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Mercredi 18 décembre 2013

**Select Committee on
Developmental Services**

Developmental services strategy

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

Stratégie de services
aux personnes ayant
une déficience intellectuelle

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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**

Wednesday 18 December 2013

Mercredi 18 décembre 2013

The committee met at 0905 in committee room 1.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Good morning, everyone, and welcome to the Select Committee on Developmental Services. We're meeting again on what we hope will be a sunny winter day in Ontario. Welcome.

MR. JIM IRVING

MS. SUE IRVING

The Chair (Mrs. Laura Albanese): Our first deputants are here, and I would like to welcome you to our committee. Please start your presentation by stating your name clearly for the purposes of Hansard. You will have up to 30 minutes for the presentation. Any time that is not used will be used by the three parties for questions and will be divided equally. You may begin any time.

Mr. Jim Irving: Thank you. My name is Jim Irving, and my wife, Sue Irving, is here with me today. Thank you for this opportunity. If you don't mind, I'll put my glasses on, because I can't—

Ms. Sue Irving: He was too vain. He tried to go with this font, but we can't read it.

Mr. Jim Irving: I tried to put it in a really big font, but obviously not big enough.

We applaud the endeavour and mandate of the Select Committee on Developmental Services and sit before you today to not only support your mandate but to offer four concrete recommendations to apply to your mandate that would be applicable to other families that fall into this adult complex not-necessarily-suited-to-group-home category.

We believe better solutions will so resolve these hopelessly isolated lives, not only for our daughter, Kristy, but can apply to all other developmentally challenged Ontarians and their affected families.

Your select committee's mandate puts focus on six issues, all of which we have experience with over our daughter's 32 years. For these reasons, we feel particularly qualified to address you today.

We've lived through all that is good and all that is bad that has unfortunately become the current situation for families dealing within developmental services as delivered by the government of Ontario today.

Today, we wish to focus on the final three issues you have identified in your committee mandate, these being the need for a range of available and affordable housing options for youth and adults; the respite and support needs of families; and how the government should most appropriately support these needs and provide these opportunities.

Please allow us to share our experiences from our life with Kristy and the extraordinary demands that are placed upon her, her family and the community that wishes the best for her as context for considerations that may be adaptable for many others here in Ontario.

In describing our life and challenges with Kristy, the Ontario population we are describing has unfortunately been dealt the hand of intellectual disability, dually or multiply diagnosed, with associated mental illness and need for highly specialized care due to additional communication and behavioural characteristics. We speak today on all of their behalf while focusing our real-life examples on our daughter.

We're the parents of a 32-year-old multiply diagnosed daughter, Kristy, who was born with Cornelia de Lange syndrome, CdLS; pervasive deficit disorder, PDD; and total deafness. To many people, she just looks pretty normal, kind of short, cute, with tiny hands and feet, yet clearly someone who relies on constant prompting to be able to fully engage with others. She will ask for your birthday as opposed to your name, and check for rings, nail polish etc. But in reality, Kristy, we are told, is one of the most complex cases of multiple disability that any of our support community has dealt with.

While CdLS is genetic and shares many traits with autism disorder, it is not inherited. She has a 36-year-old brother who has three healthy, normal children who we rarely see, even though they live in Toronto, because of the issues and exhausting time restraints that we will elaborate on for you today.

We have lived all of Kristy's life fighting for her rights, begging for appropriate supports and living a very limited lifestyle as we devote ourselves almost entirely to Kristy's unmet needs. Tragically, our son has often accused his mother of only caring about Kristy. We share this private perception as an example of how overwhelmed parents carrying overwhelming responsibilities and risks are seen by extended family members over time. We find ourselves alone.

Our goals for Kristy are unwavering: to help her to become the best that she can be in her community, with limited stigma; and to live, to the best of her ability, a life that all Ontarians expect and demand.

The first category I'll speak to is increasing consideration for coordinated delivery for aging adults. New research on aging CdLS adults is focused on the very challenging behaviours that come with the syndrome: increase in aggression towards others, impulsive outbursts, self-injurious behaviour and repetitive obsessive behaviours, all driven by their huge increase in anxiety and low moods, which develop through time and life experiences. It is very typical that these examples of deterioration come with aging in many, if not all, dual-diagnosis people.

0910

Behavioral characteristics were visible when Kristy was younger, when she required strong educational intervention techniques to learn and to manage herself. She was fortunate, though, to receive one-to-one educational support throughout her school-age years. When she graduated from the E.C. Drury school in Milton in 2001, Kristy was reasonably functioning. She had basic math skills. She could spell and write. She could read and follow directions, and had a huge social appetite to do her favourite things with her favourite people.

As a family, we had prepared for her school transition several years prior to support Kristy to move to a group home in Milton where she would be surrounded by her deaf community. All should have been good for the future.

What happened to her as an adult? After seven years in group home care, Kristy severely diminished for many reasons. Traumatic life events are very long lasting for this class of person. Group life created a cycle of unending anxiety for someone as vulnerable as her. Constant staff turnovers and departures, other clients in crisis, and union chaos and issues meant Kristy and family had little or no control over important aspects of her life. As a result, Kristy started constantly aggressing when approached. She became habitually self-injurious and withdrew from all of her social routines. She was hospitalized frequently for safety reasons. As an example, in 2009, the last fiscal year of her care in the group home, she consumed over \$227,000 in combined MCSS and Ministry of Health funding, which was not inclusive of the previous four months, when Kristy was an in-patient at CAMH to detox her from all psychiatric meds.

After her isolation in a CAMH locked 10-by-8 cell, upon her return to the group home, support workers became afraid of Kristy, so she was left in her room for up to 22 hours per day.

In March 2010, when Kristy was egregiously discharged on only six days' notice with no transition plan, she was no one we knew. She was traumatized. She had lost all access to all of her friends. She no longer had basic daily life skills. She was not eating—worse yet, ruminating up to 10 times per day—not toileting or communicating; she lacked any manner of self-control, as a

caged animal would be. We've often referred to the fact that we're aware that Kristy was willing herself to die at that point.

One solution does not fit all. Our learning is that one solution does not fit all when planned for school-to-adult transition and beyond, as is one of your mandate issues.

Starting in March 2010, we undertook to create a new life for Kristy—person-centered, self-directed, community-based living—but this path is exhausting and has changed us under its impact. We love Kristy and will do anything and everything for her, but it has cost us dearly: our family, our friends, work opportunities and our future financial well-being. Why does it have to be that way?

Our learnings are that a self-directed solution must be flexible in order to safeguard the parents or guardians who are qualified for the pressure of self-directed, individualized community residential support when group home placement is clearly an unrealistic or impossible choice.

Why will a group home setting fail in a certain percentage of adults? Group homes are fine for less vulnerable persons but will surely fail certain types of individuals: those with Kristy's behavioural and emotional complexities. Her gender vulnerability and language are just additional showstoppers. Highly anxious people like Kristy need special support staff who are very specially selected and trained and constantly inspired to manage panic disorder to get the most out of the person that's inside. There is an urgent need for wage levels to be reflective of the quality of care compatible with the vision allowing the best life for our most vulnerable sector.

Kristy's care must be gender-specific to mitigate her sexual abuse vulnerability. We cannot employ a male one-to-one worker unless we are prepared to incur two-to-one expenses so that a female person can be present at the same time. And we need both strength-specific skills and American Sign Language skills to mitigate aggressive outbursts, addressing it cognitively respecting her deafness.

Ms. Sue Irving: I'm going to pick up on the next three points that we want to talk to, which concern the gap that exists for 99% of families who have taken on the initiative of self-directed living and only have partial funding.

Jim has mentioned that since 2010, we have created a vision of what a really good quality of life could be for Kristy, but admit to this committee that because of being partially funded, it does present a significant gap to us in looking down the road to what would be a sustainable, lifelong or what we're referring to here as a legacy solution for her or for us.

Our lives since 2010 are interrupted every day, many times a day typically, and always during her habitual crisis times. To hold together, and by that I mean personally coordinate all aspects of Kristy's personal plan—and by that I mean it could be intermediating for consultants who work with us; it's for staff squabbles; it can be the car breaks down and somebody has to come fix it. It just

runs the gamut of anything you could imagine. We're the owners of this business, and it's quite intrusive.

We are really afraid and do not wish that Kristy's longer-term care becomes a greater burden on the province, the health care system or, heaven help us, that it might lead Kristy, because she's viewed as a behavioural type, somehow at some point into correctional services, as happened to poor Ashley Smith. Her family will never be the same, and it's our job to stand up for people like that to make sure it never happens again.

We're asking and advocating that funding for this self-directed model needs to allow for more coordination of care, collaboration and flexibility. So whether it's considering school needs which change, or health care needs, or certainly as aging adult people move into degenerative disease etc., it has to be adequate, it has to be scalable, it has to be sustainable, portable. It has to be able to be managed well, and it has to have transparency for government so you understand how your dollars are being spent, in order that the quality of care and the vision that we have for Kristy can become a workable solution that we can pass on to any other guardian or, alternately, family members when parents are no longer here to do it.

Again, we always want to stand back and say Kristy is not the only Ontarian with such complex needs. We don't have the actual numbers of people who fall in our category, but I'm sure that you do, and we're trying to keep ourselves grounded today to speak on all their behalf.

As Jim mentioned earlier, many individuals who are as vulnerable and complex as Kristy have additional specialized care requirements which also present, in our case and in many cases, human rights considerations. Deafness for us is just the additional overlay disability which can become the most exhausting challenge. It limits our family support capacity—and you say, “Well, why is that?” Well, there is no deafness in our family. Our family are all very important business people, and they have little time to take in their day to learn sign language. They do rely 100% on Jim and I to translate in all of our family situations, which is sad for us but the truth of the matter.

We ask also that you put yourself in our parental position: when you're always told to bring your interpreting entourage to every meeting; or if you can't get them, which is often the case with the Canadian Hearing Society, you have to be always on to attend yourself so that you can interpret and become the primary communicator during the day, whether it's at a hospital outpatient meeting, a staff meeting. Or many, many, many times when Kristy has had to go in crisis in hospital stays for periods of time, we become the overnight support staff to ensure her safety and to protect her from hurting others in hospital.

I'm sharing this only because—oh, and then constantly on top of that—sorry, I just want to mention I'm always in the hiring mode; always short of staff; always looking for new staff; always having to train them in sign language and then how to adapt that sign language for the

things that she needs to run her daily plan. And then on top of that, recognize that hospitals don't want to offer assessments or in-patient stays because they fully understand the challenge it presents to their staff, with the lack of communication skills.

So to deal effectively with this kind of situation for individuals who have these kinds of specialized care—deafness, specifically—we're saying that coordination of care is critical so that you've got someone who is specially trained by the system, who can navigate the system with knowledge, oversight; they can advocate and overcome the inherent bias that's in the health care system and that's affecting all of the dual diagnosis community as a whole.

I brought along a media binder today and I think it's referred to in your packages, and I'm going to leave it behind. In it, we've collected a number of articles that try to—our experiences reflected in what the media is seeing as well, and the health care system letting down the silent minority is exactly the example of what I'm saying, that they don't want to do assessments etc. on these kinds of individuals, so you're always, always, always pushing on their behalf.

0920

Another article I wanted to point out is—that one of the things, in fighting for her rights in hospital, that we found is the Supreme Court of Canada human rights decision that was tabled in 1997 that entitles anyone like Kristy, who's deaf and who has to be put in the hospital setting, to have full rights to an interpreter. The reason I mention this is because if we're talking about getting it right and looking long term at legacy solutions and funding for people—this is a cost of interpreting that the system is not seeing or doing it today, but it needs to be considered as we go forward and look at her lifelong needs, and we're not here to do it for her.

Christine was asking us how Kristy is doing, and we're saying that she's in a medical crisis right now. It happens when individuals' meds no longer work for them and they have to be changed, and we've got a lot of experience to understand, when people go into crisis, what's going to happen and what pressures the system is going to put on them. The reality is that when Kristy goes into hospital, it is the common occurrence that hospitals will throw neuroleptic or antipsychotic tranquilizing-type meds in excess at these individuals. They are highly sensitive; in many cases, they're allergic. It causes a cycle where the behaviours increase, the self-injury increases; layer on that that if the caregiving in hospitals isn't supportive enough, it isn't communicated in a way that the person can understand it, then the individual just becomes worse in hospital. So our greatest fear is that she ends up in a long-term hospital stay again.

Of course, hospitals don't want to keep her, so they move her out quickly, and when that happens, well, we've got the experience as well of dealing with the situations that we have when she comes home, so we need CCACs and other third-party agencies to help us for physical and home care supports. That in itself, sadly, is

something that tremendously increases our daughter's anxieties and behaviours again, simply because of the random nature by which these people get assigned. They don't always show up on time, their schedules change constantly, and somebody like Kristy, who is very reflective of the autistic community, requires a routine that isn't changed. So the reality of the fact that we're dealing with all of this—we're always in threat, when she's in crisis, that our staff are going to leave us. They come at us with concerns over their liability, so we up our insurance and we continue to look for new care workers and try and hold the good ones together so they're not afraid of Kristy.

Then, sadly, in crisis, the reality is we get more marginalized by our own families. They have biases. They have fears. They don't know how to help. They stay away, from guilt. We find that particularly hard during the holidays and special occasions because their normal traditions in their families trump accommodation to help us or Kristy. So right now, if I'm emotional, it's kind of a tough time of year.

The long and short of it is, for this kind of very vulnerable individual, we're saying, please consider that funding be allowed to include adequate guidance and coordination. Coordination of care delivery is something that we're saying, "I don't need a full-time coordinator in our model but we sure need somebody." It's something that other families could share and benefit from. It will reduce the burden on multiple ministries of government and allow our individuals to be happier and functional, and hopefully it will keep tragic crisis stories out of the media when family sponsors can't sustain or when they pass away.

Our son is terrified of inheriting the exhausting challenges we have lived with since 2010, and the constant chaos of in and out of crisis that goes on when you're always at the well begging for help. We need legacy sustainable funding.

One thing we do know, after having been at this for three-plus years, is in the self-directed model, if it's failing, we're the ones who are looked at as failing. It's the parents. We're the sole owners. We wear the criticisms of our friends and our families, of agencies and consultants. The wear and tear is always on us, and it's huge. So please understand that there is a huge gap that exists when money is given out. It does not allow or include or require that there be a resource to interface between the family and the staff.

My life is constantly hiring, training, programming, scheduling and supporting. Funding for coordination and respite is necessary for the people who are most skilled to implement the vision, but they'll burn out, and the cycle starts again.

We do want to be our best for Kristy while we're here, and to know that what we pass along after we're no longer able to is something that our son isn't going to be terrified to inherit.

Mr. Jim Irving: The mental illness and associated intellectual disabilities of our daughter, Kristy, have be-

come our mental illness. It is assuredly limiting our quality and length of life as well.

Hopefully, so far, we've presented to you that we've become something of experts on life with people with very severe needs and the constant battle to try to find the right resources, the right funding, the right people to help us out.

We wanted to make four concrete recommendations for this select committee for the adult dual-diagnosis solution that we are asking for.

Create a multidisciplinary approach to help design the system for families of aging adults who follow this path. It needs to fully coordinate vision and delivery and funding between ministries, particularly MCSS and the Ministry of Health, and allow for a coordinator-of-care role. This may be shared between families to leverage learnings and to navigate systems more economically, or to access information more simply.

Recognize that for our vulnerable total population to stay mentally well, they and their families must stay well and remain out of hospitals—they and their families. Build into this view what the real cost of hospitalization crisis care adds to their annualized care, and consider that this should apply for roles that keep people out of hospital.

Recognize the total probable cost of care for these vulnerable individuals that already lands across multiple ministries. In fact, recognize that for these vulnerable and complex people, appropriate, predictable, sustainable and scalable funding is actually cost-effective for the government of Ontario at large.

For aging adults, consider the desperate need of families supporting complex adults ages 22 to 50 to have legacy solutions, "legacy" meaning a solution that really speaks to the need for delivery of integrated services access for very specialized care with adequate self-directed funding. Funding considerations should be scalable, flexible, sustainable and portable across the province. It needs to offer transparency to audit and include the need for a specially trained—not family—manager or coordinator role to oversee the quality of care, whether it be physical, mental or degenerative.

Even when agencies with specialization exist—as an example for us, the Bob Rumball Centre for the Deaf—they do not offer complex person-centred community care coordination within their mandate nor see any incentive to take this on. Can the incentives for this type of agency be created to allow them to be seen as a shared resource for many other families struggling alone with deafness or high-intensity behavioural issues that present safety and isolation long-term impacts for family members?

Allow the LHINs to collaborate anywhere within our province for the delivery of solutions in care.

Enable psychiatric centres of excellence with subject matter experts to consult outside their regional restraints to permit access to very specialized care expertise.

Seek out other countries' solutions. An example: How is it that the UK can find a funding formula that has

allowed appropriate funding whereby every vulnerable person is fully supported at the level that that person needs?

Incent creativity and advocacy. Embrace families that can envision and enact collaborative, multi-family solutions. Advocates can forge good change for everyone.

Our last recommendation is that if the final report from this select committee mandate does not, in itself, change things, we recommend the formation of a derived task force that can effect changes from this report. Such a task force should be multidisciplinary and include system and agency participants, and parent/family representation. If additional respite support could be found to remove us from our role today for Kristy of being the CEO, the CNO, the CLO and the caregiver, Sue and Jim Irving would love to offer our time for such a task force initiative.

0930

Ms. Sue Irving: Just in summary, I guess what we're saying is that we've tried to build a model that's based on excellence. I think the province needs some examples of excellence so that families with younger children in similar circumstances can begin to understand the kind of much better person-centred, community-based lifestyle that would support their child in the future as they age.

The system needs to be looking at rewarding creativity and parent-family initiative with dollars to allow you to put plans into action. In return, what the system will get back is it will be able to point to a wide range of models that families may find useful for their particular family situation.

What's common in any family individualized support arrangement is that there will always be a need for what we call a "management board." It's a family network of friends, alliances and business associates who are not part of the system; they are not funded. They hold a vision of the whole plan. They are invaluable resources who oversee the life of that person, and they are not replaced in any way with system resources. So what we're saying is, with the right funding, the paid support dollars from government would be reserved strictly for coordination of care, a support worker and living costs.

We thank you for your time today and the considerations that we hope you will give to some of the opportunities that we've identified.

Just in closing, I mentioned the media binder. Apart from some of the articles that have framed a reference for not just our experience but what we know is the broader experience of others like Kristy out there, I just wanted to say that we tried to take a look at what's the quality of life possible for Kristy with and without adequate supports. I guess what we're saying now is we think we've done a pretty good job. We don't have it right. Our life is still full of uncertainty and unpredictability. It's fraught with community liability. Extended family members withdraw to protect themselves because they see it's challenging, and we live a bit on the razor's edge of coping. It doesn't have to be like that.

Kristy has re-engaged with the community. She may not be entirely stable all the time, but she's a contributor. She works at Meals on Wheels and she works at Unionville Home Society. It's incredible that somebody with such dire needs has the ability to do that, and we strongly advocate that it's their right. We would hope that we can make that even better going forward in the future with her if we have the opportunity to introduce the coordination-of-care role into our own personalized model.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you. We have three minutes divided by the three parties: a minute each. If you want to ask concise questions so we can stay on time.

Ms. Sylvia Jones: Jim and Sue, I'm not going to ask you any questions, because your presentation was excellent. I know that must not have been easy for you, to share some very personal situations, but I hope you understand that everybody here is here because we want to make the system better.

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

Ms. Cheri DiNovo: Thank you for your presentation and thank you for all the energy and effort you've put into this—not only into Kristy's life, but into the issue generally. We're hoping that will bear fruit with this committee, so thank you.

The Bridgepoint CCAC trial you mentioned: What is that trial?

Ms. Sue Irving: It was a trial partnership demonstration that was taken two years ago, I think it was. I think you'll find it in the media binder, actually. Obviously, even families like us that have self-directed funds, when it comes to trying to get home care supports, were always directed to rely on the CCAC. In this case, the point was put out: If families could, in fact, have access to that money and determine and apply it in their own environment in their own way to get the same kind of supports that CCAC does, how would they spend the money? Could it generate more value? I think it ultimately proved that it was highly successful. It was trialled with three different families, and I believe one of the trial individuals was the head of Family Alliance Ontario in 2012.

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

Ms. Soo Wong: Thank you very much. I just want to go on record to say thank you very much for sharing your story with us and thank you for your strength and courage, because it takes a lot, what you do. Your solution is pretty sound.

Just further to my colleague Ms. DiNovo's comment, do you know if Bridgepoint, as a teaching facility, is prepared to write their report so that we could learn some of those best practices? Do you know, from that project that you just mentioned to us?

Ms. Sue Irving: The best person who could answer that is Barb McCormack. She's no longer the head of Family Alliance Ontario. In fact, she has gone back to the UK. But I can certainly communicate with her. I don't

know if there's a vehicle whereby I can get that additional information back to you, if at all possible.

Ms. Soo Wong: I think it would be very helpful for the committee.

I noticed that you mentioned a UK model, so if there's any information from the UK model you could share with us—we're certainly going to ask the researcher to get some information as well.

Ms. Sue Irving: Yes, definitely. One of the documents that is included in the media package is the research that has been done—it's called a special report. It's Behavioural Challenges in Children and Adults with CdLS, and it's really talking broadly to the relationships between CdLS and autism. The individual who is responsible for this report is absolutely the best person worldwide to tell you about how the national system is able to support individuals like this and about the kinds of programs that they're recommending—and they're all community-based. I can also reach out and ask him to communicate directly with this committee, if you would appreciate that.

Ms. Soo Wong: Thank you.

Interjection.

The Chair (Mrs. Laura Albanese): No, sorry, the time is up. I don't have any more time; I apologize.

Thank you for your thorough presentation, and thank you for taking the time to present to our committee.

DOWN SYNDROME ASSOCIATION OF ONTARIO

The Chair (Mrs. Laura Albanese): I would now ask the Down Syndrome Association to come forward. Good morning.

Mr. Paul Bandiera: Good morning. Thank you so much. That was very emotional.

My name is Paul Bandiera. I am the president of the Down Syndrome Association of Ontario. I see that Mr. Day is handing out a package of the presentation I'll walk you through this morning.

Our goal in addressing you today was to let you know that there have been a number of great things started, but we need to work better together to have a better use of our limited resources and create a truly better family experience.

Before we get started on that, though, ladies and gentlemen, I need to inform you that a number of us have fallen into a trap of looking through this issue and lens backwards. So many of us have fallen into this trap because we are concentrated on looking at the child regardless of age, of different abilities, instead of realizing that there are also mainstream peers who need to have the opportunity to grow into the sort of extraordinary, caring young adults like the one shared with you in the story on slide 3. This is called "Change your point of view." I'm not going to read the entire text. It's there for you to take a quick scan through. It's adapted from a book that a mainstream grade 12 student wrote to her friend who had Down syndrome. What's so interesting, as you see on

this, is that that person was saying the person with Down syndrome has changed their life and made them the person that they are, and that they have a place in their heart. For those of you who don't know—and I'm sure most of you do—Down syndrome is a genetic condition that occurs in approximately one in 800 people. It's often called trisomy-21, its proper medical name. There is a wide spectrum of abilities and capabilities in those who have Down syndrome. But it's not the one in 800, as I'm pointing out to you; it's all of us who need to have this interaction. When we create this type of change where the society values all people, there will be more peer-to-peer learning within the standard classroom, with jobs within the community, and more opportunities for people, as we've just heard, to live in those communities.

As former Minister of Education Kathleen Wynne, in a 2009 equity report, wrote, "Our schools need to help students develop into highly skilled, knowledgeable, and caring citizens who can contribute to both a strong economy and a cohesive society."

I'll give you a quick background into the Down Syndrome Association of Ontario. We are a registered charity, and we're composed of the various local Down syndrome associations from across the province, and our board is made up of those members. We participate in various advocacy and awareness opportunities such as the one presented today, and we work with other organizations—PAAC on SEAC.

I must say, ladies and gentlemen, as a parent and not a government person, I've created a new glossary of all the terms that the government of Ontario is using, and it's a growing list. For those who don't know, PAAC on SEAC stands for the Provincial Parent Association Advisory Committee to the Special Education Advisory Committees.

0940

I'll move on to the next slide. What was so interesting when we looked at the focus and mandate for this select committee is how it moves—and you've heard, I know, a number of different people talk to the transition stages. Most of our organizations are centred around the five big transition phases of life, and they match fairly closely to those within your mandate. But I have a question for each of you: Did you feel like a completely different person the day that you turned two, or six, or 18, or 21—

Interjections.

Mr. Paul Bandiera: Sometimes, right?

As parents, we're often given negative feedback: "Your child is functioning at the level of a blank-year-old." Why is it, then, that the government programs are so focused, and each budget is focused, particularly on the actual chronological age of the individual versus their needs? To put a fine point on it, as you've already heard from David Carter-Whitney, a family with a 16-year-old who is currently on a wait-list for service needs to be reassessed and wait-listed on a different list when they turn 18. Clearly, we do not yet have a single family experience within our province.

We've called them silos. My wife, when she read through the presentation, said, "Paul, why aren't you showing a hurdle, and every time they jump over a hurdle, it's actually another government ministry?" That's the two piers that they need to jump over as you go from different things in each area.

What I want to touch on briefly here are the different stages that our families go through as it relates to those transitions, and the different programs and government ministries that they need to go through. Once again, those with different abilities, especially those with Down syndrome, go through a lot of different storytelling again and again and again to tell people essentially the same thing that the government already knew before they were born.

You see, ladies and gentlemen, when you move through the life of a person with Down syndrome, from the very first day they were born—yes, things could change; yes, the family may move out of the province; they may move for different reasons; they may have some other things happen, but we already know what the predictability is of how many people are likely to be born with Down syndrome and what sorts of services they'll need. As you heard a moment ago, we're not saying that one size fits all; there is a broad range. But from a planning perspective—and I've read most of the transcripts of the select committee—you have asked numerous times of the various different ministers and ADMs: "What is the wait-list?" "What are the numbers of people?" By and large, I would say, ladies and gentlemen, I have not read one single answer that says, "We really know." That is not acceptable in today's world.

If we were to take a company approach, we would look at this as the providers of the services to our people and we would quickly look to how efficiently we are managing those needs. Every touch point, every hand-off would represent an opportunity to improve service, reduce cost and improve wait times.

As I stated earlier, there's already some good movement taking place, there's a bunch of great initiatives, and I think this select committee has been formed at the right time to truly link a bunch of our inter-ministerial links. But the whole thing here, ladies and gentlemen, is that we don't need to replicate assessments. We don't need to recreate those stories. We need a better way to have networked providers. There's a handful of organizations that have tried to do this, some more successfully than others, where they've said, "Hey, we'll be the source of that information." But we need to get to—as the Irvings just shared—some form of person-centred, where it's a case file, to have this better family experience.

Very quickly, let's get into a couple of specifics. As I mentioned, with the birth of a child with Down syndrome, we say, "You're in the club," and you're in the club for life. The parents have to absorb an awful lot of reading in the first couple of years, and they need help in creating this road map. The government has a fantastic opportunity here to forecast the demand for some future services, but we need to have more understanding of what that road map needs to contain and the sorts of

things that they need to do in order to access those services.

We continue working with the hospitals and doctors to ensure that new parents, or the ones who have just received a diagnosis of Down syndrome, are presented with fair and balanced information. Very frankly, there's a lot more to do in this area, but time is limited, so we'll continue on some of the other points.

When someone is born with Down syndrome, there is a bunch of intake information that can and should be done once—call it e-health or another program name or whatever other thing. You're not diseased. You're not going to be cured of Down syndrome. You're just a person, a regular Ontarian, who has a few different needs. And, perhaps, this sort of case file could then be started so the information is contained once and you're not repeating it time and time again.

As we move forward to going to school, kids are kids. What was so interesting in the story before us is you heard how one individual had a very positive first few years in school and, in fact, kids are kids, and they're pretty accepting. If we have our children as integrated and included from day one, you get that sort of shift that I showed you on the first slide. You promote home schools—not that it's an option, not that maybe it could be considered, but that it is what should be done, where and if possible.

Parents need help in navigating the acronym soup that I've listed there, but, like all others with some developmental differences, there's a rubber band effect. From those first early years, things go fairly commonly with their peers. But as you stretch out further and further in time, it gets harder and harder to pull that rubber band. This creates the need to have extra supports available in the school.

One of the things that we think could happen with acceptance and inclusion is—have those different professionals from outside the Ministry of Education be able and allowed and, in fact, permitted to come into the school and serve their students while they're in learning mode.

You've heard from Mr. Clarke and Mr. Finlay about assessments and the individual school boards not needing to wait for those be completed. Supports can start very quickly, without having the consultation with parents to have an IEP, we were told. But who's providing those services? How many people are there, and, to the question that you've already asked there, how many are waiting for those services?

When we move to high school, we start to look at some of the changes. Again, you've heard from Grant Clarke about the new PPM 156 on transition. This is truly headed in the right direction.

The question, though, is, from the Ministry of Ed side, what are the next feedback loops that happen? How does the Ministry of Education get information about our people who have gone through the system? Are they being employed? How are they being employed? What are the things that can be done to work better together?

If the primary focus of the Ministry of Ed is the number of students and their range of scores on the EQAO, why do none of our students write the test, or very few? And, then, ladies and gentlemen, you've heard many times already, what is the magic of aging out of high school at age 21? Or not being able to work while building your skills in high school?

If a student is in a co-op program, is there not a potential to leverage that infrastructure in a little bit broader fashion, to have them have some opportunity to continue going to school and learning a skill that might create a job for them in the future?

When you turn 18, a lot of change happens in the government. I'm not so sure that that happens within the household, but different people will want different things.

I've shown you a picture of a few of my friends from the Canadian Down Syndrome Society's web page. We need to find appropriate opportunities for each of them. We need to have the funding programs on evaluation models with program outcomes—was the information that you got from Autism Ontario's Kevin Stoddart. We're supportive of that. That's really what this all comes down to, and we're going to talk a little bit more about that.

As you move to turning 18, the biggest thing for our families—and you've heard lots on this—is the DSO. It's a great idea: one gatekeeper to get you into all of the resources. Unfortunately, they're not always asking the right questions.

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Ladies and gentlemen, I'm not sure if you've heard, but one of the questions that happens in that six-hour assessment—and some parents have said, “It took me about 18 hours to actually get through the DSO process”—is: “Are you willing to give your child into a group home tomorrow if a space became available?” I'm sorry, if you're a parent of a 17-year-old that's about to turn 18 and go through this process, is the answer: “Yes, tomorrow”? Or is the question: “Would you like to have planned for an opportunity to have an independent life for your child, when they're ready, at some point in the future?” That question, ladies and gentlemen, is not being asked.

You don't have a bunch of people—and we'll talk more about that as we move forward—to find out what the needs are. People are telling us of great variation in the system. Information was sent out to tell you that at 16 you had to contact DSO to get on the wait-list. Follow-ups have been scheduled six-plus months out. Some started to wait months for phone calls to be returned.

At one of our recent conferences, someone from an office came and we asked them, “What is the standard service level for each of the nine DSOs?” They couldn't answer that. They said they were all separate. What is the turnaround time that should be there to book an assessment, receive funding, get the interviews etc.?

The requirement to have a psychological assessment for those who have Down syndrome—I think here's another opportunity to save the government some money

and some time and relieve some stress for parents. Six hours is an awful lot of time to have a bunch of information that, by and large, has been recorded numerous times, recounted to yet again a different and in many cases, an outsourced third party to record them again. Then ladies and gentlemen, once you've finished all that, as you know, you do it all over again to get your ODSP. It seems that these questions are coming up repeatedly, and you've heard these a number of times.

I know time is short so I'm going to keep moving.

As you get into being a young adult, your ODSP has climbed. You've seen, perhaps, last Friday, the release of a new paper that came out and that is called the “welfare-ization”—hard word to say—of social assistance. It's really the question here of, do we have the right model in place? For our folks who are looking to have an opportunity to work in the workplace and to find jobs, the salaries and supports that are created with the ODSP, you've already heard, are not enough. This paper from the Metcalf Foundation, by John Stapleton, really clearly shows that there's an awful lot of pressure for us to change that.

Wearing rose-coloured glasses is simply not going to change this problem. It's a difficult one, and the mechanics and math are very simple: If we can find jobs for folks who are there and wanting to work, even if it's 20 hours a week at minimum wage, they contribute \$200 to our overall economy. If they're not working for that 20 hours, they're costing somewhere, a program—where if you said it's a 1-to-4 ratio, perhaps they're costing \$200 to support them for that. We need to work together to find solutions to have them go through.

You've had Training, Colleges and Universities come to speak to you. My question is: Are there plans to allow for the use of RESPs for ongoing training and support for our people with developmental disabilities? Are there opportunities, when you looked and you asked a series of questions on that, for using those funds to get people with developmental disabilities into college? Someone asked about Durham, with only 20 seats available. That's a pittance in the grand scheme of things, and if nine times that, that's only a couple of hundred people in total for the province.

When it's time to leave home, and clearly the Irvings have shared a lot on that, a number of new parent groups have been formed recently to look at housing alternatives because, clearly, as you've heard this morning, again, the model is not working. In fact, years ago, I was told that the wait-list for housing for my daughter was 18 years, so when she was born, “Get her on a wait-list.” That just doesn't make sense, ladies and gentlemen.

If a parent were to ask you today, “Could you tell me where my son or daughter could find a residence, say, five to seven years from now, because they're going to be in their late twenties?”, how would you answer that?

You've already heard from Community Living Toronto about the services partnership table, and Garry Pruden from Community Living Toronto as well. Some of those points that have been raised are very important and good.

I think it really comes to how we are going to solve this. I'll turn to my last slide and give you a few minutes for questions.

The Mars Challenge Briefs—I believe, from talking to the researchers, you've already seen at least one of them, the Residential Support for Adults With Developmental Disability Challenge Brief, and the Youth With Disabilities System Change for Employment and Lifelong Careers Challenge Brief. I was so happy to read both of those briefs but realized very quickly that they further articulated—in fact, did a much better job than I have this morning to help you understand what the scope of those challenges are. What is problematic is that's where that report stops today. We need to find those solutions. I think it's some great work that's being done. It's important to know that we need to have some experimentation and some families work through some different models to try some new things to create that different family experience that we've been talking about.

It's important to grab hold of this timing and create some really positive change. I've listed two other ones here that relate to our federal government, just to make sure that we've got some sort of continuity. But there's a federal issue with the RDSP. I know you've heard from the Attorney General's office about some of the changes that are happening and competency and understanding what people's rights are as far as finance goes. I think that's going to become a critical issue as the new legislation gets looked at again, but there are a couple of things that are being looked at, I know, at the RDSP level as well. Ten years from the last contribution and a shorter life expectancy: Do we really need to keep the funds past the life expectancy of some of our population?

The T2200 is another format that says—once you have Down syndrome, ladies and gentlemen, you have it for life. It's not really something that you need to reapply to on a regular basis.

I'm going to close and allow some time for questions, but Ms. Bobbi Moore told you that it's important for us to realize that in order for a person to be a person, we need to value everyone. Hopefully we're moving towards a few new solutions that get us towards that goal.

Just to do a quick recap, I think there's an opportunity to stop additional assessments when they've already been done; to make sure that we have inclusion from early grades and continue on all the way through into college and university, where that's applicable; to seek out and build a stronger network with the business community and show people that there's real value for our population to create a labour pool that has meaningful things to offer; and to create a single family experience—is going to create a number of needs for new models. Thank you.

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

We have three minutes each for questions. I would start with Ms. DiNovo.

Ms. Cheri DiNovo: Thank you very much for your presentation. In my constituency we have a real success story. I can't see from your poster—it's very small—but I

think it's one of the folk on your posters: Andreas Prinz—

Mr. Paul Bandiera: Yes.

Ms. Cheri DiNovo: —and Marianna, whom I've witnessed because I was their minister all the way through—two individuals with Down syndrome whose parents and community had a circle of support and who were included in all of their community life from the get-go, who are working, are married, live on their own and need very little input from others to assist them in getting by. It truly is a wonderful story. I know we could all benefit from knowing that that's even possible. It would be great to maybe see some other materials on folk like that who have Down syndrome and who are living virtually independent lives.

Mr. Paul Bandiera: Thank you for that. I think one of the things that we need to do more of is to create a sharing of our success stories. Everyone is different and there is a broad range, but most certainly having those success stories is something that we're all working towards.

Ms. Cheri DiNovo: Yes, because that would help, I think, in giving us an idea of what success looks like and not just what lack of success looks like.

Miss Monique Taylor: I don't really have any questions. Thank you for everything that you do, for presenting to us today and taking the time to put this together. It's very valuable information and we appreciate it.

Mr. Paul Bandiera: Thank you.

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

Ms. Mitzie Hunter: I would also like to join my colleagues in thanking you for your presentation, and particularly the positive approach and recommendations and solutions that you've identified.

One of the ones that I certainly noted in your presentation was around earlier exposure to employment by utilizing the co-op avenue and really focusing on that. I thought that was a pretty innovative idea.

Also, can you comment on your experience with transitional employment programs and if you've had any exposure to that?

Mr. Paul Bandiera: I haven't personally, but I have heard a number of parents talk to me in the past.

Thank you for both questions. The first is, we have an infrastructure in place right now through high schools to allow for some co-op work. Perhaps there should be a broadening mandate that asks, can people work for pay and still go to high school? Can they go beyond age 21 to some other cut-off, if I can say that?

When you look at the transitional approach, one of the things we have heard is someone sharing a story that said, "I went to an agency and talked, and they said, 'What is your son interested in?'" "I'm very interested in music." "Great." "What jobs do you have?" "We have night shift janitorial jobs available. We've got lots of those available." He said, "So why did you ask me what it is I was interested in?" That's on the negative side.

I think there are a bunch of folks who have created their own path and have worked through it quite successfully. There is a law firm, for instance, in London where they created a job that didn't exist. They realized the business benefit, with the amount of time their paralegals were coming in, setting up the room, creating an offering of, "Welcome to the firm," and getting people in and getting them seated, looking after some of the other light office duties: distributing mail etc. They created a position for this young lady who has Down syndrome. They didn't do it for charity; they did it because it made them more money.

There's another success where I know of a grocery chain that was honoured with an award for their inclusion of a person who happens to have Down syndrome. Great. I asked someone, "So is that on your corporate intranet site? Does every other store manager know that this is having a positive impact?" The answer was no. Why not?

Ms. Mitzie Hunter: So we need to tell the employer's success story as well. Thank you.

Mr. Paul Bandiera: Thank you for your question.

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

Mrs. Christine Elliott: Thank you so much for your presentation. It was great in so many respects.

I'd like to ask you a lot of questions, but time doesn't permit. Overall, I'd just like to comment that I totally agree with your approach to this: that everyone has abilities and disabilities, and we need to recognize that people are just differently abled and that everyone has a place. I think we start from that point, and that informs all of your other decisions from there.

Secondly, I did have some specific questions, though. One was on some of the school-age points on page 3 of your presentation. One was about promoting home school. Could you just give us a little more information about what you meant by that?

Mr. Paul Bandiera: Sorry, not home-schooling, but your regular catchment area schools—so you went to the school that you would go to if you were a mainline student.

Mrs. Christine Elliott: Oh, okay.

Mr. Paul Bandiera: Sorry; thank you for the clarification.

Mrs. Christine Elliott: The other question I had was about having professionals coming into the school to do PT/OT and speech and language. Would you mean allowing the people who are from the children's treatment centres, for example, to come into the school to continue their work, which stops currently, as you know, once they reach school age?

Mr. Paul Bandiera: Right. So I think it's a broad spectrum of who could be there. That's a great question.

We hear the stories, right? There's not enough speech-language pathologists on the board staff. Parents are driving sometimes large distances to bring their child to speech and language pathologists, private ones that are paid for through their company benefits or out of their own pocket. Well, if that person was allowed to have some time within the school, it would save the parent

from driving all over the place, and I think it would help the teachers understand what the therapy is and what things they're working on, rather than having to go from speech and language therapists to the parent and then the parent back to the teachers. That's why we're suggesting that there may be an opportunity to get some further synergies by conducting some of those. Whether they're board-provided, privately provided or ministry-provided isn't important. I think it's the notion that it creates a more cohesive environment within the school.

Mrs. Christine Elliott: Do I have time for one more, Chair?

The Chair (Mrs. Laura Albanese): Yes, one more.

Mrs. Christine Elliott: Okay. Thank you. My last question was on the post-secondary aspect. I agree with you that we need to have far more places for training in college and perhaps university opportunities, but you were talking about RESPs and their use for post-secondary training or a college or university. Is there currently a prohibition against that? I'm not aware of what the concern is there.

Mr. Paul Bandiera: It depends on what those programs are, because a number of skills training or day programs provided—and you've heard a bunch of the Community Livings: If they're working on specific skills, is that something that we want to have open and say that those skills, while they're not a college or a university—sorry, I wanted to make sure I delineated between the two—if they're not a formal college or university, can they use funding to help get them to build skills to get a job?

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for being here with us today, for your presentation and for sharing your views—very interesting and very positive. It gives us a lot to think about. Thank you.

Mr. Paul Bandiera: Thank you.

Ms. Sylvia Jones: Chair, before our next presenters come forward, can I make a request of the researcher?

The Chair (Mrs. Laura Albanese): Sure.

Ms. Sylvia Jones: I think that there is an issue raised with the RESP. Can we get a breakdown of what does qualify and what does not?

Ms. Erica Simmons: Sure.

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

MS. ALISON GALLEY

The Chair (Mrs. Laura Albanese): We now welcome Alison Galley. I noticed you were in the room and you followed the other presentations, so you know that you will have up to 30 minutes to present. If there is any time left over, that will be divided equally amongst the different parties here.

You may begin any time. Thank you.

Ms. Alison Galley: Good morning, everyone. My name is Alison Galley. I'm the mother of a severely developmentally disabled 20-year-old daughter, and you can see and hear her right now in this room.

I want to begin by thanking this committee for giving me the opportunity to speak about my family's situation. I believe I'm speaking on behalf of a great many families here in Ontario. I can offer two perspectives. The first is from my role as a parent, obviously, and the second is from my role as a special education teacher in the Toronto District School Board for the past 25 years.

I'll start by telling you about my family. We are the Galley family. I am Alison, and my husband is Greg. We've been married for 28 years and have two children, both of whom are here today. Our son, Max, is 21; and daughter, Layla, is 20. Max is in university and works part-time. Layla has a mixed diagnosis of severe autism, seizures, partial deafness, scoliosis and white matter leukodystrophy. She functions at the level of 15 months and requires round-the-clock total care. She's also physically disabled and uses a wheelchair.

I believe we are fortunate to live in Toronto because—and I admit I'm a little biased—the Toronto District School Board provides Layla with the best school placement that she could have anywhere. She attends William J. McCordic public school, a segregated school for developmentally disabled students ages four to 21. She has been there for the past 15 years and is well-loved by all her teachers and support staff. I'm chair of the parent council and have been for 14 years.

Layla's school is well equipped with specialized equipment, and she has access to occupational, physical and speech-language therapists. Her program includes lots of community outings, which she loves, as well as monthly field trips to various attractions throughout our city. Needless to say, Layla loves going to school—but all this will come to an end in June, when she graduates.

We presently receive Passport funding, which replaced the Special Services at Home funding that she received until she was 18. This pays for about six hours of respite care per week and occasional weekend overnight respite care. We also get home care support, through community care access, for after-school care in our home while Greg and I are at work.

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Greg is a graphic arts technician whose Photoshop expertise is sought here and across the border. As I mentioned before, I am a special education teacher of students with communication exceptionalities, particularly autism, and I've been teaching for 25 years. A lot of people think that I was destined to have a child with special needs, and it probably has made me a better teacher, but it certainly hasn't made parenting Layla any easier.

My day begins at 5:15 a.m. and doesn't end until 11 p.m. or later, when I leave Layla's room at night. Greg and I have had pretty much the same lifestyle for the past 20 years, with Layla's needs always coming first. Diapers, dressing, bathing, feeding, laundry, cleaning up endless messes, and behaviour management fill our days, not to mention our full-time work outside of the home. There's little time for much else.

On Saturdays, we get five to six hours of respite care, and that's usually when we clean the house and run errands while Layla is out with her support worker, going to Holland Bloorview for Snoezelen or Variety Village for swimming, going to shopping malls, going to McDonald's, all the things that kids love to do.

On Sundays, she's with us, which means all errands have to include bringing her along, loading her into our wheelchair van. She loves getting out, and she usually enjoys errands, but it doesn't always make for efficient errand completion. She loves getting out into the community and gets quite restless and anxious if she has to spend an entire day at home.

My husband and I are getting older—63 and 54 years—and our daughter's care is getting more and more challenging. She weighs somewhere around 130 pounds and requires lifting and transferring several times a day. Layla is prone to frequent moodiness. You're seeing her on a good day. On bad days, she engages in self-injurious behaviour: hitting her head, pinching her face until it bleeds and biting her hand. At such times, she's inconsolable, wails loudly for long periods, and will lash out at us physically: scratching, kicking, pinching or pulling our hair. It often means a seizure is coming on.

Layla has tonic-clonic seizures which frequently happen at night, so they are difficult to track, and have been referred to as life-threatening by her neurologist. We have a baby monitor beside her bed so we can be alerted if she stirs at night.

She has periods when she loses her appetite for a few days at a time and will not drink, which makes it impossible to administer any medication and puts her at a greater risk for seizures.

Our days and nights are pretty much consumed by caring for our daughter, and we often wonder how much longer we can keep this up.

In the spring of 2012, we registered Layla with DSO, Developmental Services Ontario. We want to ensure that she has a day program in place when she graduates in June and hope that eventually she'll be placed in a group home. We were lucky to get lined up with this registry early because it did not take long for us to be assessed. Now families have to wait 18 months. We met with a very nice assessor who came into our home for two visits and determined that Layla is very vulnerable and requires total support 24 hours a day. She also told us that the potential of securing a subsidized spot in a day program was like winning the lottery—that's what she said—and to expect to pay \$1,500 per month, at least, for a spot in a day program. Layla would certainly be eligible for Passport funding to help pay for this, but being deemed eligible did not guarantee that she would in fact get the funding, because, as we all know, a lot of families are still waiting for that funding.

The most depressing news the assessor gave us was to expect to wait at least 15 years for a residential placement in a group home. Since then, I've attended several DSO information sessions. Each time, this wait time seems to increase, and it is now standing at 20 years.

That's a long time to wait. Greg will be in his 80s by then, and I will be in my mid-70s. We will be part of a growing number of parents—1,450 at last count—over the age of 70 who are still providing primary care to their adult child or family member. This is according to statistics that I found on the Community Living website. Greg will be one of the 17% over the age of 80, but what is most alarming is that 3% of parents in this situation in Ontario are over the age of 90.

My husband and I are deeply committed to caring for our daughter and ensuring that she has the best quality of life possible. We always envisioned that one day she would live in a group home and we would continue to be very involved in her life.

Had she been born in a different generation, she would have been cared for from birth in an institution, at a high cost to taxpayers. These institutions were closed because it was felt that developmentally disabled adults would have more meaningful lives if they were able to live with support in their communities.

What happened to this idea? Yes, they're living in their communities, but often with their exhausted families rather than in supported housing, and, in a lot of cases, sitting at home in front of a TV rather than interacting with their community. There are just not enough group homes or funded day programs to accommodate the needs of the developmentally disabled population, and aging parents are left to care for adult children when they are no longer able to.

Now I would like to offer my insights into how the current education system is meeting the needs of developmentally disabled students. I know from reading past transcripts of these meetings that this topic has been addressed by Community Living, and it was also addressed by our previous speaker very well. But I have to admit that I was somewhat dismayed by Community Living's recommendation that our current education system for special-needs students needs to be reformed.

The term "segregation" seems to have a negative connotation to it, and inclusive education must be the ultimate goal for schools in Ontario. They seem to feel that segregated schools, like the one my daughter attends, and segregated classrooms, like mine, should be eliminated.

Community Living rightfully honours exemplary teachers every year who teach special-needs students in inclusive classrooms. I am proud to tell you that last year's recipient of the award, Jane Dover, is a dear friend of mine, and she's here today. Congratulations, Jane. But I also feel it is time to recognize the dedication, skills and expertise that are demonstrated by many teachers in these segregated schools and classes across our board.

I invite the members of this committee to visit one of these schools. There are several to choose from. Beverley Public School was in the media last week on CBC's Metro Morning, on the radio. Lucy McCormick school is in the west end, McCordic in the east and Park Lane in Bridle Path, to name a few. I know you would be welcome to visit any one of these schools.

If you do go, take note of the spacious hallways and elevators, with lots of room for a wide range of mobility devices. Visit classrooms where you will see students engaging in all kinds of alternative means of communication—using pictures, touch screens, tablets and, of course, their own vocalizations and gestures. Look at the padded crash pads where students like Layla can free themselves from their wheelchairs for a while and have room to stretch, roll, crawl—or sleep, if necessary. Make sure you check out the Snoezelen room, which most of these schools have, thanks to tireless fundraising by administrators, staff and parents. Visit the gym, which has equipment you will never see in a regular school. In fact, even the ordinary equipment is adapted in extraordinary ways, often due to the ingenuity and creativity of the teaching staff. The entire school is adapted to meet the needs of our special-needs children.

Visiting this school or any of these schools will give you the opportunity to see in action some of the most dedicated, committed and caring teachers in this enormous school board.

These schools and classrooms do belong in our city and should never be closed. McCordic has faced this threat before, and so did Beverley, and Lucy McCormick, I believe, as well. I remember that 12 years ago, Greg and I brought Layla downtown to a TDSB board meeting on a Wednesday night. I pleaded, along with other parents, to the trustees and senior staff to keep it from closing. It worked. At that same meeting, it was declared that these schools should be turned into flagship sites for research, instruction and program development—great idea, but I don't think that was followed through. We have seen our daughter thrive, learn and grow throughout her years at McCordic, and know that these years at school will probably be the best years of her life.

1020

So now we're investigating day programs for Layla, because she finishes school in June and will need a place to go come September. According to DSO, fee-for-service is our only option, and they referred us to a list for fee-for-service programs.

Layla's on a wait-list for a funded spot, but it's based on priority status, which is determined by age of caregiver, how long Layla's been out of school and our current family situation. Well, Layla lives at home with two loving parents. We take good care of her, so it's not likely that she will be declared priority status any time soon. I mentioned this to a DSO presenter at a meeting recently, and he replied, with candour, that, basically, caring families like ours are being penalized for being good families, being good parents and taking good care of our children.

At a recent DSO information night, a number of day programs had set up booths, so I was able to do a quick survey to compare costs. The fees ranged from \$1,400 per month to \$4,400 per month for someone who required one-on-one attention. That will be a struggle for us financially, especially when we retire in a few years and are living on a fixed income. Any dreams of Freedom

55—65, 75, for that matter—are unattainable to us. I could opt to keep working, but I'm finding it increasingly more challenging to balance work with the demands of carrying for Layla. It's exhausting for Greg and me.

The prohibitive cost of day programs means that many young adults with developmental disabilities are just staying home with aging parents who are exhausted. An educational assistant at Layla's school told me recently that she runs into former students sometimes in the community and sadly observes considerable regression in their level of functioning, which she attributes to lack of programming since leaving school, staying at home, sitting in front of a TV, maybe playing video games if you're able, but that's about it. That's what fills their days.

So far, we've visited two day programs. The first was located in a community centre, a great location, a vibrant neighbourhood with compassionate staff, but they had to share the space with two other parks and rec programs, so it kind of lacked a feeling of ownership and permanence. There was not really any room for Layla to be out of her chair, which is important to her, and the elevator was very small and awkward.

The second program was housed in a warehouse in an industrial area of Scarborough—not a strong community feel about this location, no parks or amenities within walking distance. There was lots happening inside this warehouse, though, and Layla's attention was immediately engaged by the lively music that was playing. I was impressed by the staff there, too, particularly by how they were able to create a stimulating program with minimal resources and meet a wide range of ability levels and interests.

There are other programs on the list, but reports from other parents described cramped conditions and a lack of cleanliness, so they were not worth investigating.

Day programs have not been subjected to government inspections until very recently, so perhaps this intervention will lead to improvements in the future. I hope so. We haven't seen any programs run by Toronto Community Living, and perhaps they're better, but they are all funded programs. We've already been told it's unlikely that Layla's name will come up for a funded vacancy, so there's not much point in looking into them.

These day programs are in stark contrast to what Layla is accustomed to at school. "Bare bones" is how I would describe them. Gone are the resources, adapted equipment, assistive technology and floor space that are so evident in the school setting. The staff are hard-working and compassionate, but not well compensated, so turnover is common.

One program director I spoke to dreams of someday moving the program to a different location, near a park and amenities to walk to. But she expressed this desire wistfully, as though it was only a pipe dream. It shouldn't be a pipe dream. Day programs are referred to as community support programs, so they should be located in real, vibrant neighbourhoods, where the participants can engage with other members of the community while

shopping, going to the park, library, coffee shop—anywhere. They should also be adequately funded so they can afford the kinds of resources and equipment that are essential for the well-being of the participants. There shouldn't be such a stark contrast between Layla's school and her future day program.

For the past two years, I've been participating in a research project being done by Queen's University to investigate the experiences of parents as they transition their developmentally disabled children into adult service. It's called MAPS. I'll end my presentation with the statement that I usually select from a given list to describe our present situation, during my phone conversations with the research assistant: We have to work extremely hard every moment of the day to avoid having a crisis, but we are not in crisis at the moment.

Thank you for allowing me to present to you today.

The Chair (Mrs. Laura Albanese): Thank you for sharing so much with us. We have three minutes for each party. I believe it's the Liberal Party's turn.

Ms. Mitzie Hunter: Thank you so much for sharing and for bringing Layla to be with us this morning. I found it interesting that you talk about the needs of the individual. Segregated schools are customized for a range of needs; as well, for the integrated schools, we heard earlier that there is also benefit.

Talk a little bit about the transition forward for you. Right now, both of you work. As you're thinking about the constraints in the system and planning ahead for the future—and you started earlier; I believe you said that—in terms of getting assessments done and really lining things up.

Ms. Alison Galley: That's interesting, because actually, we kind of bridged that period when DSO was just introduced. So when Layla was 17, we actually had a meeting with someone from Community Living, who came to our home and did a lengthy assessment. I totally relate to that last speaker about having to tell our story over and over again.

At that time, the news she gave us was not so grim. She told us that we would probably be eligible for funding of up to \$24,000 a year, which would nicely pay for a funded day program, or she'd be eligible for a funded spot. It just left me feeling so much more positive. But because that assessment was not done before a certain cut-off date, we had to redo the whole thing. As soon as I found out about that, I got on the phone right away. This was within a month or so of DSO being started. They got back to me right away; an assessor came within 10 days. We were really fortunate; I feel badly for families that have to wait so long. Because while you're waiting—our lives are just in limbo all the time. It's really hard not to dwell on our worries as we fall asleep at night. It's hard to get a good night's sleep.

Ms. Mitzie Hunter: So your experience professionally has also helped to navigate, it seems.

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Ms. Alison Galley: Yes, it did. In fact, it did from day one with Layla. We found, in our experience, that there's

no one along this journey of raising a special-needs child. There's not enough information being shared. It's a very find-out-on-your-own system, the way it was 20 years ago.

Layla's disability wasn't evident at birth, but I did bring it to the attention of the doctor pretty early on at their checkups. I mentioned it at six months; I mentioned it at four months—she was extremely colicky, and then at six months, she became very placid and was happy to play with a toy for an hour and a half. I brought that up because I knew from my special ed background, this was not normal. But my doctor told me, "Well, just be happy that she's an easy baby because you've got another baby to take care of too." They're very close in age. Anyway, it was the same thing for—"Well," he said, "We could refer you to a pediatrician," and the pediatrician said, "Well, we could refer you to a developmental neurologist. Would you like to go that route?" "Yes, we would," and we did.

But just finding out about CCAC and home care—we didn't start that until she was about nine or 10 because we didn't know that that was available to us. No one told us. We were searching for some kind of daycare program, but nobody would take her. So that was our experience, and that's just not right. I know I had the advantage of having knowledge of places like Surrey Place, so I could say to my pediatrician, "What about Surrey Place?" "Oh, I don't know too much about them, but we can give them a call," and then they started coming into my home once a week. It was great, because I had someone to talk to, and they had recommendations for us.

It just shouldn't be that crazy process. I hope it's improved. In my role as an educator, I give parents a wealth of information, and I keep repeating it because you're not always ready to hear information when it's given to you. So that's what I do.

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

Ms. Sylvia Jones: Thank you, Alison—a very thorough presentation. I have a number of questions, but your comment about the fact that you and Greg have been such strong advocates and support for Layla has now put you at a disadvantage as you transition into that magic 21 very much resonates with me, and I see it in my own community—I'm sure we all do. I'm not sure if you were here for the first presentation, but there was an enthusiasm and encouragement for the coordinator/navigator role. Using your own example, do you see that that would have been an assistance to you and your family?

Ms. Alison Galley: Absolutely.

Ms. Sylvia Jones: Thank you. I am not as familiar with segregated schools just by virtue of the communities that I represent. Has Layla been in McCormack—

Ms. Alison Galley: McCormick.

Ms. Sylvia Jones: McCormick, sorry—her entire education career or—

Ms. Alison Galley: She started when she was just turning five, so around the SK age. We did try an inte-

grated setting. She was in an integrated daycare for two years. At first, it was okay. She had a wonderful resource teacher. Then that teacher left and she had a not-so-wonderful resource teacher. Her walker would be folded up within five minutes of me leaving. They weren't accommodating her needs whatsoever. When I picked her up at the end of the day, she would just be lying on the floor—nothing, no engagement whatsoever.

Ms. Sylvia Jones: No programming.

Ms. Alison Galley: It got to the point where, as I brought her nearer to the daycare, she would begin to cry. So when we started McCordic, it was like manna from heaven. We began to see progress in Layla that we never thought possible.

Ms. Sylvia Jones: Was that a joint decision you made with your education professionals, principals, whatever?

Ms. Alison Galley: I knew who to talk to.

Ms. Sylvia Jones: That's the advocacy component, right? You have a huge advantage over some families who don't have that.

Ms. Alison Galley: I know.

Ms. Sylvia Jones: Was it a joint decision point to say, "We would like to look at some segregated schools" or "We are familiar with the programming that is happening at McCordic, so can we go that route?" Was that part of your role as a parent advocate?

Ms. Alison Galley: Absolutely. I had heard about the school, so I was very interested. But it was difficult going into that school for the first time. It is quite shocking to see the needs of those children and how handicapped they are.

When your child is four or five years old, they don't present as being as handicapped; they don't look as handicapped. As you head into the teenage years, it's very evident—and I shouldn't be using that word, "handicapped"—I'm sorry—but back when she started at that school, that was the term they called it, "developmental handicap," and I've gone back in years now.

So it was hard, but still, I could see right away that this was the best environment for her.

Ms. Sylvia Jones: But it was a joint decision. It wasn't, "We do not want to try to integrate Layla any further, so we're going to give you this or nothing."

Ms. Alison Galley: Yes.

Ms. Sylvia Jones: Okay. Thank you very much.

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

Miss Monique Taylor: Thank you so much for your presentation today and for being here. I also don't know a lot about segregated schools. I don't believe I have any in the Hamilton area, so I'm curious about that. They're within the regular school boards, right?

Ms. Alison Galley: Yes, they are, and there are several. There are some that are located in wings in regular schools. That's a great model, but we all know that the TDSB is cash-strapped. That would cost a huge amount of money if you were going to change the model.

The segregated school, as I mentioned, has a specially adapted playground for these students. It has a Snoezelen

room. It has spacious hallways. It's the perfect environment, and they stay there for their entire school career. It's like a family feeling—

Miss Monique Taylor: So they stay right through grade school, right through high school.

Ms. Alison Galley: Certainly, I have seen some students who were performing at a level where they were moved out of that school, but that rarely happens. These children, these students are really at the bottom of the developmental ladder.

Miss Monique Taylor: Are they integrated into the community through that school also?

Ms. Alison Galley: Do you know what they do? They bring other schools into their school, and it's wonderful. They have a program called Beatty Buddies with Earl Beatty Public School at Layla's school. They have their students come in and help them learn folk dancing. Try to imagine what folk dancing looks like for wheelchair students. But it's a real highlight of Layla's year. They have them come in for concerts, school plays, and they have them come in on a weekly basis as well.

It's not like they're hiding them away, it's not like they're invisible; they're very visible in the community—

Miss Monique Taylor: They're part of the community still.

Ms. Alison Galley: —and if you live in that community, you're used to seeing them. I know there's a shopping mall close by, and when I go there with Layla on the weekends, people who I've never met before will greet her. So they are very much a part of the community.

But I think that—and this is part of my argument for maintaining segregated programs, not just schools, but classrooms like the one I teach: Every child needs to feel safe, comfortable, valued and that they really belong. In order to offer this, we need to have a wide range of programming for these students. It's not a one-size-fits-all.

Miss Monique Taylor: Thank you.

The Chair (Mrs. Laura Albanese): Very briefly.

Ms. Cheri DiNovo: Yes, just very briefly, Lucy McCormick school is in my riding—a wonderful institution. I've known many parents who have had their children there, and they are part of the community in many, many ways. I just wanted to put that on the record and say that not just for Lucy McCormick and its students, but for the entire area it's been a success.

Ms. Alison Galley: Now, I don't know if any of you will recall, but around that time I referred to, 12 years ago, Beverley School, which is located not far from here, was also threatened with closure. Ian Brown from the Globe and Mail did a two-page spread in the weekend paper. If you can get a hold of that—I have a copy of it; I should have brought it here today—it really beautifully describes what goes on in these schools.

I also recommend that you read his book *The Boy in the Moon*, if you haven't already, because I so related to pretty much every passage in that book.

Thank you so much for allowing me to present today.

The Chair (Mrs. Laura Albanese): And thank you to the Galley family for presenting to us today and for all being here. Thanks.

The next presenters—

Ms. Sylvia Jones: I have another request.

The Chair (Mrs. Laura Albanese): Sorry—Lights advisory board? The Lights advisory board is the next presenter. If you could please come up and start to make yourselves comfortable.

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Ms. Sylvia Jones: Chair, while they are situating themselves—because there are a number of us who are not familiar with the segregated school model, perhaps it would be worthwhile to find out from the various school boards across the province where there are segregated schools.

The Chair (Mrs. Laura Albanese): Yes, that's a very good idea. Also, I was conversing with our researcher about finding that article that was just mentioned.

Ms. Sylvia Jones: Ian Brown.

The Chair (Mrs. Laura Albanese): Okay.

Mr. Bas Balkissoon: Chair?

Ms. Soo Wong: Chair, we have a question about that suggestion.

The Chair (Mrs. Laura Albanese): Sure.

Ms. Soo Wong: I'll let Mr. Balkissoon speak first.

Mr. Bas Balkissoon: I'm just wondering if it would be worthwhile if research told us where they are, so we as a committee could make a tour, because I've visited those schools.

The other thing is, I'm wondering if we could also put it on our agenda that we should actually go out to DSO and see how they function.

The Chair (Mrs. Laura Albanese): Yes?

Ms. Soo Wong: Madam Chair, before we go on, with regard to Ms. Jones's suggestion, can we also ask for a breakdown from the school board in terms of the funding through SEAC, because those are dedicated dollars, and these segregated schools—how many dollars and cents? There's one education component, and there's a health care component. I remember, on the school board, the challenge of meeting those needs, and I want to see that funding piece clearly shared with the committee.

Ms. Erica Simmons: What is SEAC?

Ms. Soo Wong: SEAC is the special advisory committee that's mandated by the province. It's compulsory, and the funding for that committee and for that budgetary line must be protected. There's no deviation; if they don't spend it, they have to return it to the province.

The Chair (Mrs. Laura Albanese): Do we want to have a conversation after about perhaps visiting a DSO?

Interjection.

The Chair (Mrs. Laura Albanese): Okay, thank you.

LIGHTS

The Chair (Mrs. Laura Albanese): Welcome to our committee. You may begin your presentation at any time. Please begin by stating your names and your titles. You

will have up to 30 minutes for the presentation. If there is any time left over, that will be divided equally for questions. Thank you.

Ms. Mary Pat Armstrong: My name is Mary Pat Armstrong, and I'm the founder of Lights and the chair of the advisory board. Thank you for this opportunity to speak about Lights. I will briefly outline the scope of the model, and Donald Hale, who is a Lights parent, will talk about how Lights has helped his family, including his son Matthew. Garry Pruden, the CEO of Community Living Toronto, will tell you why his agency partnered with Lights.

To begin, 12 years ago, my husband and I helped our daughter Jenny move into her own home with two housemates and a caregiver. We have watched her thrive, making more and more decisions independently and enjoying her rightful place in her community. How good a feeling is that for a parent?

Lights was founded on the belief that each parent has the right to personal freedom, independence and a caring environment—a lot like what the mom who preceded us was just saying. Each family has the right to make their own decisions. As individuals and families make their own decisions, they feel empowered and accepted for whom they are.

I want to just briefly outline the key elements of the model for Lights. I'm sure there will be more questions about it later, but I'll just outline the key elements. Lights helps families and individuals explore creative and individualized small-group living arrangements. It helps them develop a plan, a person-directed plan, that focuses on their own dreams and their own needs, so it's a very personalized, individualized model. It helps them access websites, such as connectability.ca, that will support them. It helps them develop the resources they will need to support their new living arrangement. It helps them navigate system forms and applications. It helps them analyze their personal finances and other resources—and this is extremely important, because as they make their personal budget for their son or daughter, they have to keep in mind that they have to pay for part of that budget. So it's a very realistic budget. It helps them network with other families who have a common vision, so they can find housemates and ongoing support. And it helps them be ready for the Ministry of Community and Social Services residential funding.

Let me outline a little bit the finances behind Lights. Lights covers up to \$20,000 of each individual's annual budget for up to five years. It is our hope that a family will, after five years, have government support or have found other means of stabilizing financially, but we won't walk away from these families. These start-up funds come from the fundraising that our board does. The family covers at least 20% of their son's or daughter's annual budget, and the government pays the salary of our one staff member. If we divide that dollar figure—that is, our one staff's annual salary—by the number of clients living independently with Lights support, it's costing the government less than \$3,000 annually for each individ-

ual. Obviously, this number will decrease as the number of Lights clients increases.

Lights is also founded on the belief that to solve today's crises of the intellectually disabled, partnerships are needed. We have four very important partners: the families who help plan and fund their son's or daughter's home; philanthropists who have thus far given us \$4 million to cover our existing clients over the next five years—but fundraising at this pace will be hard to maintain going forward. Initial excitement is hard to hold in a social environment of donor fatigue, such as we have today.

We could not do without our third partner, Community Living Toronto. They have supported and advised us along every step of the way. They give us an office, they've done our website and our brochure, they give us fundraising backup support and public relations and marketing backup support. And you, the government, are our fourth partner. You are paying the salary of our one staff member. But she's now asking for help because she has 88 other families at various stages along the Lights journey.

So in summary, Lights has assisted, thus far, 24 individuals in finding a home outside the family home. Of these 24 individuals, five did not access Lights funding because they had residential funding from other sources. They used Lights for planning and networking.

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Of these same 24 individuals, three have moved on due to receiving individualized residential models funding, and one individual has moved into a supported independent living arrangement.

As a result of our success, we strongly urge the government to continue to partner with existing groups such as Lights and to expand upon these partnerships. We also urge the government to help other communities in Ontario to start a Lights program or other alternative solution that helps people achieve independent living. Lights is considering running workshops to do this.

Lastly, we urge the government to consider spreading the cost of supporting the intellectually disabled among the wider community.

At this point, I'd like to ask Donald Hale to tell you his personal story.

Mr. Donald Hale: Thank you very much. My name is Donald Hale. My son Matthew Hale is an individual who is living in a Lights-funded living arrangement with two other developmentally handicapped people. He was born on November 9, 1987. Much to the delight of his parents, Matthew was healthy and met all of his developmental milestones until he reached the age of 18 months. At that time, for some undiagnosed reason, Matthew developed a seizure disorder and his development began to regress. Later, with the assistance of a neurologist and the Macaulay Child Development Centre, it became obvious that Matthew had developed mental difficulties that would seriously impair his ability to learn and to function in the world.

He began school in the developmentally handicapped stream, first at Clinton Street public school and then at Bloordale Middle School and Burnhamthorpe Collegiate in Etobicoke, where we were living at the time, and then, finally, at Maplewood High School in Scarborough.

When Matthew was only nine, his mom was diagnosed with a very rare autoimmune disease called scleroderma, which ultimately led to her death from cancer in 2001. I've had some serious health issues of my own, including a couple of recent bouts of kidney and advanced prostate cancer, both of which were resolved by surgeries in 2009. I continue to receive treatment for these things at the present time. Both of our extended families live in Windsor. Unfortunately, they're not really able to help out or to come to our assistance at all with Matthew's care.

Since completing his education in 2008, Matthew attends a really terrific day program that's operated by an organization called Pegasus Community Project. It operates out of the Toronto parks and recreation community centre. The program is specifically designed for developmentally handicapped young adults, and costs about \$1,550 a month. I went to their holiday seasonal party yesterday, and it was a lot of fun. There was lots of excitement, singing and it was really a pleasure to see everyone that I hear about all the time.

Matthew receives funding from the Ministry of Community and Social Services Passport program to cover the cost of his day program and his transportation to and from that each weekday. But that funding only covers that cost for the day program and the transportation.

Matthew is now 26 years old and has the life skills and abilities you would expect to see in a three- or four-year-old. He remains very impulsive and requires strict supervision when he's in the community to ensure his safety. His behaviour is unpredictable and, while very much improved, it remains a great concern to those who care for him. Matthew's life centres around a series of routines which rarely vary. His world and that of those around him is constrained by the needs and demands that Matthew's condition requires. For example, Matthew talks endlessly about the same subjects: the origin of household things and clothing and the state of his mug collection. He's interested in cooking, but he doesn't really have cooking skills and isn't really capable of handling things like knives or cooking on a stove. But he's a big fan of the Food Channel and he likes watching cooking shows on TV.

He's also very interested in the TTC. Every Saturday and Sunday—nearly every Saturday and Sunday—he and I will spend four or five hours out roaming around the city on buses and streetcars and the subway. You may see us. You may run into us some time.

As you can tell, Matthew is a full-time job, requiring a lot of time, energy and patience, as he must be coaxed and encouraged to undertake nearly every task, especially those relating to his personal care.

When Matthew turned 22 in the fall of 2009, he started a new a period of greater independence, and

began making a life without his dad. A group of parents formed an organization called Scarborough Residential Alternatives that was facilitated by Community Living Toronto Scarborough Regional Council. After many meetings and a few false starts, we successfully created several functioning living arrangements for our loved ones.

In Matthew's case, he is now in a home environment that is safe, stimulating and appropriate for him and for his two roommates. Beginning in 2009, we rented a four-bedroom house in the east end of Toronto from the Toronto Community Housing Corp. We rehabilitated the house and furnished it. We were successful in finding some absolutely terrific staff people to support the roommates in their new endeavour, and Matthew and the two other young men are now living, with the assistance of their caregivers, independent lives in their own home from Sunday night to Friday morning each week. They still return to stay with their parents on weekends.

As you can imagine, all of this was quite emotionally and financially taxing on the parents. The benefits far outweigh any of the drawbacks, however. Our sons are now living more autonomous lives and are making their own choices about basic things that we all take for granted, like what to wear, what interests to pursue and how to spend their spare time. Matthew has matured enormously during this time and is happier and better behaved in his own surroundings than he ever was at home with me.

Beginning in 2011, we were successful in obtaining some financial support from the Lights program to assist in offsetting some of the cost of running the household and, particularly, for paying for the staff that we have.

The Lights program is not, however, designed to act as a permanent funding mechanism to assist parents in creating and maintaining suitable living arrangements for their sons and daughters with developmental disabilities. At some point, our Lights funding, which is currently to the tune of something around \$11,000 per year for a family, will cease, and we will be forced to rely on our own limited resources again.

For the two years that we were operating the house before we obtained our Lights funding, the amount of money that was required to operate the home was just ruinous, and it was impossible for us to continue without having the funding assistance from Lights.

The start-up and ongoing costs of creating a home such as this is enormous. We, as parents, have essentially built the foundation and made it work for the past four and a half years. Our sons' continued success and personal growth depends on having their home continuing to operate past the time that Lights funding will be available to us.

We urge this committee to examine closely the existing ministry programs, which are designed to assist families in creating their own residential alternative arrangements for their developmentally disabled young adults. Such programs appear to be available, things such as the

innovative housing initiatives and so on, but—and this is a very important “but”—they’re not presently funded.

What is needed is funding, actual dollars, in these programs to support parents in developing and maintaining appropriate and self-managed living arrangements for their grown children with developmental disabilities. By making better use of these kinds of arrangements, the ministry can reduce the wait-lists now in place for residential supports without incurring the kind of expense required if they are directly and completely ministry-funded.

Thank you for the opportunity to speak with you today. I’m pleased to answer any of your questions.

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

Ms. Mary Pat Armstrong: Now I would like Garry Pruden to speak.

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

Mr. Garry Pruden: I’ll be very fast.

The Chair (Mrs. Laura Albanese): Sure, go ahead.

Mr. Garry Pruden: Over our 65-year history, Community Living Toronto has been instrumental in developing community-based opportunities for people with intellectual disabilities. With the goal of expanding needed community capacity for residential support, we partnered with Mary Pat to create Lights in June 2009. There was a clear and compelling rationale for this investment:

(1) Wait-lists were oppressive. As you have heard, over 2,600 people are waiting for some form of residential supports in Toronto alone. Before the advent of the DSO, we were the lead agency for 1,100 of those individuals and families. Just waiting for service was no longer tolerable for an increasing number of those families—as you have heard from Donald—and they were looking for support in creating options for their family members.

(2) Innovative alternatives to traditional services were needed. With more people on the residential wait-list than currently receiving services in Toronto, an investment in new models of support was critical to help bridge the gap and ensure sustainability.

(3) Partnerships help build capacity. Lights is premised on creating partnerships with families—as you’ve heard—established agencies, government and philanthropists to open new doors for models of support. Families gain insight as to what might be possible and the strength and confidence to start their journey, which will better prepare them to take advantage of the future funding opportunities for which they so anxiously await.

As you’ve heard today, our investment has produced tremendous dividends. This is the kind of investment in inciting innovation and building capacity that our government needs to be making. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for illustrating this really innovative model.

We have three minutes for each party for questions. We’ll go to Ms. Jones.

Ms. Sylvia Jones: Sorry, my colleague is trying to educate me. So I’ll let you educate me.

Did I hear that correctly, Donald, when you mentioned that the Lights program seems to be different from the traditional group homes of three or four in that—is Matthew going home on the weekends? Did I catch that right?

Mr. Donald Hale: Yes, he does.

Ms. Sylvia Jones: Okay. And why did you make that differential?

Mr. Donald Hale: We would have been very happy to have a seven-day-a-week model. It’s just financially untenable. It’s very difficult to pay for that staff. The staff time that would have been required would have just made it too expensive, so we decided to scale back to five days a week. At some point in time, we’d certainly love to have a seven-day-a-week arrangement, and I’m sure Matthew and his roommates would as well, but that’s just not what we can manage right now.

Ms. Sylvia Jones: So it’s really a decision made on available funds as opposed to, “This is the model that we wanted, as a family, for Matthew.”

Mr. Donald Hale: No, not at all. We would have preferred to have a seven-day model, and we probably will at some point, if the dollars are in place.

Ms. Sylvia Jones: Okay. Thank you.

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

Mrs. Christine Elliott: Thank you very much—

Ms. Mary Pat Armstrong: Can I just add to that? Every family is different. Some families have seven days.

Mrs. Christine Elliott: I’d just like to thank you very much for coming and making a presentation today. I have had the opportunity to discuss Lights with Mary Pat before, and given the length of the wait-lists that we’ve been hearing about for housing, I think it’s important for us to hear about innovative solutions, and creating partnerships I think is key. Thank you very much. You’ve given us a lot to think about.

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

Ms. Cheri DiNovo: Thank you very much for this and for your efforts. It sounds like an amazing program.

What happens after the five years of the start-up funding? We’ve heard about the enormous lists for MCSS residential funding that seem daunting. The concern, obviously, is that somebody is in this wonderful situation and five years in, the funding doesn’t come through and they have to move out, which would be tragic.

Ms. Mary Pat Armstrong: As I said before, we will never put our families out on the street. All it would mean is that we perhaps couldn’t take any more new families at that point in time. We are fundraising as hard as we can, but we hope, along the way, there will be more financial support to us from the government as well, to support what we are doing. But we will always continue to fund-raise.

Ms. Cheri DiNovo: We had heard from one of the other families about the cost of residential care, which wasn’t for them the particularly wonderful option, being over \$200,000 a year. I’m wondering if you have comparables. I mean, you’re providing something and the

cost is—maybe Community Living can answer that, what the comparable cost would be both to the government and to the families for residential care, paid for completely through MCSS.

Mr. Garry Pruden: There's a wide range of supports that are required across the spectrum and for different individuals in the community. We have those services as well. There isn't one solution to this problem; there needs to be a broad range of innovations and services made available.

Ms. Cheri DiNovo: Of course. But they had quoted over \$200,000 a year for individuals, so it would be interesting to know what the—

Ms. Mary Pat Armstrong: That family probably would not be able to be supported by Lights. We couldn't afford to support them. Really, Lights is a model that will probably never be able to help families who have a huge annual budget of expense and very high needs, unless they can put more into their own budget. But what I believe Lights is doing is removing from that wait-list families who have a more moderate budget, who we can help so that the government can divide their money more appropriately amongst those other families.

Miss Monique Taylor: I know I'm going to run out of time. How many homes does Lights actually have?

Ms. Mary Pat Armstrong: Lights doesn't own any homes.

Miss Monique Taylor: No, but within the—

Ms. Mary Pat Armstrong: But of the 24 individuals who are living independently now, a few live together. I want to say maybe 13 or 15 living arrangements.

Miss Monique Taylor: So you're supporting 15 living arrangements, as in full homes with three or four per home?

Ms. Mary Pat Armstrong: Yes. We support the families individually within those living arrangements.

Miss Monique Taylor: Okay. So a total cost of a home—

Ms. Mary Pat Armstrong: Well, an approximate cost of our families is around \$32,000 annually per person. That would include rent and staffing and food and day programs and everything. Some clients come with a home already and they want the other housemates and people to share that home with them. Some group together and then rent a place, as Donald has done. Every family is different.

Miss Monique Taylor: Okay. I know my Chair is looking at me, so I'm just going to try to ignore her for a half a second and ask—

The Chair (Mrs. Laura Albanese): Last question.

Miss Monique Taylor: The staff person you have in that home—is it one staff person per home, and how is that person found, how is that person trained, and if they're sick, what happens?

Mr. Garry Pruden: This is a self-directed support system, so that we assist families in securing those staff resources. The one staff associated with Lights is a facilitator that helps families do that. That person doesn't provide any direct support in any home.

Ms. Mary Pat Armstrong: Each family drives their own situation, basically.

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

Miss Monique Taylor: Thanks, Chair.

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

Ms. Soo Wong: Thank you very much for your presentation today. I just have one quick question. On your one-sheet handout to the committee, Lights recommended spreading the cost of supporting intellectually disabled more widely. Can you elaborate on that point? What do you mean by spreading the support? I wanted to know more specifically.

Ms. Mary Pat Armstrong: Do you want to talk to that?

Mr. Garry Pruden: I think Mary Pat was referencing the fact that Lights can assist families who have the resources or can marshal resources to provide a support path for their son or daughter. Over time, because those families contribute to it, they learn through that process, in terms of what the actual needs of their sons and daughters are. They might come to understand that the safety net that they believed was necessary for their son or daughter, the capacities that their son or daughter didn't have, they in fact do have. We can, through Lights, really support that individualized and independent living opportunity for people who have more likelihood of independence or moderate needs for support.

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Ms. Soo Wong: With regard to Lights, I want to know, if you have the more complex continuing care—would your agency, working in partnership with Community Living, be able to provide that service?

Mr. Garry Pruden: We do that with individualized residential support already. We do have one individual that we're supporting through Lights in that same way, yes.

Ms. Soo Wong: Thank you. Thank you for everything you do in the community.

The Chair (Mrs. Laura Albanese): Mr. Balkissoon, one question.

Mr. Bas Balkissoon: Yes, just a question to Donald. You said you rented a facility out of Toronto Community Housing. How much of a conversion did you have to do on the interior to accommodate the three—

Mr. Donald Hale: Actually, very little. The house itself had been used as some sort of a drug rehabilitation centre or something, so it had already been sort of carved up into individual rooms. There was a large common area and a very big kitchen. Our residents don't have mobility issues, so we didn't have to worry about building a ramp or anything like that. The bedrooms are upstairs, so obviously that home wouldn't have been appropriate for someone with mobility issues.

Actually, the local city councillor, Paula Fletcher, was really instrumental in helping us get this. She just got on the phone and said, "You find something for these people," and they did, like, instantly. It really did need a lot of work, though; it was pretty run-down.

Mr. Bas Balkissoon: Maybe Pat can expand. So if we had mobility issues, then rental property would really not be available because you'd have to do modification to the interior.

Ms. Mary Pat Armstrong: Possibly. Each family has to find the home situation that would work best for their son or daughter.

I really haven't spoken at all about our one staff facilitator, who works all day, every day of the week, with these families in helping them sort through their issues and find appropriate places for their son or daughter to live. It would be up to Laura to help each family find appropriate housing.

Mr. Bas Balkissoon: Okay. Thank you very much.

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

I will now call the next presenters to come up—

Ms. Sylvia Jones: Chair?

The Chair (Mrs. Laura Albanese): Yes?

Ms. Sylvia Jones: Just a quick point of clarification. Lights is actually not an agency; it is a registered charity, and I'm sure they would love to accept any and all donations.

Ms. Mary Pat Armstrong: It's associated through Community Living Toronto, so, yes, we would love donations.

The Chair (Mrs. Laura Albanese): Last-minute plug.

KERRY'S PLACE AUTISM SERVICES AUTISM ONTARIO

The Chair (Mrs. Laura Albanese): We now welcome Kerry's Place Autism Services and Autism Ontario, who are presenting together. Welcome, and if you could kindly start by stating your name and your title before you begin. You will have up to 30 minutes. That will include questions, if there is any time left over within those 30 minutes for your presentation.

Ms. Tracy Mansell: Thank you. I'm Tracy Mansell from Kerry's Place Autism Services, the largest autism service provider agency in Canada. I'm here today to present on behalf of Kerry's Place Autism Services, along with our co-presenter, Autism Ontario.

I wanted to start out by thanking you for this opportunity, as well as acknowledging our partners with the regional offices through the Ministry of Community and Social Services and the Ministry of Children and Youth Services, who are very valuable partners in the work that we do in the regions across Ontario. I'll let our team introduce themselves, and then we'll move into our presentation.

The Chair (Mrs. Laura Albanese): Please proceed.

Dr. Jo-Ann Reitzel: Hi. I'm Dr. Jo-Ann Reitzel, and I'm a board member with Autism Ontario. I'm also a clinician and researcher at McMaster Children's Hospital and McMaster University. I work in the area of autism spectrum disorders, and what I want to be able to tell you

about today is, first of all, just how amazing the services are that we have in Ontario for children and youth with autism.

Interjection.

Dr. Jo-Ann Reitzel: We're just introducing? Okay.

Ms. Cathy White: Hi there. My name is Cathy White and I'm currently the president of Autism Ontario. I'm also wearing the hat of a recently retired educator. I was coordinator for autism supports and services with the Peel District School Board for several years, so I bring that background as well.

Ms. Gail Jones: I'm Gail Jones. I'm a director of community services at Kerry's Place.

Dr. Jo-Ann Reitzel: Thanks. What I wanted to let you know about is, first of all, the strength of the programs that we have in Ontario for children and youth with autism. The programs that we have are evidence-based. The IBI program and the ABA services are well developed. We have been able to see amazing outcomes for many children from these programs.

But what we do know from research is that we need to move forward. What we need to do is to look at the increasing rates of autism. We know that the rates of autism have been increasing quite a bit. We know that rates are currently estimated at around one in 77 children, and that was a study from 2010. We also know from research that there is a great deal of variability amongst the characteristics of children with autism and that there isn't any one treatment that fits all. What we need to start to develop is a system where we are going to be able to individualize assessments. From individualized assessments, we will build those personalized and individualized treatment programs. These programs will help with children's developmental needs, their learning needs and their mental health needs. They can also help with their family and social situations.

One of the things that I think will help a great deal is a piece that is built into the IBI and ABA programs: the professional training. There is a real strength when we have the capability of training and evaluating staff within our programs and then, through supervision, are able to ensure the quality and integrity of that care that we're giving. Through training, we need to start to build our system, though, where we are collaborating with other services and other forms of intervention; and we need to do this across ministries. Program evaluation of these collaborations is also really important and something that we do currently have in our system of IBI and ABA, but we need to advance this as we build our system of interventions for ASD.

I know that you have heard quite a bit about the great needs of adults with ASD and intellectual disabilities. We also really need to emphasize that that needs to start at a much earlier stage. We need to work at transitions, transitioning children from children's services that are across ministries. These transitions will help to build that bridge from children's services into adult services.

One thing, unfortunately, that I do feel is lacking in Canada and in Ontario is an autism strategy. I feel that if

we could start to build an autism strategy from the programs and the services that we do have, that we would have better standards of care for the assessment and treatment of children and youth with autism.

I'd like to turn it over to Cathy White now.

Ms. Cathy White: Hello. I just want to build on the collaborative theme that Jo-Ann has started. Through my experience of working in the school board and working with many of our families and agencies associated with Autism Ontario—that collective experience has highlighted to me the importance of collaboration with all stakeholders. We need to continue building on the important collaborative work that had been started several years ago with the ASD working group and the Making a Difference report that was out and the 34 recommendations, and to continue building on that work.

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We need the government to aim for a holistic approach that goes across the lifespans and includes all of the stakeholders; using an autism strategy, whether it's national or provincial, that includes supports and services that are collaboratively created, directed, implemented and evaluated by all stakeholders. Some of the stakeholders that this would include would be the individual with ASD; their family; education; community agency service providers; health providers, including those providing supports for those with mental health issues; government; residential; universities and training—it just goes across all areas. We need to continue to break down the silos, as they still do exist.

Some examples of some collaborative approaches or models that have worked were the collaborative service delivery model projects that came out when our Premier was education minister, where there were seven school boards identified around the province that worked on collaborative models with many of those stakeholders. There was the Provincial Advisory Team and regional advisory teams that identified projects and worked together. These stakeholders included the ministry, education, parents, service providers and school board staff. We have the evidence that that approach worked. It made a difference in terms of increasing parent confidence in the system and also provided increased outcomes for the children and youth.

We also have evidence that this works in regional planning tables. I come from the Peel region and there's a Peel planning group there. One of the subcommittees is an ASD Peel group, and I know that Hamilton and some other areas have this as well. For us in Peel, there are members from across four different ministries working together to identify issues within our community and to set projects and goals. Included is health, MCYS representatives, MCSS, parents, Autism Ontario, and we've had some really good outcomes there.

Another last example is Connections for Students. Transitioning students from IBI to full-day school promotes collaboration and people making a transition team across those different stakeholder groups. We have evidence that parents, again, are feeling confident in that

transition and that they feel well-supported because everybody is working together to support their child or youth.

So going forward, I want to encourage you to continue working towards a continuum of supports and services provided throughout the lifespan for individuals and their families with ASD, a continuum that is supported and evaluated by all vested stakeholders, and a collaborative approach that goes a long way to increasing parents' confidence in the system and the ability of the province to meet the needs of individuals with ASD and their families.

Ms. Gail Jones: I'm going to talk a little bit about ABA and IBI. I think most folks know those terms, but ABA is applied behavioural analysis, and it's a scientific, evidence-based approach to understanding and changing behaviour. It is an approach to learning that reinforces positive behaviours and reduces problematic ones. It helps children develop communication, social and daily living skills and, again, skills in the area of behaviour and emotional regulation.

IBI is intensive behavioural intervention, and it is a government-funded program in Ontario where a child usually works with a therapist for 20 to 40 hours a week, and it uses ABA principles.

The eligibility criteria for IBI in Ontario is that it's for children who have a more severe level of autism.

Addressing the wait-lists: Kerry's Place isn't a lead provider for IBI, but we are for ABA, so I'm going to speak to the wait-list for ABA, where we have a bit more intimate knowledge. The average for the wait-list for ABA services is about a year. It's two to four hours a week for an average of eight to 12 weeks of service for the child. Children can come in and out of this service throughout their childhood, which is great, but the challenge is, once they've received a block of service for those three months, they go back to the bottom of the wait-list and wait for a year.

While on the wait-list, in some agencies in some parts of the province, there are capacities to support families in helping to generalize those skills learned and to maintain them until they get another block of service. But unfortunately, those supports aren't available consistently across the province, and even where they are, in some agencies, in some regions, due to the demand, it's not available for all children.

One helpful strategy would be to consider a broader range of evidence-based supports, remembering that all children and families are unique and what will work for one child won't necessarily work for another child. There are a number of other intervention strategies that have been found helpful.

An additional model that has been found effective is for families to have access to an autism specialist right throughout, right from the point of diagnosis, to walk beside them, to understand the ASD and how to remain strong as a family, and then throughout the various transitions to school, to middle school, to high school, to adulthood.

That ASD specialist is more than a service navigator. It's somebody who can support, who can coach, who can help the families, yes, navigate the system, but also is a bit of an educator in terms of helping to make sure those skills that are learned in the more clinical settings are generalized across the environments of home and school.

The last point is just to encourage continued dialogue around how supports can be made available for children across the whole spectrum of ASD, because it's really frustrating for families when children at one end of the spectrum get service and others don't.

Ms. Tracy Mansell: I want to speak to the continuum of support that you've heard our panel talk about throughout our discussion here, and offer it as a model that may assist in terms of meeting some of the needs that families and children and youth and adults with ASD have.

The rationale for a continuum of support is to be responsible financially, recognizing that there is a need for the right service at the right time for families and children and their youth and adults on the spectrum.

Supporting families in the least intrusive way is the most financially viable way to be able to provide supports. The idea on this continuum—and you'll see the diagram on the second-last page of the handout—is to be able to provide some prevention and intervention in the earlier years; to be able to make sure that families are getting the right support and services at the right time; and that we are trying to make sure that families are feeling supported, and reduce their panic in terms of the future for their son or daughter.

Again, the idea is that we are keeping families and children, youth and adults in the lesser intensive supports and services. However, we recognize that there are times—and individuals who are going to need higher and more intensive supports. So it's really important to be able to offer that full continuum of supports, where you will find treatment, you will find hospitals, you will find residential services and supports, but also being really responsible in terms of, not everybody needs that high treatment, and how do we complement services and supports for families so that they're doing the right things and feeling the right confidence to be able to support their life?

An example: Families who are accessing services intensively, such as ABA or IBI, oftentimes aren't able to follow through with the suggestions and the recommendations of the clinicians. What we're finding from our autism specialists is that by being able to provide them with some other supports and services such as respite or education will allow them to be in a healthy enough place and a confident enough place to be able to then follow through with the recommendations. So to be giving someone a high-intensive support without recognizing that there are complementary supports and services that are required to keep that family together, intact and confident—not to mention that we don't want them to panic throughout their lifespan—is paramount.

Our ask to the select committee today is that you would consider really thinking about this continuum of supports and services, recognizing the need for all individuals on the spectrum of ASD to have access to supports and services across this province when they need them and to the extent that they need them in a responsible way. Thank you.

1130

The Chair (Mrs. Laura Albanese): Thank you for your presentation. I believe we start with Ms. Taylor.

Miss Monique Taylor: Thank you so much for everything that you do, which we know is very extensive, in the field that you're in.

The questions that I have are regarding ABA treatment and IBI treatment. How is it determined when a person doesn't need the services anymore, and they're contacted and told, "Sorry, it's over for your child and it's time to move on"? How is that assessed? How is that determined?

Ms. Gail Jones: For ABA, all children with ASD are eligible.

Miss Monique Taylor: Right. Sorry, I meant more IBI.

Ms. Gail Jones: Yes, IBI.

Dr. Jo-Ann Reitzel: There is a real need to develop consistent and transparent criteria that would be endorsed by Ontario. What has happened over the years that we have had the Autism Intervention Program has been a series of expert panels. In 2007, I believe, there was a clinical expert panel that recommended that children have a trial of IBI. But from the review of the literature, we knew that IBI was not appropriate for all children. We knew that only a proportion of children responded to it, and yet we really can't identify that at the outset.

What we need to be able to do is to follow a child's growth and development during the time that they are in IBI and see if it's having that intended effect of actually boosting or accelerating their development. Then what we need is the second expert panel, which was a benchmarks panel, in order to see whether the child is able to achieve those benchmarks and in that way to determine if this treatment is effective. If it's effective and having the intended effect for the child, then the decision would be to continue. If not, the decision would be to discharge, but to discharge, as all my colleagues have been talking about, to the right service for the right child at the right time. That would need this continuum of care.

Miss Monique Taylor: And with that dis-continuum, what's the transition period? I've been contacted by families who are told, "You have one month left of service and that's it. Your child is done," yet they're feeling that their child has reached these benchmarks, but there are no clear indicators of what that is. So what's the answer to that?

Dr. Jo-Ann Reitzel: I think one of the answers is in establishing these consistent and transparent criteria for discharging children and being able to educate families about the aim of IBI and that it is effective for some but not for all children with autism. There's a great deal of variability among children with autism. As I'm sure you

probably know, IBI really is effective for children with milder symptoms and for children who are young. We know that the IBI program right now is dedicated to children who are at the severe end of the spectrum.

These sorts of disconnects, I think, have been addressed quite nicely in the Auditor General's report—but asked for re-evaluation of the aims of these autism programs. Really, I feel like we don't yet have a thorough-enough autism strategy, and if we did, we would be able to see that there is a need for all and that all do deserve interventions, but it's just not all the same. It's not like one treatment for all; it's that we need a continuum and that that will change over time if we can assess those individuals' needs within their families and the context that they're living in.

The Chair (Mrs. Laura Albanese): Thank you. Before I proceed, I just want to make everyone aware that we do have a camera and a journalist here from TFO and a current affairs show called 360.

Ms. Hunter?

Ms. Mitzie Hunter: Thank you so much for your presentation. Just looking at the chart that you've put together, with the continuum of support, I notice that you framed it around the least intrusive support to families. That also really speaks to the intensification for resource allocation as well, which is something that we all have to manage and contend with.

I'm wondering, along the many areas that you've identified, if you can talk briefly about where you believe it is working and where there are gaps, from your perspective.

Ms. Tracy Mansell: Yes, I'd like to, definitely. In terms of this continuum, where it's not working—and it's not any specific service, because I think each of the specific services are working. The issue comes where there isn't the opportunity for families to fall from one service to the next service as they need it.

For example, because we've talked a lot about the ABA and the IBI, oftentimes, across the province, when a family has finished an episode of service and their time is up, the panic then comes from, "Now what do I do?" The current system right now is very siloed. So if a family has a residential service, they have a residential service. It's not that that residential service is not working; it's that there is a number of families who don't have access to that residential service.

The other piece is that families who have the treatment supports, or some of the community supports—when they come to an end, they have nothing else. So that panic or fear of what's next—again, it's families who have children in school or in children's services and they're moving on to adult services. It's "What's next?" It's the panic and the fear that causes the families to really feel that they need to grasp on and hold on to maybe a service that is more intensive than they need, or isn't meeting the needs of what their child is at that time.

Ms. Mitzie Hunter: Thank you.

The Chair (Mrs. Laura Albanese): Thank you, and I'll pass it on to Ms. Jones.

Ms. Sylvia Jones: Thank you, Chair. I'm really pleased that you made reference to, "We need to work better on the transitions." I'm wondering if you can share with the committee your experience between the transition from preschool into school, the coordination there—well, let's focus on that, because I know our time is limited.

Ms. Cathy White: I'd love to speak to that. There is a formal transition planning team and process for those children who have been in the IBI program. So, in the Peel region, we've seen those years go down towards the beginning of kindergarten for some students in IBI. So where there is an identified must-do process, such as the Connections—that is working really well.

I know that in most of the school boards—I'm assuming around the province, but for sure out in the central-west area—we host an information evening for parents of children with special needs, and then we identify a lead within the school board to invite folks to come to a case conference. We do observation out in the preschool setting, whether that's in daycare, whether that's in the home, to start to develop a transition plan in, and then we begin assigning the supports and services required.

Ms. Sylvia Jones: It sounds to me that is all related to parent education, which is great, and advocacy. Where is Kerry's Place's role with the actual school boards that you're affiliated with or working in coordination with?

Ms. Gail Jones: I think part of this speaks to the inconsistency across the province. I'll give an example. In Peel region, Kerry's Place is funded to provide service coordination, so we go hand in hand with the family, with the school board. But it's certainly not that way in every community.

Ms. Sylvia Jones: That's what I thought.

Ms. Gail Jones: It's inconsistent, yes.

Ms. Sylvia Jones: Thank you. We need to work on that.

The Chair (Mrs. Laura Albanese): We do need to work on that.

Thank you very much for presenting to us today and taking the time to be here. We very much appreciate it.

Ms. Tracy Mansell: And we just wanted to thank you for the opportunity. We really do look forward to continuing to work in partnership toward sustainable and cost-effective solutions.

MS. LINDA RUSSELL

The Chair (Mrs. Laura Albanese): We'll ask the next presenter to come forward: Linda Russell. Good morning. As you've heard with the previous presenters, you will have up to 30 minutes for your presentation. If there is any time left over, that will be used for the committee members to ask questions. You may begin at any time.

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Ms. Linda Russell: Thank you for this opportunity to tell our story. Our daughter Joanne was born 33 years ago with cerebral palsy. Joanne is physically and develop-

mentally disabled and suffers also from an anxiety disorder. Joanne requires 24-hour supervision and assistance with feeding, toileting and all areas of daily life.

Joanne requires some level of support for every aspect of her life and everything that she does. We have provided that care for her entire 33 years, and we do not regret that. However, as my husband and I grow older, we are physically, mentally and emotionally tired. Care-giver burnout is occurring as a result of the day-to-day demands, but my husband and I are determined not to see our daughter placed in a long-term-care facility. That would appear to be the only option at this time, and it is simply not acceptable.

Long-term-care facilities are not created to provide the support that Joanne needs, nor are they a place where an otherwise healthy 33-year-old woman should live. What will happen to Joanne when we die or can no longer look after her because of health issues or advanced age? She asks me who will look after her, and I don't have an answer for her. I am convinced that this is the single most important factor in the development of her anxiety disorder. If you needed to rely on other people for all of your day-to-day needs, would this uncertainty not make you anxious, or would it be too terrifying to think about?

Many families have told me that they hope that their child will die before them, because they are so worried about what will happen to their children after they, the parents, die. I understand exactly how they feel.

My dream is to see Joanne settled and happy in a safe and stimulating home before a crisis occurs. At this time, that dream could not be further from reality. We have been told repeatedly that the system is changing to better serve families. Bollocks to that. If anything, we see a system that is less able to support us, with absolutely no plan in place to improve the situation.

Most of our friends and family think that we choose to continue supporting Joanne at home. They are astounded and horrified that our society has no options available for individuals like Joanne. We receive lots of empathy but no tangible assistance.

This is a humanitarian crisis. These are people with feelings, hopes and dreams. Joanne wants to work and be a part of the community, just like everyone else in our community.

We have worked hard to maximize Joanne's capabilities. We have provided her with ongoing therapy through Erinoak treatment centre—when she was young—community experiences and continuing support. Her father and myself take her to and support her at no less than three volunteer jobs. Her work is appreciated, because she has proven herself to be a dedicated worker and one that can be counted on to complete the task at hand. However, she needs that physical support to allow her to participate in her volunteer jobs and all community activities.

We have made sacrifices for Joanne: (1) financial, because we gave up a second income so that I could stay at home and care for her, as well as incurring increased costs to support her; and (2) physical sacrifice, because

the stress of caring for her is becoming more difficult by the day.

My husband and I are hard workers. I have sat on many committees to look at ways to improve supports to individuals like my daughter. I have been a member of the board of directors of Brampton Caledon Community Living, and I have been a co-chair for the golf committee at Brampton Caledon Community Living over the last 15 years, to raise funds to assist individuals supported by BCCL. I worked hard with the executive director of BCCL to make the Connections day support program a reality.

We have done everything that we can to improve life for our daughter, including being a strong advocate for Joanne and others like her. However, the reality is we can't do this alone. We simply don't have enough money to support Joanne for the rest of her life; it is beyond our means. We have tried to create a financial plan and to do meaningful estate planning, but it simply isn't enough.

We need your help. We need a multi-year plan with a recognition that parents are aging and our adult children need a place to go and somewhere to live. This cannot wait; it needs to happen now. We need service agencies, like BCCL, to provide support to families like us and to provide oversight for the employees looking after these vulnerable individuals and oversight for the programs offered to support these vulnerable individuals.

Now I'm going to give you a few examples of what life is like for us, as a family, on a day-to-day basis. Our daughter, being physically disabled, uses a wheelchair. With the snow we've recently received, you may or may not understand just how difficult it is to push a wheelchair through snow and over ice and deal with that on a day-to-day basis. She uses a manual wheelchair, and my husband and I lift it in and out of the trunk of our car. We have done this for her entire life.

One day a friend of mine said, "Oh, you're getting Joanne in the car? I'll put the wheelchair in the trunk for you." After she did that, she turned to me and she said, "I've watched you do this for years and years and years," and she said, "It never looked like it was any effort at all. That thing weighs a lot more than I ever realized." That made me start to think about the fact that families do things on a day-to-day basis and they manage, and people see them managing and think that they can just keep doing that forever and ever. Unfortunately, that will not be the case.

It is the relentless daily responsibility that is very tiring as well. If a worker cancels, if Joanne's bus transportation is cancelled, if the day program is cancelled, whatever my husband and I may have scheduled for the day has to be cancelled because her needs come first. We live a very scheduled existence. My husband and I have to make sure that our activities fit in with the availability of workers who are there to support our daughter. We have no evening activities, because workers don't want to work until 11 o'clock at night. Most evening activities go until at least 10; by the time you get home and in the door, it's 11 o'clock. So we simply don't go out.

Our social life is more marginalized now than it was many years ago, because Joanne is like a young child. Our friends are kind, but they left that life behind long ago. I'm in my 60s; my husband will be 70 next year. Our friends are retired. Their children are grown up. They have grandchildren and when they spend time with them, they enjoy it immensely, but, boy, do they like getting back to a nice, quiet, peaceful home. We don't have that option.

Holidays are not a true holiday for my husband and I, because we take Joanne with us. There are few, if any, respite opportunities available. We enjoy having Joanne with us, but that being said, it is often harder because we are not at home in a familiar setting and equipment. It makes life more difficult. We have flown with Joanne. To give you an example—I'm sure all of you have flown on a plane—when she has to use the washroom, I take her to the washroom, and it is a very good thing that she and I are both quite slim because there is not a lot of room to manoeuvre in an airplane washroom for two people.

We look after Joanne 357 days a year. Joanne now has an opportunity to attend one—and only one—summer camp, and that is for an eight-day period of time. Fifteen years ago, there were opportunities for more summer camps: day camps, overnight camps. Those opportunities have dwindled, and as I say, that is what we do now. People work five days a week and they have a weekend off. My husband and I find that long weekends are actually more difficult for us. Weekends are not any different than the other five days a week.

Our primary focus is always Joanne. She is the one that takes most of our effort, and she is the one that needs us the most.

1150

Four years ago, my husband had an attack of arrhythmia. At the time, I thought he was having a heart attack. Luckily, a Red Cross worker was in our home looking after Joanne, and I went to emerg with my husband, to the local hospital. It became apparent that they were going to have to run tests and see what was going on, and I had to have a conversation with the ER physician to explain to him that I had to be home at 12 noon because I had a disabled daughter and the worker was leaving at 12 noon. At that point, he and I put together a plan as to how we were going to make the day work.

I left my husband in emerg while they ran tests. I came home; I picked up my daughter. The ER physician had suggested that I do what I would normally do with her on a Friday afternoon because the tests would take some time to complete, and an emergency room is not a good place for a person with an anxiety disorder. So I took my daughter to her regular Friday afternoon volunteer job, then explained to her on the way home that we had to go up to emerg to check on her dad.

To suggest that the day was stressful is an understatement. I had to choose which of the people I loved I was going to physically be with, because I couldn't be in two places at one time.

We are close to the edge. If one thing goes wrong, such as one of us requiring surgery or ongoing medical treatment, the other one will not be able to do it alone.

The system as it exists today creates roadblocks for future planning. There are insufficient funds available for Joanne's care. In fact, no funding is attached to her, unlike individuals who resided in the institutions that have since closed in Ontario.

The government has suggested that families utilize creative thinking to provide a residential model for their adult child. No amount of creative thinking will provide a suitable setting for Joanne, because of her high needs, without funding attached. And at this time, there is no funding available. Families have been asked to create a business plan for their residential model, but with no timeline for funding, this is an impossible task.

We cannot look at moving outside of our area because it is likely that we would lose what little support we have, from the part-time day program that Joanne attends to the home care hours that she now receives.

It is important that you understand how desperate we are for assistance, but it is also imperative that you understand Joanne's intrinsic value as a person in her community. Yes, it is challenging to support Joanne, but it is intensely rewarding to see her success. This is why we have supported her for so many years without complaint—that, and because we love her.

Thank you.

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

We have four and a half minutes for each party, so I believe we start with the government side.

Ms. Mitzie Hunter: Thank you, Madam Chair.

Ms. Russell, thank you so much for appearing before the select committee today and, really, for the lifetime of care and support that you've provided to your daughter Joanne and for sharing that story with openness. It will very much help us in this committee as we deliberate our recommendations and how we strengthen the system to provide supports not only for the individuals, but their families who are providing that care. So I just wanted to say thank you for your heartfelt sharing this morning.

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

Ms. Soo Wong: Do we have time, Madam Chair?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Soo Wong: I, too, want to echo my colleague's comment. Thank you for your determination. I know they were difficult day-to-day experiences throughout your daughter's growth, and now as an adult.

You commented about the long-term-care piece and the caregiver burnout and the respite. Can you share with us: Are there any best practices out there that we should learn from, that this committee should consider in terms of respite, supporting families like yours?

Ms. Linda Russell: There are very few, if any, respite services available anymore in Ontario. I use the summer camp that Christian Horizons puts on in Paisley, Ontario, so you could call that respite. Eight days is wonderful, but you're usually so tired getting her there that it takes

two or three days to recover from that, and then it seems like you're just turning around and picking her up again.

I have worked with community support people at BCCL, and they have all told me that individuals with high needs, at this time in Ontario, are not being looked at for residential settings because of the cost factor. I have spoken over the last 10 to 12 years to different people within the ministry. At one time, one person told me that I would just have to hope that people in the residential spots at this time would die sooner than later, because those spots would open up and that's how my daughter would get a spot. I wasn't terribly encouraged by that.

I have heard that any residential spots that exist right now for high-needs individuals—those are not being retained as spots for high-needs individuals. They're being broken up so that they can support more individuals. I understand the cost-efficiency of that, but, at the same time, who needs the support more than an individual of high needs?

One thing I really want to get across to you is that even though she is an individual with high needs, she can offer things to the community. She's had volunteer jobs. She's had a volunteer job at the Salvation Army thrift store in Orangeville ever since she finished school, which was when she was 21, so that's 12 years ago. She is there every Thursday hanging clothes. There isn't another volunteer who has lasted as long as she has. The other staff respect her for the work that she produces, considering the effort that she has to put into it, because it's very difficult for her to do it because of the physical disability that she has.

I have a letter here, which we received from DSO yesterday. She has been on a residential wait-list now for over 10 years, and we just got this saying that if we are still looking for a residential placement, please contact the appropriate person because there is a new application process. So that's what families get to deal with.

I did phone them. I have not—well, I shouldn't say we have not received a return phone call yet; I may have one waiting for me when I get home, because I left the house this morning right after putting Joanne on the bus, and that was just after 8 o'clock.

Anyway, I don't know what the new application process is going to involve, but I'm not sure why we need that.

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

Ms. Sylvia Jones: Thank you, Chair. So for the benefit of the community, Joanne and David and Linda have been my teachers in this education process for—I was thinking about it this morning—I think it's close to 20 years.

Ms. Linda Russell: It could be.

Ms. Sylvia Jones: I really appreciate you coming today. You mentioned the continuum of care. Many presenters have already talked about it. So, again, for everyone's benefit, Joanne's participation in our community, your involvement as an advocate—those change as she

goes through her various stages, ages. I don't like using "age," but that seems to be the magic thing that we do. Can you tell us a little bit about how that needs to be an important component of how we're going to fix the system?

Ms. Linda Russell: One of the things that I found was, when she became an adult, the services available for a communication service—any level of adult service is more difficult to access than it is or was when she was a child. I can't speak as to whether that continues to be the case now.

She attended school until she was 21 years old, so she was stimulated and occupied from 9 until 4, five days a week. She now attends a day support program. The maximum amount of time that she can have with that is two and a half days a week. The rest of the time, we, as a family, have to come up with either workers to work with her and look after her, or we do it ourselves. We have to find stimulating things for her to do in that downtime. As I say, we've got the volunteer jobs, but that's sustainable only as long as her father and I are healthy enough to be able to do that with her.

1200

We do get support from the Passport funding program. That's the Passport funding program that took over from Special Services at Home, and we use that to offset the costs of the day support program, and we use it to hire private personal support workers. My husband and I are finding that we're in need of more time off to regroup, and we're more tired, so we hire more workers. The money we get from Passport gets spent earlier in the year, and we make up the balance from our own finances.

We live on the northern edge of Peel region. Ten minutes from us is Orangeville, but they're in Dufferin. There's a boundary there. The service that you get is for Peel region; you can't access services in Dufferin, even though it's actually geographically closer. I've had families who live in Orangeville say to me, "Wow, you guys are in real trouble. You'll never get a residential placement for Joanne because you live in Peel and the numbers are so huge. It just won't happen." There's a disparity there that just doesn't make any sense.

As I say, my husband and I have looked at perhaps changing where we live. We've lived in the same home for 35 years. The home is not physically as comfortable and easy to manage with Joanne now as it was for the first 25 to 30 years, but it's next to impossible to really pick up and leave, because we're not sure that the services we have now will be available to us wherever we go. There's no continuity. There's nothing that says to us, "Oh yes, there will be a day support program wherever you decide to relocate."

Joanne does not do well with change. We've spent her entire 33 years helping her become a person within her community. We would change that if there were positives coming out of it, but to do that will be very, very difficult for her, because she will be leaving behind everything that she knows and everything that she's comfortable with. Right now, no one can give us an assurance that

there would be positives for making a move, so we're staying where we are and hoping for the best, day by day, and coming and speaking to you, saying that we really need some help.

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

Interjection.

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

Ms. DiNovo.

Ms. Cheri DiNovo: Thank you so much. I know how difficult it must be to come before us, and even more difficult to live your life some days, I'm sure. I thank you for having the courage to do both. As you say, you do it out of love.

It sounds to me like the ministry and the DSO are channelling Ebenezer Scrooge. It's that time of year. I can't imagine that Scrooge would have a more ugly response than they, and I'm ashamed, in fact, that that's what you heard from them. It's shameful.

My question is a simple one. Jurisdictions that do it better—you must have thought of this. Is there a jurisdiction that does it better, that would be a better place? If you could transport yourself to England or Australia or somewhere else—have you seen any examples of something that you think we should be replicating here?

Ms. Linda Russell: I can't say that I have any personal experience in that at all. Personally, I think that this is something that shouldn't just be handled at a provincial level. It's something that needs to be handled across Canada, because from what I gather, it's not that different from Ontario to—there isn't a province that you could name and say, "Oh yes, that's where I'd really like to be in this situation."

Our personal experience has been that recreational opportunities, respite opportunities have dwindled as we have moved forward in years. I think probably the optimum time to be disabled and get services was in the 1980s and maybe the early 1990s. Certainly, even the day support program that Joanne attends, when it first opened—it opened just as Joanne was finishing school—the staff came into our living room and said, "Joanne, what is it that you want to do?" Her answer was, "I want to work."

Now, because of an erosion of funding and because the ministry dictates to BCCL—I shouldn't say "dictates"—directs BCCL to do more with less, there are more people in the program. There is not the opportunity for Joanne to say, "This is what I want to do today." So, from her perspective, she's not being stimulated in as positive a way as she was 12 years ago. That's not BCCL's fault; that's not our fault. That is simply because everybody is doing more with less.

Miss Monique Taylor: Thank you so much for being here with us today.

The Chair (Mrs. Laura Albanese): Last question.

Miss Monique Taylor: I'm concerned: Would Joanne be able to still do her volunteer jobs, do you think, if she was housed in Community Living? Would she still have all of those opportunities?

Ms. Linda Russell: I think she could—certainly, if she were in a residential setting. As a family, we wouldn't remove ourselves from her life. We would like to see it created so that we aren't the main focal point, or even a good portion of the support network, because we want it to be developed in such a way that it assists her and supports her after we are no longer able to do that. So I would want it set up with that premise.

I would love the opportunity of being able to pick her up and take her to work for the day but then drop her off at the end of the day, and have someone else do everything else that needs to be done for her—give her dinner, give her the bath, get her to bed etc., take her out on a weekend—or take a day or two, rather than be the full-time caregiver where, right now, we get two and a half days, 9 until 4. That's our break.

For instance, if we were running really, really late, I'd be constantly looking at my watch, because I know I have to be home by 4:30. The bus will be there, and I'd better be at the end of the driveway, waiting to take her off.

There would always have to be someone working with her. The people at the store are not going to do what she requires. I'm sure that we could become creative. We do have some personal support workers who are the same age as Joanne, which makes a really nice peer-appropriate dynamic. She has a lot more fun with them than she does with her mom and dad, as your kids probably do when they're not with their parents as well.

I think it would be doable. We just can't do everything.

Miss Monique Taylor: I realize I'm done. I just wanted to say thank you. I really hope that this committee will be able to make the change in your life that is so necessary.

Ms. Linda Russell: Thank you for your time.

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

We are recessed until 1 o'clock.

The committee recessed from 1208 to 1306.

MS. COLLEEN BUTLER

MR. MICHAEL BUTLER

The Chair (Mrs. Laura Albanese): The committee is reconvened for the afternoon. We'll call forward our first presenter of the afternoon, Colleen Butler. Please have a seat. You will have up to 30 minutes for your presentation. Whatever time you do not use will be used for questions by the committee members. You may begin anytime.

Ms. Colleen Butler: Hello, my name is Colleen Butler, and this is my son Michael. Michael is 31 years old. Michael was born with an uncontrolled seizure disorder and a cognitive disability. Our journey began two weeks after Michael was born in 1982, when Michael began seizing. Prior to Michael's birth, there was no indication of any distress to him. We have been told his

focal points are a result of distress at the time of birth. The only occurrence my husband and I can think of is that the doctor had to use forceps to turn Michael, which resulted in marks on his head after delivery.

As a child, there were many challenges, but thanks to the support of our parents, school as well as my husband and I having youth on our side, we made it through. At age eight, Michael had brain surgery to remove a focal point, a golf-ball piece of his brain, in the hopes of lessening the seizure activity. Was this a success? I'm not sure, as I have no comparison. All I know is that Michael still seizures uncontrollably.

At age 10, Michael developed Bell's palsy, which has left him with the most adorable crooked smile. At age 19, Michael had a seizure and, upon falling, he broke his left arm and his right kneecap. He had to have surgery to correct a wrongly set arm and to have his kneecap screwed back together. This meant three months in a hospital bed in our living room, with a cast from foot to hip and on his arm, as well as daily physiotherapy to learn to walk again, for several months. I had to take three months' leave of absence from work to attend to Michael's needs.

In 2003, at the age of 21, Michael left the security of the regular-day Catholic school system, and our family needed to figure out how Michael was to spend his days for the rest of his life. I describe this as the worst year of my life. That yellow school bus was not going to pull up on the Tuesday after Labour Day, and we no longer had the peace of mind that for eight hours a day, Monday to Friday, Michael had a safe place to go, somewhere that made him feel secure but continued to challenge and provide him with fulfilling days.

My husband, Michael, and I attended a transition workshop sponsored by the Hamilton Family Network that exposed and educated us about the different programs and what they entailed. We heard about a wonderful program run under the Salvation Army called STRIVE Lawson Ministries, and we met a very energetic, positive and supportive woman named Lisa Schumph. We had several meetings and decided that this program was a good fit for Michael. Unfortunately, funding was an obstacle.

I spent the next six months writing letters, making phone calls, begging, pleading to obtain the funding that Michael required. I was told that funding is not an entitlement, that you are entitled to an education but at age 21 you are not entitled to anything. I still don't understand this statement. Aren't I entitled to be employed, like the next person? Isn't Michael entitled to a fulfilling life? We need help. We need support.

Unfortunately, when Michael turned 21, his disability did not disappear like the funding did. In fact, in the past 10 years, Michael's health has declined. I have always thought that the ISA funding that the Ministry of Education designates per identified student, which is meant to meet the needs of the students, should follow them for the school day program.

The number of individuals decreases tremendously after high school as many are capable of being employed, but the most vulnerable and lower-functioning are suddenly forgotten. The individuals with the most needs suddenly have nothing. We are extremely fortunate that Michael has the funding now in place for five days a week to allow us to work. The families that were not able to tolerate and endure the constant petitioning for small funding were left with nothing.

Isn't it sad that we find this small amount fortunate? What about the families not so fortunate?

Regrettably, this is not enough. Through the years, as Michael grew, my parents both passed away. My husband and I are getting older and we are no longer young parents. We have no support other than day programming. I work 8 to 4:30 and my husband works 3 to 11. Monday to Friday, I am the main support for Michael. The bit of respite we do receive, we use for after-program until I complete my work day. This allows my husband and I to work. Unfortunately, we do not have one hour of true respite.

Michael's seizures occur mainly at night, and usually I am alone. This is mentally, physically and emotionally draining. Some days, I look like something out of *The Walking Dead*. I am exhausted. I am emotionally raw. I need to function. I need to meet Michael's needs. I need to do my job at work. Michael's care has consumed my life. I am 53 years old and I have had an eight-year-old child for 24 years. My eight-year-old will never turn nine and he will always be eight.

I do not hold regrets. I do not begrudge others their good fortune. All I ask for is some help. We are presently in the process of obtaining respite funding. This is a necessity, not only for us but for Michael. We have a plan. We have toured respite homes. Unfortunately, we are unsure if any funding will be made available for us. For a weekend respite, it will cost us \$500.

We want a chance to transition Michael into residential living. This needs to be taken slowly and carefully in order not to stress Michael as undue stress will cause seizures. We need to teach Michael to live without us—simple words; a very difficult task. As we age, we need to be aware of our own mortality. We do not know with any certainty what tomorrow will bring; no one does. We need to prepare our son for this. Imagine the stress and confusion of living with mom and dad for 30-plus years. All of a sudden, something changes, and you are put in a supported-living home. You do not know the staff or the residents. "Do mom and dad not want me? What happened?" This is what we are trying to avoid.

This funding is not only to help with our own needs but, more importantly, to meet the needs and help prepare Michael. The last 31 years have been spent teaching Michael. This is probably the hardest lesson of all. My heart and my head are in a battle royal. I need to do this, yet my heart feels like I'm abandoning my most vulnerable child.

Our situation is not unique, and neither is our desperation. We want a full and satisfying life for our son, as do

all parents. I think that it is only fair that our children are recognized for who they are and are given every opportunity for a fulfilling life. They have not been handed an easy role in this world, yet they are the happiest people I know. I don't think any of us would trade them places, yet they are not given the supports or funding necessary. I think we need to put ourselves in their shoes and consider what we would want.

Families like ours are stressed, tired—emotionally and physically—and yet we carry on. We love our children unconditionally and we will stand by them to ensure that they will receive the quality of life that they are entitled to.

What price are we to put on our children? Will a parent quitting their job to ensure support for their child ease the burden? Personally, I know it will only add more stress and unrest as now, there would be financial burdens as well. For parents, their only break is going to work. If we were to give this up, where would that leave us? We would then be reliant on a subsidy or funding to support our entire family.

We are asking that you look at the funds designated and the need in the community, and aid in our circumstance. It's time to do the right thing. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. I will now turn it over to the Conservative members. We have seven minutes each for questions.

Mrs. Christine Elliott: Thank you very much, Ms. Butler and Michael. Thank you for coming to see us today. We understand the needs of many parents. We've heard from several parents so far today, and the needs seem to be pretty consistent that there are no long-term placements for their children. Can you tell us, has Michael been on a wait-list at this point for residential placement? Or are you just exploring that now?

Ms. Colleen Butler: We applied in September with DSO Hamilton for respite funding. Because my husband and I work opposite shifts, it's getting very tiring for me to do the Monday to Friday, so we're looking even for a Saturday where we could drop him off and have one day together. My husband and I don't see each other Monday to Friday, then we have the care of Michael. Our entire life is caring for Michael.

Mrs. Christine Elliott: And have they given you any kind of an indication about what they think you might be able to receive?

Ms. Colleen Butler: No. When we went down to do the application, they told us there were no funds available.

Mrs. Christine Elliott: That seems to be the case with a lot of people, from what we've heard, because a lot of people do use any Passport money they get for respite or to supplement a day program, but it doesn't end up giving the parents a break at all, just to allow you to carry on. You might be entitled to Passport funding, but there is no funding available.

Ms. Colleen Butler: Yes.

Mrs. Christine Elliott: Thank you very much.

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

Miss Monique Taylor: Thank you so much for coming here today. Thanks, Michael, for coming. I'm really happy to see you here. Colleen, I know the advocacy work that you do in our city—Colleen and Michael come from Hamilton—I know the work that you do. I know the families that you're involved with. I know the resources that you have at your fingertips, and yet you still struggle.

You briefly mentioned issues that you've had with the DSO, but what are your true thoughts about the DSO? Are they helpful? Are they necessary?

Ms. Colleen Butler: We went. It was two mornings of questions. The whole questionnaire—I didn't understand why we were doing what we were doing. We were told to compare Michael to a normal 31-year-old. I'm yet to meet a normal 31-year-old male. I wasn't sure what we were gauging him against, because that's not Michael. Why don't we talk about Michael? Why don't I tell you what we need? Why don't we discuss our situation? We're comparing him. Why? It reminds me of pay equity when you compare a baker and a clerk—you can't compare.

Michael is an individual. Michael's needs are different than the next person's. They're not any greater; they're not any worse. He's Michael, and let's discuss Michael. Let's not compare Michael. That doesn't work, because—the whole time we were there, my husband and I are thinking, “Did we give the right answer? Did we make it worse? Do you do this?” We didn't know how to do this. You're scaling him 1 to 5: Can he bathe, 1 to 5, compared to a normal male? Well, a normal male wouldn't have his mother in the bathroom. How do you gauge that? What number do you give that? Do you give it a one? Do you give it a three? Do you give it a five? Are you underestimating? Are you overestimating? The whole process is very confusing.

Miss Monique Taylor: If you could find something that would make your life easier and families that you know who are facing the same struggles as yourself, what would that be?

Ms. Colleen Butler: I think every one of these individuals needs to have a place to go. They need to feel needed. The funding needs to be there. I think maybe you need to look at how it's set up. The school system does it wonderfully. We lose it after school. There's nothing there for parents. There's nothing for these guys. And really, what 31-year-old, in any capacity, wants to hang out with mum and dad? They want to have their own—they want to have their buddies. They want to have their community, and they should have it. It's not good for them to be so reliant on their parents. I'm not going to live forever, and then what happens? I wouldn't want to be the person to pick up those pieces. Because with Michael, I turn around some days—it's only him and I in the evening—and he's right there. Like he's—boom, I walk into him. But what happens when I'm not there? My husband and my other son are going to have a mess.

1320

Miss Monique Taylor: I still have time?

The Chair (Mrs. Laura Albanese): Any other questions?

Miss Monique Taylor: Yes. Michael, how about I ask you a question? So if you could go to different programs or find something else to do with your time, what would you like to do?

Mr. Michael Butler: Bowling.

Miss Monique Taylor: Bowling? You like bowling? That's good. Any other stuff that you like to do?

Mr. Michael Butler: A show.

Miss Monique Taylor: Shows. Oh, movies. Yes, that's always fun. So they're the kinds of things that you like to do?

Mr. Michael Butler: Yes.

Miss Monique Taylor: Do you find that you get enough of those things to do? Mom keeps you busy? Or do you think that you could still do more?

Mr. Michael Butler: More.

Miss Monique Taylor: You could do more. Okay.

Well, thanks for being here with us today.

Ms. Colleen Butler: Thank you.

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

Ms. Soo Wong: Thank you very much, Ms. Butler and Michael, for coming today.

We heard from several witnesses today and in previous hearings the concern about the lack of funding for respite. Can I ask—we heard about the summer camp, those opportunities—is Michael able to access summer camp to provide some relief for your family?

Ms. Colleen Butler: We've never been offered that.

Ms. Soo Wong: Never? Okay.

The other thing here is, I hear that when Michael was younger, you were, through the school board, able to provide the necessary supports throughout the week. Now that he is—33? Am I correct?

Ms. Colleen Butler: Thirty-one.

Ms. Soo Wong: Thirty-one. In the adult transition period, that seems to fall off. Besides personal experience, Ms. Butler, can you share with the committee—besides the respite piece that we heard very clearly, how about the coordination of services? Are you experiencing those challenges as well?

Ms. Colleen Butler: Michael has been in his day program now 10 years, so it's pretty well a well-oiled machine. His funding has not been increased at all in that 10 years. He still has the funding from before Passport. I'm not sure how that all works, because the day programming takes care of that. But I know his funding was grandfathered because he came out before Passport.

He does go five days a week. The program runs until 2 on some days and 3 on the others. The old SSAH funding that we received for respite we are using to fill that void so I can stay at work and finish my day at work. So we've kind of puzzled it together as best we can.

Ms. Soo Wong: You seem to be. I just want to say thank you very much for coming to the committee and

sharing your story with us, because it's very important that we hear these life experiences, but more importantly for sharing with us your experience. And thank you, Michael, for being here today.

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

Ms. Mitzie Hunter: Thank you, Chair, and thank you so much, Ms. Butler and Michael, for joining us at the committee. It's great to see you here.

We've heard a lot about transition based on chronological age. I'm wondering, from your experience, if you can advise the committee on what would make sense in terms of looking at some of the goals. One of the goals that you talked about was not spending all the time with mom but being with people who relate to a person of that age. So can you talk about what types of transition—you know, right now, 18 and 21 seem to be the key ages, but maybe there are other options. I'm just wondering if you have any thoughts on that.

Ms. Colleen Butler: Yes. What happens is, they can stay in school until 21. The school boards do get funding until they are the age of 21, so most individuals are left in school until 21 because you don't know what else to do with them. But what happens is, very quickly they turn 21 and we don't know what we're doing now, because you get that false security. That school bus shows up every morning and takes them and doesn't bring them back until 3 o'clock. I had a woman who babysat Michael until I finished work, and he would go there after school. So we had this nice, secure little blanket, and then all of a sudden the rug got pulled out from under us.

Now, the family network in Hamilton does a wonderful job of holding workshops for parents. You take your child, and we work on their goals: what they want to do, what their interests are. They bring in different programs. It was a great thing, but unfortunately, we didn't know about that until Michael was in his last year of high school. If we had known about it earlier maybe we would've been a little more prepared. We learned about it there, and then all of a sudden, in June, he was done. Now what? So it was a panic; it was the unknown.

We made it through the summer because you always make it through the summer anyways, so we were prepared for that, but September was very hard because we were not sure. We ended up getting funding the very last week of August for him to go to program.

It was nice. It was wonderful. It was appreciated, but it was a lot of stress. It was a lot of stress that year, and I would not want to do it again. When I hear of a parent whose child is in that last year, I know what they're headed for and my heart goes out to them, because that is the worst year.

Ms. Mitzie Hunter: Thank you very much.

The Chair (Mrs. Laura Albanese): Did you have a question, Mr. Balkissoon?

Mr. Bas Balkissoon: No, I'm good.

The Chair (Mrs. Laura Albanese): I have just one brief question. You mentioned looking in the future at possibly a supported-living solution. Have you applied for that?

Ms. Colleen Butler: He's on a waiting list. We want to transition because Michael has never been anywhere but home. I don't want to drop him there one day. Actually, we went through a respite home. Michael's program no longer offers respites; we looked at Community Living. We went through the home and I said to my husband—because I'm having a very difficult time with this as a mother—"I really want to hate this place." We went through it and I loved it. It was clean; the staff was wonderful. I was so in awe.

Michael knew one of the boys from his day program; he wanted to stay. We had not told him because I wasn't sure how he was going to react, so I said, "Let's just do this and we'll pick up the pieces when we get home. We'll see." And he keeps saying, "I want to go back, I want to go, I want to go." We told him, "We can't until we get funding. We need to get funding, then you can go for a weekend."

The Chair (Mrs. Laura Albanese): So how long ago did you apply?

Ms. Colleen Butler: We applied at the beginning of September of this year.

The Chair (Mrs. Laura Albanese): Okay, thank you.

Thank you very much, again, for being here today. Thank you, Michael, for coming. It was very nice to meet you both.

Thank you, really, for sharing your life and your story with us. It will help us.

Ms. Colleen Butler: Thank you for the opportunity. We really appreciate that.

The Chair (Mrs. Laura Albanese): Have a safe return back, and all the best for the holidays.

Ms. Colleen Butler: Thank you.

PEEL CHILDREN'S AID SOCIETY

The Chair (Mrs. Laura Albanese): We'll now call up Peel children's aid society, the special needs unit. Good afternoon and welcome. We'll reset this watch. If you could kindly state your name and your title before you begin. I don't know if you had heard before, you have up to 30 minutes for your presentation. If it's shorter than that, we'll have some time for questions. Thank you.

Ms. Mary Beth Moellenkamp: Hello, my name is Mary Beth Moellenkamp. I am a senior service manager for the parent and child capacity building branch at Peel children's aid.

Mr. Steve Levac: My name is Steve Levac. I'm the manager of the special needs unit at the children's aid society.

The Chair (Mrs. Laura Albanese): Did you have a presentation for us?

Mr. Steve Levac: I do. You're getting folders currently from us, and it's pretty much just a two-handout piece with regard to what our presentation is going to be. And then there's also a handout: a little bit about our agency and the families that we serve in Peel, for reference.

First off, thank you for allowing me the opportunity to come in and speak a little bit about my work in Peel. The position that I have is a fairly unique position in child protection, in the sense that there are really only two of us in the province across the children's aid societies that do what my unit does. We have nurses in our unit and social workers who help to provide care for what we would call children with special needs, but the majority of those children are children with developmental disabilities, as well as medically fragile kids.

I have two conference protocols that I manage in the region of Peel for complex-needs-care kids. Part of managing that protocol is a community approach to how it is that we can best help and service families.

I'm one of six chairs for the service collaborative on mental health, which is the writing of the mental health strategy for our agency as well, in collaboration with that. I am the community consultant for special needs as well as the co-chair of the Service Resolution children's review committee in Peel. I'm a co-chair there, and a deliberator as well.

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For reference for you, there is some data on the front page with regard to a little bit about the special-needs unit, just to give you an idea of some of what constitutes the families that we work with.

I wanted to start with a message that a physician had delivered. The message that came to our agency unfortunately was during a funeral for one of our medically fragile children who had succumbed to their medical issues and passed away. But the physician got up to speak at the child's funeral and said that he came into this work thinking that he would make a difference in the lives of children with special needs and developmental disabilities. He thought, "I would teach them and provide them with the support that would make a difference in their lives." But what he didn't anticipate was just how much of a difference they made in his. I echo that sentiment.

I wanted to talk about what is working well in Peel, two issues that are working really well. One is collaboration. We really, in the developmental services sector in Peel, along with our program supervisors at MCSS and MCYS, have worked collaboratively together to address the issues that have been raised for families in the region of Peel. The unfortunate part is that, by default, when there are gaps in the system, child protection services is often called upon to fill those gaps in service when parents are feeling like what is available is really not significantly helping them. I'm hoping that from today's presentation you'll have a bit of an idea about what our vision would be in Peel as to what may be an early intervention strategy for providing support to families to prevent child protection services from having to be involved.

The case conferencing protocols are brilliant. It really pulls a lot of people together. I have yet to have a family intimidated or complain about that process. Really, when we call a case conference in Peel, we have a protocol that

we have all signed on to in the developmental services sector. It brings 20 to 30 professionals around a table to hear a family's story and to try to implement some services for them to help give them support in parenting their children.

In the education sector, the ASD classrooms for children with autism and the accommodations that are made for the children in the education sector really allow them to continue to have the right, like every child should, to be educated. I draw your attention to the Applewood secondary school program in Peel. It's a brilliant school program in Mississauga. I have what I would have labelled in the community as some of my harder-to-serve children with developmental disabilities in that program, and they're having tremendous success.

As well, what is working well is that we streamlined our service coordination about two years ago through CDRCP, Child Development Resource Connection Peel. There are four agencies that participate in that service coordination: both of our Community Living organizations, Kerry's Place Autism Services, as well as ErinoakKids, which helps to assign system navigators and service navigators for families, because as I'm sure you're hearing from every family story that comes in, it's a bit of a monster at times to navigate the system on your own. So these system coordinators have just been a gift to allow families to tell their story to one person and have that person help to coordinate funding, respite, treatment, assessment—all of those pieces—on their behalf.

The second piece that I wanted to talk about a little bit with you today was the education piece. I guess to start with, a bit of a relation story for all of you. If you are parents in the room, you know what it means when you have a snow day or a PA day. Those are the days where you are going to organize your work schedule around the fact that your children are going to be at home. The challenge that a lot of parents face with the education system is this: I'd ask you to imagine that tomorrow you woke up with a salary equivalent to that of just above the poverty line. You're a single parent with two kids. The routine of the kids falls only to you. You need to work to pay your rent and provide food, and you are informed that your school-aged child is no longer able to attend or can only attend for 1.5 hours a day. You can't afford child care. You can't quit your job. There is no alternative for your child to be looked after for the six hours a day that you need to be at work. Sometimes, you bring your child to school for that 1.5 hours, and 20 minutes later the school is calling for you to come and pick up your child. It's like having a snow day every day, with no resources to help support you. That is what parents endure with their children with developmental disabilities with the school system.

Children with autism can be sometimes aggressive, disruptive. Sometimes they can engage in self-harming behaviours. School systems often lack the available staffing and the skill set in the classrooms, such as training with ABA.

As a result, children are placed on home instruction, or they're excluded from school. This often leads to parents' inability to cope with the behaviours without the ability to go to work and have a break from the child and the child care piece. Or, in turn, parents are forced to have inadequate supervision plans for their children. Both of these situations lead the community to report to child protection agencies.

My belief is that every child has a right to education. We need to figure out what help our education sector needs to be able to provide safe and practical education to special-needs children and to children with developmental disabilities. It's rare that I sit at a table where school administrators are not really wanting a child in school. The challenge and the difficulty is whether or not they're resourced enough, or have an ability to be able to provide an education that is adequately resourced in schools. That's really our challenge.

The second piece I wanted to talk about, and it's a lovely diagram that I did for you with regard to an intervention. I don't know if any of you are musical theatre fans, but there was this reality TV show, a Canadian show, called *How Do You Solve a Problem Like Maria?* It was a reality show to cast the lead character in *The Sound of Music*. And I often think about, how do you solve a problem like assessment? Because children with developmental disabilities are assessed a lot.

One of the parents was just speaking about how she didn't understand all the questions and the tools that she had to complete and why there were so many assessments. We assess them, and we assess them again, and we assess them again. Recommendations out of those assessments are often unachievable. Recommendations are often never operationalized into actual practice for families.

The intervention I've given you is really family-focused, and I ask a three-prong question every time we have families in a room together with us as service providers, because, really, they are the experts. The three questions are simple: What do you have? What do you need? Who's going to take the lead to help this family? Those are the three simple questions to the community.

When you're asking about need, it's like a wish list. I often say, "Pretend tomorrow morning you could wake up and have exactly what you needed to help you continue to parent. Tell me what that is. It may not exactly fit what we have sitting in the room, or any of our programs today, but we're going to try our darnedest in the room to make an intervention fit for you."

Our job, as a community and for you as leaders, is to take what is needed and to attempt with what we have to make it work. I'm not asking that there needs to be a whole bunch of new money. It's about taking the money we have and investing it into interventions that we know will help families.

Too often we expect families to fit our programs. We, as community agencies, stick tightly to our programs and their descriptions so that we can ensure we have outcomes that support further funding, but that's not really

the ideal of what supports a family. There is an error in support, and we need to change it.

I based the intervention you have on the role that I have within Peel CAS, as well as sitting as a co-chair for Service Resolution. The majority of the families that come to us have specific asks through their service coordinator. I kept it simple. I didn't want it to look really, really complicated for anyone.

The behavioural assessment piece—we have Peel Behavioural Services in Peel. It's probably about a year wait-list, which is tremendously difficult for families to have to navigate for that 12-month period on their own. Behavioural assessments are a really practical, hands-on approach to managing behaviours, routine and structure in the home. It's based on what works for the child, and that means sensory, rewards, communication, and it's cascaded to our partners in the education sector. So it's not just a home-based intervention piece. This is really the plan for us.

The second piece to the intervention is around service coordination, and, really, it's your one-stop shopping spot for service, the keeper of the family story, the gatherer of funds for respite. They help organize the community response and the community team for the family.

I referenced the Sunburst guide, which Peel Children and Youth Planning Group, PCYPG, wrote in conjunction with several agencies. Part of it was based on a need at the time that our kids in Peel with high-functioning autism and Asperger's, with a dual diagnosis of a mental health diagnosis—coordinators didn't know what to do in these situations. They were complex and complicated young folks to have to try to coordinate for.

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The Sunburst guide was written in conjunction with the psychology department at both boards of education in Peel. It really talks about what to do and how to manage and how to navigate through these complicated situations with children who are dually diagnosed. I reference it for you to take a look at. It was peer-edited by Dr. Stoddart at the Redpath Centre as well. Like I say, it was really a massive community effort to author and to write. It's available on the website, and I've listed it on the page.

One of the two last pieces is staffing support to the home. Many of the families coming to Service Resolution, to the children's review committee, are asking for support in the home. Once the behavioural assessment plan is in place, parents need help. The only way I can sort of relate it to you is, I'm sure that at different times for perhaps those of you who are parents—or even behavioural-wise, as adults—you go to bed at night and you go to turn your lamp off and you think, “Oh, my gosh. I behaved just like my mother did today,” and wonder how that is, because it's behaviour you didn't necessarily want to repeat, but it just comes out in you. It's hard to change patterns of parenting behaviour. That's why I'm asking for the staffing support piece in the home.

Our funds: If I was to look at the percentage of funds out of the children's review committee that gets used to

pay for staffing, it's quite significant, to help support plans in homes. It's really because we're asking for this drastic change, oftentimes, and it's difficult. Parents need some help and support and assistance with that, and some role modelling, to be able to carry out the behaviour recommendations, to be able to continue to manage in their homes.

I know I heard in the last presentation the mention of respite as well, and out-of-home respite. Everyone needs a time out when managing children with developmental disabilities. Sometimes a parent just needs to sleep one full night. Sometimes they need to just go do groceries in a day, or they often just need to spend some time with the other child sibling, to be able to go to the park or go to the movies and do other things that parents just are not able to do, because they are literally like 24-hour staff for their children. The break allows them to refuel the energy, and is needed on an emergency basis. We don't have emergency respite. What we do have is emergency child protection services, and I assure you that families call us often when they're feeling that they're at their rope's end. I always feel tremendously bad that they have reached the point where they're calling the children's aid society for that kind of support. Often the difference between child abandonment, and re-energizing to continue to parent, is respite services.

I'm going to pass it to Beth to talk a little bit about our agency in general.

Ms. Mary Beth Moellenkamp: Thank you, Steve. I think the two things that I wanted to be able to speak to you about is just to summarize the impact that these things have on the child welfare sector but also to have an opportunity to talk about collaboration and integration and planning.

The Peel Children's Aid Society, as all of the children's aid societies are across Ontario, is committed to ensuring the safety and well-being of children in our communities. For Peel children's aid, one of our core values is that we're committed to keeping children at home and in their community, or with extended families, whenever possible. The challenge for us is when services are not available for children with developmental needs. It does have an impact on our system. Families often come to our attention after they have made many attempts to find additional supports, impacting their ability to cope and impacting their ability to meet the needs of their children.

Families with children who have intellectual disabilities and children who are dually diagnosed often experience underemployment and unemployment, as we heard the past speaker talk about, due to higher demands around child management. Additional stressors can impact partner relationships and can even lead to the mental distress of the caregiver, which can further lead to child welfare involvement.

These are some of the factors that lead to a disproportionate number of children and families who are experiencing these issues being seen in our services. What is of concern is that it also is a disproportionate amount in the

number of children who have to come into foster care. One of the reasons for that is that the accessibility and timeliness of services isn't available. Parents are frustrated and they're not able to cope, so they turn to us.

Not only is the accessibility and timeliness of services an impact and a reason for them coming into our care, it's also a barrier for us in our ability to reunify children when those services and supports aren't available in the community.

Of interest is that the challenges that children and families face can be seen across multiple sectors: social services, education, health and child welfare. We often hear our counterparts talk about some of the similar struggles that they have. Each sector is undertaking plans and initiatives to help address the service needs of children with intellectual disabilities and dual diagnosis.

If I use mental health as an example, Steve spoke to the fact that our agency is undertaking a mental health strategy to address the needs of children and youth, and even adults, who are experiencing mental health issues. The Peel District School Board is also doing that. The mental health sector is going under some review as well. Health oftentimes is looking to integrate services in a different way, and the LHINs are looking at how they can provide service differently. So each of us, in our individual sectors, is committed to looking at this. We've all recognized the importance of addressing the needs of children and youth through thoughtful planning and reviewing processes and structures that are in place, to look for improvement.

Collaboration in our work is happening, as Steve mentioned, at the micro levels—in collaboration, in case conferences, in some of the service collaboratives that Steve sits on—but we think that there are opportunities for collaboration to improve the services that are provided at a provincial level.

One of our thoughts, which we think of as an opportunity, is to create an integrated approach to supporting families across these sectors, including health, education and child welfare, to assist in the development of the comprehensive strategy that you're looking to, because the impact is felt in each of these sectors.

As opposed to doing it in a silo type of way, if we can have a joint strategic planning process where each of the ministries is looking at what the outcomes are that we want to achieve—if we're all seeing these specific things happening, what's working well, what are the gaps that we need to address, and what are things that we can do differently? Allowing this will help us to promote partnerships within the sector.

Each of us has a variety of expertise in our particular areas—whether that be from education, child welfare or health—which can allow us to come up with some creative solutions. The benefit of this is that it's not just supported at a micro level, but it's supported at a structural and a governmental level, which is more likely to support long-term change.

I know that the committee has heard from a number of parents, and we would echo that it's of vital importance

that we hear from the service users as well. Even in the creation of such a strategy, we would recommend—I mean, our service users are often telling us what they need, and to making that type of change, we really need to hear their voices.

In the joint strategic planning process, we see the development of a multidisciplinary approach to the work, the development of multidisciplinary teams that could use the expertise of each sector to be able to address the needs of families. Our families are often coming to the attention of education—as we said—health and ourselves, but it gives us a collaborative way and a structural way to be able to provide that service.

Peel CAS has undertaken this approach before, and we've seen the benefits of that. We have partnered with community agencies to meet the needs of adolescents, to address domestic violence, and we are currently, as was mentioned, developing a mental health strategy that's looking to develop a multidisciplinary team with our community partners.

I think, finally, one of the last points that I wanted to make is, I know that you will have probably multiple requests for funding of needed services, and there's no doubt that Peel region and many of our regions are underserved. But one of the things that we would recommend is also taking a look at the services that we are providing. Is there a way that we can do it differently? Is there a way that we can put the resources into different areas? How do we work together to promote those collaborative ideas that are going to change the outcomes for the children and families that we're all trying to serve?

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

Mr. Steve Levac: And just to end, I wanted to talk about a quote from William Arthur Ward, who's an author in the US. He really says, "Do more than belong: Participate. Do more than care: Help. Do more than believe: Practise. Do more than be fair: Be kind. Do more than forgive: Forget. Do more than dream: Work."

I've been doing child protection for 16 years. I'm hoping, by the year 2030, when my retirement kicks in, that I leave the field a little bit better than where I found it.

The Chair (Mrs. Laura Albanese): Thank you. I believe it's the NDP's turn. Ms. Taylor?

Miss Monique Taylor: Yes. Thank you so much for coming to speak with us today. It's an important piece that we definitely need to be hearing about.

I'm curious: Your unit only deals with families who have special needs. Is that correct?

Mr. Steve Levac: Correct.

Miss Monique Taylor: Okay. How many families do you feel that you're servicing? Do you have any idea how many families are actually being serviced right now by your unit?

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Mr. Steve Levac: I have seven staff, and each staff carries a caseload of about 20 to 21 families.

Miss Monique Taylor: And are all of those families at home or are they split up?

Mr. Steve Levac: No, it's a split. In fact, when I first started to manage the unit, probably around six years ago, we were probably a 70-30 split: 70% of kids in care and 30% family work. We have now lessened that to almost a 50-50 split. But it's a challenge.

Miss Monique Taylor: So 50% of your families are at home and being supported.

Mr. Steve Levac: Correct.

Miss Monique Taylor: How many of those families, really, without the support of probably having somebody walk them through all the services that—I guess you've already answered that by saying that you were 70-30; so now you're providing more of that assistance to keep them at home.

Mr. Steve Levac: That assistance, as well as looking at the complex needs designation. The children's review committee in Peel was also given the responsibility of reviewing complex needs funding requests for children to be declared complex by the ministry. Then, in turn, those parents don't necessarily have to surrender their children to child protection authorities to get residential support for their children.

What we've done is we've assisted and supported the community in being able to plan—oftentimes perhaps having those children either come into care for a very short period of time before transferring or, in turn, doing a more planned placement of children into residential placements with the complex needs designation.

Miss Monique Taylor: Thank you. With the funding cuts that have happened in the sector, how has that hit you specifically?

Ms. Mary Beth Moellenkamp: Absolutely. I think that the impact of funding cuts to the sector has been challenging. I think Peel children's aid is committed to continuing to provide the supports and services we can to the families. We've tried to make as many changes as we can, but I think that one of the interesting things is that this is a challenge that is experienced across the province, and depending on what region you're in, you're having a different impact. Peel has been historically underserved and underfunded. I'm sure that you've heard from Fair Share for Peel before, about the challenges that we have in Peel. So it definitely does have an impact on our service.

Our agency, though, is committed to trying to keep children and families at home, so what it asks us to do is rely more on our partnerships. Some of the work that Steve's team does around pulling together collaborative conferences and pulling together our partners to do the work differently is how we're trying to manage and survive with the current situation.

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

Ms. Soo Wong: Thank you very much for your presentation. I want to go back to your comment, Mr. Levac, about the educator not being properly trained and supported. Can you elaborate a little bit more for the

committee with respect to, now that the faculty of education is a two-year program, has your agency gone before the different faculties of education to raise awareness of the need for proper training for the teachers who educate in the classroom so that these students will be successful? Can you comment a little bit further?

Mr. Steve Levac: Probably about three years ago myself and the chair of the—our Service Resolution facilitator in Peel met with the director of education at the Peel District School Board to say that we were having this significant frustration with the amount of children being placed on home instruction and that the fundamental value for most of us in Peel was that every child has a right to an education and how we can make this happen better.

The director of education at the Peel District School Board, with the superintendent of special needs, actually created a position within the board of a psychologist, Dr. Bob Cambria, who specifically works with individual schools, principals and administrators at addressing complex care concerns with kids and being able to keep them in school, so sort of coming up with a plan.

The school board shares with me their funding formula. I thought ours was complex; theirs is even more complex. If you do a comparison, at the Halton District School Board, for example, which is our neighbouring school board, the high-needs formula that they use for funding, if any of you are aware of that—Halton District School Board gets, for children with disabilities, \$601 per student, whereas Peel's board gets \$339 per student—just to show the dichotomy in funding pieces with regard to that formula.

The other piece is just around the fact that, with their policies and procedures, it is often difficult for school boards and for principals to bring in outside support to help support teachers in the classroom. I have yet to find a teacher teaching children in special-needs classrooms with a background in ABA or IBI. I think if we had that, the cascading of intervention would be far simpler for us in that piece, with that kind of understanding.

The Chair (Mrs. Laura Albanese): One minute.

Ms. Mitzie Hunter: Just in terms of your role in the broader community to help families navigate the system of support, you expressed that you don't want to be a place where families give up. What does that look like in terms of your response when they do come to you?

Mr. Steve Levac: It's a unified piece. My unit's approach and the staff's approach is really to be respectful to the parents. I see us as the very last stop. Oftentimes, the staff in the unit will actually role model what good service coordination or good case management might look like.

The other piece that we've run into is the expertise of people who are doing service coordination or service navigation in child protection. I feel like over the last seven years, the system has educated me in understanding the funding that's available, or opportunities for families. Really, it's about us coming in to kind of role model and then, in turn, hand these situations back to the

community to help problem-solve with families, rather than them having to use the children's aid society for that piece.

The Chair (Mrs. Laura Albanese): We'll turn it over to Ms. Jones.

Ms. Sylvia Jones: Thanks for appearing today. I have a number of different questions, so I'm going to speak fast.

I loved your, "What do you have? What do you need? How can we deliver it?" I'm going to make that comparison to a DSO application that we have heard takes upwards of six-plus hours. You've simplified it in 30 seconds, and I did it in 15 because I'm in a hurry. To your point, if you can do that, and you're the agency of last resort, what the heck is our DSO doing with a six-hour-plus application process? Enough said.

I am interested in, particularly with your special-needs unit, what are you doing with those children who are in that magic 18 to 21 age, transitioning out of school? They're also transitioning out of your agency.

Mr. Steve Levac: Correct.

Ms. Sylvia Jones: So what are you doing?

Mr. Steve Levac: We have a formalized protocol with the DSO. So those six-hour assessments, my staff are sitting in there, through the SIS tool and the other tools that they use around assessment. The children who are crown wards within our agency, at the age of 18, receive priority with regard to planning for the DSO, so the transition out of the unit has been fairly smooth. We refer, at the age of 15, to the DSO. We keep an ongoing list, and then their staff attend to the plans of care for these children every month.

Ms. Sylvia Jones: I think by extension you've answered my next question, which is, as a child protection agency, are your clients given priority for respite, housing and other services?

Mr. Steve Levac: No, they are not.

Ms. Sylvia Jones: Just at the DSO level, you are.

Mr. Steve Levac: No. I mean, the great part about working at children's aid is that you have authority and people tend to listen to you. In that sense, I see myself and my role as being the person who needs to be the voice to get folks to listen. When I'm sitting at a case conference and people are saying, "Well, we've got a wait-list of nine months. I can do something in eight months. I can do something in six months," I will often say, "That is unacceptable. It's unacceptable to have a 10-month waiting list. We need to be able to leave the room today with this family having a plan."

Ms. Sylvia Jones: So congratulations on your advocacy, but I read that as you do have a priority. You are given a priority, because the next person who has that meeting is going to be told, "We have a nine-month waiting list. Thanks for coming."

Mr. Steve Levac: Yes.

Ms. Sylvia Jones: Okay, thank you.

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

Mrs. Christine Elliott: Thank you very much for your presentation. I had a question. You mentioned that

some of the families come to you for, in fact, respite when they are at the end of their rope. I'm just wondering, where do you take it from there? Do you try to place them on short-term placements for a week or two weeks? If so, who do you place them with? Are you having problems finding people who will take these children or young people into care?

Mr. Steve Levac: Funding is one issue with regard to respite dollars. Again, because it's a community collaborative, we often pull various community partners together. There are various funding pieces at different agencies that we sort of access through Community Living, through Peel Crisis Capacity Network. We have donors that we look to.

I'll be frank and honest with you: There are times where I sort of, semi-somewhat do private fundraising within my unit, to kind of get pooled dollars into our foundation, to help assist with that. There were also a lot of applications for some of our funding, to help assist with the respite. The majority of the time, we're referring families to Service Resolution, to the children's review committee, to obtain that funding to be able to pay for additional respite.

Again, having children with developmental disabilities in foster care is not what our system is created for, so my first line is always to push back, to try to find what we can.

Erinoak is going to be opening additional respite beds in Peel, I think, in 2015. I'm excited for that to happen. So I'm waiting for that piece. But it's always sort of a constant search. There are times, yes, when a parent is saying to us that they're done. There are times when those children, unfortunately, through child abandonment, are coming into our care.

Mrs. Christine Elliott: Thank you.

Miss Monique Taylor: Can I just ask one quick question? How many children are ending up in care because they're not getting the supports in the community?

Ms. Mary Beth Moellenkamp: Maybe I can answer that. Last year, in 2012, the top three reasons that we had for children being in our care were, one, conflict between the child and their caregiver as a result of behavioural concerns that the caregiver couldn't manage. The second reason was for mental health and substance abuse of the caregiver. The third reason was around abandonment. Those abandonment issues are usually as a result of parents' lack of ability to access resources. So it is something that we're seeing in our statistics. It's a trend that we've seen over time.

The Chair (Mrs. Laura Albanese): Thank you very much for appearing before our committee today.

As the committee members know, the next presenter has cancelled, so we have the opportunity to go through some housekeeping. As we did discuss at—

Interjection.

The Chair (Mrs. Laura Albanese): Would you like to go into closed session really quickly?

Ms. Sylvia Jones: For the processing part?

The Chair (Mrs. Laura Albanese): Yes. It's just for a few minutes. Everybody agree? Agreed. Thank you.

The committee continued in closed session at 1402 and resumed at 1430.

PROVINCIAL EXECUTIVE DIRECTORS
GROUP, COMMUNITY LIVING ONTARIO

The Chair (Mrs. Laura Albanese): The committee has reconvened, so we will call our next presenter forward, the Provincial Executive Directors Group of Community Living. Thank you for being with us this afternoon. Please take your seat. If you could kindly start by stating your name and your title before you begin your presentation. You will have up to 30 minutes for the presentation. If the presentation is shorter, we will allow for questions from committee members. Please begin.

Mr. John Klassen: My name is John Klassen, and I'm the chair of the Provincial Executive Directors Group, Community Living Ontario, and Alan McWhorter, who is an adviser to the Provincial Executive Directors Group.

Madam Chair, members of the Select Committee on Developmental Services, we welcome this opportunity to speak to you about important matters in this sector and hopefully contribute to the important work that you have before you.

The Provincial Executive Directors Group is composed of executive directors from 116 service-providing organizations affiliated with Community Living Ontario. The PEDG members participate through a regional structure coordinated by a central arm called the provincial executive directors coordinating committee. All regions of Ontario are represented on the PEDCC.

I'd like to begin with what we refer to as our shared values that are really the foundation for what we do and who we are. We believe that Community Living associations have as their primary duty to promote, enable and support communities within which individuals with intellectual disabilities and their families have:

- the assurance of a fair, respectful, safe and dignified life;
- the status to ensure their self-determination;
- full information about human rights and society's commitment to these rights;
- the resources necessary to enable full participation;
- acknowledgement of their strengths and the opportunities to develop them;
- the reasonable necessities of life; and
- the recognition of full citizenship and its consequent responsibilities and opportunities to contribute to the community.

I won't go into full detail. You have the report that we have provided you. However, I would like to highlight some parts of the report and then hopefully have time for questions. The application of our shared values, I think, is an important section that I would like to share with you. Community Living associations and others who share these values need to engage with families and their com-

munity to make things better for families, especially for those who are struggling and need support.

In Ontario, we necessarily carry a dual role, that is, Community Living associations. The one role is that of transfer payment agency, defined by contractual relationships with funding ministries, namely MCSS and MCYS. The other role, and that is an essential one for us, is our basic, original and very important role as a community organization with responsibilities to all the members of the community, whether they are service recipients or not, especially those without service.

As an organization with deep roots in local communities throughout Ontario, our members have brought to our collective awareness the struggles of many families with a member who has an intellectual disability. The situation has become worse over the last few years to the point that it has become our urgent priority. Only this morning I met with three parents who I could describe only as parents who are in desperation, who don't know where to turn and who want to find hope in a system that seems to have forgotten them.

Our inability to meet the need that we see in our communities, combined with the perception of families that the system is failing, now constitutes a threat to our shared values. The threat we perceive arises in part from the government's application of rules for agencies, interpreted so as to interfere with our ability to carry out core obligations to families and individuals with intellectual disabilities.

Community Living associations should not be forced to choose between our many important duties to our communities and the role of developing developmental services. We are currently initiating measures for Community Living associations to actively support and enable independent family groups to organize more effectively in their own interest.

As organizations in and of the community, we're being put at risk by the rules-based behaviour of a government that has focused on a narrow range of services and has lost sight of the big picture. This is made more concerning by interference with our community responsibilities in the name of accountability to the provincial government. We accept that as TPAs, transfer payment agencies, we must be accountable to use public funds as provided by contract with the funder; however, the funder has no authority, legal or moral, to impose limits or give direction on how to deal with our community in our basic role as community organizations with wider responsibilities.

At the same time, we realize that we are probably more important to families who are not getting services than to those that are. Historically, Community Living associations are the organized part of the concerned community. We are in partnership with families in our communities. For that role to be fulfilled, we must restore the balance between the business of developmental services and our first duty to our community and its people. We have to draw a line between regulated service

delivery, which is a TPA function, and our ongoing advocacy role and related community development activities.

The application of TPA rules by government to our engagement with families is distracting, and sometimes can be harmful. Application of TPA rules to our other community activities is putting our community role at risk. We must effectively manage that risk factor. I heard an example of that this morning: parents who had been to DSOs, and were no further ahead in receiving supports that they so desperately need. So we are in a position and our role then is to try to assist them to come together and, as a pooled resource, try to manage for a bit longer with their sons and daughters.

We believe a true partnership with government is still possible and can be restored. The provincial government has been a valued partner in the development of community services, but the relationship has become strained by some of the choices in the implementation of the new legislation.

Our identity as the organized part of the concerned community spans six decades. We are more than a delivery system for a government social program. Being presented to the community as such is doing serious harm to our ability to engage the community, recruit members and volunteers, and raise funds. We are concerned about the pattern of control and constraint that is being imposed. We have a structural, ethical and legal accountability to our communities through existing lawful governance structures.

A problem for us is that families increasingly accept the identity that is being imposed operationally under the 2008 act on transfer payment agencies, including Community Living associations: that is, to treat agencies as franchise operations that deliver government-approved programs, and nothing more. The relationship between families and their local association is being reduced to one of consumers and vendors of a standardized, limited menu of development services.

Structures imposed throughout Ontario, namely DSO—Developmental Services Ontario—entities, are making our community role more difficult and, we believe, unintentionally hurting the ability of communities to come together to take care of one another in traditional, informal ways. The problem is not the DSO's responsibility for assessment and eligibility determination; the problem is the excessive control of access to community organizations that can and want to support families.

We recognize that the DSO cannot do, in isolation, the job it has been given, even though the structure created by government sets them up to do just that. Families need the system to work for them—we need it to work—but it is designed in a way that prevents the organized community from working effectively. The people working in the DSO, many of whom are trying to make a dysfunctional structure work, cannot succeed without a functioning partnership with community organizations and, I might say, with families.

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We've outlined 10 implications that we feel are important to draw your attention to. I won't go into the detail that we have provided you in the report, only to take you to the recommendations that we have for each of the implications, and then we can address those further, should we have time and should you wish.

The first one is, government should be an enabler of families and individuals with developmental disabilities. Support—don't supplant—the family, taking a holistic approach in responding to developmental disabilities. Every family should have access to the range of civic and social resources that is relevant to the person and their security and participation in the community. Those resources include funded developmental services, but they also include the array of other community supports that we have mentioned here.

Government should invest in and sustain preventative services designed to build networks of supportive relationships, and prevent and mitigate crises for individuals and families. We are clear that children who are able to grow up in inclusive, fully active and involved communities are entering adult years and then finding that the same may not apply anymore. So that early intervention and prevention, and resources and supports in the community, I think, are essential if people with disabilities are going to have friends, if they're going to have a network of social supports, and so on.

Developmental Services Ontario, DSO, should be remodelled to serve more as a bridge for families to the organized part of the concerned community. It should never act as a barrier between families and relevant community resources.

Government and agencies have a mutual responsibility to defend the integrity of people's homes. We have a shared obligation to ensure person-centred, individually appropriate responses. Shared living arrangements are of many types, not all with the same degree of agency control. Residents of government-funded residential arrangements, with the guidance of their families where appropriate, should be entitled to some say in who may share their home.

The example of the three parents this morning: They don't want a funded vacancy in a group home. They don't think their son and daughters want that or need that. So they are saying, "What we really want is to be able to have a say, and they to be able to have a say, in how they live and with whom." A funded vacancy typically is a high-cost and oftentimes unwanted and unnecessary home for the person on a wait-list.

Government should recognize that developmental services function in a community context. What parents want for their children, and what people generally want for themselves, is to have a safe and secure home; friends and relationships; and a reasonable prospect for a good future. We must keep these things in perspective.

Government should invest in children and child development. We believe that earlier and more prudent investment in children's education, health and social de-

velopment is likely to reduce dependence on specialized resources later on in adult life. This is so that children can develop a network of relationships, but also friendships and informal supports.

Government should assume an enabling role in quality improvement. We have many examples now of local associations and organizations that are accredited and that have a gold standard in service delivery. This is something we would hope that government would encourage, because it is an indication of what people can expect before they receive services, and also what they can expect as they receive supports and services.

Government should practise truthful and transparent fiscal management in response to operational costs and pressures, including the following—and before I go through the list of what those pressures are for local associations, I'm sure you have heard many, many presentations on a shortage of funding. We're not coming with that message. Although we would support that, we're not coming with that message. However, we are saying that price inflation is related to the delivery of services; reporting and accountability requirements related to quality assurance measures regulations, risk assessment, policy directives, health and safety, mandatory training and quarterly reporting; labour costs, over four years of not having any funding increases, are having an impact and have put pressure on us; staff recruitment, orientation training and retention costs; our mutual responsibility to foster social inclusion and service innovation; and sustainability issues arising from the use of short-term funding to address long-term needs.

There is also a need for clarity about the related issues of innovation and privatization. The emerging pattern of diverting funds to for-profit operators for short-term, temporary solutions is undermining system capabilities. We believe this is a threat that requires an informed response from government as well as from Community Living associations.

Lastly, government should enable agencies to evaluate and, where appropriate, implement proposals for office consolidation—we're not opposed to that—partnerships or amalgamations, where such changes would not run counter to our shared values and implications. Ideas for the combining of shared administrative and human resources and/or clinical expertise and services should be considered and evaluated carefully by the agencies, with government support.

I think we want to leave the remaining time for questions. We cherish your questions and will try to answer them. Thank you very much for this time with you.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. It is the government's turn. Ms. Wong.

Ms. Soo Wong: Thank you very much for your presentation, Mr. Klassen. I'm particularly interested to ask you some questions related to your recommendations, specifically dealing with quality improvement and accreditation. Can you elaborate a little bit further? Because you made comments about some of the gold standards out there. Specifically in terms of Community Living, are

there any Community Living organizations in the province that are accredited to date?

Mr. John Klassen: Yes, there are. I don't know the exact number, and I would be guessing probably 35 by now. This would be a voluntary submission to an external review of the practices and policies of an organization. Typically, organizations have been accredited by either the Council on Quality and Leadership, CARF or Focus Accreditation. So these agencies have taken it upon themselves to enter into a process of quality improvement using an external accreditation body.

Ms. Soo Wong: Okay. So it's not mandatory across the board; that's what I'm hearing, right? They're independent.

Are you aware of how, currently, there is discussion by the government dealing with open government? You asked for fiscal transparency. Are you aware that there are hearings across Ontario talking about open government? Is your organization prepared to go and speak about this piece? That would be something that—I'm not sure you're aware of it. There's an opportunity for your group and your organization to speak, because they're travelling across Ontario.

Mr. John Klassen: Thank you.

Ms. Soo Wong: Something to consider.

Mr. John Klassen: Yes.

Ms. Soo Wong: The other piece is, I wanted to hear a little bit more about your ninth recommendation to the committee, the issue of innovation and privatization. Can you elaborate a little bit more about that concern? Because you certainly raised some concerns to me. Can you elaborate a little bit further about this threat for the operators, specifically?

Mr. John Klassen: Mr. McWhorter will answer that.

Mr. Alan McWhorter: Maybe I can respond to that. First of all, I think this is more of an issue in some regions than others, so it may not be recognized as a—

Ms. Soo Wong: So which region are we talking about?

Mr. Alan McWhorter: I would particularly refer to the southeast region. I believe it would probably also apply to the region where the Ottawa office is based—eastern, I guess. There is a long history, particularly with children who are in the care of child welfare agencies, of using for-profit contractors to provide residential services. What often happens when those children reach 18—they're then no longer eligible for child welfare—is, that developmental services agencies pick up the responsibility.

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Without the resources to plan appropriately and develop new resources for those kids, there often is no place for them. A pattern, then, has emerged of keeping the kids in the for-profit provider and flowing funding for that through a transfer payment agency to pay them. That raises other issues in terms of the standards set out in the legislation, and that responsibility for policing them is also being downloaded to agencies. There are other examples of that, but that's the main one, the pattern being

that we're spending the money but we're not developing the capability. This is a growing issue. I understand from colleagues in other parts of the province that this pattern is less of an issue in some regions and they do things in different ways, so I'm not really up to date on how this plays out across the whole province, but I know that where it is an issue, it's one of those things that keeps growing and becoming more of a problem, and it is kind of a cloud over the future direction.

The Chair (Mrs. Laura Albanese): Thank you. Sorry, the time is up.

Ms. Elliott?

Mrs. Christine Elliott: Thank you very much for coming to Queen's Park today and for your presentation. I'm just wanting to explore a little bit more about the sort of dysfunctional relationship you see now between the DSOs and Community Living and other organizations, the conflict that you see, and the lack of choices. I'm wondering if you could give us some more specific examples of that and why it's such a problem.

Mr. Alan McWhorter: Yes, okay. I'll respond to that.

The assumption, I think—let me back up a little bit. The legislation that was enacted in 2008 is, I think, a pretty good piece of legislation. There was a lot of consultation around it when it was being developed. In the implementation, we have some bumps in the road, and I don't think these are things that are fatal flaws, but they are definitely problems that need to be addressed. The way the DSO has been implemented has been part of that problem.

The reason why it's a problem is partly because of the narrow vision behind the act. It focuses on equitable distribution of resources, but only developmental services funded by government. In the context of the community, where real life goes on, developmental services are a part of it, but most of the things people need to be part of the community, if they have a developmental disability are those informal supports or things that are generically available.

Our organizations locally have always, for our 60 years of existence, been involved with families in working through things, planning with them, trying to figure out how to cobble together what people need, mainly from those kinds of resources. Now families are being told, "You have to go through the DSO," and agencies are not even provided with information about them, unless there's a referral, and a referral typically doesn't come unless there's a vacancy listed in a group home or something.

So the effect, which I'm sure is not an intended effect, has been to leave families stranded without access to the agencies that could be, and traditionally have been, supportive. For agencies not to know who those people are unless they've had previous contact with them—those that provide children's services often know people as they're growing up, but many of them don't provide children's services. So what happens at 18 is, they are referred to the DSO, the DSO processes them, and they're left in limbo, and the agency doesn't even know they are

there. Solving that problem doesn't solve all the other problems, the lack of resources and so on, but a lot happens informally when people work together.

Given the fact that the lack of resources is probably not going to change in the foreseeable future, it's more important than ever that families have access to those informal organizational supports, access to other families—someone who will help them figure their way through it without going through a formal approval process, and especially without government funding when there's not likely going to be any.

That's the problem. It's not an insurmountable problem; it's not a problem with the legislation. It's a problem with the implementation of it.

Mr. John Klassen: If you did a "before and after" snapshot, before DSO you would have seen local organizations come together around a table, oftentimes with families, trying to understand what the needs are and then to be able to match those with what exists in resources either within developmental services organizations or, as Alan was saying, beyond that: "What does the community have that would be a benefit to families?"

Mrs. Christine Elliott: Thank you very much; that really helps.

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

Ms. Cheri DiNovo: I was going to ask just flat out, should the DSO be scrapped? I'm just building on what Ms. Elliott asked. We've certainly heard some horror stories here from parents in terms of what service they provide to them, such as it is. You seem to be saying, rather than scrapped, reformed. Is that what I'm hearing?

Mr. Alan McWhorter: I think the functions of the DSO in assessing need are important functions to the system. There has to be some determination of eligibility. There has to be some basis where provincial funding is provided to support people. It needs to be provided in a rational way. I understand that.

The problem is the narrow vision, of just looking at that. That becomes, then, a wedge between families that aren't necessarily getting services and the informal things that might be done to help them.

Ms. Cheri DiNovo: You're being very diplomatic. I thank you for presentation in that regard.

In terms of the funding process, you're talking about crisis funding. Certainly we're hearing from parents how that is experienced in the field: that until your child is in crisis or until you're in crisis—we just heard from children's aid, for example, from Peel region. All of a sudden services tend to open up for you if you're about to abandon your child. But short of that, you're caught in an endless labyrinth of trying to get the help you need. How do we address this? You're on the ground. What is the more direct way of addressing that core issue which we're hearing over and over again?

Mr. John Klassen: I would boil it down to relationships with families and with communities. It can't be overstated how important that is, to be able to understand and have that face-to-face relationship with people who are struggling, who are desperately in need and who

don't know where to turn. Without that relationship continuing on, as we have had in the past and we're afraid is under threat, I think this is going to get worse rather than better. By the time the family is in crisis, we are not in a position to provide ideal supports for that son or daughter and that family.

Ms. Cheri DiNovo: Just very quickly, because we don't have a lot of time left: Part of the problem with the funding—we're having a hard time getting figures on this, wait-list figures or anything that we really need from the ministry, so perhaps you could send some of us this information.

If it's a crisis model of intervention, it's a very expensive model of intervention. If there's more planning involved and more help quickly for families, it's less expensive. But there doesn't seem to be the will anywhere to invoke that. But there's no comparison either. We don't know what we're comparing. Long-term care in a seniors' home versus getting day program respite seems like a bizarre choice because one is so much more expensive than the other. But we don't have the figures to work with. Where do we get them?

The Chair (Mrs. Laura Albanese): Thirty seconds.

Mr. Alan McWhorter: Even though I'm a retired guy acting in a consulting role now, I was executive director of the association in Kingston for 25 years. I know what it feels like on the ground.

What happens when you have a crisis to deal with typically is, the family has reached the end of their rope. An earlier intervention might have been good, but by the time it's a crisis, they've reached the end of their rope, and they need a long-term commitment. They need a residential placement; they need something like that. What happens, then, if you're running an agency, if you're the executive director of an agency that's struggling to get by, is, if you're offered funding temporarily, from a temporary crisis pot, you're in a position of saying to a family, "Either I'll make a long-term commitment, or I can't." If you make a long-term commitment, and that funding runs out at the end of the fiscal year, you can't send that person back home; you can't put them back on the street. You've got a responsibility then. That responsibility can be an expensive one.

As an executive director, I'm very hesitant to use short-term funding to address a crisis like that because you're putting your agency at financial risk, especially if there's more than one at a time, and there often are. So if it's a long-term need, there needs to be a long-term commitment. If, of course, you refuse to do that as an agency, then you're seen as part of the problem, a bad agency. If you rely on volunteers and volunteer money and fundraising, you've got a bad reputation problem if you say no; you've got a financial crisis next year if you say yes.

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We understand—I think everybody understands—that there's just not a lot of money out there. The Ombudsman is dealing with a lot of these issues. I don't know what the answer is, but the answer is not short-term money to plug holes in the dike when the holes in the

dike are long-term commitments to people, and there's no other way around it.

I think we need to be aware of that. I think we need to confront these problems honestly, instead of saying we're doing something when, in fact, it's a Band-Aid that's going to come off.

Ms. Cheri DiNovo: Thank you.

Mr. Alan McWhorter: Anyway, I'm going on too much here, but you get the point.

The Chair (Mrs. Laura Albanese): Well, that was quite comprehensive. Thank you very much. Thank you for your time and for your insight into the matter.

Mr. Alan McWhorter: Thank you for the opportunity.

HEALTH CARE ACCESS RESEARCH AND DEVELOPMENTAL DISABILITIES PROGRAM

The Chair (Mrs. Laura Albanese): We'll call now on the Health Care Access Research and Developmental Disabilities program, H-CARDD. Please come forward and have a seat.

Please make sure to state your name and title before you begin, so we can familiarize ourselves with the presenters and also for the purposes of Hansard. You'll have up to 30 minutes for the presentation. Should there be time left over, we will have questions from the members of the committee. Thank you.

Dr. Yona Lunsky: Good afternoon. My name is Yona Lunsky. I'm representing the H-CARDD program with three of my colleagues. I'll be speaking today, but I'm here with Elizabeth Lin, Hélène Ouellette-Kuntz and Robert Balogh.

You have a handout with you. The first slide—really, our title—explains all of what it is that we do. I'd like you to take notice of the three photos in our title. This is a partnership where we work together with people with developmental disabilities, with families, with scientists, clinicians, policy-makers. In these photos, you see people with developmental disabilities teaching health care providers about how to provide their health care best.

The second slide demonstrates how many people are partnered in our program. I just want to emphasize that it's province-wide in nature. We come to the table wearing many different hats. Some people are both scientists and families or scientists and clinicians, and we work, in terms of our partnerships, with either health planners from the LHINs or different ministries. We're involved with the Ministry of Community and Social Services, with the Ministry of Health, the Ministry of Children and Youth Services and the Ministry of Education. So we're all working at the table together to address issues of health care.

Our original funding came from CIHR, which is the federal funding organization for health, and we have continued funding now through the Ministry of Health's health systems research program.

The next slide—I guess you have to try hard not to read ahead—really is the culmination of our work, which

is an atlas, which I would say took at least probably four years for all these people working together across the province to put together. I believe you received a copy of the atlas recently when it came out. We've also included the executive summary of the atlas in the handouts that you have with you today.

I'm going to go through a series of slides—they look like graphs—and I'm going to explain one or two key points in each graph. I really want to focus our time today talking more about solutions, but I think in order to do that, we need to set the stage.

The first figure that I would like you to look at is the one entitled “Where Do the Data Come From?” If we are going to plan for people with developmental disabilities, the very first thing we need to know is, who are we talking about? How many people are there? What do they look like? What are their health issues? How do we plan for them? In order for us to address that issue, we worked very carefully and very closely with the Ministry of Health and the Ministry of Community and Social Services to link data from different sectors.

So what you see in this diagram, if you look at the very bottom, it says that we studied 66,484 adults between 18 and 64 with developmental disabilities. We found those individuals to study them through bringing information together from all the resources we had in terms of health services with all the information we could get from people receiving ODSP, the Ontario Disability Support Program, who were diagnosed with a developmental disability in order to get those services. We put those things together.

If you look at how these two circles overlap, there isn't a perfect overlap, and that's a very important point because what it tells us is that not everybody with a developmental disability is known, if you're approaching it from just one sector. Only about 30% of people were identified as having a developmental disability both in health data and in social services data. So if we want to plan fully for these individuals, we really need to bring our sectors together for the data.

Even though we're talking today about 66,000-plus individuals, that does not capture all the adults with developmental disabilities in our province. That's through linking data together from two sectors. We also need information from education, we also need information from children and youth services, from justice. Right? So if we really want to know who we're dealing with and plan appropriately, we need all of them there.

The next slide is a map, really, of Ontario. What I want to highlight there is that if we look at where individuals with developmental disabilities are living in adulthood, they're living across our province. The other point I want to make is that if you wanted to understand what was going on in your LHIN or in your jurisdiction, we have the ability to do that. In fact, we've presented that information in the full atlas, which you have a copy of.

We know how many people we studied, but the question is, how is their health and how does it compare to other people in Ontario of the same age and gender? This next figure shows a number of common chronic dis-

eases that we study through ICES generally in the adult population. It compares the rates of those conditions, so how many people have those health issues with developmental disabilities compared to without. The first thing you're going to notice is that in each one of those conditions, individuals with developmental disabilities score higher, meaning more individuals with developmental disabilities have those health issues than people without developmental disabilities, with the exception of hypertension.

The other thing you're probably drawn to, which is very important, given the mandate and the focus of this committee, are the last two bars: psychiatric disorder. You are interested in the issue of dual diagnosis. If I was to say what that means, the way I understand it—and it's something I've studied for a long time—it is that you're looking at psychiatric disorders or illnesses in individuals who also have a developmental disability. What you see very clearly in this figure is that almost one in two adults with developmental disabilities have one of those psychiatric disorders diagnosed in a two-year period. We looked at between 2007 and 2009. So very high rates compared to individuals without developmental disabilities. It's really, I think, one reason why it's so important to focus on that issue, but also to keep in mind that we need to think about those other health issues that are also happening at higher rates in people with developmental disabilities than those without.

Moving right along, in terms of health care visits, the next slide, I just want to emphasize that the issue is not that they do not get in to see a primary care doctor; the rates of visiting their primary care physician are similar to people without developmental disabilities, but the rates of emergency department use, the likelihood of use and also the number of visits are much higher. We also see that the likelihood of being hospitalized for something, whether it's a psychiatric hospitalization or a medical hospitalization, is also higher.

The next slide focuses on medication. We were able to study the medication patterns of about 50,000 adults with developmental disabilities in our province. The first point I want to make, if you look at the later columns in this figure, is that almost half of those 50,000 people were prescribed two or more medications at the same time, with some individuals taking as many as eight to 10 or 11 medications at once. We looked at how well those medications were monitored and very concerning was the fact that for some individuals—about 33% of the people prescribed five or more medications at the same time were not getting regular follow-up care with their primary care physician to monitor those medications. The other really important point that you don't see from the figure but is outlined in our atlas is that the most commonly prescribed medications for this population are psychiatric medications, with antipsychotic medications being the most common. This is not because psychotic disorders are so prevalent in the population; it's also because we're giving those medications most likely for other reasons. These are very potent medications with very significant

side effects, and as I mentioned, they're not always well monitored, and they're quite costly.

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Moving along, there's a lovely photo here of a primary care physician, talking about the importance of the health check or that preventative care examination. If we were to make one recommendation in terms of the primary care guidelines that have been written and which you'll be hearing more about in a little bit, it's the importance of having this regular preventative exam. The next figure shows that the likelihood of having that examination for people with developmental disabilities is not as high as we would like.

The next two figures following that look at another kind of preventative care, which is the screening that we all would like to have happen for us around cancer. There are two figures here, one on mammography and one on colorectal screening. They both show the very same disturbing pattern of individuals with developmental disabilities being less likely to get screened for those conditions. The same applies for cervical cancer, which is not shown.

There are other ways we can study the quality of care for people with developmental disabilities. If we go to the slide that's called "Avoidable Hospitalizations," we finally see the opposite pattern, where the blue line—developmental disabilities—is higher than for those without developmental disabilities. But it means they're having more hospitalizations that should be avoided or managed in the community than we would see for people without developmental disabilities. Again, this is very concerning. If we're giving the right kind of primary care in the community, we want to be able to keep people out of hospital, and we're not as successful at doing that if you have a developmental disability than if you don't.

Where do we go from here? We have three recommendations in our report, and I'm just going to review them briefly so that we can leave some time for questions. The first is that if we want to make a difference for the health care of this population, we need to focus on improving the primary care that can be provided and we need to make use of the excellent evidence that is already out there and the care standards that have been written up. I don't have them right in front of me because I forgot, but you'll be hearing shortly after me about the primary care guidelines that were developed here in Ontario, as well as some very useful clinical tools that are available to all health care providers here in our province, on paper and electronically.

When we give this care, it needs to be balanced in terms of prevention, as well as managing all of those complex health issues that I've already discussed. We need to focus on physical health care and also mental health care. We need to take an inter-professional approach to that care. It is too complicated for one physician or one health care provider to do alone. So we need to look at how people can work together as a team to provide the right kind of care. If we want the care to be successful, it's not enough just to have guidelines—we already have them. We need to make sure those guide-

lines and tools are at the hands of the person who needs them when they need them.

If I go into my electronic health record, it should pop up that I'm seeing a patient with a developmental disability, and then the tool that I need to use to help me give the best care should be right there electronically. If I want them to go and get a mammogram, I want to print a little handout for them that I can give to them and their caregiver that explains how they prepare for a mammogram and what it's about, that is written in language that they can understand. If I'm monitoring their medications, I want that clue right away of what monitoring I need to look at with those medications for that individual because of their complexities, or that I need to book a longer appointment for them next time they come in and I need to see them in three months.

The next slide looks at how we need to modify the broader health care system, because it's not just primary care. We mentioned that they're in emergency departments and in the hospitals. We need to bring all those types of care together. We need unified care plans that follow the patient, that speak to all of the complexities that everybody is aware of and that get updated and that can be followed. Sometimes that information even needs to cross sectors, so not just crossing from primary care to hospital care to specialist care, but maybe it also needs to be available to the people in social services who are involved in providing that care, for example.

Finally, if we want people to give the right kind of care, they need to be supported to do that. It takes longer than it does if you're a patient who doesn't have a developmental disability, so we need the financial remuneration to support that. There are models of that for other types of chronic conditions, where physicians receive a financial reimbursement for doing types of care, and that's the kind of thing that needs to be seen. We've seen the evidence in other jurisdictions, like Australia and the UK, where, for example, that important primary care exam I mentioned—by instituting that with the appropriate financial remuneration, we see earlier recognition of disease; we see cost-saving benefits for those individuals and their families.

The last recommendation we have is about partnerships, not just partnerships with policy and partnerships with clinicians, but at the core of it all are the partnerships we need to have with patients with developmental disabilities, with their families and with paid caregivers. So you know the phrase, "Nothing about us, without us." They need to tell us how they can advocate for their care, and they need to be educated if they're going to tell us that correctly. We can't design systems for them. We need the support to be able to work with them to do that.

I guess the last comment I'll make about that is, sometimes in health care, in chronic disease management, for example, we talk about self-management. Well, it's more than just self-management with this population. We can't just make our writing simpler and expect that everyone with a developmental disability can follow it. We need to

think about how we can also involve caregivers specifically in that process so they're working on it together.

The last two slides: I have a quote of one of the individuals who talked to us a little bit about what medication issues mean to him. A very big part of our program is hearing from people with disabilities and their families about how you would need to change things. But then we have a little picture, I guess, of the different ingredients we think are essential if you want to bring about change.

The instructions or the guidelines and the aids are those clinical tools that we've already developed and that we're continuing to develop for this population, but we need buy-in from all of the different sectors. We need the policy that is there from different decision-makers—not just policy from one area of government, but policy that crosses over different parts of government. And we need that critical mass that we've already, I think, developed here in Ontario to push these things forward.

But finally, we can't do it without the data. I think so often we go on the basis of stories—you know, things we've observed in our own jurisdiction—but we need the numbers. They can really tell us what works and what doesn't, and they can also tell us if our investments are making a difference, because we can study the changes that have been made.

The final slide just gives some examples of where our program is going. Through our continued funding, through CIHR and the Ministry of Health, we're looking more closely at that issue of dual diagnosis, or mental health and addictions. We're studying that transition that we've been hearing about here about youth who are going into the adult system, aging adults and the use of long-term care, and also women's health issues. At the same time, we're working with emergency care and primary care to try to figure out, if we make changes, what benefits do they have? So we'll have more of that evidence hopefully in the next short while, a couple of years; that's how science goes.

So we're ready for questions.

The Chair (Mrs. Laura Albanese): Thank you very much for the presentation. Ms. Jones?

Ms. Sylvia Jones: That was excellent—lots to roll around our head. But I just want to say that I'm really glad that you gave us this summary, because I actually opened up the atlas and sort of went, "There's an awful lot of reading in there," so this is helpful.

So you see an opportunity within the primary health care sector where we can get to a stage where our primary care physicians, our primary care practitioners, are able to serve the developmental disability population very well, as long as they have the tools that you're referencing.

Dr. Yona Lunsky: I think they need the tools, the guidelines; the tools actually embedded in their daily practice, and the supports of the rest of the health care system, because we can't put it all on primary care. I think that's where we start. That's the medical home. We need to recognize—

Ms. Sylvia Jones: Yes, the challenge is that's where everyone else starts, right?

Dr. Yona Lunsky: That's right.

Ms. Sylvia Jones: So even if it's only an opportunity for referral going forward, they do have to be the first—the front line, for lack of a better word.

Dr. Yona Lunsky: Absolutely, and there are models. For example, the family health team is a model where you've got not just a physician working on their own, but you've got a whole group, an interprofessional group working together so that other people can be involved in giving that care; it's not just the physician.

Ms. Sylvia Jones: I agree, and I guess the only challenge that I have had, anecdotally, with that model is, of course, you have to be rostered with that FHN or FHT in order to access those. And there are lots of excellent programs, but you do have to be sort of within that group.

Dr. Yona Lunsky: We want our vulnerable populations to be able to get into those kinds of services, right?

Ms. Sylvia Jones: Yes.

Dr. Yona Lunsky: That's really important, and we need the incentives to be there so that people are willing and able to provide the service they should be providing.

Ms. Sylvia Jones: Thank you.

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

Mrs. Christine Elliott: Not a question, just a comment: It's great to see you again, Dr. Lunsky, and thanks to you and your team for the excellent work that you're doing. It really helps inform us. I think that, anecdotally, we know that people with developmental disabilities don't always get their fair share, I guess, of primary health care. So this study is really helpful for us to be able to comment on it more intelligently. Thank you.

The Chair (Mrs. Laura Albanese): I'll turn it over to the NDP. Ms. DiNovo or Ms. Taylor?

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

A couple of questions: financial structures under that—what do you exactly mean by that in terms of managed care? Perhaps you could elaborate on that. What sort of financial structure might be put in place that would serve the community we're speaking about better?
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Dr. Yona Lunsky: For example, I know there are discussions happening right now around whether patients with different types of health complexities—if seeing them would come with a certain amount of funding that you get for seeing and serving those patients.

Ms. Cheri DiNovo: So pay doctors more?

Dr. Yona Lunsky: If you're serving a patient with a developmental disability, you recognize that it actually costs more and takes more time to see them. It can be on the basis of the patient, and it can also be on the basis of the procedure. For example, that annual health exam that we're talking about isn't something that's done or that is required for the general population in the same way, but it's really important for this population, and it takes a certain amount of time to do it. So maybe if there's an

incentive to make sure that everybody gets that exam, that can make a difference.

Ms. Cheri DiNovo: The other question flowed from what I had asked the former folk, and that is about crisis management versus long-term planning. Clearly, when I look at the charts, I'm seeing a pattern of overmedication, and perhaps overdiagnosis and overhospitalization as a result. Immediately what I'm thinking of is psychiatric drugs used to control behaviour that they were never meant to be used for, simply because that's the only way, cost-effectively, we have of dealing with folk, which is a pretty troubling trend, which is pretty horrendous, really, when you think about it. Obviously, you must have thought about that kind of backdrop to your study, and I'm asking you to go beyond the parameters of the science here and just extrapolate a little bit. We're spending more money on crisis care than we would on long-term preventive medicine here. What do you see as some kinds of preventive steps we should be taking to prevent the outcomes you're witnessing here?

Dr. Yona Lunsky: Yes, I think you're raising an important point, that we spend our money somewhere, so we may be spending our money on medications or on repeat emergency hospital visits, which are very expensive, but it's not the right kind of care we want to be giving.

I think, in terms of the direction that we could be going in, we need to be speaking with our families early on, not even when their children are young adults, but even when they're still in school, when we can reach out to the entire school system and give people education about the importance of health and a balanced approach to health care, helping them navigate that system and also making sure that health care providers understand how to navigate the social services system, for example, or the education system. The physician needs the information because that's the person the family is going to go to before they know about the DSO or anywhere else. So they get directed to the DSO. The DSO can have information to share about ongoing health care, how to monitor medications, things to be alert to, to go in and see their doctor once a year. There are probably a lot of places that we could get in earlier, and definitely I think that would make a difference.

Ms. Cheri DiNovo: Thank you.

Miss Monique Taylor: I just want to come back to the tools that you were talking about. Are those tools already available to you? Or are they tools that should be made available?

Dr. Yona Lunsky: Right behind me, I'll wave the invisible tool booklet that is sitting in my bag. There it is. That's an example of a tool that was developed here in Ontario. It's available online for all family physicians through a couple of programs. Physicians have actually mixed it in within their electronic health records, so you can pull up these tools electronically as you're working with the patient—but it's not across the province.

Miss Monique Taylor: That's exactly what I was talking about—electronically. So we don't have that across the province?

Dr. Yona Lunsky: Well, you have these. Every family physician across the country got mailed this, and you have them on your desk—but electronically embedded into your health record—depends on which team you're in. We're slowly seeing the success of that in some parts of the province, and that's something we're studying to see how it works. There are other kinds of tools that are still being developed, and our team is maybe one team developing tools. The group that's going after us will speak about some other tools that are being developed to help families and individuals.

Miss Monique Taylor: That's definitely something that we've been hearing from families: that they're lost and they don't know how to navigate the system. There should be something right from diagnosis that—the doctor would be that person—leads them in a direction of how to get the services as they're going through life. The doctor is always that key person in a person's life. Hopefully, that doesn't change. So it's an important piece.

Dr. Yona Lunsky: The H-CARDD website has a lot of information on some of these different resources for different audiences, and also the primary care website has a lot of that information. But sometimes it's how we get that word out so everyone knows about it.

Miss Monique Taylor: I'm just curious, and maybe it's for research to find for us: Which parts of the province are using these tools, and which parts of the province would still need these tools?

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

Ms. Mitzie Hunter: Thank you for your presentation and also for the research that you have provided to us. I'm wondering if this presentation is available currently in soft copy, to the Chair and to the Clerk? There's a graph here that I would like to take a closer look at.

The Chair (Mrs. Laura Albanese): Would that be the map?

Ms. Mitzie Hunter: The map, yes.

Dr. Yona Lunsky: For each of those figures, there's an entire chapter in the atlas as well that really explains all of it in detail.

Ms. Mitzie Hunter: Okay. If we can get the soft copy.

You described the type of care that would be ideal for a primary care physician with someone with multiple diagnoses. What is stopping that from happening today? What are the barriers to delivering that type of care, follow-up and consistent support?

Dr. Yona Lunsky: There are many pieces, right? One is that the health care provider might not have the information they need to know how to do those things. They may not have the time. Sometimes, when we talk about complexities, there are shared-care models, where you've got your primary care physician, for example, working with specialists in consultation with them. So if we're managing diabetes, we might have to have some of our work with an endocrinologist, with a dietitian. You need that team kind of approach, and they all have to know how to work with people with developmental disabilities and what some of the unique issues are.

I think there's the training element, there's the financial remuneration element and the connections, not only with other parts of the health system, but also with other parts of the sector, so with the direct care staff from the group home or with the family, even funding to be able to get to a doctor's appointment, even making sure that Wheel-Trans works out okay and you make it there on time, and it's at the right time of day and the office is quiet, because examinations are stressful for someone with a developmental disability. So there are lots of considerations. I don't think people always have the training or the resources to do that.

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

Ms. Mitzie Hunter: And are you—

The Chair (Mrs. Laura Albanese): Oh, sorry. I thought it was passing on to Ms. Wong. Please go ahead.

Ms. Mitzie Hunter: I will pass to Ms. Wong.

Ms. Soo Wong: Thank you very much for your presentation. I just wanted to hear your comments. On your last slide here on page 10, you identify your vulnerable sub-group, but I'm surprised that you don't put the word "diversity."

Dr. Yona Lunskey: Right. We live in a very diverse province, absolutely. This is just highlighting how there are many vulnerable sub-groups. The particular funding opportunity for which we had to put this proposal forward was interested in particular sub-groups, so that was that, plus the stakeholders, including different people from the different branches of government, different stakeholders in the community. These were the four key populations that we agreed were most important to start with.

Ms. Soo Wong: So diversity is not excluded from these four.

Dr. Yona Lunskey: Absolutely not. I think with our data that we have, it was a bit tricky at the time to identify some of those diversity issues. We can look at age, we can look at sex with ICES, with administrative data, the data we're working with. It's harder to study diversity. We'd have to link it with other data sources to get that information, which again emphasizes the importance of linking the data which already exist, which can inform our decision-making. But we don't have that information yet.

Ms. Soo Wong: Thank you.

The Chair (Mrs. Laura Albanese): Okay. Well, thank you very much for presenting to us this afternoon. We really appreciate the material you have provided and the information you have given us.

Dr. Yona Lunskey: Thank you.

SURREY PLACE CENTRE,
MEDICAL SERVICES

The Chair (Mrs. Laura Albanese): We'll now call on Surrey Place Centre, medical services. Welcome. Good afternoon. I would kindly ask you to begin by stating your name and title before beginning your presentation. You will have up to 30 minutes for the presenta-

tion. Should it be shorter, then that would allow for questions.

You may begin any time you feel ready.

Dr. Alvin Loh: Thank you so much for inviting us to come and share with you this afternoon. I'm Dr. Alvin Loh. I'm a developmental pediatrician and the director of medical services at Surrey Place Centre and also the lead of the Autism Treatment Network in Toronto for children and youth. I'm representing medical services today with my colleagues.

Surrey Place is a community-based outpatient interdisciplinary centre for people with developmental disabilities and/or autism spectrum disorder. Surrey Place is funded by the Ministry of Community and Social Services and the Ministry of Children and Youth Services. It is also a teaching site affiliated with the University of Toronto for all levels of medical training, from medical school to residency to specialist training and after, and it also does nurse education.

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Medical service at Surrey Place includes three full-time physicians and three full-time nurses in the areas of developmental pediatrics, family medicine and psychiatry. There are also consultants in neurology and ENT who come once a month. We work with people with DD or ASD and their families and caregivers, of any age—from infancy to elderly—and for any health issue, physical health, mental health or behavioural issues.

The developmental disabilities primary care initiative is based at Surrey Place Centre, and as well, Surrey Place is one of the lead agencies in the autism treatment network in Toronto.

We're delighted to be able to share with the select committee some of the things from our experience, to highlight some things for your consideration. The first is, we weren't sure, when we were looking at the business of the committee, the focus of the committee, how big of an issue health would be. So we thought our first point is to state that health is an essential contributor to the overall well-being of people with DD and/or ASD.

Problem behaviours, as you've probably heard from different groups already, can be a major barrier to social well-being—so aggressive behaviour and self-injury. What we know is that these behaviours are often a symptom of a physical health disorder up to about 40% of the time. What happens is that many medical conditions such as gastrointestinal conditions, metabolic, nutritional and neurological disorders, which are preventable, are often undetected and as a result untreated or inappropriately treated. As a result of that, adverse effects occur for the individual on their everyday functioning, and it can affect their behaviour, their communication and their socialization. These conditions can be chronic and progressive—they can get worse and worse—and can lead to premature death.

Because the interactions between behaviour and other areas are not as well known—for example, a lot of physicians, when they see behaviour, they think, "Oh, it's a mental health problem; we should maybe treat it with an

antipsychotic medication.” But they often forget that physical health can be a major contributor. The environment, if it’s very stressful, can be a contributor for a behaviour, and things like that. What this leads to is inappropriate care and inappropriate use of health resources.

For example, there’s a case where a 22-year-old man named Edward had a developmental disability and autism spectrum disorder. He had this long history of two years of self-harm, agitation, frequent awakening at nights and aggression towards others. He had very limited speech and poor socialization, and also a long-standing history of constipation. His aggressive behaviour made it very challenging for him to be placed in a group home or a day program. As a result, he had repeated visits to the emergency room because of episodes of aggression. He was treated with psychotropic medications. Eventually, after a long period of time, he was diagnosed with gastroesophageal reflux disease by a gastroenterologist, and then he was referred to a surgeon, where he received gastric fundoplication surgery to treat the condition.

Since that time, his aggressive behaviour has not recurred, and his speech and his social interactions have improved. We see the major impact of untreated physical health on behaviour and on the inappropriate use of health resources and inappropriate suffering for this individual.

The other aspect of health to touch on—we’ve talked about physical health—is mental health. In individuals who have developmental disabilities, anywhere between 15% to 60% can have a mental health disorder, depending on the severity of their intellectual disability. It’s a similarly high rate of comorbidity in individuals who have an autism spectrum disorder.

As you know, if you’re feeling anxious, if you’re feeling worried, if you’re feeling depressed, you’re not going to be able to interact socially or participate in community events, so that’s going to be a major impact on social well-being.

I just wanted to end with one of the comments or questions that Cheri raised about crisis situations, from the previous group. I think one of the problems that our group has had is that they’ve had very difficult times accessing mental health because of their diagnosis, or, because they’ve had autism spectrum disorder or an intellectual disability, there are not agencies that are mandated to treat them. There are very few professionals who are trained with the expertise, who feel comfortable treating them, so often they’re declined treatment again and again and again.

I have one patient whose mother had a seven-year-old boy, at that time, and he was depressed and anxious. He was having self-harm behaviour and aggression at school. He was threatening suicide. She called every agency on the mental health Ontario site—she’s a very capable mom—and every single one of them told her that he could not receive service from her because he had autism spectrum disorder.

She firmly said, “That’s not his major problem. His major problem is a mental health problem right now.”

But they declined, and it was only through repeated trying at the same institution that they finally said, “Okay. Fine, we’ll see him.” She was a very capable mom, so I know that this is a very challenging problem. It’s the barrier to care. Once you’re labelled with autism or intellectual disability, mental health services feel very uncomfortable treating an individual.

So I’m going to pause there and hand it over to my colleague.

Dr. Bill Sullivan: Hello. Thank you very much for this invitation. My name is Bill Sullivan. I’m a family physician based at Surrey Place Centre and St. Michael’s Hospital, so I work in one of these family health teams. I’ve also been the director of the primary care initiative that you’ve heard about that develops guidelines and tools.

But I guess what my colleague Alvin Loh has just talked about is the importance of linking health with social well-being, so just to make that point that we don’t forget about health as a component.

The further point that we wanted to raise with the committee for your consideration is that people with developmental disabilities and autism spectrum disorder—we’ll say DD and ASD—often have different and sometimes complex health issues that require knowledgeable care providers and adaptations to usual approaches in practice.

So I’ll just explain this a little bit. Accurate and timely diagnosis and treatment, as well as appropriate preventive care and health promotion, can result in improved functioning, decreased severity and enhanced management of symptoms in people with DD and ASD, and the avoidance of premature death. The generic health care system alone is ill-equipped to recognize and address the different and often complex health issues that people with DD and ASD encounter.

For example, appropriate family medicine and specialist care often is not available for these adults. People with DD and/or ASD often do not receive, for instance, the appropriate preventive care checklist that was just spoken about or appropriate management of many chronic conditions that they may have. So, for instance, in the atlas, the figure that you heard was all adults in Ontario—25%—had any kind of preventive care assessment in a two-year interval. One of our key guidelines is that everyone should be getting this annually. Moreover, what is not evident from that figure, which is probably closer to 11% of all adults having such an assessment, is that many of them would not have been adapted to their particular needs. So that’s what these tools and guidelines are meant to highlight for primary care providers, that there are other things that they should think about in addition to what they normally think about for most people who they see with a developmental disability—some specific things for people with developmental disabilities and autism spectrum disorder.

For example, we just heard about Edward’s case, that he was being well cared for by a pediatrician until about age 18 but was having difficulty finding a family phys-

ician over a two-year period that would take him on. A referral by his pediatrician to a specialist children's hospital to assess his aggression, which was actually a simple issue—he had heartburn—was rejected on the grounds that he was now an adult and that he had a developmental disability and autism spectrum disorder—that this was “not our area.”

He was finally seen by a family physician who was knowledgeable about the Canadian consensus guidelines on the primary care of adults with developmental disabilities. In there, it flags the importance of thinking of common things—there are about 60 of them—among people with disabilities that are physical health issues that can lead to changes in their behaviour. Based on that and doing this comprehensive health assessment, which, again, is adapted for people with developmental disabilities, this was picked up, as well as other things that were very preventable and treatable.

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The final point that we wanted to raise for the consideration of the committee was a broader one: To improve access to appropriate health care for people with developmental disabilities or autism spectrum disorder, there should be a provincial policy framework across sectors, addressing comprehensive care and long-term planning, that is supported by legislation and funded for such collaborations. As health care providers knowledgeable about health issues and the needs of people with developmental disabilities and autism spectrum disorders, we would recommend that this framework emphasize a number of things, and I will raise a few that are connected to these two examples that we just gave.

One is the importance of enhancing partnerships between health care providers—I'm speaking of the generic providers—and people with developmental disabilities or autism spectrum disorder, and their families and other caregivers. The emphasis here is that many people that we train have not had that encounter with anybody with a developmental disability, and I'm talking about family medicine residents. Then we expect them to be confident to accept them. That has to be part of the training.

Improved communication and appropriate information-sharing for services and planning purposes across sectors in the provincial government is also very important. I think that the example that was just presented from this research, that involved collaboration between ministries to collect data, was very important. This primary care initiative, from the very beginning, has always been co-sponsored by two important ministries: the Ministry of Health and the Ministry of Community and Social Services. That sort of communication and information-sharing across these ministries is so important.

Supporting a multi-level, interdisciplinary system of health care provision that addresses the health issues of people with DD and/or ASD, according to particular needs and level of complexity: An example of such a model has been presented already in British Columbia in their Children and Youth with Special Needs: A Frame-

work for Action. It's a document published in 2008. There are other such models, for instance, in the United Kingdom. Colleagues who are with us today are very familiar with those examples, that we could speak to momentarily.

Ensuring quality of primary care through sharing of guidelines, resources such as these tools that you've talked about, and health targets: The number of people who are getting a preventive care assessment, of all adults in Ontario, we can estimate, is probably less than 10% per year. That's an important target to be monitored. Our feeling—and I would agree wholeheartedly with Dr. Lunskey on this—is that this is the number one thing. To just get them to do that kind of appropriate assessment would make a huge difference to preventing many health issues that arise. If we could monitor and see that 5% getting up to international standards—Wales, for instance, is over 50%—this is targeted preventive care assessments.

Furthermore, recruiting, training and providing clinical support for primary care providers in the particular health issues of people with DD or ASD, using shared guidelines and resources: I think we are in a situation in medicine that was similar to palliative care five years ago or 10 years ago, of needing to train up people and make them familiar with this, as just part of general knowledge of all medical trainees.

I think I'll end with the importance of evaluation and research so that we are continuing to assess what we're doing and to improve.

Finally, joint funding and support across sectors of programs and services that develop the above goals is what we would ask for this committee to consider.

Just in summary, we wanted to raise three main points. The first is the importance of including health in your consideration. We don't want to overemphasize it, but just to recognize that, if you're talking about a comprehensive strategy, this ought to be part of that strategy. Second is the recognition that the current strategy is to use generic health care providers and services—just to recognize it. This generation really hasn't been trained to deal with very basic issues that can cause big problems for people with developmental disabilities. Finally, just to commend you for thinking about this in a very broad picture: I think you should think about what you're doing as building the basic framework for another generation. This is a very important opportunity, and we really want to just offer whatever expertise or help we could provide this committee in your very important work.

I'll finish with that and open for questions and also encourage my colleagues, who are very knowledgeable about various other aspects, when they respond, to introduce themselves.

The Vice-Chair (Mrs. Christine Elliott): Thank you very much, Dr. Sullivan and Dr. Loh. We do have some time for questions, just under four minutes for each party.

Ms. Mitzie Hunter: I was wondering about your comment, Dr. Loh, describing a reticence to treat once a

diagnosis is made. Can you talk just a little bit more about that?

Dr. Alvin Loh: Sure. I'll try to share some of the experiences that we've had with families. I think a lot of agencies tell us, "We're not mandated to treat an individual with ASD or DD"; for example, even Sick Children's hospital—a very good hospital. We were killing ourselves to try to get some of our higher-functioning patients with autism spectrum disorder, with anxiety issues, to be seen by them, but they just refused. I think partly it was their lack of training. I think that's changed recently: Dr. Peter Szatmari has come recently, someone who has just finished training. But that was part of the challenge we've had with them and similarly with other agencies. I think it's a lack of expertise, or the clinicians there are all practising in their area of focus, so no one has that area that they're interested in. No one has really mandated that someone needs to see children with dual diagnosis at this age. I think that's the problem that we've struggled with, those two issues.

Ms. Mitzie Hunter: Okay. I do want to assure both of you, with your comments, that this committee is working across ministries, including with the Ministry of Health and Long-Term Care. Any advice and recommendations that we provide will be shared. I just want to assure you of that.

What can be done to shift the culture? You talk about training, and you talk about the tools. What else can we do to move this system? The resources are within the system.

Dr. Alvin Loh: Sure. I actually like that question because I'm a part of the Autism Treatment Network. We work a lot with a group of developmental pediatricians, and we work with general pediatricians who are very interested in autism. Then there's a lot of family doctors and general practitioners who don't like autism and intellectual disability; they're a bit scared by that.

We've had a North American collaboration, and we've watched what other centres have done. I know a great project was done in Utah. They did a quality improvement project for about six months; they had funding for this. They approached people and said, "Do you want to improve your care?" What they did was, they did a one-day presentation with them, and then they went out to their clinic, asked them to identify the different things that they were teaching that they wanted to improve, and they worked with them to improve that over the six months. They did a couple of visits, and they were able, by phone call, to answer questions. It really clicked, when I saw them present, that mentorship—as Bill was mentioning, it's one of the recommendations—providing that clinical support, is really essential.

So the tools are helpful, but having the different levels—and people know, "In my area, in my catchment, I can call this person for help. I can call this agency, and they're going to mentor me." If that's set up formally, and people know about those relationships and different roles, I think it allows for easier care. People feel more comfortable taking on patients.

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Dr. Bill Sullivan: I think that's a very important question: changing the culture and actually seeing—I think the key issue for family doctors is just to encounter people with disabilities, just in ordinary life.

One of my colleagues who trained in the UK—part of every medical student's experience was they would be linked with a family that had a member who had a disability—not as a doctor, but just to get to know them.

Maybe one of my colleagues from the UK who has got a lot of experience in this, Dr. Bradley, might add to that.

Dr. Elspeth Bradley: Thank you. I've been working with people with developmental disabilities for the past 25 years, half of which was spent in the UK and half of which has been spent in Canada.

For me, when you ask that question, it's a very interesting question. But as I have observed the UK move forward in leaps and bounds, what they have done, actually, is they've had a policy document, but in implementing that policy document, people with developmental disabilities have been front and core to that document.

In fact, there is an executive committee to that document, which has been played out right across the country of 60 million people. There are co-chairs to make sure that the policy document is implemented, who are fully paid by government. One of those individuals is someone with a developmental handicap, and the other is someone who is within the developmental services. That person with the developmental handicap—they've now gone into the third and fourth person. In other words, there's now a succession in that role for the person with a developmental handicap.

What has been absolutely fascinating from that is the way in which we have raised the bar for the person with a developmental handicap. They are now doing a job that no one would have thought possible. And when we raise that bar, we are actually educating ourselves as well as educating the population with developmental disabilities. It's a really co-constructed, collaborative activity, and I think that is one way that we can begin to learn from the people with developmental disabilities in a very meaningful way.

That means, for example, in a committee like this, there would be people around the table, but we would have to make sure that the process is such that they can truly engage. This is not tokenism; this is real-life, fully participatory, collaborative work. It means we all have to change our ways of doing our business, as it were, so that we can all communicate on an equal playing field.

The Chair (Mrs. Laura Albanese): Thank you. I will have Ms. Jones continue.

Ms. Sylvia Jones: Thank you. I don't want to focus on numbers, but the reality is that funding and a lot of things are predicated on numbers.

It very much jumped out at me when you mentioned that 40% of untreated physical conditions are the cause of self-harm and aggressive behaviours. That's a pretty disturbing number when you think in terms of what self-harm and aggressive behaviour translates to, in terms of

interventions and the cost of those interventions. I think there are opportunities there for us to figure out how to lower that number quickly.

If I may pick on Dr. Sullivan, because you mentioned that you are a front-line physician, can you share with the committee—again, quantitatively—what does being a front-line physician mean in terms of how long you spend with individual patients? You know, my annual exam: Let's say it is half an hour. What is it if I had a developmental disability?

Dr. Bill Sullivan: Very good question. I guess one way of answering the question is to think, what ought I to provide to do it adequately? Often, there are communication issues and there are other people. We just had an assessment at the family practice unit, and we had the individual in the wheelchair, two caregivers, a behaviour therapist, a nursing colleague, a pharmacist and myself. You know, you can't do that very quickly, yet everybody had a very important contribution to be made.

In the old way of doing family medicine, it was kind of the lone cowboy, right? It was one person, and you did your thing, and it was very time-conscious, because that was the funding model. Now, we've moved away from that, but we still have that mindset.

I think the key thing is to be realistic about not rushing people. I also think that it is just ridiculous to go in and think that you only have one issue to discuss. I mean, that's crazy. These are complex, interdependent issues, and you've got to get them all, wrestle with them all and have adequate time to do that.

I think it's a stretch for family medicine to move into that, but that's what we're hoping. If we're going to use generic services, that's where a lot of this very important preventive care and first-line, addressing—"Oh yes, I remember this: It's very common for people who can't otherwise communicate to express themselves through their behaviour." We just need to think about what are the common things that might be going on and have time to go through our list.

Ms. Sylvia Jones: To your point, you mentioned the mentoring and the access to an expert that isn't necessarily in your family health team. Maybe it's a call to Surrey Place. Is that a doable model? It's quite frankly similar to what CAMH seems to be doing on the mental health side. Everybody doesn't necessarily go to CAMH, and yet there are physicians out in the community who absolutely use their expertise. Can that same model be transferred, modified in your situation for developmental disabilities and ASD?

Dr. Bill Sullivan: I think people adapt as best they can, and they use the resources that are available to them, the relationships that they have. The movement that I find very exciting and positive in family medicine is to have people around so that people can actually get together fairly easily. For instance, I just mentioned the pharmacist. We also have a psychiatrist who comes in, and we can easily get him involved to provide some guidance on issues.

It is very difficult to—in the traditional model, if you've got many issues going on, you're going to end up going to many different people. It's very difficult to sort out why this person is behaving—if you've got to send them to a gastroenterologist and then to these other specialists. That's why I think there is something to be said about the generalist who can kind of pick the low fruit: "Here are the common things. I know how to deal with that." Let's do that efficiently.

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

Miss Monique Taylor: Excellent presentation. The last two presentations have brought so many different thoughts of what we could be looking at in this committee. Hearing, "I have heartburn, and yet I can't vocalize that," and what that is leading into, and how many people in this province are actually going through exactly what you were just talking about, and it can be so easily remedied and change so many different aspects of what we're facing in crisis—it's astounding. Again, that's going to take me back to the tools and it's going to take me back to how we are training our physicians differently to change that mindset going forward. What is happening?

Dr. Alvin Loh: One brief comment related to that is that when someone presents with a challenging behaviour, physicians often don't have a lot of time. Someone like a behavioural therapist is trained to assess what we call the function of behaviour. If someone charts why a child or individual does a behaviour when they do it, you can kind of see, "Oh, is it a physical problem? Are they doing it when they're having fun and suddenly, out of the blue, it happens? Or do they do it when they want something, like a candy, or are they trying to get out of something they don't like, like math homework?" If you chart function really clearly, I think physicians can sometimes be told, "Oh, you know what? This looks like a medical problem from the behaviour." But the problem that our system has too is that it doesn't have a lot of behaviourally trained individuals to do that, either at the school level or at the nursing level, because there are very few paid behavioural therapists, and their wait-lists are six to 12 months long. That, I think, is the challenge for our system.

Miss Monique Taylor: That's my next question: How do people get to you at Surrey Place, and what are the wait-lists?

Dr. Alvin Loh: That's a good question. Surrey Place services the city of Toronto. It goes through an intake meeting—Leeping and Shirley often sit at those meetings. If they have behavioural issues, they will be referred to a behavioural therapist, on their wait-list. Unless the behaviour is at a crisis level, where they are extremely aggressive to others or themselves, they're on that wait-list for at least six to 12 months. In the meantime, we've tried to think, "How can we be more innovative?" In an emergency room, you triage people, right? You try to start something with everybody. You give them Tylenol if they come with just a bit of foot pain, and then you'll see them in an hour. I've been trying to discuss it with

the Surrey Place staff, about can we be more innovative with behavioural strategies of how we initiate things? It's almost like a triage model: We start something. Can we build up different levels of behavioural treatment in the community?

1600

The Chair (Mrs. Laura Albanese): A very short question.

Ms. Cheri DiNovo: Yes, a very quick question. Surrey centre sounds wonderful. How does one get one's child into it? Is there a huge waiting list? What does that look like?

Dr. Alvin Loh: You have to live in Toronto. You have to have an intellectual disability. If you're functioning at the fourth or fifth percentile, you won't get in. The waiting lists are very long for some of the behavioural therapy there. We try to see them fairly quickly in medicine if we can fit them in or consult with their pediatrician or their family doctor to get things going.

Ms. Cheri DiNovo: So the wait-list, what is that?

Dr. Alvin Loh: For behavioural therapy, six to 12 months. To see me—I'm seeing a kid tomorrow who had major issues today. I'm fitting him in. I'm a bit flexible. Generally, I would think it's a month or two before I would see a new consultation.

Interjection.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation. I know you want to sneak in—

Ms. Mitzie Hunter: Just a quick observation based on the last two presentations: We're trying to strengthen any gaps that are in the system and plug those. It seems like a medical centre of excellence for people with developmental disabilities is needed, and an investment in that.

Dr. Alvin Loh: Yes.

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

CHRISTIAN HORIZONS

The Chair (Mrs. Laura Albanese): We'll now ask Christian Horizons to come forward.

Interjection.

The Chair (Mrs. Laura Albanese): No; every seat has a microphone, so you can sit anywhere.

Ms. Janet Nolan: Pardon me?

The Chair (Mrs. Laura Albanese): Every seat has a microphone, so you may sit anywhere.

Ms. Janet Nolan: Fantastic.

The Chair (Mrs. Laura Albanese): Thank you for being here. As with all the other presenters, I would ask you to start please by stating your name and your title for the purposes of Hansard before you begin your presentation. You will have up to 30 minutes, and if the presentation is any shorter, we will allow for questions. You may begin at any time.

Ms. Janet Nolan: Wonderful. Good afternoon, everyone. It's a pleasure to be here. My name is Janet Nolan, and I'm the chief executive officer of Christian Horizons.

Mr. Allan Mills: My name is Allan Mills, and I serve as the vice-president of Ontario, also with Christian Horizons.

Ms. Janet Nolan: And it is an absolute pleasure and privilege to be here. I'm delighted to see all of you sitting around this table, asking these questions and listening to presentations. I have to say, I'm a little sad to be the last on your agenda for today. I'm sure you've had a very full day, and I will be very respectful of your time. I'm sure all of you have busy evenings ahead.

This is such a critical issue. The government and all three parties are to be congratulated for being willing to go through this process and ask organizations like Christian Horizons to come forward and share a little bit about who we are but also to share some insights that maybe we've gained over our history.

Allan and I are going to present probably for about 10 or 15 minutes. I have been known to get a little preachy, so I'll apologize upfront, but I'm just really excited about the work we do. It's wonderful to be here and tell you a little bit about us. Then we really would welcome your questions. Please feel free to ask anything. We are delighted to participate.

Ms. Hunter, I'm sad that I didn't meet you a couple of weeks ago. I was sitting right behind you at the International Day of Disabled Persons. You did a wonderful job in your comments to the audience.

Ms. Mitzie Hunter: Yes, it was a wonderful experience. We should do more of those in more places.

Ms. Janet Nolan: Absolutely. I entirely agree.

Christian Horizons is an organization that will be celebrating its 50th anniversary in 2015—I guess a year and a week or so from now, jumping ahead into the planning for sure. Christian Horizons exists for pretty much two reasons: one is to provide services on your behalf and on behalf of the taxpayers in Ontario. We are the largest service provider in Ontario, as you might know, and we provide services right across the province in all nine ministry regions. We provide services to adults and children. Allan is going to talk a little bit later in the presentation about some specifics. Actually, I guess I can just jump into that right now.

Currently, in Ontario, through government-funded programs, we support about 1,763 people through group living, supported independent living, host family programs, community participation, children and youth residential services, and children and youth and adult respite services.

We are a key player in developmental services in Ontario. We participated fully in the facility closure through to 2009. We are an accredited organization. I would like to say that we're a leader in providing innovative and creative supports to folks with developmental disabilities, as well as folks with a dual diagnosis in Ontario. We have been a part of shaping the sector.

We play a significant role in the human resources strategy, in the provincial network, in the OASIS network and in varied other capacities in a way that's really shaping the future of how services get delivered and how

we talk to you folks, our elected representatives, as you make changes to the work that we do.

If you look in your package, Christian Horizons has a strategic plan, and we have three organizational priorities. Those priorities are to support people, to celebrate our employees and our volunteers and to nurture relationships. If I could just dive into that for just a moment, really the other two priorities—the second two—exist really to help us support people.

Christian Horizons was created when a group of families came together back in the 1965, almost 50 years ago, like I mentioned, because Community Living initiatives were being created. They saw community certainly as a geographical consideration, but also that there could be a community of faith. Organizations like Christian Horizons and Reena and other organizations grew then to be organizations that partner with the Ontario government to provide services to support people.

We have a staffed team of well over 3,000 people all across the province, and they have chosen to have a direct relationship with us, so they are not unionized. We've been able to work with our staff to create what we call a joint employee association, and we take that relationship very seriously with them. It's also allowed us to be a part of the conversation in the province, ensuring that the non-unionized workforce has a voice at the table oftentimes. I think this committee has probably heard from a number of the labour unions and lot of organizations that are represented by labour unions. Christian Horizons employees do not have a labour union, so we work hard to make sure that their voice is heard.

The third priority for Christian Horizons, in order to allow us to effectively support people, is to nurture relationships. I said when I started speaking that there are two functions of Christian Horizons. One is certainly to be an excellent service provider on your behalf and on behalf of the taxpayers of Ontario, but the second is also to be an excellent bridge builder, an excellent relationship builder, partnership builder, with the broader community.

We've had incredible success basically taking what Ontario resources have allowed us to do and do immeasurably more. So we look to the church, we look to partner organizations, we look to community organizations to help them both be compelled to consider disability and how they do their business and exist as organizations, but also to equip them and provide opportunities for them to be involved.

I'll tell you really quickly a neat story about what happened just about a year and a half ago in Newmarket. There was a church in Newmarket—is that correct?

Mr. Allan Mills: Yes.

Ms. Janet Nolan: There was a church that was offering a day program to folks, paid for by Ontario. They were really struggling with the requirements by legislation to continue to do the job that they were doing. They supported about 60 people.

They turned to Christian Horizons—we had a relationship with them—to say, “Is there a way that we could

partner so that you could provide some of the infrastructure, the administrative supports, to allow us to continue to do what we're doing in our community?” And we were just thrilled to do so.

Now that program has been able to continue as it is. They're thriving, thrilled and we had to provide just a tiny piece of administrative support to allow that to happen.

So we take our responsibility very seriously on that second point: to be an excellent service provider, accredited, working with the sector, working with the government, but also the relationship that we have with the broader community to leverage, to build bridges, to build that sense of goodness out there around developmental disability.

Christian Horizons is actually an organization that's funded—

Interruption.

1610

Ms. Janet Nolan: Am I too close or too far away from the—

The Chair (Mrs. Laura Albanese): No.

Ms. Janet Nolan: Okay. That's not your beeping to tell me to speak more closely?

We are an organization that works beyond Ontario. Christian Horizons has our government-funded programs. We have our non-government-funded programs that we do fundraising for, like our family retreat, some after-school programs, some respite programs. We also work in developing countries around the world. It has been an incredible learning experience for us.

Initially, the work that we started, that is entirely funded through foundations and fundraising, was to take some of our knowledge and experience about what we learned here in Ontario. If you can imagine, in developing countries, people in poverty face unimaginable day-to-day realities, and for people with developmental disabilities and other kinds of disabilities, the reality is even more significant. Our idea was initially to replicate a little bit about what we were doing here in Canada and provide that in the developing world.

We started a group home in Guatemala and in Ethiopia. We quickly learned—

Interruption.

Ms. Janet Nolan: That's okay?

The Chair (Mrs. Laura Albanese): Just ignore it.

Ms. Janet Nolan: Sorry. I have three teenagers. I should be used to distractions.

We quickly learned, though, that that group home model, while it was great for those three or four folks that were being supported, was very difficult to sustain and really left out a whole group of people in their communities, so we had to shift gears. I'm excited to say that Christian Horizons, through that work, is reconsidering how we do our business here in Ontario, and sharing with our partners, as well as our government friends, about creating programs and services that are entirely sustainable and capacity-building, not solely looking to government for solutions but looking to the community, to

churches, to other organizations, around a multi-faceted approach to building communities of belonging.

Through our international work as well, we've been able to build partnerships with organizations in Germany, Russia and Ecuador who have really sharpened our thinking about developmental disability and inclusion and how responses certainly—we look to the Ministry of Community and Social Services and the Ministry of Children and Youth Services for support and funding and legislation that develop a robust, energetic system. But we have to look to other places—to other parts of government, to business, to the labour market, to institutions in our community—for their part in creating these communities of belonging.

I've shared with you our numbers. I do want to let you know, and I want to amplify the fact, that in the past there has been legislation that was introduced, with good reason and appreciation, around wage restraint. There was some unintended impact, unfortunately, for organizations that worked without a labour union. I would encourage you all, as our elected officials, as you consider future considerations as to how to manage issues like wages in the sector, to consider that a significant number of our staff—not just Christian Horizons staff, but staff in developmental services—are not unionized. Unfortunately, when there's legislation like the wage freeze legislation—and I can appreciate why it was created—it sometimes penalizes those who weren't meant to be penalized. That happened with our staff, unfortunately.

Christian Horizons, in our non-government work here in Canada, is focused in a couple of different ways. I want to tell you really quickly about a story—and I'm watching the time.

A couple of years ago, we heard from families—largely families that were without services, some with multiple children with developmental disabilities—that they just needed somewhere to go to be together as families, where maybe an organization like Christian Horizons could come alongside and provide them some support, and they could just have time together as a family.

As you can imagine—well, I would assume that you believe that government is part of the solution, but there are lots of other parts of the solution out there. So we raised some money, we did some fundraisers, and we created what's called the Family Retreat. We had 23 people our first year, and I think it grew to over 80 people last year. It's entirely staffed by volunteers and funded through various different fundraisers.

We had families come, and they just got to be families for the week. These are families that have incredible burdens during the year. They face challenges on every level: schooling; medical care, like you heard earlier with Surrey Place; communities; not getting invited to birthday parties. These kids have difficult days that they struggle through, and that week, we were able to bring these families together and they could just be families.

One of the nights, what we do is we take all the grown-ups out for a date night, and the staff and the

volunteers who are there take care of all of the kids: the children with disabilities and all the siblings, as well. We heard from families that they had not been able to get out alone as a couple for over seven or eight years. If you can imagine what it would be like as families struggling through the day-to-day realities of raising children with very complex needs, not being able to connect as a family is significant. We're really excited to be a part of that.

I'm going to ask Allan to briefly speak a little bit about some of the realities that we face in a moment. I want to jump ahead, to make sure that I cover everything that I need to. We have four key points that we want to make sure we amplify today.

We believe that there is value and Ontario has stood fast to ensure that organizations of faith and culture are recognized within the mosaic of developmental services. I think that is an absolute strength that you folks need to be proud of. It is incredible for me to sit at tables—all of us come to the table with different perspectives and ideas around disability, and together we shape what happens in Ontario. I hope that you have some questions for me about that reality.

We believe that education and employment for youth and adults with developmental disabilities is absolutely critical. One of the things that I submitted in my letter to this committee, in congratulations for your establishment, was to really consider cross-government solutions to this. My daughter Emma is 16, and she has grown up with a little girl named Ainsley, who is almost her age. Ainsley has Williams syndrome. Emma doesn't have a disability that has been diagnosed. Ainsley and Emma have gone to school together, they've played sports together, they've gone to ballet classes together, they've done all the things that kids are supposed to do. At 21, Emma is going to have a wonderful opportunity, if she chooses, to go to post-secondary education; Ainsley will not, and I think that is a significant thing for us to consider. I just spent a week in Germany, and I visited colleges where there are college programs that are certified, technically sound and created specifically for people with disabilities to learn a trade or a skill that they can be employed with. I'd be really excited to talk with any of you about that afterwards.

Allan, do you want to take over for me and talk about some affordable housing options?

Mr. Allan Mills: Sure. If I could bring that education example closer to home, as well, we've provided a bit of an outline in here of a program we recently were able to introduce, in partnership with Humber College, where people with developmental disabilities were able to learn culinary skills to help them be equipped for employment within commercial kitchens, restaurants, with catering companies, that sort of thing. That just provides an example of how the more we can help people shift away from the social dependency into being able to be equipped and to be self-sufficient, the better off society is and the better off they are. When you first meet people, what do you talk about? "Where do you live?" "Where do you work?" For most of the people that we're serving,

“Where do you work?” is not a question that they’re able to answer, but if we can help them with that, that really makes a significant difference. So education is absolutely important.

Affordable housing: We wanted to talk a little bit about the fact that the Christian Horizons footprint—we have over 200 homes, 150 of them that we own, that we support people in group living across the province, and that is almost a \$90-million capital footprint of little homes on typical streets where we have sought to help people feel and be included in their community, living together in groups of four, five, six people. Yet we have come to the point of realizing that we don’t believe that that is a system as a primary vehicle through which to support people that is financially sustainable for our sector, nor is it necessarily meeting our goal of inclusion.

We’re looking at reframing how we serve a significant number of the people that we serve and doing it in a different way: creating community hubs where we’re able to be in settings that can incorporate a variety of services and have a residential component, have health care and have opportunities for other people. For example, there’s a group that we’re working with in Orillia that they started off—basically, it was a Special Olympics group. They wanted a gym. They couldn’t get access to a gym, and they looked at purchasing a school, and then ideas started forming out of that simple notion of, “We want access to a gymnasium.” They ended up with a concept that involved the VON having offices on site and having respite for seniors on site. They’re looking at incorporating some supportive housing in terms of apartments for people who have developmental disabilities, and they have child care that’s looking to become part of the site as well. So we’re reclaiming a school and serving the community in a diverse way—not creating any form of an institutional setting, but an inclusive model of community.

1620

As we look at the future right now, I’m sure you’ve heard about some of the fire code issues that our sector is going to face. We know that we’ll have to spend millions to continue doing what we do in the homes in which we currently support people, and that may not be the best investment of funds.

You would have heard already that there are around 17,800 people receiving residential services within developmental services, funded by the Ministry of Community and Social Services. Our understanding is that that is serving about 70% of the people who are registered, who are asking for that support through the Developmental Services Ontario organizations. If our current funding envelope is only serving 70% of the people who need support, whether residential or otherwise, then we’re looking at a \$500-million increase in funding to expand the current model to serve everyone who’s waiting for services.

Half a billion dollars is not likely an easy sell in today’s economic realities, and we recognize that. So we’re looking at ways to be more efficient and more ef-

fective with what we do. And back to what we said around education and the ability for people to have access to jobs, that’s where we see the investment being really important. If we can shift how we support people to be a part of the community from a residential perspective, we also want to make sure our focus is on helping people bridge those barriers for education and employment.

Ms. Janet Nolan: Thank you, Allan. We do have more information in our package. We’ve included our annual report, but I’m really aware of the time and I would love to be able to take some of your questions. Please, Madam Chair.

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

Mrs. Christine Elliott: Thank you very much for coming today. It’s great to see you again, Janet. I’m really interested in the employment aspect of it. If you’d like to expand a little bit more on that, I think that’s really key. What we’ve heard from a lot of people is that their sons and daughters want to work, but they don’t have opportunities either for education or training, and then to have employers who will employ them.

Ms. Janet Nolan: Thank you for that question. You’re absolutely right: There are a number of barriers that face people. There are some great success stories, but unfortunately, those success stories are typically about families that are really competent at navigating the system and/or really kind-hearted employers. We don’t have a comprehensive strategy to encourage people with developmental disabilities to be included in the labour market.

We’ve looked at different models. Our partners in Germany have legislation that ensures that a certain percentage of people with disabilities are included in the workforce, which is a way that we could consider going. I think it would be a huge mistake for Ontario to jump forward with a percentage or a—what’s the word—

Interjection.

Ms. Janet Nolan: —exactly—without a comprehensive strategy on how to build a skilled, capable pipeline of employees who have a developmental disability. I would encourage you folks, as you consider a cross-governmental approach to this, to look at MTCU and at the college system, and consider ways that people with developmental disabilities could be included in an extensive way at the college level. We don’t need to build a separate system; we have wonderful institutions across the province that have cutting-edge technology. What we need is curriculum, what we need is teachers who understand what it means to teach somebody who has a developmental disability a skill. Then we need proactive programs. We need awareness-building within the labour market. We need, maybe, legislation around including people with disabilities in the labour market.

What I experienced when I was in Germany was that people with developmental disabilities experienced less mental health disorder, less challenging behaviour, less homelessness, fewer social issues because they were included in employment. There was a significant impact

on their quality of life and the quality of the communities that they lived in.

Mrs. Christine Elliott: That's how a lot of people derive their friends and their sense of confidence: having a job, and you can build from there. So it makes perfect sense.

Just a quick question: Are you familiar with the CICE programs at the community colleges?

Ms. Janet Nolan: Yes.

Mrs. Christine Elliott: Could you comment on that?

Ms. Janet Nolan: I can't really comment so much on the specifics, but I do understand that there are some programs. I know in Algonquin in Ottawa there's a literacy and career planning kind of approach to folks with developmental disabilities—a two-year program. I know Durham College has been extremely progressive, which is phenomenal.

What I think we need to look at, though, is a comprehensive strategy that includes PSW programs for people with developmental disabilities. That includes culinary arts programs. It includes construction trades. It includes all sorts of valuable skills that will actually not only help the fact that people need to work, it would also help our economy. Some of these jobs are hard to fill.

I visited a program at a college in Stuttgart that taught facility management. A lot of organizations that need facility managers or people to work as janitors have a really hard time keeping competent, long-term employees in those roles. Those are the kinds of programs that I'd like to see at the college level right across the continuum of different programs that they have, to include—maybe they don't become a master plumber; maybe someone doesn't have to be able to become a master plumber, but maybe they could become a plumber's assistant.

We've actually got a pilot project that we've submitted—

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

Ms. Janet Nolan: Sorry. Okay. Anyway, we've got some stuff I'd love to talk to you about.

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

Miss Monique Taylor: Thank you very much. That's really good information, so maybe you should submit some of those ideas and we can look at them as we move forward.

You caught my attention when you were talking about your non-union employees kind of getting caught in the trap of the wage freeze. What exactly did you mean by that?

Ms. Janet Nolan: Allan, actually, do you want to answer that one? You were more heavily involved in it.

Mr. Allan Mills: Sure. The wage freeze specifically targeted non-unionized workers. Across our sector, half of the employees, approximately, are unionized and therefore weren't directly impacted by the wage freeze legislation. They were, through other avenues, supported to have collective agreements that they negotiated that respected the 0% increases that were required through the legislation. But our employees were directly hit by the

legislation, so it left for them the question: "How does my employer treat me? But if I have to think about how the government treats me differently, based on whether or not I have a union, that's not just an issue about me and my employer. That's maybe more about the sector that I'm part of."

Miss Monique Taylor: Because I know that they went through a four-year freeze, right? They haven't had any pay increases. I've seen the wage scale being, I believe—I think the lowest wage I've seen on that sheet was \$12.99 an hour, up to \$20. What are your non-unionized employees being paid?

Ms. Janet Nolan: I can answer. We've done a comparison with the whole sector. We're about middle of the line. Our staff are paid between \$17 and \$20, at our top salary.

Miss Monique Taylor: So there's still a varied comparison.

Mr. Allan Mills: Yes.

Ms. Janet Nolan: Yes, they are, absolutely. All organizations have been flat-lined in our funding since 2009—sorry, I have it here: 2008.

If you look in your package, there's actually a comparison as to the impact that's had on our—certainly organizations, unionized and non-unionized, none of them have been able to receive new funding for salaries. The difference that happened is that our staff, by legislation, could not get a wage increase. Unions were able to negotiate collective agreements, and certainly there was no more funding, but organizations had to manage through those during that period of time. For our staff, there was no option.

Miss Monique Taylor: Right, and I believe the unions didn't get anything either, but regardless—I applaud the work that you do. We know that to retain good people we have to pay them good wages. We need to make sure that they're getting the pay equity and they're getting the raises that it takes to be viable in this world, right?

Ms. Janet Nolan: If I can just respond to that, one of the challenges I think that we have as a sector and as a government and as taxpayers is that we have to have reasonable salaries. I actually would not sit here and tell you that our salaries are outrageously unreasonable.

Do I want increases for my staff? Absolutely. But the issue of pay equity and cost increases is actually the bigger issue, because organizations that have been compelled by pay equity legislation have had to pay out pay equity payments over those years. So, in effect, we have had to squeeze our services to be able to afford those—

Miss Monique Taylor: And that's wrong.

Ms. Janet Nolan: Absolutely. I know that others have presented, so I won't go into that just in case there are other questions. But I don't want to leave you with the impression that I feel that it's a well-underpaid sector.

Miss Monique Taylor: In my view, it is underpaid. You deserve to be paid more, and the government needs to make sure that funding is provided for that.

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

Ms. Soo Wong: Thank you for your presentation. I just have one question. In your booklet, you share with the committee about the educational services. You commented about the MTCU, about the grants to support the learner. Can you elaborate a little bit more on how we can look upon this particular initiative with MTCU, the DSW apprenticeship program—because it sounds like it's a pretty good model to consider—and how do we expand it? Can you elaborate a little bit more on that program?

Mr. Alan Mills: The apprenticeship program is wonderful. We have quite a number of employees who are participating. Basically, the subsidy is to the extent that they can take their courses at about an 80% to 90% subsidized level. Then, when they graduate, they get a \$2,000 bonus, and the placement hours that they would otherwise have to do as a volunteer, they're able to do while employed by Christian Horizons or another developmental services organization. If they wanted to reinvest the money they get upon completion of the apprenticeship into further elective programs, they could basically complete the full DSW diploma with zero financial investment.

It's a wonderful, wonderful example of an investment in helping to equip people in our sector to be educated and qualified to do the work they're doing through the Ministry of Training, Colleges and Universities.

Ms. Soo Wong: To date, do you know how many people have graduated from this program?

Ms. Janet Nolan: Several hundred in Christian Horizons; certainly more—

Mr. Allan Mills: —across the province.

Ms. Soo Wong: Okay. Thank you very much for your presentation, and thank you for your almost 50 years of service to Ontario.

Ms. Janet Nolan: Thank you. I'll welcome you to our celebration next year.

The Chair (Mrs. Laura Albanese): Thank you for your time today and for presenting to our committee.

I think this wraps it up. I just have one quick question for the committee members before we adjourn for the day, and that is if I could—oh, yes, Ms. DiNovo.

Ms. Cheri DiNovo: A quick question for research: I was fascinated to hear about the German system. I would love to hear more about that and about the program at Humber. That would be good information to have.

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

Ms. Soo Wong: Can we also have more data and information about the MTCU DSW apprenticeship program? Given what I just heard, I want more information on that program, please. Thank you.

The Chair (Mrs. Laura Albanese): Any more requests for the researcher? Ms. DiNovo?

Ms. Cheri DiNovo: No. That's it.

The Chair (Mrs. Laura Albanese): Okay. I just had one quick question for the committee members: If I could be allowed to gather a consultation with the subcommittee to make decisions that will be needed in the future and affect the committee and we don't have right now.

The Clerk of the Committee (Mr. Trevor Day): Basically, what the Chair is requesting is—between now and our travel, there may be things that I have not anticipated. I'd like the committee to authorize the Chair, in consultation with the subcommittee, to make decisions before the committee meets again.

The Chair (Mrs. Laura Albanese): Are we good? Thank you very much. We are adjourned. Happy holidays. Happy new year.

The committee adjourned at 1634.

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