Bisnaire," the director of the CHEO autism intervention program. That's not right. Parents shouldn't have to be worried that they can be bankrupt if they dare blow the whistle and say something is not kosher.

How much power does a clinical director have over a family? I'll illustrate with my family. We have invested over \$77,000 in private therapy and a private diagnosis for our son. We raided anything that we had that had value in it: our retirement savings; we borrowed against the equity in our home. Our parents gave us thousands of dollars—they're retired. It's really costly to have a kid with autism, if you want to give them the best trajectory possible. The odds that if we have a second child that child will have autism are even greater than the 1 in 77 if you've never had a child before. We just don't have another \$77,000 for private therapy while we wait on the wait-list. My wife and I pray that our son is going to find

somebody to love him, because after we die—we can't afford to give him a brother or sister.

The independent review mechanism that reviews decisions to discharge or eligibility decisions that the regional providers make is a farce. A criminal in Ontario is innocent until proven guilty, but we can't give the same benefit of the doubt to our kids. Why is the burden of proof not on the regional provider to justify removing therapy or denying therapy, but rather on a parent to prove that it shouldn't be removed or that they do deserve therapy?

A fair process would ensure that if an error was made by a regional provider—and we're all human; it can happen—no family would be bankrupted and no child robbed of their future. Instead, the deck is stacked against families and kids. If you want to make an appeal as a parent, you've got 20 business days to request a review of the decision, or the decision stands. There's no discovery process. Before you write your request for a review, you don't actually get to see any of the test results; you don't get to see any of the files and all the paperwork that they've built up to justify discharging your child. In the very first meeting that we had to say that our child was eligible, they discussed discharging our child—in the very first meeting.

The regional providers choose what gets omitted and what gets included in the documentation that's sent to the independent reviewer. If the regional provider or the independent review mechanism administration do not meet the time deadlines or their obligations as outlined in the process, the decision won't be reversed. There's no mechanism for the decision to be reversed other than a psychologist, upon reading the cooked documents that are sent to them by the regional provider, disagreeing with that. It doesn't happen very often.

In our case, a private psychologist who advocated on behalf of our child was retroactively prohibited from supervising direct funding for IBI programs. She wasn't sanctioned by the College of Psychologists. This decision was unilaterally made by CHEO, the regional provider, at their sole discretion.

My son is going to be discharged by June 21, four days before the end of the school year. He is expected to go 67 days without therapy and have a completely smooth transition after the province and ourselves have invested to the tune of \$180,000 in his therapy. Right when we're getting close to the finish line, we're going to say, "Well, let's not run that last 10 metres of the 100-metre sprint."

When we appealed this decision, CHEO chose not to submit that part of our argument about why our son shouldn't be discharged. They just didn't do it, so the review mechanism didn't even consider our argument.

There is an expert committee that was formed to help parents of children with autism in the many challenges that they face. I read that from an article. I find it funny that there's no parental representation on that committee. There's one person who has a child with autism, but they also have a PhD and work in the field of autism. He's not

going to have the same typical dealings with the system that a parent is.

What do I mean by equality and fairness? What do I want? I want you to hold the Autism Intervention Program regional providers to account. They should be evaluated on the effectiveness and outcome of the therapy, not on the number of children on the wait-list.

The decision to make eligibility decisions and discharge decisions should not rest in the same agency that administers the wait-list. That's like paying the foxes to guard the chicken coop. We need to reverse the burden of proof when it comes to eligibility and discharge decisions with regard to the independent review committee. It should be therapy until proven ineffective.

What did I mean by value? Why did my family spend \$77,000 on private diagnosis and therapy? Well, I'm going to read some quotes from the recent Auditor General's report. I won't go very long. Please excuse the hyperbole; you know how excited accountants can get and how they like to exaggerate—not.

"Early diagnosis and treatment of autism might reduce the need for more supports and services later on in life." Sounds reasonable to me. You help a child catch up to his peers earlier, and the symptoms are less severe and they can integrate quicker—less cost to the whole system.

"We estimated that children with autism are diagnosed in Ontario at a median age of a little over three years." They're supposed to be in therapy by then. You can diagnose a kid when they're 18 months old. In Ontario, you can't access services for autism without a diagnosis.

Another quote: "Children who start IBI before age 4 do better than those who start after age 4." Makes sense. When they're that young, their brains are knowledge sponges, but it starts to fill up, and they absorb information slower and slower as they age, the problem being that the median wait time for children with autism in the three areas that the Auditor General visited was almost four years. It's a little bit of a Catch-22 there.

Due to the long wait-list for IBI services, children are not typically starting IBI until almost age 7 in Ontario. We know they need to start before age 4. That's three years after the window started to close.

1030

What do I think we should do for that? Well, once your child is deemed eligible for IBI services, you should be able to apply for a student loan, except in this case, the student's going to be our autistic child, and it's going to be an autism loan.

Parents will take on the liability, start the therapy immediately when it does the most value, and when their child reaches the top of the wait-list, then they'll be reimbursed. You're going to be spending the money when it's the most effective. Four years aren't going to be wasted waiting for funding. Four years is a hell of a long time when you're waiting for your child to say, "I love you, Daddy." You wouldn't have to choose between financial ruin and your child's potential.

IBI therapy would be more effective. School systems would not be dealing with kids who haven't had any

therapy yet, so they wouldn't have to spend as much on EAs and special education accommodations.

To give you an idea of how much three years' difference can make, I did a little research last night. Apple released the iPhone in June 2007. The share price was \$118. Three years later, they introduced the iPad. The share price was \$228. When would you rather have invested \$114 million? That's how much we invest in our kids each year. As of last night, Apple was trading for \$535 a share. When you invest makes a huge difference.

Despite an outstanding ROI on therapy, according to the Auditor General, the kids who would benefit the most from IBI therapy are ineligible. There's scientific research that shows that kids with a milder form of autism have a better outcome with IBI.

We're not talking about, "Oh, maybe these kids with milder forms of autism won't have to be dependent on the government." They could actually be scientists. They could be engineers. They could be computer scientists. They could be programmers. They could contribute, but we choose not to spend on them, not to invest in them.

So what do I want for value? I'd like to see government-backed autism therapy loans. Get the therapy earlier, and get more effective treatment. I'd like to see children with milder forms of autism receive the therapy so that they can contribute to society, and there's a lot they have to contribute.

The last point I have is oversight and ownership. This is a ministerial hot potato. You don't have to be a Queen's Park government insider to figure out that if four provincial ministries are responsible for autism services, ultimately no ministry is responsible for autism services.

The rate that autism is being diagnosed—it's being diagnosed more often than diabetes, cancer and AIDS combined. That's according to the CDC and US data.

The Auditor General estimated that between 30,000 and 35,000 children were living in Ontario with autism. That's about the population of Stratford. When you factor in parents, grandparents and siblings, now you're talking about the population of Windsor. That's who we're failing right now: a city the size of Windsor in Ontario.

Autism is being diagnosed at epidemic proportions. Ontario needs to plan and execute a comprehensive response proportional to the disorder that recent CDC reports say affects one in 50 children.

Thank you for your time.

The Chair (Mrs. Laura Albanese): Thank you for your compelling presentation. We have about a minute left over for each party to make a comment. We'll start with the NDP. Miss Taylor.

Miss Monique Taylor: Thank you so much for your time today and for bringing your family to our table. We could definitely hear the emotions that your family feels, and fairly so.

I'm glad that you brought up your thoughts on the independent review process and the mechanism, because we definitely haven't heard enough at the table about the performance measures and the benchmarks that families go through and how unfair that system is. We heard it

from our previous speaker, and now we're hearing it from you.

It's an important piece of the puzzle that needs to be brought to the table that others need to be aware of, and hopefully we can make some good recommendations to go forward with that.

Mr. Mick Kitor: The problem being is you're not going to hear about those until kids are discharged, because parents live in fear of reprisal.

Miss Monique Taylor: You're absolutely right.

Mr. Mick Kitor: So until there's a method for providing anonymous input, it's not going to happen. The decisions are arbitrary. Our son goes to a therapy centre that's been in private practice for autism for over 10 years. They told us our son was the candidate in their history who has responded best to IBI. They could not understand why he was declined and his therapy terminated.

Miss Monique Taylor: That's right, and I think that's because there is no clear process on benchmarks and performance measures. And we've heard about the wait-lists. I've been hearing a lot from families who say, "Our child has lost their treatment because the wait-lists are high and they need to move on"—

The Chair (Mrs. Laura Albanese): Sorry. I have to intervene, because otherwise the time will not be divided equally. But you both made your point. Thank you.

Ms. Hunter, a brief comment.

Ms. Mitzie Hunter: Thank you, Mr. Kitor, for your very passionate sharing of your story. We have heard your concerns, and they have been shared by others as well. They really have underscored that children with autism and other developmental disabilities need to be supported so that they can contribute to society and live as full a life as possible. I think that is the spirit in which we are conducting these hearings. Our intention is to ensure that we coordinate the delivery of programs and services across the provincial ministries and ensure that that is being done in the best possible way. Thank you.

The Chair (Mrs. Laura Albanese): Thank you, Ms. Hunter. Now Mr. MacLaren.

Mr. Jack MacLaren: Hello, Mick. Good to hear from you again.

Mr. Mick Kitor: You too, Jack.

Mr. Jack MacLaren: You and I know each other well. You've articulated your problem to me a number of times, that you're yet another desperate family in eastern Ontario where the system has failed you. You've done a wonderful job of searching out private sector IBI treatment from people who do an excellent job of delivering it and offer hope for you and your wife, and you find great frustration with the private sector, which is the regional deliverer of—

Mr. Mick Kitor: The public sector, yes.

Mr. Jack MacLaren: Yes. So you've done a wonderful job of articulating the issue and the problem.

I think we need two things: better oversight and accountability of how government does its job of delivering the service that you need, and to provide more funding to help you and other families like yours because of

the huge cost that's developed, and do it in a more timely fashion. Would that sum up most of what you would be looking for?

Mr. Mick Kitor: It would. The other thing that I would also point out is that for every parent that's able to articulate what the problem is, there's probably 10 or 15 or 20 more who know there's a problem but can't articulate it.

The Chair (Mrs. Laura Albanese): And that's very evident to us. We thank you very much again for your presentation this morning, Mr. Kitor.

Mr. Mick Kitor: Have a great day.

REV. MAGGIE HELWIG

The Chair (Mrs. Laura Albanese): We'll now be joined by Ms. Maggie Helwig. Hello?

Rev. Maggie Helwig: Hello.

The Chair (Mrs. Laura Albanese): Good morning. Where are you calling from?

Rev. Maggie Helwig: I'm calling from Toronto.

The Chair (Mrs. Laura Albanese): From Toronto. You'll have up to 20 minutes for your presentation this morning to the members of the committee. If it's any shorter than that, we'll have some time for comments and questions. You may start any time you feel ready.

Rev. Maggie Helwig: Okay, and this is going to be a fairly personal and anecdotal presentation, which isn't what I normally do. I'm an Anglican priest and I'm the mother of a young woman who has autism and an intellectual disability and who just recently turned 18.

I want to stress at the beginning that I understand very well that I'm speaking to you from a position of relative privilege. I am a highly educated professional who speaks English as a first language, and I have a partner who is able to work part-time and mostly from home so that he's able to act as a primary caregiver. Obviously, our family income is limited by the need for him to work part-time from home and by the fact that working in the church isn't a very highly paid job, but still we can meet our material needs and have some money left over for our daughter to access services. All of that, I'm aware, puts us in a very privileged position compared to many, many families.

On the other hand, my daughter, at the age of 18, has to have a responsible and familiar adult with her at all times. She can't travel on public transit by herself. She can't go to a store by herself. She can't be in school without support. She'll never be able to live independently.

1040

She understands what it means to have a job, and she wants to have a job, but she's going to need a lot of support to be able to achieve that goal.

She doesn't have any siblings, and she isn't close to her cousins, so there's no certainty about who's going to be there for her when her father and I aren't around. So, despite our relative privilege, we do live in a constant state of anxiety about her future.

With regard to developmental services in Ontario, I have to say our experience has been mixed at best. Our experience with the transition from the youth system to the adult system has been profoundly discouraging and, I would say, frightening.

My daughter was diagnosed at the age of three and a half. At that time, IBI was only offered up to the age of five, and the waiting list was long enough that we were advised that there was really no point in putting her on the list. She has never received any funded IBI intervention. I know that the age limit has been raised. There may have been some way we could have accessed it later; if there was, nobody ever told us what it might be.

We have paid for her to have specialized educational help, speech therapy, occupational therapy. We've done that with help from her grandparents, and we're very lucky that we've been able to do that because, really—and I gather this reflects the experience of the previous speaker as well—everything we've been able to access has been in the private sector. We've really never had any funded therapeutic or educational interventions, with the single exception of a few weeks of behavioural intervention focusing on social skills, which she received about a year and a half ago. So that's a few weeks over the course of her entire childhood and adolescence. Everything else has been private sector.

When she was about six or seven, and we had essentially no help or supports in place, we were in crisis at that point. We couldn't cope with her needs and behaviours. We didn't know where to turn. Again, I'm someone who's really unusually well qualified to navigate bureaucracies, but I had so little guidance that what I did was to start flipping through the phone book and calling organizations that I thought might help.

I found Community Living. I am very grateful that I did. A worker came to visit us and told us at that point about Special Services at Home funding and Assistance for Children with Severe Disabilities, connected us with a parent support group and offered us advice and moral support for some years. No one had told us about these basic programs until that point.

We never got a great deal of funding from Special Services at Home, but it was enough to have a respite worker for a few hours on weekends, and some help in sending her to appropriate day camps. We've never been able to afford an overnight camp; that's out of the question.

Although I understand the reasoning behind the re-organization so that your lead agency is simply set by diagnosis, that means we don't have access anymore to Community Living, which was a support to us for years. I'm sure that Surrey Place is doing the best they can. We did access the one very short-term program I mentioned via Surrey Place. But autism is a really, really common diagnosis; their caseload must be enormous. We have very little communication with them. I don't know if we have an assigned worker at Surrey Place; we probably do, but I don't know who it is. We haven't heard from them. I don't know who to call.

Of course, when my daughter turned 18, we lost Special Services at Home. We lost Assistance for Children with Severe Disabilities. There are, in theory, adult programs to replace these, but in practice, at this stage, we have nothing.

I started calling ODSP and Developmental Services Ontario shortly after she turned 17, and I was told at that point that it was too early to start making these calls. She's now 18, and we're not receiving anything from either service. I have phoned our ODSP case manager repeatedly to ask when she will be assessed for eligibility; I have invariably gotten voicemail. I have left messages; I have not been called back.

My daughter should be receiving ODSP or, at the very least, be in the process of establishing eligibility, especially when I went to the trouble of making contact very early. She's not getting ODSP. I have no idea when she might be assessed for ODSP.

I did at least speak to our assigned worker at Developmental Services a few days before her 18th birthday, so I give them credit for returning my call. Much earlier, I had faxed in her diagnoses and was informed that she was eligible for DSO services on the basis of her disability, that she was genuinely disabled, and that the next step was an interview to determine her needs and what suitable programs might exist. So when I spoke to our worker last month, I asked when that interview might happen. What he said to me was that she's on a very long waiting list, about a year and a half long. He couldn't tell me when she might actually get to the top of that waiting list. However, he said, "There's no money in the system anyway, so we couldn't offer her anything. So it doesn't really matter when she gets the interview. There might be money in the system again someday, but we don't know." You can imagine that it was extremely discouraging to hear that the assistance for which my daughter is eligible may or may not ever be available to her at some point in her life.

ODSP is not returning my phone calls. We are paying out of pocket with no support whatsoever for her school, for her respite worker, for her extracurricular programs, for her occupational therapist. We are managing this with help from our extended families. As long as I'm working full-time, we can do this, but it makes it very difficult to put money away for her future. She will need support all her life, and she will outlive her parents by decades.

My daughter wants to be a contributing member of society. She's learning to cook. She goes to work with her father. She works at school to learn basic office skills. She's really doing her best to develop the skills to take her part in society, but there's no structure to help her develop and apply these skills. There's no prospect of appropriate supported housing, maybe not ever—maybe when we die. I don't want my daughter spending her adult years watching television in a nursing home after her parents die, which I know very well is a possibility because I know people it happened to.

I also don't want my daughter to end up homeless, and I know that's a possibility because in my job in the

church I deal with many people on the street, and as someone who knows developmental disability, it is blatantly obvious to me that many of them are homeless, are marginalized, are desperately poor because they have developmental disabilities and they are not getting the support and the help they need. They can't care effectively for themselves and society is not caring for them, and they come to my church for a sandwich and I think, "Is this my daughter's future?"

If I, as a person with privileges and options, feel this much frustration and terror about my child's future, I can only imagine what it's like for people who can't pay for private sector services, who are trying to navigate the system in a foreign language, who have children with more severe behavioural challenges than my daughter has. I hate to even think what it's like for so many people out there because I know what it's like for us, and I know that we're coming at this from a very privileged place.

That's all I have to say at this point. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for sharing your experience with us so intimately.

We have about three minutes for each party to ask questions, and we will start with the Liberal Party and Ms. Wong.

Ms. Soo Wong: Thank you, Ms. Helwig, for sharing your story with the committee. There are a couple of us on the committee from Toronto, so first thing's first, I need to ask you which riding, which area you live in so that we can follow up with you off-line to ensure that—

Rev. Maggie Helwig: I'm not doing this to try to get help for myself personally; I'm trying to do this so that the system works better—but I live in Trinity-Spadina.

Ms. Soo Wong: Okay. We would like to get some personal information from you off-line, so I wanted to follow up on that piece.

The second question I need to ask you is regarding the services that you received when your child was in school. So I need to ask—

1050

Rev. Maggie Helwig: She has never been in public school.

Ms. Soo Wong: She was never in public school?

Rev. Maggie Helwig: Except in kindergarten.

Ms. Soo Wong: In kindergarten. In terms of improvement—because this committee also will be providing recommendations to the Legislature. Can you share with us, in terms of priorities, what you would recommend this committee consider? I heard the frustration about the lack of information shared with you and that you tap on your own family and your own personal resources to ensure some resources—

Rev. Maggie Helwig: Okay, are you talking about youth services or adult services?

Ms. Soo Wong: Well, currently for your daughter.

Rev. Maggie Helwig: I think clearly the adult system is obviously incredibly poorly resourced. I think maybe people think there is more point in putting resources into the youth system because maybe you can make them be normal and then not have to fund it. But the adult system

is hugely, hugely poorly resourced. There just needs to be more resourcing in the system as a whole, but especially for adults with developmental disabilities.

Ms. Soo Wong: Okay. My last question to you is with respect to your comments about your daughter's unemployment issues. Are you getting enough—are you getting any—services and support for your daughter with respect to her training and employment opportunities out there in the community?

Rev. Maggie Helwig: At this stage, no. I mean, we have talked to her school. Her school is also looking to see if they can find any possibilities. We have enrolled her in a continuing education course at George Brown, but this is all stuff that we're looking for ourselves. We're getting no support at this stage in any formal way, no.

Ms. Soo Wong: Again, thank you very much. We will definitely want to follow up with you with this good stuff.

The Chair (Mrs. Laura Albanese): And now, Ms. Sylvia Jones.

Ms. Sylvia Jones: Thank you, Maggie, for sharing your story. I have a few questions because you are not the first parent who has talked about the frustration of the transition from youth to adult and that process. You mentioned that with one exception of a couple of weeks, all the services that you have been able to provide to your daughter have been through what you had found privately. Is that accurate?

Rev. Maggie Helwig: It is, but as I said, we have had at least funding from Special Services at Home and Assistance for Children with Severe Disabilities. That helped pay for the private sector service.

Ms. Sylvia Jones: But not until Community Living made you aware of it.

Rev. Maggie Helwig: Yes.

Ms. Sylvia Jones: Which I guess in and of itself is disturbing, that you would have had to wait until your daughter was—you mentioned six?

Rev. Maggie Helwig: I think it was when she was about six, yes.

Ms. Sylvia Jones: I mean, kudos on you for your advocacy, but it sounds like there were numerous opportunities for people to share what little limited opportunities there were and they didn't even do that.

Rev. Maggie Helwig: Yes, I think there are a lot of communication problems in the system. As I said, there may be other programs that we should be trying to access now that I don't even know about. I'm never confident that I know about what's out there because I know that things are so fragmented.

Ms. Sylvia Jones: And it is a moving target, of course. Things change. If you were making one recommendation to us as a committee trying to formulate our suggestions, what do we need to do first and foremost? What would have helped you the most when your daughter was diagnosed?

Rev. Maggie Helwig: I think at the point of diagnosis, parents need a lot—I mean, it's hard to receive informa-

tion at that point in a sense because there's the shock of the diagnosis and the coming to terms with that. There needs to be some kind of continuing relationship set up. You know, if you get a diagnosis and a pile of information thrown at you at that point, I'm not sure how capable many families would be of processing it at that time.

Ms. Sylvia Jones: Fair enough. We've talked about the concept of a navigator, which would essentially take you through the stages. You would be familiar with that concept in your professional role. Is that something that you could have seen value in?

Rev. Maggie Helwig: I think that would certainly be helpful. I think until the system is better resourced, the navigator is going to be in much the same position as our worker at DSO, saying, "I can't offer you anything anyway." But I think that having a navigator for families certainly would be helpful, absolutely.

Ms. Sylvia Jones: Okay, thanks for sharing it.

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

Ms. Cheri DiNovo: Hi, Reverend Helwig.

Rev. Maggie Helwig: Hello. Hi.

Ms. Cheri DiNovo: Cheri here. We know each other.

Rev. Maggie Helwig: Yes, we do.

Ms. Cheri DiNovo: Thank you very much for your advocacy work. What you have brought forward, I just wanted to reassure you, is not unique. We have heard that the system is broken, maybe irretrievably so, from a number of folk who have come forward. Your experiences—of course, as you probably know, you're not alone. I just wanted to say that first off.

To follow up on what Ms. Jones had asked about suggestions, one of the speakers today was talking about the particular challenges of an ASD diagnosis and, again, getting treatment there. You say your daughter was not in school at any point—

Rev. Maggie Helwig: She has been in a private school since kindergarten.

Ms. Cheri DiNovo: Okay. Did she get ABA or IBI treatment anywhere along that, as part of the schooling?

Rev. Maggie Helwig: Her school is based on IBI principles.

Ms. Cheri DiNovo: Right, okay.

Rev. Maggie Helwig: One of the things that many families have advocated for, for some time, is that those schools—there should be a way that funding for IBI can happen through schools which use IBI principles, like her school.

Ms. Cheri DiNovo: I hear you. Again, you've gone to the private sector because that's all there was.

Rev. Maggie Helwig: Yes.

Ms. Cheri DiNovo: Did you check out, though, the public school system? They are also supposed to provide—we've heard of EAs. We've heard of problems with it, but—

Rev. Maggie Helwig: She was in the public sector for junior and senior kindergarten, and it was pretty much a disaster.

Ms. Cheri DiNovo: It was a disaster.

Rev. Maggie Helwig: She was assigned an EA for part of the time. The EA had no specialized training and was not familiar with IBI or with autism spectrum whatsoever.

For grade 1, what she was offered was placement in a kind of mixed special-needs class, which again would not have included any IBI component or any specialized training in autism or autism spectrum disorders.

Ms. Cheri DiNovo: Thank you. My colleague has a question.

Miss Monique Taylor: Hi, Ms. Helwig. This is Monique Taylor. I'm just curious: What was your experience in the private school with the IBI training? I know that the curriculum would have been exactly what your child had needed, but for sociability aspects, could you explain what that experience was like for her, without her being in the "normal" realm of children?

Rev. Maggie Helwig: I think that it has been a good experience for her. Particularly for children with autism spectrum who find social interaction so very difficult—

Miss Monique Taylor: Right.

Rev. Maggie Helwig: —that's actually the most nightmarish part of the public system. That's the hardest part to navigate.

When she's in a specialized environment, where a lot of attention is paid to supporting and developing the ability to interact with other people, that has been something that she would not likely have had anywhere else, and I have seen her behaviour improve tremendously. I have seen her social skills improve tremendously.

If that kind of very intensive social skills training could have happened in an environment with neurotypical children, perhaps that would have been the ideal. But the intensity of the focus and training on behavioural and social skills, I think, is the crucial thing. She interacts with neurotypical people at church and in other parts of her daily life, and—

The Chair (Mrs. Laura Albanese): Ms. Helwig, I'm sorry. I'm going to have to interrupt you, because our time is over.

Rev. Maggie Helwig: Okay, sure.

The Chair (Mrs. Laura Albanese): But on behalf of Miss Taylor, what is the name of the school?

Rev. Maggie Helwig: Kohai.

The Chair (Mrs. Laura Albanese): Kohai. Thank you very much for your presentation to the committee today.

Rev. Maggie Helwig: Okay, thank you.

The Chair (Mrs. Laura Albanese): It's very much appreciated. Have a good day.

Rev. Maggie Helwig: You too.

MS. SILVANA CACCIATORE

MR. BRIAN JACQUES

MR. KEN MACLAM

The Chair (Mrs. Laura Albanese): We'll now call Silvana Cacciatore to come forward. She's the first in-

person presenter of the day. Good morning and welcome. I know you were listening in the back, so you know you have 20 minutes for the presentation. Please state your names and your titles, if any, before you start, for the purposes of Hansard.

1100

Ms. Silvana Cacciatore: Okay. Before we get started, we want to just kick off our bargaining campaign. It's called Turnover Tuesday, so we'd like to share turnovers with you today. And we gave out little pamphlets.

The Chair (Mrs. Laura Albanese): I believe each member got one.

Mr. Brian Jacques: My name is Brian Jacques; I'm a support worker for Community Living Thunder Bay. I've been a support worker for 10 years.

Mr. Ken Maclam: My name is Ken Maclam; I'm also a support worker at Community Living Thunder Bay, for about 10 years. I'm also representing the provincial youth committee for OPSEU.

Ms. Silvana Cacciatore: Should I start talking?

The Chair (Mrs. Laura Albanese): Yes, please start talking—

Ms. Silvana Cacciatore: Okay, I'll start. I would like to start by thanking you for giving us the time today to address you on the crisis we face daily as developmental service workers. As I said before, I'm Silvana Cacciatore, and Brian and Ken are with me also. I hope that at the end, we will all be able to answer questions.

I am a front-line developmental service worker at Avenue II Community Program Services in Thunder Bay. I have worked in developmental services for over 25 years; I have worked at Avenue II since 1991, and I have seen a lot of changes. We are a relatively small agency and have just 100 staff members. Of these, approximately half are casual, a quarter are part-time and the remaining quarter are full-time.

Our budget has not changed in more than four years. As costs increase, our budget does not keep pace with inflation. That means there is less of everything. The budget is stretched so thin, and the expectation put on everyone affected is to do more with less.

If I take a vacation day or call in sick, the people I support have no access to services. There is no budget for backup staff, so individual hours are cancelled, which often leaves family members in crisis.

There is less money for support time at my agency. I remember a time when the focus of our job was to integrate individuals into the community through employment or recreation. This can no longer happen unless they use Passport funding.

The Passport funding system does not provide enough for people's needs. I see families every day who have very limited access to services with the individualized funding they receive. Families have commented that they have been approved for Passport funding but are still waiting to receive the money. Some of them have been waiting a long time without access to the services they have been promised.

A lot of time, effort and money is being put into meeting the requirements of the ministry, such as quality assurance measures, fire regulations and health and safety. Yes, these might be important, but when your agency has to worry more about meeting requirements and deadlines, filling in the appropriate forms and doing the paperwork, these all take away from our limited resources. The focus is taken away from why we are really there: for the individuals we support.

And I don't understand how it is that QAM is valued highly while Passport system funding encourages using non-qualified, uninsured service providers. This seems to me to be a double standard in respect of quality care and in respect of the people who depend on developmental services. Due to a lack of Passport funding, families can only afford to hire people with no education, no first aid, no NCI, and no criminal reference checks are needed.

There is a very high turnover in staff at the agency where I work. Half of us are casuals who have to work two or three jobs to survive, and often these people end up quitting. This is not good for the people we support.

I myself have to work two jobs. I have two kids. I can't make ends meet with just one job, even though I have full-time work and have been working here for over two decades and have a university education.

The saddest thing for me, however, is knowing that at the agency where I work, we can't support anyone new. Unless someone actually passes away, not one single person in Thunder Bay can expect to receive services at our agency.

I know what that means for the people who are on the wait-list. There are more than 800 people in the Thunder Bay area on the wait-list for day services, and more than 200 people in Thunder Bay on the wait-list for residential.

Can you imagine what it is like to be a parent or a family member caring for a person with a developmental disability? When their kids were 18 and under, they were able to go to school and receive services. Then they turn 19, and the funding is cut: They have to stay at home with nothing to do and nowhere to go until they get off of the wait-list. They will be at home until someone dies.

More than 10,000 OPSEU developmental services workers want to know how the government plans to fix the crisis in services for people with developmental disabilities.

It is time for a serious commitment to properly funding developmental services. Ontario families are stressed and pushed to the limit, waiting for access to services. Lack of adequate funding means there are not enough staff to meet the needs of people waiting for services.

Finally, I just want to say that while I am grateful that you have all taken the time to visit Thunder Bay, I am disappointed that there is not an MPP from the north on this developmental services select committee. We have very specific challenges; for example, with regard to travel time to access care and accessibility of specialized support resources in smaller communities.

Thank you for your time.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. We have about—sorry, I have to calculate here—four minutes for each party. We'll start with Ms. Elliott.

Ms. Silvana Cacciatore: It is okay—Brian wants to say something.

The Chair (Mrs. Laura Albanese): Oh, you still want to speak? Okay, please, go ahead. Sorry.

Ms. Silvana Cacciatore: Brian wants to give a story. I forgot; sorry.

Mr. Brian Jacques: I just want to say a story, because I've been a support worker for 10 years, and it's extremely frustrating when we don't have enough staff. I've been directly hit with that because in a home that I work with, I work with three gentlemen. One has autism, and the other two are undiagnosed and could potentially have mental health issues; they have never been diagnosed. The story I want to share is that due to lack of funding and a staff shortage, I actually was assaulted and had a concussion because there was not enough staff on. That is extremely frustrating to me because the only person who cared in the agency and even came to me was my direct team leader. That is sad. The person who assaulted me, it was not his fault; it's the fault of all of us—not having the funding to support people's needs. Have any of you ever been to a group home and actually seen what happens? It's sad that we cannot support the people with the amount of staffing they need. It's extremely sad. For staff to get assaulted on a daily basis is not right. The people who we're trying to support—it's not fair to them, and it's not their fault. We don't have enough staffing. That's where things need to change.

The Chair (Mrs. Laura Albanese): Thank you, and thank you for the apple turnovers that you brought, which are really delicious. I will pass it over to Ms. Elliott.

Mrs. Christine Elliott: Thank you very much for coming today and for your presentation. Just a couple of comments: one is about your concern that there isn't a northern member on this committee. What I can tell you is that we are really interested in finding out about the specific issues in the north. We are here for two days of hearings, and we will be going on to Moosonee as well. It was really important to all of the members of our committee that we do get that specific knowledge. I just want to reassure you that we are eager to learn and to take those matters into consideration.

Secondly, with respect to the issues that you've raised about staffing, costs and so on, we have heard about that before. It has been expressed to us also by some of the managers of some of the organizations. They're equally concerned about staffing levels and how they're going to be able to cope with things like paying pay equity out of existing budgets. There is a concern about that and making sure that both residents and staff are safe, so I appreciate you bringing that forward to us. It is something we definitely will be focusing on in our future deliberations in the committee.

1110

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

Ms. Cheri DiNovo: This is more a question for research again—sorry, Erica. Coming back to this wait-list issue: We've just heard that about a thousand people, one way or the other, in Thunder Bay alone, are waiting for services, whereas the ministry says there are 2,300 across all of Ontario. There were 4,500 who are in long-term care, so there's another 4,500. I would love to know what the total is of our presenters on wait-lists versus what the ministry says are on wait-lists. Clearly, there's a real problem there with getting actual figures. So I wanted to bring that forward.

Thank you for presenting. Thank you for what you do with so little—and that's what this committee is charged with doing. Clearly, the system, as it stands, is not working.

Miss Monique Taylor: Good morning. Thank you for the turnover. I know it's going to be a great snack at the perfect time of day.

This is excellent. You're talking exactly about what's happening, about the lack of resources, about the high turnover rates of staff and how hard it is to keep staff when they're underpaid and overworked. It's a very stressful environment.

What is the ratio in your home of clients to workers?

Mr. Brian Jacques: We have one to one, but—

Ms. Silvana Cacciatore: In the high needs—

Mr. Brian Jacques: In the high needs. But there are days when all three of us can't even support one person because he doesn't—

Miss Monique Taylor: Because the needs are so high.

Mr. Brian Jacques: Yes.

Miss Monique Taylor: It's so unfortunate. We're hoping that we will come up with the solutions for how to deal with matters like that, what needs to change to move forward.

Thank you so much for bringing your piece here and just being here and for the work that you do. I know it's hard work, and I know you do it for the right reasons.

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

Ms. Mitzie Hunter: Thank you for your presentation today and the stories that you've shared. The reason we're out is to hear from people like you about how to make this system better, because we recognize that we need to improve. That is what we're here to do.

I want to let you know that the MPP for Thunder Bay will be joining the committee for tomorrow's set of hearings.

Like my colleague Ms. Elliott says, we are listening right across the province because we're looking to strengthen the system right across and coordinate across ministry areas.

I had an opportunity to visit with Community Living Toronto in my particular community in Scarborough. I went into the high-needs group homes, which require 24-hour specialized care, and just had a wonderful experience there. I also visited the respite programs for children and the day programs—and also hearing about how the network is supporting families and giving them resources

and support to be able to manage through various cycles in a child's and an adult's life. It's very important that we actually see. Hearing is important, but seeing is also important.

I fully respect the work that you do. Know that we are listening for ways of improving and strengthening this system of supports for people with developmental disabilities right across the province.

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

Ms. Soo Wong: Thank you for sharing with us about the issue of workplace safety. I'm particularly interested to hear from all three of you, or one of you, in terms of best practices, from your professional experience. Can you share with the committee some of the best practices out there with respect to a facility like yours, and how do we improve that? Because your safety is our concern as well.

Mr. Brian Jacques: We're all trained in NVCI, which is non-violent crisis intervention. I'm actually one of the trainers. We have to have that to work in the workplace. But that can't prevent everything from happening. When I got my concussion, I was sitting there, talking to the one individual, comforting him because his mom had made a phone call and said that she wasn't coming to get him, and he was stressing about it. He got up and I got assaulted. It was nowhere near my fault, nor his; it was just the situation. But two staff on, compared to three, which there should have been, and now all of a sudden we have three staff? You have to wait until an accident happens. I mean, my injury could have been a lot worse than it was. Then what? It just gets put on the side burner: "Oh, we'll do better next time." No. Do better now. Don't wait for something bad to happen.

It's extremely frustrating because I see workplace injuries all the time, and it's sad. That shouldn't be happening.

Ms. Silvana Cacciatore: And it's very high. It is, I believe, 65%—

Mr. Brian Jacques: Sixty-five per cent of our staff at Community Living are on modified work. That's not right.

Ms. Silvana Cacciatore: Sixty-five per cent.

Ms. Soo Wong: Thank you very much for that.

I'll follow up with a staff question. Madam Chair, before we go to the next witness, can I ask the researcher, as part of the questions from the committee, can we get some data from the Ministry of Labour as pertains to reporting of injuries and accidents as relates to residential homes where workers are being assaulted or hurt, directly or indirectly? And do we have those data for the past five years?

What is the follow-up—because those homes should be inspected—and then what is the responsibility from the Ministry of Labour resulting from these inspections and following up with these cases? Because if I hear the number is 65%, where is the prevention? Where are the measures from the Ministry of Labour to deal with this sector? We know these workers are at risk. Furthermore, what strategies have been done to deal with it?

Also, the last piece here, Madam Chair, through you to the researcher, is the chief prevention officer. I want to know what is his responsibility to ensure this sector's workers are safe, because that's his mandate.

Okay? So thank you.

The Chair (Mrs. Laura Albanese): Yes, his mandate is in prevention; however, as they pointed out, we also have to look at standards that are not there right now.

Now that I've recomposed myself, I just want to thank you for your presentation once again, and for really pointing out the fact that there's not enough staff to meet the needs most of the time. Certainly, your safety is paramount as well. We need people like you to help in the sector. Thank you for the work that you do.

Just a reference for the various MPPs: Tomorrow, the MPP for Thunder Bay, Bill Mauro, will be joining us. He's in Toronto today. We've also been in contact with Michael Gravelle. And Friday, for example, we're going to Ottawa; we'll have Ottawa MPPs there. So they're joining us as we travel across the province.

Thank you very much for what you do every day. Thank you and keep safe.

MS. BRENDA PARRIS

The Chair (Mrs. Laura Albanese): Next we will be joined by Ms. Brenda Parris via teleconference.

Ms. Brenda Parris: Yes, indeed. Hello.

The Chair (Mrs. Laura Albanese): Hello. Good morning. How are you today?

Ms. Brenda Parris: Very well. Can you hear me?

The Chair (Mrs. Laura Albanese): Yes, we can hear you very well, thank you. Where are you calling us from?

Ms. Brenda Parris: I'm calling from Toronto.

The Chair (Mrs. Laura Albanese): Oh, from Toronto.

Ms. Brenda Parris: Yes, and I have lived in Ottawa for a number of years, so I know services in that area as well.

The Chair (Mrs. Laura Albanese): Excellent. You have up to 20 minutes to present to us today. If the presentation is any shorter, that will leave time for some questions.

Ms. Brenda Parris: Yes, I'm familiar. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. You may start any time.

Ms. Brenda Parris: I want to start by saying why I wanted to present to the committee. I've been following your work and reading the transcripts. My husband and I are adoptive parents of a young man, 27 years of age, with a developmental disability, who is on the autistic spectrum. Recently, through an accident in his group home, he has now acquired a spinal cord injury resulting in paralysis, so now we have a higher level of need for service and care. I've seen both sectors at play, the autism sector and developmental services, and I can comment on the differences and the tensions between them.

1120

I also want to present because I am one of the families that gave up custody of my child in order to receive services. This was the trend, as you know, a few years ago. My son became a crown ward in order to get residential help and treatment, so I know what it feels like to have your kid declared abandoned in order to get the services he desperately needs. I'm thinking here of Ms. Telford in the Ottawa area and other similar cases.

Unlike other families, I chose to keep my son in a stand-alone or segregated program in the school system, what is called in the Toronto school board a low-incidence school. Either he was in a special needs class or in an entire school devoted to their needs. In my case, it was Frank Oke; other parents, I know, have mentioned Beverley Street school etc. I did this not because I was opposed to integration, but I didn't feel the school board could adequately educate him and keep him safe in an integrated class setting, as our kids are often picked on, bullied and highly vulnerable in our modern high schools.

I also speak as a visible minority family—black Canadian—in a mixed-race family, dealing with the issues of race and racism in trying to get services in a sector that is uncomfortable and unwilling to incorporate cross-cultural understanding. As you can imagine, in large urban settings, this is increasingly an issue.

I speak as a professional—that's another hat I wear—social work administrator, executive director and a policy person in the former old office of the handicapped in the early 1980s. I was around for the changes in the system with the introduction of deinstitutionalization. So I understand the policy and program development over the years that we've seen. Sometimes I feel like we've been standing still for 30 years in terms of real, fundamental change, but I'll come back to that later.

And finally, I speak as a parent and as a mother. I'm active in parent groups on both sides of the spectrum, the autism groups and the developmental disability groups. I see a real difference in parent expectation and approaches in advocating for their children. I want to provide you with some truth about what happens on the ground and the practical realities day-to-day of these programs that we're talking about and often are touting.

Parents are often paralyzed and unable to think ahead, as they are struck at the level of sheer survival and fear for the future. We often feel abandoned and betrayed by agencies, by government and by our communities, communities that still persist in thinking that, in the phrase I use, "Doesn't the government take care of that?" You often have to hear that said when you talk to people.

I want to focus on just two issues identified in your mandate, because other people have spoken to other issues and I don't want to be repetitive. I want to speak about the range of housing and affordable housing options—I've been working with two parent groups trying to look at housing options for our young adults—and secondly, how the government should most appropriately meet these needs and provide these opportunities.

There are a couple of practical suggestions I'd like to offer.

First off, I want to offer an entirely different perspective in some thinking outside of the box, to ground my comments and to ground my solutions in a different paradigm, because I think we're stuck. I've read all the proceedings of your committee and other groups, and I've read some of the documents provided by the groups. I've heard the parents' voice in the wilderness, their desperation, and I've heard the usual self-defensive response of the government ministries and the agencies that deliver services.

The starting point for me is the usual linking of disability issues with welfare issues and, by extension, with a poverty, welfare mindset that shapes and delimits our responses to problems and their solutions. I contend that the major flaw in our way of thinking about these issues is the role of the welfare ministries as a lead ministry. Welfare and social assistance, which is the underpinning of the work of the ministry, is a minimal level of support. Welfare programs are discretionary, as said by some of the ministry presenters, and as such, not a mandated service or an entitlement service.

All decisions and plans based on an MCSS ministry model will only provide good-enough care, not the quality of care that parents want and need. These welfare levels of care will guarantee a life of poverty and economic and social disadvantage that we are continually trying, on the back end, to solve. Well, maybe we need to start looking at the front end.

As long as they always view our proposals and changes within this framework, we'll never really improve until we have a real philosophical change and transition in how we view these problems.

Many solutions are seen through a welfare lens. For example, when we talk about housing, it's always talked about in terms of public subsidized housing. There's no discussion about using the co-op model, where a group owns, or individual home ownership. Many, many parents that I meet and talk to all around the city and province are very scared of this option for their children, because they see, depending on the community you live in, some of the safety issues and drug issues in these communities, and they're terrified that their kid, if they're not going to end up in a nursing home, might end up in a subsidized environment where there are no supports to support them.

For example, many of the agencies are running group homes, what I call the new institutions. They take all the money from the clients and leave them with what we call the comfort allowance of \$135. I question why. Why do we do this? It guarantees poverty and continues the poverty framework. If you were to regularly rent housing in the community, say, in a rent-geared-to-income housing project, you'd only be paying around 30% of your income in rent. That's a huge difference in disposable dollars. Why do we do this? Because the welfare mentality is we don't want people to get ahead at our expense.

In terms of some of the presenters, they've been talking about inter-ministerial functions—a lot of discussion about this. It will always be problematic whenever you talk about inter-ministerial committees or solutions, because the operating principles are diametrically opposed. At MCSS and children's services, there's a welfare model, and that will prevail, so no wonder the Ministry of Municipal Affairs and Housing doesn't have a really specific response when you ask them to present to the disability issue. They view housing in terms of a principal, generic, open-access option, and they've devolved the authority to other people to do it, but they're not viewing it in the same sort of welfare mentality. I think that's going to be a continuing problem in any inter-ministerial solution you may suggest.

So I would suggest that we start with different principles and different paradigms, and that we accept that there are genuine differences in our needs, compared to other groups. I'm not saying that we're better or worse. I'm just saying there are genuine differences, and those differences I see as our fundamental vulnerability and dependency. These are constants. It's nothing to be ashamed about. It's not a bad, negative thing to talk about our vulnerability and dependency of our children. Our kids have lifelong needs that need to be fulfilled. We need a security of care for them and a certainty of continuity. That's what I maintain is different from other groups that may not have that lifelong need.

Secondly, I see it as an area of three-legged responsibility. I, as a parent, and my family have responsibilities, the government has responsibilities in the provision of supports and services, and our community has responsibilities to be accepting and welcoming of us. Our accident of fate should not destroy us or our family life. We'll assume our rightful but appropriate level of responsibility. It's not right that families should live in impoverishment, live in fear or worry, or bear the exclusive burden of responsibility.

Thirdly, I'd like us to switch to a model of mandated services, not discretionary. We seem to have lost, in the intervening years, our unique Canadian value of universality of service. These, to me, are very important principles that we used to believe in in Canada. We need universality of funding and universality of citizenship and participation.

Let's save the expense and pretense of pretending we're looking at eligibility with the DSOs. It's still the same model of basically excluding, or defining who's in and who's out. I would argue that we're all in, because as long as there's a particular need, it should be met in some appropriate manner.

These are difficult things to say sometimes, because everyone worries: "Well, does that mean there will be floodgates?" Not necessarily, but you have to start on the notion that universally, children with disabilities, who then become adults with disabilities, have needs that need to be met and should be met by our society.

1130

Fourthly, I'd like to increasingly transfer more of the roles to the Ministry of Health and Long-Term Care.

They're mandated to provide health services. I'm thinking particularly of the support services here. They're not discretionary in the way that welfare ministries are.

I think some services should be government-funded and government-run. Always devolving down to transfer payment agencies is a limited solution, and I think that we can do better than that. If we accept my argument about continuity and certainty of care, then some of that should be government-function-provided, consistently across the province. I'm thinking here of something like a service navigator role, because we continually hear about how parents don't know about things.

Not all parents are served by Community Living, and if you look at the numbers, they show that. I think your numbers show that there are 65,000 people, technically, with a developmental disability, but only 17,000 are receiving services. Well, what happened to the other 30-odd thousand? And, of course, they're increasingly growing in numbers with the autism group. So they're not being served, and they often are not the only people who can speak on behalf of parents.

Funding increases: I think it's a given. Everyone has been talking about the need for more money, and let's not tippytoe around that. When my son was in children's services, when he was a crown ward, the agency was paid \$320 a day for his level of need. As he approached 21, I was warned to expect an inferior level of service in the developmental sector, and I was told that, if lucky, they operate at something like \$90 per diem. Why we can justify going from \$320 to \$90 per diem is beyond me when the needs have not changed—of course, in his case they've increased because of the physical disability. So I think we have to accept as a given that there is a need for money and we need to find it. I think it's an appropriate request to make of our community and of society, and let's do it as wisely as possible, but I think we really need to understand that there needs to be more money in order to get better services and more services.

I would also like that that new funding not only be given to transfer payment agencies. Nothing will change unless attitudes and practices change, and I think we need to allow for some new innovation. I'd like the government to open up the list to other transfer payment groups, parent groups and community groups; allow the funding to develop micro-boards, which they use in British Columbia; and allow families to have funds transferred directly to them.

I know there has been discussion of direct funding; often the unions are concerned about it, because they see it as a devaluation of a public service role. I take a more balanced approach. I think direct funding can be used to good effect. It is used, in a sense, with Passport funding and Special Services at Home, but I'm suggesting that, even as people become adults, funding for their housing component could be given directly to families. Families can group into groups—micro-boards, which is what they're doing in BC—and can often combine services and funding.

Community Living itself, or agencies like it, are not the only advocate. They're often caught in a dilemma; I

call it the pact with the devil that they made. When the deinstitutionalization thrust happened, most of those people were transferred to group homes and Community Living or similar agencies. I think the big problem that these groups that were community advocates made is that they allowed themselves to become mere service deliverers. They allowed themselves to have a pact with the devil by accepting too little money for the people who were coming out of the institutions. They accepted these low rates of funding and the minimally enriched programs of care that that results in. I think this is unfortunate. When you ask for too little, you only get a percentage of too little every year. I think it was tactically a big error. For me, I do not view most of the transfer payment agencies as my advocate because of it. They are caught in the horns of a dilemma. They are service deliverers delivering programs that are increasingly poorly funded and poorly administered, and they can't get out of that rut.

I'd like to change that a bit by making funds available to new groups who can demonstrate their effectiveness and innovation and not shy away from giving money to new groups instead of the same consistent old gang.

I know direct funding—giving directly to families—is often stigmatized. There's often this underlying fear of the welfare mentality that I talked about. We're afraid to give money to people directly. But I think the UK experience and the BC experience can show us there are ways of doing this efficiently with the full accountability that you need whenever you do give money to anyone. I know the Ministry of Health is starting to do this. I would like to suggest—one of those low-hanging fruit suggestions—that we increase the funding for some of the attendant-care projects and increase the funding for the direct-funding projects that families are using, and let this happen even if you want to do it as a pilot project to demonstrate its effectiveness.

I'm coming to the end here. On the inter-ministerial discussion—I know there are lots of presentations on this—if you do anything in that as a solution, they need to have a clear mandate and a timeline and accountability. When housing and Comsoc and all the other people sit down at the table, there's no reason they can't do co-operative and collaborative arrangements: Housing can provide some funding and direction on the physical plant, and Comsoc and health can provide funding on the supportive service front.

This should be encouraged. Indeed, with the housing dollars, I suggest that the service administrators be instructed to come up with a plan with how they're going to meet the housing needs of this community.

Paramount is the need for the continuum of care and support, and in particular, family support for parents to help them deal with their fears, their pain, their panic and their worrying. My experience—and I've tried to work with parents on housing; I find they're unable to take steps due to the panic and the paralysis of worry and fear. If we knew that funding stayed with the person and travels with them and not with the program, and if we

knew there was some consistency, I think it would enable parents to step back and be able to think about future planning and not live just in the crisis of the moment.

I'll leave those points for you now. I will send this to you in written form. As you know, I was just informed at the end of the week last week that I would be speaking to you. It had been my intention to provide a written summary, so I'll make sure you get it. Thank you very much for this opportunity.

The Chair (Mrs. Laura Albanese): Well, thank you very much for your presentation. Unfortunately, we don't have any time left over for questions, but we do appreciate your suggestions and your input into the process. Thank you very much and have a great day.

Ms. Brenda Parris: Thank you. I do note that other groups were given 30 minutes, so if there are any questions any of your members have, I'm happy to—

The Chair (Mrs. Laura Albanese): Only ministries were given 30 minutes. Every other presenter has been given 20 minutes.

Ms. Brenda Parris: Oh, okay.

The Chair (Mrs. Laura Albanese): Yes, okay. Thank you very much.

Ms. Brenda Parris: Thank you.

ONTARIO ASSOCIATION
OF RESIDENCES TREATING YOUTH
PARTNERS IN PARENTING

The Chair (Mrs. Laura Albanese): We'll now be joined by the Ontario Association of Residences Treating Youth, OARTY, and specifically by Rebecca Harris. Hello?

Ms. Christine Rondeau: Hello. Actually, it's Christine Rondeau, on behalf of OARTY.

The Chair (Mrs. Laura Albanese): Yes, good morning.

Ms. Christine Rondeau: Good morning.

The Chair (Mrs. Laura Albanese): Where are you calling us from?

Ms. Christine Rondeau: I'm calling from Ottawa.

The Chair (Mrs. Laura Albanese): Oh, from Ottawa? That's great. Your name, again?

Ms. Christine Rondeau: My name is Christine Rondeau.

The Chair (Mrs. Laura Albanese): Christine Rondeau. You have about 20 minutes for your presentation to the committee. You may start at any point in time.

Ms. Christine Rondeau: Excellent, great. Thank you so much. Thank you for inviting OARTY to this important information-gathering. OARTY is the Ontario Association of Residences Treating Youth. I'm speaking today on behalf of OARTY but also on behalf of my own company, which is Partners in Parenting in Ottawa, as well as a parent of a special-needs child. So I'm coming at you from three levels.

OARTY is a provincial association that represents 70 member agencies that provide private residential care and

treatment to approximately 3,000 children, youth and adults on a daily basis.

A significant number of our clients are in the DS sector, and OARTY continues to work with your ministry. We started off with the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, and we did a presentation there. But we're also continuing to work on developmental services day to day and, more significantly, working with the agencies that can provide service to people in need.

1140

OARTY members are very eager to work with government in order to help create an Ontario where individuals have the best opportunities to succeed and reach their full potential based on person-centred planning, and the freedom of choice and individualized funding comes into that for sure.

The ministry emphasizes flexible services. That is one of our hopes, that people—individuals, parents, families—will be provided with a full choice of services that are available within Ontario. Right now, the system tends to work through a transfer payment system, and the transfer payment systems dictate or create the spaces for individuals with special needs to reside. Ideally, there would be a more fluid system, one that could offer a choice to families and individuals as well as one that can offer the right support to the client and create more fulfilling environments for individuals to live as opposed to just living in a group home that they're plunked into because that's the only space available.

The way it sits right now, and from our hands on in the private sector, we support many, many individuals with developmental disabilities mainly starting from children—children who have come through the child welfare system and children who grow up in the system, and then, at age 18, get moved from that system into the adult system. Typically, the children who come through the child welfare system are the lucky ones. They are the ones who get support right through their lives. The children who remain at home with their families that don't have those supports—they end up with the burden in the end, where their child is now perhaps 18, 19, 20, their other children are leaving, and their child with special needs has no options or minimal options. Again, it depends where in Ontario you reside because things are different across the province.

One of my pieces is to look at how we streamline things across the province so that they are more effective. I know with the development of the developmental service agencies, the DSOs, that the goal there was to improve streamlining into the system for adults. But from my perspective, it has just created another layer of bureaucracy and another layer of frustration for families and parents on two fronts. One, there's the process, which is great; there's actually an entry point to the system, except families then feel like there should be the next step, which means money allocated to their child so that they can continue to have support.

Going back to what we do in the private sector, the private sector offers high-quality treatment in residential

care at a cost-effective price point, a clear understanding that OARTY is a part of the system. Although we're not a TPA and we're not incorporating as part of the system—incorporating it as part of the system will enable the government to treat considerably more adults with the same investment. So because our system operates differently than a transfer payment system, we can provide care to more people, with less money going out to infrastructure and more money going to the person.

The private sector has open spaces. When we hear that there are waiting lists, it really makes us cringe. When I get families calling me saying, "Do you have a space in your home?" and I say, "Yes," and they say, "We've been told that there's a five-year waiting list," or an eight-year waiting list, "How do I get my child into your system?"—there's no easy answer to that.

Some families can advocate, and some families have the ability to be the squeaky wheel, which is, from my perspective, what DSO was supposed to remove. But it's still occurring on the ground floor. Families who are connected or understand the system have the ease of access of getting their child service.

Another point that's pretty significant is there are a significant amount of individuals who are in hospital—dual-diagnosis clients, clients with medical needs—who are bogging down the health system. I feel that there need to be better relationships across the board from the Ministry of Health, the Ministry of Community and Social Services, the Ministry of Children and Youth Services, as well as the Ministry of Education.

When children are born with special needs, it needs to start at that moment. Systems need to be established at that moment for families so that throughout the youth's life, there is a support network in place. Right now, the system is not there, but as it continues to grow, the system needs to be better managed with all the ministries that are involved and all the ministries that touch. Children are born in a hospital. It starts with the medical and then jumps to education very quickly, and then in there comes the child and youth services, and children become adults. So it needs to be a continuum and a coordinated effort.

Going to the families of children with special needs: I see a lot of families, because we provide foster care and residential and day supports to adults with developmental disabilities. So we see a lot of families when they come into the system and they are burnt. They're in crisis. They need support.

I think if an infrastructure is built that can provide support throughout, similar to what currently is happening with Special Services at Home—although that system has some flaws, but it's a good start—where families are provided with dollars to support their children, it can continue to grow. There needs to be a better collaboration across the board, in terms of hospitals, in terms of schools, but starting with providing the family support. That's an obvious need. I see depressed and defeated parents who are so desperate for support, so trying to fight the system, that they need action.

Differences across the province are sometimes difficult to swallow, let's say. Here in Ottawa, we have quite a good system in terms of the private system working directly with a transfer payment system that contracts the private sector to provide support because there aren't enough transfer payment agencies or the transfer payment agencies perhaps aren't as flexible in providing care to the dual-diagnosis or the complex-special-needs children, youth and adults.

1150

The model that we have in Ottawa is one that is an anomaly across the province. Working at the provincial level through OARTY, I see that there are not a lot of opportunities for the private system in other regions, but I think that is something the government should look at, and it should look at how we can tap the unused beds that are there and how we can have the private operators create a system that is not built on infrastructure but is built on individual needs of the client.

Just an actual example of that—you know, there are some really neat things happening in the system with individualized funding. Most recently, we've had a youth who just recently turned 18 and has complex-special-needs funding. He's not from the Ottawa area but from one of the local counties surrounding Ottawa. His parents were working with an agency that provided a week on and a week off support while he was a child.

Two things occurred for this young man. The program that he was in was a children's program, and on his 18th birthday they cut support. He can no longer go to this children's program where he was getting a week on and a week off support. The TPA-funded program was not successful and closed their bed, moving from a large nine-bed home to a small three-bed respite home.

The family themselves needed a full-time placement for their youth, so the supporting agency contacted Partners in Parenting to see if we had any vacancies. We did, we had a vacancy, and we matched the space for the youth toward the family, got to know the youth, and started a transition plan, all within a month of the first phone call. Now this young man has a full-time placement where he's matched with age-appropriate peers.

We have a three-way agreement between the community agency, the parents and Partners in Parenting, even so far as the parents themselves receiving funding from the agency, and they pay directly for the child's residential care. This is happening now in two of our cases, where the parent pays directly with funds that they receive from their transfer payment agency.

The family is involved; they have choice. They were able to decorate their child's room. They work closely with us. We're trying to get this young man into school, because he's been out of school for the last two years.

Government and community agencies need to change their philosophy about families and start working with them on creating opportunities and not continue to fund transfer payments solely based on infrastructure but actually look at the need to decrease the waiting lists that are out there and decrease the community pressures: not

just the people who are waving their hands, but the people who have been on the waiting lists for five, six, seven, eight, 10 years. I think in all of the years that I've been working directly with families, I have only seen two clients who have been at our day program actually get a transfer payment spot—two community clients in all of these years. It is so rare that somebody off the community list actually gets housing support. Families are urgently requiring the support before they drop their children off at hospitals, before they drop their children off at developmental service agencies.

The other piece I need to mention is that there is no entry point for children into the system. For over 18, it's Developmental Services Ontario. We can understand the system. Prior to your 18th birthday, there is not an entry point. In the past, it had been the children's aid society that would look at agreements with families to provide support and care, but that was taken away years ago. Now, at this point, if a family requires support, there are hoops that they have to jump through—not just one but multiple; many years and years and years of hoops—to try and get their child identified for some additional supports, let alone to be brought into some kind of a residential support system. There needs to be the creation of an entry point for a child who is identified at birth right through the system so that families can understand what the system is and know the expectation and know the limitations of the system, so that they can plan with external supports, right?

I know we often hear that the system is saturated. Absolutely it is, but the funding is not being brought down to the lowest level, which is the child or the individual who requires the support. The funding is going to support agencies. The funding is going to support middle levels and agencies, but what we need is the actual on-the-ground programs that will provide the supports to children, to babies, to youth.

There are cases of children sitting in Sick Children's Hospital for years and years and years who—we have presented to take that child with the right support. It would have meant that there would have had to be an agreement with the Ministry of Health and an agreement with the Ministry of Community and Social Services, but boy, that's really hard, to get all the players at the same table looking at one child. In the end, children stay in hospital, and people with dual diagnosis stay in hospital, even though private sector agencies have beds available. When you look at the cost of health versus the cost of residential care, you're talking minimum \$1,200 to \$1,500 a day—minimum—in a hospital setting, and you're talking maybe \$250 to \$300 a day in a private residential care facility that would provide that person with all of the daily care needs that they required, including additional staffing that hospitals cannot provide.

The biggest piece that I bring to this is that individualized funding is essential. Families need to be identified early, and support needs to be an integral part of having a special-needs child. My husband and I adopted a little girl with cerebral palsy. At the age of two, she requires

physical care. She requires all sorts of special equipment. We get a minimal amount of money from Special Services at Home, which is great, and we use every single penny to make sure that she has independence in the community like any other child. Building on that to the next level is really important. Being able to know that when she's 18—she's now 10—and an adult, what is the next step? At 21, she's out of school. What is the next step? Where does the Ministry of Health fit in? Where does the Ministry of Education fit in?

Collaboration is vital for success, and making sure the funding is there, almost attached, when a child is born, and used appropriately for the child's care, not used to build infrastructure around transfer payment agencies and mid-level agencies. Focusing on supporting families and creating resources for families is vital.

In conclusion, OARTY would like to continue to work with the Ministry of Community and Social Services and the Ministry of Children and Youth Services to ensure a seamless transition for children from children's residential care to adult services. We believe that together we can create a holistic, seamless, cost-effective system for adults and children in the developmental services system. The private sector is ready, willing and able to support clients and willing to expand services to continue to support adults.

1200

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

Ms. Christine Rondeau: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation, Ms. Rondeau. It was quite comprehensive. And thank you very much for adding your voice to the process that our committee is going through. Thank you so much. Bye-bye.

Ms. Christine Rondeau: Thank you. Bye-bye.

The Chair (Mrs. Laura Albanese): We are recessed until—

Ms. Sylvia Jones: Can I ask one research question?

The Chair (Mrs. Laura Albanese): One research question.

Ms. Sylvia Jones: The previous presenter, Brenda Parris, from Toronto, made reference to micro-boards in BC. It's a family housing model. I wonder if we could get a little more detail on how they're doing that.

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

Ms. Cheri DiNovo: Yes, and on that same note, the UK model has been mentioned, and the Australian model. It would be interesting to know what they do.

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

Mrs. Christine Elliott: I have one further question; several of the earlier presenters were speaking about it. I think it was Mr. Mick Kitor who was speaking about the process for getting your child into an autism program, and the discharge criteria and the review mechanism. I was wondering if we could get some more information about exactly how that all works. I'd like to understand that better.

Interjection: Not very well.

Mrs. Christine Elliott: Apparently not, but I'd like to know a bit more about that.

The Chair (Mrs. Laura Albanese): Please finish, Ms. Elliott.

Mrs. Christine Elliott: No, that's fine.

The Chair (Mrs. Laura Albanese): Okay. Ms. Taylor?

Miss Monique Taylor: I would also like some information back about PPM 140. We were hearing quite a bit about that this morning. It doesn't seem like it's actually being implemented as it's supposed to be, so some information back on that would be great. Thank you.

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

Ms. Soo Wong: Thank you very much, Madam Chair. With regard to next week, I believe we are hearing in Toronto Monday and Tuesday.

The Chair (Mrs. Laura Albanese): Yes, we are.

Ms. Soo Wong: I want to ask a question through you to the staff. Do we have space, either Monday or Tuesday, to invite—yesterday, we heard a lot about concerns dealing with families with FASD. We have experts at St. Mike's hospital, as we heard yesterday, as well as at the Hospital for Sick Children. Is there room on either Monday or Tuesday to invite these experts, who are in our backyard, to hear about FASD? We really have not heard from the Hospital for Sick Children and St. Mike's. One of the witnesses talked about a St. Mike's program. I want to ask that question, Madam Chair, through you to the staff about next Monday's and Tuesday's schedule.

The Chair (Mrs. Laura Albanese): Do we have room?

The Clerk of the Committee (Mr. Trevor Day): As it stands now, Toronto is being scheduled as we speak. We have 42 spots available over that time. We've asked for a third of those spots from each of the parties, and your selections are being contacted right now and asked if they can appear.

If you would like to invite someone specifically in for a period of time, it will reduce one of your selections or three of your selections, depending on the time. It would be something that is up to the committee to determine, if they'd like to pull off one of their selections, or a portion of time, and replace it with, in this case, an invitee for the committee.

Ms. Soo Wong: Okay.

The Chair (Mrs. Laura Albanese): Would we have time to invite them—we can't meet again—when once we finish the hearings, we're not allowed to meet until the House resumes?

The Clerk of the Committee (Mr. Trevor Day): That's correct. The committee will have used up the days allotted to it by the House.

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

Ms. Cheri DiNovo: I would just suggest to Ms. Wong that maybe you use those as a couple of your picks.

Ms. Soo Wong: Okay. Well, my other comment, Madam Chair, is that if that's the case, we can rewrite. If

there's no time allowance, I have to see what our picks are.

With respect to the issue of FASD, we consistently heard concern about FASD yesterday, so if we could write to St. Mike's and the Hospital for Sick Children.

I also know—and I think one of the witnesses yesterday also commented—about children in care who are currently with FASD. There are experts, there are agencies, currently in Ontario that could shed some light and provide some best practices to this committee. I think it would be due diligence for this committee to hear from these people, whether in person or in writing to this group.

So I will follow up, Madam Chair, with the researcher—I have to look at the list—and then the second piece is to get some written submissions from these experts. I just wanted to note that on the record.

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

Mrs. Christine Elliott: Just another possible consideration with respect to that. I know we have a deadline for the submission of our interim report, but we will have another opportunity following that to investigate any other topics that we think need to be followed up on. So that might be an opportunity post-February 19 to call some witnesses in, to see if they'll come and speak to us to answer some of the additional questions that we have.

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

Ms. Mitzie Hunter: One of the questions, the first time I heard it in listening to all of the presenters, was on the issue of race and racism and getting the sector to be responsive in a cross-cultural way. I hadn't heard that before; it has not been raised. So I don't know how we explore that—maybe getting back to Brenda Parris, because it was something that she made as a comment. But I have noted that, because it was the first time that it's been raised for us.

The Chair (Mrs. Laura Albanese): Okay. We'll adjourn for lunch, and we'll continue to discuss later. We'll be back at 1 p.m. in this room.

The committee recessed from 1206 to 1303.

MS. CINDY WALKER

The Chair (Mrs. Laura Albanese): The committee is resuming its session.

Good afternoon, Cindy Walker; thank you for being with us today and for adding your voice to the work of this committee. You may begin anytime you feel ready. You have up to 20 minutes for your presentation. If it should be shorter, then we'll divide the time equally amongst the parties for questions. Thank you.

Ms. Cindy Walker: Committee Chair, committee vice-chair and honourable members of Parliament, I would like to thank you for the opportunity to address the committee. My name is Cindy Walker, and I am here today with many different perspectives. Formally, I have had roles in the health care field, specifically in complex continuing care, acute care and long-term care, as well as

roles in post-secondary education. Today, however, I speak to you as a mother, advocate and legal guardian of Jeremy Walker. I must say it is very hard to present a life in such a short time frame. As I talk, I will also be a voice for my son Jeremy, my husband Ron, our son Daryl and our daughter Crystal—they happen to be in the audience there, Daryl and my daughter Crystal.

Our son and brother, Jeremy, is 36 years old. Jeremy lives in an apartment in the front of our home. My story is not unlike others you may have heard or will hear in the next few days. I am sure, though, that themes will be similar. Jeremy was born in an era where autism was rarely heard of and poorly understood. Jeremy's preschool years were filled with many questions as to why he was the way he was. Many specialists and experts were involved. Over the years, these individuals could not understand or describe why our little boy behaved this way.

When Jeremy entered school, the questions continued. However, formal testing would not begin until he was eight years of age. During this time, speech therapy was started, and we were told perhaps we were dealing with dyslexia. Our boy was different, but we managed as we could. It was not until he entered adolescence and needed to move to a secondary educational facility that we were required to have more expert and specialists involved.

My husband and Jeremy's siblings loved Jeremy as he was. We were led to believe he was mentally delayed and accepted him as such. Yet the school system did not understand his behaviours and demanded further testing. We were referred to a short-term assessment and treatment centre. Jeremy failed miserably; he required sameness, and he didn't follow the direction given to him to attend programs. This led to physical restraint, and he regressed and did not respond at all. No one knew what to do and what was wrong with our Jeremy.

At the age of 15 years old, Jeremy moved to an adult psychiatric facility. It was during this time that chemical therapy was started. We were not allowed to let Jeremy be as he was, as we were informed he had a "major psychiatric condition and he was in need of treatment." I was told I was in denial and my son "would need medications for the rest of his life." During his treatment, Jeremy became very ill. He suffered from neuroleptic malignant syndrome, precipitated from his treatment medications. Sometime into his treatment, he developed a tardive dyskinesia. I was told this condition may never go away. Fortunately, it did over time.

I brought him to London, Ontario, for further assessment and, to my dismay, more chemotherapy was started. At this time, I was told he would not be able to go home as he was too ill. I did not believe this so I brought Jeremy home. He was 17 years old. He suffered from medication-induced delirium, and it was at this time, after numerous diagnoses and chemotherapy to accompany the diagnoses, that I decided to discontinue Jeremy's prescribed treatment, as it was putting his life and well-being in jeopardy.

At the end of his 17th year, Jeremy was diagnosed with autism. I was introduced to Wesway, a respite

agency. At the age of 18, Jeremy wanted to become independent and live away from home. He moved to a one-bedroom apartment. We had some supports in place for him through the Wesway agency, but this proved to be inadequate. After another trial in a small one-bedroom house failed, Jeremy moved back to the family home.

We moved with Jeremy to the country, where we reside today. Our family was in need of more support at home. I was told I was at the maximum number of hours and this would not be possible. Our son was growing up and difficult to handle in the community. Our younger son Daryl was 16 years old at the time. Being a young male, he was in charge of running after his brother. Not unlike other autistic young men, Jeremy would walk and run for miles. He had no concept of time or distance. However, he could not find his way back home and would get lost frequently. We feared for his safety in the community, but the worst fear was being in an institution, medicated and restrained. This was no life for a young adult. We were in need of help.

When Jeremy was 19 years old, we were told about a pilot project, called the Choices Project. When I called to ask about the project, I was informed that the pilot was over and if I wanted in, I was to find someone who already had funding in the project. After months of advocating and many letters and phone calls, I was told we were able to have some funding to hire staff to look after Jeremy at home. We were excited to have some funding to pay the staff. We were happy to be able to do a shared-care arrangement, where we would be part of Jeremy's life but could hire the staff we needed to keep him safe and secure. I wish I could stop here and tell you how wonderful things were, yet I need to continue.

1310

More assessments were required, and the experts and specialists came, once again, to our home. Many questions followed. When I asked why we were being assessed again and again, I was told, "Things change, and Jeremy may get better with the proper treatment." We needed to explain our story over and over again. Our story about requesting supports is lengthy. I can tell you, though, that it was and is a demoralizing process. The process was and is humiliating to our family. The inadequate funding was harmful to all of us in the family.

Jeremy's brother, Daryl, requested to speak to a representative of the Ministry of Community and Social Services. He was not able to continue his high school education, as he was helping our family care for Jeremy. He was not able to talk to anyone. The door of communication was closed to him.

A few years ago, we were required to have a team of behavioural specialists in our home in order to maintain our funding. Medications were offered once again—the same medications that were trialled with disastrous results in the past. Once again, I had to explain what had happened, and I was told, "It may not happen again in another trial." This time, I held my ground and I refused. I requested proper experts from the Geneva Centre.

It is important to note that my funding was always in jeopardy if I didn't open my home to whomever the

Ministry of Community and Social Services wanted to send in.

“Creative options” is a term frequently and continuously used by MCSS. I was once told of a creative option by a Lutheran Community Care Centre program manager. She proposed that we build a cage outside my son’s apartment door to save money for overnight staff. She wanted it high enough so he couldn’t climb over top of it and locked to keep him in. I am saddened.

One time, I asked how much money it would cost to look after Jeremy elsewhere; I was shocked to hear three to four times the amount that we were funded at the time.

The system wanted us to explain over and over again, year after year, just what Jeremy’s behaviours were, to look at strategies to cut his support costs down.

Fortunately, for years, we had a planner who listened to our story and fought as much as she could, telling our story and advocating for us. Now this planner has left, and we begin a new journey with a new specialized support coordinator. In a recent communication regarding funding renewal, this support coordinator stated, “I am open to sitting down with you and/or Cindy to discuss and brainstorm other ways to save or look at low-cost/no-cost service to add to your team of supports,” and, in another communication, “I am available to assist with planning for other resources and supports creatively.” We are back to square one.

I’m going to do an add-on here that’s not documented in this paper. We have done creative options since this little boy was born, to the point where we are in severe debt. When we didn’t have the proper funding, we needed to keep him out of the psychiatric institution because he was at risk, so we took him out of there and we had to support him. I couldn’t work; I had to stay at home. It took two of us, because he was such a challenge. To support the family, we had to keep on going back to school to live off of OSAP. I went to school for another five to six years. I have three degrees now, but I also owe a lot of money. We did that until I was able to advocate for the supports that I have now, which enabled me to start working again in 1999. That’s when I started work again. So I just needed to talk about the creative options that we have done and what it’s done to our family.

As I was saying, we are back to square one. It is funding negotiation time. My husband, Ron, developed a new budget to include WSIB increases as well as a wage increase for staff that are making many dollars less an hour than any other agency in the city. Responding correspondence from a representative of MCSS replied that IF budgets have been frozen and increases have not been accepted. We have been informed that there is no appeal process. I have that correspondence if you’re interested. My husband and I are always on edge at this time of year: There is never a guarantee of funding for Jeremy. Our son will be as he is, and no amount of medication or treatment will change that. Why is there always the need to fight for and justify our funding every year? We feel we have developed a very cost-effective and innovative model of support for our son.

The following are our recommendations:

- facilitation, coordination and integration of health services in the community for individuals with developmental disabilities;

- development of a community outreach program to ensure timely access to service for those who have a developmental disability

- development of a system to monitor needs of informal caregivers of those with developmental disability;

- recognition of families who choose to develop and maintain innovative models to keep their loved ones supported in a home environment;

- support for the informal caregiver when they take on the role of coordinating services in the home;

- funding should be directed into the health care system to train hospital personnel. It is very, very difficult for persons with developmental disabilities to get the proper medical care—very difficult;

- the Ministry of Community and Social Services should be more welcoming of families, in particular siblings, that want to share their stories. There should be more of an open-door policy;

- more funding into emergency respite for siblings assisting with family members with disabilities;

- access to grants and bursaries for siblings that live with a family member with a developmental disability; and

- continuation of individualized funding for residential supports so more unique innovative models can be developed by families.

I have given a brief overview of my family’s journey through developing systems. It is my hope that others will learn from these experiences and not have to go through the same pain and suffering as my family had to. I look forward to a more receptive partnering of families and the service system. To this day, my family and I continue to be challenged on support decisions as opposed to partnering together to nurture our gifts, strengths and contributions. Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you for sharing with us the difficult times that your family has endured. Thank you for your courage, for not giving up and still fighting for Jeremy. We have only about a minute for each party to comment. Miss Taylor, I’m picking up where we left off in the morning.

Miss Monique Taylor: We don’t have a lot of time. Thank you for being brave enough to come here to speak to us today and for sharing your story with us. Your life is hard enough already, and to come and have to spell that out to us is not an easy thing to do. We appreciate your time and your energy for being here today.

Ms. Cindy Walker: Thank you.

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

Ms. Mitzie Hunter: I also want to say thank you so much for your openness and sharing your story. Our goal here, what we’re trying to do, is to put together a series of recommendations that will help improve the system for individuals with developmental needs and to ensure that there is a coordinated system of supports across their

lifetime. I want to thank you for sharing your story and Jeremy's story with us today.

Ms. Cindy Walker: Thank you.

1320

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

Mrs. Christine Elliott: I too would like to thank you very much, Ms. Walker, for being here today. We know that this isn't easy for you, to share your family's story. All I can say is that we appreciate the fact that you took the time to be here, and that we take your concerns very seriously. We know that families like yours are exhausted and stressed beyond measure. We want to do something meaningful at the end of all of this to make your lives easier and to allow your son, in your case, to have a happy and productive life.

Ms. Cindy Walker: Thank you.

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

MS. MARILYN LEITERMAN

The Chair (Mrs. Laura Albanese): And now, we call on Marilyn Leiterman to come forward. Good afternoon.

Yes, Ms. Wong?

Ms. Soo Wong: Madam Chair, just before we have the next witness speak: Given the recommendation from this witness about the siblings issue and support, can we ask staff to get some data from MCSS with respect to funding and support for siblings, and what the resources allocated to families with siblings are? Because this is the first we've heard of this concern.

The Chair (Mrs. Laura Albanese): Yes, okay.

Ms. Soo Wong: Let's get some data.

The Chair (Mrs. Laura Albanese): Thank you. Welcome. You'll have 20 minutes for your presentation this afternoon. Should it be shorter, that would allow for some questions from the committee members. You may begin any time.

Ms. Marilyn Leiterman: Thank you, Chair and assembly. Thank you for this opportunity to be here. We had discussed whether I should bring a presentation etc., but for well over a decade I've been dealing with the issues I'm about to discuss, so I'm quite well-versed on it.

I am a parent of five children. Three of them are my foster children and two are bio. Four have disabilities, including FASD, ADHD, ODD, ARND and the gamut—the gamut is large. Through necessity, over a decade ago, I was given this little child and he was undiagnosed with FASD—fetal alcohol spectrum disorder.

Through necessity, and in finding ways to support this child, I went to college. I had to go back to school, and I took FASD education through Alberta. I've really had to learn a lot about this disability. To date, FASD is the most misunderstood and most undiagnosed disability across the board. I spend days, weeks and months 24/7 within the field of FASD, supporting parents online,

creating parents' groups and support groups, and working with support groups.

We still struggle. This is northern Ontario, and a lot of people consider northern Ontario separate from southern Ontario, as sort of another province. We find that there's a lot of difficulty with supports for FASD.

My child is now in grade 4. He still has trouble with the stress of school and understanding what's expected of him. It's very common in persons with FASD to have poor memory, poor cognitive skills and lack of cause and effect, which is learning from their mistakes. He continues to struggle. To get him supports in school—I'm lucky enough, and I say this almost tongue-in-cheek, that my son goes to school with someone with autism. The child with autism has support, so he's able to piggyback with this child.

My son's issues are profound. He is diagnosed with a mild intellectual disability because, just this year, as many of you know, FASD was put within the DSM-5—finally; we've been fighting for that forever.

What I'm looking for here, I guess—I mean, there are many things, but what I see working within a social service field and working with people within it is that these children are misdiagnosed and misunderstood. They don't get the support that they need in school to understand their disability. They're very vulnerable to being bullied and vulnerable to being influenced by others. They very often have poor math and reading skills; they do okay in the first couple of grades and they start falling back, and the gap keeps widening on their education, so they start losing self-confidence.

Then they get into trouble within school, acting out and behaviours, because they'd rather be seen as a bad child than as a dumb child.

Unfortunately, with this disability—I mean, the real definition of FASD is mental retardation in many cases. The IQ under 70 very often happens. But sometimes it doesn't, and I think that's partly where we misdiagnose: if someone has a fairly high IQ, if they come across as well-spoken, they come across that they are understanding what's asked of them, and they actually aren't. They're not understanding a lot of it.

So what I see and what I have parents contacting me about is that the child quits school, leaves school, gets into gangs, drugs etc., and then they are in jail. As many of you know, there's all kinds of literature on the high numbers of persons with fetal alcohol spectrum disorder in jail. We need to stop this. We need programs that have vocational skills.

My children are very talented. However, they are not going to be intellects; they're not going to be academics. They are very skilled vocationally. All of them want to be part of society. They want to learn. We need programs in vocations. We need protection factors put in here. Like the lady was speaking about with her child with autism, the same goes with FASD. I do not want a cage for my children. I want help for them. I want programs where we can work together and help them succeed and where all can be part of society and contribute to society.

My son, the youngest, will struggle throughout his school life. The gap in grade 4 is already increasing tremendously, so his self-confidence level is really starting to sway. And it's weighing on him. He knows he's a little older than the other kids. He knows he can't learn the same as them.

I became an FASD educator. I had to learn about sensory integration. All of these issues affect the brain. We need changes within the physical part of schools etc. A lot of kids can't handle sight, sound; different stimulations affect them. They are not able to focus and study. There are all kinds of things that we can do to help children with FASD.

One of the biggest challenges is that we know that one in 100 will be diagnosed formally with FASD. That leaves about six who will never be diagnosed. They're still struggling with school. People look at them like they're the bad kid, the kid who just doesn't get it, the kid who doesn't care, the kid who doesn't want to participate. Here, they can't handle it. They will never be diagnosed. If they don't have the facial features, if they don't have disclosure from the parents, they will never be diagnosed. However, going into schools and speaking to teachers, there are two to three children within every single classroom who have some issues, undiagnosed issues that need to be addressed for the success of these children. We want success; we're looking for success. We want to work together to find a way, first of all, to prevent FASD, but for those who are affected, we need some programs to help them. It's easy to say, "Okay, I want supports. Okay, I want programs," but we need to discuss at length what those programs could look like, what they would be for their support.

I welcome any questions because, like I said, I've been doing this for so long that I have thousands of things swimming in my head and I might miss some pertinent things that you guys want to know or hear.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation. We have about four minutes for each party and we'll go in rotation. Ms. Wong?

Ms. Soo Wong: Thank you very much for sharing your family's story and particularly your advocacy work for that many years. We certainly heard you.

Now, can you share with the committee, with regard to your school board, what they are doing to support your child from the time your child was diagnosed with FASD?

Ms. Marilyn Leiterman: Sadly, FASD is not in the criteria for exceptionalities, so I'm going into the school and saying, "Here's this invisible disability. Help my child," and I'm getting, "Oh, well, we can only assess two children per year per school because of funding." My son was lucky enough that he had enough difficulties, so by seven years, by grade 2, they assessed him.

I had to be the strength, the advocate, from day one every single year. Three of the boys are going to school and are still struggling. Every single year, I have to go back into the school, address the issues with my children, seek out the new teachers and explain their issues with the teacher in order for them to be helped.

1330

Ms. Soo Wong: My next question is, at the school board level, are you part of the SEAC committee, where you can advocate for system-wide support not just for your family but for others?

Ms. Marilyn Leiterman: I have been in the past. I have some very good friends that are in it. Because of all the work that I do, I had to step back from SEAC.

Now, while I was in it—I mean, they are very creative. The boards are getting creative with working with children with these issues. My problem is, let's diagnose it for what it is. Let's recognize the issue, and let's listen to the parent, because the parent knows. The parent is always pushed to the back of the issue. All the professionals know better and know more—it's the parent that knows. If you have a parent coming in and saying there's something with this child they need help with, then they need help, and that's it.

Ms. Soo Wong: My last question is, in your school board, are parents able to participate and be members of the SEAC committee? Because we heard that parents are not invited members unless they belong to an organized group. I just want to know, from your experience at your current school board here in Thunder Bay, can you or other parents be active members of SEAC?

Ms. Marilyn Leiterman: I have a gentleman here from SEAC. I can ask him directly, because it has been a while. David?

Mr. David Fulton: No, it's an appointment by organization.

Ms. Soo Wong: Okay, so it's by appointment for the Thunder Bay District School Board. Am I hearing that? Okay, thank you very much.

The Chair (Mrs. Laura Albanese): Thank you, Ms. Wong. We'll pass it to Ms. Jones.

Ms. Sylvia Jones: Thank you, Chair. Thank you, Marilyn. You mentioned that you are an FASD educator. I'm hoping you can help me with this: In terms of the school involvement, the school side of it—obviously, one of the things I'm hearing you say is you would like FASD to be considered one of the exceptionalities. Is that right?

Ms. Marilyn Leiterman: Absolutely.

Ms. Sylvia Jones: Okay. What are some other fixes or recommendations that we should be looking at, at the school level?

Ms. Marilyn Leiterman: Well, number one, from the time this child was three—in JK, I was going in, and I would bring sheets into the school to cover up things so that it wouldn't be so distracting for him, so he could learn.

One of their newest policies is to have all work, say, shown on the walls—everything up. We know that children with autism, FASD, Asperger's and many of these disabilities cannot handle overstimulation. They need things calmed down.

If the policy is written by the board, that seems to be it. It's extremely difficult to get in and work for change of any kind that would be beneficial. We've found, with

going in and training in different areas, that what benefits one benefits all. If it's a better study atmosphere, then it's better for all.

There just seems to be—it's extremely difficult to get any change, to be listened to. I'm a professional in this field, and it's still difficult, you know?

Ms. Sylvia Jones: Do I understand it correctly that your children have always been part of the regular stream? There's no separate classroom that they've—

Ms. Marilyn Leiterman: No. The thing with fetal alcohol syndrome is that it's almost a cruel disability in some ways, because there's a lot of intellect going on. However, for the child to bring forth the knowledge and display what they know—it's often stuck up in the brain.

For instance, two of my three boys know they're different, but they sure don't want to be in that crowd of kids that look different. They absolutely do not want to look different. Like I was saying earlier, my son who's one year older than the rest of his classroom is super hyper-aware that he's older, and he does not want to stand out for any reason. These children are hyper-sensitive to ridicule.

We have a lot of information on school shootings etc., of the children, and the background can have FASD. They've been challenged. They've been pushed to their limit. They feel rejected. They feel like they're not part of society and no one understands them and no one cares. They're just very, very explosive at times and reactive to a situation.

I know I'm straying a lot, but like I said, there's years—you're going on.

Ms. Sylvia Jones: Thank you.

The Chair (Mrs. Laura Albanese): I'll pass it on to Ms. DiNovo.

Ms. Cheri DiNovo: Thank you so much for coming and presenting and sharing your expertise.

We've heard from other presenters about FASD—the lack of diagnostic ability of the communities to even get a diagnosis and the fact that it's not covered by OHIP. Those are two obvious things.

You mentioned that you'd like to see programs in place. Can you think of a program that would make a difference? Is there one you can think of that we should be doing right away for FASD kids?

Ms. Marilyn Leiterman: Absolutely. Number one: Listening to the parent on the needs of the child would be your priority. Anti-bullying programs that are starting within the schools are good. Mentoring is more important than anything. If these children have one person who believes in them, who's standing in their corner to help them, it will make a difference for them the rest of their lives. Many of these children are set aside. They're on the fringe. They're misunderstood. They're looked at as odd or weird or different, so they lose any strength they had and they start failing, and then they go to violence, drugs, crime etc. very often.

There are some good cases. For instance, with my youngest, we're hyper-vigilant with everything that we do with this child. But a lot of children will never be

diagnosed. The diagnosis piece is important, but we know that not everyone is going to be diagnosed and they're still going to suffer with this disability for the rest of their lives.

So listen to the parent; listen to the needs of the parent to help the child for the programs.

But I would say, number one, that mentoring would be huge—and looking at the child's ability level and working with them at that ability. I have horror stories of kids coming home and having homework to do, and they're just done. By the time school is over, they're done; they can't do any more. They're made to do homework for the next day, say, and they're super frustrated. They don't want to go to school anymore; they want to quit. So in my household, I say, "No, we're not doing any homework."

The Chair (Mrs. Laura Albanese): Thank you very much, again, for your input to the committee. You have some valuable suggestions, and it helps us to learn more about FASD.

Ms. Marilyn Leiterman: Thank you very much for having me. As far as programs go, I could sit down and probably write out a very long list.

The Chair (Mrs. Laura Albanese): You may want to submit that to the committee.

Ms. Marilyn Leiterman: Sure.

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

SIoux LOOKOUT FIRST NATIONS HEALTH AUTHORITY

The Chair (Mrs. Laura Albanese): We'll now be joined by the Sioux Lookout First Nations Health Authority via teleconference.

Ms. Janet Gordon: Hello.

The Chair (Mrs. Laura Albanese): Good afternoon. How are you?

Ms. Janet Gordon: We're good. My name is Janet Gordon. I'm a director of health services for the organization. With me are Susan Chapman, a health services supervisor, and Christine Sawanas, who works in the MMW—Mashkikiwininiwag Mazinaatesijigan Wichiiwewin—program, which is a program that we are in partnership with Surrey Place to coordinate and provide clinical services for clients in our community.

Can I go ahead?

The Chair (Mrs. Laura Albanese): Yes, you can go ahead.

Ms. Janet Gordon: Okay. We would like to thank you for giving us an opportunity to make a presentation to you about our area, about our organization and about the programs that we deliver for the developmental services.

Sioux Lookout First Nations Health Authority is a regional organization for the communities that are north of Sioux Lookout. We work with 31 First Nations communities. We have approximately 25,000 people that we provide services to—not just in developmental services, but in other health care services that we provide.

Most of these communities are remote, fly-in communities. There are a few communities that are accessible by road, but we provide a varied number of services. We have managed physician services for a community. We have programs like the tuberculosis control program, and we also have mental health and counselling that we provide.

1340

We have other programs, like the community wellness response program, which deals mainly with addiction services. We have a needle exchange program. Then we also have the developmental services program, which is what we're going to talk about, in the areas of transition and clinical support.

We also have hostel services that we oversee and have, so we have accommodations of up to 100 beds for people that need to have additional medical care or tests and that need to come out to Sioux Lookout.

We have a board of directors who are from our communities. We also have a chiefs committee on Health that provides us with support and direction. We work with other health care organizations, such as the hospital Meno Ya Win Health Centre. We work together on new initiatives, or we also keep each other informed with the health services that we provide.

So our program—the MMW program—is such that our money flows through Surrey Place. This program gives us an opportunity to provide clinical and psychological services in terms of assessment and counselling to our clients within the 31 First Nation communities.

We also have the transition program, which is in partnership with Community Living in Sioux Lookout. This transition program is for ages 16 to 24. The program is to increase and strengthen clients' involvement with the community, whether it's in a work environment or a schooling environment, just to support them that way.

We've been doing these programs for about seven years, and plus the transition program came into that and we were able to have that program longer. We've had 109 referrals to date. Now, it could be more in the earlier years. At this point, we have 55 active files between our two programs, and we have two workers who we have within these two programs.

So our community infrastructure, as we talked about, is remote. The way that we deliver care is through Telehealth, and we also have an outreach program where we go into the community.

As you know, most of our communities have poor infrastructure, in terms of recreational activities. We have a poor economic base in our communities, so there is a high unemployment rate in our communities, and people rely on the welfare system. Because of remoteness, we also have a high cost of living in terms of food, clothing, hydro, all those things, so it really affects our clientele.

In terms of infrastructure, we have overcrowded housing and poor housing conditions and problems with adequate access if our clients have physical disabilities as well as developmental disabilities that they might have.

A lot of our issues are that we have individuals who tend to not be identified early with developmental

disabilities, just because there are not enough services on the ground to be able to provide that expert assessment and follow-up. We have a lack of specialized community services for all of our communities. They could also be misdiagnosed.

The school programs don't have adequate programming that would better support people with developmental disabilities. Most of our communities also have limited school access. Some of our communities only go up to grade 8. There might be some that go up to grade 10. Very few go up to grade 12, so if people have to go to school past that, they have to leave their home to do that.

Those are some of our issues. Certainly, the high cost of food also leads to poor nutrition, and we also have no means of providing respite services to families that have family members who have developmental disabilities. Just on that—and with our communities, I don't know if you're aware of this, for the last 15 years, I believe, we've had a high number of suicides in our communities. I think we probably pretty much have—maybe 300 suicides and a huge number of suicide attempts.

In the last five years, we've had huge issues with addiction, mainly around a huge increase in OxyContin addiction issues in all of our communities. With these areas, it really has impacted on people who are marginalized already in our communities in many ways. So when they are in a family that has these issues, then they're pretty much further compromised in terms of their well-being and safety.

The other issue that we also have is certainly FASD; it's a significant issue in all of our communities. Certainly, poor diagnoses or late diagnoses—and it's due to a lack of resources that are available to our communities, whether it's expertise or whether it's on the ground to support these communities further.

I guess there is a systematic issue of not having enough resources for our program on the ground, and that we're trying to provide services to 31 communities with two people, supported by a team from Toronto, and that we are stretched to deliver service and at least trying to monitor the clientele that we have.

1350

Certainly, one of the other issues that we also have looked at that we have issues with is around training for our staff, as well, that's limited in this area.

That's a really quick overview of our program and some of the challenges that we have and the gaps that we see in our communities.

The other thing that I should mention is that one of the huge issues also is language. What happens in our communities is sometimes when people are born with developmental delays—a lot of times they end up with their grandparents, and their grandparents only speak their language, so certainly there are issues around language barriers in terms of providing support to that family. A lot of times, when people end up, say, in the justice system, if they are removed from their communities and then end up in jail, it's something with no support, and it certainly creates a lot of other issues in terms of removing them from their home and things like that.

Navigating other systems like health care, mental health services and developmental services is, I think, even more challenging for these people who are our clients, to navigate the system, and sometimes their families are not able to support them in that area as well.

Certainly, I think we don't have anybody on the ground who could support these families. We do it by visiting them at home or talking to them on the telephone or doing it through Telehealth, but nobody to provide them with ongoing support if they need it right at the community level.

The Chair (Mrs. Laura Albanese): Thank you, first of all, for illustrating so well the services that you do offer and the challenges that are faced by the community that you serve. We have about a minute each. Ms. Jones.

Ms. Sylvia Jones: Very quickly, I wonder if you could share with the committee where the diagnosis takes place. We've heard a lot about FASD, but whenever you are trying to assist families and children, where is the diagnosis happening?

Ms. Janet Gordon: In terms of FASD, the diagnosis happens for our current clients through Surrey Place. I guess FASD could be one of those diagnoses, right?

Ms. Sylvia Jones: Yes.

Ms. Janet Gordon: We used to have an FASD program, which is not in existence any more. I know some of our physicians have gone ahead and have gotten extra training around FASD, so they might diagnose and do a referral based on their knowledge. Then we have a local support which is called Firefly, which could also do some diagnosis up here.

Part of the problem around developmental delay for the support or service that we're trying to do is non-insured health benefits which are funded through Health Canada will not fund for people to get assessed or people to get treatment around that area. So that's a huge barrier, whether it's from birth or whether people are needing help right now as they get older.

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

Ms. Cheri DiNovo: Just a quick question, and thank you so much for your presentation. What one thing could we do to make your job easier? Is there one thing that this committee could recommend, if you could put that forward?

Ms. Janet Gordon: I think one recommendation, I guess, would be that we would have a more robust system for supporting people, whether it's at the community level or whether it's at the referral level here in terms of treatment or whether they need to be in a group home situation.

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

Ms. Mitzie Hunter: That was going to be my question.

I would like to ask, if you could put your recommendations in writing to the committee, regardless of which level of government is responsible, and put that forward to us, because I think that there are many issues here that need to be unpacked and that should be addressed.

Ms. Janet Gordon: Yes. We could do that certainly. We'd be happy to do that. When would you expect that by, just so that we—

Ms. Mitzie Hunter: In the next couple of weeks. The committee will continue to do its work over the course of the next few weeks.

Ms. Janet Gordon: Okay.

The Chair (Mrs. Laura Albanese): Within the next couple of weeks would be great.

Ms. Janet Gordon: Okay. I mean, we have most of it in writing, so I don't think there's much to it, I think; reformat it and make our recommendations really stand out for our communities. That'll be good.

The Chair (Mrs. Laura Albanese): That's fine, and thank you again for presenting this afternoon.

MS. DIANA BRAMMALL

The Chair (Mrs. Laura Albanese): We now welcome Diana Brammall. I hope that pronunciation is right.

Ms. Diana Brammall: Yes, it is.

The Chair (Mrs. Laura Albanese): Good afternoon and welcome to our committee.

Ms. Diana Brammall: Good afternoon.

The Chair (Mrs. Laura Albanese): Where are you calling from?

Ms. Diana Brammall: I am calling from the big village of Highgate, Ontario. I am about 45 minutes west of London.

The Chair (Mrs. Laura Albanese): Okay. Welcome again. You will have 20 minutes for your presentation. Should it be shorter, that would allow for questions from the committee. You may begin at any time.

Ms. Diana Brammall: Good afternoon. My name is Diana Brammall, and I am a parent, sister, community member and advocate. I would first like to thank this committee for undertaking this important review of supports and services for the disabled population. I will not be going through my original submission page by page due to time constraints, and will focus on the systemic issues that have caught my attention during the past 16 years of accessing supports and services for my brother who has Down syndrome.

My brother also has anxiety disorder and is deemed non-verbal due to unintelligible speech. He wears bilateral hearing aids and uses a Telus smart electronic speech output device to communicate outside of his immediate circle of family and friends. My brother will turn 20 this summer and has been in my care since he was 39 months old. He was transferred to my care from family services in Nova Scotia to Peel region in Ontario.

Our first meeting with our family's physician set the course for the next 10 years of my brother's life and was instrumental in the huge gains he made during those first 10 years in my care. Family health teams were not yet developed but my family physician worked in a multi-physician office and was one of the first to become a family health team, once they were implemented.

The first question the doctor asked me was if we wanted the team approach or the community approach. The team approach would mean a referral to SickKids in Toronto, and they would assign all specialists, or we could choose our own specialists in the community and be referred to Erinoak. We chose the community approach as I already had two children who had accessed varied community pediatric specialists and I was comfortable with our quality of care.

All individuals receive their diagnosis from a member of the medical community. I would stress that the starting point for data collection is with the medical community. A central reporting body for doctors and clinicians to report a new DD diagnosis would ensure that all individuals are represented in the data. Conditions that are not present at birth but are diagnosed at later stages of development, such as fragile X or autism, could then be captured in the data collection process, giving a truer picture of the numbers of individuals requiring services.

1400

Another critical area is communication between patient and doctor, especially for those with verbal communication disorders. The use of PIC symbols in the medical community is a wonderful tool that is fully implemented and utilized in the United Kingdom.

My brother was fully integrated through elementary school, and his therapy supports were coordinated by CCACs through the various therapists at Erinoak. This is not the same standard across the province. In Chatham-Kent, the therapists are coordinated and employed by CCACs. The regional children's treatment centres and Bloorview offer services to our population that cannot be matched in terms of expertise.

Erinoak was a lifeline for our family and offered access to one of the most important aspects of supporting a child or adult with a developmental disability, and that was a behaviour therapist or behaviour supports. Two of the most important people in my brother's life, in terms of our family understanding him, were the behaviour therapist and the developmental pediatrician that were available to us the entire 10 years we lived in the region of Peel. Since moving to Chatham-Kent, those two very important pieces of our puzzle are missing.

Satellite programs are already utilized in many medical facilities and would fill an immediate void for these services in our area. Investing in expanding the services offered at the treatment centres and removing the age restraints for funding would open up a wealth of talent, ideas and resources from a diverse group of expertise and specialties. An expansion of these services would also serve the non-verbal population that is virtually eliminated from services once they turn 18, if you reside outside of the GTA.

As a member of the special education advisory committee for the Lambton Kent District School Board, I was extremely dismayed to see the interpretation of policy directives by board administration. Although legislation and policies are specifically put in place for equal access, the move between school boards was an eye-opener for me as an advocate.

To say the school boards have absolute control over their individual jurisdictions is putting it mildly. In spite of all the issues that my brother experienced within the Lambton Kent District School Board, to this day I have not had a personal conversation with the man at the top. The superintendents and directors act like a bunch of ruling-class kings who don't need to concern themselves with the peasants. This is a direct contrast to the relationships with the board personnel at the Peel district public school board.

The systemic issue within the school system is not due to a lack of policies or legislation. It can be directly attributed to the beliefs and attitudes of the school board leaders. Access to services should not be dependent on the beliefs of a small group of leaders.

My written submission goes into greater detail of the systemic issues my brother faced, once relocated to the Lambton Kent District School Board, and they include access to services that you have already heard are fully funded by the Ministry of Education, such as hearing equipment and communication aids.

In our 10 years with the Peel board, I only had to advocate on my brother's behalf twice, when new principals came into the school. Since moving into the Lambton Kent District School Board, I have had to use my skills as a union president to get services, and it has been a continuous, ongoing process that won't end until he graduates next year.

Although I haven't made contact yet, I will, in the next six months, be connecting with St. Clair College in Chatham. They currently have a program called Options, which is targeted towards those with developmental disabilities. Unfortunately, this program is only available to approximately 15% of the disabled population that it is intended to serve, as the prerequisites to qualify for the program eliminate any individual who requires support to travel to and from the college.

My brother has expressed an interest to go to college. My other children have gone to college, so my brother sees this as a normal part of life and growing up. He will apply to St. Clair College, and although he does not have enough Passport funding to cover his entire support needs to attend as a part-time student, we will, as a family, ensure that he is still able to access the opportunity. I don't expect this to be an easy request, but we'll rely on the Ontario Human Rights Code to argue his right to attend, if it's necessary.

I have been following the Law Society's review of our consent and capacity legislation with great interest. I am in a different position than most of your presenters who are parents, as I am a sister, and the federal laws for the RDSP did not mention siblings in their definition. I opened my brother's RDSP the year after they were first offered and have enjoyed watching the balance grow quickly with the federal bond and grants that are applied, along with our own contributions.

Once my brother turned 18, though, in 2012, the law automatically determined he was an adult and the bank sent a letter requesting to make him the plan holder. This

is not possible, as he is not contractually competent. Because the federal legislation did not specifically name siblings, I would require legal guardianship to continue as the plan holder. As a former union president, I have an issue with taking someone's rights from them and was frustrated with trying to explain to the bank that I could not, in good conscience, take away his rights in order to protect them.

I then contacted a lawyer who specializes in disability law and was advised to just wait it out, as the legislation I was seeking was going to be forthcoming in the new year. I did receive a letter this past October from the bank, informing us that a letter from our doctor explaining that my brother was not capable of managing his own finances would be sufficient to have me continue as plan holder.

I will be purchasing a house in Chatham for my brother so he has the option of living in the city or in the country as he matures. I am hoping the new consent and capacity legislation will help in the process of arranging his life with the same legal protections that are afforded to the rest of society without removing those very rights I am trying to protect.

I mention the house purchase because if you review the legal process of purchasing a home, how does one, without the legal capacity for consent, sign for a mortgage? How do they build a credit rating? These are the types of issues that I will be facing in my attempt to set up his life and not impact my own financial situation negatively.

PLAN Canada is an effective resource for families but is not available across the province. PLAN is affiliated with professionals who deal specifically with our population. This is a very important piece of the puzzle that is missing for many families: the ability and knowledge required to plan for a person's entire life, covering all aspects of financials, taxation, will and estates, RDSPs etc. You need a different expertise than what is available generically. PLAN brings those professionals together and offers the resources to parents in easy-to-understand workshops that are accessible online and in person.

The first page of my submission is entitled *Developmental Services: Two Regions, Two Realities—the Numbers*. As a chief negotiator against a large multinational corporation, my research usually includes a review of financials. When I reviewed the CRA website for charities and funding provided to the three Community Living organizations I've had experience with in the past 16 years, I was absolutely dumbfounded. The discrepancy between the two jurisdictions is blatant and unacceptable. We cannot, as a society, continue to throw money at agencies and institutions that show absolutely no regard for the public purse.

I contacted Community Living Chatham-Kent on numerous occasions to get further clarification on their posted numbers, but was given the runaround by the executive director and HR manager.

Brampton Caledon Community Living has their information readily available and provided answers to my

inquiries immediately. Again, if I look to legislation and policies of the ministries and the agencies themselves, I can see that the language is there to correct this blatant misuse of public funds, but what I can't find is someone who is willing to do anything about it.

On page 21 of my submission, you will find a list of all the individuals who I sent a copy of my submission to. From that list, I have only heard from the St. Clair Catholic school board, the MCSS and this committee.

The St. Clair school board was concerned about the lack of coordination in our municipality, and they do their best within the confines of those powers. They are more successful at this than the public board.

The MCSS thought I had sent the submission to them by mistake. When I elaborated that the issues contained within were largely within the jurisdiction of their office, I was given a thank-you and have not heard anything since.

Families are grateful that the institutions are closed. I had a family member who was in Huronia when we were children. She was a few years older than me. The conditions we would find her in when we visited made a lasting impression on me that I never want to see repeated for this population again.

For most parents and caregivers, we don't care for our children with the thought of, "I can't wait for them to move into a group home." For most parents and caregivers, this comes at a point of crisis. That is a very important point that I cannot emphasize enough. Group homes and long-term-care facilities are not where we dream for our loved ones to be. It's where they end up because that's all that is offered as a solution to our long-term issues of, "What happens to them when I am gone?"

I have had a very difficult time attempting to understand the process for accessing services through DSO. When we apply, we are assigned to box headings such as community participation supports, residential supports or person-directed planning etc. Each of these box headings also has subcategories, such as "Passport" under community participation supports, and "group living" under residential supports.

1410

I have been unable to get a straight answer to my question from any agency or ministry and was only told by the MCSS that if we were not interested in group living residential supports, then our name should not be on that list. I had to argue with our DSO representative to have my brother's name removed from the group living subheading check box. I'm the only individual in my extended group of disabled caregivers who has removed their loved one's name from the list. I point this out because when the government released the \$42.5 million, my brother's Passport amount was increased significantly. It more than doubled. I was excited and immediately started contacting the other disabled caregivers and was surprised and perplexed that none of my peers, many who are near crisis themselves, were not included in the same financial windfall that my brother received.

There needs to be more and better communication from the MCSS about the changes that are taking place.

Our area has not had a presentation to explain any of the workings of this new system since late 2011, early 2012. Why was my brother's Passport increased and not others in my community with a greater need? Why is the priority access system in our area offering day program spots to students who are still eligible for two to three years of more schooling through the Ministry of Education, while students who have recently graduated sit at home and do nothing? Is this considered a collaborative effort under the MCSS? These are questions that I have been unable to get answers to.

I have read the Hansard transcripts for all the select committee meetings that have already taken place, and I would like to speak to the union side of this issue. I would like to reiterate that families don't seek group home living. It is the only option that most know is available. I would also like to point out that there are other ways to maintain a unionized skilled workforce without having a physical work location to be organized out of. Standards of care are increased when we have well-paid, full-time educated staff. A union helps ensure that those standards are maintained.

Many caregivers are here with me in spirit today from my community of Chatham-Kent. We thank you for your time.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. We do have about two minutes for each party to comment or ask questions. It would be Ms. DiNovo who would start this round.

Ms. Cheri DiNovo: Thank you, Diana, very much for your presentation. I have a question related to the point you were just making in the last moment there. When I was in Sweden, there was a program there where unionized—this was a care-at-home program, assistance for families who wanted to maintain their offspring or their brother, who have a family member with developmental disabilities, but they were unionized and they were supervised. But they were homeworkers. Is that what you are pointing to, that kind of system?

Ms. Diana Brammall: That is the exact kind of system that I'm referring to. I have made contact with Unifor to discuss starting a community chapter for just such a thing.

Ms. Cheri DiNovo: Thank you.

The Chair (Mrs. Laura Albanese): Any further questions? Ms. Wong?

Ms. Soo Wong: Thank you very much, Madam Chair. Diana, I'm particularly interested to hear more about your frustrations dealing with the Lambton Kent school board, because you went from the Peel District School Board with a pretty good support network for your brother, yet when you moved from one jurisdiction to another, I sense from your comments to our committee that you had lots of challenges. Can you elaborate further with respect to the director and the superintendent, with respect to your advocacy work, but also to ensure that your brother receives the proper resource supports so that he will be successful?

Ms. Diana Brammall: Those took many years to develop. It took me almost four years. It wasn't until last

year, which was his fourth year in the Lambton Kent district school system, where I could actually say he had a successful year and he progressed. It was the first year that he didn't stay the same or regress, and a large part of that was those supports that he lost once he moved into their system. There was no behaviour support. The staff were not trained, or if they were trained, they weren't utilizing that training to deal with these students appropriately.

With the non-verbal population, or those that are deemed non-verbal—my brother speaks; my brother talks. We have conversations. Other people don't understand those conversations, though. So he's at an advantage to true non-verbal people because he is able to communicate somewhat. If it wasn't for that ability to communicate, it may have taken me much longer to figure out where his supports were lacking.

Ms. Soo Wong: Thank you for sharing your story with us.

Ms. Diana Brammall: You're welcome.

The Chair (Mrs. Laura Albanese): Diana, thank you again—oh, we have Mrs. Elliott who would like to say something.

Mrs. Christine Elliott: Thank you very much again, Diana, for your presentation. I was just interested in asking a little bit more about the Passport funding that your brother just received an increase in. I've heard from other families that all of a sudden it has just sort of appeared with no particular explanation. Is that what happened in your case?

Ms. Diana Brammall: Very much so. It consisted of a phone call to say I was receiving more funding, and then I received a letter with the new funding amount and a package explaining the new rules for spending those amounts.

Mrs. Christine Elliott: Okay. Thank you very much.

Ms. Diana Brammall: You're welcome.

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

DUNDAS LIVING CENTRE

The Chair (Mrs. Laura Albanese): We'll now move on to Martha Fox, board member with the Dundas Living Centre. Hello?

Ms. Martha Fox: Hello.

The Chair (Mrs. Laura Albanese): Good afternoon.

Ms. Martha Fox: Good afternoon.

The Chair (Mrs. Laura Albanese): Welcome to our committee. We're ready for your presentation. You will have up to 20 minutes to speak to us. Should the time be less than that, then there will be an opportunity for questions and comments on behalf of the members of the committee. You may start at any time.

Ms. Martha Fox: Thank you very much. Also in attendance with me is Dr. Janice Tomlinson, who is also a member of the board of the Dundas Living Centre.

Dr. Janice Tomlinson: Hello. Good afternoon.

Ms. Martha Fox: The board, our families and our community partners welcome this opportunity to provide

our thoughts and experiences for consideration by members of the select committee. Thank you very much.

Our board is a non-profit charitable organization which represents individuals with developmental and additional disabilities who reside in Dundas, Hamilton, Flamborough, Jerseyville, Ancaster and Stoney Creek. We also represent their families and numerous community partners who have been integral to the development of these individuals as citizens and contributing members of their communities.

For the past eight years, our board, parents, caregiver volunteers and community partners have been working toward one goal; that is, to create an intentional community where individuals with developmental disabilities may transition from their family homes to a residential home in their community where they may continue to attend their day programs, continue to work, participate in volunteer activities and live full and active lives in an environment that is safe and secure and which fosters independence and individual choice.

Parents and families of adult children with disabilities in the Hamilton region, and I would suggest in the entire province, have a common bond: critical planning for the future of their adult children when they, the parents, can no longer care for them. These families know and have been meeting the unique needs and desires of their sons and daughters as a lifetime priority. They are in the best position to design and establish a residential home that will build on current long-term friendships and peer supports within this adult group while utilizing family, volunteer and community supports and paid staff.

These adults currently live with their parents who are in their senior years, parents who are increasingly less physically and emotionally able to care for them. Fifty per cent of these caregivers are on their own. Many have lost members of their extended family who were also providing some care relief or who were part of a future care plan. There is continual stress as parents worry about securing long-term care for their adult children. The need is great and immediate.

The model that we envision will provide a superb community home and be remarkably productive, mutually beneficial and sustainable well under market costs. It takes advantage of currently underutilized vacant space in our community and is based on significant sustainable partnerships with others who are elderly and/or low-income. Being innovative and cost-effective, accessing underutilized space and partnering with marginalized groups in our community are elements which have been dictated to us by the Ministry of Community and Social Services over the past eight years.

1420

Despite adhering to direction from Madame Meilleur, former Minister of Community and Social Services, and more recently initial encouragement and advice from the current minister, Ted McMeekin, our proposal for a residential home as a pilot project, easily replicable in other communities in the province, has been dismissed.

Minister McMeekin has indicated that our model cannot happen and that his ministry has no legal authority

to support our proposal, that doing so would be unfair to those with greater needs. He has stated that fairness demands that places in residential settings be allocated to those with the greatest need and that a standardized assessment process administered in a consistent manner supports the determination of need." He has also stated that though there is a need to seek creative partnerships, any proposal seeking public funds must adhere to the basic principles and legislative requirements of the developmental services system.

I want to offer that all of our sons and daughters have been assessed through a Developmental Services Ontario office and many have been waiting for residential supports consideration for 20 years.

Surely Minister McMeekin realizes that the system is flawed and that no amount of policy creation and money is going to address current housing needs of those with disabilities unless new and innovative solutions are in place to stop the growing numbers of those in crisis in the first place.

Much of our current dilemma is that good public policy and effective service funding of the past has been replaced by huge bureaucracies that force families to fit into existing and inflexible systems and that penalize or dismiss families that are trying to initiate thoughtful and long-term solutions for long-term, sustainable options for residential planning and supports. For a truly equitable system, some individuals may need to be treated differently. An example would be to have a parallel funding route apart from response to crisis which would support families working together with their adult children to create cost-effective residential options that are both economical and reflective of the lifelong care required of their sons and daughters.

Right now these families are forced to engage in planning only when critical situations arise and choice is limited and often imposed. The Dundas Living Centre's philosophy is founded on the UN Convention on the Rights of Persons with Disabilities, ratified by Canada on March 11, 2010, which states that persons with disabilities have equal rights to choose their place of residence, where and with whom they live on an equal basis with others, and that they have residential and other community support services to maximize inclusion and participation in their community.

Our sons and daughters have spoken. They have chosen their place of residence and with whom they wish to live, just as our neurotypical sons and daughters have had the option of doing. We cannot deprive them of this right.

The model of the Dundas Living Centre provides the government of Ontario with one long-term option in assisting people with developmental disabilities, an option that moves 20 people off the Developmental Services Ontario list, that provides safe and affordable housing and, most importantly, is the choice of the adults with developmental disabilities, their parents and caregivers. Our current system of providing residential supports is based on a response to crisis and urgency.

Our families have been told support for residential planning for their sons and daughters will not be in place unless the parents are dead or otherwise unable to care for them. We have to start somewhere to develop a parallel and sustainable system of preplanning and pre-emptive solutions to the current crisis-driven system. Our families are trying to circumvent a crisis by finding safe and supportive housing for our adult sons and daughters now, when they can continue to contribute fully in their communities. This group of individuals knows each other, supports each other and are amazing adults, but they need help from the government of Ontario. They cannot live on their own.

In 1983, Community Living Toronto proposed a residential model similar to the Dundas Living Centre model. The government would not fund the model, opting instead for a dispersed model of homes with three to six residents. Now we are faced with waiting lists of numbers reaching 20,000 individuals who require residential housing.

“Ontario must move beyond the crisis-driven system that has essentially produced the housing crisis now confronting adults with developmental disabilities and their families.” That quote is from *Ending the Wait: An Action Agenda to Address the Housing Crisis Confronting Ontario Adults with Developmental Disabilities*, from the Ministry of Community and Social Services, September 2013.

Chris Beasley, chief executive officer of Community Living Ontario, wrote in a letter to me last October, “When I first got into this field 15 years ago, I thought that group homes were the only option for our kids. I now realize that there are a range of other possibilities. Unfortunately, scarce dollars and long waiting lists make these options difficult to realize.”

We are suggesting that other models, such as the Dundas Living Centre, should be considered by the government and could be considered as pilot projects, with a research base to find out the strengths and needs of the model and to determine criteria for ensuring success. This option has the potential to significantly reduce the waiting lists referenced by Mr. Beasley and at more than 40% less cost per year than the traditional option of group home residence.

The Ministry of Community and Social Services needs help to make decisions that support ideas which are creative, passionate, make common sense and economic sense, and are in the best interests of our most vulnerable citizens.

Premier Kathleen Wynne stated in April of this year, “Families are very innovative, and if we can find a way to put resources in families’ hands and have families working together with professionals, we can provide the right programming.”

In March of last year, Minister McMeekin said, “The government has obligations to find new and creative entrepreneurial ways to house the developmentally disabled, either individually or in clusters. Maybe regulations or laws need to be changed.”

We hope that both the recommendations of this select committee and the expected Ombudsman’s report move the province in the right direction and do so quickly. Thank you.

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

We have about three minutes for each party to respond. To the government side.

Ms. Mitzie Hunter: Thank you so much for your presentation and for the work that you and these families are doing to get to the goal that you’ve stated, which is to provide a safe living environment for your children.

I’m wondering about the model that you’ve described—if there are other partners that you’re working with in addition to the families who have come together.

Ms. Martha Fox: Yes, we have been working with—initially it was Contact Hamilton. We have a strong letter of support from them. We’ve also been working with Rotary. We’ve been working with Civitan. We have a partnership with the Sisters of St. Joseph. We’ve also been working with additional contacts with the city of Hamilton. That’s some, just off the top of my head.

There is really no level of government or service group in our area that we have not touched base with and worked with over the last eight years. We have quite a number of letters of support from a broad range saying that this option makes sense, is doable right now, and fully supporting where we’re headed.

The Chair (Mrs. Laura Albanese): Any further questions? Mrs. Elliott.

Mrs. Christine Elliott: Hello, Martha. It’s Christine Elliott. How are you?

Ms. Martha Fox: I’m well. Thanks, Christine. Happy new year.

Mrs. Christine Elliott: Thank you, and to you as well.

Thank you very much for your persistence and the persistence of your group in moving forward with this project. It is truly an innovative solution to a very, very pressing need, and we’ve been hearing about that constantly in our hearings so far.

1430

As we’ve discussed in the past, it seems to be that the ministry’s concern about this is, first, it might be considered queue-jumping, but in fact, many of your sons and daughters have already been waiting for about 20 years for a placement.

Secondarily, there seems to be a concern about the size of the project, that it’s considered too big, that it’s considered to be an institution, and that the ministry is sort of dismissing it out of hand.

Could you comment a little bit more on that for the benefit of the committee, please?

Ms. Martha Fox: Certainly. In long discussions with the current minister, Ted McMeekin, who’s also our MPP and has known quite a number of the sons and daughters we’re talking about since they were young—there has been reference to a waiting list. Most recently, we’ve been told there isn’t a waiting list. It’s actually a pool, and individuals in the pool rise to the top of the pool when they are in crisis or in some type of urgent

circumstance. Then they receive whatever level of support that might be, whatever the residential option may be that makes sense at the time.

Of course, what we've also been told is that there's no guarantee that any residential option that comes out of a response to urgency or crisis is going to be in the community where these individuals have grown up and have jobs and volunteer placements and work and day programs etc.

Again, I guess our issue is that the whole idea of a queue is problematic. To indicate that the only way you get residential support and service is if you come to the end of the queue, or you rise to the top of the queue, with the results then being wholly unsatisfactory—in other words, we've been told before that if something happened to George and I, our son Matthew, who's almost 33 and has been waiting for residential support and planning since he was 18—we've been told we'd have to die for him to get support, and that support could be anywhere. So despite the fact that he is fully engaged in work, a job placement, day programming—and I can go on and on—in his community, he could end up in Barrie, with no connections to his community.

So when we talk about a queue, it's a queue you don't want to be in, because the results of coming to the top of the queue are not good. When Minister McMeekin has talked about jumping the queue, what he's really talking about is that we are trying to step off the crisis/urgent-driven response route and offer an option of preplanning and pre-emptive crisis response. That's what is really being discussed.

What has become very clear to us over the many years we've been working on this is that there is absolutely no landscape—and in some circumstances, no understanding—of why parents want to support getting off the urgent-crisis response route and have the option, perhaps through individualized funding or other kinds of mechanisms, through maybe not only the Ministry of Community and Social Services but maybe in consideration with the Ministry of Health etc., to be able to do this pre-emptive planning that doesn't support only a crisis response.

Mrs. Christine Elliott: So you're trying to head off a crisis, and you're trying to be innovative in your solution in a cost-effective way.

Ms. Martha Fox: Absolutely.

Mrs. Christine Elliott: It seems like a winning solution to me, and I certainly would hope that government would take it on, at least as a pilot project.

Ms. Martha Fox: Well, you know, our son requires significant support. We were told that for him to go into a group home tomorrow, it would be \$175,000 a year. With the model that we have, Matthew would be able to move into the Dundas Living Centre, and we'd be looking at an average cost of \$68,000 a year per resident. That is a huge, huge savings for the province.

The Chair (Mrs. Laura Albanese): Thank you. I believe someone—is it Miss Taylor who wants to comment?

Miss Monique Taylor: Yes. Hi, Martha. Thank you so much for joining us today and for bringing your story

to the table. It's something that, as we've been going through the process—I'm from Hamilton Mountain. I've been watching your case and wondering what the issue was and why it wasn't moving forward. I really do appreciate you coming forward and stating that, really, there is no reason other than your families are not in crisis.

Ms. Martha Fox: That's the bottom line. Minister McMeekin has also most recently categorized us as a private group of privileged parents, as Christine mentioned, who are trying to jump the queue. We couldn't hear anything more offensive, quite frankly.

Miss Monique Taylor: Yes, I can imagine. I think it's quite interesting, and I know the need in our community for these kinds of homes. I know many families who are looking for homes for their now-adult children, and this is just the solution that seems would fit perfectly. We know that we need to look at different solutions for different families, because we're not cookie cutters and we can't all be treated the same, that some things work better for some than they will for others. This sounds like a resource that would work for some families who have the ability to do so. I wish you all the best of luck. I hope that this committee will help move things forward for your process also.

Ms. Martha Fox: Thank you. I just wanted to also—I realized I didn't address the inquiry from Christine about an institution. The reality is when I think about an institution, I think about a place where someone is put and they don't have choice. What we are envisioning is about as far away from an institution as you can possibly get and, quite frankly, if our son was placed in a small home where he didn't know anyone and he had no choice, he lost his job, his day program etc. that would be institutionalizing him, not the model we are considering.

I have a lot more information that I certainly could send that maps out the particular model that we're talking about, but I do want to say to the committee that a great number of parents in our groups were offered institutional placements for their sons and daughters when they were infants. I know we were. Both parents said, "No way, no how; we are going to raise our sons and daughters with the support of our communities." And to now have the suggestion that a model that we are envisioning in any way would be reflective of an institution is an incredible slap in the face. As I've said, it's about as far away from an institution or institutional culture as you can possibly get.

The Chair (Mrs. Laura Albanese): I want to thank you for your presentation and for your input, for presenting to us your plans and this project. We are trying to look at the issues. We're trying to get at the core of the issues in a very non-partisan way and looking at multi-ministerial help, because the reason why this committee has been formed is to find a comprehensive developmental services strategy because of the urgent need that currently exists.

You can send us in writing more about your proposal, and that will be welcome. Thank you, Martha, for your time today.

Ms. Martha Fox: Thank you very much and thank you for the honourable work your committee is doing. If there is anything more that we can do to assist moving your agenda forward, we're most happy to do so.

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

Ms. Martha Fox: Thank you kindly.

The Chair (Mrs. Laura Albanese): We are now going to take a small break. The next presenter has cancelled. We will resume at 3 p.m. sharp.

The committee recessed from 1439 to 1500.

MR. GEOFFREY SHEA

The Chair (Mrs. Laura Albanese): And we are back in session. We will now hear from Geoffrey Shea. Hello?

Mr. Geoffrey Shea: Hello.

The Chair (Mrs. Laura Albanese): Hi. Good afternoon. How are you?

Mr. Geoffrey Shea: Good afternoon. Fine, thanks.

The Chair (Mrs. Laura Albanese): We are here, all ready to listen to your presentation. I don't know if you know: You will have up to 20 minutes to talk to us. If your presentation is any shorter than that, then there will be opportunity for questions and comments from the members of the committee.

Mr. Geoffrey Shea: Okay, great. Thanks very much for agreeing to listen to our story. I'm going to speak about our son, Yoschi, who is 20 years old. He was born with a physical disability, and those limitations led to the creation of a developmental disability.

Yoschi was born with quadriplegic cerebral palsy. He can't use his hands or feet. He can't stand or walk. He can't hold things or point or press buttons. He often experiences a spastic tension throughout the left side of his body. This caused his left hip to become dislocated and painful, which resulted in a surgery. Over time, he developed severe scoliosis, which now makes sitting upright in his wheelchair uncomfortable. Yoschi is also very hard of hearing. He wears hearing aids, but he relies on lip-reading to enhance his comprehension. Because he has very little core trunk support, he has difficulty mustering enough breath to make himself understood when he's speaking, so he talks in a whisper.

As a result of all this, he requires 100% assistance throughout the day and also has to be repositioned several times during the night. Someone has to help him by turning the pages when he's reading a book or clicking the mouse when he uses a computer or selecting the music or TV shows that he wants, in feeding, dressing, shopping, going anywhere, and also, of course, interpreting for him when he needs to converse with a person who's not trained to understand his quiet voice.

In two recent DSO-related assessments, Yoschi was identified as having developmental disabilities, compounding his intense medical and physical support needs. He has missed out on many experiences in life and their related developmental milestones. Since he requires constant care and assistance, he has little sense of independence, privacy, responsibility or autonomy. His

communication barriers have prevented him from making friendships.

These things notwithstanding, Yoschi is bright, cheerful and inquisitive. He's finishing up high school this year, doing a co-op placement, writing articles for a local entertainment magazine. He's working on his second documentary film, about young children who have a fear of thunder. He's interested in languages, particularly etymology and foreign languages. He especially enjoyed native studies and parenting in high school, though he struggled with trigonometry and had to retake the course in order to pass.

Yoschi is now eager to expand his engagement with the world. He's interested in exploring post-secondary education. He's intrigued by the notion of independent living, even though he has so little experience with independence. He hopes to make friends. In general, like many people his age, he's ready to embrace life.

That's the story of where we are now.

The past 20 years have been very challenging but also very rewarding. Yoschi's schools have been very accommodating, providing one-on-one EA support throughout the day. We've been receiving enough financial support so that he can have a few hours each day with an attendant. Of course, his mother and I put in a lot of time, but that's to be expected with raising children, whether it's driving to music lessons or hockey games or helping with homework.

Yoschi turned 18 two years ago now, and with high school coming to an end, we're really starting to experience the long-term ramifications of living with a complex disability, and the prospects are very frightening.

First, though, we received a letter from assistant deputy minister David Zuccato around Yoschi's 18th birthday, saying that he would be automatically transferred to Passport funding. That offer was later rescinded, and we've been on various waiting lists since then and have not been receiving any funding. Once the support provided by the school system is over in June, it seems we will be on our own to plan for the rest of his and, indeed, our lives.

In talks with family support services and DSO and other parents, it seems that our options are bleak. These seem to be the alternatives: If Yoschi continues to live at home with us, and we're resourceful and lucky, we might be able to put together, through various funding supports, enough so that he can have eight hours of attendant care per day, perhaps five days a week. That would be enough support to allow both of his parents to continue to work, but it means that all of our non-working hours will be involved in providing for his care. In this scenario, he will not be able to continue his education, because we live in rural Ontario. His social life and ability to explore the world intellectually will revolve around the interests and abilities of his caregivers. Our capability to contribute to his day-to-day needs will diminish with age and our own physical abilities. His needs will be increasingly demanding throughout our retirement, which will not be very rich, since both of our careers have been impacted

by the demands of the last 20 years. And when we die, he will have to radically and quickly adjust to some sort of long-term-care facility.

The next alternative that we can imagine is that Yoschi moves to a long-term facility sooner. From what we understand, these range from quasi-independent living facilities, where he might be eligible for three or four hours per day of attendant support, to nursing home-like facilities with greater staff availability but no opportunity for developing or exercising independent skills.

In these two scenarios, I think we can image this bright, curious, charming young man spending the majority of the rest of his life parked in front of a TV.

The final scenario that we can imagine for our son is one in which he is provided with attendant support for the entire day, and where he can make life choices based on his interests and abilities. He could then move to a city, where he could continue his education. He could carry on interviewing people so that he can write articles and make documentary films. He could meet people and make friends, perhaps find love, and contribute to society with his many abilities and strengths. This is really the only viable model of support—the one that I just outlined—but it's beyond what almost any family could provide.

If the government is going to continue to insist that the responsibility for providing services to adults with disabilities falls to aging parents, we're inviting a series of tragic and heartbreaking ends, in many cases.

Still, we have to acknowledge that the severity of Yoschi's physical needs, combined with his developmental challenges, places him at the far end of the spectrum for any care or support system. But support for these individuals should not be considered optional, provided when and if resources become available. This has to be considered a minimum level of social responsibility.

We, as a society, can say that someone who has a level of need imposed upon them by a physical and/or developmental disability should not be further harmed or stifled by inadequate care, but should be provided with the resources that will allow them to access the same opportunities that the rest of us take for granted.

I know that government resources are limited and balances must be struck, but any level of support less than the one that we're proposing here is, in effect, a punishing sentence imposed by the government on the most disadvantaged members of our society.

I suspect that your recommendations to the House will be multi-faceted, including structural modifications and possible policy revisions. But please, I'm asking that you not settle for creating a foundation for change or a framework for improvement. People who are in situations as extreme as Yoschi's require substantial support and the commensurate investments. So please also recommend dramatically increased funding levels as well.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you, Geoffrey, for your presentation. You mentioned that you live in rural Ontario. Where are you calling from?

Mr. Geoffrey Shea: We live in the town of Durham, north of Guelph, south of Owen Sound.

The Chair (Mrs. Laura Albanese): Thank you. We will now move to questions, and we will start with Ms. Jones.

Ms. Sylvia Jones: Thank you, Geoffrey. It sounds like you have made a pretty incredible life for your son Yoschi.

Am I correct in hearing that your Special Services at Home funding was pulled at 18 and now you are waiting for Passport.

1510

Mr. Geoffrey Shea: That's right. As I mentioned, we did receive a letter from the ministry saying that that would not be the case. By the time that letter was rescinded and we were told that we did have to apply, it has taken years of being on waiting lists just to even get the application in.

Ms. Sylvia Jones: A bit of a cruel joke. It's one of the things that we are discovering here, the inter-ministerial challenges. It does beg the question of why Special Services at Home doesn't stay in effect as long as the individuals are being served at home, but I guess we'll leave that to further debate.

Your vision for Yoschi; have you had an opportunity to present that, discuss that, with the DSO?

Mr. Geoffrey Shea: Oh yes. We've had meetings with the DSO, and they have prepared a Passport application for us. As I say, it took a couple of years to get that to happen, but we have recently done that. They've recommended some local resources we might look at. There's a respite care facility not too far from here where we might be able to arrange to drop Yoschi off for weekends. But we're trying to plan for his long-term care and life, a life that, eventually, we will not be involved in. None of the options that have been presented to us look remotely tenable.

Ms. Sylvia Jones: I understand. Thank you.

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

Ms. Cheri DiNovo: Thank you so much, Mr. Shea, for your presentation. I have to say that I was really impressed with Yoschi's achievements in school. I would probably have flunked out of trigonometry, too, just to let you know.

Mr. Geoffrey Shea: Helping with the homework was not easy.

Ms. Cheri DiNovo: I want to follow up on this Passport letter that you got from the ministry: One minute you get it, one minute you don't. When you, which I'm sure you did, asked them, "What's the situation," what did they respond?

Mr. Geoffrey Shea: We didn't ask them about the situation; we just received this letter out of the blue saying that we were getting funding, so we didn't do anything. It said that partway through the following year, we would be contacted about having to update our file and things like that. Then, six months later, we got another letter that said, please contact DSO and get an assess-

ment, and you have to apply for Passport before you can get it.

Ms. Cheri DiNovo: So there was no explanation as to why? Basically, sleight of hand: “Here it is; no it’s not”?

Mr. Geoffrey Shea: I think the follow-up letter said that the initial letter was written in error.

Ms. Cheri DiNovo: Ah. Okay.

We’ve heard from a number of presenters, of course, at this point. One of them suggested that what’s really needed is a system of entitlement rather than a welfare system, where it’s discretionary, like health care: If you go into a hospital, you get looked after if you have an OHIP card because you need it. Would you support such a movement in thinking?

Mr. Geoffrey Shea: Yes, I think so. I think that’s ultimately what I’m looking for, something that, if we determine that these disadvantaged people in our society have this need and have had this need thrust upon them, we need to step up and say that we as a society can take care of that. It shouldn’t be a case of going on to waiting lists that are 20 or more years long or providing services when and if resources become available. I think entitlement is a much better way of considering it than, say, charity.

Ms. Cheri DiNovo: Thank you.

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

Ms. Soo Wong: Thank you very much for your presentation, Mr. Shea. With regard to your comments about your interest for your son to go on to post-secondary, can you share with the committee some suggestions? I think you also shared with us that you’re from rural Ontario and that you are interested in having your son go on to further education. Can you share with us, in terms of support from the Ministry of Training, Colleges and Universities or Ministry of Community and Social Services, how we can help your son so that he can continue on with his education? Can you provide some insight on that part?

Mr. Geoffrey Shea: We’ve started to research what sorts of options are available. I work in the Ontario university sector, so one option that I could imagine would be that he would attend a college or a university. His communication issues are so limiting, and his physical needs are so great, that he would require an immense amount of support, far greater than any student at the university that I’m associated with has ever received. So that might be kind of pie-in-the-sky or wishful thinking on our part.

I gather that there are college programs that are set up and tailored to people who have physical and developmental disabilities. I don’t know very much about them. I think there are some near where you are today, aren’t there? Are you in Sudbury?

Ms. Soo Wong: We’re in Thunder Bay.

Mr. Geoffrey Shea: In Thunder Bay. Okay. I thought there was one in Sudbury.

So if there was a school that had tailored or tailorable programs, that would be an option as well. Doing something through correspondence is a possibility, but it’s not

a very life-expanding opportunity. It further insulates Yoschi from the world, and the insulation that he has experienced in the first 20 years of his life is what has held him back. I mean, the reason that he had so little sense of autonomy, independence or responsibility is because he has been insulated from so much, so I’m eager to see him participate more in the world.

He’s interested in education. Participating in school thus far has been the highlight of his life. He does get to get out. He does have people around him, usually all filtered through his one-on-one EA caregivers. But I think that with the little experience that he’s had, the idea of continuing school is the best thing that he could imagine happening, and I tend to agree. I’m a big proponent of the value of education and lifelong learning, so I’d love to see him continue to expand in all aspects, intellectually and socially, in ways that further education can provide.

Ms. Soo Wong: Okay. Thank you.

The Chair (Mrs. Laura Albanese): Thank you again for presenting to our committee today. We really appreciate you sharing your story, and hearing about Yoschi’s life. Thank you for your suggestions.

Mr. Geoffrey Shea: Okay, thank you. I look forward to seeing your report.

The Chair (Mrs. Laura Albanese): Thank you. Have a good afternoon. Bye-bye.

Mr. Geoffrey Shea: Thank you. Bye-bye.

MS. LOIS HACIO

The Chair (Mrs. Laura Albanese): We’ll now call on Lois Hacio. Yes, take a seat wherever you feel most comfortable.

Ms. Lois Hacio: Okay, thank you.

The Chair (Mrs. Laura Albanese): If you need a glass of water, please go ahead and take one. You may start your presentation at any time. I know you were sitting in the back, observing the hearing, so you’ve heard, more or less, what the rules are. Feel free to go ahead any time.

Ms. Lois Hacio: Good afternoon, committee members. My name is Lois Hacio. I’m here to speak about the quality of assistance for my adult son, who has a mental disability, notably schizophrenia. As well, I would like to talk about housing for the mentally disabled and services provided.

My son is 33 years old. Just a brief history: He had some health problems at age 15, such as chronic rhinitis and tonsillitis, and there were other environmental stressors. At that time, my son demonstrated some abnormal behaviours and so was hospitalized.

Going back to grade 1, his teacher said that he was ADD. He also had difficulty processing verbal information and also had tics from anxiety. She recommended that he repeat grade 1. This affected my son’s self-esteem many years later.

In those days, there were no assessments, and no special education teachers to evaluate or assess children

and give them the one-to-one assistance that he or she requires to be successful in school.

1520

My son had no mental health problems from grades 2 to 7. When my son's health did deteriorate in grade 9, I had to take him out of school, and his high school provided a tutor for one course. When he returned to classes that year, he became catatonic in one of his classes and was sent to the hospital, to a psychiatric unit.

After discharge, I requested a tutor for my son but was told by the guidance counsellor that a tutor was not available and they would not provide one, so I home-schooled him myself to finish his grade 9 and later assisted him with nine more credits from adult education, who were very supportive.

He finished his last credit at the age of 30 and received his grade 12 diploma while in the psychiatric hospital, with the assistance of the social worker, psychometrist and a volunteer. Goal-setting is important for those with disabilities, and it's baby steps to get there.

My son has been institutionalized three times long-term, twice for two years and recently for a three-year period, to finally receive housing in February 2012. At one point, between hospitalizations, my son had an apartment. However, his anti-psychotics were being changed most frequently, so he was never stable.

I worked out of town as a special education teacher at the time, and every Friday evening I would drive three hours to get my son groceries and then return back to work early the next day, on a Saturday.

The case workers at his apartment never recorded if he had picked up groceries on his scheduled day, and workers changed from day to day so I could never find out if he was taken out for groceries. Sometimes he would say that he was not feeling well, which meant that he was having hallucinations or delusions, so he would not leave his apartment.

It is desirable that case workers are present seven days a week in an apartment setting, because if someone with a mental illness needs to talk to someone, a trip to the hospital might be avoided. Also, activities are very important as a part of programming for their clients, ideally seven days a week. Most programs with case workers in an apartment setting are five days a week.

In a psychiatric institution, there is structure, healthy meals and a caring staff trained in mental health. Out in the community, in an apartment setting, there can be a lack of structure or access to healthy meals close at hand, which can cause stress. Community kitchens would be an asset, or delivery of a small meal, such as supper, later in the day. Presently, Meals on Wheels have volunteers deliver a lunch for a fee.

In 2010, my son was desperate to get out of the hospital. I phoned numerous agencies to find housing suitable to meet his needs, because the social worker at the psychiatric hospital said no housing was available such as homes for special care or high supportive housing. There was no suitable housing to meet his needs.

Finally, the social worker at the psychiatric hospital found one place run by the Salvation Army where case

workers ran a program five days a week, and so his name was on the list for one year or longer. He was accepted there after an interview process. We took on the lease, and then I received a call from the psychiatrist's intern, who I didn't know. She wanted to know if I wanted my son's name on a list for high supportive housing. I told her we'd just found a place and that the social worker had earlier told us that there was no high supportive housing.

Later, in a meeting with an assertive community treatment team, otherwise known as ACTT, and my son's psychiatrist, it was recommended that he go into high supportive housing with 24-hour care. The ACTT worker stated that they could not see him as often as needed if he had gone into an apartment—only twice a week for one hour, but every day for med delivery.

My son did not want to go to the high supportive group home because it would be with older adults. He also was sent to a high supportive group home while in the hospital, but he demanded to go back to the psychiatric hospital, as the bathrooms flooded two days in a row and this was stressful for him.

There needs to be a variety of housing available for those with mental disabilities, depending on their needs.

At my son's present address, there are other people living there with a similar illness. Sometimes my son has had anxiety caused from one of the clients in the building, and he has gone to the hospital numerous times on a weekend to talk to someone in mental health. This is more likely to occur when the case workers are not there on a weekend, and he always takes an ambulance. On the other hand, he has made some positive friendships with others in the building.

Since February 2012, I have been assisting my son with housekeeping and laundry, and I also bring groceries or meals to him. I have contacted an intake worker at the community care access centre but was told he wasn't eligible for housekeeping unless he has personal care.

Recently, it was recommended to me to still get an assessment with the CCAC. The case worker at my son's residence had told me a year ago that she would put my son's name on a list with Ontario Works for housekeeping, and it would take a year or so to get the assistance. However, I recently learned that this was not done. When I contacted Ontario Works, I was told that they receive funding for housekeeping for clients, but if the funding was to run out and I was the next one on the list, my son would not receive assistance.

On a positive note, the support of the occupational therapists who have taught my son cooking skills has enabled him to cook on his own. The ACT teams previously had occupational therapists; presently, they do not. At the psychiatric hospital, there are occupational therapists, and it was they who contributed to teaching my son this life skill.

I have thought about the Lights model for supportive housing for those with mental disabilities, and it could work as a good model, provided there was 24-hour support and funding for those who need the support.

Four years ago, I inquired with the LHIN regarding funding for high supportive housing. However, I later learned that the funding would go to a home for addictions, since there was already some high supportive housing for mental health but none for addictions.

My son has never taken drugs, as far as I know, but while he was at the psychiatric hospital he told me that he was offered “funny tobacco” by another patient while on a smoke break outside. The nurse later informed me that a patient had brought marijuana into the hospital grounds.

In terms of caring for a disabled child or adult, if the person is not treated with a medication that helps the person, more demands are placed on the caregivers, to the point of exhaustion.

From October 2012 to August 2013, my son’s psychiatrist raised his antipsychotic injection. My son became more delusional, having more hallucinations during that entire period, and I would have to stay with him from 6 p.m. to 12 p.m. at his apartment because of his anxiety. He would put himself in the hospital after every injection. Then he would be discharged from emergency and he would come to my home, where I would have to care for him for at least a week or longer because of his anxiety and positive symptoms. Eventually, I would have to phone the ACT team to tell them that I was exhausted, that I could not care for him any longer at my home and that he would have to go back to his apartment.

I would send numerous reports of observations to the psychiatrist, and my son would end up getting another injection because of doctor meetings being postponed to a later date.

I have seen that high doses of antipsychotic medication, in my son’s case, cause greater side effects and make a person who already has a disability more disabled, with weight gain, changes in hormones and heavy smoking to compensate for more symptoms.

Eventually, my son had a severe reaction to the injectable antipsychotic. When the medication doesn’t work and causes much suffering for the patient, this further consumes a parent’s life and leaves adults with disabilities even more dependent on their parents, with no respite.

In terms of services provided for those with developmental disabilities, compared to someone with only a mental illness, I see in our community that there may be more options for those who have a developmental disability. For example, my neighbour, who is a nurse, has a son with Down syndrome. He lives with her and he requires 24-hour care; she has to do most things for him. He cannot be at home alone while she is at work.

She told me that her son is in a ministry-funded day program called Passport, where she can use funding to pay a suitable worker of her choice \$12 an hour to take her son out into the community for four to five hours per day. This has been a very successful program, allowing her to work and support her son in her home, and it also does allow for caregiver respite.

As my son is the same age but has a mental illness, he is only taken out into the community once or twice a week by an ACT team worker for one hour.

At his apartment, there are case workers, but some of the scheduled activities are not to his interest, and he does enjoy going out into the community. A day program for my son, such as Passport, would suit his needs; however, it is not available to him.

1530

Also, I tried to get respite at one time through Wesway when my son lived with me, but I was told that respite wasn’t available for parents who had a son or daughter with a mental illness; that they were not funded through the LHIN to offer respite.

Just to sum up, quality of life for those with disabilities goes hand in hand with the medications that they may have to take. Some research in Ontario shows that 50% of those with a developmental disability are taking antipsychotics.

I see in our medical system, with psychiatry, the system is not set up to search for an underlying biological problem, and it seems to be a trial-and-error approach. Thomas Insel, director of the National Institute of Mental Health, stated in December 2013, “Diagnoses of mental disabilities is based on clinical symptoms with no objective laboratory measure. We need to begin by collecting the genetic, imaging, physiologic, and cognitive data to see how all the data—not just the symptoms—cluster and how these clusters relate to treatment response. Patients with mental disorders deserve better.” This would be personalized mental health care and would require an interdisciplinary team.

We need to provide our hospitals with the research, funds and beds to improve the quality of life for those with disabilities and their families.

Thank you.

The Chair (Mrs. Laura Albanese): We thank you for sharing your story.

We have two minutes for each party for questions or comments. Miss Taylor.

Miss Monique Taylor: Good afternoon. Thank you so much for taking the time to come and share your story with us. I was not part of the Legislative Assembly at the time when I know some members of this committee did the exact same thing for mental health issues. I’m sure that they’ll be speaking on that. This is the first time that it has been brought to our attention here, so I’m really happy to hear your piece of that puzzle. You’re right: We’re working on one when we have another one falling behind. It’s so unfortunate. It just seems like it’s a continuous circle, what’s happening here in the province.

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

Ms. Cheri DiNovo: Thank you so much for bringing this forward. It is interesting. What you described really should be a developmental disability, if it’s a mental developmental—your son clearly exhibited some issues from an early age. I thank you; you’re the first person who has come forward with the mental illness label that, of course, denies him funding from other pockets—not that there’s much out there; he’d be on a waiting list for another 12 years for it. But it is interesting, and I hadn’t realized that that silo had been created.

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

Ms. Soo Wong: Thank you very much for being here today and sharing your story with us.

We had several experts come before the committee from the Centre for Addiction and Mental Health, and there were some comments made about dual diagnosis and the mental health correlation piece.

On the last page of your presentation, you talked about the inequity between the developmental services currently being provided for those—compared to those with only mental health illnesses versus those with developmental disabilities. Can you share with us, if you were to have one wish in terms of priorities, what would that be—to provide you with the respite, provide you with the support so that you have a quality of life and so does your son?

Ms. Lois Hacio: I like the Lights idea of supportive housing. However, his needs are high, so I would say he would require someone having to be in the building 24/7. Basically, it's like high supportive housing. It's very important that they have activities and learn life skills and set goals—goal-setting. I do really like that Lights idea for having to choose something that would be suitable.

Ms. Soo Wong: Can you follow up with the Clerk to share that model of Lights with us so that we can follow and hear more about it? That would be really helpful if—
Interjection.

Ms. Soo Wong: Oh, we have that. I see from my colleague across from us. Okay.

Then in the last paragraph of your presentation to us, I'm particularly struck about some of the data you share with us today. About 50% of those with developmental disability also have some antipsychotic—

Ms. Lois Hacio: Actually, I heard that from a previous proceeding. One of the other doctors had mentioned that out of 50,000 people that they looked at from ODSF records, 25,000 were on antipsychotics, and not just one—five to 10. And there was no doctor follow-up or it was very difficult for them to see a doctor. I find the same problem because there's a lack of psychiatrists. It's very difficult to see a doctor sometimes.

Ms. Soo Wong: Okay, thank you.

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

Mrs. Christine Elliott: Thank you very much for joining us today and for making your presentation. I'm so sorry that you've had so many difficulties with your son over the years. I can tell you that there are three members of this committee, myself, Ms. Jones and Mr. Balkissoon, who served on the previous Select Committee on Mental Health and Addictions. Our report came out a few years ago and in many ways this report was sort of a subset of that group because we realized that there were people who were dually diagnosed or who had a developmental disability that also needed services. I would say the need for service is equally great in both the developmental services sector and the mental health sector. We addressed a lot of the issues that you're speaking of today in our report.

The government is in the process of unfolding a mental health strategy. It's been aimed at children and youth so far, but my understanding is they are moving towards addressing some of the issues in the adult sector. We'd be happy to send a copy of the report to you or indicate to you where you can find it. We'd certainly be happy to get your feedback to see if it satisfactorily addresses the issues that you've been speaking about today. But certainly we think that the issues in the mental health world are equally as important and we're committed to doing something about that as well. So thank you.

The Chair (Mrs. Laura Albanese): Ms. Hacio, thank you again for being with us today and sharing your story. It's truly appreciated.

Ms. Lois Hacio: Thanks very much.

MS. PATTI ZIMMERMAN

MS. JAN HUDYMA

The Chair (Mrs. Laura Albanese): Now we call on Patti Zimmermann and Jan Hudyma to come forward. Good afternoon. Thank you for presenting to our committee. You will have up to 20 minutes to speak to us. Should your presentation be any shorter, then there will be opportunity for questions that will be asked by members of the committee. You may begin any time you feel comfortable. I know we're all getting a copy of a handout that you have provided us with.

Ms. Patti Zimmermann: Do I need to use this or can I just talk the way I want to talk?

The Chair (Mrs. Laura Albanese): Start just by stating both—

Ms. Patti Zimmermann: Yes. I'm Patti Zimmermann and this is my friend Jan Hudyma.

We both have special needs children—actually young adults. They're both 20 years of age. My girlfriend and I are here representing our children. Erika is my daughter and Jessica is Jan's daughter.

Both of them have special needs. Both of them are autistic and they also have intellectual disabilities and physical disabilities, so it's not just one component. They both need one on one, and they do usually get that through the school provider that they're going to the schools in now.

Sorry, I'm just a little bit nervous here.

We have dedicated our lives, of course, to our children and we want the best for our children. When there is no programming once they finish school—as of this year, they will both be 21 years of age and there will be no more school for them. So what happens to the children? Where do they go? Do they stay home with mom and dad or do they go to programming?

Every single one of you people here gets up in the morning; you have a sense of purpose. Do our daughters have a sense of purpose? If not, why not? Or how come they don't? That's part of our speech today: There is a need of programming. She needs to get up every day and have a sense of purpose as well.

1540

We have more or less come up with ideas and solutions in regard to the problem, which is lack of programming. With the lack of programming, the only way there is an empty spot or an open spot is if some other participants pass away. That's plain and simple how it is. Unfortunately, there are not enough spots, and people have to wait many, many years in order for these areas to open up.

On that note there, I just want to pass it over to my friend Jan. Jan will talk about the solutions that we both have come up with. It has to be a partnership. It has to be networking. It has to be a collaboration between us and, of course, the government. We're not alone. It takes all of us to look after our children, and it should take all of us to look after the young adults and the adults with special needs as well.

Ms. Jan Hudyma: Hi. Our suggestions are pretty simple. We didn't want to reinvent the wheel.

(1) More programs that are economical for parents, caregivers and the government: Specifically, these services will be for adults, so why not use a portion of their ODSP, the Ontario Disability Support Program pension, to pay for the services? The programs would be subsidized for low income, but most would use their pension to pay for the programs.

(2) Network with existing agencies in Thunder Bay, Lutheran Community Care or Wesway. Expand their programs; don't reinvent the wheel.

(3) The curriculum could be based on the secondary schools' special-needs programming, which we both found to be comprehensive. They cover daily living skills as well as recreational activities which enhanced our daughters' quality of life.

Thank you for the opportunity to address you.

The Chair (Mrs. Laura Albanese): And thank you for coming here this afternoon. We will have about five minutes for each party to ask questions and to make comments. Ms. Hunter, I guess, will start.

Ms. Mitzie Hunter: Thank you both for joining us here today and really sharing a part of your family's story with us. I'm interested in your second recommendation to network with existing agencies. You've cited two examples. Can you describe your experience working with such agencies and how that type of networking would enhance their quality of life?

Ms. Jan Hudyma: Well, Lutheran Community Care is the hub—it seems; I haven't had much to do with them yet. My daughter is on a waiting list. They seem to be the hub for assisted living. They do some respite, and they have some apartments, that kind of thing. They seem like a natural choice because they are already up and running. Any involvement I've had with them, they've been wonderful.

Wesway is a respite centre in Thunder Bay. I would imagine both those organizations, if funding became available, might be interested in expanding their services.

Ms. Patti Zimmermann: So it would be like a partnership between Wesway and the group that we're presenting to now. Like I said, Wesway has group homes

around various areas in town here. They have seniors' homes as well, they have for the younger kids, and they have for the teens-young adults as well.

Ms. Mitzie Hunter: So what are you doing to prepare for when your daughters turn 21?

Ms. Patti Zimmermann: I've been phoning Bill Mauro almost every month and talking to him and mentioning to him that there needs to be programming for the kids. Unfortunately, the lack of money because of all these—wherever the money should be going; as much advocating as I can do, as well as Jan is doing, too, talking to the schools, trying to be in partnerships with the schools. There needs to be more of that. People need to hear of our plight and say, "Oh, okay. Now I see it."

I don't know if any of you people here have special-needs kids; if you do, then you might know what it's like with autistic children. Then when you have other disabilities as well, there's a lot that goes into play: OT/PT, speech, not to mention they can't be left by themselves. I just can't go out for a night with my husband and say, "Okay, Monique, do you want to take my daughter for the night?" It's not going to happen. I need somebody who knows about autism; you know, she has seizures. Jan's daughter has physical disabilities. I mean, it's nice that you people are all here, but you haven't walked a day or an hour in my shoes. You don't know what it's like. You're hearing what it is for me. You can hear it in my voice, how passionate we both are about this.

Like I said, you go to these agencies and ask them what they need as well, but you need to get comments from the family members too, because families are so much more important than the agencies and maybe schools or whatever the case may be. We're just two people, but two people who are trying to make a difference as much as we can for the enhancement of our children's futures.

Ms. Jan Hudyma: So I'll address it too. I work full-time. I'm a single parent. I have another child. So what I've started to do is look into—my daughter is looked after, before and after school, by a sitter. What I have to do is pay money out of ODSP to pay for that. That's what's going to happen in July. And I'm hoping somebody who's an EA, a young EA, who would like to work extra hours, if they work part-time at the school boards, casual—get them to do a couple of days and my sitter do a couple of days. That's basically what I'm going to have to do.

I have no problem using her pension for care for her, but it would be really nice if there were actually set programs to send her to, instead of piecemeal, that kind of thing.

Ms. Mitzie Hunter: Right. So the income that's coming in from the ODSP program, you're using that to provide support services.

Ms. Jan Hudyma: I use it to pay for services, yes.

Ms. Patti Zimmermann: It's supposed to be used for room and board, according to the government, but \$832 doesn't go very far. Where the heck in the world—or, say, Thunder Bay, for that matter—can you live for \$832 a month, with everything? It's not going to happen.

Ms. Mitzie Hunter: Okay. Can I ask one more question?

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

Ms. Mitzie Hunter: Just on the daily living, life skills, that's something else that you're recommending, that there are more supports for that. Is that something that both your daughters are actively involved in right now, and that you hope—

Ms. Patti Zimmermann: Right now, they're in school. They do daily living; they do all kinds of cooking, things like that. I know my daughter is not employable. I can't just let her go to Walmart and say, "Okay, be a greeter at Walmart." Who's going to watch her? She needs help when she goes to the washroom. Unless it's mommy or a care worker or a caregiver—she can't do it herself. She doesn't have the capability to do that—plus the mindset too, with the autism, you know? They're moderate to severe. Autism is very multiplex, and unless you're a doctor—and even some of them don't know everything. Every autistic child is totally different. Routine and continuity are very important.

The Chair (Mrs. Laura Albanese): Thank you. I will now pass the microphone to Ms. Jones.

Ms. Sylvia Jones: Thank you, Patti and Jan. I just want to assure you that we're all here on this committee, serving on this committee, because we believe strongly in improving the system. Have some faith that we are wanting to hear from you, and we're trying to learn from everyone, as we see the changes across the province.

I'm curious: Because of the ages of your daughters, I'm assuming you're going through the lovely DSO process. Is the school assisting you in that transition at all? Is there any involvement on the school board side?

Ms. Patti Zimmermann: Well, when you've done transitioning, they usually start it—now it's age 14. The school hasn't done anything. We were involved with an agency, the CAS, in the programs from the CAS. My worker was CAS and kind of introduced me to the transition program and to the DSO services. They had talked to the school and consulted with the school in regard to what they feel would be necessary and what they need to know—you know, comments and stuff like that—but, no.

Ms. Sylvia Jones: Okay, but in terms of the actual transition post-June—

Ms. Patti Zimmermann: No. They're doing a little bit of co-op, but again, co-op involves her going to the airport for a ride. Co-op involves her going to the hospital, although going to the hospital is not, to me, in the best interests of my child, but I guess that's what they feel. It's just getting her out and integrated into society—you know, things like that. But she doesn't go per se to, say, maybe do shredding of paper or taking telephone calls or dropping off files here and there in an office or something like that. No, she isn't capable of doing that.

Ms. Sylvia Jones: Okay. One other question: You make specific reference to the Lutheran Community Care Centre and Wesway, both of which we've heard of from other presenters here today. Are there any other day programs that you're aware of in Thunder Bay?

Ms. Patti Zimmerman: Possibly Avenue II, but again, for all of these day programs, there is a long wait-list in order for you to get in them.

1550

Ms. Sylvia Jones: Of course.

Ms. Patti Zimmerman: And like I said, unless you pass away or move away to another country or wherever, the openings are very few and far between.

Ms. Sylvia Jones: Yes.

Ms. Jan Hudyma: I think March of Dimes has something. However, it's the same with my daughter: You couldn't take her and leave her somewhere, even if it was fairly supervised. She needs somebody to really kind of watch her—not that she would run off or anything, but if somebody said, "Come with me," she'd go with them. Yes, she needs more one-on-one—or not even one-on-one, but just a little more supervision than some programs can provide.

Ms. Sylvia Jones: Quite frankly, that's what we're trying to grapple with because, as you well know, there is a whole spectrum, so we have to look at individualized programs and individualized services. To your point at the very beginning, that all of us deserve to have a quality of life, it's not all the same, but that doesn't diminish it in any way.

Ms. Patti Zimmerman: Some of the programs out there, like Jan mentioned—March of Dimes, and there might be some with the city programs—you have to have a worker go with you. Well, that's fine; I can provide my worker, but not for eight hours a day or six hours a day. If any kind of worker wants to stay, they want a very good wage, something that's comparable to what an educational assistant or an SSP in the Catholic school board wants, so you're looking at \$18 and up. Well, if you're only getting \$832 a month, tell me how far that's going to go.

Ms. Sylvia Jones: Are you looking at all at Passport, or is that a lovely waiting list too?

Ms. Jan Hudyma: We both have—

Ms. Patti Zimmerman: We have Passport 2, yes, but Passport 1 turns into Passport 2, and then the funding for that doesn't necessarily match up to what it should match up to. Right now we have Passport 1, and however it has been diagnosed from years gone by—it used to be SSAH, Special Services at Home—

Ms. Sylvia Jones: Yes, and then at 18 it flipped over.

Ms. Patti Zimmerman: —and then once they turn 18, it goes to Passport 1, and then once they turn 21, it goes to Passport 2.

Ms. Sylvia Jones: Right.

Ms. Patti Zimmerman: But like I said, the money doesn't always increase. It stays relatively the same, but the needs of the individual increase as well.

Ms. Sylvia Jones: Well, for one thing, they're not at school for seven hours.

Ms. Patti Zimmerman: Well, they're at a school and they're more—

Ms. Jan Hudyma: That's the problem, yes.

Ms. Patti Zimmerman: That's the whole problem there. There is really nothing for them. If your child is functioning—I'll say the three things—and can feed themselves, can wipe themselves or can talk, you're fine, but if they can't do any of those three, what happens there?

Ms. Sylvia Jones: Thank you.

Ms. Patti Zimmerman: Thank you.

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

Ms. Cheri DiNovo: Yes. Thank you so much for coming forward. I know it's not easy; I know your lives are not easy; but thank you for being courageous enough to be here and take this time.

Trust me, I want to again reassure you that we—or some of us, anyway—don't think the system is working at all.

Ms. Patti Zimmerman: It's not. The system is broken.

Ms. Cheri DiNovo: And clearly, what we're doing in this committee is to try to see how to make it work, so I want to assure you of that. Your stories will not be lost; your experience will not be lost. That's number one. What you've brought forward as issues, other families are grappling with too, so you're not alone in that at all.

You're experiencing one transition, which is the out-of-school transition, which is, again, troubling and not handled well.

The other transition, which I'm sure you've thought about, is down the road when you get older and your families get older. Have you thought about that at all? If there was one recommendation about that time, when perhaps your children outlive you—have you thought about that and what government should be doing to help you make sure that your children have a future at that point?

Ms. Jan Hudyma: My daughter is on the list for assisted housing, because I'm a firm believer that she's not going to live with me forever. I think it's a natural progression, whether you have special needs or not, that you move out of the house. I know that there are bound to be good places for her to go that she'll probably really enjoy.

So, yes, she's on a list, and by the time she's about 25, I would like her to be in an assisted-living spot. Lutheran Community Care is the spot where her name is placed on a five-year application, I believe it is. So, yes, I've definitely thought about it.

Ms. Patti Zimmermann: The same with me. She's on a list as well with Lutheran Community Care.

Ms. Cheri DiNovo: Thank you very much.

Ms. Patti Zimmerman: Thank you.

The Chair (Mrs. Laura Albanese): Miss Taylor, did you want to add something?

Miss Monique Taylor: Thank you so much for being here with us today and for sharing your story. I hear your frustrations. You're right. I don't have a child with a disability, and that's why I'm here: to learn and to see what kind of recommendations we can put forward to make it better for families like yourself. I really do appreciate your time.

I've heard, "There's a place here," or, "A place here." Have you had help with finding resources in Thunder Bay? I'm not familiar with Thunder Bay. Is there a resource place where you can say, "This person is going to help me to see what's there for my children"?

Ms. Patti Zimmermann: There really isn't anything like that that I know of in town. We just deal with Wesway and Lutheran Community. I have phoned them and talked to my workers and said, "What about this? What about that?" Again, if your child is more independent than what our children are, yes, there probably is stuff out there for them. But, again, like I said, our children need workers with them 24/7. Like I said, I can't just drop her off there and say, "See you in five hours, honey." It's not going to happen.

Miss Monique Taylor: No, no. I understand. What would your thoughts be on a transitional worker from the time of birth to the time of death, to make sure that there's somebody there to guide families through—

Ms. Patti Zimmermann: That's a perfect world, but we know we don't live in a perfect world.

Miss Monique Taylor: Well, it's recommendations that have to come from somewhere, right?

Ms. Patti Zimmermann: They used to do that. Apparently, Lutheran Community Care used to do that in the past. But, again, I don't know if it's because of a lack of funding; workers—I don't know how that has transpired. But they used to, in years gone by, go into the school system and help them make the transitions to various programs and things like that. But, like I said, they don't do that now.

Miss Monique Taylor: What has your experience been so far with the DSO?

Ms. Patti Zimmermann: Again, we're just on a waiting list right now. I phoned them, but they're, "No news is good news." They more or less tell me—I complain to the ED, and they're kind of like, "Okay, fine. We'll just write her name down." The ED hasn't called me back at all. To tell you the truth, I don't even know who the ED is of Lutheran Community Care. I know Daniel from Wesway. I've talked to him on various occasions. But, again, their hands are tied too, and I'm told that they're not allowed to advocate or lobby for any money, because if they do that, then they can lose the funding—again, this is what I'm told—that they already have now. So their hands are tied, too. Again, I'm not certain who has made those stipulations or not, but that's what I've heard.

Ms. Jan Hudyma: I've got to say, Lutheran Community Care was helpful. When I phone them, they'll give me some ideas. When her name went on the application, they were helpful with certain things. I did find community care access helpful. She doesn't have much to do with them right now, but for quite a few years, she did, and the nurse manager I had was very helpful with, "Do you need help with this, help with that?" So that was one spot that was good.

Ms. Patti Zimmermann: I deal with CCAC, the community care access centre, and there's an agency in town, Bayshore, so I do get home support for my child, or

respite, like three hours on certain days—things like that. They're good that way there, too. Then there's another agency in town. I'm not certain what the name of that agency is, but it's something like Comcare.

The Chair (Mrs. Laura Albanese): Thank you very much. I want to thank you both for presenting to our committee today. I want to assure you that all of us—each MPP here on this committee—believe that there is a need for a more comprehensive strategy. We're here to listen to what you need, to what your challenges are. We know there's a need also to better coordinate the programs and the services that are available in the province. That's why we have this committee. So we're hoping to make a difference in your children's lives.

Ms. Patti Zimmermann: You have this committee here now, and you've finished going through the whole province of Ontario—

The Chair (Mrs. Laura Albanese): We have an interim report due at the end of February and a final report due by the end of May.

Ms. Patti Zimmermann: Okay. So now does that information go to the MPPs here in Thunder Bay?

The Chair (Mrs. Laura Albanese): Yes, and Bill Mauro will be with us tomorrow, and someone from his office, I believe, is here today. But, in any case, he will be with us tomorrow. All MPPs are kept informed as to what we do.

1600

Ms. Patti Zimmermann: So you're various MPPs from around the province?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Patti Zimmermann: Okay.

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

Ms. Patti Zimmermann: Thank you very much for listening to us.

MS. BARB WENTWORTH

The Chair (Mrs. Laura Albanese): Our next presenter is via teleconference: Ms. Barb Wentworth. Hello?

Ms. Barb Wentworth: Hello.

The Chair (Mrs. Laura Albanese): Good afternoon. How are you?

Ms. Barb Wentworth: I'm fine. Thank you very much for giving me this opportunity.

The Chair (Mrs. Laura Albanese): May I ask where you're calling from?

Ms. Barb Wentworth: I'm calling from Toronto.

The Chair (Mrs. Laura Albanese): We have up to 20 minutes available for your presentation. If it's shorter than that, we will have an opportunity for comments and questions. You may begin any time.

Ms. Barb Wentworth: Okay. I taught special education with the Vancouver School Board back in the early 1980s, while at the same time raising my three children. I'm very proud of all of my children, who have grown into warm and caring individuals—even Mark, who has managed, through a very difficult life, to maintain his sense of humour and whose favourite adage is “Be

careful.” I want to share some stories of Mark's journey through his life.

We met Mark in Vancouver when he was four years old and thought that we would adopt him. He would join a big brother who was eight years old and a young sister who was a one-year-old. When we realized the amount of care that Mark would need and the amount of future unknowns, we worked out an arrangement to become life-plan foster parents, not really foster parents at all but Mark's parents in every way, except that we would not take on the financial responsibility for his extra needs. His diagnosis at the time was cerebral palsy with a Parkinsonian-like tremor and a developmental delay.

We enrolled him in the local school kindergarten and after the first hair-raising morning, he was sent upstairs to a specialty program for autistic kids. We went through one crisis after the next, and several years later we moved to Toronto. His challenges continued and escalated.

When I had to have surgery for a major health problem, Mark went into a group home, and he has been living in a supportive living environment for many years now. Everyone involved in supporting Mark has been challenged.

Mark's ability to tell us what is going on with him is extremely limited. We would go along in a steady line and then, inexplicably, have a crash where he would lose skills. All hell would break loose with his behaviour. Then he would pick it up a bit, but never up to his previous functioning ability, and go along for a while and then crash again, losing skills and behavioural control. This continued as he slowly declined in his abilities, both cognitive and physical. The last crash came with a five-week hospitalization when he was 39 years old, where he lost his ability to walk and to move his body much at all.

For a short time, we had a team that included New Visions Toronto, where Mark lives, Surrey Place and CAMH dual-diagnosis/CAIR team. Things were very challenging and very perplexing.

Luckily, Mark was sent for genetic testing at age 40 and came back with a MECP2 diagnosis, atypical Rett syndrome. Finally, what had always been so confusing started to make sense. His symptoms lined up with those of Rett syndrome: reduction in hand skills, reduction in communication skills, stages of slow neuro-motor regression, extreme kyphosis and scoliosis—that's a curvature of the back—swallowing difficulties, peripheral vasomotor disturbances—that's excessive sweating and cold hands and feet—sleep disturbances, laughing-screaming spells, diminished response to pain, intense eye contact-eye pointing.

Many of these symptoms we had perceived as behaviour problems and had used behaviour programs including time-outs and psychotropic drugs. All of this was done with the best information we had at the time. He is now being successfully weaned off his mood stabilizer medication.

Now that you have a background on who this young man is, I want to walk you through how Mark experiences his day. I want you to understand what service cuts in developmental services really mean and why what you

are doing is vitally important in reducing very real suffering in human beings who have no way to effect any change for themselves. We often fail them and increase their suffering through policies that don't address their needs.

I wish that Mark and I were in the room with you because this is a bit hard to do without being able to see you. However, I invite you to join me. I want you to step into Mark's shoes and take a look at his life from what I imagine might be his perspective. I want you to get comfortable in your seats, and while I am finishing my presentation, do not move at all. Do not move your arms, do not move your legs, do not squirm in your chairs. You can move your head, but just sit still and see how it feels. Know that you cannot move until someone comes and moves you. It doesn't matter if you are uncomfortable, it doesn't matter if you are in pain, and you are incapable of telling anyone how you feel. This is one of the Rett symptoms that Mark has—a diminished response to pain. That means that he feels pain but he does not respond in ways that would be easily interpreted by us.

So here we go: New Visions is a great group home. The staff is responsive and caring. But this is what is happening after five years of no funding increases and the extra legal obligation to absorb a half-million-dollar pay equity requirement, all with no extra dollars.

Remember, don't move. Pretend you're Mark. Okay, so staff gets you ready for bed at 9 o'clock at night. You don't sleep through the night. In fact, you have been recorded as having over 300 instances of central sleep apnea in one night. That means that your brain forgets to tell you to breathe and you wake up terrified. You need staff to come in and move you if you are uncomfortable at night, and you have to stay in bed until at least 9 in the morning, when the day shift comes in for work. That's a long 12-hour night when you can't stay asleep, are physically hurting and are often startled awake in a panic. Bedtimes and wake-up times are predicated on when staff is available to do the work, not based on what would work better for your comfort, and there is nothing you can do to change that.

Now you are up and ready for your day; however, a staff person has phoned in sick and there is agency staff on. They don't know you. They don't know how to read the subtle signs of when you are in pain. You can't go out. One of your coping skills is to distract yourself from your discomfort. How much easier that is to do when you have an active life out in the community. But staff have chores to do; staff have increasing amounts of paperwork to do. You rely on staff for your quality of life, and those staff are continually stressed by having to do more and more with less. There is nothing you can do to make your situation better.

Are you still sitting still? Maybe you have an itchy nose? You just have to put up with it.

Sundays are a real problem. You really like to go to church; in this case, the First Unitarian Congregation of Toronto. You love to sing and you "la, la, la" with great gusto. Usually tears roll down your cheeks because the music moves you. Afterwards, people come up and tell

you how they really like to hear you sing. You love this community and are loved in return; however, staff doesn't come in early enough to get you ready to take Wheel-Trans to church. Mom has to spend \$30 a week to hire a cab to get you to church on time. This is not doable in the long run. You may lose this community because there are not enough financial resources to allow for sufficient flexibility. You may have to stay home. That makes you feel sad, and there is nothing you can do to change that.

You look and see a large plastic jar on the dining room table with a sign on it to collect Canadian Tire money to go towards the purchase of a van. Perhaps you think this is an embarrassing way to fund necessary transportation. One time, you took the New Visions van to go to Hamilton to meet with the Ontario Rett Syndrome Association experts, but the alternator broke on the way. Luckily, you got off the QEW and limped home, all the while wondering what the contingency plan was if CAA had had to tow the van. I have never heard of a CAA wheelchair-accessible tow truck, and New Visions has had to sell off vans to try to reduce operating costs due to the five-year freeze in the budget.

If you are sick and have a fever, you have to take the TTC bus up to Bloor to see your family doctor or get wheeled up many blocks to St. Mike's hospital because New Visions can't afford to buy and struggles to keep old vans in good repair because transportation is not in the budget. They are doing the best that they can. And Wheel-Trans is increasingly busy, so it's another stressor in the system. There is nothing you can do about this.

You really like to go home to see mom and your sister, but mom needs to find a way to get you out of your wheelchair so that you can stretch and get freshened up. Mom was happy to get a donated ceiling track and lift; however, to install the track cost \$350, to fix the lift cost \$424, and to buy a tilting bed, which you need, was a bargain at \$300. That's over \$1,000, and the wheelchair ramp that was put in a few years ago was approximately \$700. All this is funded through mom's line of credit.

Are you still sitting still? Remember, you need someone to come and reposition you and you have no way of telling them what you need.

You like to help in the kitchen and watch what's cooking, but there has been no increase in the food budget in the last five years. That makes it hard on the front-line staff who do the shopping. There is nothing you can do about this.

Because Rett syndrome may eventually have a genetic fix, you are hopeful that the researchers can keep on working. It's very exciting that studies with mice have shown that the mice actually can get much better. Wouldn't that be wonderful? A new problematic development means that the Ontario Brain Institute now requires a one-third match of funding from the host institute or there is no grant. If there are no grants, there is no lab. You would prefer that your researchers spend their time doing research and your front-line staff at your group home spend their time working with you. Fund-raising for necessary operating costs is like gambling,

and you suffer the loss, because everyone is out looking for big dollars from the same sources, pushed there by a government that refuses to understand that these dollars mean the difference between a tolerable life and one of misery.

1610

You are an adult now, and you need a substitute decision-maker for medical decisions. You have to go to the Consent and Capacity Board to ask that your mom can sign on your behalf. The Consent and Capacity Board is very formal. They send a lawyer to represent you, but the lawyer has no background at all in people with DD and probably has never spoken with someone like you. At the hearing, someone says hello to you and then ignores you for the next two hours while they are going through their processes. Mom tries to be subtle and keep you amused and reassured. For a process that is there to defend your human rights, maybe some accommodation and training on how to include someone with DD would bring a little more humanity to the process and make things easier.

Are you still sitting still? Uh oh; you just got a cramp in your leg. Better use whatever coping skills you have, because someone has to notice that you are in distress and guess what the distress is about and then do something about it. Until then, the reality is, you have a cramp in your leg and no way to do anything about it.

Because mom has to make complex medical decisions on your behalf, she has to have access to a team that can help come to an agreement on the best way forward for you. Support is critical to reduce stress for the decision-maker and prevent mistakes. A Rett syndrome clinic has been opened that is a model for good support and responsiveness. As an adult, you do not have access to that clinic; it's for children. The one Rett syndrome doctor in Toronto is challenged with too few resources, like not having a secretary. Listen to this: You had an appointment in November 2013; the next available regular appointment with this Rett specialist is February 2015. The system is under-resourced in so many ways, and there is nothing you can do about any of this. You are totally reliant on others.

So while sitting perfectly still and knowing that you cannot move, without someone realizing that you are in discomfort or pain and being available to move you, let me tell you this: If we really were able to live in Mark's shoes and to have some idea of his challenges and their impact on his life, we would make different decisions about how we provide support to him and others living with disabilities. I credit Dr. Elspeth Bradley from Surrey Place for her teaching about trying to mirror what a day is like for many people with developmental issues. To me, it is the best way to feel the challenges and the discomforts that are a reality for those we support.

Quality of life is not just a measure of happiness, involvement and engagement. There is another level to quality of life that deeply concerns me: That is the unimaginable, lonely depth of despair that is experienced when you cannot articulate your pain, both physical and

psychic, and when you have absolutely no capacity to effect change for yourself. Therefore, your experience of being cared for absolutely depends on adequate funding for the people who look after you and adequate funding for your living environment.

I have given you the challenge to sit still for a set period of time, knowing that you can't move, that you need someone else to recognize and respond to your need. Then imagine that, day in and day out, every day. This is just one example of the many ways people are vulnerable. Explore this as much as you can as you go about deciding on a future direction for government policy so that you can truly appreciate the impacts of your decisions.

I have attached an OASIS operating pressures survey from July 2013 wherein agencies supporting people with special needs report that existing group homes are cutting staff hours and eliminating positions and gapping and closing programs and increasing the number of clients without additional resources. This is a recipe for disaster, and it is already happening. I have also attached a letter from Mr. Andy Rotsma, executive director of New Visions Toronto.

Here are my concerns: that you will rob from Peter to pay Paul, starve existing group homes, either to save money or so that you can open new ones. We have a moral responsibility to do better than that. The ramifications of the five-year budget freeze are already being felt. That has to stop. All the cuts and/or freezes have direct, negative impacts on my son's life, and he is totally reliant on what we provide for him.

I'm concerned that staff will leave the profession or go on strike due to lack of adequate wages. In fact, contracts are set to expire on March 31 of this year. That's just plain scary.

I'm concerned that burned-out, under-resourced and rotating staff will cause my son to suffer extraordinarily.

I'm concerned that governments will continue to mandate important policies that take money to implement and then not provide that money; for example, pay equity, new quality assurance requirements, new mandatory training for staff and new fire marshal requirements for automatic sprinklers. All this is to come out of an operating budget that has not increased in five years.

The worst for me is that governments do not have a realistic appraisal of the efficacy of fundraising to cover necessary operating costs, preferring to offset their own obligations instead of providing adequate financial support. It just doesn't work.

Remember, the experience of being cared for and how you experience that care is absolutely dependent on adequate funding.

Mark's favorite adage is "Be careful." He says it all the time. It is his statement of concern and caring. I think he means: "Be careful. Don't hurt yourself. Be careful. Don't hurt me. Be careful with life. It is a precious gift."

So I say, please be careful when you make your recommendations to the House. Please know that people with developmental issues are suffering. They are suffering along with the people who love them and must wit-

ness the courage with which they must live their lives. Find your courage. Don't fail them. Be careful.

The Chair (Mrs. Laura Albanese): We thank you for your presentation. We have about a minute and a half for each party to make comments, and we are to begin with the Conservative Party. Ms. Jones.

Ms. Sylvia Jones: Thank you, Barb. I have a question. How long has Mark been living with New Visions Toronto?

Ms. Barb Wentworth: About 15 years.

Ms. Sylvia Jones: And how was that process when you went through that? Because, as you probably know, there have been some changes with the DSO and that process. I'm curious as to how your transition was 15 years ago.

Ms. Barb Wentworth: Well, I went in for brain tumour surgery, so I don't remember it at all. Because he was a governmental ward when he was a kid, he just went into a children's group home and then stayed there and finally moved over into New Visions, which is a really appropriate placement for him. I didn't go through what natural parents go through with having to go on waiting lists or do any of that. I can't really comment on that.

Ms. Sylvia Jones: So your transition was as a result of a crisis, really? That's how the placement occurred.

Ms. Barb Wentworth: Yes, it was. Yes.

Ms. Sylvia Jones: Okay. Thank you, Barb.

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

Ms. Cheri DiNovo: Yes, Barb, I just wanted to say thank you for your presentation. It was thought out; it was beautiful. It gave us an insight for a second or so into what you and your son are going through. I want to just reassure you that we have heard similar stories from many parents across the province, that you're not alone and that we here are committed to making an absolute difference and that I hear very clearly that funding is one of the ways in which we can make a difference. So I just want to thank you for everything you do.

Ms. Barb Wentworth: I—

The Chair (Mrs. Laura Albanese): Yes?

Ms. Barb Wentworth: I have a real problem with the whole issue of fundraising for everything because that seems to be the—"Well, if we don't have enough money, we'll just get everybody to fundraise and that'll take care of it." It just doesn't work. Using that as the way forward or the way to presume that we can support these individuals isn't going to work, and it just puts more stress on the whole system. A lot of what I am doing is dealing with the crisis with my son's personal life and his health issues. I don't have time to kind of get involved in all of the other things, but I do know that that is one issue that just puts incredible pressure on, and it means that it's a crapshoot whether you're going to get it or not.

Ms. Cheri DiNovo: I agree. Thank you.

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

Ms. Soo Wong: Thank you very much, Barb, for your presentation. In your presentation, you shared with the committee your concern dealing with the Consent and

Capacity Board. So can you share with us in terms of your experience, particularly with your son, how do we improve that board? Because obviously your son is not the only one who will be needing that support, and because you commented that there are lawyers with no background or knowledge about people with DD. Can you recommend or suggest to this committee with respect to that board and making sure the legal counsel for that board and the lawyers have some knowledge and skills to support yourself and your son in the future?

Ms. Barb Wentworth: Well, I think the first thing is that it took me over a year and help from many people to try and figure out how to even get before the Consent and Capacity Board, so there's not a lot of good information about how to go there. I'm still not clear. I think if you're a parent and it's your child, that when they're children, you just sign on their behalf. It becomes very problematic if you have any kind of clinical research trials or anything that needs a consent with an adult.

1620

I think the background thing is that everyone has the right to speak on their own behalf and sign on their own behalf, so when you have to give that up—I'm not sure whether I'm the only parent who has to go through that, because I'm [*inaudible*].

I think that a lot more education, I think that some in-house training—and for Mark to sit there for two hours and not understand the process. I understand that there are legal requirements to be done in this type of a process, and it's a serious process, but I also think that there needs to be some kind of accommodation so that people with a developmental disability who are going through that process have a bit more support than what they do.

Ms. Soo Wong: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much once again for sharing your story, your experience, and for giving input to this committee. It is truly appreciated.

Ms. Barb Wentworth: Do people who present to this committee get a copy of the report mailed to them, or do you have to go through some other process to get that?

The Chair (Mrs. Laura Albanese): I believe that that's something that we will need to discuss with the committee, but if you will keep in touch with the Clerk, Trevor Day, I am sure that there would be no problem in providing you with a copy of the report.

Ms. Barb Wentworth: I would really appreciate that. Thank you very much.

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

Ms. Mitzie Hunter: Madam Chair, I wanted to see if the committee would agree to us exploring the opportunity, given that we're in Thunder Bay—I was quite moved by Patti and Jan's very practical presentation and recommendations about how they are navigating their own community. They seem to have received good supports from the Lutheran Community Care Centre, which is located right here in town. It services the northern Ontario region. If it is at all possible, with the talents that we have in the room, with our Clerk and his team, to

have them come here, because we do have time in the afternoon tomorrow, would you be open to that? It seems like an agency sort of juggling lots of things, and maybe it can give us some insights and perspectives.

The Chair (Mrs. Laura Albanese): If the committee members agree, what I would suggest is to have our Clerk perhaps phone this afternoon, while we're listening to the next presentation, and find out if there is any availability on their part to come and see us tomorrow afternoon. Ms. Jones?

Ms. Sylvia Jones: Or leave it open to them, if it is appropriate, for a site visit—

The Chair (Mrs. Laura Albanese): Or for a site visit.

Ms. Sylvia Jones: —because we do have that window.

The Chair (Mrs. Laura Albanese): Okay.

The Clerk of the Committee (Mr. Trevor Day): How long a presentation are we inviting them for?

The Chair (Mrs. Laura Albanese): How long a presentation are we inviting them for? The regular 20 minutes? Yes. Well, we have the flight to Moosonee tomorrow to deal with as well. Yes, let's see if we can accommodate them; if they can come here, it would be great, and if not, we'll inquire about a site visit. Thank you.

MS. CONNIE HARRISON

The Chair (Mrs. Laura Albanese): We'll move on to the next presenter, who is also joining us via teleconference. Connie Harrison?

Ms. Connie Harrison: I'm here.

The Chair (Mrs. Laura Albanese): Yes, hello. Good afternoon. How are you?

Ms. Connie Harrison: I'm fine.

The Chair (Mrs. Laura Albanese): And where are you calling us from?

Ms. Connie Harrison: I'm calling from Toronto.

The Chair (Mrs. Laura Albanese): We are ready to hear your presentation. You will have up to 20 minutes to speak.

Ms. Connie Harrison: All right. I'll try to discuss a little bit about how we got here and where we're at right now and what we hope for the future, because my son is aging out of the system right now. He's aging out of the children's system.

The Chair (Mrs. Laura Albanese): That's fine. Thank you. You may begin any time.

Ms. Connie Harrison: All right. I'm Connie Harrison, and I'm the mother of Boris Cibic. He was born in 1993. Even as a little boy, he was aloof and he didn't really make a lot of eye contact. Finally, someone said they thought he had autism.

He was diagnosed, first of all, by a medical doctor, but according to the rules then, you had to have a psychologist diagnose him, to get the care, the money or the help, so we had to go to Surrey Place, which we used to call "squirrelly place" back in the day, because a lot of

them really blamed the mothers and things like that, and called the mothers cold and aloof.

Back in those days, it was pretty hard getting services, and a lot of the services were pretty bogus, like the behavioural therapy, which turned out to be a joke. Getting daycare spaces was very difficult. It was horrible.

We've progressed since then, but my son's autism is severe. He's non-verbal. He stims a lot. He has pica—does everybody know what pica is?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Connie Harrison: Okay. Anyway, he's pretty aggressive—very aggressive—and his doctor was saying, from very early on that he needed to go to a group home. I kept fighting it and kept fighting it, even though he was getting worse and worse, except the process to get to a group home was basically through one of the children's aid organizations, and they would just shame you.

Finally, we had to go that route, going through children's aid, and it was like, "Oh, you're this horrible person, putting him in the group home." It was only later on, because they were trying to get us to make him a crown ward, that one of the MPPs back in the day, Marilyn, helped us to get services without that sort of thing.

He's been in a group home since he's been about six. He was originally in one in Toronto, and then there weren't any more spaces in Toronto as he got older, so he had to go north of Toronto to a community—well, I'm going to say the community: Barrie.

So he's up in the Barrie area, and his family is always trucking up there to see him. We're on the road a lot to visit, and we feel sad that we're not close, because we wish he was closer, but the fact is that group homes are far away for many families—not just those who live in Toronto, but those who live in other places around the province, because there aren't that many group homes.

He's also in a group home where he's probably one of the older guys there, because there's nowhere for older ones to go. People seem to have a notion that autistic kids stay that way forever, and they don't think that they'll need somewhere to go. There are very few places for our people to go, especially the ones with high needs. It's also hard for them to have opportunities in the community. It's hard for them to have good schooling. The whole issue up in Barrie with the blockers was an example of a complete breakdown in communication between parents and the school boards. Thankfully they've addressed that issue.

I'm just saying that I'm getting on in life. I'm 58 years old. I have two children who are non-autistic, and they're working, and they're going to be there for Boris when I'm gone and fight for him as I've always fought for him. I guess that, as a mother, what I really want to know is, what are we going to do? I know people want to spend a ton of money on these therapies. Frankly, I don't see any scientific proof that they work.

All I can say is that we need to put money into group homes and other facilities like that. We need to put money into education, so that kids can have good classrooms for themselves. Forget about inclusion, because if

you're not going to have real inclusion, don't even bother. Good classrooms serve our kids so that they can be who they are. Also, we need to make sure that parents who are keeping kids at home get every bit of support that they need, so that they don't burn out, because a lot of people are keeping kids at home, and they're burning out quickly.

My son mentioned this to me earlier—he's at work—and he was saying to maybe make some kind of a deal with private groups that are offering certain services to help parents fund these things if they can't afford it, because some parents can afford it and some can't afford different things.

If you're going to put more money into autism, you're going to have to make sure that the people who look after our kids are qualified, because right now I'm seeing a lot of sad sacks—people who have really poor educational qualities. They go to these diploma mills, they come out, and they work with our kids for very little wages. You're going to have to pay good wages, and you're going to have to make sure that people are properly educated to look after our kids, because this stuff with hiring somebody who's just a PSW is not good enough, especially when they're having to restrain a lot. Things are going to happen that are bad if you've got people who are not trained properly doing constant restraints.

I don't know. I could go on and on and on, but I don't see any magic cure coming down the line for these kids. I just don't. All we can do is make them comfortable and keep them safe and as happy as possible in the community. That's going to require a political will that I haven't seen out there for quite a while. I have not seen that will.

1630

A lot of people just avoid us like we're the plague and vilify our children, as was done in Barrie last year, calling them monsters. What can I say? It has become a "them and us" kind of attitude, and I don't like it. I'm hoping, whatever this committee comes out with, that they're going to realize that you need a political will, you need to respect people with autism, and you're going to need to put money into paying to see that they are properly looked after.

My son had an iPad stolen. His belongings are like he's nothing, like he's a nothing person.

I get scared. I was sick recently, and I was frightened to die, because I want to keep alive to fight for my boy. I've been fighting now for 20 years. Occasionally, we see rays of light; we see some politicians who care. I wish all of them cared. They don't understand the struggle we go through, and this is not just with autism, but it's with other developmental delays. It's very, very sad, and it's mainly shame and blame the parents. We have to go begging for what the kids need, and it's more shame and blame, calling our kids bad names. Yet everybody talks about inclusion. I just wish people would do what's right, put the money there and start doing things that are right for the kids.

I don't believe in institutions, okay? I really don't, because that's not really good. But in some cases, you're

going to need to have them, because there are people who are hard to serve, and it is true. When you do have these institutions, make sure they're safe and secure, and you're hiring people who are not horrible people, like what happened down in London, Ontario. You have to have a high standard for our kids.

Maybe I'm asking for the moon; maybe I'm asking for too much. But I really want to see—I would actually like to see autism in its own ministry, and get away from having it a little bit in health, a little bit in Comsoc, a little bit in education. I would like it in its own ministry, because I'm tired of us being the orphan child in Ontario. Everybody is scared of us—the politicians, because we're going to ask for money to make things better for our kids.

I guess I'm going to conclude it by saying I don't know what kind of world Boris is going to be seeing in the next 10 or 20 years, if all of you guys and your various parties can come together and figure it out. But there has been a lot of lost opportunity over these last few decades for our kids, and I don't know what Boris has to look forward to.

I guess that's all I can say. Please realize that for good staffing, you're going to have to pay for it, and for good care, you're going to have to pay for it. The kids grow up; they're not kids forever. People need to see it and treat it like it's a health issue, not like it's some public shame.

The Chair (Mrs. Laura Albanese): Thank you very much for your open, frank, touching presentation. I will give my colleagues the opportunity to ask some questions. We'll start with Miss Taylor.

Miss Monique Taylor: Good afternoon, Connie. Thank you so much for joining us today. I realize that the issues that you and your son have to face on a daily basis are not easy, and then to have the energy and the strength to come here before us today and to give us your time and speak to us to educate us with the difficulties your family faces is really important. We're very thankful for that.

Connie, I'm just curious about what your thoughts are on the DSO, because you're right in the middle of that process now, I would take it.

Ms. Connie Harrison: A behemoth. Sorry. I'm speaking my mind here.

Miss Monique Taylor: What did you say? I'm sorry, I missed it.

Ms. Cheri DiNovo: A behemoth.

Ms. Connie Harrison: A behemoth.

Miss Monique Taylor: Oh, yes.

Ms. Connie Harrison: I wanted one-stop shopping, and what I got was Godzilla.

Miss Monique Taylor: Right. You know what? Thank you for that, because we're definitely hearing that from pretty much every presenter that has been before us.

Ms. Connie Harrison: That was the one [*inaudible*] told him what we wanted. Oh, my God.

Miss Monique Taylor: Like I said, you're right. We've definitely been hearing from many presenters that

the DSO just isn't working like it should be working and families are still struggling—

Ms. Connie Harrison: Before it was a crazy quilt, and now they give us that.

Miss Monique Taylor: Yes. Thank you again for sharing with us. We hope that this committee will be able to make recommendations to make life easier for you and your family.

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

Ms. Soo Wong: Thank you, Connie, for sharing your experience with the committee, and your passion on this—

Ms. Connie Harrison: Soo, you know Boris. You helped him get an eye doctor back when he was a baby.

Ms. Soo Wong: Oh, this is a small world.

Ms. Connie Harrison: It was the eye doctor over at East General—because his tear duct wouldn't open. You remember.

Ms. Soo Wong: Yes. Thank you for reminding me, and thank you for everything you do for your son, as an advocate for this piece.

Ms. Connie Harrison: Thank you. It is a small world; it's very small.

The Chair (Mrs. Laura Albanese): Soo can't get over it, from her expression. I guess she's going back in time.

Ms. Connie Harrison: I have a memory like a steel trap, by the way. Even if it was 30 years, I would remember.

The Chair (Mrs. Laura Albanese): That's good.

Ms. Elliott.

Mrs. Christine Elliott: Thank you very much, Ms. Harrison, for your presentation. I think we're all hearing the frustration in your voice. I can only assure you that the goal of this committee is to make sure that your sons and daughters—whether they have autism, a developmental disability, dually diagnosed—have a chance to have a life like everybody else. That encompasses housing issues, employment issues, educational issues, social issues—just being able to live a life like everybody else.

The bottom line we are hearing from parents is that because of the way the system is set up now, their children don't even have a chance at the most basic things that we take for granted.

So please be assured that we are very committed to finding some solutions that are going to allow that to happen and to make sure, in your case, that your son has a chance at a happy and productive life.

Ms. Connie Harrison: Thank you.

The Chair (Mrs. Laura Albanese): Thank you, again, for your presentation. Have a good afternoon.

Ms. Connie Harrison: Should I just sign off now? Is there any more?

The Chair (Mrs. Laura Albanese): No, that would be it.

Ms. Connie Harrison: I'll get a copy of the report?

The Chair (Mrs. Laura Albanese): Yes, our Clerk has noted that.

Ms. Connie Harrison: Thanks so much, everybody.

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

MR. IVAN SOLANO

The Chair (Mrs. Laura Albanese): We have one last presenter for today, via teleconference: Ivan Solano. Good afternoon. How are you?

Mr. Ivan Solano: Good afternoon. I'm fine. How are you?

The Chair (Mrs. Laura Albanese): We're all pretty good, thank you. Where are you calling us from?

Mr. Ivan Solano: I'm calling from [inaudible].

The Chair (Mrs. Laura Albanese): Sorry. Could you repeat that?

Mr. Ivan Solano: I'm calling you from Toronto. I'm from the University of Toronto.

The Chair (Mrs. Laura Albanese): Oh, okay. Sorry, the audio was not very clear and we had not understood.

Mr. Ivan Solano: Would you like me to change phones?

The Chair (Mrs. Laura Albanese): Are you on a speakerphone?

Mr. Ivan Solano: Yes [inaudible].

The Chair (Mrs. Laura Albanese): It may be better, because it seems like you're cutting out from time to time as you're—

Mr. Ivan Solano: Oh, is it? Do you mind if I give you another number?

The Chair (Mrs. Laura Albanese): Yes, that would be fine. Just give us one second. We're consulting our technical team.

Mr. Ivan Solano: Okay.

1640

Ms. Soo Wong: While we're waiting, can I ask a question?

The Chair (Mrs. Laura Albanese): One second. Yes, so while we're waiting, Ms. Wong has a question. Is that a research question?

Ms. Soo Wong: A research question; that's right. The witness Barb Wentworth: In her presentation, she talked about the Consent and Capacity Board. I'm seeing some consensus among members here—I think we need more information. So if we can get more information about this board, the type of staff working for this board, as well as the training. I'm hearing about the whole issue of the knowledge piece of these individuals working for this capacity board, and the access, because it was very clear from this particular witness that the access piece is a concern, and the staff and the lawyers with limited knowledge of DD and what have you. I think if we could get more information about the Consent and Capacity Board, it would be really helpful.

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

Mrs. Christine Elliott: I would agree. I think that was something that I had flagged as well. If we could also get some more information on supported decision-making as well, because I think that can play into it: to allow people to have more of a say in their own life decisions. While they may not be legally deemed to have the power to

instruct with respect to financial or personal care decisions, that they have a say in it directly.

The Chair (Mrs. Laura Albanese): Okay. I believe Mr. Solano is back online. Hello?

Mr. Ivan Solano: Yes, I'm here.

The Chair (Mrs. Laura Albanese): Okay. You'll have up to 20 minutes to make your presentation. If it's shorter than that, we will ask you some questions or make some comments on what you will present to us. You may start at any time.

Mr. Ivan Solano: Just to introduce myself, my name is Ivan Solano. I'm a physiotherapist by training, and I am currently doing my PhD studies at the graduate department of rehab science at the University of Toronto. My research aims to review accessibility in terms of usability contracts to prospective target users. But today, I am not speaking only as a physiotherapist and not just as an academic researcher, but also more importantly as an advocate for kids with learning disabilities, as a father of a child with a learning disability and as a person myself with a learning disability that continues to impact my work and studies.

I shall, just to guide you in my presentation, begin with a brief research background, if you don't mind, on Canada and the impact of learning disabilities.

The Chair (Mrs. Laura Albanese): Yes. I just wanted to ask you: Could you speak just a little bit slower?

Mr. Ivan Solano: Okay. Did you want me to repeat what I said?

The Chair (Mrs. Laura Albanese): No, no, we understood. It's just that because of audio purposes and the way it's coming through, if you speak just a little bit slower, it would be better for everyone. That's all. Thank you.

Mr. Ivan Solano: Okay. I was just thinking of the time. Thank you.

So I shall, again, begin with just a brief research background on the impact of learning disability here in Canada for kids and adults with learning disabilities. Then, I will move on to the real implications for kids with learning disabilities and families with learning disabilities.

Research is showing that kids with learning disabilities are unique and provide the rest of us with a different way of perceiving our world that we normally take for granted. However, stigma continues to be felt, and lack of support, both from the community and, as well, from public offices. This puts a lot of pressure on us, the families and for many of us who are just starting to have families and whose incomes are not even there, and it feels like we are alone in this plight and clueless on how to navigate our way around for resources and help. Fortunately, we are in the rehab field, so we know our way around, and fortunately, my parents were both doctors, so they were able to guide me through this process.

What this meant for many, though, who are not in the same plight, have not been fortunate to get adequate support, is developing a high risk for negative implications.

These were shown in the studies by Mallett, Rosenthal and Keys, identifying learning disability as one of the factors that lead to family conflict and substance abuse in youth who are in Canada.

Also, according to the Learning Disabilities Association of Canada, Canadians with a learning disability are twice as likely to drop out of high school. About 30% of Canadian parents who have kids with LD also reported not being able to afford their kids' learning aids, which is also the same story in our case. As well, Canadians with LDs are two to three times more likely to develop mental health issues and overall poorer mental and physical health, compared to the general population.

A study by Hankivsky in 2008 showed that dropping out of high school does not only hurt the person and the family, but also impacts Canadian society and government in terms of health expenditures, social services, programs, education, employment, increases in criminality and lower economic productivity.

However, the LD impact obviously crosses beyond education and extends to the home. Baker Collins, in 2013, demonstrated the significant impact of childhood events, including struggles with LD in school and their social environment, that increases the risk to adult homelessness. When the homeless participants in the study by Baker Collins were asked what they think were the significant factors in their becoming homeless, 45% said, "Insufficient education." Instead of mentioning missing resources as what could have helped them, more participants indicated that knowledge of the available resources would have been very helpful.

On another aspect of focusing on the results of special education services as perceived by the street youth with learning disabilities here in Toronto, and how their learning was supported or not, Saldanha, in her doctoral study, highlighted the issues perceived by students and youth regarding special education classes, those being the stigma attached to it, and educators not being fully competent to address the learning needs of students.

On the other hand, the youth participants reported that the hands-on participatory and strength-based method of instruction were found to be helpful, as well as having peer support groups, life skills instruction, self-advocacy and, in a way, for the program to become invisible. This implies that the support program does not treat them as highlighting them as special in a negative way but, rather, as kids with different learning needs.

The current reality, which I will be exploring further, is also that there is still a gap in accessing and delivery of resources. A more recent study, by Patterson in 2012, demonstrated that difficulties associated with LD in childhood are potent risk factors for developing a number of adult health and psychiatric problems, including substance abuse.

On a positive note, though, in a 2012 study by Harrison, a program they developed called the learning opportunities task force for post-secondary students with learning disabilities, demonstrated lower dropout rates and a higher academic success rate.

This is what the research is showing, and it is very accessible to everyone.

I just wanted to highlight what it is for the average person. For the real issues that impact us families, as a group, these are some of the comments that I have gathered from my colleagues who have learning disabilities and who have kids with learning disabilities—and also, a desire from the family care office at the University of Toronto and from the focus group of parents with kids with learning disabilities.

One of the comments is that the Ministry of Education could issue clear guidelines on the 13 special education exceptionalities and perhaps even define them in a standard way. For instance, giftedness has no metrics associated with it; everybody comes up with their own definition. Also, people have what's called a disorder—ADD or ADHD—so they get more support in the schools. Many of them feel they are out in the dark, especially those classified as ADD or ADHD.

It takes way too long and too much intentional parent effort—financially, emotionally—for the administrative mechanisms to identify and finally put accommodations in place. So a child with special needs has to have their plans set up in advance, so that when they enter the classroom environment, the set-up for success is already there, and not the other way around, wherein the child experiences the difficulty and stigma, and then only the program starts in place. If there are other special-needs students in the class who have been identified and accommodated, then this often interferes tremendously with the success of the others.

1650

The Ministry of Education could also provide support for the executive functioning problems experienced by many people with learning disabilities and developmental disabilities by purchasing a demonstration syllabus of homework that will help educators, similar to Blackboard but available for different levels of schools.

The Ministry of Education could also coordinate a project to buy electronic textbook licences, so that students could access them from their home and their computer, as this can become very expensive. Dyslexic or blind students could also turn on text-to-voice features for these textbooks.

Class sizes are simply way too big, as well, in publicly funded schools, including Catholic schools. Average size across the board is meaningless in the context of the experience of an individual student who needs to be able to focus with minimal distractions, whether visual or auditory.

Necessary accommodations are also only available occasionally—certain hours per day or days per week—and dependent upon time-sharing of very limited resources, potentially across schools or even just within a school, based on the relative population of students with special needs. Special-needs kids need smaller class sizes.

It is also really hard for parents with kids to find social support for their kids. Many kids with developmental disabilities and learning disabilities have behavioural issues, but that doesn't mean that they cannot play.

However, there are limited opportunities for parents of kids with learning disabilities to have their kids play just like a regular child; they have to set up actual play dates for that, because the other kids wouldn't want to play with them.

Availability and access to comprehensive psycho-educational assessments are also an issue. These take too long, and by the time the kids get assessed a lot of other problems have already started. It would be better if it were very accessible and comprehensive. Also, the psychoeducational assessments offered in schools are only limited to what is already identified, and that doesn't help, because it only identifies what is already known as a weakness, but it doesn't comprehensively assess for strengths which could be used as a way and a strategy to teach the child.

The special OT, PT and ST services—or the occupational therapy, physiotherapy and speech therapy services—are also limited. The disability is not cured; it's permanent, and continuously evolving with the age of the child. The visits, as experienced by my wife, who is an occupational therapist in the community, could range from seven to a maximum of 20 visits, depending on the complexity of the condition. While the visits are geared to provide strategies to the caregivers, when the services end, the caregivers are not equipped with the appropriate skills and knowledge to continue to remediate their own child intervention, long after the PT, OT and speech therapy services have ended.

Also, educators need more training in how kids with developmental disabilities and learning disabilities learn, because we are not the same across the board. It is different, and they cannot just focus on the weakness. They have to give us the benefit of the doubt that we are not stupid or slow.

As a person, as an adult and, lastly, as an adult with a learning disability, it is also difficult to access support from the university through accessibility services, just because my disability could impact my normal life. However, I have never asked for any—I have never required assistive devices for my regular life, such as communication, because I was able to compensate.

However, schoolwork is more mentally intensive, and that's where I'm asking for support. Because my disability impacts my regular life as well, I am not able to access funding or support such as special hearing devices.

I believe that this is it. That's all.

The Chair (Mrs. Laura Albanese): Thank you very much. The presentation was very comprehensive. I will turn it over to the government side and Ms. Hunter for some questions.

Ms. Mitzi Hunter: Thank you so much for your presentation and the energy and the passion with which you delivered it.

I was wondering about your comment about the demonstration learning tools and the need for more of those. You mentioned Blackboard as an example. Do you think that there is enough innovation occurring in this field to develop those types of learning objects for this group?

Mr. Ivan Solano: I can only speak for what's happening in the university level. Yes, there is, but I am not sure about what's happening in the regular school boards, the elementary or the high school level. I could speak to what you say, that yes, it's possible and it does help us, as university students, the support given in Blackboard. It's helpful, but I don't think it's really accessible for students in the middle and elementary school and high school years. I don't think the Blackboard has been developed that much yet.

Ms. Mitzi Hunter: Okay. And you believe that these types of tools and technologies could assist in learning?

Mr. Ivan Solano: I don't think it's what I believe. I think it should always be based on evidence. The ministry or the provincial government could always conduct a short-term study on this, because we do not want to just waste funds; that's very limited already. So it would be good to conduct—if it is effective, and then we could roll out and implement this program. It has to be evidence-based.

What is my experience is that we have been given too many assistive devices that we don't really need and are not helpful. There is not much evidence if it's really helpful. It's just that the people who are selling them to the schools are saying, "Hey, this helps," but then it just becomes another gadget that doesn't actually work.

I believe that the devices for programs that need to be implemented have to be based on evidence.

Ms. Mitzi Hunter: Thank you.

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

Mrs. Christine Elliott: Thank you very much for your presentation, Mr. Solano, and for the emphasis on the educational issues around children and adults with learning disabilities.

One of the things that we've heard is that all children learn differently. Some children are visual learners, some are auditory learners, and then of course there are particular needs related to children with autism. We've heard about children with FASD, and now thank you for the information you've provided us on learning disabilities.

I think one of the things that we need to take a look at—and you mentioned it—is the issue of teacher training. We expect teachers to be experts in all things, and I think that there probably is a need to provide teachers in the classroom with more information and support so that they can do their jobs as effectively as possible. We also heard about educational assistant training over the last couple of days. I think all of those are really important as we go forward. Along with your suggestions, we will certainly take them into consideration. So thank you.

Mr. Ivan Solano: Thank you. Just a point to what you mentioned: I think more than just the training, they need to learn to proceed within the way we do perceive our world, because there are teachers who perceive that providing extra support is a crutch, and I think that's an

obsolete framework. We need support not because we are helpless and we need a crutch but because it helps us. I think teachers, especially the older ones—many of the teachers who are not in their youth anymore are still in that medical disability framework. We are able to, but we need support.

Mrs. Christine Elliott: Thank you.

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

Ms. Cheri DiNovo: Again, thank you very much for your presentation. What particularly stood out for me is that you're speaking as somebody with a lived experience of a learning disability. We haven't had very many come forward who have spoken for themselves; we've had others speak for them. So I want to encourage you in that regard because I think there's a great need to hear from folk themselves who experience developmental disabilities of whatever—and yours obviously are not as severe as many of the others we've heard from. So thank you for that.

Second of all, just to pick up where Ms. Elliott left off, we definitely heard about the lack of training, though, for educational assistants, particularly where those on the autism spectrum are involved. I know that you're eloquent in saying to see the world through, in a sense, different eyes, but out of your research, are you going to be making specific recommendations of what that training might look like? Because I think that would be very helpful.

Mr. Ivan Solano: Yes. Despite the focus group at U of T, we are doing our own advocacy and will be making our own recommendations, yes.

Ms. Cheri DiNovo: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. That's wonderful. Once again and finally, a last thank you on behalf of all the members of the committee and good luck with your research.

Mr. Ivan Solano: Thank you. I just wanted to speak to what was mentioned. I don't know; it might not be here—I think it's very challenging. That's why I still need support and I took longer than usual to finish my degree. But why I'm doing this, even though it's difficult, is because I wanted to show kids with learning disabilities and parents with learning disabilities and the government that we are capable and we are very much capable, that we cannot just be homeless or unemployed. We have more use to this society than what used to be expected of us.

The Chair (Mrs. Laura Albanese): And you have every right to a very productive life and a happy life. Thank you.

Mr. Ivan Solano: Thank you.

The Chair (Mrs. Laura Albanese): Bye.

Mr. Ivan Solano: Goodbye.

The Chair (Mrs. Laura Albanese): And we are adjourned until tomorrow morning at 9 a.m.

The committee adjourned at 1701.

SELECT COMMITTEE ON DEVELOPMENTAL SERVICES

Chair / Présidente

Mrs. Laura Albanese (York South–Weston / York-Sud–Weston L)

Vice-Chair / Vice-Présidente

Mrs. Christine Elliott (Whitby–Oshawa PC)

Mrs. Laura Albanese (York South–Weston / York-Sud–Weston L)

Mr. Bas Balkissoon (Scarborough–Rouge River L)

Ms. Cheri DiNovo (Parkdale–High Park ND)

Mrs. Christine Elliott (Whitby–Oshawa PC)

Ms. Mitzie Hunter (Scarborough–Guildwood L)

Mr. Rod Jackson (Barrie PC)

Ms. Sylvia Jones (Dufferin–Caledon PC)

Miss Monique Taylor (Hamilton Mountain ND)

Ms. Soo Wong (Scarborough–Agincourt L)

Substitutions / Membres remplaçants

Mr. Jack MacLaren (Carleton–Mississippi Mills PC)

Clerk / Greffier

Mr. Trevor Day

Staff / Personnel

Ms. Erica Simmons, research officer,
Research Services

CONTENTS

Tuesday 14 January 2014

Developmental services strategy	DS-287
Ms. Carrie Groulx	DS-287
Mr. Greg Bonnah	DS-290
Ms. Helen Leask.....	DS-292
TIPES.....	DS-295
Ms. Jennifer Wyatt	
Dr. Jeff Sherman	
Mr. Mick Kitor.....	DS-298
Rev. Maggie Helwig	DS-302
Ms. Silvana Cacciatore; Mr. Brian Jacques; Mr. Ken Maclam.....	DS-305
Ms. Brenda Parris.....	DS-308
Ontario Association of Residences Treating Youth; Partners in Parenting.....	DS-311
Ms. Christine Rondeau	
Ms. Cindy Walker	DS-314
Ms. Marilyn Leiterman	DS-317
Sioux Lookout First Nations Health Authority	DS-319
Ms. Janet Gordon	
Ms. Diana Brammall	DS-321
Dundas Living Centre	DS-324
Ms. Martha Fox	
Mr. Geoffrey Shea.....	DS-328
Ms. Lois Hacio.....	DS-330
Ms. Patti Zimmerman; Ms. Jan Hudyma	DS-333
Ms. Barb Wentworth.....	DS-337
Ms. Connie Harrison	DS-341
Mr. Ivan Solano.....	DS-343