



Legislative Assembly
of Ontario
Second Session, 40th Parliament

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

Official Report of Debates (Hansard)

Friday 17 January 2014

Journal des débats (Hansard)

Vendredi 17 janvier 2014

**Select Committee on
Developmental Services**

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

Developmental services strategy

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**

Friday 17 January 2014

Vendredi 17 janvier 2014

The committee met at 0900 in the Marriott Inn, Ottawa.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Good morning. I call the Select Committee on Developmental Services to order. We are in Ottawa, the nation's capital, so good morning to Ottawa and to all the people who are here in the room to hear our committee today.

MS. DONNA THOMSON

The Chair (Mrs. Laura Albanese): I want to call up our first witness, Donna Thomson. How are you today?

Ms. Donna Thomson: Very well, thank you.

The Chair (Mrs. Laura Albanese): You will have up to 20 minutes for your presentation. If it should be any shorter, that will leave some time for questions or comments by the members of the committee. You may start at any time you feel comfortable.

Ms. Donna Thomson: Thank you for the opportunity to address the Select Committee on Developmental Services this morning. My name is Donna Thomson, and I am a mother, author, advocate and teacher. My husband, Jim Wright, and I have two children, Nicholas and Natalie.

Our son, Nicholas, is 25 years old and has severe, complex disabilities: cerebral palsy, severe scoliosis, epilepsy, mild developmental disability, chronic pain, gastric dysfunction, low vision, severe sleep apnea and osteoporosis. Nicholas's disabilities and chronic health conditions mean that he does not walk, is non-speaking, tube-fed and largely confined to bed. I will tell our story briefly.

Nicholas has had 76 hospitalizations and nine major surgeries. At first, Nick's emergencies were mostly gastro-related, but later, orthopaedic complications related to his hip and spine were the cause of acute pain. Nerve blocks and a surgically implanted spinal cord medication pump were tried to no avail. The nerve blocks caused painful nerve damage, a situation not alleviated by oral medications, including morphine.

About this time, Nicholas was diagnosed with severe, untreatable sleep apnea, and he was discharged to the palliative care team at our children's hospital.

Nicholas's care was impossible for me to manage at home. Overnight, Nicholas required hands-on care every 10 to 20 minutes. My husband and I were exhausted, not only from nursing Nick intensively since his birth, but also from struggling to access whatever limited services and funding we could.

The local coordinated access committee heard our case several times and declined further assistance. We had availed ourselves of the maximum allowable community resources, but that assistance barely touched our needs.

I reported to a community nurse that Nicholas's pain was uncontrolled and the prescribed medication was having little or no effect. When I expressed concern about possibly over-medicating my son to calm the pain, children's aid was called in to investigate our family.

The children's aid caseworker found our family to be loving and responsible, but at risk due to a lack of home help for Nicholas's very high needs. At that point, children's aid became our sponsor in the appeal process, and via the office of the child advocate, our case went to the IMPAC committee.

After several reviews at that level, we finally received a funding package that met our needs. By this time, Nicholas was 17. We chose to direct that funding to the Ottawa Rotary Home, a local children's respite facility. They staffed our home as they would one of their in-patient clients. Like many families today caring for very high-needs loved ones in Ontario, we were forced to fail badly before we were allowed to succeed.

Nicholas is now 25, and the story of his adult support is long, so I won't go into it here. But I would like to share with you that Nicholas has a wonderful life. He lived with us until 2011, at which time he moved into the Ottawa Rotary Home. There, he is thriving with the aid of loving and professional support staff who meet his medical needs and challenge him to pursue his many interests, from his sports blog to supporting his beloved Ottawa Senators hockey team. He has a very busy and fulfilling life that engages family and many friends. In short, Nicholas is an inspiration to all and a contributor to his community.

Since our son was born, I have advocated for the assistance I believed Nick needed. Many service providers, government officials and medical professionals have helped Nick and our family over the years. Everyone

wanted the best for us, yet at times it seemed as if we were speaking different languages. It was as if we were all birds in the same nest but arguing about how to fly. In the end, coordination and co-funding between the Ministry of Health and the Ministry of Community and Social Services provided an answer for our family.

But inter-ministerial coordination alone will not solve the varied and complicated problems of children and adults with disabilities in this province. Ontario's demographics are changing. We have a population that is aging into disability. At the same time, we have the first generation of children with disabilities, raised in family homes, who are surviving and aging. Many of these adults with disabilities will outlive their parents.

There is one constant in all these scenarios: families and family caregivers.

British social change expert Charles Leadbeater said, "Your vantage point determines everything you see." All of you on this committee have heard from people with very different vantage points on Ontario developmental services. I have read through all of the Hansard testimony, and the most frequent question from the committee members was, "If you could change just one thing, what would it be?" The search for a simple answer is perfectly understandable, given the daunting task before the committee, but I believe that nothing will effectively change if we approach this very complex problem by changing just one thing. We require a holistic approach that engages and leverages the assets of all levels of society. That approach needs to address the needs of families with very high medical needs through to milder, but lifelong, support requirements.

None of us know what to do to correct our systemic problems and how to alleviate the stress on families. There are pockets of success in the province and some models of good practice, where families who know what their children need have managed to create solutions. But these few success stories are not well known. We must learn how to scale that success and make those effective solutions available to all who need them.

In order to scale innovative solutions, families, government officials, service providers, the private sector and concerned citizens must develop a shared vantage point. I believe that shared vantage point should be the goal to support families in looking after their loved one with disabilities, from birth to death.

Every family will have a different idea of what kind of life they value for their son or daughter with a disability, and for the family as a whole. As with all families, that idea of what constitutes a good life will change over time. Supporting families in such an individual and fluid way is an extremely complex challenge.

But Ontario has a history of brilliant innovation in the disability sector. The electric wheelchair was invented here. So was the Henson trust.

The RDSP is a perfect example of government working together with families to leverage collective assets with the aim of supporting someone with care needs. The fact that government does not track expenditures of the

person with a disability reflects a recognition on the part of government that people spend money on what they need, in the most efficient way possible. It recognizes that people with disabilities and their families do not belong in the welfare system.

0910

The Special Services at Home program is another model that recognizes the capabilities of families to use their financial assistance creatively and wisely. It is extremely popular and over-subscribed because it supports families in the family home.

The private sector in Ontario can support our families. An innovative corporate social responsibility strategy that rewards employees with caregiving responsibilities to give back to society by looking after their own is one idea worth pursuing.

We need to build on our history of bold innovation in Ontario, and we have the opportunity to do that now. You will be familiar with the new MaRS Discovery District Solutions Lab in Toronto. The mandate of the Solutions Lab reads as follows:

"The MaRS Solutions Lab develops new solutions to improve the lives of people and strengthen the resilience of society. As a change lab, we bring together governments, corporations, non-governmental organizations, foundations, academia and the greater community to help unravel complex problems from a citizen's perspective. We collaborate with partners to develop, prototype and scale new solutions."

The Solutions Lab has already been asked by the Ontario government to propose innovative solutions to the problem of wait-lists for supported housing for adults with developmental disabilities. But housing is only one issue you have heard about in these hearings. The problems facing our families are much more complex and varied. I believe the Solutions Lab is an excellent place to begin seeking answers to our collective needs, but the lens of their inquiry must be much, much broader. The lab should be examining ways in which multiple partners across Ontario society can collaborate to support our families giving care.

Another creative Ontario model of complex problem-solving in society that could assist us find ways of helping families thrive is—it's not an Ontario model, sorry—Grand Challenges Canada. The Grand Challenges model solicits great ideas, tests them out and provides assistance to scale them to the wider population. We need this approach for Ontario families because currently none of us knows how to fix our problems.

The stories you are hearing reflect complex problems that are intertwined with other complex problems. Every solution and good idea in action you have heard about is just that: one good idea for a single individual or a single community. Government is constricted somewhat in its ability to innovate by the imperatives of accountability, transparency and privacy. Those concerns are important to ensure the public trust, but the clock is ticking and Ontario families need solutions now.

The issues before you are not just about services; they are about helping families to thrive. The Ontario govern-

ment must set the tone and agenda for real change in order to provide hope for the future to families supporting a son or daughter with disabilities. This committee has the unique opportunity to provide inspiration for just such change. I have changed my thinking about disability and possibility; I hope you will too.

If there's one thought I'd like to leave you with today, it's about value: how society, the government and everyone values our children with disabilities. There is a lot of talk about our children and how much they cost. I can tell you that my son will never be employable and it costs the taxpayer a great deal of money to maintain his very life. But I would say that the value of our children is directly related to the value of all the families who love all of our children. It's not just about the value; we can value our children as much as we value all of the families who support us. I value my son. I love him. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for your presentation this morning. We have about a couple of minutes for each party to comment. Ms. Elliott.

Mrs. Christine Elliott: Thank you very much, Ms. Thomson, for your very thought-provoking presentation today.

I want you to know that we value your son too. We value all of the sons and daughters of all the parents who are here today. We recognize there are a series of concrete problems here that we need to solve: respite, residential issues, day programs and all the rest of it. But more than that, we are trying to see the bigger picture too, and we're trying to make sure that we can incorporate everyone into our society, that everyone has a place and that we recognize the unique abilities of every individual. It's not about what someone contributes in a monetary sense to society; it's about what they contribute to make us all better people, and all of your sons and daughters do that. I just want you to know that we are thinking through that lens as well.

Ms. Donna Thomson: Thank you. I would also like to say that this question is about much, much more than just services. We need a cross-sector approach to address all of the life issues that families face in trying to meet the challenges that they face on a daily basis. Our children are not just about services either.

Mrs. Christine Elliott: We agree. Thank you.

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

Ms. Cheri DiNovo: Thank you very much for your story and for sharing your pictures, as well. Absolutely, every single human life is a life of value and dignity.

One of the themes that we've heard over this last week and before that is that this is a system in crisis, veering from crisis to crisis, rather than a system that actually provides—not just about services, but provides a quality of life for families with children with developmental disabilities which all families should experience. We want for your children what we want for our own children. All children should be treated with that degree of dignity. So I want to assure you of that.

Also, we're looking at possible jurisdictional solutions too. There are other jurisdictions that do things different-

ly and, some would say, better, so we're looking at some of those; for example, some that have no waiting lists for services. That might be a way to go. We don't have time to do it now, but if you think about other jurisdictions that do things better, if there are any of those examples, we would love to hear from you as well.

Ms. Donna Thomson: Essex county, for example, had an innovative model that they proposed to this committee that involved the municipality and other organizations. There are good models out there. We don't know how to scale them. We have MaRS Discovery District Solutions Lab, which is prepared to look at complex social problems and figure out ways to scale them.

Single solutions do not work for the range of issues that families face. That's why we need very, very clever, innovative people who are specialists in innovation and design to figure out how we can provide a good life to somebody with a mild developmental disability in northern Ontario and somebody with high, high, complex needs in another part of the province. These are complex problems, and they're going to require a way of going about finding the answers that we have not done before. If you want a solution that you've never had before, you have to approach it in a way that you've never approached it before. That is what I am asking this government to do.

Ms. Cheri DiNovo: We just want to thank you for your expertise. We've heard from a number of families who have provided some phenomenal expertise in this area, so we want to thank you for yours.

The Chair (Mrs. Laura Albanese): We'll go on to Ms. Hunter.

Ms. Mitzie Hunter: Thank you so much for bringing Nicholas's story to our committee and for the ideas that you've suggested.

The MaRS Discovery District: You're right, they are a centre of innovation in this province and we should be tapping into that. I know that the committee has heard that recommendation, and we will follow up and make sure that we bring that to bear as we do our work.

0920

I also want to emphasize that we are looking broadly. A lot of the solutions that have been brought forward go even beyond Ontario into other parts of Canada and even internationally, so our scope is quite broad for the work that we're doing in terms of really looking at strategies that can help to strengthen our system of supports across a lifetime for people with developmental disabilities and dual diagnosis. That's something that we're taking into account as we prepare our recommendations.

Listening to families, to parents, to the community is a key part of the work that we're doing as a committee, as well as to the experts, so we're bringing it all in, and we are committed to doing the best job that we can to improve the system.

The Chair (Mrs. Laura Albanese): Thank you very much, again, from all of us for your presentation this morning.

Ms. Donna Thomson: Thank you.

UNITED FAMILIES OF EASTERN ONTARIO

The Chair (Mrs. Laura Albanese): We will now call upon the United Families of Eastern Ontario to come forward. Good morning.

Ms. Suzanne Jacobson: Good morning.

The Chair (Mrs. Laura Albanese): You can make yourselves comfortable. Whenever you feel ready, you may begin your presentation.

Ms. Jocelyne Brault: Good morning.

The Chair (Mrs. Laura Albanese): If you could please introduce yourselves beforehand.

Ms. Jocelyne Brault: My name is Jocelyne Brault. This is Suzanne Jacobson at my right and Amanda Telford on my left. We are members of the steering committee of United Families of Eastern Ontario, also referred to as UFEO.

UFEO is a coalition of individuals and over 20 family-focused groups committed to improving the lives of all children and adults living with a developmental disability in eastern Ontario. Our membership includes Autism Ontario, the Down Syndrome Association, Family Alliance Ontario, Community Living and the Ontario Rett Syndrome Association, fetal alcohol spectrum and so on, and we represent thousands of individuals and families in our region.

Our vision is for individuals with developmental disabilities to have the same choices and opportunities as the rest of Ontarians. As an organization, our vision is that all people with developmental disabilities have access to the necessary supports and services they need in order to have access to the same opportunities and choices as other Ontarians, thus enabling them to participate to the fullest extent possible in their community and in society throughout their lives.

We are very pleased and very grateful to appear before this select committee today. Although we acknowledge that much has already been said by those appearing before this committee concerning the problems confronting the developmental sector, we would like to summarize our main concerns before discussing some possible solutions.

The system, unfortunately, has become a system of wait-lists and gaps. In the children's system in eastern Ontario, there is a wait-list to get diagnosed of about 24 months. Children are not being identified at the first sign of a developmental delay. After being diagnosed, there is a wait-list to receive treatment, as long as two years, in eastern Ontario. Then, there's a wait-list to receive psychiatric assessment, treatment and continued support at home for children who have a dual diagnosis. Then, there is a wait-list to receive Special Services at Home funding to assist parents to pay for costly services and respite, and it's about five years long. Then, there is another wait-list and gaps to have access to recreational activities and camps, especially for children who have challenging behaviours.

In the adult system in eastern Ontario, there are waiting lists to get assessed by Developmental Services Ontario at the age of 18. Once assessed, there is another

wait-list to have access to funding from the Passport Program that assists people who need support to get integrated and participate in their community once they finish school. There is a waiting list for funded day programs. There is a waiting list for funded residential options, and there is a gap in educational opportunities and training for employment. Then, there's a wait-list and gap in accessing psychiatric assessment, treatment and support, again for people who have a dual diagnosis.

We are all aware, unfortunately, that these problems will only get worse with time if we do nothing.

The establishment of this much-needed select committee shows that our government recognizes this growing problem and is committed to take action. For that we are grateful.

We encourage you, as you consider the policies and programs that are needed, to keep in mind these four principles:

All people with developmental disabilities will have access to the supports and services they need in order to have access to the same choices and opportunities as other Ontarians their age. I'm talking about the right to receive service, just like the right to receive education or the right to receive health care.

All people with developmental disabilities need to be identified immediately—immediately—in order to receive immediate supports and services that they need in order to reach their maximum potential.

All people with developmental disabilities will receive supports and services, from cradle to grave, with no interruptions during all transition periods: from a child entering school, a child entering high school, the adult sector, finishing school and so on and so forth. Right now there are gaps at every transition period with nothing for parents to rely on.

And finally, all people with developmental disabilities need to have the right—they need to have the right—to receive these supports and services throughout their lives in order to plan for a stable future, and continue to have access to the same choices and opportunities as other Ontarians.

These principles are not new; they are enshrined in the UN Convention on the Rights of Persons with Disabilities, which Canada ratified in 2010.

The Ontario government also stated in their 2006 document called Opportunities and Action that, “The fundamental vision is to support people to live as independently as possible in the community and to support the full inclusion of Ontarians with” developmental “disabilities in all aspects of society.”

Ontario and Canada are not alone in facing this challenge. There is a very good example of another first-tier nation that has been successfully meeting this challenge for several decades, and that country is also a federal system. That country is Germany, which has had its own share of fiscal obstacles, as Ontario is facing at the moment. We understand there are differences between the two countries, but there are also many similarities, and I would suggest that there are more similarities than differences.

I had the opportunity to go to Germany four years ago to go and have a look at the system. I spent a lot of time in two working environments, two workstations for people who were adults, and also talking to a parent. The highlight of the trip for me was the fact that there was no wait-list.

I was able to ask the parent, “When the child was diagnosed, what happened to her?” There is a team that goes into the family that assesses the needs of the child. After that, the needs of the child are taken care of, whether they need treatment, rehab, speech therapy or respite care as needed for the service. They are taken care of and supported from cradle to grave. When the child enters school, the types of programs they are offered—once the child finishes school, there is a two-year training period, if the child is able, to train to provide to have a job in the workplace. If the child is too severely disabled, they work in a sheltered environment.

Business is on board. By law, businesses of a certain size have to hire so many people with disabilities. If they are not able because of the nature of the industry, they have to provide work for them in the sheltered workshops. If that is not necessary, they have to pay a certain amount of money to help that system continue.

In Germany, they’ve had this system in place for decades. For every German person who you speak to, it’s as—they’ve always been there; it’s as normal as anything else in their community. They know they’re there; they know they work. They are part of society. They are not an outside group; they are really part of society.

I think we need to look at models that would take into consideration the four principles that we have outlined. These models have worked for decades—they’ve ironed out the problems—and we need to look at them. This is probably not the only model that works, but it’s certainly the model that I have experienced. The parents are certainly not stressed the way we are.

0930

I must say that this parent was shocked to find out, in Canada and in Ontario, the amount of wait-lists that we have to contend with. I kept asking her, “Do you have a wait-list to get this treatment program?” She kept saying, “No.”

I kept asking. I said to my friend who interpreted for me, “Please ask her again: ‘What do you mean, there’s no wait-list? Do you not have to wait a few months, a few years?’” She kept looking at me like I was having some difficulty understanding what she was saying to me, and kept telling me, “No, there is no wait-list.” This was at every transition, and it was overwhelming for me to listen to this and to see how much we struggle here.

I understand that everybody wants the best. I know that all members of this committee here want the best for our children; I really, truly believe that. But I truly believe as well that we need to look at other models, to see how we could incorporate them in our system here, to become more efficient and to have a quicker solution to the problem, obviously. Time is of the essence here.

At this point in time, one area that has not been addressed in the committee overview is the significant

difference that early identification and intervention make on cost savings. Suzanne Jacobson will cover that aspect.

Ms. Suzanne Jacobson: Thank you, Jocelyne.

Madam Chair, I sit on this committee representing the children with the United Families of Eastern Ontario. We want to bring to the committee’s attention that it is critically important, in developing your strategy and recommendations, that the committee also focus on early identification and intervention.

In reading your focus elements on education, recreational needs etc., it became immediately apparent that there is a potential for a major gap in strategy of care for persons with a developmental disability.

The gap that we are referring to is from the infant stage to the preschool stage. The earlier a child is identified—at the first signs of a developmental delay—the earlier the child receives effective intervention and the better the life outcomes. Better outcomes mean a reduced cost in the need for services, which of course is a great savings when we’re trying to deal with the huge numbers of children. And it’s not just about the costs. It’s also about the quality of the individual’s life, and the life of the families.

I’d like to share with you briefly the story of my two grandsons, Alex and Nathan.

Alex is nine years old today. He has received many, many services through our public system: his assessment and diagnosis; several blocks of speech therapy; occupational therapy; intensive behavioural intervention, or IBI therapy, at 25 hours a week; and Transitions for six months. He had a full-time aide with him in the regular school system.

All of these services were provided after months and years of wait times. Alex regressed, behaviours became ingrained, and the window of opportunity was missed.

Alex was showing classic signs of autism by 15 months of age, yet he was 20 months before he was identified, and 30 months before he was diagnosed. He waited almost a year for speech therapy, and 10 months for occupational therapy, when he was self-injuring. He was four and a half years old when he began the intensive behavioural intervention therapy. Alex is now in an autism classroom with six children, two aides and one teacher.

The costs of services for Alex in his short lifetime has been great, and it will continue for the rest of his life.

His brother, Nathan, on the other hand, who is now six, was identified at 18 months and diagnosed at 21 months—not because he was more severe, but because he was being assessed through a sibling study every three months. This time, we knew what we needed to do. While privately paid for, Nathan began weekly speech therapy immediately, and I mean a week after he returned from Toronto. Within three months, his language skills had gone from a seven-month-old level to an 18-month-old level. His social skills were blossoming.

By age two, he was in a private intensive behavioural intervention program, for just 12 hours a week. By age four and a half, Nathan no longer required his intensive behaviour therapy program. As he came to the top of the

wait-list for the IBI therapy two years later, he had improved too much; he did not qualify.

While Nathan still has some speech therapy, he is in his local school in grade 1, without an aide, and his recent report card said “strongly performing at the grade 1 level.”

The costs of services for Nathan have been a fraction of those for his older brother, Alex, and Nathan has a real prospect of becoming a very productive member of society.

While this story of Alex and Nathan is on autism, we know that all developmentally delayed children will improve with early identification and effective intervention.

Madam Chair, we encourage you and your committee to expand your area of focus by just two more years in the lifetime of these individuals to include the period from infancy to preschool. Action in this early period will pay positive dividends out of all proportion to the costs of the support and services for this very young age group.

In closing, we applaud this initiative and encourage you, our government and members of all parties that represent Ontarians, to make a conscious decision and put in place the policies and programs that would respect the principles of timely and equal access for all developmentally disabled Ontarians to the supports and services they need and will need throughout the full extent of their lives.

The Chair (Mrs. Laura Albanese): Thank you very much for your thoughtful presentation this morning. We do have just under a couple of minutes for each party. Ms. DiNovo?

Ms. Cheri DiNovo: Thank you so much and thank you again for talking about some of the solutions. The success story of Nathan is a very, very rare one that we’ve heard in this committee, and it points the way to what we should be doing, absolutely. We are in a crisis model here, where only families in crisis get looked at, where wait-lists are administered and endless assessments are done with no hope of anything coming out of them. We get that this is a system in crisis, so I thank you for that.

I loved your point about moving from what’s been considered a welfare discretionary system to a system of entitlement, just like any other health care system. If you walk into a hospital, you get treated. Hopefully, there’s no wait-list for that, even though that’s become a problem, too. And I liked the German example.

We also heard that in Saskatchewan there is mandated no wait-lists—so a little closer to home. There are lots of examples of how to do it better and I thank you for raising them with us.

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

Miss Monique Taylor: Thank you so much for your presentation and for being here with us today, and for all of the work that you’re doing on a continuous basis, for knowing the need that is out there for families. What a story. We have perfect proof right there between Alex

and Nathan: the differences between receiving those services on time and not.

Definitely, the wait-list is something that we’ve been hearing about. We are hearing from other jurisdictions that there are no wait-lists and families are succeeding and they’re not stressed out like we are here in Ontario. It’s really a sad state when we see that with every family we talk to, it’s assessment after assessment, it’s wait time after wait time, it’s one challenge after another challenge. It’s unfair, it’s not right, and we’re determined here to try to make life better for you. Thank you so much again for all of your efforts and for being here with us today.

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

Ms. Mitzi Hunter: Thank you so much, on behalf of the families, for sharing your stories. Certainly, the example that you’ve given of the German model is one that we have heard and we need to take a closer look at. I also appreciate the recommendation that the supports are from cradle to grave, as you said, and that they should be seamless in terms of the transition points—particularly on the impact on the child as well as the family.

I also have noted the power of early identification, diagnosis and treatment, and, really, the lasting effect that that has on the child, but also on the pressures that it creates on the system itself. We really need to look at it from that whole perspective. I just want to say thank you for that.

I believe my colleague has a comment.

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

Ms. Suzanne Jacobson: May I just interject briefly here? There is a study from UC Davis that shows this. The research shows they are changing the brain of the child when you intervene right away, and I’m happy to leave that—

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

Ms. Soo Wong: Thank you for sharing your experience and sharing your expertise with our committee.

We know, we have heard and we also hear from the experts about early intervention and early diagnosis, but wearing my previous hat as a professional in health care, there are some parents who are reluctant to have that early diagnosis and that label. From your experience with some of these families, what suggestions or considerations should this committee consider—because not every family is ready for that type of early intervention.

0940

Ms. Amanda Telford: A province-wide public education campaign about the early warning signs of developmental disabilities.

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

Ms. Suzanne Jacobson: I’d like to mention as well that I am in talks with doctors. They’re very uncomfortable with making a diagnosis and a referral. They also know there are long wait-lists, and they want to get the help to the child. If we just follow those developmental milestones and if the doctors were made more aware of it at that one-year checkup where we have the Nipissing identification tool that can begin right from two

months—so at that one-year checkup, the doctors are aware of what they need to be looking for. They're not dismissive or, "Oh, let's wait and see. He's a boy, and boys are slower. We can wait." No. If they're not meeting the developmental milestones, you must act immediately.

For those parents—no one wants to hear any concern. I don't want to hear that my child might have a hearing problem, a sight problem or whatever, but if we, at those first signs—if it was a speech problem, then let's link them up right away with a speech pathologist. Let's see what's going on here. Is this a cultural thing? Is this the way the family is at home, or is there something more going on here? We don't treat cancer by saying, "We think you have cancer. Here's your surgery date, your radiation date and your chemo date." We say, "We think you might have cancer," we do further tests, and the course of treatment evolves based on the information that we get. That doesn't happen in autism and in the system for developmental disabilities.

That's a good way to get these parents here. Right now, the savvy parents are the ones whose kids are being picked up, and the others are falling by the wayside.

The Chair (Mrs. Laura Albanese): Mr. MacLaren, I believe you had some comments you wanted to make.

Mr. Jack MacLaren: Thank you. Mrs. Brault, thank you very much for being here, and thank you to the other ladies with you on your committee. I first met you about a year ago when you came into my office. I was most impressed with your presentation, which was very much what you said today, that you have lived with your daughter, who was severely handicapped—as have other people in your group.

In recent years you've had time to do research, work and to try to make things better for others. We all really appreciate that very much. You've gone to the trouble to form your committee. You've gone to the trouble to travel to Germany and come up with ideas, and I know you've considered many other models. You've been working very hard along with all the other ladies who have helped you. You came to Queen's Park and we introduced you to Christine Elliott, our health critic. I just want to thank you for all the work you've done. I want you to know that it has made a big difference. We hear you. Your ideas are great and we will certainly be considering them very thoroughly and completely, and they help us to do a better job.

I want you to know also that this committee—all of us are here because we know we're not doing a good-enough job. We are failing the disabled people and families of Ontario. We hear that across Ontario. We've been on a road trip this week around Ontario, to the north, and not just Toronto and Ottawa. Whether we're in Moosonee, Thunder Bay, Toronto or Ottawa, the problems are the same: Government is not doing a good-enough job. We hear that from you and we've heard that everywhere. We are here, all of us, to try to do better.

I guess I would sum up by saying that as a caring society we have a responsibility to help those who can't

help themselves. I think that sums it up pretty well. Thank you for being here.

Ms. Jocelyne Brault: You're welcome; thank you.

Ms. Amanda Telford: And thank you for the committee.

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

Ms. Jocelyne Brault: I just wanted to add that UFEO has made a video that depicts the life of a family living with a child with a developmental disability. We will submit that with our written presentation. It's four and a half minutes. It's not very long but I think it's very telling.

The Chair (Mrs. Laura Albanese): That would be wonderful. Thank you again for presenting to the whole committee this morning. We really appreciate your ideas and your insight.

Ms. Suzanne Jacobson: Thank you for the opportunity.

FETAL ALCOHOL SPECTRUM DISORDER GROUP OF OTTAWA

The Chair (Mrs. Laura Albanese): We'll call now on the Fetal Alcohol Spectrum Disorder Group of Ottawa. Good morning. Please make yourselves comfortable. As you have heard, you will have up to 20 minutes for the presentation. Please begin by stating your names. You may begin anytime.

Ms. Elspeth Ross: Thank you. My name is Elspeth Ross, and I'm here today with Barbara Sabourin. We represent the Fetal Alcohol Spectrum Disorder Group of Ottawa, not the coalition of Ottawa. I co-facilitate our group with psychologist Dr. Virginia Bourget. We have been meeting at CHEO, the Children's Hospital of Eastern Ontario, since 1999. I am also a member of the FASD Coalition of Ottawa and FASD ONE, Ontario Network of Expertise, two working groups. I work as a volunteer educator in FASD, providing current awareness by emails internationally via the Yahoo listserv FASD-Canadian-News.

Perhaps my best qualification to speak to you today is as a parent. Our story is different from many because in 1981, when we adopted our first son, we were told about prenatal alcohol and advised to look for help. We later adopted a second fetal-alcohol-affected older boy from Saskatchewan. Many birth, foster and adoptive families simply don't realize that their child is affected or has a developmental disability.

We see from your transcripts that four of the ministry people who spoke to this committee mentioned FASD, but only in passing. The speaker for children and youth services mentioned FASD with autism on October 30. On November 13, the person from education spoke of FASD with ADHD. The Attorney General/correctional services spoke of it with mental illness. Aboriginal affairs mentioned one program. No researcher or speaker for agencies such as Community Living has mentioned FASD at all.

We are glad that some of our colleagues have spoken to you about FASD in London and Thunder Bay, and we won't repeat too much. I refer you to our fact sheet, which you're getting, What is Fetal Alcohol Spectrum Disorder?

FASD is an umbrella term that describes the range of effects that can occur in an individual who was prenatally exposed to alcohol, and it includes fetal alcohol syndrome. These effects can include lifelong physical, mental and behavioural difficulties and learning disabilities. FASD is a developmental disability. Most people have not FAS, but ARND, alcohol-related neurodevelopmental disorder. People talk well and present well and look like everyone else, but they have invisible brain damage.

The Public Health Agency of Canada has used the prevalence rate of 1 in 100 for FASD since 2005. The annual cost of FASD in Canada has been estimated at approximately \$7.6 billion. See our fact sheet.

No two people with FASD are the same, but they are all at risk for school difficulty, mental health issues, difficulties maintaining employment, and addictions. Common challenges are with executive functioning: judging, planning, delaying gratification, consequences, organization, impulsivity and memory. Supports and services and tailored programming make a difference. People with FASD need an "external brain" to help them with daily life. They have many talents and skills, and we build on these to maximize potential.

My sons with FASD are now 34 and 31. They were labelled with ADHD when they were young and always got special ed, which helped a lot, although it was not always appropriate. We didn't have to fight for it in those days. Both graduated from high school and one graduated from college. Both are good drivers, although one has lost his licence. My older son has never had behavioural problems and was married for about seven years. Both work part-time in summer in brick and stone with the same long-time boss. They live together in a second house on our property. It is not independence, but interdependence. One has ODSP support. One has diabetes, type 2, so there are health concerns.

We're in constant touch and help them with money management, keeping important documents, filling out forms, understanding time, scheduling and reminding about appointments (that's the external brain), taking them to doctors—yes, I go in with them—and buying groceries.

Problems with the law have been minor. A policeman who knew about FAS—yes, one—tore up a summons for my younger son when, at 17, he was caught shoplifting from a store at 2:30 after going there for a job interview at 12 noon. Does that make sense? Impulsivity. We get letters from collection agencies demanding payments for sums like \$237, again for something that my son doesn't know anything about, he says—maybe getting on a bus without paying or something like that. He lost an apartment funded through ODSP because his supposed "friends," met on the street, moved in and caused trouble. Then my son said, "Well, it could happen again."

0950

They are in some ways at the top of the spectrum, although neither is working at the moment. A second house helps, but unfortunately, most families do not have that advantage.

As with other developmental disability families, we also need to plan for the future: Who will look after them in the future?

Our FASD Group of Ottawa and a support group at Wabano aboriginal health centre are the only specific FASD services in Ottawa; both are volunteer. When parents find out there are no designated services for FASD, some are not willing to try for a diagnosis, since they say it would be stigmatizing and would get nothing.

There has been FASD training in Ottawa, but contacting any agency for help will not necessarily get you to the right people.

Parents have to educate themselves about FASD and ask for help for their child's symptoms. As parents, we are training professionals one at a time and need to be vigilant, because professionals often see only the behaviour and not the brain damage.

A professional study from FASD stakeholders, *Moving Forward*, in 2008 found that the biggest needs of families are help with schools, finding respite, help with transition to adult services, finding supported living and employment—sounds familiar to everybody—but found a lack of trained professionals who know and understand FASD.

Most affected people have an average IQ, or even higher, and don't qualify for DSO supports; they're considered high-functioning. We can't get by the gatekeeper in Ottawa—Service Coordination—to get programs.

We need acknowledgement from the province and from agencies that FASD exists. FASD ONE is calling for a provincial FASD strategy. Ontario should take note and work on prevention, because there's going to be more FASD in future. Women are drinking almost as much as men, and binge-drinking is up for young women and those up to 35. Some 50% of pregnancies are unplanned.

The Ontario Select Committee on Mental Health and Addictions, to which five of us in FASD spoke across the province in 2009, had only one line on FASD in its final report, that "individuals with autism, eating disorders, fetal alcohol spectrum disorder, or a dual diagnosis are orphaned by a system that seemingly has no place for them"—page 1.

But the interim report included things that we're putting in our recommendations to you today. On page 31, it says that "FASD has 'orphan' status, as no ministry assumes responsibility for it, and it lacks an OHIP billing code."

Nothing has changed. We need the same services as other families in this province with developmental disabilities. We can provide examples of innovative services from other provinces, where the phrase "developmental disabilities and autism and FASD" has meaning, and Community Living includes help for FASD. Examples

are peer support in Yellowknife and programs in Alberta and BC.

We are heartened that the Journal on Developmental Disabilities from Ontario had a special issue on FASD in 2013, and that NeuroDevNet, which researches brain development, chose to study FASD, autism and cerebral palsy.

Services for people with FASD in Ontario are needed so they can contribute to society as best they can, and this will reduce costs in general.

I will now ask my colleague Barb to speak to you.

Ms. Barbara Sabourin: Thanks, Elspeth. Good morning. I'm Barb Sabourin, and I'm also the mother of someone with FASD.

Knowing that my presentation is public, I have chosen to not use my son's name, so that I can protect his privacy and that of my family.

My son was finally diagnosed with alcohol-related neuro-developmental disorder, ARND, by the genetics clinic at CHEO when he was 16 years old. We tried earlier, but we had not been able to get information about his birth mother's alcohol consumption. The concern at the time when we adopted was that she had taken other substances which are much less teratogenic than alcohol itself.

The requirement was to have documented statements by a health professional that she drank during pregnancy, including estimates of how much and when—not an easy thing to obtain years after going through an adoption, and for many parents, this is impossible to obtain.

In addition, we had to put together a package with recent psychological assessments, which we paid for; an educational assessment, partly done by the school; copies of IEPs and report cards for at least three years; and a questionnaire. That was quite the undertaking and quite the significant package of information that we had to provide. It's not easy to do.

The diagnosis came with a discussion of what our expectations were in terms of services. It was pretty clear that none came with the diagnosis. I knew that, but still felt the diagnosis was important.

Currently, we do not have any services provided, other than getting into ODSP. We've been told that my son qualifies for services through DSO, even though most people with FAS do not—my son does have a dual diagnosis—but we've been waiting almost a year for the intake interview. We don't even have the name of a contact there; the letter informing us of his status was anonymous and unsigned.

I started attending the FASD Group of Ottawa, which Elspeth runs, when my son was about 14. Up until then, we felt alone. We had no support from anyone: not from children's aid, as we had completed the adoption process; not from the schools, who really didn't know how to manage our son; and not from friends, who just didn't understand. That is one of the things about FASD: It's an invisible disability, isn't well understood and is totally isolating.

Just to give you some examples of parenting in the earlier years, I remember going on trips with my son to

visit other family members, because I felt that was the safest environment. I had to hold my son's hand the whole time that we were travelling. If we were on a plane, he was right beside me all the time, not even going to the washroom by himself. If we were in an airport, he was right beside me, holding my hand. Imagine that with someone who has high energy. Really, throughout the years, it was quite tiring for me to travel.

I also remember keeping to a very strict routine for bedtime, because once you change the routine and allow any change, like a later bedtime for a special occasion, it becomes that change every night. My son can't differentiate between the situations.

This sort of reminds me of research done by Dr. James Reynolds at Queen's University on an animal model, with guinea pigs. He had a maze, and then they had to get to the food. The affected guinea pigs could get to the food when he set up the maze to start with, but when he changed the maze—my memory is he said it took, like, 200 times for them to get to the food, compared to the normal guinea pigs, who would adjust their behaviour.

Any change in routine for a child with FASD can cause a total breakdown. There were no sleepovers at friends' houses, no overnight summer camping trips. Daycare providers were picked very carefully, as were camps. The camps from the city of Ottawa, for example, where the children start off in a gym, were a definite no. My son would get overloaded way too easily.

I just want to make a couple of points on education, and I know you've heard from the ministry. Middle school was hell: no differentiation of services, no longer a really defined structure, and no one teacher in charge that I could talk to. Homework was more and more of an issue, and I would get notes at home that would say he hadn't completed whatever task in whatever time, like somehow I could fix it.

No information passes from one teacher to another without the parents being the conduit. Teachers are not required to look at IEPs—even the resource teachers—before the students start, or at any time during the year, even though principals are accountable for implementing these IEPs.

I understand that some improvements have been made, but funding has also been cut. I think that improvements in the education system are definitely needed.

My son has finished school now, as he is over 21. The implementation of the 21 rule is a little different than you might think, as a parent. It doesn't mean you can go until the day you turn 21. It means that if you turn 21 during the school year, you can't start the school year, so your end date is actually the term before you thought it was.

He had a transition plan, which is like a project plan. The goal statement for my son was "to prepare students for entry to the world of work upon graduation from high school, and, as appropriate for each individual, to prepare them for independent living and employment etc."

Then there was a list of actions, and all the actions were things the school had already been doing, like having co-op placements and work placements. It really

didn't help at all. That is definitely an area that could use improvement.

We're now in limbo. My son lives at home. He is not currently employed or attending any skills programs. We're waiting for the DSO meeting to see what that brings. We're trying to avoid a crisis before that, even though that may be the only way to get service. I don't know that my family can survive another crisis.

You've heard about the cause of FASD and the prevalence, with about one in 100 births affected. That's about the same as hepatitis C in Canada, yet look at the service provided for people with hepatitis C.

That means there are probably about 120,000 or so people in Ontario who are affected by FASD, and about 800 in Ottawa alone. So why am I always feeling like I'm the first to ask for something, and why do I always have to educate every caregiver about what FASD is?

It being a spectrum, like the autism spectrum, individuals will have different levels of ability and disability, but some of the key areas are executive functioning, decision-making and judgment. This means that on the severe end of the spectrum, individuals with FASD need constant supervision so that they don't harm themselves or others. At the other end of spectrum, individuals may just need a caring adult to listen to them and give suggestions on things, or to check in on them from time to time.

1000

Now, in front of you, on the first page, you have our recommendations. I'll just go through them briefly.

The first is to acknowledge that FASD is a developmental disability and to include FASD explicitly every time there is a list of examples of developmental disabilities. This would make all the services accessible for those with FASD. We have enough hurdles to jump over without adding that one every single time.

The second is to recommend more FASD diagnostic centres and to fund them so that getting a diagnosis is accessible. The only clinic here is the genetics clinic at CHEO.

The third is, as with the diagnostic centres, to provide for qualified caregivers to provide respite care so that these struggling families can get a bit of a break and can continue to parent these children; similarly, to provide for assistance with the transition from school to post-school, so that these individuals can become contributing members of society and live as independently as possible.

The fourth is to ensure the education system treats FASD as what it is: a developmental disability caused by organic brain damage and not as a behavioural problem. Time-limited interventions, such as the section 23 classes, are not sufficient, as these individuals have permanent, organic brain damage.

Also, I'd suggest doing an evaluation of the education system to see if it's really meeting its goals, including looking at examples of IEPs, talking to school councils for schools with a high proportion of students with developmental disabilities, such as Sir Guy Carleton Secondary School here in Ottawa.

The fifth is to provide better coordination of services, and I know this is part of your mandate. This includes reducing the number of assessments required for each of the different services. The ministries you've heard from, or will hear from, should work together and not in isolation. This is especially important as individuals with developmental disabilities become more independent. For more details, as Elspeth mentioned, I think, look at the Select Committee on Mental Health and Addictions report. I know you've already recommended that—that you will include that in your research.

The sixth is to create a way for Ontarians to know what services are available and how to access them, other than by talking to other parents. There are so many different rules, access points, forms, assessment requirements etc. that it's really hard to figure them all out, and you might miss a service that might be available to you.

The seventh is to insist that curricula for all health professions regulated by the province—and I would go a little bit broader—include training on FASD. Continuing education should be provided for those who are already certified. Training is available, and has been provided here in Ottawa, and yet it's very hard, as Elspeth said, to find a caregiver who has that training.

Our eighth and final recommendation is to recommend the creation and funding of more case manager positions to help people with developmental disabilities. These would be especially useful for individuals with FASD who need an external brain or scaffold to cope with the requirements of everyday life.

To close, thank you for the opportunity to speak to you today and for the work that you're all doing. We look forward to reading your report.

The Chair (Mrs. Laura Albanese): We want to particularly thank you for presenting to our committee this morning. Unfortunately, we don't have time left over for any comments from all the different members, but we will take your recommendations into consideration. FASD has been a concern that has been brought to our attention throughout the different hearings. I know there are some members who are very interested in learning more about that. Thank you very much.

MULTIDIMENSIONAL ASSESSMENT OF PROVIDERS AND SYSTEMS

The Chair (Mrs. Laura Albanese): We'll now call on the Multidimensional Assessment of Providers and Systems, MAPS, program of research. Is that correct?

Ms. Hélène Ouellette-Kuntz: That's correct. Thank you.

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

Ms. Hélène Ouellette-Kuntz: Good morning. I'm Hélène Ouellette-Kuntz from Queen's University. I'm here today with Virginie Cobigo from the University of Ottawa. I want to thank you for this opportunity to share our research with you.

I want to begin by ensuring you that we do recognize the importance of increasing investment in services.

What we are going to be talking to you about is a research program and the importance of investing in the creation of evidence and having evidence to monitor the effectiveness, the impact, of policy changes or service changes.

MAPS stands for the Multidimensional Assessment of Providers and Systems. I want to give you a little bit of background to help you understand who we are and what we do and, most importantly, why we do this.

The Ministry of Community and Social Services had a long history of funding, teaching, service and research at Queen's University, and I believe you'll hear about that later this morning, mainly in support of Rideau Regional Centre. With the closure of Rideau, the ministry committed three additional years of research funding to Queen's University. In order to obtain those research funds at Queen's, we had to submit a proposal for how these funds would actually help the ministry in transformation, in support of new policy directives.

I took the lead and brought together an excellent team of academics from diverse fields and multiple universities. As you can see on this slide, there are five universities from across the province represented on our research program.

The other point I'd like to make is, our research team has the capacity to do research in French and English and around looking at the realities for different communities across the province.

What we proposed to the ministry nearly five years ago was to work with the policy, research and analysis branch, as well as the community and developmental services branch, regional offices, transfer payment agencies, families and individuals with developmental disabilities to inform the assessment of services and supports for adults with developmental disabilities in Ontario. The timing of our proposal corresponded with the adoption of the services and supports to promote the social inclusion of persons with developmental disabilities, so that served to focus our work.

We developed conceptual models based on literature reviews and extensive consultations, and those consultations included families and individuals with disabilities.

We also explored specific policy areas through applied research to highlight how existing data could be used or new data collected in the context of an assessment of quality across the sector. The specific areas we explored are described, along with some of the findings in the briefing notes that we sent to the committee. Scientific papers that we've published and reports that we've produced for the ministry are all available on our website.

We are the first group to have had the opportunity to explore these issues at the provincial level and in collaboration with policy-makers and service providers. Therefore, we have information that is relevant to policy-making and service planning at the provincial level.

The focus of today's presentation will not be on those specific research projects but rather on the main, overarching aim of the MAPS program, which was to identify how best to monitor the quality of developmental

services in Ontario. We think this is critical to any kind of system improvement effort.

We learned that some jurisdictions have committed time and resources to measuring quality across their systems and are having a significant impact on services. In the United States, agencies can opt to collect data on key indicators for a sample of service recipients that are then submitted to a third party, to a research institute, which analyzes the data such that states can compare their achievements on policy-relevant issues. The program, which is called National Core Indicators, was established in 1997. Americans acknowledge that this long-standing program provides the ability to create benchmarks in national norms, compares change over time and across regions, allows the development and measurement of strategic goals, and enhances system transparency.

In the Netherlands, government-funded services must report on the quality of their services. They can choose an approach from a number that are approved by the government. In one such approach, the Quality Qube, which is included and described in our report, provides the organizations with a framework and, again, third-party support for this evaluation. But the targeted priority areas that any agency adopts are developed in consultation with service users, families and staff within those agencies.

The lessons learned from that Dutch model include the importance of monitoring outcomes for the service users, not just processes or outputs of services. It also acknowledges the importance of representing the perspectives of all stakeholders—the individuals, the families, the staff that work within the agencies—and of reporting that is tailored to the needs of those who will use the information to then improve services.

While neither of those approaches fits perfectly for our Ontario context, they were quite informative, and our stakeholders here in Ontario, which included family members, agencies and the ministry, to whom we presented the models were quite enthusiastic about them.

1010

As previously said, we reviewed existing data and data collection practices that could inform quality improvement. The first thing to recognize is that all information that is needed cannot be found in one place or through one mechanism. As you've heard, in order to examine age-related transitions, which are quite important, data are needed from different sectors. Within the DS sector, much data are collected. Many service agencies routinely engage in user satisfaction surveys and collect or collate additional information for accreditation or continuous quality improvement purposes. And all agencies report on compliance to quality assurance measures to the ministry.

In addition to collecting quality assurance compliance information from all service agencies, MCSS also collects information on recipients of the Ontario Disability Support Program and Ontario Works. Recently, MCSS has invested in DSCIS, a new data system which you may have heard about, and over time DSCIS will provide

information on all individuals eligible for adult developmental services and supports.

Through examination of current-day collection practices and consultations with stakeholders, gaps and limitations in the current systems—and they are plural: systems—of data collection were identified. Most importantly, Ontario stakeholders have told us that there is a lack of information on how to improve the services. The data that are available generally fail to inform where and how improvements could be made and are not reported in a timely and relevant manner to those who could act upon the developed knowledge.

I'll turn it over to Virginia.

Dr. Virginie Cobigo: To address these concerns from the stakeholders, MAPS would like to propose a way for which you assess the quality of the services for adults with intellectual disabilities in Ontario. This is to engage in a continuous quality improvement approach, which means that data is collected on an ongoing basis and is reported to those who can act upon the knowledge developed.

Our recommendations are to improve data collection and utilization, and develop the capacity of the developmental services system to collaborate with all stakeholders and be responsive to the knowledge developed through data collection.

Through the MAPS work, we have developed 150 indicators relevant to several priorities and service planning. We recognize that our 150 indicators are a lot to implement quickly, but as H el ene mentioned, Ontario has the capacity to use some of the data that is currently collected for quality improvement purposes immediately. Other data would require additional efforts or linkages across sectors, programs or agencies.

I would like to say that today we have decided to focus on some of our indicators that are more relevant to the priorities of your committee to illustrate how data collection could be improved in Ontario. Current activities assessing the quality of services for adults with intellectual disabilities tend, right now, to focus on the compliance processes and outputs, as H el ene mentioned, when Ontarians with intellectual disabilities, their families and service providers call for a shift to measuring the impact of the services on the lives of persons with intellectual disabilities. We present here in red some findings from the MAPS study.

Of about 200 parents requesting services in all DSOs in the province, as you can see, one of our indicators is the percentage of parents who report that their son or daughter has community activities, and only 66% of the parents answered positively.

Another indicator is the percentage of parents reporting that their son or daughter has friends who are not paid to be their friends or are not family members, and only half of the parents think that their son or daughter has a friend.

These numbers illustrate sad stories of social isolation, but they gain further meaning when compared with other jurisdictions. These indicators are taken from the Nation-

al Core Indicators and thus allow for comparisons with US states, but if we would be to standardize data collection in Ontario, then it would allow us to compare across regions in Ontario, which is not currently possible.

We also learned from our consultation that it would be important to provide information on what really matters for persons with intellectual disabilities and their parents or friends. For example, we asked the question to persons with intellectual and developmental disabilities: What should be our target when trying to improve their social inclusion? They said that what really matters is when they feel they belong to groups of friends and acquaintances. But belonging to groups of friends is not currently captured in the data collection in Ontario, so we don't know about what really matters for the service users.

Collecting data is not enough if it is not used for service improvement. In a continuous quality improvement approach, all stakeholders should and must be responsive to the knowledge developed. Data is currently collected on the number of persons requesting services, the number of persons receiving services, their waiting times etc. For example, in our study on the parents requesting services, we found that only 19% of them received services within six months. The most commonly received services were community participation, support respite and residential supports. This information is relevant and useful for policy planning and service assessment, but it would be more useful if there was a process by which we could report on this information to those who can act upon the knowledge developed. Currently in Ontario, there is no such process.

Furthermore, Ontarians with intellectual disabilities and their families urge the developmental services system to consider their perspective when assessing the quality of the services, rather than focusing on whether or not we comply with standards and policies. The waiting times are important information, as we just said—but would provide a better appreciation of the quality of the services if we knew how the services are responsive to families in distress. For example, in our study on parents requesting services, we surveyed them on their levels of stress. Some 23% of the parents we interviewed were reporting high levels of distress six months after requesting services, and 42% of them reported moderate levels of distress after six months.

Services for persons with intellectual disabilities, as H el ene mentioned, are not the responsibility of one single ministry or one service provider. Therefore, improved data collection and utilization would require linkages between multiple data sources, as well as inter-ministerial collaboration and communication. At time of transitions, it is even more important. For example, when we would like to know about the work needs of young adults with intellectual disabilities, we would require linkages between the education sector and the developmental services sector, which is not currently possible in Ontario. In the absence of such linkages, we still can serve the users of developmental services or recipients of ODSP.

As part of MAPS, we surveyed about 2,000 recipients of ODSP who were identified as having intellectual and

developmental disabilities, and we asked them about their work experiences and their education attendance. Some 73% of the sample reported that they attended high school, but this number is not by itself very informative. What is most informative is to break it down by age groups and to see the trends in the data. You can see with the trends in the data that policies around inclusive education have an impact on the attendance in school of persons with intellectual disabilities. This also demonstrates the importance of observing trends rather than looking at overall measures, and observing change over time and understanding the impact of policies and service planning.

Variations in regions are also important. For example, we learned that persons with intellectual disabilities in rural regions are less likely to have gone to high school.

Finally, another way of showing that overall measures don't tell an accurate story is to look at numbers of work experience in adults with intellectual disabilities. If you look at these numbers, you could say that 40% of adults with intellectual disabilities have worked for minimum wage or above—but this is lifetime experience. We know from our data that most of them didn't keep their job for long. So better indicators of the quality of the services would be to look at job tenure over time, as well as wage levels—track them over time and compare them with local and international benchmarks.

1020

Ms. Hélène Ouellette-Kuntz: So, as shown, some data does exist. There are significant gaps, however, if we wish to understand the impact of policy and services on people's lives. There's no way to measure the effect of policy change such as the recent transformation of the sector and changes to come.

There's a need to build capacity; improvements to data collection and utilization are crucial for transparency and accountability. The ministry is supporting MAPS for an additional year to work with agencies and data holders to move this agenda. A long-term commitment is, however, required to reach this objective.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you for being here this morning, for coming here. We have about a minute for each party to comment. I believe it's the government's turn to start.

Ms. Mitzie Hunter: Impossible to do in a minute, Madam Chair.

The Chair (Mrs. Laura Albanese): You're going to have to try.

Ms. Mitzie Hunter: I thank you for your presentation. It does warrant further consideration, and I'm glad to see that it's already embedded in the ministry's work.

The focus that you wanted to put on it was on the sense of belonging. What is the most important way to do that? I'm even looking at your slide that looks at productivity, and I see volunteerism is very high. That is a way to achieve belonging. So I just want to get your sense of what is the best way to track that.

Dr. Virginie Cobigo: There are proxies we could use, such as participation in different activities. But you could participate in activities and not feel any belonging to the people who are around you. You can go to work and not feel any belonging to your workplace or your colleagues.

The perception of persons with intellectual disabilities on how they feel in their community would be very important to capture to get a real picture of their inclusion experiences. However, it's more costly and more difficult to get data from persons with intellectual disabilities, so it would require additional considerations. But it is feasible, as we have demonstrated through the MAPS work.

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

Ms. Sylvia Jones: Thank you. I have a specific question related to page 5, which is your thermometer. I want to make sure that I understood you correctly. Number 10 was, "I can't do it anymore." Was that the 23%?

Dr. Virginie Cobigo: It's the high distress level.

Ms. Sylvia Jones: To me, "I can't do it anymore" is crisis. So 23% of your study—

Ms. Hélène Ouellette-Kuntz: —are in or approaching crisis. This is likely an underestimate, because these are people who participated in this study, so they had to feel well enough to do so.

When we look at people who engaged in our study, our rate was 33%, but when we get to six months and who's still in the study, the percentage drops down. I think it's showing that we are losing people who are too distressed to remain involved.

Ms. Sylvia Jones: Not surprising.

My other question is, can you share with the committee the cost of your study and the timeline?

Ms. Hélène Ouellette-Kuntz: We received three years of funding at \$400,000 a year. It included the conceptual work as well as the specific project, such as the ODSP survey of 2,000 individuals, follow-up of families over a two-year period, staff surveys that were done and other components. There were many, many different activities undertaken.

Ms. Sylvia Jones: Thank you.

Interjection.

Ms. Hélène Ouellette-Kuntz: Good point, Virginie. An important thing to recognize is that our contribution as faculty members within universities is not counted in that. We are already paid to do our work, and this is part of our work.

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

Ms. Cheri DiNovo: Thank you for the work you've done. It's imperative that we have data collection if we're going to move forward. Some of those figures are staggering, and they basically buttress what we're hearing, really anecdotally, through this committee's work over the last week and the next. So it's interesting to see that what we're hearing is what you're finding statistically. It's also sad that it has taken this long to get it from you.

Hopefully, we can make that investment pay off to the parents, because I can see some parents who would like to have \$400,000 coming their way, too. So, hopefully, this is an investment that produces results in the long term. Thank you.

The Chair (Mrs. Laura Albanese): Thanks once again for being here today.

MS. JOYCE RIVINGTON

The Chair (Mrs. Laura Albanese): We'll call now on Ms. Joyce Rivington. Good morning. I know we are running a few minutes behind, but it should be okay.

Ms. Joyce Rivington: Good morning, My name is Joyce Rivington. I have my friend Barbara King with me because my voice is going this morning, so if it gives out, she will continue.

The Chair (Mrs. Laura Albanese): That's fine. You may begin anytime.

Ms. Joyce Rivington: Okay. I would like to thank the select committee for giving individuals with developmental disabilities and their family members the opportunity to have a voice.

I live in a rural area, in Carleton Place, in Lanark county. My husband and I are in our mid-sixties and have three children. The youngest, Ryan, was born on January 18, 1978.

Over the past 36 years, the largest and most difficult hurdles we have had to overcome stemmed from attitudinal barriers, imposed limitations, intolerance, and systems' resistance to change. Inspiration and strength have come from the knowledge and support of families who, like us, had vision and hope. We do not want our children's disability to shape and define their lives. We want them to have a good life.

I brought a couple of pictures here to give you an idea of what I think is a good life for my child.

What I wanted for my son was that he would have experiences that all children have: to participate in birthday parties, school field trips and grade 12 graduation. He has continued to do those things today. I'd like to share the journey of how I acquired that, and at the same time reinforce the fear and concern that we all have for what has occurred and continues to occur in developmental services in Ontario.

When Ryan was born I sensed from the beginning that there was something wrong. He was admitted to CHEO for testing, resulting in a diagnosis of "developmental delay of unknown etiology and failure to thrive," and the neurologist telling me, "There are places for children like this." This comment was the first indicator to me that children with developmental disabilities are not valued.

The doctor at the developmental clinic had a softer touch and said, "Take him home and love him." My idea of love was putting love into action. I researched information and found out about the importance of sensory motor stimulation—Doman-Delacato brain patterning. This involved enlisting volunteers from the community, which I co-ordinated. People who came to help Ryan got

to know him and care about him. We continued with the program for three years and kept his muscles from atrophying.

Having been born in the late 1970s gave Ryan the advantage of the infant stimulation program, Special Services at Home, and an integrated preschool program, the first in Lanark county.

By age five, Ryan was not walking, only weighed 22 pounds, and was not able to gain weight. His physician sent us to SickKids in Toronto to begin the nasogastric tube feeding program. After only two weeks on the supplementary feeding program, which we did at home, he started to take his first steps. During this stay at SickKids he was also diagnosed with a rare genetic syndrome.

At age five, Ryan was also non-verbal. By chance, a support worker started him on the McGinnis Association Method of teaching speech and language, which was used at Sagonaska School, a Ministry of Education demonstration school in the province. With a great deal of intervention, practice and consistency, he began to make individual sounds. Despite severe oral motor problems, there was clear evidence that Ryan was making significant gains. The speech pathologist who monitored Ryan's program did not agree with the method and instructed the worker to discontinue the program. The situation was one of the most disheartening and unbelievable experiences I had encountered. Ryan was being denied the potential opportunity to acquire speech as a means of communication. It was a battle, but was only a warm-up to the battles we would face to acquire an inclusive education for Ryan.

The Ministry of Community and Social Services was promoting integration at preschool. When it came time for Ryan to register for school, an employee from the local social service agency explained to me that there were two choices: either send him to the TMR school in Smiths Falls or the TMR school in Almonte. I responded that Ryan was going to the same school that his sister and brother went to in Carleton Place, and she told me that that wouldn't happen in Lanark county. To make a long story short, Ryan did attend his community school in Carleton Place, but it was a gruelling process, to say the least.

The Ministry of Community and Social Services regional office in Kingston was supportive of parents like us. Actually, two program supervisors offered to help me develop a statement of needs identifying details of the type of support that Ryan would require to be successful in an integrated school placement.

1030

I just want to interject here and say that I feel fortunate that I lived in MCSS South East Region because I believe there have been quite a few ministry employees who were exemplary, who understood the vision and went out of their way to help families that wanted more flexibility, choice and inclusion for their children.

Ryan started elementary school just as the Education Act changed in 1984-85 and the IPRC process came into

effect. I am sure we set a record for the number of IPRCs held in one year. It was all worth it, even though it was an extremely painful process. Ryan gained an inclusive education, not without our share of tears and glitches.

I was a member of the Lanark county special education committee, SEAC. We had a strong group of parents on the committee. We worked with organizations to promote inclusion, and organized workshops and joint conferences. We also promoted Circle of Friends, and Ryan had a circle of friends in elementary school and high school.

I was involved in developing Ryan's individual education plan to ensure consistency and continuity. In 1995, going from elementary school to high school, I requested that a transition plan be developed utilizing strategies that had enabled Ryan to be successful, and be carried out in high school.

The high school was a bit apprehensive at first, but they did a great job. Ryan also had the benefit of having a great educational assistant who moved with him from elementary school to high school. I think one of the most memorable and gratifying experiences was watching Ryan take part in a Christmas band concert. There were some people in the audience with tears in their eyes. It was an amazing experience and a true example of inclusion.

During Ryan's last couple of years of high school, I requested that he have co-op placements. This was something new for them, and by the end of high school, he had two volunteer job placements in the community, which have continued to the present. At the end of high school, Ryan had a concrete and meaningful transition plan for life after school.

Ryan also attended his high school prom in Hull. A mother of one of the girls who was in Ryan's circle of friends offered to be a chaperone with me for the event. When true inclusion and acceptance works, it works, and it is truly amazing to witness.

The end of school led to the next big hurdle. Ryan was in the highest funding support category for exceptional students. He was now moving from the education system back to the Ministry of Community and Social Services. In order to receive funding in Lanark county, a social services organization had to present the individual to the service providers' table. I requested that I present Ryan's case. This created resistance because it was not a common practice in Lanark county. I presented an individual plan which required money to implement. I was told that there was no money. I received a letter from the service providers' table advising me that they could possibly piece together support translating into attending segregated programs, which was all that existed in Lanark county.

What concerned me about the process was that individuals who didn't understand and did not really know Ryan were participating in making life decisions about the direction Ryan's life would take, and they would not have to live with the outcome of the decisions they were making about his life. This is how and where people with

developmental disabilities lose their ability to choose what kinds and types of support and services they want and need. Decisions are not based on needs, wishes, dreams, goals. They are based on who is in crisis and where there is a vacancy.

What was equally disturbing to me was that from 1984 to 1999, when Ryan graduated from high school, the social services system at the local level had not changed or progressed in 16 years. MCSS started infant stimulation programs, SSAH, integrated preschool, and then things just seemed to stop—an entire system stuck in the past.

I am thankful that system limitations were not able to limit Ryan's potential. Today, he is a self-confident and happy person. We are extremely proud of his accomplishments, which can match or exceed any of us because he has beaten the odds.

Ryan's life now is individualized and he has a person-directed plan that has evolved over the years. His weekdays are spent in the community with a variety of meaningful activities which include volunteer job activities, socialization, physical exercise, continued learning opportunities and recreational experiences.

Three years ago, my husband and I decided to move forward with our plan to build a house with a section that would be Ryan's, to give him pride of ownership of his living environment and to ensure that in the future he would have the foundation in place to maintain choice and control of where he lived.

Ryan requires 24-hour support. He has medical, physical and personal care needs. As a family, we are continually planning and trying to do our part to make sure that Ryan has a safe and secure future.

Most of us take for granted being able to direct our own life, make choices in all areas of our life and have support from people who love and care about us.

The institutions for the developmentally disabled have closed, but there is still that ominous cloud hanging over their lives. Individuals and families have been reduced to begging for support desperately required to live a life of freedom and choice. The transformation that is occurring is a contradiction to the key elements of true citizenship rights.

I have a few other comments that I think are important:

(1) Individuals with developmental disabilities live below the poverty line, and ODSP is not adequate to cover food, shelter and clothing. It is unrealistic to consider using any of this money for support requirements.

(2) Families who have their children at home provide a large percentage of natural support. Illness and the natural aging process create the inevitable need for additional support.

(3) Since the implementation of the Passport Program funding in 2006-07, there have been no cost-of-living increases and no apparent mechanism in place to enable increases. If and when agencies receive base budget increases, the increase would not appear to apply to Passport funding and individuals who utilized direct funding dollars.

(4) The proposed changes in Passport funding guidelines last year appear to be restrictive and inhibit freedom of choice.

(5) The ministry promotes the use of the American Association on Intellectual and Developmental Disabilities'—AAIDD—supports intensity scale, SIS, to determine levels of support needs. In the USA, there are four funding levels with annualized funding allotments exceeding \$100,000 for support needs, depending on the individual's specific needs.

This is the manual. I don't know if everybody's seen that. I have it in my presentation—a copy of the first page and where to find it.

In Ontario, there are waiting lists for assessments and excessive waiting lists for funding. The maximum funding available through the Passport Program is well below the annualized funding dollar amounts used in the USA relating to the SIS. It appears that the ministry is using a tool to measure needs but not following through with the purpose and intent of the process; that is, to determine the amount of funding that an individual would require to have a good quality of life. The maximum amount of funding available through the Passport Program is excessively below the annualized funding dollar amount in the US.

(6) The current situation in our province does not reflect meaningful quality of life. The same organization, AAIDD, has a statement as to what points they believe are important in quality of life, which I've included in my presentation. Although the SIS is utilized here, it is not creating the characteristics of quality of life.

(7) "The Natural Authority of Families," Michael Kendrick, point number four, which I've included: "Families have a stake in outcomes. For example, they have to live with the long-term consequences of service failures to a greater extent than any other party, except the person themselves." Thank you.

The Chair (Mrs. Laura Albanese): Well, thank you very much for being here this morning and for sharing the story of Ryan with us and for your recommendations.

I will turn it over to Ms. Jones or Ms. Elliott—for the sake of time, just for a comment.

Mrs. Christine Elliott: Sure. Thank you very much, Ms. Rivington, for being here today. You've raised a number of points that have been raised by many other presenters. I'm just very glad that you were able to find some resources and supports to create a meaningful life for your son.

My question really relates to the individualized planning and how you were able to do that. Was that just something that you and your family did on your own, or did you receive any outside assistance in order to do that?

Ms. Joyce Rivington: Mainly because there has not been a lot of support for the type of life I wanted my child to have. I know a lot of families and organizations across the province. Somehow or other, years ago, we all connected. A Windsor organization has been very instrumental—I know parents from there. I knew parents in

Toronto who were forerunners in this type of movement—John Lord.

So I compiled all the information and I made a proposal, and I just persisted. Persistence and determination is what it is, and it takes a lot of energy, but it was my child. I mean, we do spend a lot of time and energy on our normal children, and I've had to spend a lot of time, but it has been a learning process. I didn't look at it, or teach my other children to think of it, as negative. At some time in all our lives, we need help and support. It has paid off.

1040

Mrs. Christine Elliott: That's wonderful to hear. But it is so draining for many families, just in the day-to-day care of their son or daughter, that it's really hard to be able to pull those resources together by yourself. We have really looked at the concept of a navigator, having someone to help parents plan for their child's lives and to even inform them about what services and supports are helpful.

Thank you very much for presenting to us today. That's very helpful.

Ms. Joyce Rivington: Thank you.

The Chair (Mrs. Laura Albanese): One second; we have comments from each party.

Ms. Joyce Rivington: Oh, sorry.

Ms. Cheri DiNovo: Thank you so much for this presentation and for introducing us to and supplying the supports intensity scale as well; that's helpful.

It strikes me that a lot of what is being experienced is people being assessed and the point of assessment is lost.

Ms. Joyce Rivington: Yes.

Ms. Cheri DiNovo: The point of assessment is so that you get some assistance and the assistance matches the need, but that's the part we're not seeing. So you've made that very clear, and I thank you for that.

The \$100,000 mark that you talked about in the American assessment model pales in comparison to what we're paying out for long-term care and hospital beds. These are inappropriate places where folk with developmental disabilities are being housed, and they're costing a whole lot more than the money that perhaps you might get, or families might get, if the assessments were actually followed through on. So thank you very much.

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

Ms. Mitzie Hunter: Thank you, Madam Chair. Thank you, Ms. Rivington, for being here today, for sharing Ryan's story, and for all that you have done to provide that loving home for him.

What I appreciated about your presentation was that you guided us to where there were things that were working right within the system, such as your experience with the regional office in Kingston and the support that was provided, and where you believe that there needs to be improvement.

In addition, you've also given us some very valuable comparative data as well, such as the supports intensity scale.

I want to thank you for the thoughtfulness that you've put into this presentation, and it's very helpful to us.

Ms. Joyce Rivington: Thank you very much.

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

MS. IMAN SEIFELDIN

The Chair (Mrs. Laura Albanese): We'll now move on to the next presenter, Iman Seifeldin. I hope I pronounced that correctly. I'm probably totally off.

Good morning. How are you?

Ms. Iman Seifeldin: Fine, thank you.

The Chair (Mrs. Laura Albanese): Thank you for being here today.

Ms. Iman Seifeldin: My name is Iman Seifeldin. I came here today to talk to you about my son, Karim.

My son has a complex disability: cerebral palsy, spastic quadriplegia, severe developmental delay, autism spectrum disorder, scoliosis, severe communication disorder, pica-like behaviour, and aggressive and self-abusive behaviour.

Karim is 21 years old and completed school in the summer of 2013. It was a great experience, being in the DH classes, the developmentally handicapped classes, in the school system.

He has lived at Welcome Home group home in Ottawa since he was 11 years old. I have a very good relationship with staff and the director, Mr. Pelletier. I am a single parent and have had serious health issues, so I physically was unable to care for Karim at home, and I was faced with no other option but to place him in a group home.

They say I am a good mother, and I am very involved in my son's life. I love my son dearly. I have always attended his school meetings, home meetings and medical meetings, to make sure that everyone understood Karim's needs. He has problems keeping weight on and is extremely thin, so I make him special meals to encourage him to eat. I also hire a support worker, who helps me take Karim out on the weekends.

I have lived in a state of anxiety and fear for Karim's future for many months now. Karim does not have stable funding for a day program, and the group home where he lives cannot keep him on a permanent basis if he does not have a day program because it does not have adequate funding to support Karim during the day. The group home offered to provide a day program if the ministry would give them additional funding. The group home, however, did feel it was in Karim's best interests to have day activities outside the group home.

I thought we had everything in place for Karim's transition from school. The school had been on board to make sure Karim had a smooth transition. An assessment had been completed by the DSO, and the report identified the importance of transition planning. A day program, ICSS, had provided a proposal for the cost of a day program for Karim and had visited Karim twice when he was still in school. Karim had good support for his transition, and the only thing missing was that there was

no stable funding being made available by the Ministry of Community and Social Services for Karim to have the long-term security of a day program.

Without secure funding, Karim's group home placement is at risk. All that is in place are short-term solutions. There is funding until the end of March 2014, but then what will happen to Karim?

I am constantly in a state of worry and fear. I thought we were being proactive in planning for Karim's future when we looked into day programs well in advance of him leaving school. Now I feel that planning for Karim to have stability in his life in the future is at risk.

I also feel that the system is very disjointed and confusing. Karim has a case manager at Service Coordination. There is another individual at the DSO, but he was not the same person who did the assessment on Karim. Then there was another committee, the adult service resolution process, which considers people who are priorities for funding at the service providers' table. For some reason, even though Karim was leaving school, his file had been closed, and he was not prioritized to the level required for funding.

Karim's worker from Service Coordination knew in April 2013 that Karim could be discharged from the group home if he did not receive funding. The group home had to put in writing to Service Coordination that it would not provide support to Karim during the day even though the group home only received funding for residential accommodation for Karim.

All of this confusion has been going on since April 2013. It is my child's life, and people don't seem to understand.

I was told by the adult service resolution person that she did not want to know my son's name because he would be identified by a number. She gave me still another name of a person who I should be dealing with at Service Coordination.

I feel like my son is not even a person. His future is uncertain. There are so many layers of bureaucracy and a lot of confusion and time wasted, making families feel frantic and like they are going around in circles.

What will happen to my son if he does not receive funding for a day program? Could he end up in a nursing home? I am so very frightened and worried for Karim's future.

I am thankful that I heard about this committee, and I want to thank everyone on the committee for giving parents like myself the opportunity to speak about the concerns we have for our children and their futures.

I am including some correspondence with my written submission. I'm sorry it's quite a bit, but we're just trying to give you an overview of some of the communication that has been going on and the new processes that have been put in place. Nothing came out of the resolution processes because we ended up having the same term, which is, "No funding; the government is not injecting any more money in the process." I was told that we have to wait for somebody to die to have money in the system to support people like my son. Thank you.

1050

The Chair (Mrs. Laura Albanese): Thank you, first of all, for sharing your emotions and your uncertainty with us, which is perfectly legitimate. I will turn it to my colleagues to make their comments and ask you their questions. We do have about three minutes for each party. Miss Taylor, you can start.

Miss Monique Taylor: Thank you, Iman, for coming to speak with us today and sharing your story and Karim's story with us. It's not the first time we've heard that people who are living in group homes are not getting the day programs that they need, and it's so unfortunate. It's like, because you have the group home, you're automatically privileged and you don't get to be on the list for the other day programs that are so necessary.

I mean, the group home is a place to sleep and to be cared for in your daily living; it's not about the quality of life, of getting out into the day programs and those other vital services that are so necessary. So thank you again for raising that attention that we have discussed and finding that that's a problem.

I also wanted to know your thoughts on the DSO and the services that you've been provided with that.

Ms. Iman Seifeldin: The first assessment I had—actually, it is attached to the SIS assessment. The ADSS assessment was done by a lady by the name of Heather Williams. We had two meetings with her. It is a very comprehensive assessment. It does cover what my son needs and it has been identified clearly, which is great. It did identify that he is going to need day activity when he graduates at 21, but nothing was done with that. We had to wait again and do an update when we were really in crisis at the time that he was just graduating. The assessment was done in February 2011 and he was graduating in 2013, and nothing was done with the assessment. Service Coordination did not even have a copy of the assessment, and I provided my copy to them.

Miss Monique Taylor: Right. We know that assessments are very, very expensive to be done, and to be done when they're not even being used is really a shame. I really want to thank you for providing us with correspondence. This puts us into your life in a very delicate way. I appreciate you taking the time to do that and allowing us to see that correspondence and the dialogue that's happening between yourself and the services that are being provided to your family. Thank you once again.

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

Ms. Mitzie Hunter: Thank you, Ms. Seifeldin, for your presentation and for sharing your journey so far with Karim, and also for providing the detailed assessment. I agree with you that it was a very good assessment and it clearly outlined what the needs are. It seems like we're hearing again that where the gap is matching those identified needs with the resources and the supports within the community for you.

The information that you provided to the committee is what we are considering in terms of, how do we improve the system of supports? Clearly, your son has multiple

diagnoses and requires that level of support. How do we work together as a system so that all ministries are working together in a coordinated fashion so that you don't experience the level of uncertainty that you have right now?

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

Ms. Soo Wong: Thank you very much for your presentation. I want to ask two quick questions. First I want to hear your comments, specifically when the agency asked you not to name your son—instead, the numbering. Can you elaborate a little bit further to the committee?

Ms. Iman Seifeldin: The process for prioritization: They take away the information about it and they are represented without their information—what's the name and what's the group home he's in. All the information is blacked out when they are presented to the table for prioritization, which really does not make much sense to me because they are persons. They have rights. I do not have a problem with my son's name being mentioned in any service that he'll be getting.

Ms. Soo Wong: You have expressed concern to the committee with respect to the nutritional concerns. Was there any follow-up from either the Ministry of Health through your physician, or—

Ms. Iman Seifeldin: Yes. Oh, yes. He had another problem with the system—that when he was in school, he had a dietician as part of his health team. He had a physiotherapist, a speech therapist, an OT who would look after him and give us recommendations. We are following until now the recommendations of the dietician that have been recorded, and there has been a lot of information about his diet coming from his dietician, which we lose. Once you're 21, you lose these services and they don't come automatically. You have to reapply. And you hardly can see them, once a year if you can—while they were available in the school system and OHIP was paying for them. What is the difference when you change and be 21? Why is that taken away from you? You are still the same person with the same disability. Reaching 21 should not have any difference, because for this group, they are the same people, whether they are 21 or a teen. They still have disabilities that take them to a toddler or even a younger person. So at 21, we should not punish them for turning 21.

Ms. Soo Wong: Thank you.

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

Mr. Jack MacLaren: Ms. Seifeldin, I see you live in Kanata, which is my riding, so I am your MPP.

Ms. Iman Seifeldin: I actually don't live in Kanata.

Mr. Jack MacLaren: Oh. I see your address is here. That's Kanata.

Ms. Iman Seifeldin: Oh, no.

Mr. Jack MacLaren: At any rate, what I was going to say is that perhaps one of us—I would offer to try to help you. It seems like what you need immediately is to get funding so that your son can continue to stay in the group home that he's in, which seems to be quite satisfactory.

Ms. Iman Seifeldin: Yes.

Mr. Jack MacLaren: And what's unsatisfactory is that funding is not there, so I'd be happy to try to help you with that, so perhaps we could meet after this meeting and we can set up a meeting with you at my office, if you would like.

Ms. Iman Seifeldin: Yes, I would appreciate that.

Mr. Jack MacLaren: And we'll look into the problem. I know all these good folks, so I've got some good friends to ask for help, and we'll do the best we can to help you.

Ms. Iman Seifeldin: Thank you.

Mr. Jack MacLaren: Okay.

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

Our next presenter has actually cancelled. The 11 o'clock will not be able to make it.

We will call the following presenter up, the Queen's University Department of Psychiatry.

Yes, Ms. Wong?

Ms. Soo Wong: Madam Chair, while we wait for the next witness to speak, can I ask—

The Chair (Mrs. Laura Albanese): Make your way as Ms. Wong is speaking.

Ms. Soo Wong: —the researcher to follow up on a couple of things for me? First, the witness from the MAPS people, their study—because I have some more questions, so I'm going to give them to Erica so that she can follow up to the committee for me, because with regard to some of the data, I want some more data.

The last witness shared with the committee—I want some more clarification from the Ministry of Health and Long-Term Care with respect to special diet funding for those over 21, so someone with a diagnosis of DD or ID and with a medical order that the person has special diet needs. So my question is, how does the Ministry of Health and Long-Term Care fund special diets for those with these kinds of medical conditions and why is there “discrimination” because of the age?

1100

Then the other question here is with respect—

Ms. Erica Simmons: Sorry. What was the last—

Ms. Soo Wong: Discrimination over the age group. Because that particular witness said her son got all this medical dietary support prior to 21. We know the Ministry of Health does fund nutritional—

The Chair (Mrs. Laura Albanese): But they've changed some of the rules, so it could be because of the change in the rules.

Ms. Soo Wong: Yes. I don't know.

And then the other question, Madam Chair, is the process where the committee, which I think was the assessment committee—that instead of naming her child, there is a number. Can we get the protocol or procedure when they go before the committee? Is it a requirement that they do not disclose the name of the individual? Is that part of the Integrity Commissioner or the privacy act? I don't know. But why isn't it allowed to be shared with the committee when they are discussing the client?

The Chair (Mrs. Laura Albanese): The researcher would like to know also the details of what you require in regard to MAPS.

Ms. Soo Wong: I will give that to her at lunch.

Ms. Erica Simmons: Okay. Thank you.

DEPARTMENT OF PSYCHIATRY,
QUEEN'S UNIVERSITY

The Chair (Mrs. Laura Albanese): Okay. Thank you for waiting patiently for a second here. Please introduce yourselves as soon as you make yourselves comfortable. You may start any time. You will have up to 20 minutes for your presentation.

Dr. Bruce McCreary: Good morning and thank you for making a spot for us today. I'm Bruce McCreary. I'm emeritus professor of psychiatry at Queen's. On my left is Dr. Jessica Jones, who is an associate professor of psychiatry. She's a clinical and forensic psychologist. I'll mention that perhaps a little later in relation to some of the complex cases we deal with who happen to be in conflict with the law. On my right is Dr. Muhammad Ayub, who has been with us for a few months, having trained, as did Dr. Jones, and me a little bit, in England. We have recruited him—some would say seduced him—to come to Canada to help us out with what I'll describe in a minute as a very distinct manpower shortage in the field of mental health professionals serving people with developmental disabilities and dual diagnosis.

As the senior citizen in the group, I can tell you that what you're doing was last done, as far as I know, in 1971 by Walter Williston, who was engaged by the Ontario government to review the care of people with developmental disabilities in Ontario and to develop a report with recommendations. I remember meeting Mr. Williston, and I want to make one quotation from his report, because it has to do with how things have evolved in Ontario since 1971, and in that sense it's important to understand that evolution in relation to the challenges we face today.

The quotation is, “The concept I strongly advocate is that it is far more economical and humanitarian to give to the handicapped the total care he needs in his own community than by providing for it in an institution.”

The impact, really, of the Williston report and the events that followed can be categorized into three: de-institutionalization—and as you know now, by March 2009, all of Ontario's institutions were closed; social inclusion, which is the focus of current policy; and the third thing, which in fact we're in a way going to focus on, integration of people with developmental disabilities in mainstream health care services.

Presently, I think you might agree, care in the community is not more economical; it's more expensive. Quite frankly, if you haven't spent, as a government, enough money on it, you can explain at least some of the challenges you're hearing about.

Secondly, there are significant gaps in the provision of community supports for individuals and families. I know

from the transcripts that you're hearing that message over and over and over.

You may not have got quite as clear a picture of the third point, that there's unacceptable neglect of the special health and mental health problems to which persons with developmental disabilities are predisposed. I know you've highlighted dual diagnosis; in fact, dual diagnosis affects 40% of people with intellectual disabilities, a factor three or four times the rate that occurs in the rest of the population.

Some of the challenges, I think, are reasonably clear. I think the historic perspective is interesting because some recommendations are needed now to sort of redirect the way things have evolved since 1971. We have a suggestion to make today in terms of perhaps shifting the direction a little bit.

The suggestion is this: to engage Ontario's six academic health science centres in reversing contemporary neglect of the health and mental health problems of persons with disabilities. I'll try and explain a little bit why we need to do a better job. Essentially, if you're going to integrate people with disabilities in mainstream health care services, and if the staff in that mainstream are not adequately trained about the special needs of people with intellectual disabilities and dual diagnosis, we clearly have a problem, and the problem is, in many senses, in the first instance, educational.

An academic health science centre, just so we're all on the same page, is a post-secondary institution training physicians and nurses and rehabilitation therapists and dentists and pharmacists in collaboration with what used to be called teaching hospitals. It still is teaching hospitals, but it goes beyond that, particularly perhaps in relation to this population, to other agencies in the community that serve people with intellectual disabilities and dual diagnosis.

This slide shows you a list of some of the agencies that our division relates to in southeastern Ontario. Why we relate to them is that they expect from the academic health science centre specialists help in caring with people with complex needs. That help sometimes is direct and very often is indirect in the sense that we're dealing with professionals who didn't have adequate training in this field, so the consultation is really to provide direct help but also some further education for the practitioner who was shortchanged during their training. The services, really, then of an academic unit are specialized care, training of health care professionals and what you heard from Hélène and her colleague in terms of research.

Our former vice-principal used to say it's a three-legged stool, and if one leg is missing or short or whatever, it doesn't work optimally for anybody. If they all are in place and work together effectively, it's win-win. That's not a political statement because he made it before the current Premier was identified.

We're in Ottawa, and if you go over to Carling Avenue and drive down there, you'll see the highly respected—and it is respected—cardiac institute, the

Heart Institute. If you continue your drive around Ottawa, you will find nothing, in terms of intellectual disability or dual diagnosis, that's comparable.

1110

Just to put that in a bit of context, this is a cost-of-illness study report from the Netherlands. In fact, it's the only one I know where a jurisdiction has said, "What do we spend on cancer? What do we spend on congenital anomalies? What do we spend on intellectual disabilities?" etc.

At the top of the list—and it's there in green—the most expensive diagnostic group is intellectual disabilities. It's more expensive than heart disease. It's more expensive than cancer. To think of the emphasis placed on other conditions—we don't deny those other categories the respect they deserve, but to neglect this population is not right. It's not fair.

The academic health science centres, in our view, need to be harnessed, because we know that people in training are shortchanged in terms of education about these matters. In fact, we know we don't have enough clinical educators with the specialty knowledge that Dr. Jones and Dr. Ayub bring in from Britain so that we can keep our program at Queen's going.

So this is a long-term suggestion in the sense that if you said today to the six academic health science centres, "Set up a special program in relation to intellectual disabilities," it would likely take them two or three years to set up, in terms of including recruiting people with the necessary expertise, because we haven't trained them, quite frankly. But we have to start, and the sooner we start, the better.

Finally, in terms of a concluding comment, it seems to me that if the policy is, and is going to continue to be, integration of the people we're talking about in mainstream services, we simply have to train the people to look after them. If we don't, we're shortchanging them—seriously. There's data in many jurisdictions about premature mortality, not to mention all the enhanced daily problems and disability experienced from illnesses that they are predisposed to that are undertreated.

I hope we have some time for questions and comments, because we didn't want to give you a belaboured presentation, and we want to make sure you have a chance, if there are puzzles in what we're suggesting.

The Chair (Mrs. Laura Albanese): Yes, we can. There is some time left over for questions and comments. It will start with the government side: Ms. Wong.

Ms. Soo Wong: Thank you very much, Dr. McCreary, for your presentation. Your colleague from another department presented to us just recently. What's the collaboration between your department and her presentation with respect to the data for MAPS, and how does that support in terms of solutions and policy improvement? So what is her research in MAPS, and what is your department doing, in terms of interdepartmental collaboration?

Dr. Bruce McCreary: The three-legged stool I mentioned: service, training, research. An academic unit, like the division we're from, has the three functions.

It so happens that the people who are working on the MAPS project—Hélène Ouellette-Kuntz, whose office is literally across the hall from mine, is focused on research. She doesn't provide specialized care; she provides some training to epidemiologists in training. She's an important member of our team, but so is a clinical psychologist, and so are psychiatrists, and so are primary care physicians, and so are occupational therapists and social workers. So this is inherently an interdisciplinary effort. When you ask an academic health science centre to address the problems in the field, you're trying to buy a package with three legs. That's the connection.

Ms. Soo Wong: We heard earlier from parents, not just in Ottawa but across the province, that there's poor coordination and communication. We look to experts like yourself in the academic community to share with us how much collaboration and communication between the department of psychiatry and your colleagues with the faculty of education—because we know these young people with DD and ID are in our classrooms. We consistently heard that educators and health professionals are not properly trained, so I need to hear from you. Are you collaborating with your colleagues in different faculties and different disciplines?

Dr. Bruce McCreary: I think the answer is yes, but I'm going to answer it quickly and then perhaps the others will comment as well. We have included in our handouts a booklet that Dr. Jones and I have just published on how to train health care professionals, and it includes how to relate to teachers, to caregivers who are family members, to caregivers who are agency staff and so on.

In the tool kit of a well-trained physician or nurse or social worker or OT is the ability to coordinate at a local level so that the package that a family receives hangs together as distinct from what they often report now, where there is no communication. If you don't train your providers on how to communicate effectively with other disciplines, it's, again, not too surprising they don't do it very well.

Dr. Muhammad Ayub: And I'd like to answer that question. I'll give you a comparison: The last organization I worked for, in England—they are called health trusts. It was a mental health and learning disability—which is equivalent to intellectual disability—trust which provided service to about 1.4 million people in northeast England. Just that trust had between 25 to 30 consultant psychiatrists who were dedicated to intellectual disabilities.

When Bruce McCreary and Jessica Jones interviewed me for my job, they were very clever, actually. They didn't let me know that there is no dedicated intellectual disability training in Ontario or in Canada. I thought that it'll be a service for a small population, because just one psychiatrist can't do that. I realized that it's about a half-a-million population which I'm expected to serve, with no interdisciplinary support, apart from one psychologist. So how many jobs can one person do? I think the problem is what Dr. McCreary has already suggested:

that you don't have enough people on the ground to coordinate. If you don't have the nucleus that can coordinate different bits after service, then it doesn't happen.

I only arrived in May, and the place where I worked for a 1.4-million population had more than 100 dedicated beds for intellectual disabilities, patients with psychiatric problems. There were none in the region of half a million. I managed to get two; now, I have to look after those two in-patients. I have to provide care to everybody living in the community with intellectual disabilities and psychiatric problems. I have to teach undergraduate medical students. I have to teach postgraduate trainees. You can't expect that to happen.

The problem is not that there is no will, that there is no motivation; the problem is that there is no manpower. Unless you address that issue, you are likely to continue with these problems in the next 10 or 20 years.

1120

For comparison, I'll explain what training I had. After five years' training in psychiatry, I had three years' dedicated training in intellectual disability psychiatry to qualify to become an intellectual disability psychiatrist. How long do my colleagues in Ontario have for intellectual disability? Zero; they don't need to have a single day's exposure—maybe a week actually. We run a crash course for five days to cover what I covered in three years. They must be very bright and somehow exceptional to acquire the same skills. When I see patients—I'm not intending to criticize anybody—I see glaring gaps in terms of diagnoses, in terms of treatment they receive because people haven't been trained; they haven't been exposed.

The problem Ontario is having now, Britain had it about two decades ago. They started closing their institutions a couple of decades ahead of you. At the time they thought, "We closed the institutions; the problem is solved. We don't need specialist services." They have come full circle, actually. You need a core of specialist services to look after the most difficult and most complex people. That core specialist service supports the other services. Unless you have that core, your other services are orphaned. They can't survive. I have seen my general psychiatry colleagues; they so much appreciate just my presence so that they can ring me and seek advice about one of their patients. When they are in a difficult situation, they can ask me to have a look at one of their patients.

I think you're lucky that you had Dr. McCreary, who had an interest. He went to England to acquire some special training. A few decades ago, he established that division. Otherwise, it would have been non-existent. There are only two academic health science centres that have those divisions. One of them is just because of Dr. McCreary's own personal sustained effort.

I think that's the answer: You need to have a core to coordinate training and to coordinate care.

The Chair (Mrs. Laura Albanese): Thank you. Now, I just wanted to have a word with the other two parties on the committee. Obviously, this answer has gone over the time that we had at our disposal—

Dr. Muhammad Ayub: Oh, I'm sorry.

The Chair (Mrs. Laura Albanese): But at the same time, because we had one of the presenters cancel, do you agree that we can use this extra time for further questions? Is that okay? Okay. Ms. Elliott.

Mrs. Christine Elliott: Dr. McCreary, Dr. Jones and Dr. Ayub, thank you so much for being here today. I think you've brought a critically important perspective to us. We have heard, as you mentioned earlier, Dr. McCreary, about people with intellectual disabilities and with dual diagnosis not receiving appropriate primary health care as well as care for their particular situation in the province of Ontario. I appreciate your suggestion; I think that's really important in order to be able to train health care professionals, whether they be family physicians or whether they intend to become specialists.

One of the other issues that has been brought to us is the fact that, like psychiatry—I think this is similar with developmental pediatricians: It's not something that's seen as being a very sexy thing to do in terms of medicine, that there are other specialties that are seen as being more important. Quite the contrary. I agree with you. But I guess one of the things is getting to medical students and getting them to see this as being a pathway for them that is going to be both personally meaningful and remunerative.

I understand that the medical students group have a list that they're now thinking of posting, a registry of where there are openings. Certainly, there's no question there's an opening in this area. Hopefully that will help entice young people to become interested in becoming developmental pediatricians. That's just a comment. The other is a question: When people do go into these specialties, how do we remunerate them appropriately so that they can take the time that they need in order to give good, quality care to people with intellectual disabilities or with dual diagnoses—because sometimes they feel reluctant maybe to take them on because of that additional time? I'd appreciate your comment on that.

Dr. Jessica Jones: May I speak to that?

Dr. Bruce McCreary: Sure. I'll let Jessica speak to it in a moment because, as you may know, as physicians we can at least bill OHIP for services. It takes longer than the OHIP fee schedule accommodates to serve people with complex needs. But a bigger problem is clinical psychology, social work and OT, which don't have a mechanism to charge their services like OHIP. Jessica can—

Dr. Jessica Jones: As Dr. McCreary said, I trained both in Canada and in the UK so I've had the comparison of both. I think after working 10 years in the UK and coming back here, capacity building, as he speaks to, is essential, but it's about timing of training.

In the UK at the point of graduation, no matter what specialty you go into, all psychiatrists, psychologists and nurses have done a mandatory rotation in developmental disabilities or learning disabilities irrespective of what specialty they go into. For me that accomplishes two goals. One, we're attracting them early on in terms of exposure and garnering interest in the field, if we're

lucky, but also tackling some of those stereotypes and misguided assumptions about this population. I find in Canada we're playing catch-up and that we're trying to educate experienced professionals—already confident clinicians that may not be open to learning at that point. It's a challenge—and that's the physicians as well as all other professionals. For me, at Queen's, we're trying to do it one student at a time, but it's a drop in the bucket. So trying to get them early on is very important because it also tackles those societal norms that you heard out loud on your first day in terms of how do we do that.

Secondly, the funding mechanisms: I can say from my clinical experience here, responses are being left to government funding programs—so we think about medication, which you've heard about because it's funded through the physicians, as well as the criminal justice system, unfortunately, because they can't say no.

So, yes, capacity building in terms of professional supports as well as the whole funding mechanism for non-physicians or allied health professionals is a huge crisis.

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

Ms. Cheri DiNovo: Thank you, Doctors—a wonderful presentation and absolutely necessary, so I thank you for that and I thank you for the book.

We have heard across Ontario, as you have read, probably, if you follow the transcripts at all, about the lack of diagnostic centres and the lack of ability to find any treatment whatsoever in some communities. We just came from Moose Factory where it's isolated communities and many First Nations communities can't get to a centre at all. One of the thoughts that came up was of satellite centres that would at least provide the minimal diagnostic abilities. I know your background is in part in forensics. You're absolutely right. We heard about a study in Alberta. Some 60% of inmates in the penal institutions there are thought to have FASD. Again, how do you get a diagnosis of FASD if there's no centre anywhere near you that can give it? I'm wondering if you could comment on this idea of perhaps—I mean, we have big centres now but you have to get to them and there are huge waiting lists. What about more mobile-specific satellite centres? Is that a possibility, do you think?

Dr. Jessica Jones: I think it is. It's about manpower and about attracting interest early on in health care students and professionals, because for the lack of having DD-dedicated programs we have to infiltrate to normal curriculums—so garnering interest again at a level when students are still figuring out what specialty they need to go into.

Dr. Muhammad Ayub: We already do clinics in Belleville and Brockville. I'm planning to start one in Peterborough. I think we are trying within our capacity, but how thin can you spread a small number of people? Unless you have those centres, you can't mend—a parallel is the World Health Organization trying to integrate mental health in primary care in the world. It has never worked because you need to have the centre that trains specialists, and then—you can't bypass this

training and having skilled professionals. You can't have any—but, yes, your question about remuneration: I think if you have dedicated positions for intellectual disability, psychiatry and psychology, that would create a chain where people from training have the prospect to move into those positions. So now anybody can apply for a position or anybody is expected to serve intellectual disabilities—which is fine for the majority of clients. But if you have dedicated positions or intellectual disability experts, that would create a bigger attraction for people to go through the training, so that they can see a clear path.

1130

Dr. Bruce McCreary: Could I comment? Words sometimes are important. In fact, I've used the term throughout today “academic health science centre,” which means something to many people in Kingston. But in fact, the newer term being developed to substitute is “academic health networks,” and Queen's I think is an example of that. We have a growing medical school and a fixed population base, so we now have satellite training centres. I think the idea of a network encompasses that. So you can find a head office in Queen's, but you can find a training package in Oshawa or Peterborough, and in the case of Western, down in Windsor and so on.

So I don't think we should get too focused on “centre,” if it means it's all concentrated in one city and everybody in the region has to travel there. That's not, particularly with this population, a particularly feasible enterprise.

Ms. Cheri DiNovo: It clearly depends on the people first.

Dr. Jessica Jones: Absolutely.

Ms. Cheri DiNovo: Thank you.

The Chair (Mrs. Laura Albanese): Thank you for your most interesting presentation. If members still have questions, perhaps they can address the presenters off-line. Thank you again.

PEOPLE FIRST OF ONTARIO

The Chair (Mrs. Laura Albanese): I am going to call the next presenters up, People First of Ontario. Good morning and welcome. How are you today?

Mr. Kory Earle: I'm good, and how are you?

The Chair (Mrs. Laura Albanese): We're good. Thank you. You'll have up to 20 minutes for your presentation. I see we have a copy of it, and you may begin at any time.

Mr. Kory Earle: Perfect. Just a warning to Jack: Don't ask me any tough questions just because you're from this area.

Good morning, and thank you for allowing me to have the opportunity to speak on behalf of People First of Ontario today. I will address some of the concerns our members and others face in this province. I must say, since I've indicated coming to the select committee, a lot of responses have gone on with regard to direct funding. So although direct funding is not in your presentation, it

is something I will briefly hit on, as most of our members are certainly facing it today, and also the need for supports, not just through agencies—but for people to hire their own support workers, which in fact does save the government money, so people can have support at home. We hope at the end of this meeting that we'll continue to work together, ensuring that the most vulnerable people's voices are heard.

Let me first talk about who we are. Our goals are to promote equality for all citizens; to assist other people trying to speak up for themselves and make their own decisions; and to teach our members about the rights, abilities and strengths of People First of Ontario.

Our driving force: We want people in the community to see us as people first. The problem is we are still being labelled with damaging words like “retarded” and “slow.” We have been taken away from our families and communities and have been kept in institutional settings. We have been kept in segregated workshops and schools apart from the people in our community. People have forgotten that we have the same dreams and the same needs as everyone else, as they do.

The objectives of People First are:

- to promote equality for all persons who have experienced being labelled developmentally disabled;

- to assist each other in speaking up for ourselves and making our own decisions;

- to teach the community about the rights, abilities and strengths of people who have experienced the label of developmental disability;

- to hold meetings and discussions for the purpose of organizing and educating people with developmental disabilities;

- to increase the membership, help new chapters get started and provide continuing support in order to further these objects. I would be remiss if I didn't point out that Lanark county is here today. They're just outside of Ottawa. They're here as one of our local chapters in the province;

- to raise funds and acquire property for the purpose of People First.

I would now like to talk about a few areas that we are concerned about, which is no surprise: poverty.

Ontario Disability Support Program: We and our members are very concerned about ODSP being cut. Already, many of us cannot afford a good place to live, nutritious food, transportation and other basic necessities. Far too often, the disability sector is one of the first things cut, and we do not want it to be slashed. For many people on ODSP, it's their only source of income. We must start looking at the income that people get from ODSP and ensure that they are getting enough money to cover rent, utilities etc.

Far too often, people with disabilities are targeted first. The government can be a champion for making people with disabilities have and live a better life and not be living below the poverty level.

It is suggested that the Ontario Disability Support Program and Ontario Works will be combined together.

We believe ODSP and OW need to be separate. We understand that both entities are social services. If the government is considering doing this, and if this is to do some cuts by putting it like one stop, then the government must ensure that ODSP and OW remain different and that our members and the citizens know how it is changing. That's a huge concern that we get day in and day out from our office, about that happening.

Developmental Services Ontario: I will talk briefly about this and also talk briefly as a family member, someone with a twin who is experiencing the system right now, actually, as we're going through the process.

Assessments: I've heard right across this province that the supports intensity scale assessment that people have to go through before getting support or being put on a wait-list is something that breaches privacy and, in fact, only labels people more. Some people have had the SIS assessors at their home for six hours and more. Other barriers to access to supports include the requirement to have a psychological assessment, even when there has been a clear developmental diagnosis given medically.

I could go on and on about how we need to change the assessments. I hope that you, as a committee, will take action on changing the assessments and making sure that the individuals are dealt with in a respectful manner.

The time to get a meeting takes more than needed. My twin, who deserves a better life, should not have to wait long for the assessments. He received a letter in July 2013, and the meeting has been cancelled three or four times. We now have one on January 29, 2014. I marked down the dates, but I'm also prepared to cancel, just in case.

1140

Developmental Services Ontario must be the same right across this province. I question things like my twin getting denied for supports in Ottawa until mental health pointed out that he should have gone through the southeastern and not the Ottawa region. When they put him in the southeastern region, he did get accepted for an assessment. In fact, it said that he was grandfathered—but denied in Ottawa. I take that with very much concern, and I think this shows a lack of information that's going on right across this province. If it's going to happen in Ottawa, if it's going to happen in different—I can tell you, it's happened in different areas. Talk to members of our organization in London. They will tell you first-hand. Again, I ask that you recognize that this needs to be changed and it has to be the same right across this province.

Wait-lists: With over 9,000 Ontario citizens with disabilities who are on a wait-list for supports, the government must act to resolve this issue. People's lives are at stake. People need support, and without immediate and appropriate intervention, we know that people will be hurt and some will die. The wait-lists will grow. We have enough challenges. We don't need our government or this committee to turn away. We are in crisis in this province, and I hurt for many that don't have someone to support them in their own community.

Hiring a support worker: When the new act was brought into force, it was supposed to ensure that people

could hire their own support worker. We have heard that the reason this has not happened yet is because there is no new money, although if there is no new money, I question why it was even an act, if it was going to give choice and equal opportunity.

My twin, who was through an agency three or four years ago, only spent an hour a week with them, and he was schizophrenic and then diagnosed with a developmental disability, so a dual diagnosis. I can tell you right now that he would rather hire his own support worker that he can trust and where he can be the employer, which has a huge impact on people being able to have that control over their lives. We're hopeful that this will be available in the coming days. By hiring our own support workers, it gives us power to make decisions about who comes into our homes and our lives. I know many people would benefit from this, and in fact it would give people choice. As well, people hiring their own support workers may actually save the government money. It is our hope that you, the committee, will take action on this issue.

Let's be clear that the Ontario Disability Support Program that many get to survive should not be used to hire support workers. I had so many calls yesterday about that. I'm telling you right now, if that's the case, you can be guaranteed we'll be the first organization up here battling against that. Our members do not want that. It's bad enough people are below the poverty line. We don't need governments dictating decisions by our members and by many people who face challenges. Let them have a life that they fully deserve.

Another issue is picketing in front of people's homes. We spoke out against this over the years. As you know, many agencies are funded by the Ministry of Community and Social Services. When there is labour unrest or a strike happens, the workers should not be allowed to picket in front of people's homes, as their safety, their privacy and their security are at stake. We have tried to bring the bills forward to deal with this important issue. We have nothing against unions or the employers. We want people to not have to worry if a strike happens. There have been recent strikes, one in 2007 and one in 2009, where people have lived in fear of picketing workers outside their homes. I have met many people living in group homes and I cannot put into words how scared and betrayed people feel. I hope this committee will support us in making picketing in front of people's homes illegal, as we fear that many more strikes could happen in the near future. We must put an end to that. We say that we need the trust of workers, but we must make it clear—and I think that's why my twin has turned off to hiring his own support worker, because he knows they will not strike.

Jobs: People with disabilities really want to work. It is shameful that only 25.9% of employers hire people with disabilities in Canada. We and others want jobs that pay real wages. This is something that this committee can push. Jobs must be something that people can and want to do—not have it decided for them.

Inclusive education: We need a better system when it comes to inclusive education. People should be in regular schools and classrooms, and when they graduate, they can feel proud. We must start looking at colleges and ensuring that when people with disabilities apply and only have a certificate from high school, the college or university must accept it.

Ontario is one of the worst provinces when it comes down to inclusive education. That's a fact: Look at other provinces and territories across Canada. As an inclusive rep, I far too often know about that and hear many stories. I can tell you right now, when I was in Newfoundland a couple of years ago, when people stood up from Ontario, they said, "Don't feel proud of the province when it comes down to education," because we're behind when it comes down to inclusive education in this province.

I too often know about segregation; that's what I was put through when I was young. Everyone should be included in all aspects of school life and not separated or segregated from anyone.

Housing is a huge issue. No one should expect someone to find a place for \$700. The money that many of our members get on housing is not enough. People are having to bunk up with people that they don't even know. I encourage this committee to work with the housing study group in this province, which I am proud to say that I'm part of. I got confirmation that they're speaking on Monday. You'll have an opportunity to hear that.

Something that I'm proud to stand behind and recognize: not everybody supports the idea of group homes. As far as I'm concerned, they're a smaller version of institutions in this province. Group homes should not be the answer, in my view. People with disabilities deserve choice and independence. Group homes are not that; in fact, when they share a place, they don't get a choice in terms of who they share the place with in the group home. When they come and go in a group home, it's not home to them. That needs to be dealt with. An average of four and up people in a group home—I can tell you, if someone told me that I would have to be in a group home, boy oh boy, you'd better watch out.

When we talk about hiring support workers, they can do that when persons live independently in their home. Having to hire a support worker is not saying that you can't hire them 24/7; it still saves money at the end of the day. It shouldn't be a money factor, because people's lives are at stake. But I know the question raised every time is about money. People with disabilities did not decide the deficit in this province, nor should they be neglected by this province, and that is what is happening.

We must remember that not everyone has a family or someone to advocate on their behalf. We must work with all those who are affected and start hearing all those who have no one. My twin is lucky to have us, a family; however, many don't.

People First of Ontario wants to work with this committee, all parties and the government to change how things transpire moving forward. It is very important that

individuals are always at the forefront when decisions are being made. We are happy to work with this committee on many issues. Again, this is the beginning, and I hope that what our members bring forward to, and what I bring forward to—this committee will take into strong consideration, because people are dying by the moment.

I'm proud that this committee is structured, but I'm also concerned for many who don't have here—although I told our vice-president it felt very lonely, because I'm very lonely here in Ottawa today because I have nobody beside me, but that's okay because I can fight any battle all by myself. People's lives are at stake. We need to get this crisis under control.

1150

People with disabilities can be a champion for that if you work with them, not against them. Encourage them and support them; don't go against them and don't discourage them. Let them have the life that they deserve. Quit dictating what they need. Unless you're in their shoes, you don't know what they experience.

Thank you for allowing me to have the opportunity to speak here today—and to many people who are in the audience, our address will be on our website, People First of Ontario, next week, with our comments.

Briefly, direct funding: As I mentioned, people are losing direct funding. I got so many messages yesterday that I could share of many people that direct funding—people are scared about Passport; people are scared about direct funding. There's a huge concern, so I ask that you take that into consideration. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. We do have the possibility to make a comment. Mr. MacLaren.

Mr. Jack MacLaren: Kory, good to see you again. You are an exceptional person, as any of us who have had the good fortune to meet you in the past—and many of us have because you come to our doors, you knock on our doors, and we appreciate that very much. You are a born leader: You are president of People First of Ontario, you were president of People First of Lanark County, and I believe you're president or vice—

Mr. Kory Earle: First vice.

Mr. Jack MacLaren: —first vice of People First of Canada. So you do a lot of travelling, more than most of us, I'd expect. We see your face at Queen's Park, and you tell us you watch us on TV, so you smarten us up quite a bit, Kory.

Excellent presentation: You've highlighted all the points that are salient here, problems that need to be fixed. I'd like to thank you for that. The one about not allowing workers to strike in front of homes—you've talked to me about that personally before. We haven't heard anybody else this week anywhere speak of it; that's very important. We know we have labour negotiations coming up at the end of March with a number of unions, and that could potentially happen. I would say this group really has an obligation to make sure it does not happen, because we understand. You explained it clearly, and we get that. So thank you for that. I would say that's probably our most immediate goal right now, because March

31 is a date that's not going to go away, and that would be a terrifying, terrible thing if we allow those kinds of confrontations to happen, as they have before, eh?

I won't go over everything you said, because you've said it all well and we all hear you. I would say, summing it all up, that basically what we need here is a different attitude—a better attitude—as a society towards developmentally disabled people and families and caregivers and that it's a desperate situation and that basically, as a society, as the people of Ontario, as the government, we have not done a very good job with it. I think probably summing that up, it would be fair to say that, as a caring society, we have a moral obligation to help people who can't help themselves. We are all here to do just that, Kory. I think you know that, and we know you're watching, so we'll do the best we can.

Mr. Kory Earle: Thank you.

Mr. Jack MacLaren: So do you have any comment on any of that, Kory?

Mr. Kory Earle: I do want to, first of all, thank you, Ms. Elliott, for bringing this forward, and I certainly watched that over the course—and my hat goes off to you, and certainly every party. I believe everybody here on this committee is for the best interests of people who have been labelled in this province. I truly believe that, and my simple comment was—taking my hat off, of who I represent as a citizen—this concern is going to still continue to be here unless it's dealt with today. I'm proud to represent an organization that deals with a lot of this, and I can only say that if you get millions of people with disabilities in a room and you go against them, you better have a helmet on, because I can tell you right now that they will speak out, whether you look at different communications. I'll be the one supporting them, so I won't be going up against.

Thank you so much, Jack, and thank you for your comments. I'm proud of the work that I've been able to do over the last eight years, and I know that I look forward to working with this committee, whether I'm with the organization in the coming days or not.

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

Ms. Cheri DiNovo: Thank you, Mr. Earle. That was a brilliant presentation. I thank you so much for all the work and advocacy you do. I wanted to let you know that, as the poverty critic for the New Democrats, I travelled across Ontario and that the overwhelming answer I got from anti-poverty activists everywhere was not to merge the ODSP and OW, so I wanted you to know that we're committed to not doing that.

You also probably heard me earlier talking about these assessments that go nowhere and result in nothing. It's draconian; it's Orwellian. We should stop doing that.

I have a question about your 9,000 on the waiting list. I've been asking about waiting lists since the beginning of this committee. Boy oh boy, is there a discrepancy. I trust your figures more than the bureaucrats'. I just want to know where you got them. We heard from one of the ministries that there's only 2,300 on the waiting list.

Then we heard there were 4,500 in long-term care, so I'm adding those in, so there's another 4,500—because I'm sure their families and they don't want to be in long-term care. I'm sure they are waiting for something better. So I was just wondering where those figures came from.

Mr. Kory Earle: Yes, and I can certainly put it in an email and stuff like that.

Ms. Cheri DiNovo: Sure.

Mr. Kory Earle: I also want to remind people that we met with the Minister of Community and Social Services in April. His number was a lot higher than 9,000. So I want to remind the committee that he did pull up his numbers as well. I'm using 9,000 people, but it's higher than that. I'm just being safe by saying 9,000.

We got our numbers from work with different partners in this province where they do a lot of figures—just like the 25.9% for jobs. There were a lot of forums that actually developed that. We still don't know how much it's gone down, because there hasn't been an answer to that.

Ms. Cheri DiNovo: Yes. We're doing our own little research in Community Living and through others to try to gain their figures, but I guess it points to the work of MAPS, too. I mean, we just don't have raw data here that's reliable in any way, shape or form, which is absurd.

Mr. Kory Earle: Absolutely.

Ms. Cheri DiNovo: Absolutely absurd.

Anyway, I thank you so much. What you do is fabulous. We'll take everything else to heart that you've got in here. Thank you.

Mr. Kory Earle: Thank you so much.

The Chair (Mrs. Laura Albanese): And now we'll turn it over to Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you, Mr. Earle, for your presentation. I think you did extraordinarily well on your own there.

I want to let you know that I am the parliamentary assistant to the Ministry of Community and Social Services and work with the minister, the Honourable Ted McMeekin. I know he's very committed in the transformation of social assistance in Ontario. A complete review was done by Frances Lankin and Munir A. Sheikh, which provided recommendations, and all of those recommendations are being reviewed now by the ministry and broken into a phased approach. I know you're part of the partnership table as well—

Mr. Kory Earle: Absolutely.

Ms. Mitzie Hunter: So you do have a seat at the table and can make your views directly to the ministry as being a part of that. So there aren't any sudden plans for this merger, and I'm sure you've seen in September 2013 improvements that were made as a result of the work that Frances and Munir have done.

I have a question for you based on a comment that you made. You talked about how people with developmental disabilities can become champions for their own cause. Part of your founding principles is: "Nothing about us without us."

Mr. Kory Earle: Absolutely.

Ms. Mitzie Hunter: That's one of your strong mantras and positions. How do we work with people with developmental disabilities so that they become champions for this cause?

Mr. Kory Earle: Thank you. [*Inaudible*] sat down with Ted. There's no question that he was put in with a whole lot of unravelling to do with this government and other governments.

Let me be very clear, and with all due respect: I did send Ted an email asking him about the merging—no response to date. It's about two months later. So I want to bring that to light, because when I bring an issue forward, I expect a response in the proper manner—because if it's a concern that our members are facing, you can only imagine the stress they're going through.

So to hit on “champion”—talk to them. Walk the life that they're going through. Meet with them. Don't have them meet with you at your office. Meet with them, and say, “What do you want to do? What are the things that you're going through?” and let them tell you, because I can tell you, you'll get an earful, but you'll get an earful in a respectful manner. They will tell you what they want—the same dreams, the same hopes, the same desires as everyone in this room wants.

We don't want to have a system—the Premier said it very clearly on December 9: People with disabilities have been failed by a model of institution in this province. Is that the way that this committee wants to go forward? Is this the way this committee wants to support group homes, in other ways? I don't think so. What I believe in is that if you sit down, and if you chat with an individual, they will give you what you want—but meet them. Start meeting with people who don't have anybody, as well. Talk to them, because I can tell you right now, as soon as they get someone on their side, they'll champion it and they're going to champion it for days, months and years to come.

I want to remind this committee that our board is having an outburst right now. There's a “hiring your own support worker” thing that just came out, that was just launched, and part of that says that ODSP should be used to hire support workers. Part of that was part in that. I can tell you right now, our names are on that. Shame on the ministry for allowing that to happen, because we never once supported that. We opposed it since the very beginning. That documentation I forgot to bring here today; it's on the ministry's website. I want to remind everybody here today: We don't support that, we don't support part of that document, but yet our names are being used on it. As an organization, I take that as an offence and I take that as an insult.

We need to be very clear—I can go back in all the emails—start meeting people face to face. Quit meeting people on the telephone. You'll get better reception. So thank you.

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

The committee will recess until 1 p.m.

I have to let all the people who are in the audience know that the room will be locked for an hour because

we have a lot of equipment in here, but you're welcome to come back and to continue to listen to the proceedings then.

Thank you very much.

The committee recessed from 1201 to 1302.

MS. ANNE RAHMING

The Chair (Mrs. Laura Albanese): Good afternoon. The committee is back in session. We will start immediately by calling up our first witness for the afternoon, Anne Rahming.

Hello, how are you?

Ms. Anne Rahming: Hi. I'm well, thank you. I've been looking forward to this for a while. Thank you very much for inviting parents to speak to this committee. I'm looking forward to sharing a little bit of my son's story. It's a great opportunity for us. We hope that this leads to some positive outcomes.

Before I introduce my boy wonder, I thought it might be helpful for all of you here to get a little bit of a window into his world and what's it's like, so bear with me.

Interruption.

Ms. Anne Rahming: —light when others don't. He gets hypnotized by it, he focuses on it.

Interjection.

Ms. Anne Rahming: No, this is actually supposed to be happening. He needs to have his eyes blocked sometimes so that he remembers what the task is that he's supposed to be doing. Strong smells bother him and are very difficult; his food tends to be pretty basic as a result. He's calmed by cuddles, bounces, hugs and forts with sofa cushions. If this is bothering you right now, then you'll be really happy that I can do this. We'll just move to the next slide, if I can find the mouse. My son can't do that; he's not so lucky.

This is him at the piano enjoying one of his sessions with Erin Parkes, who teaches music to kids with special needs. This is one of the few times in his day that all of those outside sounds don't drive him nuts, and all of that light kind of becomes background noise like it does for the rest of us, because in this environment he is good at something. He loves music; he has perfect pitch. He knows how to do solfège, so he sings the notes and then plays them on the piano and has a great time at it. It's one of the few times that he gets to be a little boy like the little boys that I imagine you've seen over the course of many days as politicians.

Here's another picture of my son with his older brother Neša on the trampoline. As you can see, Mića is a happy child. He laughs easily. He's obsessed with everything that has to do with Caillou and Dora, and our former psychologist in the room could attest to that. We had to do programming around Caillou for a while.

He loves swinging and sledding, and if you didn't look any closer than this photo, you would think he's just what he actually is: a kid, just like Sue McGowan's son; just like Heather Rose's daughter Molly; and just like Autumn Alberelli's twins—who are both at the severe end of the spectrum—Oscar and Sophie.

But all of these kids have autism, and all of their parents are praying that your panel's recommendations will bring long-sought good news from government.

Let me tell you a little bit more about Mića's story first.

Our son Mića was diagnosed at the age of three with autistic disorder and is considered to be at the severe end of the autism spectrum. As you can see from this photo, early years were pretty much what every parent experienced: lots of cleanup, lots of laughter. Not much seemed out of the ordinary until almost year 2.

The quizzical looks started around 18 months and were really quite obvious by the time he was two years old. It was then that we found out he wasn't hearing very much. We flash forward through two surgeries, hearing problems, apnea problems, and finally we got a diagnosis a year later that there was a much bigger elephant in the room.

We were lucky because our retired parents—my husband's in Serbia, and mine in Quebec, both somewhere far away—were able to help us pay for the prescribed intensive behavioural intervention therapy, albeit at a much lower level of intensity than we would have done in a perfect world. Our parents understood that to not act would have been to lose all hope of our son ever enjoying the benefits of adult independence or the simple human joy of connecting with other individuals. I mean, the fact that he loves this great iPad is great—and I do think the iPads are absolutely wonderful for kids on the spectrum—but making friends is even better. To wait until our name reached the top of years-long lists for diagnosis and then for assessment and then finally for intervention would almost certainly have doomed him to a lifetime of dependence on others and, even more sad than that, isolation. As parents, if it was in any way in our power, we had to ensure that that was not what happened to him.

We're not saying anything, my husband and I, that you have not already heard this week, I am sure. Of that, I am absolutely sure. Our son and the other children like our son need intensive therapy now, not later.

I was actually disheartened yesterday when I saw the story, that I'm sure you all saw, of a mother who is waiting for her adult child to get a place in group care so that she can die. The response of the politician who went to see her was, "Well, obviously, the question on the top of everyone's mind is what will happen once you're gone." That is not the top of our list. The top of our list is what we can do to make sure that when we're gone, they don't need us as much as they do now. If we wait until the question becomes the former, we've failed. I'm not saying anything that you haven't already heard.

While it's certainly incumbent upon this panel to address the huge crisis that already exists within the adult community, it's also your responsibility to ensure that the generations of children who are currently being diagnosed with developmental disorders do not experience the same fate. To do this, you need to be brave and you need to move away from the status quo.

As Ontarians, we're aghast when a child with a grave medical issue such as congenital heart failure or leukemia

does not receive intervention in a timely fashion. We're aghast because we believe that we live in a part of the world where we care about our kids so much and we have the fiscal resources to put them ahead of other social and economic issues that make their way onto the political agenda. As Ontarians, the notion that people with other neurological disorders, like cerebral palsy or Alzheimer's, would go untreated for years seems inhumane, and yet we have a system that makes parents wait for diagnosis and then wait for treatment. We are right to be aghast, because we believe that our society has a duty to protect the most vulnerable.

1310

Mića needs your help if he's going to make the most of himself in adulthood. He needs our help, that is for sure, and we're happy to provide it as his parents, but he also needs yours.

In case you're wondering, our son is doing a great job in IBI at the moment. As you can see in this photo, he's also integrating very nicely into an Ottawa Catholic School Board school that he attends every afternoon with the support of an educational assistant. Just over two years ago, he would have reacted to anyone outside of his immediate family more like a wounded animal than a typical human being.

While he continues to have very low verbal skills—for example, he can ask for what he wants, such as, "I want a drink," or, "Give me pizza," which is often what we get—he certainly is not considered to be anywhere close to moderate or high verbal skills.

He adapts well to new routines now. He enjoys reading Dr. Seuss books, to the point of frustration sometimes on the part of his parents. He takes piano lessons three times a week. He looks forward every day, even on PD days like today, to school time and Sunday swims.

These steps forward have not come as a consequence of the benevolent hand of bureaucracy. To the contrary, our family has found out, as so many others have already related to you, that the bureaucracy for accessing developmental services in Ontario, whether it's by design or by evolution, has become a system of closed doors. Any strides towards accessing needed services are viewed within the community as pure luck or as the consequence of parents like us pushing and advocating for their children night and day, and at times knowingly pitting ourselves against other parents to get the few resources that do crop up above the waterline.

We can speak most to the place that the Autism Intervention Program plays within the system, as we've been on that wait-list, gone through those assessments, fought for funding, and we currently design our son's programming under their standardized criteria. As citizens—because we're those as well, not just parents—we were very angry last year when the Ministry of Children and Youth Services silently endorsed the use of clinical continuation criteria by the AIP, going against its own policies and procedures as outlined in *Early Learning for Every Child Today*. Instead of continuing to endorse the principle that children should be assessed as individuals

with unique patterns of development and learning and not assessed in comparison to others, our children, children with autism at the severe end, are now subject to clear benchmarks that override the common sense of developing programming according to each child's pace in learning and interests.

Teaching to a test and standardizing hours of therapy and programming for children with different challenges is precisely what applied behavioural analysis is not supposed to be about, or indeed the early intervention version that we call IBI. If you look at the program guidelines, they concur with that point of view. However, over the years, the ministry has allowed the AIP regional service providers, what we call the RSPs in our lingo, increasing leeway into how they manage this file, requiring only that they show "success" with wait-list management. The consequence is that clinical arguments are now being used to herd children through early intervention when it is clinically not advisable to do so in the views of supervising clinicians—not in the views of parents, but in the views of the people who deal with them on a day-to-day or month-to-month basis. The new independent review mechanism that we spent so much time setting up is viewed by parents with increasing skepticism, as it's being fed information by the same RSPs and has limited interaction with the parents or indeed the clinical groups that are actually undertaking the care.

In short, neither our government bureaucracy nor we as citizens seem to be in control of how the early intervention system for autism therapy actually works. Speaking from our personal experience, it's impossible to know what effect this has had on our son, but we do know that despite the huge economic burden we now shoulder—because, as you know, the cost for full-time intervention is somewhere in the neighbourhood of \$60,000—the cost has been, and continues to be, for us, worth it.

The system is broken. There is simply too much system and not enough service. We are pleading with you to be brave and to look westward for answers. I know that sounds like a crazy notion. Why would we look west for answers in our country? But I'll tell you what every autism family is constantly debating in this province: If you have a kid at the severe end of the spectrum, how do you get to Alberta?

The province of Alberta begins from a very different place than we do. They begin with the family, and they ask, "What can we do to ensure that the family will thrive with a child with special needs?" We're asking you to think along the same lines. Stop spending the money on a bureaucracy designed to tell us that we don't have the money to do the right thing, and instead spend the money or redirect the money to families who provide the documentation that their children need help today.

A direct funding system is more efficient, more flexible and more effective for our community. We can see the success rates in Alberta—and I feel sorry for Alberta because they're experiencing an influx of us, but there you go. The point is that that is supposed to be the point. It should be a flexible, efficient and effective system that

uses taxpayers' money in the most fiscally responsible way.

We—and I'm talking not just on behalf of my husband and myself, but we in the autism community here in Ottawa and beyond, because I now participate in a number of communities of parents across the province—have heard three statements over and over again as we advocate for direct funding as the new system for autism service provision. Usually they come from people who are within the bureaucracy or from people who have studied the bureaucracy in the past. "What about the places in Ontario where there is no direct funding? What about the poorest people in Ontario on the waiting lists? Wouldn't parents just abuse the system if they got the money directly?" Those are the three questions that seem to crop up over and over again.

On the first point, it is true that some regions of Ontario, particularly the northern region, may be challenged by the lack of private providers at the moment. But keeping a monopolistic system in place does not create new providers. We are not advocating for doing away with the organizations. Every region has an RSP at the moment. Putting the tax dollars back in parents' hands and having us either purchase services from the RSPs or from private ones creates real competition in every region and across the province.

I should add—which I didn't have in my notes—that, for example, our current senior therapist is on a flight internationally to go and do a face-to-face supervision with a child that she has not actually seen face-to-face for over a year but has been supervising via Skype. So the idea that a single region not having private provider availability should be driving the current system becomes a moot point in an era where Ontario is increasingly connected through the Internet.

The status quo is actually quashing competition, and, more to the point from the standpoint of our tax dollars, it's raising labour prices in the market. I'm not advocating that we should start paying our therapists minimum wage, because they do a really, really difficult job. But when we have a wage gap that is, in some parts of the province, three times as much being paid to an RSP's therapist versus the private provider's therapist, all that you get, for those of you who have done labour economics, is a push upwards; it's never a push downwards on the prices. And it's the parents who pay the cost of that and, ultimately, the taxpayers as well. The status quo is also raising labour prices in the market, which will make it only that much more expensive for us to continue to fund the same system over time.

On the second point that I made earlier, my husband and I have a lot of trouble not getting angry. I should add—and my MPP, Jack MacLaren, is in the room, and knows my husband—that my husband is a new Canadian from Serbia who came to this country and worked 18-hour days at minimum wage jobs for the first two years that he was here without stopping—six days a week. When you talk about the poorest people and how you're going to help them, he usually perks up to find out if he would fit himself into that mould. The poorest parents on

this wait-list are the worst-served by the current system. To say anything else and to put the current system as a reason for being on their back is a lie and is egregious.

1320

They are the most likely to have minimal parent training, as they struggle to make ends meet, and more so than other parents who are also overwhelmed are challenged to make it to the intermittent parent-training sessions that are offered. They are also most likely to wait for service and pay for no therapy during those critical early years of their child's development. As a consequence of both of those factors, they are most likely to be the parents of children who develop extreme behaviours that will stay with them into their teen and adult life. In what way is that a system working for them?

Finally, the notion that parents of children with autism, particularly those with severe autism that never sleep and bounce at 4 a.m. in the morning, will go wild and spend funding on a drinking binge or at a casino is absurd. We are struggling every day with children who have a severe disability. The last date night we had as a married couple was two years ago. Do we sound like the kinds of parents who are likely to abuse the system? What concerns us, in fact, is that so much energy seems to be put into worrying about us abusing the system and so little into the fiscal abuse going on within it by those holding the fiscal purse. How did that happen? From where we stand, the onus is on us, our son's parents, to ensure that he succeeds. To do that, we need to be able to use the fiscal resources that are available as wisely as possible so that we can provide, as the program guidelines stipulate, high-quality, evidence-based intensive behavioural intervention—nothing more and nothing less.

Redirect funding to the families and you will find, first of all, that we have a more efficient mechanism for using the services available in our province and, secondly, that we will have a better long-run clinical outcome for the growing community of children being diagnosed with autism spectrum disorder today. Thank you for listening.

The Chair (Mrs. Laura Albanese): Thank you for your presentation, an impeccable presentation, I should say, very well-presented. Unfortunately, we don't have any time left for questions or comments. Jack, don't look at me like that—I have to be fair and allow the same time for everybody. But we really appreciate your comments and your recommendations to the committee. We will keep them close at heart. Thank you.

Ms. Anne Rahming: Thank you very much.

ONTARIO RESIDENTIAL CARE ASSOCIATION

The Chair (Mrs. Laura Albanese): We'll call now on Ontario Residential Care Association to come forward. Good afternoon. Make yourself comfortable.

Mr. Len Goddard: Good afternoon, Madam Chair and all MPPs from all political stripes, I understand—and I hear you're working as a harmonious group.

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

Mr. Len Goddard: That's a great experience, eh? Congratulations.

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

Mr. Len Goddard: My name is Len Goddard. I'm the president of Ontario Residential Care Association and also the executive director of Sonshine Families.

Who are we? I deliberately asked one of you earlier if they knew what an OPR was—nope. We'll tell you. Part of 100-plus OPRs across the province, we provide residential respite and other support services to children, youth and adults. OPR means outside placement resource. We are part of the system, but we're outside the TPA block. Our members are one or more of the following: for-profit, not-for-profit and registered charities. However, we all operate on a fee-for-service basis, which means we are only paid when we are actively serving a client. There is no guaranteed ongoing funding and no capital investment by the government. Our services fall under the ministries' regulations, including the QAM—quality assurance measures, and we're reviewed on that regularly.

Interjection.

Mr. Len Goddard: Did you want me to stop for something? Oh, okay.

We provide many of the services to our citizens with special needs such as the following:

- group homes, with a wide diversity of client profiles, some for males, females, children through to senior citizens;

- foster homes with parents and staff educated and trained in the care of special-needs clients;

- respite programs using facilities in the city, in camps and homes, and again with a diversity of programming that meets the clients' needs; and

- day programs that include services to total-care, dually diagnosed clients, as well as work programs. Recreational, educational, vocational and rehabilitative needs are provided for.

Some of our member agencies have been involved in providing services and have been active in this field for several decades. We have successfully demonstrated the ability to quickly adapt our programs to meet the specific needs of individuals. We often receive very challenging clients that are not able to be placed in many TPAs. We believe in and are committed to providing our clients with the best possible quality of life. We are often frustrated by the pain that the system can inflict on many of our clients and their families.

I'd like to ask Margo Babe, who's the adult service manager of Sonshine Families, to share but a few of the stories drawn from our agencies across the province. I will share our recommendations when she is finished.

Ms. Margo Babe: Good afternoon.

So how does the current lack of a comprehensive collaboration of ministries affect families in our community? What happens when funding is not individualized or portable?

Unique individuals require unique funding solutions. This requires ministries to work together to provide sup-

port for different areas of life. A person-centred plan designed around a person's individual needs must involve family, friends, school and community members, but must also have a government and ministries willing and able to create a circle of support, which includes a circle of flexible funding. Because of the current inability to provide such a circle, the system is failing many of our citizens who require support.

Here are some examples.

A gentleman with a developmental disability and some aggressive behaviour has successfully been supported at a group home for several years. He fell and broke his hip. The group home could continue to provide services but requested funding for renovations to make his home accessible and for some at-home medical supports. However, this was not available, so the gentleman remained in hospital for a long period of time.

Children who are in care of CASs with multiple complex care needs such as autism, Asperger's or fetal alcohol syndrome, for example, intellectual disabilities and mental health diagnoses, or intellectual disabilities and physical disabilities, i.e., complex care needs: They have found a successful placement in foster or children's group care, but because they have a birthday—i.e., they turn 18 or 21—they are now under adult services, and even though the home they have lived in for many years is willing and able to continue providing the support they need to be successful, they must move because adult services does not have the ability or desire. Agencies have been told, "We do not work with for-profits." This is also a problem for providers of respite for children who have worked with families for years and are able to provide excellent care because of the relationship and knowledge developed over these years. This child now becomes an adult by age and cannot be provided respite in this home because of no available funding.

We need to support the development of lifelong care plans and providers with lifelong relationships and knowledge.

Another example: a young teenager with a developmental disability who requires support for all areas of activities of daily living. She's blind, she is non-verbal, she requires a wheelchair for support, and she can at times display self-injurious behaviours towards herself and others. She lives at home with her single mom and younger brother. An agency begins providing support by taking this young lady to camp in the summer, and then the same agency is able to provide support at their respite program in a group home. Mom becomes pregnant with twins. Her teenage daughter now requires immediate placement for at least six months to a year, as the family doctor says mom cannot continue the primary care because of her pregnancy-related health issues. The agency that has been providing support for over five years offers to care for this lady. However, because this is considered new funding needed, the family is only offered placement in group homes, which are transfer payment agencies, which have vacant beds which are funded. This young lady is placed unsuccessfully in two such homes, and the

family and client are traumatized and still left without support. The original OPR agency now cares for this person five days a week out of compassion and highly subsidizes the cost from funds they really don't have.

Another example: At a recent meeting, children and adults with fetal alcohol syndrome were identified as falling through the cracks because they require support across different ministries, such as the Ministry of Community and Social Services, the Ministry of Education, the Ministry of Health and the Ministry of Correctional Services. Because this cannot be organized, many of these individuals end up in jail.

For example, a young man with fetal alcohol syndrome and a developmental disability was living successfully with loving support in a foster home. When he became an adult—he had a birthday—because of the funding, he could no longer stay there. He ended up returning home to his biological family, who were not able to care for him. He then ended up in the wrong crowd, and with a "friend" robbed a McDonald's. However, the next day he felt guilty, so he returned to the McDonald's—if he hadn't returned, he likely would not have been caught—and confessed. He was arrested and ended up in jail. One of his issues was picking at his cuts. He cut himself on a food slot in his cell and picked at it until it became infected. He ended up dying from blood poisoning. The system failed and, I would say, abandoned this young man.

Another example: A gentleman with a developmental disability and mental health issues has been involved with the justice system and has been threatened that any more such involvement will result in a jail sentence. This individual is in no way equipped to survive jail time.

1330

Temporary short-term funding through Service Coordination Ottawa has been found, and he is successfully placed in an OPR group home for adult males. But what happens when this funding runs out? We need not only the Ministry of Community and Social Services but the ministry of justice and mental health to come together to provide the support needed to allow for continued success and keep this young man out of an expensive jail cell.

Another example is a vivacious, outgoing, full-of-life young woman in her early 30s who has cerebral palsy, which affects her ability to walk, speak, eat etc. She requires help with personal care. She has lived her whole life with her parents, with her mother being the primary caregiver. Her parents are now elderly, in their seventies and eighties, and, for the first time, start to look for immediate respite care.

They find a service they are happy with, which provides respite service in the form of summer and winter camps. This young woman attends these camps for several years and forms strong bonds and relationships of trust with the caregivers. Then her mother passes away. Her father, with help from some aunts, continues to care for her, but the father and aunts are in their eighties now.

The father now requires a residential placement and would like to place his daughter with the same agency

that provides the respite at camp. This agency can provide an appropriate residential space with the same consistent caregivers and an active day program, which would meet her social, mental and recreational needs for a vibrant woman of her age. However, there is no way to access funds.

Instead, this young lady is placed in a nursing home where the rest of the patients are elderly and frail. This bed is not less costly, just one that is block-funded; however, this is not an appropriate placement for this young, vibrant woman.

Our last story will be presented by Tina Kokkinos. She's going to speak about her sister.

Ms. Tina Kokkinos-Marins: Hello, my name is Tina Kokkinos-Marins. My sister is Nikki Kokkinos, who is a 43-year-old autistic adult with no verbal skills and behavioural issues. She was the unlucky one who didn't get early treatment. Now she is 43, and there are huge issues.

Nikki has always lived at home, and in 2005, our mother, and Nikki's main caregiver, passed away, leaving my father to care for Nikki on his own. She attends a four-hour day program at OCL since the age of 18. It has now become overcrowded, and Nikki gets no benefit from it and just sits there. But they tell us that the spot is funded and untransferable, so we can't look for a better-funded day program for her.

We have been hiring caregivers in our home to take care of Nikki, but it is very disruptive since there is such a high ratio of turnover with caregivers who come in the home. My father and Nikki are alone in their home, and I am always worried that I'm going to get that dreaded phone call when something has happened.

Nikki was assessed by DSO two years ago and was placed on the priority list, and due to the urgency of her care, a service coordinator was assigned.

Finding a placement for Nikki seems very difficult. She is extremely vulnerable and has behavioural issues. As well, the family's main priority is for a secure group home.

Our case manager was able to find Sonshine Families as a respite for us. She loves it there, and we love it there for her. But we've been told that this is a private agency, and it can't be funded. They won't fund it for us.

We've gone through service resolutions, contacted the Ombudsman of Ontario, as well as our MPP. We've received absolutely nothing.

We pay out of pocket for respite for Nikki right now at Sonshine Families. She is happy; we are happy.

It is only a matter of time before something happens. My father is 82; Nikki is 43. It's only a matter of time before my father, who has had two heart attacks, will have one and will pass. Nikki will be alone in that home.

They tell me that she will be taken and placed in a hospital. It seems ludicrous to us that the ministry would pay for a hospital bed that costs five to six times more than a spot at Sonshine Families group home. It just seems ludicrous. The fact is, she won't be able to stay there. She has huge behavioural issues; the hospital won't accept her either.

It's like I said: It's only a matter of time before something happens. The question here is, when it does, who is liable? Will the government not be liable for neglect? We often ask that question. I have my own family, I work—we've exhausted ourselves, and I know many other families in the same boat. But when a family finds a placement where you know your loved one is happy, is cared for and you can at least have some peace, and they tell me we can't have funding because it's not a funded spot—we don't know where to turn. It's just impossible, and it's unbelievable. With direct funding, we would use it for the place that is perfect for Nikki.

One more thing: Without direct payment to families to find good placement—it allows for competition. There are, right now, I know, funded positions. Even in the day program she goes to, it's funded, but it's not any good anymore. It's overcrowded. With money direct to us, there would be competition and people would find better places.

Mr. Len Goddard: How can these challenges be better met with existing funds? Services must be more individual, client-centred and focused. The development of the DSO system is positive, particularly the evaluation and assessment of each unique individual's needs and the level of care these needs require.

I sat on the ministry's systems planning table when transformation of the adult system was under discussion. At that time, there were to be two parts to transformation. One, the assessment and evaluation piece, has been implemented. However, the second part of the transformation of funding to an individualized funding model that is implemented based on the assessment that has been done has not happened. Somehow, the old system of block funding was retained. That wasn't the original plan. Money through the DSO could be client-focused, not agency-focused. Funding must become attached to the client, not to agencies. This will enable the system to provide for more unique, efficient funding to be used in person-centred planning. This individualized funding would allow services to be developed around a specific client, with the input and the involvement of the family and the entire support circle.

This type of funding would also be able to follow the individual through the different stages of life. This would mean that perhaps a child could even have funding that could move with them into adulthood. This would involve a shift in thinking from block-funding large institutions—schools, agencies, hospitals, and even corrections programs and prisons—to funding individuals based on their assessed needs. Hopefully, this would allow support to happen in the community and reduce the need for the services of these large, costly entities.

The DSO could manage these funds. Hopefully, this would also prevent the passing-of-the-buck syndrome between ministries that takes place now. We could create a model in which all ministries of the same government could work together to provide better outcomes for all individuals and their families with special needs in Ontario.

Don't opt for a hospital or correctional bed at \$1,500 to \$2,000 a day when a bed or services that are six times

less expensive could effectively provide the care required, while maintaining continuity for the client. For accountability, one ministry could take the lead.

We owe it to our communities to make the system accessible through shared services between all ministries, at the same time ensuring that service is provided for every dollar spent. Respectfully submitted.

The Chair (Mrs. Laura Albanese): Thank you. We can allow for about a minute's comment from each party. Continuing from this morning, it's the NDP's turn.

Miss Monique Taylor: Thank you so much. Thank you all for your presentation. Bringing perspectives to the table of different clients who don't have a voice or somebody to advocate for them is so important, so thank you for that a piece of it. Thank you for sharing your sister with us and the troubles that you're facing, because it is a crisis, what's happening in this province. You're not the only family that's going through this, and I don't say that to belittle what your family is going through. I say that because we understand, and it's so wrong, and something really needs to happen.

1340

We have to be looking at other scenarios of how the funding is being directed. Direct funding is something that we've heard a lot of families saying is necessary. Some families aren't able to deal with that direct funding, and we understand that. We can't have a cookie-cutter situation for everybody in this province. Families are individuals and need to be treated as such.

Thank you all so much for being here today.

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

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you so much for taking the time to be with us today and for articulating each of those stories. It really helps to focus us as we're looking now to get into the stages of drafting our report, having conducted our hearings across the province. We are hearing some common themes. So I want to say thank you for that.

I note that you have some specific issues that are relating, and you're trying to get the attention of the ministry, of your local member. I think that that's very possible, so that you can get the assistance you need to get the answers that are available. We'll ensure that we follow up with you on that as well.

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

Ms. Sylvia Jones: Thank you for your presentation. I think what you've done with your examples and your family experiences is shown the need and the value for different services along our life, just like all of us.

While I would never question you, Len, I do have one question.

Mr. Len Goddard: Sure.

Ms. Sylvia Jones: In your first point, you say, "The development of the DSO system is positive, particularly the evaluation and assessment..." I have to tell you, we haven't heard a lot of that. We've heard a lot about, "Why is the DSO assessing my child for a diagnosis that we were given 15 years ago, 16 years ago, 18 years ago?" Without putting you too much on the spot, why do we need another assessment at that 18-to-21 age?

Mr. Len Goddard: I think that what the system has learned previously is it was often the squeaky wheel that got the grease, and the decision was made that we need to evaluate everyone on an equal footing so that apples are compared to apples, not to oranges. So that's what the DSO is now doing.

I don't think there's as much complaint about the DSO in the assessments—at least, from what I'm hearing—as that when you make the assessment, nothing happens afterwards. It's a dead end.

Ms. Sylvia Jones: Yes, we are hearing a bit of, "If I already have a medical diagnosis, a medical assessment, why are you forcing me to go out and get a psychological assessment?" That's an added cost to the family, and I'm just wondering what the value of that is, other than a bit of a make-work project.

Mr. Len Goddard: Yes, I hope it's not that. I would just say that if we have two or three assessments from two or three different people—for different clients, from different professionals—you have to have some means by which you can evaluate it fairly and equally. I think that's what the system's trying to do, so that when you grade it later, as to who is in grade 1, 2, 3 or 4, as far as needs, you know you've done a fair, equal assessment.

The Chair (Mrs. Laura Albanese): Thank you. That explains it for us in clearer terms than we've heard until now. Thank you very much for your presentation this afternoon.

Mr. Len Goddard: Thank you.

OTTAWA-CARLETON ASSOCIATION FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

The Chair (Mrs. Laura Albanese): Our next presenters are the Ottawa-Carleton Association for Persons with Developmental Disabilities. Welcome. As you may have heard previously, you have up to 20 minutes for your presentation. Should it be shorter, that will allow for questions and comments.

Mr. David Ferguson: Good afternoon, and thank you to all of the committee members for your participation in this process. It is appreciated by this sector.

My name is Dave Ferguson, and I'm the executive director of Ottawa-Carleton Association for Persons with Developmental Disabilities and Open Hands. With me are Bill Cowie, president of the board of directors of OCAPDD, and Bonnie Dinning, past president of OCAPDD and current board member of OASIS.

Having followed the transcripts of the committee, we were certainly aware that it has been a challenge around time and opportunities for questions, so we are going to attempt to limit our comments, or shorten them, to invite time for more discussion.

Bill's going to talk about OCAPDD's work with regard to establishing a national coalition, and Bonnie will speak to her experience as a parent of a young man with a developmental disability and the innovative residential service that has been created for him. I will share

a few comments about OCAPDD and also the issues facing the sector in Ottawa.

OCAPDD is similar to many community-based developmental service sector agencies that you're familiar with and will have heard and received presentations from, from across the province. We've been operating for almost 60 years and provide a full continuum of community-based services. We provide approximately 1,000 individualized services per day, operate with a \$25-million annual budget and employ 550 staff.

In 2007, OCAPDD began managing Open Hands, a DS sector agency in Cornwall, and two years later amalgamated it with OCAPDD. Also, for the past three years, we have been providing financial and payroll services to another Ottawa-based DS sector agency on a contractual basis. Also of note, OCAPDD was one of the first six organizations that formed OASIS in 1996, and we've been very actively involved with that organization since that time. In fact, I've spoken with some of you before in my role as chair of the OASIS labour relations committee.

OCAPDD and other DS sector agencies in Ottawa and eastern Ontario face the same challenges as others across the province: long wait-lists, frozen resource levels, increased operating costs and pressures including wages, pay equity and reduced capacity and ability to respond to service requests. Two things that are different here in Ottawa are that Ottawa has had a central intake process for approximately 20 years, and also what I would call managed competition, and I think the presentation just before us spoke to that as well. The central intake process here had been with Service Coordination for that period of time. We've gone through the process and have had the experience here—that other parts of the province are just going to—of having that distance, if I can describe it that way, from families on the wait-list, which has been frustrating for those families and frustrating for organizations.

With the managed competition, it has existed through the OPRs, and Len has talked about that. From my perspective, there is nothing wrong with that managed competition. I believe it's starting to spread across the province, and I would agree with many of Len's comments. The issue from my perspective, however, is it's not so much the direct funding issue; it's more about an entitlement or rights-based service. We can speak more to that later.

One other unique aspect to the DS sector in Ottawa is that there was a period of time here when several agencies had been declared hospitals by the labour board and the Minister of Labour. When a hospital, we were covered by the Hospital Labour Disputes Arbitration Act, or HLDAA, resulting in a no-strike, no-lockout environment. This was changed by legislation in 2001, and, as you are no doubt aware and referenced earlier in the session today, the sector is now subject to strikes. And again, you aware that this spring, there is going to be a serious threat of work stoppages in this sector in the province—obviously, a concern to many of us.

Before I ask Bill to share his comments, I would like to make one follow-up comment to Dr. McCreary's presentation this morning. We had an individual we were supporting who was having severe challenges, and he ended up in the hospital, in the emergency department. He had severe behavioural challenges, and the staff were working with the psychiatrists there, and the psychiatrist's comment was shared with me later. He expressed it out of frustration, not out of any kind of condemning or demeaning manner, but his comment to my staff was, "I feel like I'm a veterinarian. My skill set is completely gone"—because his skill set was based on verbal discussions and communication with his patients. So I certainly support the recommendations in terms of the training for the medical community. It is urgently needed. I was quite surprised and pleased to hear about the amount of attention that the UK provides in that.

With that, I will turn it over to Bill.

Mr. Bill Cowie: Thank you, Dave, and thank you for this opportunity to address the select committee. We welcome this chance to present to you some background not only in the issues we have faced as Ottawa's largest service agency for the developmentally disabled, but also on one of the initiatives we are taking now to address them.

Dave Ferguson and I have spoken, and he has identified for me at least three broad areas of stresses in the system that need to be addressed: the issue of competitive wages for people who are providing services in this sector, the whole issue of capacity-building and organizational development, and, of course, the waiting lists.

1350

In the past year, one of the ways we have tried to address these sectoral issues is to try to broaden the discussion in order to bring more players to the table, specifically by promoting a national strategy or program for the disabled. The need for and feasibility of such a strategy has four primary sources and clear indications that the provincial resources were limited and that all of the problems would not be able to be addressed at that level, at least not in the foreseeable future.

Second was the Drummond report recommendation 8-9, which recommended engagement by the federal government in supporting individuals with disabilities, especially those who are unemployable.

The third driver of this initiative was the Australian example—the introduction of something called the National Disability Insurance Scheme in Australia—and the existence of similar programs in Germany, the UK, New Zealand and elsewhere.

Finally—and I think you will attest to this. I've been on the board a number of times. This is my second round as president. When I came back a second time, I saw the same discussion with the same people saying the same things when I was on the board before. The system was in stasis. We talked about all the marginal changes and so on and so forth, but the critical elements of the system were not changing and the debate was remaining the same. The discussion and the discourse needed to

change, or at least start to be more hopeful is more the word that I want to use here.

Our purpose is to tap federal resources with the province's so as to enable the building of a universal insurance or support scheme for the disabled that is, as I say, universal and comprehensive. We believe that only with this approach can the challenges of the sector, which I have identified and which are decades old—only then can they be addressed. Those are the issues of waiting lists, strengthening organizational development, capacity-building and competitive wages.

With this in mind, our first primary task was to bring the communities involved with the disabled together in the cause. I will put my appeal out there right now to everybody in this room to join us in this.

To that end, we are working in five streams. First of all, we are fostering partnerships and cultivating allies for promotion of this agenda wherever we can find them. I've been in touch with some of the organizations in this room. We've also been in touch with Ryerson University and the disabled studies group, and we are also getting support from OASIS for this, leading towards what I hope will be the creation of a national coalition.

The other thing we're doing is drawing attention to our efforts from members of Parliament, in the Senate, on the Hill, and mobilizing the political community to the cause. We have met with senators and members of Parliament, with further meetings planned when Parliament returns. It is our intent to engage all parties in the debate, and to date the response has been very encouraging and supportive.

The third thing we've done is we've undertaken research to better understand the national picture, both in its similarity and diversity. In this, we've received some federal funds for research, and we have a summary report on our findings. What is interesting about that is the commonality of problems across provinces.

In addition, one of our board members, while in Australia, conducted research on the Australian model, asking the particular question, "How did you manage to do it? How did you create a universal social program in this time and age?"

Most urgently, we're working to find the resources to create a national secretariat to carry out the administrative load that this is going to require as we move forward, which is something beyond the capacity of our particular board to do.

We are also soliciting support locally and provincially—as I say, engaging OASIS and Community Living. Even as recently as yesterday, we were presenting both to OASIS and Community Living in that cause.

What has been encouraging so far has been the response from Parliament Hill. Numerous Senate reports and others over the years have addressed this issue, and the push from below is being very welcomed. In fact, the discussion has been going on on the Hill quite extensively, but what they have lacked is the national push from below.

What is problematic for this agenda is that the community of the disabled is so fragmented. Many different

players coming to the table and a more unified voice would be most welcome; that is why the need for a national coalition.

The other problem, and I saw this in some of the presentations this morning, is data. We saw this when we were trying to do the provincial studies. We know so little about each other, about our standards, what works and what does not work, and what is the magnitude of the problem. Without better data, any national program would be making policy in the dark, and that clearly has to change.

The initiatives do not address the immediate problems of this sector. We are talking the long game here, but it is a game worthy of engaging and represents only one more link in the chain of improved support for people with disabilities that began in earnest almost 60 years ago.

Thank you.

Ms. Bonnie Dinning: I have a good-news story to tell you. In 2007, MCSS released a call for proposals for innovative housing models. In response, two families, of which one was mine, approached OCAPDD with the idea of forming a family-agency partnership to provide housing for our sons. The proposed model involved the purchase of a home by the parents, the provision of personal support by the agency for the sons, and conflict-resolution support to both parents and sons.

Conflict resolution became an important support that the agency provided. It was something the families could not have undertaken on their own. It eventually became clear that the sons were not well matched for living with each other, and one family left the partnership. The agency took on the role of creating a new match, which has been very successful.

So why am I telling you this story? I believe this is an example of an incentive that has allowed two families to invest in Developmental Services Ontario. I've been active with family community groups over a long period of time and, more recently, was the founder of United Families of Eastern Ontario. I heard, many times, families saying that if only they had some support, they could create solutions for themselves. This project allowed us, as a family, to do that. It also allowed us to remove two people from the waiting lists locally, both our son and also his current housemate, who has no family to assist her.

I also believe it's an example of how families can access quality support. Unfortunately, purchasing services from an agency is usually beyond the financial ability of most families. I really do hope that as you develop your report, you will consider ways to make the valuable resources which are currently available for those supported by agencies available to those who would like to purchase them. We need access to supports that are more viable and financially available.

That's all I have to say today. Unless any of my colleagues have any other further questions, we would like to give you the opportunity to ask us questions.

The Chair (Mrs. Laura Albanese): Yes, and we do have about two minutes for each party, starting with the government side. Ms. Wong, or Mr. Fraser?

Mr. John Fraser: Thank you very much for your presentations. Thank you very much, Dave, for the work that you do and, Bill and Bonnie, for the volunteer work that you do.

I want to ask a question in regard to the example that you found in Australia and what you're proposing as a national strategy, if you could flesh that out a little bit more in terms of how that looks from a policy perspective—if you've got that far.

Mr. Bill Cowie: Australia, as you know, has a governance structure much like Canada. It's a Westminster model under a federal system. The states were responsible for the developmentally disabled and, like in Canada, there were unequal services across states and unequal services within states: different standards and different priorities.

Through a really magnificent push—a bipartisan effort, in the case of the Australians, with strong political leadership coming from key people in both parties—and as a result of a committee that was struck under the prosperity commission, the ministry of finance led the charge on this, in a document called Pay Now or Pay Later, in which they basically made the argument that if you don't put your money into the needs of the developmentally disabled early and extensively and comprehensively, you will pay a lot more later. That's what opened up the discussion, and that's why it became largely an economic discussion rather than a rights discussion.

In the end, when they went through all of this, and through very strong financial supports for promotion and an excellent advertising campaign—we've documented all of this and we have presentation on this—it ended up, by the end of this cycle, that the Australian people as a whole just ended up saying that, economics or not, it was the right thing to do.

Mr. John Fraser: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. From Mr. Fraser, we'll go to Ms. Elliott.

1400

Mrs. Christine Elliott: Thank you very much for your presentation. I think it's really an intriguing idea and something that we would like to know more about.

I just made a note here that you mentioned that you got some federal funds for a study, that you had a—

Mr. David Ferguson: We applied for a summer student grant and received a small amount of money and were able to hire a university student who did the research for us over a number of months.

Mr. Bill Cowie: A genius, by the way.

Mrs. Christine Elliott: Is there a report available that we could—

Mr. Bill Cowie: Absolutely.

Mr. David Ferguson: We certainly have the presentation that was made to OASIS over the last two board meetings. We can certainly submit it to the committee.

Mrs. Christine Elliott: Terrific. That would be very helpful. Thank you.

The other thing—I just made a note, Mrs. Dinning, of the comments that you made: if only families had some

support they could create solutions for themselves. We believe in that too. One of the things that we're looking for, as part of this committee, is innovative housing solutions, because we know that we cannot eliminate the current wait-list by doing the same things that we're already doing, and that one size doesn't fit all. Individuals need different supports depending on their needs. I just hope you know that we will be bearing that in mind as we go forward.

Ms. Bonnie Dinning: Great. And I'm aware that the committee was working on that, so that's great to hear it's going to move forward.

Mrs. Christine Elliott: Thank you.

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

Ms. Cheri DiNovo: Thank you very much for your presentation. A couple of questions—absolutely, it's coming through loud and clear that we should have a rights-based system, an entitlement-based system and not a discretionary, i.e., welfare-based system. That's come through very, very clearly, and I don't think we argue with that at all.

We are a provincial body. We would love to see the feds step up, but in the meantime, we've heard good things about what's already happening in Alberta and Saskatchewan, primarily mandating an end to wait-lists, for example. In a sense, it's a step towards what you're talking about, but if you mandated that, the funds would have to follow. So starting at the mandated, I was wondering if you could comment about that.

Mr. David Ferguson: Again, I think that's fundamentally the issue, from our perspective. Like education, like health, if every Ontario citizen who had a developmental disability was entitled to some resources—we're not here saying it's the same for everyone—an individualized approach. But the fact that there would be resources there for them through their life, that, we believe, would address those three chronic problems that this sector has faced for many, many years.

I think that one of the aspects of why this is coming to a bit of a crisis, ironically or indirectly, is as a result of the closure of the facilities. Although that's been really positive, that was a buffer in the system and that was an entitlement system. Lots of people didn't want to be there and shouldn't have been there, but that's where a lot of the challenging individuals ended up. Those people are now being supported in the community and putting pressures on all aspects of the system.

Ms. Cheri DiNovo: Right. Okay, thank you very much.

Mr. Bill Cowie: If I could just add to that, one of the things we discovered in our cross-Canada survey was there were a lot of myths out there about whose program was good and whose wasn't. We've discovered things—we would be surprised by some of the results. The Saskatchewan one, where they went after the waiting list, was an interesting example. We need more detail on that. Alberta is having some issues of communication and coordination and of engagement of parents. It's caused a bit of an issue out there.

Ms. Cheri DiNovo: Okay. Thank you.

The Chair (Mrs. Laura Albanese): Very interesting to know. Thank you very much for contributing to our discussion here and presenting to the committee.

FAMILY ALLIANCE ONTARIO

The Chair (Mrs. Laura Albanese): We will now call on the Family Alliance Ontario to come forward.

Ms. Cindy Mitchell: Karen Inwood is one of our board members. She's going to hand out the documents to everyone.

The Chair (Mrs. Laura Albanese): Thank you, Karen, for handing out the documents to us. It's Cindy Mitchell, right?

Ms. Cindy Mitchell: Yes, my name is Cindy Mitchell.

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

Ms. Cindy Mitchell: Okay. Thank you. My name is Cindy Mitchell. I'm vice-chair of Family Alliance Ontario. Our president recently resigned and moved back to the UK. We've heard a lot about the UK system. She actually moved there for better services for her daughter, and she now has better services. She had that in less than a few weeks upon arriving.

Who is Family Alliance Ontario? FAO is an alliance of citizens that offers knowledge, tools and networking opportunities to individuals with disabilities and their families, to assist them to realize a vision of having really good relationships and choice and control in their lives and by enabling inclusion and meaningful contribution and participation in their communities.

Family Alliance Ontario is volunteer and not-for-profit. We're a provincial organization composed of individuals who live with disability, of families and of their allies. Our allies include 14 family networks across Ontario. I'm happy to say we have a couple of members of Family Alliance from Ottawa here in the audience.

Throughout this brief we will say "families." When we use that term, we include parents, grandparents, siblings and others who provide direct, non-paid care for someone they love, as well as friends and advocates for individuals who do not have a family to help or support them.

FAO has represented the individual and family voice for over 20 years. We have provided position papers and we've attended focus groups with the ministry, with community and social services, and with members of Parliament to express our concerns about the system.

With this presentation, we—and I, because he's my friend and he was my boss—are remembering Peter Dill, an activist, a parent, a trailblazer, a long and tireless advocate for full and authentic inclusion for people with developmental disabilities as equal and full participants in society. This past week, Peter's family, Ontario families, family networks and people with disabilities and their extended families and supportive networks lost a steadfast leader. He was an ED of an association. So

leaders in associations exist; parent leaders exist out there. We need to get back to that.

I'm really pleased to be able to present to you on behalf of the FAO. As you've already heard over the many days of hearings, the current system really is devastatingly broken. You've heard from the assistant deputy minister of social policy development for community and social services that MCSS is on a journey. This journey has taken 10 years and it's taking too long. We say "bad," because in its development logical, sound and transformational amendments that were presented early on were ignored. We continue to be disheartened by the length of this journey.

In 2004, when the journey began, the then Premier, Dalton McGuinty, described how broken the system was, and I'm going to quote him. He said that "there are parents out there into whose arms is born a child with special challenges, and I just have the greatest admiration for them. It's 24/7, 365 days a year. They can never let up. And they fight and they kick and they scratch and they claw when it comes to securing government services, because they want what you want and I want for our kids"—what everyone wants. "They just want the best."

Mr. McGuinty did get it right when he identified the struggles, but he also got it wrong. People are not expecting the government to provide just the best; they're expecting their children to have just an ordinary, typical life, the same as anyone else in Ontario. Some just need a little bit more support. Is that not what it means when we hear that it takes a village to raise a child? What is even more disheartening is that the struggles have become worse and people are now scratching, clawing and kicking to secure services but end up at the bottom of a wait-list.

This is why we are pleased this committee is tasked to develop recommendations and a comprehensive strategy that encompasses all of you working together. That's absolutely wonderful. We're very encouraged by this.

FAO believes that every citizen is entitled to a regular, ordinary life. Every individual, regardless of challenges they face, has a talent and has gifts to share and contribute to those around them. Every person can participate in their community. They just may need a little bit of support to do so. The level of support required varies with each and every person. This is why one size doesn't fit all, and you've heard this over and over again today.

In her apology to survivors, Premier Wynne said, "[W]e strive to support people with developmental disabilities so they can live as independently as possible and be more fully included in all aspects of their community."

FAO and all the people you've been hearing don't see this happening. We hear from more and more people and their families of the inability to get necessary supports to participate. We have some of these stories included at the end of our submission, but it's way too long for me to get to it. You'll notice I'm not reading directly from what you have; I'm kind of covering some of it off.

We've included those stories and we have noted that individuals have been cut off from supports that they depend on to allow them to participate in community simply because they've had a birthday—they have turned 18. What goes away are the supports that have assisted individuals to lead as ordinary a life as possible.

1410

By definition in the new legislation, a developmental disability must be acquired before age 18. This is a prime example of why the legislation is bad.

Our assistant deputy minister spoke in his deputation of the need for societal change. In the words of a very wise woman, a well-known advocate in Ontario, Judith Snow, "Society will change when I am in it."

When individuals leave the school system at 21, they have lost all of their supports because the system is so underfunded. How can society change when some of our citizens are stuck at home on the couch with no supports available to assist them to participate in their chosen community?

For many years now, developmental services has been based on the welfare model, and you've been hearing this over and over and over again. This model negatively impacts people. It also negatively impacts their family, and it negatively impacts Ontario. For true transformation to take place, the model must change to one that provides for economic growth.

When people with developmental disabilities leave the school system, they lose all sorts of supports. That's a significant loss, and there's a significant loss for the family: a loss of income, a loss of pensionable income, for the parent who must stay home with that person. That income is already woefully inadequate for individuals. Individuals can get OSDP, but we know that that income is woefully inadequate for people with developmental disabilities.

There's a psychological toll to primary caregivers in Ontario who are providing care 24/7, as Dalton McGuinty said, 365 days of the year, to support their adult children. FAO hears this from single parents, from very senior parents, and from many parents now who are currently supporting elderly parents.

Our society assists to provide intense care for a child with special needs because we recognize the responsibility of society as a whole to care for our future citizens. That is why the Ministry of Community and Social Services has programs to assist those children, and why Special Services at Home exists to provide that extra support. It's absolutely imperative that our society continue to support children into adulthood and that we don't have a break in that support. The need is there in childhood and the need continues on through adulthood. Contrary to an unspoken belief, those needs do not miraculously disappear just because somebody has an 18th birthday. It's not a very good birthday present for anyone in Ontario.

For almost 25 years, FAO and our affiliates have continuously asked the ministry to allocate 25% of new funding to individualized approaches. This has not

happened. Currently, only 9% of the \$1.7-billion budget is directed to individualized approaches. The remaining 91% is directed to transfer payment agencies for programs that support a significant minority of people. Ontario continues to invest the majority of funding into a minority of its citizens with developmental disabilities to continue to participate mostly in segregated and congregated settings. Ontario continues to talk the talk of social inclusion but is clearly not walking the talk.

The current system of supports is heavily dependent on families yet does little to acknowledge that dependency, little to ensure that primary caregivers stay healthy or to address the financial impact of caregiving on citizens in this province. It's estimated that an average family provides the equivalent of \$80,000 per year in unpaid supports—you heard from a well-spoken mom earlier about the cost in supports for a young person with autism—yet there's no recognition for that financial investment. Through the family response to the Ombudsman's office investigation—I know well over 1,000 families have responded to that—it has become painfully evident that as the system operationalizes its new policies, this vital piece, this support to family caregivers, is missing.

For true transformation to take place, it's imperative that services no longer be based on a welfare model but be recognized as an avenue for economic growth worthy of financial stimulus. Resources invested in the individual not only provide for the opportunity for meaningful community participation; they also provide income for people and an opportunity for parents to be wage earners and opportunities for parents to contribute to our pension plan. The individual, through community participation, becomes a consumer and adds to the economy of a vibrant Ontario. Now there are four Ontario citizens adding to our economy and adding to our community.

For people without developmental disabilities, relationships almost naturally occur. For people with developmental disabilities, because of attitudinal barriers, the building of relationships sometimes can take some intentional effort. Over time, the breaking down of attitudinal barriers will occur. This is a paradigm shift that MCSS has identified as a key element in their transformation journey. However, if society is unable to discard the assumption that people with developmental disabilities lack capacity or are unable to participate or need protection or should be hidden away, this will never change. The breaking down of these barriers requires Ontario to walk the walk: a true commitment and a significant financial investment in the developmental services sector.

The system is built and continues to be built on supporting a system instead of supporting people, supporting the individual. In reading the presentations from various ministries, it is apparent that, despite claims of inter-ministerial co-operation, this clearly is not happening. MCSS does not appear to know how many young people with developmental disabilities are living in long-term-care facilities. How can that be? People receiving services as a child need to reapply for services as an adult.

The list goes on and on. The system has become very good at dissuading people from even applying because there is no hope of receiving support, service, and certainly not funding.

Family Alliance is calling for action and rapid change to the current developmental services system based on human rights and principles of true citizenship and social inclusion and self-determination, including significant and effective inter-ministerial collaboration and a substantial investment of financial resources, specifically targeted to individualized funding and individualized approaches. This must be equitable, portable and inclusive of independent facilitation and planning so as to meet the needs of Ontarians living with developmental disabilities.

Furthermore, FAO believes that any support system must be based on essential human values. FAO recommends that developmental services adopt a set of guiding principles according to which services should be established and measured. These principles are: human rights, social inclusion, self-determination and citizenship. With these principles, not only will the lives of a person with a developmental disability be enriched; so too will the lives of the family and the community become stronger. Only by having an individual actively participate in the community and sharing their gifts and sharing their talents with others will those attitudinal barriers change. Then we will see that paradigm shift in society that MCSS claims to envision.

I'd like to identify some of the current problems. There are many problems with the system as transformation continues to very, very slowly roll out. We're just commenting on a few of the most glaring, and you've certainly heard this one: Developmental services is a discretionary program. By definition, according to Webster, "discretionary" is an adjective meaning "available to be used when and how you decide" or "used when necessary." In this situation, funding is available depending on when and how someone at the ministry decides to allocate it or decides when it is necessary.

With a discretionary program, one can turn a blind eye to the needs of individuals, citing inability to provide services or not enough resources or no clear data or no knowledge of real need. An entitlement to services evens the playing field. Most importantly, it identifies the value of the person. Everyone deemed eligible will receive the level of services based on their need.

1420

Premier Wynne, in her apology to the people who suffered in Huronia Regional Centre, said, "A government's responsibility is to care for its people, to make sure they are protected and safe...."

"In Ontario, all individuals deserve our support, our respect and our care."

The duty to support our most vulnerable is our government's most important responsibility.

We have also heard about block funding. I know we're all saying the same things. This is really good. We've got themes happening. As we said earlier, the majority of funding is currently allocated to transfer payment agen-

cies with which the agencies develop programs and residential supports. The system continues to build to support the old system instead of being developed to support the individual and move to personalized budgets, direct funding, individualized funding. There are lots of ways we can describe that. FAO prefers personalized budgets. We'll empower the individual and their support network to seek out the best supports for that funding that's allocated. This will serve as a catalyst for service delivery agencies to respond to the needs. There's evidence of that around the world. We have international evidence that has been shared with government over and over again. It will encourage service organizations to find ways to individualize their supports, to move forward and to change and move towards social inclusion.

DSO: We have heard from families that DSO is just an added layer of bureaucracy that has created a barrier to access supports and services. DSO is also creating a barrier between the needs of families and individuals and real action to prevent crisis in the community. The assistant deputy minister describes one of the key roles of the DSO as to provide information to individuals of other available services in their community, such as health care and community programs. He goes on to say that DSOs have added significant value to the system and are achieving a very important purpose. I have to tell you, families across the province are saying, "What is the significant value to the person? What is this value to the family?" Nobody is feeling that. We're 10 years in.

This single access point has morphed into a multi-level process that actually prevents people from seeking the help from some lovely community organizations, like Peter Dill's, that have been there for families for 30 years or more. Our members tell us that the DSO staff are not responsive. We're hearing that more now because I think they're overwhelmed. I don't know how long you could hear all these terrible stories from families and not just get desensitized from it.

You've also heard about the welfare model. Developmental services has been based on a welfare or charity model of providing supports and services. It's time to change that model and change it to a model that's rooted in economic growth for Ontario and looks towards authentic social inclusion for people.

The application process and assessment are lots of times being felt as very intrusive for families, and they're purely deficit-based. Our families feel—and it might not be because of the assessment; it might be because they're so desperate and they're so much in crisis—like they're just on a race to the bottom of a list.

Independent facilitation and planning provides an opportunity to move forward with a real actionable plan based on strengths and choice and control of the individual and their support network. Providing funding and services and supports to individuals and their families enables ordinary life to happen. Ordinary life happening is good for Ontario.

The Chair (Mrs. Laura Albanese): I just have to let you know that you're about 30 seconds away from the end of the time. I want to give you the chance to wrap up.

Ms. Cindy Mitchell: All right. I just have to—the lack of trust in Ontario really saddens FAO. We heard a little bit of this coming forth at this table where it was said that people fear direct funding and that they thought it might not be politically correct, that the money might not go where it's intended. Twenty-five years of direct funding through SSAH cannot be wrong. Our auditor cannot be wrong. Christopher Wrigley, a 37-year-old man from Meaford, Ontario, said he's not wrong and his mom is not wrong in regard to exceptional management skills. He said, "I've made a really good effort to live on provincial allowances and my mother is an excellent manager, but has made huge sacrifices for me to live a stimulating life in my community."

The Chair (Mrs. Laura Albanese): And I'm sorry; at this point I have to stop the presentation, because we have a long list of people, and otherwise everyone would fall behind. But we are thankful that you gave us the whole package, and we will make sure to read it carefully. I can assure you that all the members of the committee will be taking this in close consideration.

Ms. Cindy Mitchell: Okay. Thank you very much.

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

Ms. Cindy Mitchell: After sitting here for one hour, everyone's saying the same thing, over and over and over again.

The Chair (Mrs. Laura Albanese): But everybody adds something new, a twist that is new, and that is important for us. Thank you very much, and thank you, Karen.

Ms. Karen Inwood: You're welcome.

The Chair (Mrs. Laura Albanese): Thank you again for distributing these to us.

FAMILIES MATTER CO-OPERATIVE

The Chair (Mrs. Laura Albanese): We'll now hear from Families Matter Co-operative. We'll ask the executive director, Miriam Fry, to come forward. I know you've been in the audience as well, and I'm sure you know how this works by now.

Ms. Miriam Fry: For sure. Our presentation will be handled by Nancy Brodie, who is our past president, but I'm available for questions.

Ms. Nancy Brodie: I'm Nancy Brodie. I'm the past president of Families Matter Co-op, and I'm the mother of a 30-year-old young woman with a developmental disability, although she would say that she has an intellectual disability—here we go with terminology. We're also here with Sharon Edwards, who is the president of Families Matter Co-op.

That's a tricky name. People always get it a little bit wrong: Family Matters. Anyway, we say, "Families Matter." Families are important.

We are an Ottawa-based, member-driven, not-for-profit co-operative, so a little different model from some of the organizations that you may have heard from. We were established by families and friends of people with

developmental disabilities to empower and strengthen families to help support and have their family member have a really good life in the community. The way we try to do this is by connecting families with each other and making sure they have the information and the resources they need to really make an impact on their lives and the lives of their family member.

We try to raise awareness of the challenges facing families, so we're really glad to have the opportunity to be here today to do that.

We gave you a long list of some of the activities we undertake, but there are a couple of things I wanted to highlight. We have created new affordable housing in our community by working with developers and service agencies, and we now have 14 people living in affordable housing with some kind of support. It was partly through the partnership with the developers and also through the innovative housing funding that Bonnie Dinning mentioned benefitting from.

We have also created a social enterprise called Laundries Matter co-op—

Ms. Miriam Fry: No, it's actually Laundry Matters.

Ms. Nancy Brodie: Oh, Laundry Matters co-op. Gee, I get it mixed up too. We currently employ—

Ms. Miriam Fry: We employ eight individuals part-time, in co-operation with a long-term chronic care hospital. We do the personal laundry for approximately two dozen people who don't have family to rely on.

They earn money every week. Because of their intellectual or developmental disability, they work in teams, in coordination with their day program, but they are very proud of the work that they do, and they do a very, very good job. They have been doing this now for over a year, and we are slowly growing our business and hoping to start a second business.

Ms. Nancy Brodie: A couple of other activities that we're involved in: For many years, we've been involved in a transition fair in Ottawa for people in the school system who are reaching that age of transition and their families who desperately need information. Rather than have them go out to all the organizations, we decided to try to bring all the organizations together. We've also run a workshop called Beyond Graduation, where we bring together families and students with a developmental disability and help them try to make a plan for the future.

1430

These are some concrete activities we're involved in, and virtually all of them are in partnership with some other organization in the community. We really try to act as a catalyst.

We'd like to talk about some of the things we think are working well, some of our concerns and then some of our suggestions for improvement.

What's working well? We have ODSP. It's an entitlement. A lot of people have been talking about the need for entitlements. Well, that's one program we have. There have been good improvements to ODSP. There has been an increase in the rates and a reduction in the clawback of employment income, which has made a huge

difference to a large number of people who have part-time, minimum-wage jobs. They now have double the income that they had before because it's not being clawed back.

We look, as family members, at the Disability Tax Credit, which is a federal program but it's something that benefits many individuals and families. Again, the federal initiative of the RDSP, but then the provincial ability to integrate that with ODSP is very well received by our members and many families of people with disabilities. We also look upon something like a Henson trust as a building block when parents are trying to build a safety net for their children. Parents are trying to do their best to plan for the financial future of their children, and all these programs help them do that.

If we look at some of the concerns, and I think a lot of these you've heard from many other organizations, one that we see particularly is the difficulty families have navigating the system. Miriam talks every day to families; we meet them at our Beyond Graduation workshop; our members encounter them in the community. They don't know what they need. They're not aware that they can ask for assistance and they need advice on how to utilize the few services that are available. These needs are particularly strong at times of transition, and that's transition from the school system into adulthood and also transition into old age, and I don't think we've seen all the concerns there. They're just going to be hitting us more and more. So one of our roles is helping families navigate that system.

The concerns about lack of services or lack of capacity in the service sector: Miriam has come up with some figures in the Ottawa area. There are about 900 people on the wait-list for day programs and 900 people waiting for residential support. You've seen the provincial figures. Just looking at it from the Ottawa area, these are pretty huge numbers.

The way we see the DSO process evolving is, yes, there is a rigorous assessment process which should bring us equity across the province. But there's a waiting list even for that assessment process, and there are no services available at the end of the process that match the needs that are identified. When a child leaves school, families often bear the full responsibility for support, and this is a burden, not just on the individual who doesn't have the support and who isn't living a full life in the community, but it's also a burden on the family members and often the extended family.

Finally, I'd like to talk about lack of support for innovative solutions. Many families are in a position where they can provide some financial help, but government policies don't always encourage that. Many families would like to have individualized funding. They have lots of ideas of what they think is best for their family member and how they could best meet those needs, but, again, the demands for individualized funding are growing; the waiting lists for the Passport program continue to grow.

We have many families that are interested in supporting home ownership for their child, and they may have some financial resources to enable them to do that, but

how do they get the supports that they need in the home that they may be able to afford to buy? Funding those supports and sustaining them over time is very difficult.

We really look forward to the transformation of the developmental services sector, but from our point of view, it seems to really have stalled, that the assessments are slowly being done, and meanwhile there are many things that seem to be on hold.

Another principle that's really key for Families Matter Co-op is the right of individuals and families to choose the supports and services that best suit their individual needs. We know that there needs to be a strong service support sector. We know also that a lot of families would like to have individualized funding and could do many creative things. So we'd like to see MCSS continue to work on options for more direct funding, and partner with agencies to create individualized support. We would really like to see supports be more portable. But we desperately need a better overall system of supports, to make good choices possible.

I think you may have heard this from a few other presenters. There are some individuals who have very complex needs and who need a lot of support, a lot of services—multiple disabilities; families who are aging or under stress. So we need a strong support service system, and it should be person-centred and it should match not only the needs of the people, the individuals, that come out through an assessment, but also their dreams: what they want to achieve and where they see themselves in the world, in the community. But how do we make improvements in this area?

I think Miriam was a member of the Housing Study Group of the provincial partnership table, and one approach they took was to try to come up with some clear, achievable targets in the supported housing area. We think that is maybe a practical approach, something that can maybe achieve some results, and maybe that targeted approach in other areas would work as well.

We would really like to see different ministries working together. We feel that there is a lot of research and approaches that have been taken in the health care sector, in the mental health sector, that have achieved results. Can we make that same kind of concerted effort in the disability services sector to try to make some concrete steps forward? We would encourage action on the action plan of the report of the Housing Study Group.

There are many people who need a little, and a little can make a huge difference. With a little help from government, families can help a lot. Some of the ideas we have, that we think wouldn't cost governments a lot of money, wouldn't require huge extra investments, are:

- Increase the flexibility in ODSP.

- Increase the amount an individual can receive as a gift and have in a bank account without penalty.

- Relax the rules related to shared living. I've investigated this area, thinking of my daughter's future. I thought, really, that the regulations around who can live together, and at what stage of living together is your ODSP going to be reduced, just don't reflect reality or the way people live these days. Why should people who

decide to live together end up with fewer resources when, actually, they're trying to build a better life?

—Maybe we should consider introducing a support component to ODSP. Maybe this is a mechanism to extend the entitlement aspect to the support area.

The Disability Tax Credit is something that hasn't increased for quite a while. Maybe that's something that could be increased. It could give some more money in the hands of families that they could use to make a big difference.

1440

Some other areas where we have some suggestions: this whole area of supporting families to navigate the system. Give support to organizations like Families Matter Co-op that can provide this support. Again, this is something that's happening in the mental health sector with patient navigators. I think it's something that we need in the disability services sector as well.

We've heard about the DSO assessments and the need for many families to have to go back and get a psych assessment that they never had in the past or that isn't up to date. Well, if this is part of the assessment process, then there should be some money made available for families to get those assessments that are needed. Money should not be a barrier to the assessment process, surely.

There should be more flexibility overall in the allocation and reallocation of resources to encourage grassroots creativity, and I think you've probably heard many different areas of creativity and ideas of how that can be done. We see that there should be more focus on co-ordination and support in transition stages, especially into adulthood. There are some models we've heard of where school boards actually have a transition coordinator at the board level and they really put a focus on that. Maybe this is a model that should be more widely followed. One of our members who works in the school system said, "You need to support that transition, not at age 17, but it needs to be something that starts much earlier." Maybe it could be through peer relationships with other families who have gone through the process in recent years.

As I mentioned earlier, we think it's really important to engage broader government expertise beyond the Ministry of Community and Social Services to address the complex problems that many people with developmental disabilities have. So we need to look at housing: When we worked with developers to establish places for people with developmental disabilities in affordable housing, this was hugely innovative. They said, "Oh, we set up spaces for people with physical disabilities," but they had never considered having spaces for people with developmental disabilities in housing co-ops or other models of affordable housing. So let's look at the housing and affordable housing strategies, and include people with developmental disabilities. Again, the health care system is—you've heard about how there needs to be more education there, but, again, I think maybe we can also learn from some of the progress made in the health care system.

That's the end of our presentation, and we'd really welcome the opportunity to answer any questions from our experience.

The Chair (Mrs. Laura Albanese): We really have time for just a brief, brief comment from each party. We already have the next presenter via teleconference ready to go. Christine?

Mrs. Christine Elliott: Thank you, Chair. I will be brief. Congratulations on all of the innovation you're doing with very limited resources. I would just be particularly interested in some of the innovative housing solutions you've developed and learning more about how you've worked with developers in order to create those housing opportunities. So if you have any written material you could provide us with or perhaps we could have a conversation offline, I think that would be really helpful to the committee. Thank you very much for being here today.

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

Miss Monique Taylor: I would also be interested in seeing that model, and I'm just curious—a yes or no answer—did you have problems with the ministry when you were doing these housing initiatives?

Ms. Nancy Brodie: Yes and no.

Miss Monique Taylor: So those are the kind of issues that we need to hear. We need to know where things went wrong and where we need to further support those initiatives because it's definitely something that we need to be doing, moving forward. Thank you so much for all the work that you're doing.

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

Ms. Mitzie Hunter: Thank you, Madam Chair. I also really felt that this was just a trove of information for us as we're getting into our drafting the report and just very clearly presented what is working well, the things that are helping to support the system and then, of course, the areas that need improvement. So I want to thank you for taking the time to be here today to provide this input, and for the work that you are doing. I'm also looking forward to hearing more about social housing and how you are managing to get that message out to developers, who oftentimes have a different model that they're using. They're starting to see the benefits of doing that, and I think that would be a very interesting thing for us to hear.

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

Ms. Nancy Brodie: Thank you.

Ms. Miriam Fry: Thank you.

The Chair (Mrs. Laura Albanese): If you could put anything in writing, as all the members have suggested, that would really be helpful to us. Thank you.

MS. KARIN STEINER

The Chair (Mrs. Laura Albanese): Now we're joined by Karin Steiner via teleconference. Hello? Good afternoon, Karin.

Ms. Karin Steiner: Yes, hello. Thank you very much for allowing me to follow up on my written submission to the committee. I really appreciate the teleconferencing

option, because I live about 200 kilometres from Ottawa and about 300 kilometres from Toronto.

The Chair (Mrs. Laura Albanese): So we will allow you to make your presentation.

Ms. Karin Steiner: I'm contacting you as one individual who has been trying to understand how to navigate the DSO system for about seven years now, ever since my son Nicolas, who is an adult with severe autism, transitioned from school to home.

My letter dated December 31, 2013, asked the committee to address the urgent need for policy-makers to provide direct, individualized residential support options for families or caregivers of adults with developmental disabilities. My letter included two attachments, A and B, comprising the letter I wrote in January 2013 to Ombudsman Marin and a series of exchanges amongst myself; my MPP, Mr. Hillier; Minister McMeekin; and the southeastern Ontario region's MCSS officials.

Although my letter to Ombudsman Marin—attachment A in my letter to you—focused on a range of what I perceive to be systemic problems, specifically problems with the new intake process, the new database and the issuance of percentile scores to service needs that are not clearly linked to service provision or funding, today I will focus only on one issue, given the short time frame. That issue is the urgent need for individualized residential supports that could be managed by caregivers, or by caregivers working closely with a case management agency.

In attachment B of my letter to you—that's the letter of May 17, 2013, the last letter in the series. It's from Josephine Fuller's office, and it states, "Currently the Passport Program is the only ministry-funded program that supports direct funding. Recipients of Passport purchase community participation supports and/or respite care. Presently there is no direct funding program to purchase residential service."

I have to admit that I was really quite surprised to read that statement, given that both ADSS reports on my son—one in 2012, and a revised report in 2013—included the following categories of residential supports under section 4, "Services and supports," on page 22 from the 2013 report:

"Service type 1

"Which one of the following MCSS-funded residential supports is currently provided?

"—supported independent living

"—group home

"—host family home

"—individual residential model

"—specialized accommodation

"—outside paid resource

"—other."

In my son's case, the report indicates accurately that no MCSS-funded residential supports are currently being provided, yet there's quite a wide range of possible supports, according to that list that I just read. One problem here is that, on the one hand, I'm told that no direct individual funding options currently exist for residential

supports, yet the individual residential model is listed as a possibility in my son's ADSS reports.

My letter to Ombudsman Marin flagged the need to examine the IRM—I think that's the acronym for individualized residential model—as a possible form of direct funding. My understanding is that caregivers or agencies applied for a grant for individualized funding for innovative residential plans, and those who got the grant were given funding in a way that could be construed as direct support to individuals. In 2007, 89 individuals were apparently living as part of an IRM arrangement in Ontario, according to a summary report by Carver and Associates, dated July 2009, called *A Home That's Right for Me*.

1450

I'd like to know more about how those 89 people have fared over the past seven years and why newcomers to the DSO have not had opportunities to apply for IRM funding. Also, how many people are living in so-called specialized accommodation, and what does that mean? How many benefit from the outside paid resource or other residential supports? Are these categories not possible direct support options?

Additional questions from me and my son are: How does one qualify for individualized residential supports? Does my son Nicolas's score in the 84th percentile on the SIS qualify him for individualized residential supports? If so, if he does qualify, why hasn't there been any movement to provide the supports he needs? He entered the new database in 2011. If he does not qualify, why did I bother sitting through a grueling five-hour-long interview process to be included in the new database and why have I had to invest so much time and effort just to have very basic questions answered?

In short, as I stated in my letter to your committee, I'm very, very frustrated as a caregiver who is doing her level best to work within the various systems that have emerged over time, but I'm deeply concerned that the new DSO bureaucracy, its costs and opaque practices, will obliterate the possibility to serve families like mine with legitimate requests for appropriate supports.

In closing, my main concern each and every day is what will happen to my only child, Nicolas, when something happens to me. I have not yet found a reassuring answer either from the DSO, my case management agency or MCSS officials in southeastern Ontario, and that's why I'm appealing directly to MCSS in Toronto via this talk with your select committee.

That wraps up my remarks, and I certainly welcome any questions you have about my situation.

The Chair (Mrs. Laura Albanese): Karin, before I pass it over for any questions, where exactly are you calling from? You did mention that it was 200 kilometres from Ottawa, 300 from Toronto.

Ms. Karin Steiner: I'm in Hartington, which is 40 kilometres north of Kingston, Ontario.

The Chair (Mrs. Laura Albanese): Okay. Now, you've illustrated quite well the difficulties in navigating the system. I will offer my colleagues a possibility to ask

more questions. At the same time, through this committee, we are looking at the concerns in a general way. We're not addressing a specific case, not to say that—that could certainly be forwarded to the ministry. But as a committee, I just wanted to make the premise that we're not doing that as a whole, as a committee, because we're trying to address the gaps that we see in the system as a whole. We can't really address a single concern in itself. That is not the mandate of the committee. But having said that, we will make sure that your specific concerns are forwarded to the ministry.

We will now have Ms. DiNovo comment and ask any questions she may have.

Ms. Cheri DiNovo: Thank you, Karin, very much for your articulate delivery of concerns. The first thing I'd like to say is that you're not alone. We're hearing the same thing from just about every parent across Ontario. Certainly, it seems to us on this side, in the New Democratic Party, that the DSO is not functioning. Any organization that all it does is put parents through assessments and delivers wait-lists as a result of those assessments, not services, is not functioning. The situation is clearly in crisis. You're experiencing that crisis, and for that we are deeply saddened. It's certainly true that your child—and you—has every right to be treated the same way as every other child in every other family that doesn't happen to have a developmental disability, and that means equal access to housing, to education, to health care—everything you should need. Really, that's all I can say.

I would suggest, though, to meet with your MPP because, certainly, if you were living in my riding, I know I and my staff would try to go to bat for you with MCSS, and I think that is our role. I don't think that's beyond our role. So I would suggest that you do that. You'll probably hear frustration from your MPP through that process, but you might actually get some results as well.

Again, thank you so much for your testimony before us, and our heart goes out to you.

Ms. Karin Steiner: Thank you, but did you receive my written communication?

The Chair (Mrs. Laura Albanese): We have been travelling, as you know, in the last few days, but we do have your written communication.

Ms. Karin Steiner: Okay.

The Chair (Mrs. Laura Albanese): We will be sifting through all the written communication for sure. Rest assured, we will be doing that.

Ms. Karin Steiner: I ask that question because attachment B of my communication actually includes one letter written by my MPP to Minister McMeekin, as a result of the letter I wrote to him. I did not receive an answer from the minister, but I did get a response from Josephine Fuller, who's the director of southeastern Ontario's regional branch of MCSS. We've had a couple of communications and, again, I found those communications uninformative, and there has not been any help.

Ms. Cheri DiNovo: We hear you. Thank you.

The Chair (Mrs. Laura Albanese): I will ask Mitzie Hunter, who is also the parliamentary assistant to the minister, to say a few words and to address this.

Ms. Karin Steiner: Thank you.

Ms. Mitzie Hunter: Thank you, Madam Chair. Hello, Ms. Steiner.

Ms. Karin Steiner: Yes.

Ms. Mitzie Hunter: We definitely have heard your case and your concerns. As the Chair has said, we'll ensure that that gets back so that the ministry can do its follow-up. I think that's important that we do that.

I was wondering if you would be able to share your perspective, from a community basis, on just what you're experiencing as a parent. You mentioned this is your only child and that you have some concerns. Today we talked quite a bit about building an inclusive community and a sense of belonging for people with developmental disabilities. I think that that's something we have heard and seen through our travels through this select committee. So I was just wondering if you could share what you're experiencing for your child from your community perspective.

Ms. Karin Steiner: Thank you for the invitation to speak to this issue. When my son graduated from high school in 2007, I mentioned he graduated from school to home, because there were no supports available to him. Where we're located in Ontario, just north of Kingston, we are caught between agency services. There are services, say, day programming services, in Kingston and there are some available in Sharbot Lake, north of us. So where we live, never the twain shall meet.

As a result, I actually started a non-profit charitable organization here in South Frontenac township called New Leaf Link, which has a website: www.newleaflink.ca. The program that I started—because my background is in education—is an inclusive program that brings adults with developmental disabilities together into meaningful activities. It is a day program. We have an arts program and we've got a healthy living program, as part of New Leaf Link's offerings.

I've been working very hard to create opportunities for my son in our home community, because it is a very good place to live. I think living out in the country has been quite therapeutic for Nicolas, and he has had the opportunity to build relationships with people over time. A very key element of autism is the social realm and the difficulty in the social domain, so the long-term relationships are important ones to hang on to. Some of his friends from high school are part of New Leaf Link, and we do get new students coming to the program each year.

1500

We've tried to work, as a community, from the ground up. I spearheaded the initiative along with some other family members with sons and daughters, who have come together. In that sense, I think we have created a place where people feel that they belong and want to continue to grow together.

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

Ms. Karin Steiner: I've worked very hard to try to create opportunities too, and I'm willing to work with

MCSS to try to create opportunities now for residential supports, because that's the next thing for me, in my thinking. I've tried to pave the way for some daytime supports, but now the residential piece is the missing piece, and we definitely need supports in that realm.

The Chair (Mrs. Laura Albanese): Okay. Ms. Steiner, I'm going to pass it on to Ms. Jones for other questions.

Ms. Sylvia Jones: Karin, I think I remember you presenting to our committee when we were studying Bill 77.

Ms. Karin Steiner: Yes. Yes, Sylvia.

Ms. Sylvia Jones: Yes. Thank you for your continued advocacy. You're sort of reinforcing my belief—and tell me if I'm putting words in your mouth—that, depending on where our children are, we need different services; we need different opportunities; we need different supports. The fact is that you started New Leaf when you saw Nicolas needing some additional challenges, and now you're looking at the residential component.

Can you share with the committee whether that is what you have seen locally, or is there another way you would describe it?

Ms. Karin Steiner: No. I think you describe it well, Sylvia. Especially in rural areas—there are a different set of challenges in rural areas, and also with different disability groups. People with autism, for instance, are more sort of individualistic. I'm not certain that the DSO understands that there might be major differences across different types of groups in the system—

Ms. Sylvia Jones: You're being kind, Karin.

Ms. Karin Steiner: That's certainly my belief, that it isn't a one-size-fits-all model that's going to work. That's why I'm very interested in the individualized residential model, or some other innovative, individualized model for residential supports. I don't think the DSO recognizes that.

I see systems thinking versus people thinking, or—I'm not sure. Well, certainly it's not a very humanitarian perspective that comes out of the systems that have been foisted upon us. I would really like to see your committee ask some questions about the validity of the current system that has been brought in and also, who's benefitting from the DSO and its new protocols?

Ms. Sylvia Jones: Rest assured, we're doing it.

Ms. Karin Steiner: Okay, great.

Ms. Sylvia Jones: Thank you very much, Karin.

The Chair (Mrs. Laura Albanese): Thank you, and have a good afternoon. Thank you so much.

Ms. Karin Steiner: Okay. Thank you.

MS. LINDA NILSON-ROGERS

The Chair (Mrs. Laura Albanese): We will now call Linda Nilson-Rogers to come forward and present to our committee. Hello, Linda.

Ms. Linda Nilson-Rogers: Hello.

The Chair (Mrs. Laura Albanese): Good afternoon, and welcome.

Ms. Linda Nilson-Rogers: Thank you. My name is Linda Nilson-Rogers. I'm thankful to be able to present to the committee today as Sarah's mother. Sarah will be 29 years old this year. She lives in her own apartment in Almonte, Ontario.

Sarah's road to freedom and independence has been achieved by vision, hard work, frustration, persistence and determination to live in her community with the support she needs and deserves. This is Sarah's story of how we got to where we are today and what is still required.

When Sarah was young, it was important to me that she was integrated with her peers in the regular school system. It was also important that she was in her community and participated in activities that all children her age enjoyed. Her early years were important because they set the foundation for her to be accepted and appreciated for her gifts, strengths and contribution.

In June 2006, we had a setback. I injured my back and was unable to provide the care that Sarah required due to neurosurgery, leaving me with limited mobility. During that period of time, Sarah was receiving respite support from a group home which was operated by an organization in Almonte, the Mills. She was also receiving Special Services at Home funding. When she went into the group home full time, she lost that SSAH funding. My illness was unexpected, so it was difficult for me to think straight. I did not realize the full impact that placement in a traditional group home would have on Sarah and myself with regard to freedom of choice and individuality. The loss of SSAH funding, which is now called Passport adult respite, has been a stumbling block to us today in trying to build a life for Sarah in her community.

After Sarah had been in the group home for a while and I was feeling better, I knew this was not where I wanted to see Sarah for the rest of her life. As Sarah's mother, I knew we had to take steps to move her forward in her life. I wanted her to move out of the group home and have supported independent living, SIL, support in the community.

The pressure for change has always come from me to move forward with Sarah's life, teach her new things and help her be more independent. I found the first apartment and made arrangements with the landlord. We agreed that Sarah would share the apartment with another individual. It worked for a while, but the other individual's situation changed and he had to move back to the group home.

I found another opportunity, which lasted about a year, but the person whose parent owned the house decided she wanted changes for her daughter and Sarah had to move out.

Sarah moved into her own apartment in Almonte in January 2013, and the Mills was providing 16 hours of support weekly; that would be SIL support. When the original proposal was submitted in 2006, the Mills' proposal for Sarah was 35 hours of residential support, which is what she would require according to them to live in a group home. I feel she required more than 16 hours of SIL because I was providing a lot of natural

support to ensure her independent situation was working. What we wanted for Sarah was more creative support and what we were getting was an extension of group home support. There was considerable inconsistency and changes in staff. There wasn't a flow to Sarah's life. Her home life was also being controlled by "shifts." Sarah's life was not controlled or directed by Sarah.

Over a three-year period, with much advocacy on my part, there were some improvements, but I always felt there was resentment, impatience and lack of understanding in what the dream for Sarah's life was in the future. The organization is unionized, which also created additional complications and inflexibility of hours. Sarah's life with respect to her home and individuality in her home were contingent on too many external forces.

I am in my sixties and have experienced how health issues can impact the care you are able to give your child. Although Sarah lived in her own apartment, I spent a large number of hours creating and modifying things in her home to make it work for her and, at the same time, enable her to do more things herself. My biggest fear with the type of SIL support she was receiving was that when I am no longer in the picture, the vision that Sarah and I have for her life will fade and she will be redirected to a group living situation, as it is easier for an organization like the Mills to monitor and control. It was even suggested to me by a ministry official that if Sarah needed more support that perhaps she should move back into a group home. That was a wake-up call for me.

I am persistent and, as Sarah's mother and a long-time advocate for her, I know exactly what she needs to have a fulfilled, meaningful and safe life in her community. I had a concrete plan and ideas. I kept sharing my ideas and kept having meetings with the Mills, and just recently a miracle happened. The Mills must have decided that it would work better for Sarah if they let another organization provide SIL support to her.

Now Sarah is receiving SIL support from the organization that provides her with job activities and various day supports. It is also an organization in the county of Lanark, Lanark County Support Services. They provide support in four towns in the county. LCSS is an organization that engages families and empowers them. They don't take offence to my ideas, and we work together. Having this change makes me feel like a ton of bricks has been lifted off my shoulders.

1510

To put the difference in a nutshell: Sarah's life flows; it is not fragmented. Support is more personal, reliable and consistent. Sarah is the captain of her own life. Sarah is directing the support she requires. We don't feel like we are getting the runaround; we are moving forward at last. When we talk to people, they really listen. There is an intrinsic comprehension of what our goals and vision are for the future. There's creativity and accountability to Sarah and her family. There is flexible and person-centred support.

There is one piece of the puzzle missing. This became even more apparent to me in December when I broke my

leg. I provide a considerable amount of natural support to Sarah. As I previously indicated, the traditional system approach eliminated a lot of freedom and choice. One of the vehicles to promote choice was individualized dollars through the former Special Services at Home Program, which has now become Passport funding for adults. My next step will be to advocate for additional flexible funding, as this component needs to be in place to support Sarah when I am no longer able to support her. For example, there is not flexibility in SIL dollars for unexpected health care, professional development days or closures. Right now, I do not get time off and I am fill-in support. Funding for new safeguards for these types of situations is not in place or available now.

I am an involved parent, and because of that I have seen a lot of upsetting things occur in systems over the years. What about people who have developmental disabilities who do not have families, good advocates, and can't speak for themselves? There are far too many organizations out there that are providing traditional supports that do not want to change or have incredible barriers and obstacles that prevent change. People with developmental disabilities and their families are suffering. I trust that the work of the Select Committee on Developmental Services will create change in the right direction.

Thank you for inviting families and individuals. We are far too often the stakeholders who are put aside when decisions are made.

Thank you very much for hearing me.

The Chair (Mrs. Laura Albanese): Thank you for sharing your story with us. It is the government's turn to start the questioning.

Ms. Mitzie Hunter: Thank you, Ms. Nilson-Rogers. I really appreciate the story. You've shared the story of Sarah's life, and thank you for sharing the photographs. Are those pictures in her current setting?

Ms. Linda Nilson-Rogers: Yes, they are. She has an upstairs-downstairs apartment with a washer and dryer. She does her own laundry. She does her housecleaning. Yes, she has some quality control there. She has a yard that she has to help maintain, raking leaves and shovelling snow. She's capable of a lot of things, but needs prompting. She always will need some support around food and preparation of food, that sort of thing, but she stays alone at night and is quite capable in a lot of instances. I think she's much happier than she has been for years, and that's the most important thing.

Ms. Mitzie Hunter: I think that's very good, that you have advocated for her so that she can live as full a life as possible to her fullest capability.

Ms. Linda Nilson-Rogers: I think we should all be able to do that.

Ms. Mitzie Hunter: Yes, I agree. Thank you.

The Chair (Mrs. Laura Albanese): Mr. MacLaren?
Interjection.

The Chair (Mrs. Laura Albanese): No, we're not done yet. It goes in a circle.

Ms. Linda Nilson-Rogers: I'm sorry. I'm very nervous.

The Chair (Mrs. Laura Albanese): Please do not be.

Mr. Jack MacLaren: Well, Mrs. Nilson, I would say to you that your daughter is a lucky person; she has a great mother. You've done a great job.

Ms. Linda Nilson-Rogers: Thank you.

Mr. Jack MacLaren: We know it hasn't been easy. We've heard a lot of people present to us and tell us about the difficulties that the system presents. As you pointed out, the system is very resistant to change, and that's something that this committee is certainly going to consider. A lot of people have spoken about independence; I guess patient-centred or person-centred would be a way to put it. What does Sarah want? What kind of future does Sarah have a right to and does she want? You've been a great advocate for her, and it wasn't easy. You've had a few little stumbling blocks where you had health problems that put you out of business for a while.

Ms. Linda Nilson-Rogers: The last stumbling block was December.

Mr. Jack MacLaren: Yes. At any rate, I'd say good on you. You've done a great job. You've identified a problem, and that's something that others have also mentioned to us, so we're aware of it as a committee and we'll certainly be taking that into huge consideration. Sarah's rights have to be first choice. I think we have to try to make change that will consider that, so thank you very much.

Ms. Linda Nilson-Rogers: Thank you.

Mr. Jack MacLaren: Oh, and by the way, Almonte is in my riding, so I am her MPP.

Ms. Linda Nilson-Rogers: Yes. I think there needs to be, with a lot of the larger agencies, especially from what I've seen, more accountability for results. There isn't enough.

Mr. Jack MacLaren: Yes.

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

Ms. Cheri DiNovo: Yes; thank you. It was a wonderful presentation. It was so good to hear a good story. Lanark County Support Services sounds like a very positive organization. Could you tell us a little bit more about them? I understand they operate in four counties. Who is in charge of them etc.?

Ms. Linda Nilson-Rogers: I deal with a lady named Leigh-Anne Giardino, who is the supervisor in Almonte. Debbie McEwen is actually supervisor of the area, and she works out of Smiths Falls.

I first found out about LCSS basically through a program they put on at high school called Transitions. They did weekly two-hour bouts of getting Sarah into a work placement, finding things for her to do. It was a really wonderful thing because she got used to going out into the workplace. Everyone—I'm not saying it because she's my daughter—likes working with Sarah. I believe they were instrumental in a lot of the things she does, getting her out and about in town and just ensuring that she wasn't left on her own to make mistakes that weren't righted.

Ms. Cheri DiNovo: Is it kind of a Community Living organization? I'm just wondering.

Ms. Linda Nilson-Rogers: They have a day program. Sarah—because I had the accident and had surgery, she ended up having five days a week in their day program, which has been really great. She has job placements, some of them paid, some of them volunteer, but she's always busy. They've been so supportive of her. It's just wonderful. I can't say enough about them.

Ms. Cheri DiNovo: Thank you. To my colleague.

Miss Monique Taylor: Great work with everything that you've been doing and making sure that Sarah is getting the life that she wants to live. That's absolutely so important. You've actually been the role model of what we're looking to put in, and that's a navigator. We're thinking that a navigator in a person's life could help make those transitions where it's necessary. When mom and dad aren't around or not able to make those—and to tell the story again and again and again—

Ms. Linda Nilson-Rogers: Yes.

Miss Monique Taylor: —of Sarah's life, that there will be something in place to make sure that there's consistency to the flow of Sarah's life. Great work. Thank you for everything that you're doing.

Direct funding is actually something that would work in your benefit.

Ms. Linda Nilson-Rogers: Yes, it would. It would work in Sarah's benefit.

Miss Monique Taylor: Thank you.

The Chair (Mrs. Laura Albanese): Thank you again for your dedication and your determination and for presenting to us this afternoon. Best of luck.

Ms. Linda Nilson-Rogers: Thank you so much for having me.

MRS. CORA NOLAN

The Chair (Mrs. Laura Albanese): We'll now call on Cora Nolan. Good afternoon, Cora.

Mrs. Cora Nolan: Good afternoon. My name is Cora Nolan, and this is a friend of mine, Joyce Rivington. She presented earlier today.

I live in the village of Franktown in the county of Lanark. My husband, Claude, and I have two children, Pauline and David. Our son, David, who will be 39 years old in March, has a developmental disability, limited speech, numerous medical challenges and needs supervision and support 24/7. This is a picture of David. He's actually smiling in it too.

David has always lived at home with us, and as aging parents we want to ensure security for his future when we are no longer alive.

David spent most of his school life in a segregated school. As a young child, David was in receipt of Special Services at Home funding, which gave us the first opportunity to purchase supports that would meet his specific needs. When leaving school at 21, the only option offered in our county was a segregated day program that offered traditional supports. We did try this, but David was very

unhappy. He did not want to attend, and this caused him frustration, anxiety and regression. It became very apparent that this did not meet his needs.

1520

We realized that if we wanted him to have a full, interesting and productive life, similar to what you and I experience, then we needed to design a personal plan for him that would meet his needs and lifestyle, based on his needs, interests, strengths and the skills necessary to function and be personally successful to the best of his abilities in his community.

In 2004, we developed a personal plan with a budget and began our quest to acquire funding to support it. We approached ministry personnel in the Kingston area office, and we're fortunate in that they were open-minded. They could see the benefits to David and acknowledged that this was a financially responsible approach to meeting his needs. We did receive some funding that allowed us to implement part of David's plan. This personalized, direct approach enables David to have a varied and interesting life. Quite frankly, it has not been an easy road to travel and there have been many stops, twists, turns and tears along the way. But it is amazing what a difference this approach has made, not only to David, but to our family as well. He is happy, enthusiastic and proud of himself and his accomplishments.

Individual direct funding is not a program, it is a lifestyle that is person-directed. We believe in this approach because it enhances quality of life through individualization for David. It promotes true choice. It respects his rights and encourages flexible opportunities and options. There is a true recognition of respect and dignity, and there is individuality, which ensures a better and more meaningful quality of life now and in the future. Individuals with disabilities have the same wants, needs, rights and expectations as anyone else.

David has come a long, long way from when doctors told us he would never walk or talk and advised placing him in the Rideau Regional Centre. He has faced challenges medically, personally and physically that would challenge any one of us. He has shown courage, determination and strength in trying situations, and has prevailed. He is happy, loved, cared for, and his strengths, needs, likes and dislikes are being met in a variety of unique and creative ways. Isn't that what most of us want for ourselves?

Our ultimate goal is to have adequate, annualized dollars to implement and support his entire personalized plan, and include cost-of-living allowance increases, to enable us to pay his support workers a reasonable salary.

In 2010, we built a home with accommodation for David to have his own space within our family home, and he is really enjoying this ownership. It also provides security and stability for his future. We are aging parents; this year my husband will be 71 and I will be 69. This past year was a wake-up call for us when my husband was diagnosed with cancer. It involved surgery, recovery and six months of chemotherapy. Quite a jolt, and it made us face the potential problems and the need to have

adequate and secure funding supports in place to provide stability and security for David. We are continuously stressed and worried that David's current funding will be cut or reduced. We go from year to year not knowing what processes or applications will be changed or required.

I realize that not everyone or every family wants to take the time to plan, implement and supervise an individual plan for their son or daughter, where you hire your own workers, self-administer funding, do record-keeping and all related paperwork. I acknowledge that it does require a great deal of time, but we consider it investing in David's future. We live with the results; therefore, we are going to ensure that his needs are met in a responsible way. I also know very few families in our county are being encouraged or supported in developing and using this approach to meet their sons' and daughters' needs.

Yet, parents and families who choose this approach are left out of the information loop. We are not advised about possible changes until decisions are already made. This select committee is a good example. We did not hear about it until mid-December, only by chance by a newsletter from a local parents group. I immediately phoned to request making a presentation to this committee in Ottawa.

Parents and families and individuals with developmental disabilities are the ultimate stakeholder. Professionals and governments come and go. Parents know their child best. They are the experts and ultimately live with the results. Therefore, it stands to reason that every parent wants what is best for their child.

In June 1996—that's 1996—a document entitled *In Unison: A Canadian Approach to Disability Issues*, a vision paper developed by the federal, provincial and territorial ministers responsible for social services, "sets out a blueprint for promoting the integration of persons with disabilities in Canada." It was reaffirmed in December 1997 "to make disability issues a collective priority in the pursuit of social policy renewal...." I feel that since that time, a great deal of time and money is spent spinning wheels and going in circles.

Some of my concerns, suggestions and recommendations: Invest in people and individuals, not systems or another level of government.

Stop putting individuals in boxes and assigning them numbers.

An individual requires and needs varying levels of support. No two people are exactly alike.

Supports must meet the needs that are necessary for a rich and meaningful quality of life with choices and flexibility.

Individualized plans must be developed by persons who know the individual well. Encourage families, who best know their family member's need, to develop the plan and attach a budget, with access to the funds to implement it. Otherwise, it's a waste of everyone's time.

The Ontario Disability Support Program funded by the ministry is an entitlement program for shelter, food and clothing for individuals with developmental disabilities, and it also needs to be increased.

Funding to provide support to individuals with developmental disabilities should be an entitlement, not a discretionary program.

Entitlement, meaning:

—same deal for everyone;

—to be active participants in society and do meaningful and productive activities of choice;

—to choose their own lifestyle, system of support and friends;

—to continue to learn and experience personal growth and development;

—to dignity and respect for human worth;

—to recognition that the individual is the key stakeholder in all decisions that affect their life. “No decision about me without me.”

In conclusion, I wish to thank you for the opportunity to tell our story and to express my opinions and beliefs. I would like to finish with this parable; it really says it all.

“Beyond Programs: A Parable

“In the beginning, there was placement, and lo, we were happy when it happened, as placement was not mandated for adults who happened to experience severe disabilities.

“And so, we said, this is good.

“And placements multiplied and filled the earth.

“And then, we said, let us make programs, which focus on serving clients. And clients were defined and labelled, and grouped according to their labels. And programs created services for each label, and state agencies developed unit costs for each service. And programs prospered and multiplied, and we said, this is very good.

“And as programs multiplied, a cry arose: Let us evaluate these programs to see how good they really are.

“And program evaluation, state regulations, quality assurance compliance plans and other program measures were created. And they filled volumes.

“And in those times, a person arose who was a client, but who was also a prophet, and said:

“I don’t want to be a client. I want to be a person.

“I don’t want a label. I want a name.

“I don’t want services. I want support and help.

“I don’t want residential placement. I want a home.

“I don’t want a day program. I want to do meaningful productive things.

“I don’t want to be ‘programmed’ all my life. I want to learn to do things I like, and go places which I like.

“I want to have fun, to enjoy life and have friends.

“I want the same opportunities as all of you: I want to be happy.’

“And there was a long silence. And lo, everyone realized that they must look beyond their programs. But they were troubled and they asked:

“‘How can we do this? Would not each person need their own unique program and system of support and his own individual measure of quality?’”

“And the prophet replied:

“‘Even as you say, so should it be done—just as you do for yourselves.’”

The Chair (Mrs. Laura Albanese): That’s beautiful.

1530

Mrs. Cora Nolan: I’ve included a copy of that in the package, and also a copy of the cover page for In Unison, which gives the information to get copies of it. That was 1996, and I know families were really excited when they saw that because we thought, well, there’s federal, provincial—they’re all going to work together here and we’re going to go someplace, and it didn’t go anywhere.

The Chair (Mrs. Laura Albanese): Well, we’re trying to work together now and to go places. I will now allow, is it Ms. Jones or anybody who would like to—Ms. Elliott.

Mrs. Christine Elliott: Thank you very much for bringing this parable to us. I think it really does say it all. It encapsulates all the concerns and frustrations that many people have been bringing to us. I guess all I can say is what we’re hoping to do in this committee is to work past that and to work past what happened in 1996 too with the Vision paper and really make something happen that’s going to be meaningful to families. But we certainly will take a look at this. Maybe it will give us some help going forward about what the thinking was at that time and help propose some solutions that are going to make a difference.

I’m certainly very happy for you, that you’ve been able to find some solutions for your son David, but you’re right: It’s because you and your family, as family members, have done so much as individuals. But we need to also be mindful of the fact that there are many families that don’t have those resources and aren’t able to do that, and so we want to make sure that everybody has the same opportunities. But congratulations on what you’ve been able to do for your son.

Mrs. Cora Nolan: I just got tired fighting with everybody, and nobody could seem to see what I wanted, so it was just easier to do it myself.

Mrs. Christine Elliott: Well done.

Mrs. Cora Nolan: With help from friends—lots of friends.

The Chair (Mrs. Laura Albanese): Miss Taylor.

Miss Monique Taylor: Hi. Good afternoon. Thank you so much for your presentation today and for taking the time to put a presentation together and to come and share it with us. It is so important that we hear from you and the trials and tribulations that you’ve gone through with David. Knowing that David has a good family and an advocate is so important, and we’ve been talking about that. We need to make sure that people have somebody to be able to guide them through our process and that our process isn’t so hard to navigate, where wheels are spinning continuously and people are getting nowhere. It’s something that—we’re dedicated to be trying to making a difference here. We thank you for your recommendations. We’ve heard them, and we will definitely put them into consideration, so thank you so much for your time.

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

Ms. Mitzie Hunter: Thank you for putting the presentation together and for sharing this story. I was curious, when you talked about the information loop. I thought maybe you could talk a little bit more about what you would like to see happen in a proper information loop. It seems what we've been hearing is that while children are in school, all the way up until age 21, there seems to be a very natural communication through the schools, but once that ends, then there's just the absence of consistent communications and an information loop. I thought maybe you could share what you would be looking for in proper communications.

Mrs. Cora Nolan: I guess it's because we're doing the individualized approach, so we're not involved with agencies and that, so we don't get the normal flow of information that you might get through them. We basically depend on family groups to get information about what's going on. I would suggest to most families that they do join local family groups or provincial family groups or access some on the Internet, even, to get information about what's going on around the province. It was just by chance that we got it with this one. So you're doing your own thing, but yet you're not getting the information.

Ms. Mitzie Hunter: But we could utilize the family networks as an appropriate channel to communicate our information about changes and things as they progress.

Mrs. Cora Nolan: Yes, and the Spotlight thing from the ministry. Spotlight: It's the newsletter that comes out from the minister. We get it all the time too. It might be helpful to have something like that in there of upcoming things that are going on at the ministry level, maybe.

Ms. Mitzie Hunter: Sounds good. Thank you.

The Chair (Mrs. Laura Albanese): Well, thank you once again for being here and listening to us today and following the proceedings. Thank you.

HUB FOR BEYOND 21 FOUNDATION

The Chair (Mrs. Laura Albanese): Our next presenter is the Hub for Beyond 21 Foundation. We have the program manager with us. Good afternoon.

Ms. Jane McLaren: Good afternoon. My name is Jane McLaren. I am the program manager for the Hub for Beyond 21 Foundation. We're based out of Cornwall, Ontario, serving Stormont, Dundas and Glengarry counties. We are a day program. We're a non-profit registered charity that is a day program offering services for developmentally disabled persons 21 years of age and older.

As I've been sitting here for the past little while, I've been hearing everyone say that at the age of 21, all the services seem to fall off the map, and we are one of those agencies that are trying to fill the gap. In fact, back in 2010, it was a group of parents who met with the Upper Canada District School Board and identified a real need and a real gap within our area. They got together and, along with the Upper Canada Leger Centre, they hosted a town hall meeting. They really hoped that they would

have 20 or 25 families that would attend that meeting, and instead they had over 100 families come out. It really highlighted that there was a huge need in our area—there is a need, period, but definitely a huge need in our area.

We were fortunate that UCDSB got behind us and supported us, and in January 2012 we opened our doors. We're all of two years old. We're a very young organization. We are 100% fundraising funded. We receive no ministry funds, so we're out there begging and borrowing and writing grants like so many organizations are today. We started two years ago with a very, very small group. We had two staff and just a few participants, and we've grown now such that we have 19 participants in our program.

Our mission is very simple: to offer a structured, meaningful, inclusive and community-based environment where dependent adults with developmental disabilities continue to thrive and grow socially, physically, emotionally and intellectually. We're open to anyone over the age of 21 with a developmental disability. We don't actually have a cap. It's not 21 to 30 or 21 to 42; we don't cap it. We've had 65-year-olds come and apply to be in our program, which really shows the tremendous need. We do have an intake assessment process where we look and see if the needs of the person who is applying match what we are able to offer. That's how we meet and screen out whether or not that 65-year-old's needs are going to be met by our program, or whether they are better served in another program.

The participants come from 9 in the morning until 3 in the afternoon, Monday through Friday. Because we're in a school—we actually are given free space by Upper Canada District School Board—we are closed over the Christmas break, and we have to close for the month of July because they have to come in and do the cleaning in the school. But we are open from August straight through.

We have five different programming areas that we run.

We have recreation, or physical healthy lifestyle.

We have kitchen: The participants prepare their lunch, and they have to clean it up as well. We do have a dishwasher, which is a nice bonus, but they do all of the preparation and all of the cleanup of meals. They also do the menu planning. They do the grocery shopping. They are responsible to go out and pay the bills, to plan it. And you know what? Even with my staff, doing groceries for 12 to 15 people is not really all that natural. I grew up in a little bit of a large family and it doesn't faze me, but it's a real challenge to teach people how to buy groceries and cook and prepare meals for groups that are 12 to 15. So we also have to break it down, because realistically, if our participants go on to a lifestyle of living independently, they are not going to be cooking lunch for 12 people in their home. So we also have to break it down so that they are preparing just for themselves or for one or two people as well.

We do social skills, life skills, and we also do creative expression.

So those are our five areas. They're programmed over four different spaces each day. Everybody does the rec-

reaction each day. Everybody, of course, does lunchtime. And then we have two different 1.5-hour blocks where we offer two different programs going consistently.

One of the greatest challenges we face is that we have participants who are coming in and are going to be working towards independent life and towards living in an apartment and gaining independence in the community. Then we have others where that simply is not within the scope of their future. They are working at gaining skills, gaining community, and working towards what they can. But many—well, not many, but we have a few who are non-verbal. So when you try and mesh those who are going to succeed at living independently and we're working with them on budgeting and we're working with them on city transit and we're working with them on life skills, and then you have those who are totally non-verbal and are never going to get there, it's hard to mesh those two together. So we run two programs at the same time, split them off into two groups, so that we can work on needs.

1540

Every single participant has an individualized plan, and we review those plans every single month as a team to make sure we're not fitting and sitting in gaps. We plan weekly. If you go on our website, you will not find a monthly calendar. Our weekly calendar is very deliberate because it allows us to change week by week by week and sit down and say, "Where are we meeting the goals of our participants? Where are we missing them? Where do we need to change on a weekly basis?" rather than getting into a month and getting to the end of a month and realizing, "We really focused on this, but we've left those behind." It allows us an increased flexibility and an increased accountability.

We do have a fee for our program. Our participants are charged \$25 for the day. That includes all of the food and transportation within our program, if they have to get to and from, but any transportation or outings, any special events; everything is covered under that \$25. Most of our participants do claim that back under Passport funding to the extent that they have it.

We've had a lot of successes for two years. We've got Trillium funding; we've had funding from the city of Cornwall. We had a private foundation give us a grant and purchase us a van, which was a wonderful assistance. That allowed us to bring in more participants because we're limited by who we can transport.

If you look under sociology in a hierarchy of needs for every individual, you'll see that there are five: physiological needs like food and shelter; safety, security; love and belonging; esteem; and self-actualization. I think there's a lot of focus within the world of provision on the physiological needs and safety, but then there starts to be a lack. That sense of love and belonging, esteem and self-actualization that allows us to truly grow and function in a community is often what's missed. I really think that comes out of a sense of community.

If you look at our name, we're called the Hub for Beyond 21 Foundation. That's very deliberate. We are a

hub because the heart of our focus is to have a place that develops and encourages a continuing and ongoing sense of community for the developmentally disabled. At the age of 21, they graduate out of school, and school is a community. It's the place, as you heard earlier, where communication is happening, where friendships are happening. Even if you are in a segregated class within, you are still in a community within the school community. There are all these extracurriculars that are going on, and then school is done and you go home. And what do you do? We hear over and over again from our parents that the reality after the age of 21 is television and video games. All of a sudden, they're no longer connected with the friends that they had in school. Our community, when we leave, usually comes from the friends we develop within our employment setting, the friends that we carry through from our friends, our family. We have our family and our extended family; for some, it's our faith community, which, again, often comes through family. But our greatest connections are coming from employment and volunteer opportunities, and that's not existing for many of those who are within the realm of developmental disabilities.

Even when parents are successful in programming, many of those programmings—and I have one parent; God bless her. Her child went Monday through Friday, from 9 in the morning till 5 in the afternoon. That mother ran herself ragged for an entire year and had her child in program upon program upon program his first year after he graduated. She got to the end of the year and she said, "He had a phenomenal year of his time being spent, but it was just putting in time." So the second year, she picked those key programs that he really enjoyed and kept him in those and they both had a life, instead of just programming.

The problem is, I call them "go, do, leave." They go to the program, they do the program, they leave the program. They may develop a friend, if they're going to bowling on Thursday afternoons, and they really may like to go and sit down with Johnny at that program, but there's no relationship or extension of community outside of that program. So one of the key focuses of the Hub for Beyond 21 is the opportunity for the developmentally disabled to create and develop a sense of community and, out of that sense of community, to develop that sense of safety, to develop that sense of self-actualization, that sense of self-esteem, that sense of value that carries them forward as humans and allows them to continue not just their skills but to develop their sense of community and contribution to community and to develop into their future.

Over and over I hear exactly what I've been sitting here hearing this afternoon. We hear from our parents, "We don't know what's going to happen to our children when we're no longer able to care for them." We hear, "I don't know how to access funding. I don't know how to access programs. I don't know how to find programs—or, if I can find programs, I don't know how to validate the quality of the service provider."

SD&G is not a huge city. We have a huge rural community. We have many parents who are taking their now-adult children all over the place in order to find services. They're taking them out to farms in order to do equine therapy, animal therapy and farm therapy, with no way of validating whether the person is a good-hearted person who is working with the developmentally disabled, whether they are a person who has put in the time and effort to get qualified, or whether they are a person who just saw a way to make some money and is going off and doing this. It's the same thing within music programs, the same thing within arts programs.

At the same time, there is tremendous value in connecting and networking out into the community, but it is all falling back on the parents in order to find and set up and program. Then it comes back to this whole sense of community.

After the age of 21, these developmentally disabled adults—they're now back in the home—need adult peers. They need friends. They need adult opportunities in employment, housing, recreation and leisure. They need independence, defined to whatever their specific capabilities and capacities are. They need funds to be able to transition to adulthood in the future. In summary, they need the same opportunities that everyone else had, the same opportunities that we all had: the chance to grow, to succeed and to fail, and to define their future as they walk into it, and not to have their future defined for them by a lack of services or funding.

In the short two years that we have been a program, focusing not just on life skills and social skills but focusing on this whole sense of community, what we are seeing is, we have two that have come to us, worked with us and left our program, and who are now working—living independently and working—which is so exciting.

Out of the 19 we currently have in our program, six of them are actively volunteering. They are with us part-time, and they are out volunteering in the community part-time.

We're seeing an improvement in impulse control and a decrease in negative behaviours in our participants. We're seeing improved social skills, even basic things like the ability to pass food around a table instead of just grabbing it or just sitting there, not knowing that you can actually ask for seconds—basic skills.

Increased communication: Participants who have come in to us with very limited or almost straight echolalic expressions are increasing their communication and their ability to carry on communication.

Increase in peer relations: We are starting to see friendships form within our program now. They leave on the weekends, and they go shopping together. Even more exciting, they're networking into the other programs that are existing, into our community. They're saying, "Okay, the Handi Social Club has a Halloween party, but I don't really want to go alone because I don't know them all that well," so two or three of our participants get together and go. They're starting to network into other groups within our community, but going together. They're starting to connect, network and knit in.

They're learning skills like yoga, Zumba and different things like that within our program, gaining confidence in it, and then they're going home to their neighbourhoods—they're coming out of Long Sault, Ingleside, Morrisburg, Martintown and Alexandria; they may be 45 minutes away from us—and they're joining yoga where they live. So they're becoming knitted into their neighbourhoods and developing friends in their neighbourhoods, because they've gained confidence and skills in the program to take out into the community. That sense of community is so key and is so critical.

Do we have challenges? Absolutely. Fundraising a program is a huge challenge. You're not just sitting there each day trying to figure out how your programming is and how you're going to meet the needs of people. You're constantly sitting there wondering if you're going to have the money to keep this program up and running next week, next month or next year. Fundraising, of course, becomes increasingly challenging year after year after year, because everybody's knocking on everybody's doors, asking for money.

Transportation is an issue. We have people who literally drive close to an hour and a half to get to us, because we are based out of Cornwall. We hope to have satellites so that there is less transportation, but that is a huge challenge, and there is no funding for transportation. Our parents can fund our program under Passport, but they cannot get money back if they have people who drive.

We're 9 to 3. If you work 9 to 5, you can drop your participant off with us and go to work, but what do you do at 3 o'clock? You've got to pay somebody, and you don't get that money back. So that's a huge transportation issue and a huge funding issue.

1550

Hours are an issue. We would love to be able to go 9 to 5 and be able to accommodate so that it makes it easier for parents who are working, but that comes back to funding as well. My staff like to be paid. They aren't paid great gobs of money, but they do like to be paid.

Fund capping: My parents always run out of money in terms of Passport. And where do you put the money and how do you get the money? They're constantly coming to us and asking us, "How does the system work?" They don't understand it. They want us to walk them through it, which is really challenging for us, because then I have to become an expert on all of the system as well so that I can advise them, which I'm not. But they need someone who can walk them through that system because they're confused and they're lost and they're scared that they're not going to get the money and they're going to be financially strapped and stressed.

Space is a challenge for us. We're in one room, and we're very fortunate because the school does give us that room and it's a wonderful room. It used to be a staff room, so we have a kitchen; we have private bathrooms. We actually have a private entrance so that we don't have to go through the entire school to access it. It's in one of the schools that was closed. They just let us paint a wall,

which schools don't do. We're really lucky, but if we had a whole house, the difference that we could make in terms of teaching—it goes back to that full funding issue again.

The other thing is just the time to promote us. We have to go out in the community and make us known. The DSOs don't make the parents know about us. The agencies that should be letting parents know we are there—they don't tell the parents about us. It is up to us to go out and promote in the community and let the parents and the families know who we are, what we stand for and what we represent. That becomes another onus for us and it also becomes more dollars, because we've got to put the dollars out in promotions and fundraising in order to do it. That's a huge challenge.

We are very fortunate that we're a United Way agency. We were the only new United Way agency accepted in our area. Again, that comes with going out with United Way and doing the sponsorship, but it also really assists us in promoting and getting known.

Beyond 21 has no intentions of stopping. We have no intentions of giving up. As you heard earlier from Karin, one of our plans is to develop and expand into residential and to have a residential setting for adults. One of our other dreams is to have a respite care centre for adults as well. We have the three facets. We also hope to expand into social enterprise so that the developmentally disabled will have increased employment options. In the future, that's where we hope to go. We're just starting, but we definitely want to go and expand.

There are a lot of needs for this population. The day program is not the be-all and the end-all for every single one of them. We want to expand; we want to be there; we want to just do everything we can.

If I had to encapsulate us in a nutshell, I'd say Beyond 21 is about dreams and visions. It's about the value of community, it's about the value of belonging, and it really is about seeing potential instead of seeing disability.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you for a very insightful presentation into the programs that you have at the Hub for Beyond 21. We have one minute each, so that we don't get caught behind.

Ms. Sylvia Jones: Does that mean I just talk faster?

Okay, so I'll ask the silly question. I'm assuming you have put together a funding proposal in to MCSS.

Ms. Jane McLaren: No.

Ms. Sylvia Jones: Why not?

Ms. Jane McLaren: When the board first formed and approached MCSS, they were told that they would not be funded. Even the residential: We have looked into it and we've been told, "There is no funding; do not apply."

Ms. Sylvia Jones: You have to put the words "pilot project" in front of it and then you at least get in the door. Okay. Thank you.

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

Ms. Cheri DiNovo: I just want to say thank you, because it's such an encouraging, exciting story. If any-

thing deserves to be funded, it sounds like yours does. Again, we see this wonderful initiative coming forth, starting with parents and catching steam and going on. Clearly your passion for what you do is catching, and I think we've caught a little bit of it.

I just want to thank you so much for making the trek down here. You have so much else on your plate to do, but thank you for letting us know what it is that you do, that you love, because you clearly love it.

Ms. Jane McLaren: Thank you.

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

Ms. Mitzi Hunter: Thank you for presenting an innovative program approach. I was going to ask you how you plan to scale up. I think you have some ideas there. Maybe the work that MaRS is doing—you can link into that, because they are looking at scalable solutions across multiple communities.

I think it's good that you're a United Way agency. It adds a lot of credibility to other funders, so I think another cycle of that is very appropriate.

I do agree that the pilot approach is a good path to linking in to the government, but with an agency partner. I think that having that conversation—there is an openness for that. So I would really encourage you, either through your Community Living or advice through the DSO—of an appropriate agency partner to talk about your residential programs, to talk about your scalability. I would believe that they would be open to that.

I believe my colleague here also has a question.

Mr. John Fraser: Just very quickly, I wanted to say thank you very much for your presentation. Your comments on community and belonging and what people need really connected very well with an earlier presentation by the MAPS people about people having relationships outside of caregivers post-21. You're filling a gap that's there, and that's very important. It's a good thing that you're doing that. Thank you very much.

Ms. Jane McLaren: Thank you.

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

MS. ANDREA STADHARD

The Chair (Mrs. Laura Albanese): We'll now move to our next presenter, Andrea Stadhard.

Applause.

The Chair (Mrs. Laura Albanese): You have fans in the audience. Good afternoon.

Ms. Andrea Stadhard: Good afternoon, everyone. Sorry, I'm very nervous. This is my first time ever being at a forum like this, so bear with me.

The Chair (Mrs. Laura Albanese): Do not be nervous. If you need any water or anything, just feel comfortable and make your presentation.

Ms. Andrea Stadhard: I'll probably get water after.

I'm a front-line worker—can I say where I work? I work for Tamir foundation. It's a Jewish organization that supports adults with developmental disabilities and other dual diagnoses. I kind of just want to go through the way the budget is set up now and how the participants

are living right now, based on the current budget, so just some scenarios. We can go through my handout a little bit afterwards, if there's time.

My first scenario is a man in his mid-20s. He has autism spectrum disorder, a seizure disorder, and he is also non-verbal. In the past year, he has had an increase in violent behaviour towards his peers, staff and his environment. It was recommended by his psychologist and his behaviour management consultant that he take a vacation from his day program to allow him to regroup. His parents also agreed with this recommendation. Almost immediately after the recommendation was tabled, it was denied by his residential supervisor, stating that there was no additional money in the budget to support this individual. This person continues to attend his day program and continues to have violent outbursts—an otherwise gentle man who enjoys giving hugs to preferred friends and staff now needs a break from the everyday. When he becomes violent at program, he takes away from the other participants. When he becomes violent towards his peers, he instills fear and distrust. When he becomes violent towards his environment, he damages items the other participants depend on for day-to-day supports.

Just recently, this person experience an unexplained increase in seizure activity and required a visit to the emergency room. The staff supporting him had been working a 12-hour shift already and went to the hospital with him. She ended up having to extend her shift, so she was there for 15 hours. When she called the on-call supervisor to see if she could be relieved, the supervisor said that there was no one else to cover and maybe she should call the parents. So she ended up calling the parents. The parents said, "No, it's not convenient for us to stay at the hospital." She called the supervisor back and the supervisor said, "Okay, just leave him alone at the hospital." Just as a reminder, he is autistic, he is non-verbal and he acts out physically. Even people whose first language is not English have a translator to ensure the best possible health care.

My second scenario is of a young man with a developmental disability, also non-verbal, and by all accounts very healthy. He has been experiencing back problems, rendering him unable to walk. He would benefit from regular massage therapy as a preventive measure but cannot afford the service as he must save his modest money for his personal necessities. Providing this individual with additional financial support now may prevent him from depending on the use of a wheelchair later.

1600

My third scenario: An older man with Down syndrome has been working for many years at the same job, shredding confidential documents for the government. He is reliable, trustworthy and he works hard. He lived in an apartment in a supported independent living setting and took the bus to work independently. He began to show signs of dementia, and when it became unsafe for him to continue living in his SIL apartment, he moved into a group home that provides 24-hour support. He tried to get access to riding on Para Transpo, but he did not fit

their criteria, so he continued to take the bus to work. One day on his way to work, he made a wrong turn and was spotted walking on the Queensway.

My last scenario: Here's a story of a senior male with a developmental disability living in a group home. Although he can speak, he is considered non-verbal. In his earlier years, when he lived at Rideau Regional Centre, he had the potential to become aggressive towards others, but it could be prevented once staff were aware of the antecedent and could change things around to avoid physical aggressions. Now he is much older. He has less tolerance of situations and becomes violent towards others without explanation. He aggresses against others, including members of the community. This person has been exempt from programs and now remains at home with one-on-one staffing. The only difference between this scenario and the one I shared earlier is that, in this instance, the aggressor has been violent against a member of the community. He gets to stay home because it costs less than a potential lawsuit.

Those are my scenarios. All of these things have happened in the last year and a half, and there's a lot more that go with it.

With my handout, I have bullets of just how the budget is affecting the participants now. Just to skim over a couple of the bullets that are really, really important—probably our fifth bullet down: Persons with developmental disabilities currently live on an extremely modest monthly budget of an average of \$113 a month. That money is supposed to cover personal hygiene, entertainment, extracurricular activities and everything else that can come up under the moon.

An example of how this whole system isn't working right now: Imagine getting free tickets to your favourite sporting event but learning that you can only watch half the game because the staff supporting you at the game finishes his shift before the game's end and his employer is not willing to extend the shift. Would you only go to half of a game? Not many people would.

Vacation: Vacation is defined as a period of time spent away from home, school or work in order to relax or travel. People with developmental disabilities have a very modest income after they pay for their shelter and their food, so a vacation for a person with a developmental disability is maybe three days and two nights. That vacation also includes going on vacation with the people that they live with and the people that they go to day programs with. So they're essentially not getting a break from any of their everyday life situations. They're always with the same people. We're not really doing it justice when we could be expanding it to saving up to go to a different city with friends from another group home or friends that you went to school with. We're not really keeping that inclusion part of it alive because it just doesn't fit the budget.

There are residents in need of updates to accommodate declining changes in individuals' physical, emotional and mental states. For an example, we have a group home with eight individuals. These guys have been together for

years and years. They love each other. But now there are forms of dementia that are coming into play, so where you had two individuals who were the best of friends, one is now targeting the other. So one is essentially being bullied by the other person. There's no help. Where it used to be fine to have one staff to stay asleep in that house, it's not possible anymore. Because the dementia is taking over this person's life, he's becoming unsafe to himself and to others. He's throwing things down the stairs. He's sneaking into other people's rooms and trying to aggress against them in the middle of the night. So now his housemates don't feel safe. There has got to be a system in place where we can support the people with changing needs as well as still giving the positivity and the respect and the dignity that we're supposed to be giving to the people who are watching all of this go on around them.

Am I out of time?

The Chair (Mrs. Laura Albanese): You still have time.

Ms. Andrea Stadhard: Okay. For day programming, I am a front-line day-services worker, and what we're seeing now is our day supports are running at full capacity. I've been at the same program for 10 years and I have seen the staff number stay the same, but the numbers increase. When you have such a diverse group of individuals who come in and they want support, we're supposed to be able to provide individualized services. We're supposed to be able to look at supports for someone who has autism, who might need the sensory part of his life fulfilled, before going on to something else. It's not possible; it's just not working. And it's not working because staff are overstretched. I'm not even supposed to be here to talk about staff—it's all about the guys—but you have to understand that when you add 10 more people because of Passport funding to a program where the staff doesn't increase, it doesn't get better.

My last blurb on Passport money: It sounds great when you introduce it and you say, "Here, families. Take this money and find a program that suits your son's or daughter's needs." The problem with that is when you start warehousing people—because this is essentially what it is—and fitting as many people into a day service as possible so that they have day supports to give their family a break, we're overwhelmed. The system is overwhelmed. There's not enough vans; there's not enough staff.

We have all the opportunity; we have all the community supports. We just can't get to them because we're dealing with one-to-one behaviours. We're dealing with people with pica who cannot be left alone because they will ingest something that could potentially kill them. The risk is different because we're pooling people in the same group. You cannot lump everybody underneath the same—it's not fair.

It's great to provide day services. People need day services, and sometimes without the day services they have nothing else. We know of people who are staying home with their parents because they don't even know

what supports are out there, or they do know what supports are out there and the government has given them this Passport money, but there's no space for their children.

I talked to a woman last night who was with her son at Thursday Nights Rock. She has a good family support system, but it shouldn't be his family who's taking care. He needs that social involvement, which he is missing.

One more example: Loeb dances. An agency, OCAPDD, has Loeb dances for every holiday. They're awesome. All the guys like it. I went to the Christmas party last month and I saw a participant dancing on the floor with her mother. When you think about it, it's not inappropriate to dance with your mother, but if you're at a social event with your peers, you should be dancing with your friends. There is something amiss when these guys don't have friends, and I feel bad when I say to them that I'm not their friend because I'm paid to be there. It's not a fair statement, but it is the reality, and we have to be everything to them. So please keep that in consideration. Open up the wallets and support these guys the best way that you guys can.

Thank you.

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

I will turn it over for questioning, and we'll start with the NDP. Miss Taylor.

Miss Monique Taylor: Great, thank you.

Thank you for your presentation and thank you for being here today and for knowing that there's a need. I mean, it's quite obvious, through the people you spoke of, through the things that you say are necessary for change, that you get it. You're working in the system, you're seeing what's happening on a day-to-day basis, and you know there's a problem, and you've taken the time to step up to that problem and say, "I need to do something about this."

1610

By doing that, you're here and you're speaking to us today, because we've also realized that there's a need. That's why we've called people together to please give us a suggestion. You're living it every single day with people in these programs, and families are feeling these struggles every day. It's so important that we're hearing these struggles, and that we work together to try to find solutions.

You were talking about friends, and I'll put a plug in: In my city, there's a program called Club GAIN. It's for young persons—I believe 13 to 24 are the ages that can attend—and no parents are allowed. You're not allowed to bring your worker. There's adult supervision there, and it's about being with your peers. They dance, and they're allowed to touch in a respectful way, and they're allowed to kiss. It's helping with that sociability. They're building relationships, they're being with their friends and they're finding love in this world. There's no government funding for that one either, but it's something that people are taking initiative on, standing up for the needs that we see in our communities, so that's what I have to say on that. Thank you for everything that you do.

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

Ms. Mitzie Hunter: Thank you, Ms. Stadhard. I really appreciate your frank approach in which you shared those stories and what you see every day as a front-line worker. I see a lot of compassion and joy in you, because you're talking about some very tough things, but you're still able to present them in that way. I really appreciate the work that you and your colleagues and peers are doing.

I have two separate questions, just from your comments. The day supports, combined with the natural supports from the families—from your perspective, how do you see that working? Because what you're saying is that the system is stressed and overwhelmed, even within the day programs, just due to the pressure for space. Families are relying on the day programs so that they can get a bit of a break or continue to work, but they very much want to continue to be involved in their son's or daughter's life to provide some of those natural supports. When does that work well? That's my question.

Ms. Andrea Stadhard: The thing with that is that their parents, before the Passport funding—so for the people with disabilities who already had a spot in their day services, for their parents, it was an expectation: “This is where I would send my child, this is the programming that will get done, and I'll be happy with it.” There was an expectation, like sending your kids to school. You just knew every day that your kid was going to school, there was a place for them and they would be safe.

For the people who are coming in with Passport money—it really is the Passport money; there really is nothing else—they're coming in and dictating what they would like to see. That's fabulous, but give us the structure, because it would be very honourable to be able to give that individual every single thing that they need to meet every goal on their list and check it off. We can't do that now, based on the numbers.

We're very grateful when parents take some time off and come in to volunteer. They come and see what we're doing. They see what we're working with. We don't even have a functioning TV, so it's up to staff teaching a class on the wilderness to bring in their tablets, pull up a video—because we actually have WiFi—and say, “This is what it is.”

To be able to go to a museum, that costs money. The frog exhibit was at the Canadian Museum of Nature the other day. It was too much money. We couldn't afford to go, so, “Let's go back to program, and look it up.” There are just so many things amiss, because it's a fish pool. It's a barrel of fish, and now we're thinking that all of these fish are the same. It's not right.

Ms. Mitzie Hunter: How many people are in your program?

Ms. Andrea Stadhard: In my location—I'm on Donald Street—we have 30 people, and we have two different programs that run out of there. The program that we work in is a life skills and job skills program. Our sister program next door is more recreational. So,

depending on your level of need is where you're going to be.

Ms. Mitzie Hunter: Thank you.

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

Mrs. Christine Elliott: Thank you very much, Ms. Stadhard, for coming forward to us today. I think you've brought a unique perspective as someone who is working on the front line in the day program. You've brought a number of concerns to us that, frankly, I wasn't aware of before, so thank you for that.

You've talked about the division of your day programs into one that's based more on life skills and job-readiness skills, and one based more on recreation.

You also mentioned some of the concerns about some of your aging participants, some of them with more aggressive behaviours and perhaps early-onset Alzheimer's. Is that another program that you would see would be useful to open, separate from the other two?

Ms. Andrea Stadhard: Absolutely. I think that it would be beneficial to have a program that deals specifically with people who are going through dementia-type issues as they're getting older. They're getting older, and you can't send them to a seniors' home. What has happened in the past is that you sent somebody with a developmental disability, with dementia, to a seniors' home. They're not trained to work with these individuals.

We go to school to work with these individuals. We want to see the best for them. If they snap, you can't send them to the ROH and say, “Please fix this.” It's not a fixable thing. There's got to be another outlet that supports our guys properly.

Mrs. Christine Elliott: Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you again for presenting to us today.

PARTNERS FOR MENTAL HEALTH

The Chair (Mrs. Laura Albanese): We'll now ask Partners for Mental Health to come forward. Good afternoon, and welcome to our committee. As you have heard, you will have up to 20 minutes for your presentation. If it's any shorter, we'll have time for comments and questions. You may begin any time.

Mr. Jeff Moat: Thank you very much. Maybe we'll start with some introductions.

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

Mr. Jeff Moat: My name is Jeff Moat. I'm the president of Partners for Mental Health.

Mr. Michael Dixon: I'm Michael Dixon.

Ms. Janet Osborne: My name is Janet Osborne.

Mr. Jeff Moat: What we'd like to do this afternoon is take you through an initiative that our organization has pulled together in response to a pressing issue that's facing our young people today.

Before I get into the details of that initiative, I would like to start by having Janet Osborne share her story. Over to you, Janet.

Ms. Janet Osborne: I'm one of the volunteers for our local Partners for Mental Health. The reason I was looking for a group to join is because it will be three years in February when we lost our 18-year-old son to suicide. My first reaction was, I can't not do anything. I have to stop any other young people from taking their lives.

What I'm really hoping to achieve by all this is, the school system—even though he was 18, he was still in the public school system. The teachers were seeing different affects from him: not going to class, not showing up for exams, not handing in homework. After we met with the school afterwards, we were told that. Most of all of this, we didn't even know, because he was 18.

We understood from the principal that he was brought in to some of the teachers and was given a pep talk to do whatever he can. But other than that, because he missed so much time, they basically wrote him off as a dropout and never really addressed the situation.

The day before he took his life, he actually told one of his close friends that he was planning to kill himself. In her view, she figured that she did the right thing by just trying to talk him out of it. She didn't tell us; she didn't tell her parents—other than what she knew: “Well, I'll sit and talk to you and tell you that, no, you don't need to do that, and we're here for you,” and whatnot. But he went ahead and did it anyway.

1620

My biggest issue is, our children are being taught at school about drug issues; they're taught about sex education; they're taught about puberty and all those things, but never have they ever spoken about mental health. They're not taught what to do when their friends are talking about suicide. They're not taught to go to a parent; they're not taught to go to a guidance counsellor. They're watching their friends deteriorate into drugs and alcohol. They're seeing the changes.

I'm dealing with one of his friends right now who has come forward just before Christmas and almost broke my heart saying he can't live with the guilt anymore that he couldn't have stopped him. Now his parents have to pay for psychology treatment because I recommended that he go see a psychologist before he does harm to himself, because his attitudes were pretty much the same as my son: He never spoke to anybody. I'm just fortunate enough that he came forward and said, “I can't deal with this anymore. Can you please talk to me?”

We need to have the funding and the resources in Ontario spread across all these aspects. It's not a fix in one area; it has to be across the board. Students need to know and it needs to be part of the curriculum, I would even suggest, right from middle school on, because they're getting younger and younger all the time.

I strongly urge you to listen to what Jeff is proposing. Hopefully it will trigger some hearts to help out so we don't lose any more young people, because there are too many being lost already.

Mr. Jeff Moat: Thanks, Janet. Sadly, the story that Janet tells is actually more common than we may all

think it is. Too often we feel that suicide, the death of a young person taking their own life, is someone else's problem, but we know that for every death by suicide there are hundreds of attempts, and that for every attempt there are hundreds of ideations. When you actually do the math, this touches hundreds of thousands of young people. The reality is, it is in all of our kitchens; it's in all our backyards. This is an issue that touches all of us.

Before I get into some of the specifics of what we want to put in front of you, I just wanted to take a brief moment to tell you a little bit about the organization called Partners to Mental Health.

We're a national charitable organization. We're accredited by Imagine Canada. We were founded by the Honourable Michael Kirby, who, by the way, sends his regards to everyone in the room today. He created this organization to improve mental health in Canada by mobilizing Canadians to accelerate, in his words, a social movement which collectively will serve to break through the social prejudice that surrounds mental illness and effect real and lasting change.

Through active and collaborative engagement of individuals, schools, businesses, community leaders, governments and other stakeholders, Partners for Mental Health is beginning to open a dialogue, educating and informing Canadians, changing attitudes and behaviours, influencing policy, raising some money and beginning to redefine the current norms around mental health and mental illness, because what we call normal today is actually quite abnormal.

For a young person, regardless of where they live in this country, to wait, on average, 12 months to access mental health services, in my opinion, is actually quite unacceptable. If that's the norm, that's abnormal.

Three out of four young people who need services in the mental health system don't get them. Imagine if we denied three out of four kids cancer therapy or that wasn't available. What do you think would happen? It would be completely unacceptable, yet because it's a mental illness we accept the norm. Only one out of four kids that need access to these services get them.

Suicide is the number one cause of non-accidental death for young Canadians. We lose an average of 760 kids a year. That's the size of a typical high school in this country. Almost all young people who die by suicide have an underlying mental health problem. So we took it upon ourselves as an organization to create a campaign called Right By You to rally Canadians from coast to coast to lend their voice and to take action in support of suicide prevention, and ultimately to ensure that mental health-related services, treatments and supports are available to all young children when they need it, because right now, if a young person needs it, they're going to wait, unless you have the financial resources to do it. We have a classic two-tier system in this country: We have the haves and we have the have-nots. I think for most Canadians that would be unacceptable.

We're calling on provincial and territorial governments to double the number of kids receiving access to

mental health services and treatments. Right now, 500,000 young people get those treatments. Over three years, we'd like to double that number. When we look at programs in Australia, in working with some of our subject matter experts here in Canada, we've come up with a model that we think is certainly something that is worthy of further investigation. It's modelled off an EAP system, an employee assistance program. In Australia, what they do is they provide a certain number of sessions, and these sessions are provided by not just psychiatrists, but psychologists and social workers and other accredited psychotherapists.

That's what we're proposing. We're looking at providing kids access to eight sessions provided by one of these professionals, and if we look at an average hourly rate of about \$125, that's \$1,000 per child. Are we not willing to invest \$1,000 per child? Across all provinces and territories, if we want to double the number of kids getting those treatments, that works out to be \$500 million over a three-year period for all the provinces and territories. It's not the be-all and end-all, but it's a start. It gets kids into the system, and after eight sessions, if they need triage deeper into the system, then that's what will happen. But let's get kids access to the treatments they need sooner rather than later, because you know as well as I do, if a young person—or any person for that matter—is denied treatment, and they wait, what do you think happens over 12 months? Their condition deteriorates, and sadly results in tragic consequences, like suicide.

I'll pause there, and thank you for your time.

The Chair (Mrs. Laura Albanese): Thank you. It's a touching presentation, to say the least. I believe it's the government's turn to start this round. Ms. Hunter?

Ms. Mitzie Hunter: Thank you so much. There's a lot here to unpack, and I know we don't have a lot of time. I was wondering, in terms of the numbers that you're capturing, does that include aboriginal youth as well?

Mr. Jeff Moat: That's a great question. Certainly, when we talk about service provision, we talk primarily in urban environments. But what's really important is the fact that when we talk about problems in urban communities, I can guarantee you that the problem is exacerbated in rural communities and deplorable in First Nations and Inuit communities. What we've put forth in our more detailed propositions is the fact that we recognize the cultural differences in these communities and that the treatment, whether the delivery channel or the type of treatment, needs to respect the cultural differences.

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

Ms. Soo Wong: Thank you very much for your presentation, and Ms. Osborne, I'm very sorry to hear about your loss. I just want to acknowledge that piece.

During the past year, all three ministries—health, education, children and youth services—made significant announcements in Ontario. Are you aware of these announcements?

Mr. Jeff Moat: Yes.

Ms. Soo Wong: And have you had any conversation with any of the ministries, particularly in the pieces that

deal with nurses in our schools targeting for mental health, and the recent announcement from Minister Duguid for training, colleges and universities to support post-secondary students? So I just want to hear a little bit about your conversations with the different ministries about your program.

Mr. Jeff Moat: The conversations we've had, and thankfully, by having a chairman like Mr. Kirby promoting this particular policy—he has been successful at socializing this particular policy with every deputy minister, in most cases almost all ministers of health right across the country. I'm happy to say that the receptivity to this has been quite favourable.

1630

Certainly, there have been some changes, as you have just recently spoken about. The reality is that mental health services in Ontario and across the country have been historically underfunded, which has led to the patchwork of services that we have now. No real mental health care system truly exists. We just feel that it needs to be given a larger share of the health care budget.

In looking at CAMH's figures, they show that mental illness—I'm looking at my numbers here—constitutes more than 15% of the burden of disease in Canada, yet these illnesses receive, still, less than 6% of health care budget dollars, and 60% of family physicians rank access to psychiatrists in Ontario as fair to poor. That is still unfortunately the situation we contend with. Certainly, some positive strides have been made forward, but I guess we're saying that more needs to be done.

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

Mr. Jack MacLaren: Thank you. Jeff, I'd like to thank you for coming. You speak well and you identify a problem we're all aware of and you just highlight it in a very intense way.

Janet, your words are very powerful. Sorry for the loss of your son.

Michael, you and I know each other. You've come to my office and talked about Partners for Mental Health and your Right By You program. I think we were in the Hazeldean Mall one day when you had a booth set up to promote it, so I'm very aware of what you're doing. Who you are and what you're doing, I'm aware of because of you, Michael, so thanks for that.

We all read about these terrible tragedies that happen. I have three kids who went through high school, in West Carleton high school, which is rural, and that was about 10 to 15 years ago, depending on which one of my daughters you speak of. In a couple of years, it was three kids who took their lives. It was a shocking time in the school. It was just devastating for families and the community, and nobody could quite understand it. It's powerful. So thank you for coming here.

We know we need to do better, and we hear you, and I guess we're the right people to talk to because this committee is dealing with the developmentally disabled and mental health. So thanks very much, Michael, and I look forward to talking more with you. You're a great advocate in our community here, so thank you for all you do.

Mr. Michael Dixon: Thank you. One thing: As a funeral director for over 20 years, I've seen this first-hand. I've seen the numbers go up and up and up and the ages go lower and lower and lower.

One thing that I've always remembered and has really got to me is that we talk all the time. We tell our kids that, "When there's a problem, please come and see us as mom and dad." We had a young man who passed away. His family came to our funeral home, and it was in between Christmas and New Year's. He was a popular kid. He played hockey; he was in the music club; he was in theatre; he played baseball—lots of friends. We tell our kids to do the right thing. He did the right thing one day, and he went to his mom and dad and he said, "You know what? I'm just struggling. I'm doing well in school but I'm not happy."

So mom and dad do the right thing by going to their family doctor. They had a meeting with the family doctor and that family doctor did the right thing too and he went and got him an appointment with a professional. But the problem was, that appointment was seven months down the road, with no help in between then and seven months down the road.

Unfortunately, this young man, who probably could have brought a lot to our country, didn't see any way out. I've always remembered that, and I think it speaks to what we're talking about too.

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

Mrs. Christine Elliott: I know we only have time for a short comment, but I'd just like to thank all of you for being here. Janet, despite your terrible loss, thank you for having the courage to come forward and be so involved with such a worthy organization. I think you know I am very familiar—I have met with your founder about it. You know that I'm a big fan. I think it's really important because we've talked about a lack of services for people with developmental disabilities—that's what we've been primarily talking about here, but we know that about 40% of people are also dually diagnosed. We know there's a high incidence of mental health troubles with people with developmental disabilities as well.

We need to build capacity. One way of doing it is through the way that you have promoted, with a number of services being available at no cost to families. I think that's something that we should take a look at implementing into Ontario's plan because, as much as we've implemented policies and procedures for early diagnosis, we also need to be able to follow that through with treatment.

Thank you very much for being here, and we'll look forward to doing whatever we can to promote your program.

Mr. Jeff Moat: Thank you very much.

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

Ms. Cheri DiNovo: Again, just to echo everyone, thank you for your presentation and thank you for your incredible courage in coming forward. Our hearts and our prayers are with you always.

I'm a United Church minister by trade, as well as being a politician, and I've worked with a number of

families over the years who've lost children. I also have seen it first-hand, working with one of my own children trying to get through the system, but with happier results than to end up committing suicide—still alive today and grew up. But it was a struggle, so I'm absolutely in support of what you're doing.

There's another organization of parents in Toronto. I don't know if you've made links with them or they with you. It's called Tragically OHIP. It's a group of parents who got together, came to Queen's Park and did a presentation. I supported them. All of them have had situations with their children, some successful and some not, all with mental health issues. Most of them are parents with some means, so they mortgaged their homes to get the help they needed and sent them out of province, almost invariably to the United States, for help. They were advocating for OHIP coverage for more psychiatrists and more psychologists for children so they didn't have that seven-month wait period that you speak about. I'm just putting that out there as an organization you should make a connection with. They even have mugs and everything. They've got their own huge thing happening in the GTHA.

But anything else we can do to help—and certainly through this committee we will be advocating as well.

The Chair (Mrs. Laura Albanese): And I too want to thank you for bringing this to our attention. Every child and youth deserves support, especially for suicide prevention. To you, Ms. Osborne, I just want to say no mother should have to go through what you went through, and thank you for your courage.

TIPES

CASPA

The Chair (Mrs. Laura Albanese): Now we'll hear from TIPES and CASPA.

Ms. Mitzie Hunter: Madam Chair, while the next presenter is coming, I wanted to just let the committee know that the presenters—not these recent ones from Partners for Mental Health, but the ones before—were from the Tamir foundation. I know that some people were asking. It's the Tamir foundation here in Ottawa.

The Chair (Mrs. Laura Albanese): So is that all clear? Okay.

Good afternoon.

Ms. Deborah Wyatt: Good afternoon.

The Chair (Mrs. Laura Albanese): We're ready for your presentation. Thank you for being here.

Ms. Deborah Wyatt: Thank you for having us.

The Chair (Mrs. Laura Albanese): As you know, you'll have 20 minutes, and if it's shorter than that, then we'll have questions and comments. You may begin.

Ms. Deborah Wyatt: Can you hear me?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Deborah Wyatt: I'm Deborah Wyatt. I'm clinical director and co-founder of TIPES, Thinking in Pictures Educational Services, and this is my twin sister,

Jennifer Wyatt, who is the executive director and co-founder of TIPES.

We also created a not-for-profit called CASPA, which we're going to talk about a little bit later. But first, since most people know us from TIPES, I'm just going to give you a bit of a background about our charitable organization.

TIPES is a charitable organization that caters to children, youth and adults with autism and related or additional exceptionalities. Pretty much our charity was created to support the families in any way we can. We offer multiple programs, respite, IBI therapy, consulting to parents and professionals and social integration. In collaboration with psychologists, we're also able to offer things like ADD-ADH coaching and psychological assessments.

The mission: Really, we have three goals of why we created TIPES. The number one thing was that we felt that it shouldn't really matter what the diagnosis is. As long as we're able to support these families and these children, we will. Often we do find that some children may be given a diagnosis of autism and another exceptionality, and for that reason they may not be eligible for any support from government funding. A second goal was to have the proper number of professionals in the field, because it is still quite a new field. The third goal was to have charitable status, so we could fundraise monies to offset the costs of IBI therapy—which, I'm sure you're aware, there's a long waiting list, so parents are feeling that they need to get into intervention as early as possible so they can better help their child reach their full individual potential.

1640

With that said, I wanted to talk a little bit about our history over the last 11 years. I am grateful, and so is Jen, to be able to have met those three goals, and we do intend on being able to meet that moving forward.

I would like to paint a picture for you, to better understand what it is like to live with a child on the spectrum or with other diagnoses, to understand what the hardships are that these parents are going through right now. There are two routes, which I'm sure you're all familiar with; if you guys are aware, I can skip that part, but—

Ms. Jennifer Wyatt: The DFO and the DSO.

Ms. Deborah Wyatt: The DFO versus the DSO. Would you like me to go through that? Yes? Okay.

So there's the DSO option: When a parent first starts to see that there might be some issues, they describe to us that they will go to their GP, and they will say, "They are not reaching their milestones." Often, doctors will say, "Well, let's wait a little bit longer to see if we can have some progress," and you'll come back in a couple of months. The parents will then come back, and they will end up referred to a psychologist. To get the DSO option and have the government provide that assessment, it's about a year to get that assessment completed, and then they're able to sit on a waiting list to eventually receive treatment, which seems to be about two or three years to be able to get, here in Ottawa.

Once they reach the government-funded agency, they are offered a DSO position first, and then parents can go to their programming and get the IBI. Once they're finished with the IBI, they will transition into a school program, and that's when parents continue to feel that they're having a bit of a battle, because it seems that there aren't enough resources within the school system to support their children. Once that's completed, they find that, with university and for adult life, there is a lack of services and supports to be able to get them into vocational skills programming and whatnot.

Should the child decide to do a DFO option, the parents are having to pay approximately \$1,500 to \$2,500 for a psychological assessment, but the advantage to that is that they then get on the waiting list a little bit sooner. They can start intervention right away and hire a private provider such as TIPES, and then parents are paying out of pocket to enable their children to reach their full individual potential as soon as possible.

By the time they get the call, two to three years later, they often get the option to go to the DSO or the DFO. If parents want to wait for DFO, it seems that they have to wait between six to 18 months to be able to get a direct-funded option. A lot of parents, we find, feel that they just want to stay with the private provider they're at, because their child has already made great gains. With transition, they just feel that they want to continue where they've started, so parents are then forced to wait a little bit longer to get that funding.

Something that we're finding is that they've done so well in the three years that they've been with us while waiting that sometimes they don't get funding at all, because their child has progressed so much. Meanwhile, we've got parents who have almost lost houses trying to afford what's best for them. Although we do do fundraising, with the number of children we have coming in every year, we're not able to offer it for free. The most we can do is offset the cost.

It goes on from there with the government not having enough resources in schools—and then looking for adult life. Many parents say to us now that they don't know what's going to happen when they're no longer here. Who's going to take care of their child?

That kind of paints the picture of what these parents are going through.

Now I'm going to pass it over to Jen, who's going to actually speak about CASPA. CASPA was created, really, to be more of an advocate program, and to help with collaboration. One of the problems that we were finding is that there aren't enough resources, but I think that we need to start working together as professionals in the field, so CASPA was created to focus more on regulating—and to have everybody come together.

She's going to talk more about that within CASPA. That's the document that she has provided to you. She's going to give further details on things that we feel the government could be doing to better the support for these families.

With that, I guess I'll hand it over to you.

Ms. Jennifer Wyatt: Is it possible to get a time check? Because I want to leave time for questions.

The Chair (Mrs. Laura Albanese): We're at almost seven minutes, 6:50.

Ms. Jennifer Wyatt: All right. So I'm going to skip down to what we already know. IBI is the only documented and highly supported treatment option for individuals with autism to potentially catch up to their peers in their learning trajectories. This is very possible. The most recent studies suggest that the highest likelihood of success in IBI, defined as a change in the rate of development, is achieved by using a high-intensity and relatively long duration approach.

Do you have it?

Ms. Deborah Wyatt: Yes, it's page 1 if anybody is looking.

Ms. Jennifer Wyatt: The majority of large population studies recommend two or more years of intense therapy lasting about 30 to 40 hours per week. IBI is most effective when children are younger. Research has shown that the most critical period to provide services is under the age of three and that to achieve significant results above that age requires an increasingly high cost per case.

Problems: Currently, there are long wait-lists that can last anywhere from 18 months to three years to receive services. The high cost of IBI on families makes therapy hard or impossible to access. There is inconsistency between families in terms of funding across the province. The longer wait times mean that the likelihood of the effectiveness of IBI at a lower intensity is reduced.

Currently, there is no governing college or body, so individuals are practising IBI without proper credentials or experience. So now we have people practising who don't really know what they're doing.

Due to financial and geographical constraints, not all families have the ability to shop around and choose the therapy that the parent determines is the best for the child.

The current system penalizes families for providing their kids with privately funded early intervention. The current system penalizes parents for opting for DFO, as there is a provincial cap of \$39 per hour and rules that often require they pay for additional services.

Schools are reluctant to allow IBI service providers into the school to ensure transition, which reduces the chance of the child successfully integrating, and IBI is not currently covered by all private insurance providers in Canada.

So the results: Low-income families are discriminated against because they cannot afford the IBI while they sit on the wait-list. Families with higher incomes are also discriminated against, because they are penalized during the assessment for IBI they can afford. Parents complain that children are being discharged without transparent, non-discriminatory, ethically sound processes being followed and with little recourse aside from complaint mechanisms that lead to the same individuals. Parents complain that some children are being discharged unfairly in efforts to make the wait-list move. Not all children

are being treated in a similar fashion or according to principles of fairness and best practice.

The effectiveness of the government's IBI program is being reduced because best practices, applying intensity and duration, are not being followed, resulting in more money spent. Long-term savings to the government and taxpayers are not being realized at the levels they should be. Again, IBI is not implemented as intensely as it should be for long enough—i.e., children finally get funding, then, with not enough funding, they don't continue the therapy, and then they regress, and then we end up having to pay for them later on as well.

Okay, so if we skip on through, we've come up with some things that we thought might help with these problems. What needs to be done? I'm on page 3.

Ms. Deborah Wyatt: We like to focus on the positive, the answers and solutions, if we can.

Ms. Jennifer Wyatt: Yes.

Create a governing association, a standard supervised by a governing board, which provides licences for all centres. Now, this is something that we have already done, and I'm actually working with Autism Ontario and Toronto to try and collaborate on this approach and get this completed. The association will also be responsible to cap and revise the hourly rate price each service provider can charge. This should prevent, hopefully, inflationary issues with future funding.

The provincial government can directly pay an approved service provider chosen by the families, as an efficient and effective mechanism for guaranteeing that funds are used appropriately. Government can continue to audit the centres if required. I assume that will probably be something you still have to do.

The association will be responsible to audit the centres to ensure they continue to meet the professional standards, and the association, which we're already doing, will also work with insurance companies to try and push for IBI to be covered by group benefits. We did have a very positive conversation with one of the insurance companies, actually. We asked for \$10,000 a year, and they said that if we don't ask for \$25,000, they're not going to talk to us. I'm hoping that's a positive thing.

1650

Most importantly, the money is going to the families.

If you go down to the government savings, I calculated the numbers. These numbers are from the government. Using your current budget, you actually can reach almost every child on that wait-list immediately, rather than having them sit and wait.

I'm going to skip over to the overall results on page 5. The results of doing this would be:

—a minimal to no wait-list;

—accessible to everyone regardless of socio-economic status;

—earlier intervention most likely results in more effective therapy;

—an effective professional program is more readily available due to CASPA;

—everyone receives the same amount of money and time so no one is discriminated against;

—depending on how parents spend the money, home-based therapy or in-centre-based, the money can go quite far;

—families get a real choice of their programming, provided that their choice is licensed;

—CASPA ensures professional standards or professionals and centres;

—all children are discharged through a transparent, ethical standard;

—no pressure for anyone to make the wait-list move;

—everyone is treated the same;

—more children are likely to reach their individual potential and earn the option of attending a regular classroom setting without requiring assistance, thus saving taxpayers money; and

—families receive choice and can make the decision of which program is best for their situation.

Below that, we've got some examples of other provinces within the country that are already using this method. One thing I will highlight in the numbers: When I calculated it, using the 3,100 children who are diagnosed on the list, if you divided that up it would result in about \$53,000 per child per year, right from the get-go. I know that some of you are probably going, "That's not enough for a full IBI program. Some of them can cost upwards of \$70,000." But I think if you can reach the kids early enough, you're also giving parents the option to go to work and possibly kick in the difference, whereas right now, most of our moms have to stay home to take the kid to therapy or wait while they're sitting on a wait-list because there's no one to look after them.

Those were my main points.

Is this going on or off or is it just me?

Ms. Deborah Wyatt: I think you get too close to it.

Ms. Jennifer Wyatt: Oh, okay.

Ms. Deborah Wyatt: Jen and I would both like to just say we're very grateful to all of you for allowing us to come and speak to you today. We think it's wonderful that this committee has been developed because we do think that all of us working together is really going to make a difference for these families, and we both feel if there's anything more we can do for you, we're more than happy to help make this the best it can be for these families.

The Chair (Mrs. Laura Albanese): Okay. We'll start with comments. Mr. MacLaren.

Mr. Jack MacLaren: Thank you. It's great to see you here, Jennifer and Deb. We've gotten to know each other fairly well. You've come to my office to talk about autism, to talk about TIPES and to talk about CASPA. Beyond that, we've had chats with Dr. Sherman, we've been to Queen's Park, and you've met with Christine.

You've put some time into trying to do a better job treating kids with autism and helping the families of Ontario. There are a few roadblocks along the way called "government," "DSO" and things like that, so I'm going to ask you some tough questions here.

We know you do a great job, because the parents tell us. They tell us that the kids whom you treat are doing

better; they're improving. They run into the money problem because you can't do it for free. You do train people, so you obviously have well-trained educators or you wouldn't get the good results that you do. I think I heard you tell me one time, and maybe you could comment on this, that once you get these people trained, you're not, unfortunately, able to pay the higher wages of, say, CHEO, which offers the direct service option. You lose them to CHEO sometimes. Basically you do the hard work of training the people and they basically steal them from you with higher wages. That's one question.

The Chair (Mrs. Laura Albanese): Is that a question or a statement?

Ms. Deborah Wyatt: Is that a problem? You want to know if that's a problem? Yes.

Mr. Jack MacLaren: Go ahead.

Ms. Deborah Wyatt: We've been fortunate. A lot of our staff does stay with us, but we definitely do compete with government agencies who have higher salaries, usually because they have—what's the word I'm looking for?—unions in place.

Mr. Jack MacLaren: Yes.

Ms. Deborah Wyatt: So that is a problem for us, yes.

Mr. Jack MacLaren: At one time, you were telling me how many kids you treat and what your budget is and you were comparing it to CHEO, so I'm going to ask you to give us those numbers, if you would.

Ms. Jennifer Wyatt: We've serviced over 150 families in the last eight years. To give you an exact—I don't really know. Our operating budget has never been more than \$1.5 million and we've serviced all those children. Now, granted, they are not necessarily doing 30 to 40 hours a week, because it's whatever the parents can afford.

The government program: I'm not really sure on the exact numbers of that; you'd have to check. I think they are closer to \$7 million or \$8 million, possibly. I don't know. One of you would probably know this better than me. I'm sorry; I don't know.

Ms. Deborah Wyatt: I think the audit actually has a stat in there on how much more it is to fund the DSO provider, so I think maybe that's the best resource.

Ms. Jennifer Wyatt: I had seen a document that said \$14 million, but I can't tell you specifically what was in that.

Mr. Jack MacLaren: Basically, I recall you telling me you treat more kids better for less. You don't have to answer that.

Ms. Jennifer Wyatt: I was going to say, I don't think we can say that.

Ms. Deborah Wyatt: No, I don't think we would ever say that, plus we offer a different—I mean, we don't really want to be comparing to them, because we've never worked for them; we haven't worked with any of their children. They also offer, I believe, a different form of therapy than what we do, so I don't know if it's really that comparable. But I do know, when you look at the audit, that it is more expensive to fund—it seems that

way—a government-funded agency versus giving the money directly to the parent.

Ms. Jennifer Wyatt: Yes, that's true.

Mr. Jack MacLaren: Okay. Anyway, thank you for all the good work you do. Thank you for coming forth and working on trying to make things better.

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

Ms. Cheri DiNovo: Thank you. Your enthusiasm is catching, so thank you for that. A good note to end on for today.

I was trying to follow along to see where the savings actually were, but it's the direct funding model, number one, and, number two, it's salaries. Is that where you would say, if you looked at the two issues that are different between you and the government?

Ms. Jennifer Wyatt: Yes, and I think some of the savings goes beyond just the provincial level too. I was watching on the news last night that Canada spends about \$51 billion a year on individuals who are on stress leave because of anxiety and what have you. I think this relates to that in that most of my parents are home on stress leave.

Ms. Cheri DiNovo: Oh, yes. I'm not even talking about other costs, but just the direct costs of the IBI treatment that you provide.

Do you know, per hour, what you are paying therapists versus what the DSO therapists, for example, are being paid?

Ms. Deborah Wyatt: I don't know that. I'm not sure.

Ms. Jennifer Wyatt: I know that their—well, actually, I don't even know what their current salaries are. I know that it's obviously more than what we're paying, because people are motivated to go there. They have a union, right? We can't compete with a union.

Interjection.

Ms. Jennifer Wyatt: Yes, I know it's less. It depends on their qualifications, how long they've been with us. Obviously, we do have a chart identifying that. It's usually—I don't know if I should say—

Ms. Deborah Wyatt: It depends on education, their background. We do what we can to support our employees, obviously, because they really are—

Ms. Jennifer Wyatt: Fabulous. They do the work every day.

I can tell you that the most for an instructor-therapist is—I don't even think it's anywhere near \$50,000. I know that they are going there to start above that. I have no idea what they get.

Miss Monique Taylor: One of your recommendations is about regulations, training, and making sure that there is government structure. I think that's a really important piece that I don't believe we've really heard about around this table, of regulating that sector: very important. Benchmarks: How are you determining your benchmarks for success?

Ms. Jennifer Wyatt: Wait. Are you referring to the benchmarks that the DSO has in place or are you talking about—

Miss Monique Taylor: I'm talking about IBI training. How are you determining when they are reaching the

levels that they should be reaching, and discharge? When do you know enough is enough?

Ms. Deborah Wyatt: Every child who comes through our door has a program that is catered to their individual needs. We do have assessments which I know are commonly used among the government-funded agencies as well.

One of the resources we use is called an ABLLS. There's also some other curriculum we'll put in as well called the Carolina Curriculum. There's a psychologist who is involved as well. We also use the testing to make sure that they're progressing correctly. And then, when the ABLLS is pretty much coloured in, that's a good sign that they're ready to transition into school.

The problem we're faced with right now, though, is that a lot of these resources are meant for people who are up to the age of six. They're assuming these things are going to be done, so that when they get into grade 1, they'll be more successful with the transition. But we're finding we get a lot of kids when they're older.

I do think that these programs can be effective. The children that we have received at the age of two are the ones who are into the school system right now. We might support them with a couple of hours of more like tutoring right now, to help them with some of the academic skills, but they might be down to paying for five, six hours a week because they did intervention at 25 to 40 hours a week, starting at the age of two.

Regardless, if they come in at six, we're going to be looking to have all of these goals met before we're going to transition them out, because I feel that if we transition them out too early, we're not doing justice to them or the family, really.

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

Ms. Mitzie Hunter: Yes, Ms. Wong is going to do it.

Ms. Soo Wong: Thank you very much for your presentation and for your passion about this topic. That's really refreshing, as one of our last witnesses.

I'm particularly interested—on page 3, you talked about an outcome-based approach. Am I hearing that if we consider, as a government, adopting what you suggest, it will reduce the wait time?

Ms. Deborah Wyatt: If these figures are correct—

Ms. Jennifer Wyatt: Yes.

Ms. Deborah Wyatt: —which is what we got from the government.

Ms. Soo Wong: Okay. My next question here is, what's your organization's relationship with the local school board? Very clearly, if you start the early intervention, it feeds back to JK/SK. Can you share with us your relationship with the local school board and any activities you're currently working on?

Ms. Jennifer Wyatt: I can probably tell you that as far as the school board goes, it's kind of hard to say. We find it's more that it depends on the school and the principal. There are lots of schools where the principal invites us in, and there are no issues. Then there are other schools where it's almost impossible. We'll request in

September to go in, and it's May before we're sitting around a table.

Ms. Soo Wong: Thank you.

Ms. Deborah Wyatt: But I do want to say that we are very much looking to work with the government agencies.

Ms. Jennifer Wyatt: Yes, absolutely.

Ms. Deborah Wyatt: I don't think you can say one is better than the other. It's just a matter of us all working together.

Ms. Mitzie Hunter: I just wanted to clarify: Do you use IBI treatment?

Ms. Jennifer Wyatt: Yes, we do.

Ms. Mitzie Hunter: Okay. What treatment does the DSO use? You said it was—

Ms. Deborah Wyatt: It is IBI. It's just the model that we use. There are a few out there. I don't know if you've

heard of the Denver-Colorado model; there's the verbal-behaviour model. We personally use direct instruction. It's a model that has been around—I believe it has been the longest—since 40 years ago. One of the psychologists that we happen to work with often, he just believes that you don't recreate it. If it's effective, then we're going to use it. We seem to see really great results with it. In fact, I have yet to see a child not make progress. That's just why we've chosen to go with that model.

Ms. Mitzie Hunter: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation, which concludes also our day here in Ottawa.

For the committee members, I just want to say that we are recessed until Monday, January 20, at 9 a.m. in Toronto. We're adjourned.

The committee adjourned at 1703.

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. John Fraser (Ottawa South L)

Mr. Jack MacLaren (Carleton–Mississippi Mills PC)

Clerk / Greffier

Mr. Trevor Day

Staff / Personnel

Ms. Erica Simmons, research officer,
Research Services

CONTENTS

Friday 17 January 2014

Developmental services strategy	DS-381
Ms. Donna Thomson.....	DS-381
United Families of Eastern Ontario.....	DS-384
Ms. Suzanne Jacobson	
Ms. Jocelyne Brault	
Ms. Amanda Telford	
Fetal Alcohol Spectrum Disorder Group of Ottawa.....	DS-387
Ms. Elspeth Ross	
Ms. Barbara Sabourin	
Multidimensional Assessment of Providers and Systems	DS-390
Ms. H��l��ne Ouellette-Kuntz	
Dr. Virginie Cobigo	
Ms. Joyce Rivington.....	DS-394
Ms. Iman Seifeldin	DS-397
Department of Psychiatry, Queen’s University.....	DS-399
Dr. Bruce McCreary	
Dr. Muhammad Ayub	
Dr. Jessica Jones	
People First of Ontario	DS-403
Mr. Kory Earle	
Ms. Anne Rahming	DS-407
Ontario Residential Care Association	DS-410
Mr. Len Goddard	
Ms. Margo Babe	
Ms. Tina Kokkinos-Marins	
Ottawa-Carleton Association for Persons with Developmental Disabilities.....	DS-413
Mr. David Ferguson	
Mr. Bill Cowie	
Ms. Bonnie Dinning	
Family Alliance Ontario.....	DS-417
Ms. Cindy Mitchell	
Families Matter Co-operative.....	DS-420
Ms. Miriam Fry	
Ms. Nancy Brodie	
Ms. Karin Steiner	DS-422
Ms. Linda Nilson-Rogers	DS-425
Mrs. Cora Nolan.....	DS-427
Hub for Beyond 21 Foundation.....	DS-430
Ms. Jane McLaren	
Ms. Andrea Stadhard.....	DS-433
Partners for Mental Health	DS-436
Mr. Jeff Moat	
Mr. Michael Dixon	
Ms. Janet Osborne	
TIPES; CASPA	DS-439
Ms. Deborah Wyatt	
Ms. Jennifer Wyatt	