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Lundi 13 janvier 2014

**Select Committee on
Developmental Services**

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

Developmental services strategy

Stratégie de services
aux personnes ayant
une déficience intellectuelle

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ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

SELECT COMMITTEE ON DEVELOPMENTAL SERVICES

COMITÉ SPÉCIAL SUR LES SERVICES AUX PERSONNES AYANT UNE DÉFICIENCE INTELLECTUELLE

Monday 13 January 2014

Lundi 13 janvier 2014

The committee met at 0903 in the Delta London Armouries Hotel, London.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Well, good morning, everyone. I give a welcome to all the members to London, where we start our week of public hearings for the Select Committee on Developmental Services. Welcome to all of you.

I wanted to mention that the coffee is up here, but you are more than welcome to come up and have coffee or tea, if you wish.

PARTICIPATION HOUSE PROJECT (DURHAM REGION)

The Chair (Mrs. Laura Albanese): Having said that, we'll move directly to the first presenter, Michelle Marshall, executive director of the Participation House Project of Durham region. Welcome. As you're taking your seat, I will specify that you'll have up to 20 minutes for your presentation. Should there be any time left over after your presentation, that will leave room for questioning by the members of the different parties. When you begin, if you could please state your name and title, just for the purposes of Hansard. You may begin at any time.

Ms. Michelle Marshall: Great. Thank you very much. Good morning, respected members of the panel and guests here today. Thank you for providing me with this opportunity to speak before you and to provide insight that might help to address some of the critical issues that are before us, and also to explore how we might shape a healthy future for developmental services.

My name is Michelle Marshall and I run an organization in Durham region named the Participation House Project (Durham Region). In the role of executive director, I am inspired by people every day in ways that I can't even begin to explain, but this in good part is due to the wonderful staff and volunteers that dedicate their skills to helping the community, the leaders and direction of a selected few, and the commitment of all to doing things differently, not for the sake of just doing it differently, but because we're on the endless mission to do things better.

In the spirit of doing things differently, what you have in front of you this morning is my presentation that's a little bit different than probably what you're used to seeing; that's for you to read later. I'll cover everything within it. But our organization is inherently collaborative and I wanted to provide you the opportunity to contribute to the discussions as much as I do, so my plan is to leave a lot of time for questions where we can talk through the different points of this morning.

Here's what we're going to talk about:

I think that, first and foremost, it's important that I'm able to demonstrate to the committee that Participation House Project is a progressive innovator that does not shy away from changes and prides itself as a provider of environments that promote continuous learning and as a provider of quality services.

With the recent relocation of our administrative office, we sought out partners to share space with us to minimize our administrative costs, but with a view to providing a centralized access point within an accessible community-based facility of high visibility. We share our administrative space with the DSO of Central East Region, the regional children's complex special needs service coordinator, and also the Passport delivery agent, all with a view of making services easier to access for families in Durham region.

By now you've heard from many organizations and families about the dire situations that grow within the developmental disability community. As an accredited organization, the Participation House Project, Durham region, has risen to the challenges that have been put before us and we've found new ways to deliver services that build capacity while maintaining the quality in our service delivery. Over the past five years, and since the time of the funding freeze, we've been able to expand our services in the community access supports by approximately 35% through the introduction of a blending of publicly funded services and fee for services or grant applications.

However, having said that, creativity has not been the only factor that has enabled us to do this work. By and large, our commitment to provide transparency and partnership with our employees has played a very pivotal role. Our employees have also ensured that we all play a role in ensuring financial sustainability of the organization. We have done this with three priorities that have

guided us in our decisions. The first is that we always want to find ways to maintain our current positions and the services that we provide. We want to maintain the quality of our services as we expand them. And we want to make sure that we maintain our ability to continue to be responsive to our community's needs.

Through a collaborative team approach, we meet regularly to find ways to cut costs, neutralize our costs, or create new revenue from existing resources.

I provide you this preview of our track record to preface my comments when I say that despite all of these good efforts and commitments, we now find ourselves at a critical crossroads where the hard work of our team may be compromised if something doesn't give.

Durham region is one of four quadrants that used to be part of Central East Region. As you probably are aware, through the realignment it changed as of January 1. Historically, Central East Region has been a very progressive region. We've provided much leadership for the province through the establishment of centralized regional resources such as the Community Networks of Specialized Care and regional complex special needs coordination services. By and large, we've been very successful in the implementation of these excellent models of services, and it's been through a collaborative planning table known as Central East Planning. This committee is comprised of partnerships between MCSS regional office and representatives from the four quadrant planning tables and from the regional resources. Together we've been able to successfully implement and help transition our community of practice into a blending; with the introduction of new initiatives such as the DSO, we've been able to maximize our resources with minimal duplication, and all with the commitment to do the best and most with the limited resources we have.

I am proud to have been appointed as the chair of the regional planning table, but now I'm fearing what planning might look like within the new realities of a new region. You see, Central East Region is the only region that was divided in half when the ministry recently announced their realignment from nine to five regions.

0910

In reference to correspondence that was circulated to announce this realignment, I know that the intention was not to impact families or direct services, but this is not the reality. Sadly, when the decision was made based on the math of how many people were being served and the number of people waiting, the realities of the community within Central East were overlooked. So through this division of all regional offices, the regional resources will be taken away from Durham, Peterborough, Haliburton, Kawartha Lakes and Northumberland because the current regional resources are housed in agencies within York and Simcoe regions.

As a community, we made a commitment to use our funds wisely when we created regional resources, but now these efforts and commitments have been undermined unintentionally, and our families and our communities will suffer. During a time when organizations

are already feeling stretched, the leaders of these transfer payment agencies in Durham and in HKPR will not only have to learn new processes, new planners and procedures, they will also be taxed with the financial costs that are related to retraining our staff, our community and our partners, and reprinting of all brochures and policies and procedures, to name but a few.

In my submission to you, I have provided you with some statistics to help place a face to the needs of the Durham community and Central East Region. Currently, within Durham region, the waiting list would look like this: group homes, 551 people waiting; supported independent living, 283 people waiting; associate family, 113 people; day supports, 331; and respite services, 267. Specifically for Central East Region, group home is 1,260; supported independent living is 359; associate families, 234; and non-specified requests, 794. These are all non-duplicated numbers that were effective as of December 31, so they're very current.

Although I've provided you with a focus to the needs of Durham and Central East Region specifically, it's not that I'm unaware of or that I'm in disagreement with what has been presented as the provincial challenges. Moreover, it's to provide a local face to the critical provincial issues that my colleagues and the families who presented before me have highlighted to you.

So where do we go from here? In review of the transcripts of the presenters that came before me and the questions that have been put forward from all of you to them, I'll attempt to proceed where things left off and to provide some additional insights. I'm not a doom and gloom kind of person, and I refuse to lose hope. Despite all the obstacles I've just shared with you, here's what I think we should do.

I have read discussions and have heard inquiries that have asked for guidance and have asked us to identify short-, medium- and long-term interventions. The truth of the matter is that if we continue to respond in a way that prioritizes one person's needs or the most in need over another person's, we're just perpetuating the core issues that the transformation agenda was put in place to overcome. It's a travesty, really, that families and individuals have to reach crisis before they receive supports, and this has to change right now.

When we take an inventory of the needs and the characteristics of people who are currently on the waiting lists for services, we can quickly identify that we have two key audiences and motivations for necessity of service access. We have those who have languished on waiting lists for often greater than 15 to 20 years and whose life experiences and choices were very different than those of the people of today. The societal values and the strides of inclusivity were not their reality. They were robbed of options and supports that would have prepared them to be ready for the realities of a future system that doesn't follow a 24-hour model. To further compound their situations, because these individuals and their families have been isolated from their communities and having access to preventative or proactive supports, their support needs

when they do engage with agencies are usually much more complex and much more expensive. And usually, other needs are much more immediate.

The other target audience that I would identify are those who have had different experiences: those who are well-informed of their rights and are poised and prepared to transition from school into adult life. As a community, we've taken more responsibility in playing a role that empowers these individuals and has prepared them for independence and self-actualization. However, if these young adults are left to waiting lists for services, then these skills, too, will be lost.

We cannot continue as a system based solely on "most in need." We must stop the dysfunctional cycle that violates the rights of Ontario's most vulnerable citizens. This is why I'm suggesting that we need to take a two-pronged approach when addressing the immediate needs of today. We cannot begin to plan for tomorrow without getting our house in order. So what I'm suggesting is that we look at critical immediate needs—that would be looking at increases to case management, residential supports, day services and respite, while at the same time looking at providing proactive and preventative approaches that empower individuals and keep families from going into crisis, and that's in the areas of respite, life skills, training, case management and employment supports.

We cannot begin to plan for tomorrow without getting our house in order. Moreover, I have faith that tomorrow will be looked after through the leadership that the AODA language and the transformation agenda will bring.

I'd like to thank you, again, for providing me the opportunity to speak before you today, and I'd like to give you the opportunity to ask me questions about what I've provided to you.

The Chair (Mrs. Laura Albanese): Thank you. I think we have about two and a half minutes for each party. Ms. Elliott, you may begin.

Mrs. Christine Elliott: Thank you very much and good morning, Michelle. I have the pleasure of knowing Michelle quite well and knowing the great work that she does in our community.

I'm wondering if you could just spend a few minutes, Michelle, talking a little bit about the supports that Participation House does provide in the community and some of the things that you're working on, as well, to address the needs, particularly of young adults with autism.

Ms. Michelle Marshall: Sure. Thank you for the opportunity. Participation House provides a spectrum of services from residential to respite, as well as community access and day supports. We provide them in a community-based situation, but we've also largely tried to find ways to partner to prevent duplication of services.

Over the last few years, we have partnered with the Abilities Centre to create and expand our supports and, again, to make them much more accessible to individuals in our community and within a community fully-

accessible environment. We've been able to do that by bringing our services, that we previously had provided to only funded individuals, to a community resource centre, where they can access other programs and services. So where once we may have supported, say, 10 people, we now support two groups of five, which has reduced the costs for other people to purchase services. So we have been able to provide it more cost-effectively to families while expanding our services.

There are some challenges with that, because under the new DSO legislation, any of those vacancies, because there is partial funding by ministry—it does have to go through the waiting lists. Of course it has to then go through, trying to find the match and being able to partner families into those resources. It cannot be done as quickly as it has been in the past. That's something that's happened more recently, as day services have been something that now are overseen by the DSO.

Mrs. Christine Elliott: Thank you.

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

Ms. Cheri DiNovo: Yes. Thank you very much for your presentation. Obviously, what we've heard from you, we've, in a sense, heard from others.

You talked about the two-pronged approach to redressing problems. So I'd like you to go a little step further maybe and say what's necessary to achieve that two-pronged approach. Is it money? Is it changes to the DSO? Maybe you could—

Ms. Michelle Marshall: Sure. I think, at the end of the day, it's money. I think it's fair to say that. We all own our own homes; if we don't invest in preventative maintenance, the reality is, you're going to be replacing your roof. You're going to have a big bill. I think we're in that situation, because for so long there hasn't been adequate funding to meet the needs. The needs have continued to grow, and there have been no new resources.

A lot of the resources that we've seen as of late have been to infrastructures, such as the DSO, and to other processes, as well as providing dollars for training. I think it's all been with the view that it's going to build some more capacity, but, really, what we've got, at the end of the day, is someone saying, "Here's the end of the line," with no new services.

So we're at a point where there do need to be resources specifically for services, but what we've seen is, when we talk about doing training and providing employment and respite, those are all band-aid services. As you all know, the reason we're here today is because we're at a critical crossroads within the sector. This is just a band-aid solution, and it's actually not going to be able to help the people who are most in need, and they will continue to rise to the top and will be the people who keep you awake at night. So I think that we need to make some serious investments.

0920

Yes, we're right: We need to look at employment and respite for those individuals that I identified as, really, they're ready and they're poised. We want to make sure

that we empower them so they're less reliant on 24-hour services, because truly, if we're going to build capacity in the future, we need to better prepare people so they're not looking for those 24-hour models. But if we do that in isolation, we are going to continue to have these families that come forward in a critical, crisis situation where there are not the adequate resources to respond. These are generally individuals, at the time they entered the waiting list, who were looking for 24-hour models. As they remained at home and isolated from services and other supports, any skills that they might have had as they exited the services of entitlement for children have been lost. There might have actually been more health-related issues as well that have compounded it.

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

Ms. Mitzie Hunter: Thank you, Ms. Marshall, for your presentation and certainly for the effort that you've put into preparing this for us. We will definitely include it in our report-writing considerations.

I know that you have a little bit of concern around the changes in the regional model. I do want to assure you that the intention there is to streamline across ministries, based on the regional models that we have for ministries, and that there is no impact on the public, there are no offices that will be closed, and the public will continue to interact as they do. We are in the early stages of that, and we'll be working together to ensure that there is that seamless transition. It really is intended to streamline and to make it consistent with other ministry processes across governments.

Also, in the area of transitioning and working better with our Ministry of Community and Social Services and the Ministry of Children and Youth Services, particularly for this client group, you've also expressed some concerns there as well, and we've certainly heard that as we've been listening to others during the course of our hearings.

I'm wondering, with the work that you're doing in the community, how do you see making services and supports available in a much more integrative way across the communities? Is that something that you're seeing, that we need to develop a better culture of inclusion of people with developmental disabilities, and is that something that you can comment on for us today?

Ms. Michelle Marshall: Sure. I think that, culturally, there has been a huge shift in the sector for many years. This isn't something new because it has been put into legislation. If anything, the legislation has been put in place after, to support those of us who were trying to make strides, and also to ensure that we create a groundswell.

I think that we're on the right track and taking steps forward in expanding our communities and also their awareness of their responsibilities to helping being part of the solutions, because if we truly want inclusivity, we need to make sure that everyone understands what their role is in it and that it isn't only under the Ministry of Community and Social Services or Children and Youth

Services. It needs to be a full-community approach to that.

As far as the challenges within our community, I think that I understand what you're saying. Certainly, I can appreciate, and did address that I know the intentions of the realignment were not to disrupt services. But specifically within Central East, because we are the only region that is being divided in half, at the time that we receive resources, rather than dividing those and saying, "Well, you have four quadrants; we'll divide that by four. Go away into your quads"—we wanted to make sure, because we understood that there were exceptionalities that needed very specific resources. But to put those in place and have quality that we could provide to people of that high level of need, we needed to be able to centralize our resources, and that's what we did.

It is unfortunate, though, for the people of Durham region and HKPR, because all of those resources are now within Simcoe and York and they're being divided and taken to another region. For our families, it will mean loss of services, because there may be things in other communities but they're not going to be the same.

I do believe, and what I've heard, is that we've been very progressive as a region. We have a really great community planning table that has been very diligent in making sure that we use our dollars wisely and that we make sure that we're being responsive to community needs. Those were created, centralized, for really the full spectrum of needs within the four quadrants, and those are being taken away from us. I do have to have faith and hope, though, that through our planning table we'll be able to continue to communicate what those challenges look like so that we can work through some transition. However, I think it's of importance that we can't put our heads into the sand. We need to be aware and we need to address that head-on as a priority because, like I said, this is one region and this is not going to be the same experience as that of the other regions that are being realigned.

The Chair (Mrs. Laura Albanese): Thank you for presenting to us this morning. You may be free to go. Thank you.

Mrs. Christine Elliott: Some of us aren't as familiar with the realignment that Ms. Marshall was speaking about. I wonder if our representative from MCSS might be able to give us a briefing at some point about when that was done and for what reason. Would that be possible?

The Chair (Mrs. Laura Albanese): Okay, thank you. We will put that in our agenda during the week.

MS. SUSAN BURO HAMM

The Chair (Mrs. Laura Albanese): We now call on Susan Buro Hamm to come forward. Good morning, and welcome to our committee. I believe you were present when I gave instructions, so you know you'll have 20 minutes. If there's time left over, we will delve into questions. You may begin at any time.

Ms. Susan Buro Hamm: At the core of Canadian beliefs lies socialism. One of its tenets is to protect and take care of those most vulnerable. Yet here we have Ontario failing miserably those young adults with developmental disabilities. It has been hopeless, bleak and absolutely shameful. The time for change is today, and the solution lies in listening to those most affected, such as my family.

My name is Susan Buro Hamm. I'm from St. Thomas, Ontario, in Elgin county. My husband, Abe, and I have four beautiful girls: We have Lexi, who is 20; twins, who are six; and a wee foster daughter, who is three months old. Lexi has epilepsy, metabolic disease, mild CP, and is globally developmentally disabled. There is no umbrella or syndrome for Lexi to coattail on to—just a lot of puzzle pieces that don't quite fit. In 2010, Lexi was the victim of a horrific bullying incident. She was assaulted on a school bus. It was videotaped and it was posted to YouTube. Since that day, Lexi has developed severe mental health issues. It's the mental health issues and her complex medical needs that have brought us to crisis, time and time again. Having a dual diagnosis is a very challenging entity in its treatment and in a family environment.

Let's talk about crisis for a moment. I often talk about Lexi in terms of crisis, but people forget that there are four other family members who are greatly affected by her illness. There's a toll on my marriage, on our finances, on our other children and on our extended family. So let me tell you about crisis for a minute; I'm going to tell you what it looks like for my family. When Lexi turned 18, in one fell swoop we lost our pediatrician, our family support worker and our respite. We then had to enter into the foray of adult developmental services under Developmental Services Ontario—I'm going to refer to that as DSO from now on. What an experience that has been. First we are required to prove that our child is indeed developmentally disabled, as if the prior 18 years of ACSD, assessments at CPRI, numerous specialists and special education were all for naught. I don't understand how the government, in its infinite wisdom, could not just cross-reference and easily see that she indeed was handicapped.

At Developmental Services Ontario, you have to have an invasive in-home assessment. Our assessment was 10 hours long, spread over three days. We then waited for a report on the assessment. Then the report is passed along to a mysterious priority panel who prioritizes what level of priority your child sits at. What happens then? Action? No. You're placed on waiting lists for any type of services you might need: residential, job training, recreational, specialized mental health care—anything you need, you wait for. So I know she's on wait-lists, but I have no documentation to tell me what specific wait-lists she is on, where she is on the wait-lists, and no updated information. I've asked for documentation and have been denied this request. There's no way I can appeal any process at the DSO. There's no appeal process and there's no tribunal committee. When you go to ODSP

and there's a difficulty, you're always able to go to a tribunal committee. There's nothing at the DSO. You have no way of getting your message across. There's no way to be heard, and I find that the lack of transparency is very painful. I've come to believe that the DSO is simply a manufacturer of wait-lists. It serves no other purpose.

0930

The thing about crisis is that it waits for no reports and no assessments. All of us fluctuate and change in the blink of an eye; people with a myriad of complex needs, as well, their needs can change in the blink of an eye.

The DSO process took months, and in those months, Lexi became much sicker. So my child has severe mental health issues, and due to her illness, her cognitive functioning has dropped significantly. The original assessment we had done at the DSO is now null and void because of her illness, so we have to do the process all over again, only this time, there's a big backlog to send the assessments on to the priority panel. So I'm on a waiting list to get on the waiting lists. That's ironic.

In February 2013, Lexi became sicker. I called the DSO on a regular, daily basis, updating each and every excruciating detail of Lexi's illness. The thing about accessing resources is that you have to be brutally honest with yourself and every service provider you encounter. Our lives are wide open. I will not hide behind any stigma. Lexi was suicidal, psychotic, running into traffic on our busy street, banging her head, uncontrollable rages—she was incredibly ill. Nothing was done for us at the DSO level—nothing.

We went to Community Living Elgin and they provided us with emergency funds. My family and another local family ate up the entire emergency fund in Elgin county—two families. We were able to work with Community Living, and they were able to provide short-term, temporary respite. Respite is crucial to our family. It allows us to breathe, to regroup and to focus on our other children. It cost our family \$2,300 for a weekend of respite—\$2,300; it's way more than our mortgage payment.

Those emergency funds lasted a short four months. In those four months, Lexi became even sicker. It was a sad time in our lives. We truly needed a worker in our home every waking hour to keep Lexi stable and secure and to protect our family. The DSO was aware of this. The Ombudsman had taken on our case. Jeff Yurek, our local MPP, was incredibly supportive. Yet there was nothing in our rural county: There are no emergency beds, no centre-based crisis intervention, no respite. There was only hopelessness.

Our crisis reached an all-time high when I became ill and I required surgery myself. Lexi was then hospitalized at Regional Mental Health here in London. I nearly died. I needed a second surgery. Imagine this: I'm her main caretaker, her unpaid case manager, her advocate, her support system, and I could not do a damn thing.

It was monumental, a massive crisis in our family. My husband was caretaking our younger children and attend-

ing to me. He's Lexi's stepfather, and while he loves her immensely, I'm her main caretaker. I called the DSO from my hospital bed, begging for help. An upper-level manager told me to abandon her to the hospital and that they would deal with her. As well, as I'm begging and pleading for a group home placement, the upper-level manager coldly said to me, "As of 12:36 today, no one has died to provide your child a bed in a home"—so utterly callous.

You might ask where my family was in all of this. My parents and my in-laws are aging. They have medical needs of their own. Two years ago, my mom fell and broke her leg, had a heart attack, and she moved in with us. I took care of her for six months. Last year, my in-laws were involved in a serious car accident, and they're healing from their injuries. So family members that used to be able to provide support are no longer able to. Our support system has shrunk.

I am one of the sandwich generation: I am actively caretaking my immediate family and my aging parents as well.

For 20 years, I've been a strong advocate for Lexi, always seeking resources for her and other community members. I've met every new challenge with determination and courage, and rarely take time to feel sorry for myself. I co-facilitate a parent support group in our county. I am Lexi's case manager. I receive no pay for this incredible amount of work that I do. I cannot work, as employers are not very sympathetic about our constant crisis. I spend hours on the phone or at meetings, pleading our case. If I don't understand, I ask questions until I do understand. I keep pushing and annoying the heck out of agencies and, I'm sure, government offices as well. I owe it to Lexi. I take my role as a parent very seriously. I am virtually helpless these days because I'm unable to access services that will help my child get better, to thrive, to be successful and to have a fulfilling life. The wait-lists seem insurmountable. We become more mired in crisis from our inability to access those services.

Lexi graduates in June; she is done high school. What becomes of her? There is no longer any transition planning in our community—none. There are no job training programs. Day programs cost anywhere from \$50 to \$200 a day. There are only wait-lists. She deserves to have a fulfilled life like any other 20-year-old but needs daily supports to accomplish that. Her most basic human rights are trampled on.

So let's talk about solutions. You've heard about our crisis and what it looks like for our family. Let's take a few minutes and talk about solutions. The first step in solving a problem is admitting it's broken. Services for adults with developmental disabilities do not exist, except on paper. They are only empty words and false information. The MCSS website talks about services for adults with developmental disabilities. It should have the following disclaimer on it: "Caution: While in theory everyone receives these services, at this time there are only wait-lists available."

You cannot misinform parents or consumers any longer. You have to admit there's a massive failure and start fixing it. It is only going to get worse in the years to come. Trust me; there are parents coming up the line who are going to lose their funding with their children at 18, and they're already mad. Do not lay blame; do not analyze it; fix it. We need long-term, sustainable solutions, with various ministries working together to share costs and funding. We need to be innovative in our solutions. Combinations of formal and informal supports are what have been successful worldwide. If I hear one more government official say to me, "Experts say," I truly am going to vomit, because I am the expert. I live it 24 hours a day, every single day. Twenty years of experience I have; 20 long years. So ask me. Utilize my experience. Don't tell me what I need. Listen to my voice. Hear me. I'm more than willing to help. I'm more than willing to do my share. I'm willing to offer up solutions and to work with you.

We need rural solutions, not just urban solutions. In Elgin county 10 years ago, there was no wait-list for residential placement. Today, that list has grown to 114 people. We need local resolutions in our community such as housing, psychiatric services for dual diagnosis, crisis beds, and respite funding.

Our most immediate need is housing—safe, supported housing. Other parents and myself have formed a non-profit business called Elgin Active Living. We want to buy a local closed school and turn it into apartments for adults with special needs. We have partnered with another non-profit business that runs a phenomenal day program. This business will purchase space in our building and will run the day programs and provide staffing to our apartments. We will have a community centre attached as well. We will have enough land to provide job opportunities for our clients such as gardening, a café, a bookstore and a pet-sitting service. We have tried innovatively to find a solution to our problems, but the reality of this dream is a difficult one. Each family in our group has suffered a major crisis in the last year. There is hope in innovation and partnership, and the government needs to partner with groups such as ours.

We need more immediate crisis intervention for those with a dual diagnosis. It is an area that needs more funding, more research and more time than I can give it today. While dual diagnosis falls under CMHA's mandate, it is still not given enough emphasis in the world of mental illness.

I leave you today with one last thought. It's not a pretty one; it's harsh and stark and it haunts many of us as parents. I understand why parents are forced to abandon their adult children. It's not because they're cold or callous; it's because their hearts are broken and their spirits are crushed by years of traumas, crises, endless paperwork, and meetings upon meetings with teachers, principals, doctors and specialists. We have health problems ourselves that develop from years of stress and crisis. We are aging, and that in itself leads to health difficulties. We have government edicts that change with

no thought or research into how those edicts affect our families in the long run.

0940

I'm one of those parents who has lain awake at night wondering if the next crisis will lead us down the road to abandonment, and that is a horrible, horrible thing to have to face as a parent.

So today, I call to you out of the darkness that is the stark reality of adult developmental services. I hope you heard me, but most of all, I pray that you remember Lexi. Thanks.

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

We have about two minutes for each party. Miss Taylor or Ms. DiNovo?

Ms. Cheri DiNovo: First of all, thank you for your presentation. Personally, we're horrified by what you've had to go through. It's unconscionable. I can't apologize on the government's behalf—I wish I could—but there are no words for that. You've given a wonderful presentation.

A couple of questions: You must have looked into and thought about other jurisdictions that do it better. Can you point to one? Is there a light somewhere of someplace that delivers services better than we do here?

Ms. Susan Buro Hamm: I think we're so mired in Ontario, all over, that it's hard to seek out those resolutions. When we began researching about trying to find our own solution to housing, we looked at other countries. We looked at other small projects. I believe the ministry has supported a small project in Quebec of the same type of idea that we have. It becomes their home. They have a home for adults with developmental disabilities; it's like a farm. So we began to look at these types of ideas, innovative ideas, ones that would make us feel secure as parents, that we could have control in, that we could have a say in. They're very few and far between, and we've actually sought in other countries and taken ideas.

Europe has fantastic ideas and placements of adults in homes. We did look out there but in terms of accessing services and things, most communities have their hands tied and have even greater waiting lists than Elgin county.

Ms. Cheri DiNovo: And just quickly, the DSO: What would you do with it?

Ms. Susan Buro Hamm: I'd get rid of it completely. Right now, you have people who are sitting there earning dollars and you have top-level executives and you pour all this money into staffing and offices, and they have done nothing. They have done an assessment for my child, and if I run into crisis and call: "Okay, we'll update your file." That's it. Any other services, any other thing—there's nothing. I'm not sure what the replacement would be, but it's a useless entity. It really, truly is. I've gotten nothing but an assessment and wait-lists. That's it.

Ms. Cheri DiNovo: Thank you.

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

Ms. Hunter.

Ms. Mitzie Hunter: Thank you so much for coming today to appear before the committee and to share your story, and Lexi's story as well.

I have two quick questions, I hope. You talked about types of job training, and what would be helpful?

Ms. Susan Buro Hamm: For Lexi to be able to have an independent, wonderful, fulfilling life—Lexi probably has the ability to have some sort of job, not full-time, but training. So whether it be a volunteer position, whether it be a paid position, she needs a full-time worker there with her—the ability to access that quickly and efficiently.

And transition planning: They took the money that used to be at Community Living for transition planning and they gave it back to the schools, and they said the schools are now going to be doing transition planning. That doesn't exist in our school; there is no transition planner in our school. So we need transition planning to help them, because at 20 years old you're thrown out and there's nothing for her to do. She cannot be at home. That will make her mental illness—it's a crisis waiting to happen, I can tell you that. I can guarantee that.

She needs job supports. She needs immediate access to job training, and it needs to be permanent.

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

Ms. Jones.

Ms. Sylvia Jones: Thanks for presenting today, Susan. I am interested in learning more about one of your solutions. The Elgin Active Living Centre sounds like a pretty creative innovation for parents who are having their own challenges. I wonder if you could share with the committee: Who have you presented that to? What kind of blocks are you getting? Is it the residential mindset? Help us.

Ms. Susan Buro Hamm: It is. Most of the parents within the group have children who are going to need residential placements sooner rather than later. They're going to need incredible amounts of support. We have varying degrees of—you know, a family that has an autistic child with Down syndrome, another one that has a physically handicapped child who is in a wheelchair. So we have all kinds of different levels of care needed within it.

It's really unique in that when we began looking for a solution, we realized that, you know, we put this intense pressure on the government to provide solutions. We can work together and come up with a solution. With Elgin Active Living, we thought, "There are tons of empty schools in our area." We toured the schools. We went and looked at them and we found one that meets our needs totally. It has an incredible gym; it has open space for a day program. The classrooms are all going to be converted into accessible apartments. We're going to have a main dining area. We're going to have opportunities for our clients to have jobs, volunteer jobs, and to be an open part of the community and revitalize that area.

We've presented to Jeff Yurek; we've had a news conference; we've spoken to various groups in our community that are very, very supportive. We've talked

to schools so that parents are made aware that they are welcome to join our group.

The other thing is that it's a cost saving. We actually did a cost comparison. I'm not sure if you're aware that in a group home, depending on the level of care needed for your adults, costs can be anywhere from \$200,000 per year upwards to \$1 million, depending on the level of care needed. We've actually done it so that we pool our pot of funding and we're able to utilize—for example, Lexi doesn't quite need so much support when she's sleeping, but some of the other clients do need support. So we pool our funding and we save money that way in that we're not using the typical model of assigning—you know, "That family needs \$1 million in care." We're spreading it out so that we're able to help more families effectively.

We can fit anywhere from 12 to 16 clients in the facility. We hope to actually do it with other—we've looked at other schools and expanding. It's a model that could be used and utilized across Ontario.

Ms. Sylvia Jones: Thank you. And to that, very briefly—

The Chair (Mrs. Laura Albanese): Thank you. Sorry, the time is—no, I'm sorry.

Interjection.

The Chair (Mrs. Laura Albanese): Sorry. They didn't get that.

Ms. Sylvia Jones: The DSO manager who made that comment to you should be counselled to other employment.

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

Ms. Susan Buro Hamm: Thank you.

CANADIAN MENTAL
HEALTH ASSOCIATION
WATERLOO WELLINGTON DUFFERIN

The Chair (Mrs. Laura Albanese): We'll call now on the Canadian Mental Health Association from Waterloo, Wellington and Dufferin. We have two presenters here with us this morning. Good morning. Welcome to our committee.

Ms. Adrienne Crowder: Good morning. I'm just going to introduce, and then we'll do a little bit of back and forth.

First of all, we're just really appreciative of the work you're doing. It is so important. We're very grateful we have an opportunity to share some information and hopefully help you in your decision-making.

My name is Adrienne Crowder.

Ms. Angela Allt: I'm Angela Allt.

Ms. Adrienne Crowder: We have interesting roles. We have roles called service resolution. Angela works within Waterloo and Wellington counties; I work within Wellington and Dufferin. We'll explain those roles a little more, but we have the opportunity to see cases vertically, so we see them from front-line through to either ministry or LHIN representation, and we see them

horizontally across multiple ministries, so we see social services, health and justice. From that perspective, we're going to share some of the information that impacts us in our work and that we're hoping will help your committee.

Ms. Angela Allt: Again, thank you for the opportunity to be here this morning. We are both very appreciative of it.

I'm the service resolution facilitator for Waterloo and Wellington for adult mental health and addictions. But part of my caseload is comprised of individuals who are dually diagnosed, and those are the folks I'll be focusing on this morning.

In my role, I'm tasked with finding supports and services for the most complex and difficult-to-serve individuals in the region. People are referred to service resolution when a primary support or community partner cannot access appropriate services and/or are experiencing difficulty in supporting the person.

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In reference to the dually diagnosed in our region, my role could include things such as advocating for support coordination, advocating for admission to in-patient services, assisting with sourcing and referral to outpatient expertise, and working amongst community partners, including mental health agencies, developmental agencies, police, probation, hospital and housing providers, to come up with a plan to support the person. I assist in finding housing for people with very challenging behaviours and/or complex needs, and I participate in system-level initiatives that develop increased capacity to support people, such as a program specific to our region, the Extraordinary Needs Program, which funds a variety of extra supports to enable people who are in hospital to be discharged to the community, people who would otherwise have to continue to stay in the hospital.

In the adult mental health and addictions service resolution stream, those with a dual diagnosis generally make up approximately 20% to 25% of my caseload at any given time. The amount of time and effort put into managing and resolving their challenges, as compared to other individuals on my caseload, is much higher due to the nature of their difficulties.

In 2013, both streams of service resolution, as represented here this morning, undertook an examination of the consequences and costs of the lack of comprehensive service planning for those identified as being dually diagnosed. An overview paper was produced that looked at the service usage of just five individuals in Wellington county over the course of a year, and we have made that available to you. It was discovered that seven different hospitals were accessed. Two correctional facilities, two police services, probation services, and 10 community-based mental health and/or developmental service providers were involved with the clients at multiple points in time. A breakdown of the individual usage of services, as reported, can be found in the accompanying handout.

What can be surmised from even the briefest examinations is that these individuals and others like them experience a multitude of issues that are bringing them

into a cycle of hospital visits, both in-patient and out-patient, interaction with the police, courts, correctional facilities, probation and services which provide temporary housing. The cumulative financial impact is significant and does not serve the clients well.

Looking at the number of types of contacts and service usages only tells us part of the story. What those are showing us is the result of what brought them to that point, particularly in the case of police, courts, custody and hospital contacts, so we need to look at what preceded those contacts to understand what is going on.

In looking at those cases that have come to service resolution for the dually diagnosed in my service, the most common issue, be that the presenting issue or what has led to other problems, is appropriate housing. I say “appropriate” because most of the folks have had a number of failed housing placements. For those who are dually diagnosed, their needs in terms of housing can be very high. What they need is a place to call home that is equipped to deal with the challenges they can pose. These folks generally have very little insight into their mental health and developmental conditions. This often lends itself to making very poor choices about their lifestyles, leaving them vulnerable to various types of abuse if left to their own devices. This includes substance abuse, befriending and/or being used by other people who often get them into trouble with the law, financial abuse and medication non-compliance.

When we have somebody with a dual diagnosis who starts using substances, they become even more difficult to find a home for. The substances will complicate both their mental health and developmental issues. Depending on their drug of choice, over time their cognitive functions may become even more compromised, leading to increased inability to care for themselves, as well as lending itself to more psychotic episodes which will, again, result in increased visits to the emergency department and/or in-patient admissions. They are also at increased risk of legal involvement.

With someone with such a history, it’s very difficult, if not impossible, to find any type of supportive housing that is willing to consider admitting the person. Placing them in an independent living situation is not viable, as often the person is not capable of managing on a day-to-day basis. Behavioural problems are often the reason for a failed placement. Trying to house someone in a setting where the staff does not have an understanding of the behaviours or how to manage them is a recipe for failure. Often when clients are stressed they can become verbally or physically aggressive. Depending on the individual, often the situation can be resolved through the use of de-escalation techniques, if you have properly trained staff.

There is a small group of people who do require a more secure setting due to their regular outbursts, which can be physically aggressive. These clients do need a hands-on approach, and may need to be placed in safe rooms for short periods of time. We do see clients that are in the community who actually need this type of housing; usually they are spending a significant amount

of time in our provincial jails. When not in custody, they’re usually in housing for only a short period of time before offending again.

There is another group of clients who also remain in hospital. In Waterloo-Wellington, that means they’re at Grand River Hospital, in specialized mental health at Freeport. These folks are designated as alternative level of care, meaning that their active treatment at the hospital is complete and they are as good as the medical staff expect them to be. They’re ready to move out. However, even with the program that I mentioned before, that enables individuals to get out of the hospitals with extra supports, we usually don’t have suitable housing to manage their behaviours, so they sit in the hospital at an approximate cost of \$1,000 a day.

Another area of concern is the lack of coordination between ministries. For my purposes, I’ll again just focus on the housing issue. We have, of course, two streams. We have the developmental sector stream, which does have more housing but, as you’ve heard before, the wait-lists are long. On the mental health side, we have a patchwork of homes which are run by individual organizations, and we have two homes for special care in the region.

The Homes for Special Care Program is funded by the Ministry of Health and provides additional monies to the operators of the homes, which are privately owned. They provide the care to the residents. Those homes for special care are staffed 24/7, and they can work with individuals who are relatively stable. Those people need medication management, meals provided, laundry, cleaning—kind of day-to-day type things. They usually require supports to go to appointments, and they may need occasional verbal de-escalation due to behaviours. They’re not the highest-needs clients, but they do require close monitoring.

The problem is that only those with a strictly mental-health diagnosis qualify for the program. Those who are dually diagnosed do not. We know that a segment of the dual-diagnosis population can be successfully housed in homes for special care, as we currently have a few people who are living there, in a few of the private beds available within those homes.

In order to put them in those beds, funds from the service resolution budget are used to provide the top-up over and above what the client was able to pay on their ODSP. The number of people who can be helped in this way is minuscule; the service resolution only has a very limited budget and has to cover a number of different types of service gaps in the region.

In terms of residences run by community organizations, there are only two in Waterloo-Wellington that have the ability to accept dual-diagnosis clients. Again, this has only been possible through either service resolution funding top-up or our Extraordinary Needs Program, and there are very few spaces in these residences. They’re small. Again, they are only able to take people who are reasonably well-stabilized.

So it would be helpful if the Ministry of Health and the Ministry of Community and Social Services could

work together to come up with a shared funding plan to support dually diagnosed people, not only in homes for special care but other types of housing, including community providers that are willing and able to provide the physical buildings but require funds to adequately and appropriately staff the homes, particularly high-intensity rehabilitation or treatment homes.

Just very briefly: We have ongoing issues in getting access to services, both in-patient and outpatient—so, clinical services. We have a lack of beds for in-patient assessment, diagnosis and treatment. We have a lack of specially trained physicians and trained clinicians, and we have a need for intensive education for those in the mental health clinical fields as they relate to dual diagnosis. Some work has been done in this area, but it remains an area for ongoing need and training.

The Chair (Mrs. Laura Albanese): Thank you. So we'll—

Ms. Adrienne Crowder: Sorry, if I can—

The Chair (Mrs. Laura Albanese): Oh, you will continue? Sorry about that.

Ms. Adrienne Crowder: Angela's role is adult mental health in Waterloo-Wellington. My service resolution role is children's services in Dufferin and Wellington, and also developmental services through the whole lifespan in Wellington and Dufferin

Just to give a little bit of context, only the cases that are at the tip of the iceberg come to service resolution, but, by virtue of the fact that they've risen to the tip of that iceberg, you get to see where the breakdown has happened en route. So service resolution cases have that kind of oversight.

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In the children's world, the typical case sitting in service resolution will have representatives from children's mental health, the developmental sector and education and then sometimes some specialty services. In the adult world, typically representation is developmental services and sometimes adult mental health, and often justice is involved.

What I want to do is just give a very quick breakdown of what the overall picture looks like and then go into some of the thematic challenges. Just to give you a sense of what a service resolution role and caseload looks like, last year, 2012-13, 72 cases came through Wellington and Dufferin; 42 were children's cases and 30 were adults; 61 were in Wellington; and 11 were in Dufferin, just in terms of slicing and dicing the numbers.

In the children's cases, 63% of the cases had an autism spectrum disorder diagnosis; 18% had a fetal alcohol syndrome diagnosis—I'm mentioning that because fetal alcohol doesn't have any dedicated services. There are no camps; there are no specific behavioural programs, and yet they're a bunch of children who have very high needs and who present major challenges to the community to respond to their care. Thirty-eight per cent had aggressive behaviours in the children's world; 36% had been hospitalized at least once before coming to service resolution; 23% had a modified school day; 9% were in section 23 classrooms; and 4% were not in school at all.

In the adult cases, 27% had no permanent housing; 45% required 24/7 care; 45% required modified support, meaning up to six hours per day; 33% had been hospitalized at least once prior to coming to service resolution; 13% were directly connected with the justice system; 45% had a dual diagnosis; and 40% had an ASD diagnosis—so just a sense of who comes through the service resolution process.

I want to speak to three key challenges. One of them you've heard repeatedly. Forgive me; I have to throw my hat in this ring too because it is such an important piece: housing. In Wellington county, the Developmental Services Ontario is aware of at least 60 clients who would take 24/7 care today if it was offered—that's a DSO process in terms of how they would qualify someone. We have, in Wellington county, at least 60 people. We have about three vacancies a year. Those vacancies become due because someone dies or someone leaves the county. There is a gargantuan gap between the need and the resources. Out of those 60 people waiting, we know that at least a third of them are between the ages of 18 and 30, a third of them have high behavioural and self-injurious behaviours, and a third of them live in Guelph. Those are some of the breakdowns of who needs that housing.

I have this in my written document, and I'm sure you've heard this from other people: The level of support that has gone into other service systems such as education has been disproportionate compared to what has happened in developmental services, where the needs are great and the funding has been low. I guess my question is, how does this make sense? Where can we begin to close a gap that is this size? How quickly can we put a solution in place? We have a vulnerable population who, by definition, cannot advocate for themselves. In a relatively wealthy province, it's very hard to work in a system where you can't help your clients.

Group homes are not a one-size-fits-all solution. There are many people, as Angela mentioned, with dual diagnoses who are not well suited to live with other people. Their needs are not ever going to be social in how they work. There really need to be some much more innovative models. The model we just heard about in Elgin is the kind of model that really responds to some of the ways that we can serve people.

Housing was the first thing. The second one is that how families with developmental services are funded and supported is really inadequate. Special Services at Home is a maximum of \$10,000 per family. ACSO is income-based, and if you have an income of over about \$50,000, you don't qualify. The amount of care that high-level children need in terms of respite over the summer holidays and Christmas and winter breaks is huge; families cannot afford, and there are not the resources, to house these people in respite.

Parents absorb the challenges of raising their children with developmental disabilities, and many burn out. Sitting at the service resolution table, I hear of single mothers developing cancer at a rate that is way above

random. I hear about couples divorcing, which results in precarious care and support for already vulnerable children. Parents report broken bones, severe bites and concussions from attempting to redirect aggressive children. In 38% of the kids who came through service resolution, aggression was a key component.

There is a huge family violence epidemic, I would say, in our province that is basically hidden. The level of physical harm that goes on in families is staggering, and it's apparently acceptable because the children are—it's non-volitional and the children can't help themselves, but the cost to our communities is massive: through health care, through the cost to families and the cost to those children.

Parents need skilful coaching and hands-on support. They do not need consultation; they need hands-on support to raise a child with developmental disabilities. They need to know they're not alone and that they can access flexible responses as they need them. Parents need good respite and they need enough of it.

I'm very passionate about this. I have had a long career in social services in Ontario. I had not worked in the developmental sector until about three or four years ago, and my eyes were opened. I didn't think I was particularly naive; I was very naive.

The third piece I want to speak on is the schools. Although schools are mandated to support children up to 21, how that gets operationalized varies from school board to school board, school to school, principal to principal and teacher to teacher. Some children are getting wonderful experiences. Someone with exactly the same behavioural or diagnostic profile living two streets over going to a different school may be having a terrible experience. In service resolution, I have had more than one eight-year-old who's not in school because the school cannot handle the aggression. That has this huge compounding effect. The child doesn't get their social needs met, the parent gets burned out, and the school doesn't have to step up and address the fact that they've got difficult children in their boundary whom they need to work with. It's very compounded.

I would really encourage there to be a way, if the province could possibly find a way, to hold schools more accountable for actually delivering on the services that they are mandated to deliver. That would really be a very helpful step.

Forgive me; I need to breathe.

I do appreciate the opportunity. Working in the service resolution role, there's an opportunity to help, but we can't help enough and we can't help in the ways that are needed.

The Chair (Mrs. Laura Albanese): Thank you. Did you need to add something in?

Ms. Angela Allt: We're just going to do a quick closing.

Housing is key. We don't believe anyone would suggest that we go back to the days of large institutions to house people. Indeed, we want to see people not just housed but have a place to call home. However, the

institution of the correctional facility all too often seems to be where a number of our clients end up spending significant amounts of time.

Appropriate housing for the dual-diagnosis clients could be best realized, as we said, by joint consultation between the Ministry of Health and MCSS and joint funding; provincial standards for clients with developmental disabilities in terms of health care services for addictions; developing a process that tracks clients across the service system so that the total cost of hospital time, jail time, court time, ER time etc. is available—and it will be cheaper to house and support clients appropriately in the community rather than having costs hidden in multiple service systems; and resourcing schools so that they can serve the clients with challenging developmental disabilities, resulting in no client with a developmental disability being sent home based on their behaviours.

The Chair (Mrs. Laura Albanese): That doesn't leave any time for questions, but at the same time, I want to first of all thank you on behalf of the committee for the work that you do and for the wonderful presentation you gave us illustrating some solutions. Thank you for all that you do.

Ms. Sylvia Jones: Chair, while the next presenter is coming up, can I ask a question of the researcher?

The Chair (Mrs. Laura Albanese): Absolutely.

Ms. Sylvia Jones: I want to confirm I heard that right. Homes for special care are not available to dual-diagnosis clients: Can you delve into that for us? Thank you.

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

Ms. Soo Wong: I also noticed that there were quite a few questions that the previous witness shared with the committee—and if the researcher could also get some answers for the committee. On the last page of the handout that was shared with us, how do great models of support—can we identify some of them? About the school boards: This is not the first time this committee has heard about the inconsistencies of school boards in the delivery of services. I am particularly interested to know—on page 2 of the report, the witness talked about increased funding to the Ministry of Education, 172% over 10 years, despite declining enrolment, yet another ministry has greater needs and less funding. Can we get some answers?

Where's the accountability when we give extra funding? That's why I'm trying to get some answers to those questions that have been identified by the previous witness.

The Chair (Mrs. Laura Albanese): Thank you, Ms. Wong. We'll welcome the next presenter at this point—

Interjection.

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The Chair (Mrs. Laura Albanese): Sorry? You had more questions?

Interjection.

The Chair (Mrs. Laura Albanese): We'll move on to the next presenter?

Ms. Erica Simmons: Yes.

COMMUNITY LIVING
OWEN SOUND AND DISTRICT
COMMUNITY LIVING
WALKERTON AND DISTRICT

The Chair (Mrs. Laura Albanese): Mr. Hill, executive director of Community Living Owen Sound and District and Community Living Walkerton and District, correct?

Mr. Rick Hill: That's correct. Thank you.

The Chair (Mrs. Laura Albanese): Welcome. You may begin any time.

Mr. Rick Hill: Thank you. I have my notes written down, so I'll read them. That way I know I'll stay within the time limit; excuse me for that.

My name is Rick Hill, and I'm executive director of both Community Living Owen Sound and Community Living Walkerton. I mention that it is my 30th year of work in the Community Living business. One of the unique aspects of work in a Community Living organization is that the work we do does span entire life cycles from birth to death, as an intellectual disability is a condition present throughout a person's life.

What we have learned in our work is that the earlier the intervention, the better things are in the long run. People who don't work in this field often believe that it's special work, that it's not like what is experienced by the so-called norm. It's special work for sure, but not for that reason.

Let me give you an example of how it's much like everyday life for people. One of the employees at Community Living Walkerton just returned to work after being on maternity leave for a year, with her first daughter. Co-workers were asking Mary how her daughter was managing the change with mom at work. She said she was doing well, as she had been preparing her for this day over the past few months, leaving her with different sitters in her home and in other people's homes. This early intervention proved helpful for both babe and mom. A similar story could be told for any stage of life, whether it's going to school, whether it's graduating or whether it's getting your first job etc. The earlier that you begin on that path, the better.

This basic understanding of human development is ingrained in the thinking of developmental services professionals but is less obvious in other sectors. Can you think of another line of work or sector that requires this lifelong perspective to be applied to all of their work?

The reason I'm focusing on this aspect is that in preparing this presentation, I have noted a shift over the past 10 or 15 years whereby responsibility and authority for publicly funded developmental supports and services has been divested, downloaded or dispersed, depending on your definition, amongst multiple ministries, and that the primary authority of MCSS, Ministry of Community and Social Services, has become focused exclusively on adults, leaving no one with an overall authority or eye on the big picture. Decades ago, as closure of provincial institutions for children and for adults with development-

al disabilities was the vision, a system of community supports was put in place through partnerships with community-based organizations. The vision included programs for infants, preschoolers, youth, adults and seniors, all under the authority of MCSS.

This was in the 1980s, when I first started in the field. I recall many meetings talking about making sure that a full continuum of services was in place. Special initiatives were undertaken in areas such as dual diagnoses, supported employment, Special Services at Home, family support. Over time, the gaps seemed to be covered, and the task then began to get the right mix of services.

Then of course, budgetary pressures began to impact, and recessions of the late 1990s began a trend of dismantling or dispersal of programs from the authority of MCSS. I'm proposing that the select committee consider the impact this divestment has had, which creates unnecessary transition points between funding silos and removes the benefit of overall authority for the full funding envelope. Might this divestment be one of the primary reasons why a select committee is needed today? I believe the approach of having multiple ministries each responsible for small portions of publicly funded services forgets the fundamental principle of lifelong continuum and early intervention.

I have a couple of examples of how this plays out. In the Ministry of Children and Youth Services' presentation that the select committee heard early on, it was stated that there were only two programs provided by MCYS that specifically targeted children with a developmental disability. Those were identified as programs related to autism and the Infant Development Program. I want to speak about infant development programs.

There are 49 programs in the province and two sponsored by the organizations that I lead. As the name suggests, the program is for infants, and the funding criteria specify that the infants served must have an identified delay or be at risk of delay. Indicators of being at risk would be such things as low birth weight, premature birth or multiple births—twins or triplets, for example.

Infant development programs typically use a home visiting model. The infant development professional works with both the parent/caregiver and the infants, using play and often physical therapies. Infant development staff are trained to administer many assessment tools to help pinpoint areas of delay and serve a case coordination function, with referrals to other services when indicated. Most importantly, parents and caregivers are engaged in their child's development and learning, one of the few opportunities for parent engagement as we now embark on full-day learning in our schools by the age of four.

In Bruce and Grey counties, approximately 7% of all babies born are referred to the Infant Development Program. Annually, we handle about 160 new referrals each year, and we work with infants up through the age of five, although most are not seen beyond the age of four. Typically, the six full-time-equivalent workers in

Bruce and Grey counties are actively visiting 250 infants. That's a ratio of one worker for every 40 infants, more than double from when the program was first initiated; at the time, it had a ratio of 1 to 15.

The primary issue facing infant development programs is that the programs' funding level has not been sustained. When it was a part of the developmental services envelope under MCSS, it received the same attention as its adult counterparts. However, since the program has shifted to MCYS as a stand-alone program up against child welfare, children's mental health and even autism funding, the funding has deteriorated year after year, now going 12 years without any base increase.

Significant lobbying by program sponsors such as myself has only resulted in a series of reviews or studies, none of which produced any action. It has been stated by researchers that the return on investment of early intervention services is \$3 to \$9 per every dollar invested. Presently, it costs about \$1,800 per year per child for infant development services.

Provincially, there are 3,200 infants referred and waiting for this service to begin. As any parent knows, in what seems like a blink of the eye, your newborn child, your baby, is graduating. There's no time to waste in waiting.

Why has this program not been sustained? In my opinion, MCYS has been a poor match for it, a small, unnoticed program up against the MCYS backdrop of child welfare and children's mental health. The ID program belongs with the broader developmental services program funding under one ministry. I urge the committee to recommend restoring a sustainable level of public funding to this program and shift it from MCYS to the developmental services portfolio, wherever that is.

I also want to speak to another aspect of Early Years programs that also highlighted for me the fact that dissemination of the developmental services portfolio is a problem. Neither MCYS nor the Ministry of Education mentioned it in their presentation, but it's an important program in the developmental services life cycle, and that is special needs resourcing.

Special needs resources are funded as part of the child care envelope, once a part of the Ministry of Community and Social Services, then moved to MCYS and now moved on to the Ministry of Education. The Ministry of Education has bundled the child care funding with federal grants into an Early Years division, and it flows out to tier 2 municipalities. In my region, that would be counties.

As the name suggests, special needs resources provide preschool resource teachers to provide developmental programming for children with identified delays in two or more areas of their development. Unlike the Infant Development Program, where a risk of delay was a referral, in special needs resourcing, it would be an identified delay in two areas.

1020

In most areas of rural Ontario, where distance and transportation are a real concern, preschool resource

teachers travel and alternate their visits between the child's home and licensed child care centres. The goal is to help prepare parents engage with their child's developmental needs so that the child makes a smooth transition to school or to the child care centre.

Since taking on the special needs resourcing program, the Ministry of Education has revised the guidelines for the program. These revised guidelines would eliminate or greatly reduce the home visiting component of this service. This would effectively remove the parent engagement component of the present special needs resourcing model. In rural Ontario, there are many reasons why parents may choose or may not be able to have their child with special needs attend child care. Removing their children from the special needs resourcing program will only increase the caseloads on the already oversubscribed Infant Development Program, which is the most commonly referred-to program for infant development.

Once again, when funding specifically for children with developmental needs becomes managed by ministries who do not see or appreciate the lifelong journey, poor decisions are made. It's easy to see how, when the Ministry of Education, which is primarily focused on and accustomed to an institutional model of service, encounters a program or service like this, silo thinking takes over, and it rationalizes focusing child care funding on only child care centres.

The final example that I wish to cover in the presentation deals with another program noted in the MCYS presentation, and that is funding that is attached to children with complex special needs. The presentation noted that funding for this program has increased from \$22 million in 2002 to \$105 million today, and the number of children served is now over 800, a good number of them living in children's residential services.

While it was suggested that the program serves a target population broader than developmental services, I would ask the committee to confirm this, as I would estimate, based on the numbers I see, that a very high percentage of children and youth served end up making a transition to adult developmental services. I believe that it would be as high as 90% of the children.

Once again, my point is that by establishing the program under MCYS, a new transition point is created. Children with complex special needs become adults with complex special needs, and this dual authority creates inefficiencies, gaps and, goodness knows, undue stress for families and individuals.

I know of one instance where a young adult who was involved in a complex special needs program now has his adult funding spread over two different service agreements, one with MCSS and one with MCYS, and that budget is also spread over three separate line budgets, all within the same agency. So when each of his team members sees him, works with him, we as a service provider need to allocate costs across three different budgets. It's the same worker, same person, no difference in the service area or the support being provided, but the cost splits three ways, and not in three equal amounts, either.

Also, each budget has its own service targets and reporting requirements.

This young person's family must worry: What happens to this young adult, with his complex special needs, who is going to need lifelong support, when the Auditor General or some other controller asks, "Why is MCYS funding services for a 30-year-old?"

I wrap up by asking this select committee to restore the funding for the Infant Development Program and sustain it, and gather all the multiple funding envelopes specific to developmental services under the authority of one body.

Over the past few years of so-called transformation of developmental services, one would think people inherited an intellectual disability at age 18. This has created unnecessary and costly transitions, and also meant that services for infants, children and youth with intellectual disabilities have been cut adrift.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. I believe it is—no, it's your turn. So Ms. Elliott.

Mrs. Christine Elliott: Well, thank you very much, Mr. Hill, for your presentation. What you said makes a lot of sense to us. The Infant Development Program is something that I wasn't aware of, so thank you for bringing it to our attention, that the funding had been decreased for that.

One of the things that we also have noticed is that there is no one with a central responsibility for developmental services. It's very fragmented. Do you think that MCYS really needs to be involved in this aspect of it at all, or could everything be consolidated into the one ministry, into MCSS?

Mr. Rick Hill: I think there are different models, and I think it's worthwhile to take a moment and look at it. This hasn't been a big point of discussion with my colleagues across the province in terms of how it would look if different. But certainly in British Columbia, for example, the government has assigned all of the funding envelope not to a ministry, but sort of to a crown corporation notion. You're well aware of the different options available.

I just think that the more you spread the funding out, the more transition points you get and the more need, then, for inter-ministerial work, and the stars never align, in my mind.

Mrs. Christine Elliott: I'm not sure if I have time for one more question, but I'll try to get one in. Could you just speak to some of the particular challenges that you face in a largely rural area?

Mr. Rick Hill: Specific to children, just to mention on that, one of the advantages is that you don't have a lot of overlap, so there aren't a lot of different programs. A Community Living organization in rural Ontario serves a lot of need. But for children and youth, the issue around the special needs resourcing in child care is with the changes in the full-day learning. Children are, of course, now eligible for school at an earlier age, and most

children with special needs are taking advantage of that. The aspect of rural child care is a real issue. Layer that, then, when you have a child with special needs, how they manage in that child care centre, for example—it becomes a real problem. I don't have the solution today, but I'm just pointing that out as an example of how one ministry that has a different focus applies a different lens to the solutions there.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): And time is now up, so we'll go to Miss Taylor.

Miss Monique Taylor: Thank you, Chair. Good morning. Thank you so much for your presentation today. I also had not heard of the Infant Development Program, so I'm glad that you brought that to the table today.

You mentioned that there were 160 referrals every year. Do you have a number—and I may have missed it; I apologize if I did—of how many are actually being served? Is it just the 160 and then—what are the numbers?

Mr. Rick Hill: All of the 160 would be referred and seen, so there would be, actually, 160 new referrals each year that do get service.

Miss Monique Taylor: Right, and they're referred, I believe, at birth, or—

Mr. Rick Hill: We have referrals from, for example, pediatricians as late as three years old or older, so they don't all come at birth. As milestones are missed or as delays or concerns are raised, then a referral gets made. It's not all babies, infants, newborns who are referred. They're of different ages.

Miss Monique Taylor: You were saying that the funding hasn't increased in 12 years. How much of a deficit are you feeling? What's your situation?

Mr. Rick Hill: In the example of Community Living Owen Sound, we have approximately three full-time infant development workers, and we reduced that by half a position in the last five years. The impact is that you rob Peter to pay Paul. The manager is no longer half-time; she's quarter-time. As sponsor of the program, you inherit other costs when one program hasn't been keeping up. In Grey-Bruce, we've reduced a full-time FTE, one FTE, over the last five or six years by not replacing workers.

1030

Miss Monique Taylor: So is there a wait-list—

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

Please answer.

Mr. Rick Hill: Yes, there is a wait-list. Provincially, I mentioned that there was a wait-list of 3,200 infants. It varies depending on, of course, the birth rates and the different geographies etc.

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

Ms. Mitzie Hunter: Thank you so much for your presentation. You talked about how to coordinate the services across ministries. That's part of the intent of what

we're doing here through the select committee: to look at that coordination through a person's entire life and how we provide the appropriate levels of support, so your input and the insights that you have from the work that you do across such a large geographic area is extremely valuable.

You talked about the models that could potentially be looked at, and you mentioned British Columbia. I'm wondering if you could expand on some of the things you see that are advantageous in that consolidated view.

Mr. Rick Hill: I think the select committee would have a lot less of a problem getting answers if it was consolidated funding. I think this is a special population of people that we're dealing with. They have very unique needs. You've heard some of the stories today; they're unlike any other sector that we're responsible for. They're vulnerable people, people with all different needs. I think that the more we can do to keep an eye on the big picture there, the better. If you take a pie and you divide it up, the next thing you know, everybody goes home hungry. It's too hard. My suggestion is to take a look at that as an option and consult with the partners.

There's a need for our medical community to respond to people with developmental needs. I'm not saying "special doctors for this population," but where funding is primarily focused on children or adults with developmental disabilities, then I suggest that it be put in an envelope and looked after and managed that way.

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

Mr. Rick Hill: You're welcome.

MS. JOANNE SMITHERS

The Chair (Mrs. Laura Albanese): I will now call on Joanne Smithers. Please come forward. When you are ready, you can start your presentation by first stating your name for the purposes of Hansard.

Ms. Joanne Smithers: Thank you. Sorry; I'm suddenly nervous here. My name is Joanne Smithers, and I have been front-line staff with Community Living Guelph Wellington since 1999, working in a variety of programs including behavioural and medical homes. I'm currently in a home in Mount Forest, Ontario.

In my role as a support worker, I have the responsibility of advocating for those in my care, of giving voice to those who can't always speak for themselves. That's what I'll try to do here today.

I also have a dual role, however. I am the president of my CUPE local, representing 430 staff—the majority of whom, you should be aware, are mostly women. I'm also here to represent them today.

I'd like to start out today by introducing you to the people who I support. They are unable to be here today, so I will be passing around some photos and telling you a bit about them. Just for clarity, my executive director has given me permission to share these with you today.

I'll start with Bev. Bev is a 68-year-old gentleman who formerly resided at Midwestern Regional Centre.

Bev is non-verbal, but he will grunt, groan and yell at times to show you what he wants. Bev has limited mobility due to advanced arthritis, and he now requires a wheelchair or staff to walk him. Bev has pica tendencies, which means that at times he will ingest latex gloves, strings, carpet and drywall. Bev loves horses, he loves watching movies and he loves van rides. Bev requires staff to toilet and bathe him, and Bev requires 24-hour care and supervision.

This is Shaun. Shaun is a 34-year-old gentleman who lived at home with his mother prior to coming to Community Living. Shaun's mother, unfortunately, has now passed away. Shaun has Down syndrome, he's hearing impaired and he is completely non-verbal. Like Bev, Shaun also has pica tendencies; Shaun will ingest latex gloves, balloons, plastic bags, strings, feces and yard debris such as grass and dirt. Shaun loves repetitive motion, and he has a swing set that he uses in the winter months. Shaun likes to float around in a swimming pool, and Shaun also requires 24-hour care and support.

This is Marleen. Marleen is a 58-year-old woman who, prior to community living, lived in a nursing home. Marleen has an unknown condition that is now causing severe deterioration of many of her skills and abilities. Marleen is unsteady on her feet, and she is no longer even semi-independent. Marleen used to be able to use some limited vocabulary, but she has now lost that ability. Marleen loves to colour. She loves to go out, especially for coffee or when I take her shopping. Marleen enjoys simple one-on-one time with staff doing things like just colouring or painting her nails. Marleen has seizures, and she requires staff to toilet, bathe and, now, feed her. She requires 24-hour care and support.

This is Penny. Penny is a 62-year-old woman who has been institutionalized since birth. She was expected to have a very short life, and she has proven everyone wrong. Penny is blind; she has epilepsy and chronic aspiration. Penny doesn't like to be around people much. She prefers to spend time alone in her room, and that is where she is the most calm. When agitated, Penny will hit herself on the head and she will poke at her eyes with her fingers. Penny caused her own blindness many years ago with this self-injurious behaviour. Penny is in a wheelchair and she wears a brief. She requires staff to toilet, bathe and feed her, and she also requires 24-hour care and support.

Finally, I want you to meet Paul. Paul is a 55-year-old gentleman who formerly lived at Midwestern. Paul is probably the most independent of the people I support. Paul cannot walk, but he crawls and pulls himself around with his arms. Paul is non-verbal, but he can understand most things that staff tell him. Paul has a wicked sense of humour, and he often laughs at staff and his housemates. Paul likes to go out one-on-one. Paul doesn't like to be crowded, and he will hit if he feels people are too close. Paul loves music. Paul also requires 24-hour care and support.

These are just five of the 138 residential clients that Community Living Guelph Wellington supports. We also

provide support to 176 people in vocational programs, 155 in life skills and 98 in supported independent living. I believe we can provide quality public, not-for-profit support through our agency, with an emphasis on individualized planning, not individualized funding, but we need your help.

The people we support are aging. Their needs are increasing and are becoming more complex. We need more resources, not less. A year ago, Community Living Guelph Wellington was forced to cut 90 hours per week, and most of these were direct-support hours. These cuts have had a direct impact on the people we support. The cuts have impacted the ability of staff to get the people we support out into the community as well as increasing the amount of time staff are required to work alone. Just picture having to provide all the supports to the people I have just told you about today and then having to do it alone.

What it means is that we're less able to take Marleen out shopping or for coffee. I'm less able to just sit and paint her nails for her. I have less time to take Bev out for a drive to go look at horses or to take Paul out one-on-one for a van ride. Shaun has less ability now to go swimming. These are the things that make their lives special, and without these, all we have done by closing the institutions is change the room they're sitting in.

We all know there are wait-lists. Different people seem to have different numbers, and I'm not sure this committee has even been provided with complete numbers on this. We know that in crisis people are being placed into long-term care, and we have heard that they're also taking up beds in the youth system, unable to move on to the adult system, which is causing a wait-list for those services.

Why did we close the institutions just to reinstitutionalize the people by putting them into long-term-care homes? I have to wonder if in 10 years the government is going to have to issue an apology to these people. Once someone is placed in long-term care, do they come off the list of those waiting for beds in the DS sector? I suspect they do. Would this not skew the numbers of those on the waiting list to make it seem smaller?

1040

Currently it seems we are providing a reactionary support to those coming into service. I believe these must be more expensive and they are tremendously stressful for the families, but, more important, for those we support. When we have parents in their sixties, seventies and now even their eighties being forced to care for their children, we all know that a crisis is waiting to happen when they die. Parents have told me they are terrified of what will happen then. They know chances are there's no way they are going to get a placement before that happens.

Once the parent passes away, we are now in crisis mode. We now need to find emergency services for the person who is struggling with the loss of a parent and possibly the only caregiver they have ever known. They are losing their home and familiar surroundings,

suddenly having to live in a strange environment with strangers and not able to understand what has happened. There is no way to do a gradual transition. Many of the people we support have huge difficulties with any changes in routine. They deserve better than this.

Many agencies are dealing with aging infrastructures, homes that were not designed for the complex needs of the people that we now support, putting a large physical burden on the staff that is providing those supports. As we have heard, we have homes that do not meet the new fire codes. Community Living Guelph Wellington has not as yet had the order to put in a sprinkler system, but from what I have been hearing, it's coming. This scares me, as that money will have to come from somewhere.

Our vans are aging and they need to be replaced. Costs for hydro, food, and general care needs have all increased. The people we support are now having to pay for more and more things agencies used to provide. This sector needs more funding.

The agencies are falling behind on pay equity, as you have heard. This is causing many employers to worry about unpaid liabilities. Yet the women in our workplace deserve equal pay.

As you have heard from many employers, retention of qualified staff is a large concern. Community Living Guelph Wellington staff agreed to take three years of wage freezes. Add to that that staff have not received pay equity since 2010, and then the cuts to hours mean many staff are now making less than they did in 2010. The staff at Community Living Guelph Wellington have identified this as a serious issue that must be dealt with in upcoming negotiations. We simply cannot fall further behind.

Many but not all of the parents I have spoken with are asking for more individualized funding because they know they have no hope of getting a suitable residential placement. Many of the others that do want the individualized funding for now also acknowledge that at some point as they age they will need agency residential supports and are worried about the ability to access these in the future. Our sector needs more funding. Parents should not have to live in crisis.

Finally, I cannot stand up here and ignore the fact that over 100 collective agreements in this sector are expiring on March 31. Failed promises, lack of funding and poverty among staff are at a boiling point. Staff feel they have been ignored and overlooked for years. We are not babysitters; we are professionals and would like to be recognized as such.

In a recent survey that my local did, staff indicated that they can no longer continue without increases to wages and benefits. They identified equally, however, that they were worried about job security and workload among staff, as we're working alone more often. For years we have been told we have to do more with less, both on the job and in our personal lives. Staff have indicated they can no longer continue in this way. Something has to be done. The people we support deserve better, and so do the staff that provide those supports. Thank you.

The Vice-Chair (Mrs. Christine Elliott): Thank you very much, Ms. Smithers. We now have approximately three minutes each for each of the parties to ask questions. Ms. DiNovo, would you like to start?

Ms. Cheri DiNovo: Sure. First of all, thank you very much, Joanne, and thank you for being privy to—being here, listening to all the other presentations.

A couple of questions, actually, for research. I think we've asked these before, and I'm not sure we've had answers yet.

Wait-lists: We asked the ministries this and they didn't seem to be forthcoming. We need to know how many people are on wait-lists for all the services and we still don't have that.

Long-term care: We've asked a couple of times now how many people with developmental disabilities are in long-term care. Again, we need those numbers. Again, ministry—I know we have ministry folk here—we really need to know that. You raise the issue of, “Are they coming off?” If they're in long-term care, if they're coming off wait-lists in the DSO, we need to know that as well—so those three things.

For you, Joanne, just in terms of others, is there a jurisdiction that does things better? If you look to a jurisdiction—we're sort of mired in all of what's wrong with our system, and there's clearly lots wrong with our system. Is there some place that's doing it better?

Ms. Joanne Smithers: I'm not sure. I know there are researchers out there who have looked at different models and different things. I believe it's Saskatchewan that now mandates services, so it's not a choice anymore. There are no wait-lists because you have to provide services, which I think is something that Ontario really needs to look at. I know from just general talk that I have heard that the UK and Australia seem to do it better than we do. Australia also no longer has wait-lists and that.

Ms. Cheri DiNovo: Thank you.

Miss Monique Taylor: Thank you for being here with us and for spending all of your time with us as we've been going through this process. You've been at every single hearing, and we appreciate that. I also really want to thank you for bringing the voices of the people who you serve to our table today and describing what their life looks like and what their needs are.

I'm quite concerned with the lack of funding and the increase in base funding that your sector has received. What's going to happen with those folks as we continue to go into years of an aging population?

So I just want to thank you, and if you have anything else to add during my time, you're free to do so.

Ms. Joanne Smithers: No.

The Vice-Chair (Mrs. Christine Elliott): We'll now move to Ms. Wong.

Ms. Soo Wong: Thank you very much for your presentation. I note that you have identified a number of concerns and issues to this committee, so can you share with us, in your final comments, what are some of the priorities? If you wave a magic wand, what would be one

priority that, in your sector, you think would be the first thing we should consider?

Ms. Joanne Smithers: Well, I think probably the biggest priority has to deal with the wait-lists. I think there are too many people who have absolutely no access to services, and then when they do finally get services, it's in crisis mode, which makes things much, much more difficult for the staff who are having to look after the people, as well as being really difficult for them. I hesitate, though, to put that above trying to retain qualified staff because I believe that that also benefits the people we support. I don't think you can do one without the other, and the fact is that retention in this sector is becoming a very big problem.

I had a co-worker who works full time, and she had to go out last year and get a second job. She took a job waitressing at a truck stop, and she was shocked because she said she made more money there.

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

The Vice-Chair (Mrs. Christine Elliott): Yes.

Ms. Soo Wong: Okay. We have heard consistently now about the concern with DSO, and we also heard that we need to be more centralized, or have one ministry lead the delivery of programs and services. From your experience and your professional work in this area, which ministry would you consider? Or should we be looking at a crown corporation like they do in BC? If you could share that view with us.

Ms. Joanne Smithers: Off the top of my head, I want to say the Ministry of Health because they have more money. But we all know that with dual diagnosis—I don't know what the answer to dual diagnosis is because they fall under both. So I don't know what the answer to that part is.

What was the second part?

Ms. Soo Wong: In terms of centralized delivery—

Ms. Joanne Smithers: The DSO—I don't deal directly with the DSO, so I really can't answer that. But from what I have heard from parents and what I've heard at this committee, the DSO seems to me like it's a lot of money going on administration costs that could be handled by the agencies themselves and perhaps go to front-line services.

Ms. Soo Wong: Thank you very much.

The Vice-Chair (Mrs. Christine Elliott): Now we'll move on to Ms. Jones.

1050

Ms. Sylvia Jones: Thank you very much, Joanne. I gather from your initial comments that you do not support individualized funding at all.

Ms. Joanne Smithers: No, it's not that I don't support individualized funding, because some of the parents really, really do like it. I'm just more concerned with us focusing more on individualized funding when even those parents have said that at some point they are going to need agency funding.

Ms. Sylvia Jones: Yes, I think that's partly what we as a select committee are trying to do, from that diagnosis

right to the end of life, because, to your point, we have supported independent living, we have respite care, we have work programs, so some way, over the period of a client's lifespan, they're probably going to tap in to multiple programs. I think that's why a lot of parents like the individualized funding: because it gives them some options and input into, "This is where my son or daughter is at this particular moment in time." I think we have to do a better job of making sure that individualized funding is available to the families and the individuals who need it, but I would hate to see it disappear.

Ms. Joanne Smithers: I do have one concern with individualized funding—and I don't know exactly how it works. It's more on the accountability piece of it, because parents get a pot of money and then they have to decide how to use it. I have a number of staff and I've talked to a number of staff around the province who work for parents and are paid cash under the table because the parent says that they can pay them, then, \$12 or \$13 an hour cash—they don't have to pay taxes on it—so they can get quality staff that maybe at an agency are making \$20. I don't know exactly how that accountability works, but I know I've heard this from more than one area: that a number of people do it under the table so that they can get more services for the money.

Ms. Sylvia Jones: One point of clarification: They actually have to present a program and a vision and an idea of how they're going to do it. There's no family that's just getting a cheque with, "Go ahead and spend it"; you have to actually put together a proposal that's quite detailed. I guess to some degree, that's why it's so frustrating for parents when they've gone through all of that background and work to then be told, "There is none. We don't know what the waiting list is, we don't know when you're going to get it, but good luck."

Ms. Joanne Smithers: Yes.

Ms. Sylvia Jones: Thanks for the presentation.

The Vice-Chair (Mrs. Christine Elliott): Thank you very much, Ms. Smithers, for your presentation today and for your ongoing support of the committee.

MS. LYNN HAINER

The Chair (Mrs. Laura Albanese): Now we ask Lynn Hainer to come forward.

Ms. Lynn Hainer: Thank you very much. You have my presentation coming around to you here.

I come with a few different hats today. A few of you I've met before, so it's nice to see you again. First, the reason I'm here is mostly because of my son, Mitchell, who is now eight, but I also sit as a councillor in the town of St. Marys. I'm an accessibility committee member. I sit on the local advisory committee for the St. Marys Memorial Hospital and within the HPHA. As well, I'm the former chair of Parents in Perth, which is a family organization in Perth county. I also sat as a SEAC member for Avon Maitland District School Board. I hope to bring a little bit of a different context to some of the things you've heard today.

Slide 2: I've named it "Mitchell Inc." because my son's name is Mitchell and it is a business. It has been a full-time job for me for six years. We were living in Toronto and we decided we couldn't keep up with the pace anymore. We decided to relocate back to St. Marys, which is my hometown. That full-time job, we've now taken to a close. I now work full-time. I now know that I have 10 years or so to actually contribute financially to my family. We're going to take that time to make sure we are setting up a future for him and for us.

On the front page, you'll notice our family picture, which is my husband, Rick, and my daughter, Johanna, who is two years older than Mitchell.

Mitchell has a rare condition called Pitt Hopkins syndrome. I've given you the URL there. We would love for you to come and take a look at the website to learn a little bit more about it. Just to give you a context, when we first went through genetics testing, there was no blood test available for his disorder. There are only 200 children around the world who have it, and he was two before there was that blood test. He was successfully diagnosed at the age of four.

Through some parent-funded international research, we now describe Pitt Hopkins as having a severe intellectual disability, hyperactivity, non-verbal and on the autism spectrum. The reason I put that last piece in is because of the number of times doors were closed when Mitchell was a child for receiving autism services because he didn't fit the required diagnosis for autism. I understand that with the new autism criteria today, he still would not qualify for those services even though researchers say he's on the spectrum.

I wanted to comment on the previous presentation a little bit about early intervention. We had really great success in Toronto, actually, with Surrey Place and others that provided care for Mitchell. The CCAC was on board: We received OT in the home and it was very successful for him. He didn't sit until he was two and a half, so he had real physical issues, and he didn't walk until he was almost four. So again, the path that he has taken is just tremendous.

Moving on to the next slide: I put this first because our priority as parents, first, is to keep Mitchell safe. What I found as he was growing was that every six months, there was something new that we were dealing with related to his curiosity and his skill sets completely changing. What we've found now is that we're really worried about his lack of understanding of danger, from crossing the street to wandering off, stranger danger and dangers in the home—so hot water in taps, stoves, stairs, choking and general falling because of his gait. What we found was there were no funding programs to help us to make sure Mitchell was safe in our home. They would rather have him go somewhere else, should there be somewhere else to go, than help us put in those little things that would make it safe for him. Two easy things, which I think are currently in the program, would be to extend the eligibility for the Healthy Homes Renovation Tax Credit to anyone who is eligible for the T2201 Disability Tax

Credit. Right now, it's seniors only, but our kids fit into the same dangers that you're finding with elder care.

We've been very fortunate to receive March of Dimes funding for our home. We have an accessible washroom for Mitchell now—they widened a doorway for us so he wouldn't trip as often—and we have a ramp to the front of our home. Some of the things I asked for during that grant process were things like helping to reorganize my kitchen in a way that I could put up gates so he could be safe as an adult. My husband is 6 foot 6, so my son is going to be very tall. He can now step over the child gates we have in place. We don't have the next solution to this problem, and a March of Dimes program would be perfect for trying to deliver some of those solutions for families.

The next slide I've labelled Mitchell and Ian. I want to thank Ian's family for allowing me to talk about their relationship. Ian is a triplet, and another elder sibling. I was presenting for a Pitt Hopkins mothers' retreat in North Carolina a few months ago, and I wanted to get perspective about Mitchell from others besides myself. The reason I have the computer up here is I wanted to see if I could play the video so you can hear how Ian is describing their relationship. I will be around at lunch if you want to actually see the video.

Video presentation.

Ms. Lynn Hainer: I will leave that for later, then. Basically, what Ian is saying is that Mitchell cares about all of his class; he cares that everyone's included. He talks about the fact that Mitchell goes to visits him in the hockey game. Even though Mitchell can't play, he comes out and supports his friends. He really appreciates his friendships. If you have a chance, I'd love to show you during the break the video we had done for our Pitt Hopkins day.

1100

This is just a scenario that I'm looking at. As I sit here and I read your transcripts and hear the people speak, I almost think this is like A Christmas Carol. We've had our apology in the House for the past. We're now hearing the crisis of today. I want you to think of Mitchell and his peers as our gift for the future: things that we can be doing to reform the system today, to know that these younger children will have the experience of living a fully included life where they are safe and they have the supports they need. As I'm sitting here, I find that to be kind of a relevant story as we're moving through the different scenarios related to developmental services.

Mitchell, who is now in grade 3, attends and has always attended school with his peers, with accommodations and supports, but what will happen to their friendship as they age? How do we, as parents and as a community, encourage and support their friendship?

Mitchell's Special Services At Home funding is currently underfunded. We receive \$2,000 a year, which was actually transferred from the Toronto monies to us out in Perth county because there were no monies available when we did our move, so we thank goodness for that. But still, it's underfunded from what we qualify for by about another \$3,000, from the last time I've seen

the numbers. With the current processes, he will be wait-listed for Passport at 18.

How will Mitchell fulfill his participation commitment within their friendship? I really believe that community participation and inclusion is the obligation of the person being supported as well, and that they have commitments, similar to you in your adult friendships. You have a commitment to return phone calls, to be engaged and to be interested. If Mitchell doesn't have the supports available, he won't be able to hold up his end of the friendship and, really, how could his friends be expected to always do the work to make sure he's included? It has to be that two-way street and that's what the funding will do for him.

My vision of participation, as Mitchell becomes a teen, is that Mitchell and Ian will choose to go to the movies and also with their other friends, and that Mitchell will be able to coordinate his own support worker so that he can go. When Mitchell is 16, he and his friends aren't going to want his mom taking them to the movies, right? They're going to want some independence, and that's what he can do with his own support worker. That's my vision for where I see we could add value if we are changing the system.

The next slide: Mitchell's future. We look to support Mitchell to be able to share his gifts in a way that enables him to fully participate in his community. We're still learning about Mitchell's gifts, but we're watching, and are very open, to see what he offers to his friends and to his community, and we listen to that. But we also recognize the challenges with his disorder and his hyperactivity.

With that, recognizing his hyperactivity, we look to leverage his gifts with engaging others—so, a very social guy—but he also has to be very physical and active, so we envision a place where he could work, volunteer or even own his own business related to a sports industry. Imagine an indoor soccer camp, something that could include kids to adults. We have big visions for what Mitchell could accomplish, but he's going to need support, and he's going to need his family to be engaged in that process as well.

We're doing the things that we need to do. Mitchell has his RDSP. We are focused on our Henson trusts. We're doing all the things that we can, as parents, to ensure that he has the tools, that we can make this happen.

But we also want Mitchell to be able to communicate and make choices on where and how and who he's going to live with. I think that's very important. We, as adults, each get to choose those things in our lives, and I think all of our children can do the same.

Our plan is that Mitchell will end up having the family home and that Mom and Dad will move out, and that he will have roommates and that they will be supported in that home. Again, that's the vision. There are lots of rules and regulations. If I decide that Mitchell needs two roommates versus one—you know, going from a personal home to a group home—but those are, again, things that we have time to figure out and hopefully get the support through specialized, individualized funding and other supports for housing programs.

I've moved on to my next slide. I sit with and listen to the health care side a lot. I liked the phrase "right care at the right time in the right place." I think this is equally important to this committee, because I think that if you look at the context throughout what we're talking about, it fits very well into what the Ministry of Health is talking about, related to their services. Again, I keep that as kind of—if you're looking for guiding principles, that's one that I'd look to you to remember as we're moving forward.

We are looking for more of a self-administered program, so person-directed planning, to understand what Mitchell is going to be doing with his day. We may actually choose agency services, as was discussed just previously, but we want to have the choice. We know that there are great people in all different realms, whether it's Mitchell's circle of friends or within the agencies that currently support us.

We receive different buckets of money, so we're trying to manage which form to send in for which monies to make sure when—sometimes one bucket is empty and the other one's not, so then we have to redo the forms. We receive some funding hours right now through CCAC, our supporter, again, on the health care side—a personal support worker. One Care, who is our local support agency, does not have pediatric workers in the town of St. Marys who can fulfill his hours when we need them filled. Our workers probably like to work more with seniors and not with pediatric, challenging, physical little boys. We have had the opportunity to actually outsource those hours to Community Living St. Marys, and we now get supported through them. Before that happened, we were leaving hours on the table because we couldn't find people to actually work those hours, and we didn't have the ability to have our own worker come in and do that, the trusted circle of support that we have for Mitchell, because of those monies being enveloped.

The other perspective that I heard today, and again, it's in my guiding principles on the last page, is one person, one funding. I look at all the different envelopes and how much time and overhead we have within the ministries related to managing this one person. We need to look at their lives as a single entity and try and support them better that way. When I look at all the different agencies that end up supporting us and the management that goes into those very few hours that we get, I wonder how many other people or Mitchell could get a few more hours because of that extra management that's involved with that.

I'm going to shift a little bit to education, because that's where Mitchell is right now. He's in a grade 3 classroom. I sat on SEAC through two or three budgets with them in Seaforth. It's very key, especially in the boards with declining enrolment, that the special education funding formulas aren't working. We need to have more of a student-up planning process versus a random formula-down approach that you'll see with the SEP and the high-needs amounts that are occurring. The type of children who are in the school system now are more

complex perhaps than they were before, and there's more of them. There are more different diagnoses that are happening—as well as those who aren't specifically diagnosed who are receiving special education supports. Even things like tutors to help the general population are sometimes coming out of the special needs education program, which I think is a great thing because it helps overall education levels to be higher-achieving. For Avon Maitland, I was speaking with our superintendent last week, and she indicated there will be about \$700,000 over their special education envelope this year for providing special education services.

There's a real groundswell with parents around access to curriculum. Our kids aren't going to school to be babysat or to learn life skills; they're there to access the curriculum. We need to support our teachers to ensure that they understand how to accommodate their curriculum to reach every student in their classroom. Challenges with having the right EA support, should an EA be the one that has been selected through the process to support our children—to make sure that they fit the learning profile and the physicality required of the job. The staff selected are not always able to manage the child effectively. Again, I look to Mitchell, who is an eight-year-old boy, very strong. We need to make sure that we have someone who can successfully manage his school experience and the safety of him and the others while doing so. That needs to be paramount over the desire of who wants to be in that building. I'll say it that way.

From a SEAC perspective, if you look at the membership requirements: Parents are specifically excluded from participating on SEAC. You need to be part of organizations to sit. I sat because I was the chair of Parents in Perth; that's how I got in as a parent. If you want special education to be accountable to the children, have a few parents sitting around the table to talk about how special education is being delivered in their school boards, and the conversations will be very different. The associations I sat with were amazing, but I think, as we don't go to talk about our specific children at those tables—we talk about experiences and how their funding choices are going to be delivered and how that will impact school experience. I think that's another thing that you need to perhaps look at: changing up the selection criteria for that committee.

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On a positive note—so what's working for our school board—we are going down the path of full inclusion within Avon Maitland. They are closing their segregated classrooms. It's a slow process. That's the vision of the board, certainly, working from elementary school up through to high schools and working through those challenges. My comment to that is, how can we assume full community participation if it's not how we teach? Our school board has been very good. Our specific school has been exceptional, since it opened in 2010, on building an inclusive community.

Again, it's not documented research, but Mitchell's diagnosis is that he is non-verbal. He has learned so many skill sets related to speaking and verbally com-

municating, it is amazing. People who come in and re-test him for his Special Services at Home, his application, say how amazing he is with his language skills. That is directly related to the fact that he is in an inclusive classroom. His peers in the US system, where they prefer—some of our parents are preferring special education schools. Their children are not having the same verbal experience that Mitchell is having. I put that totally to the kids. It's not to the parents or to the speech consultants. We help. It's the kids.

The Chair (Mrs. Laura Albanese): I just want to let you know that you have about a minute and 15 seconds left.

Ms. Lynn Hainer: Okay. Well you have the rest of my presentation.

What I really wanted to talk to you about lastly was the DSO. We are not at the level of needing to go to DSO yet, as Mitchell is eight, but I believe strongly that our kids, specially kids as complex as Mitchell—we have the test results, DNA, that tell us what our kids have. We need to be spending the time in understanding the needs of those who are on the margins. Spend the time with those families who really need to figure it out.

We have been in the system, again, eight years; others have been in 18 years by the time they get to the DSO. It's not adding value. I concur with the other comments that the \$12 million that is being spent on the DSO should go directly into services and that fully funding the system is what is required to ensure we start moving beyond this gap.

The last piece I want to just quickly talk about—that's with my municipal hat on—is around housing. We have housing and homelessness plans that are coming in. If you, at the provincial level, are really auditing that they are meeting the needs of their community, so options for housing around people with intellectual disabilities—when that ministry came and spoke to you, they indicated that they had no specific plans or requirements to segregate out how they manage that participation group within their own sector. Make sure, when those plans are coming in, that we are addressing those. We need to have funding envelopes that don't include building housing, that will have choices where they're living. Sometimes their disability does not allow them to live in those congregated social housing projects because of the noise, smells and everything else that makes it unsuitable for them.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your comprehensive presentation. Thank you for introducing us to Mitchell and for the very valuable suggestions.

MS. DIANE WHITE

The Chair (Mrs. Laura Albanese): We'll now ask Diane White to come forward. Again, you may begin whenever you feel ready.

Ms. Diane White: Thank you. Good morning. My name is Diane White. My husband, Dave, and I live in

St. Thomas, Ontario. Together, we're raising two sons, Alexander and Aidan. While they both have developmental disabilities, our Aidan is my reason for speaking with you here today.

I'm just a mom. That's all I am. I'm going to share my story and a day in the life of Aidan with you for my presentation. This is so you may come to understand the parental commitment and the need for support in raising a child with complex needs.

From the moment Aidan became our son, I gave up my banking career and began to focus on his care and on striving to assist Aidan on his journey to achieve his potential and to become the person he is meant to be. Immediately, I sought out supports and services through early intervention and support groups. I quickly learned, though, how to advocate for his needs, becoming a medical and a developmental expert. Aidan has had major surgeries, including open heart surgery and the removal of a cataract from one eye. I learned to ask the important and sometimes really hard questions, and I expected the respectful answers from professionals. Sometimes I was successful and enjoyed a positive relationship with doctors and therapists, and other times I became discouraged at the lack of knowledge and/or co-operation. But I never gave up.

When Dave's career afforded us the opportunity to move to different cities throughout the years, each time I started over, seeking services and support groups. Where there were no support groups available, I connected with schools and classmates of Aidan's or Alex's, and started and facilitated my own local support groups.

Currently, I co-facilitate a support group, the Sharing Network for Challenged Kids, in St. Thomas. I assist other families in procuring any services to which they and their child are entitled. I volunteer within our community as a mentor and as an advocate for any family who requires it.

My husband and I, together with two other families, have founded and incorporated a not-for-profit business called Elgin Active Living Centre, which was referred to earlier today. Our vision for this project is to raise the funds to purchase one of the local closed schools and convert it to a residential facility with attached 24/7 supports and a day program. This facility would house approximately 12 to 16 young adults with various needs, with developmental disabilities, regardless of the cause of their disability, whether it was Down syndrome, whether it's autism, whether it's fetal alcohol spectrum disorder, with developmental or intellectual disabilities. They would have access to supports, as much or as little as they would require to be successful. But EALC is another story.

Aidan was born with Down syndrome, a congenital heart defect, a bowel blockage and a cataract. As one doctor who met us declared, Aidan seemed to have got the Cadillac version of Down syndrome. Over the years, we've been welcomed at Ronald McDonald homes in both Toronto and Hamilton as Aidan has undergone corrective surgeries. We have met and worked with top

ophthalmologists from the optometry department at the University of Waterloo. We've had to seek out the services of dental specialists, gastrointestinal surgeons and hematologists. To say that Aidan has successfully fought and recovered from all of his medical conditions would be an understatement. But then, at age eight, Aidan was further diagnosed with autism.

To sum up my son's conditions, he has Down syndrome, autism and gastrointestinal concerns, is prone to skin infections, and is blind in one eye. He requires care, supervision and support 24 hours a day, seven days a week.

I'm going to now share with you a typical day in the life of Aidan. I'm not going to go into policy. I'm not going to go into—I have a solution at the end, but I think you just need to hear my day with Aidan, or Aidan's day with me. This is typical.

As you can imagine, school currently takes up a good portion of his day, and he is gone, on a school day, from the house for six and a half hours.

Aidan struggles with falling asleep, so most mornings I need to wake him up. I get up at 6:30. I go in, I wake him, and he's grumpy. "No schoo. No schoo today for Aidan, stay home, Mommy," he says. And every day, I call his bluff and I tell him, "It's great. You can stay home with Mommy." We go back and forth, him saying he doesn't want to go, and me saying, "You can stay home." And then all of a sudden, he says, "Mom? Mom? Mommy? Go schoo today?"

So, finally, about 10 minutes into our morning, I can get him out of bed and take him to get toileted. He cannot do this himself. Our conversation during that time is all about his routine for the day, starting with his all-the-time, every-day breakfast—waffles—except on weekends, when it's pancakes.

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He goes through his day, pausing after each activity to await my verbal "yes" in agreement. If I don't respond with that "yes" and nodding, he continues repeating it until I do respond, only to have to start all over again. We do this about five to six times, until he's ready to be dressed for the day. Aidan has sensory issues, which means each article of clothing must pass his inspection. He doesn't care what they look like; he cares what they feel like on. I dress him in his approved clothing. He cannot do this himself.

Off we go to the kitchen, where he bounces on his exercise ball while I make his waffles and pour his milk. He cannot do this himself. I cut the waffles into bite-sized pieces on his plate and give him a fork, and he sits eating, using his fingers. While Aidan is eating his breakfast, I make his lunch for school, and it's always the same: chocolate milk, two yogurts, two puddings, a small container of crisps and a thermos of chicken noodle soup—the smell of chicken noodle soup in the morning is really starting to get to me, I have to say—but he cannot do this himself.

Once his breakfast is done, I wash his hands and face and brush his teeth. He cannot do this himself. We go to

the front door, and I put on his socks and his shoes or his boots. He cannot do this himself.

The bus arrives at 8 a.m. at the end of our driveway, and I walk him to it, to his waiting monitor, so he won't run away or onto the road. Boy, can those six and a half hours that he's at school go quickly—although many times it's not six and a half hours; sometimes it's less than an hour. Our school's staff is wonderful in his program, but on those days when Aidan is unable to appropriately behave or to successfully interact with staff and peers, I need to be called upon to come and get him.

His day at school is very structured. It's very predictable for him. Unfortunately, it can become boring for him sometimes, but when we try to change the routine and the predictability he can become combative and non-compliant. It's kind of a Catch-22 situation. I have also had to seek out the option of a day program where his need for one-on-one support results in a weekly fee of \$850.

Aidan's bus brings him home by 2:30, and I need to go out and get him off, but before he'll get off the bus we need to go through the remainder of his day, as we discussed it in the morning. God forbid there's a change—maybe I'm not making something that I said I was for dinner, or maybe one of his support workers is ill. That will make him not even get off the bus, so I lie about whatever I have to.

Once off the bus, he may walk with me up to the house and come in, he may choose to run out onto the road or he may even decide to sit down in the middle of the driveway—it doesn't matter what the weather is. When he sits down, he refuses to get up for at least 15 minutes, and no amount of cajoling, begging, pleading or bribing will get him up until he decides.

Once in the house, I remove his jacket, boots and socks. He cannot do this himself. Then it's a trip to the washroom again and using his vacuum—yes, his vacuum. He received his own for Christmas and loves to stand with it on, making the same sound as it, so I plug it in and I turn on his vacuum. He cannot do this himself.

French fries at supper are Aidan's idea of vegetables, and they're served on their own plate with a dab of ketchup. The other plate is reserved for the meat—and, of course, ketchup. Aidan loves chicken: beef-chicken, turkey-chicken, ham-chicken, fish-chicken or just chicken. As long as it has the name "chicken" in it, he will eat it. His food is cut into bite-sized pieces. We give him a fork, and he uses his fingers. I pour his milk. He cannot do this himself.

Aidan is showered and shaved every other day. I turn on the shower for him, adjust the temperature, undress him and help him into the shower. I wash and rinse his hair, I scrub and clean his body, and I foam and shave his beard, sideburns and moustache. He cannot do this himself. I rub him dry. He sits on my lap. I dress him in his pyjamas and dry his hair. He cannot do this himself.

At bedtime, he has a whole routine of juice, jammies and songs. When that's done, he lays down for hugs and kisses, goes through tomorrow's routine, is assured that

it's not raining and not thundering out, and is tucked in. Within five minutes he's up again for the same discussion: the routine tomorrow and whether it's raining or thundering. He wants a drink and has to go to the bathroom. We talk to him and send him back. He's up again within five or 10 minutes. For all of those same reasons, it generally happens eight to 10 times a night.

Finally, about an hour and a half to two hours after we start, he is asleep. Most nights, he wakes several times through the night, and he parties and sings. He doesn't want you there. If you walk in, he looks at you like, "What are you doing?" He just wants—he's just awake. Then, at about 6:30 the next morning, we start all over.

Aidan does not participate or co-operate in any of his necessary health care. He is physically resistant to any kind of medical or dental intrusion into his personal space. That means that for any ordinary physical or dental examination, he has to be sedated. He is unable to take oral medication, which means hospital trips for even simple antibiotic injections.

Travelling with Aidan requires careful and thorough planning and support as he requires a pushchair for the safety of himself and others.

We have been in crisis as I became ill and attempted to access an emergency bed for Aidan. At Regional Support Associates, there's a waiting list.

Now, imagine I'm one person doing all of this, or imagine there's no school for the day, or imagine I'm ill, and understand that Aidan is nearly 19 years old, and I've been doing this for all his life. Fortunately, for my family and our Aidan, I have the ability to advocate effectively, to speak to decision-makers and policy-changers.

I have somehow managed to find the time and the energy to devote to case-managing my son's life. I have been loud enough to have successfully obtained some sustainable, I hope, funding to support Aidan as he awaits an appropriate residential placement.

I have two wonderful support workers who assist Aidan in the community for approximately 24 hours a week, but we have no weekend respite. We have no overnight respite. There is no transition planning available to families anymore. There is no case managing or facilitating. There's no crisis intervention.

The current model of service delivery is, in a word, unsatisfactory. The new Developmental Services Ontario had the potential to be a great centre for assessing, centralizing and delivering service, but instead it is only a gatekeeper for all wait-lists for all services—simply a middleman.

We keep being told there's no money in the system, yet agencies are developed or expanded. People are hired. No one, from front-line workers to managers to executive directors, has the ability or mandate to truly help our families.

We need a permanent solution in the form of a non-partisan committee or corporation that is sustainable and constant throughout each provincial election, no matter the governing party, that transparently oversees the delivery of services in a fair and equitable manner. This committee or corporation will be responsible for ensuring

delivery of any and all services and supports required by our special population.

The ministries directly answering to this committee or corporation would and should include the Ministry of Children and Youth Services, the Ministry of Community and Social Services, the Ministry of Health and Long-Term Care, the Ministry of Municipal Affairs and Housing and the Ministry of Education.

Transitions from children's services to adult services need to be seamless. Ministries and agencies need to stop forcing parents to once again prove their child's disability in order to qualify for adult services.

I am sad, I am tired and I'm broken. My greatest wish is that we can find a wonderful and supportive place for Aidan to live and thrive and be happy in. My greatest fear is that Dave and I will not be healthy enough, or maybe even not around, to ensure that this life-changing transition for Aidan is the positive and joyous one he deserves. He cannot do this himself. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for sharing your story. We have about a minute and a half for each party for questions, and they start with Ms. Taylor.

Miss Monique Taylor: Thank you very much, Chair. Thank you so much for your presentation today. Thank you for bringing Aidan here to share him with us and the life that you live.

I'm curious, as the other speaker spoke about the Elgin Active Living Centre: Where are you in that process, and is it working? Are you getting stopped? What's happening?

1130

Ms. Diane White: We were stalled because of crises in my family, crises in Sue's family, crises in the other family. When you're dealing with your own personal crises, as much as your heart and your mind want to help out in the community, you're stuck. I became quite ill and just couldn't manage it. But we are trying to get back together and find a direction. We've done a budget. We've had Tom McCallum from Community Living Elgin mentor us. As Susan indicated, we've spoken to Jeff Yurek, our MPP. Christine Elliott came and met us on occasion; and Joe Preston, our MP locally. We've talked to different people. We need to find someone who will give us direction at this point. We have ideas, but we need some direction and some guidance to bring it all together. We have the passion, we have the vision, but perhaps collectively the six of us adults don't have the skills to really bring it to fruition on our own.

Miss Monique Taylor: So—

The Chair (Mrs. Laura Albanese): Sorry; I'm going to have to move it on. I apologize.

Ms. Wong.

Ms. Soo Wong: Thank you very much for sharing your story with us today. I listened intently to the concerns about the—this is not the first time we have heard about the desperate need for respite. Can you share with us, in terms of your research—obviously, you've done a lot of homework on this file—where are the best practices when it comes to respite care across Canada or elsewhere?

Ms. Diane White: I think BC has definitely led the foray in developmental services across the board, whether it's inclusion, whether it's education or whether it's support and respite. I've lived in Chatham-Kent. They had a wonderful respite home for children that was accessible seven days a week. I don't know if it's still there, but it was wonderful for the families to be able to access it. There was co-operation between Community Living, Chatham-Kent and the school board so that for any individual who was in school and stayed at the respite home for the week, the bus would still come and pick them up there.

When we moved here, there was nothing like that. Eventually, they came up with a children's respite home that serviced two children under the age of 18 every other weekend. That's all. It was not even accessible.

When I went into crisis, we were given a sum of emergency funding and we were able to access the respite home for Aidan even though he was an adult because it was sitting empty every other week. Again, that was \$2,300 if he went to that alone. That respite home has since been closed and is being turned into a group home for four transitional youth who have, under the government's guise, already been on the radar, but there were no plans made for them to transition out of their child group home residential placement into an adult one. Now, as a result of that lack of planning, Elgin county has lost its only respite home.

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

Mrs. Christine Elliott: Thanks very much, Diane, for coming to present to us today. I think it's really powerful, telling us Aidan's story and what a day in the life looks like. I've also had the pleasure of meeting with you in St. Thomas, as you mentioned, and hearing more about the Elgin Active Living Centre. I think you really underestimate your own talents and abilities and those of your group. It seems to me that you have a wonderful plan. Really, what you need now is just a capital investment in order to be able to buy the building. I think you know very well what you want to do with it.

I do have some additional information that you've provided me with. Would it be acceptable to you if I shared it with the other members of the committee so they would have a more complete understanding of what it is that you have in mind?

Ms. Diane White: I would love that. Absolutely, yes. Thanks, Christine.

Mrs. Christine Elliott: Thank you. I'd be happy to do that. We're happy to help you in any way we can.

The Chair (Mrs. Laura Albanese): Thank you for presenting to the committee today. It was lovely to meet you and Aidan in the picture.

Ms. Diane White: Thank you for the opportunity.

COMMUNITY LIVING ST. MARYS AND AREA

The Chair (Mrs. Laura Albanese): We'll now call on Community Living St. Marys. I believe we have two

people presenting, Vickie Logan and Harold Holland, if I pronounced that right. Please take a seat. Feel free to start whenever you feel ready.

Ms. Vickie Logan: Good morning. I am Vickie Logan and this is Harold Holland. It is our honour to represent families from St. Marys and area who have met to discuss the challenges we see in the developmental sector as it is functioning at this time.

Two families could not join us today. The teenage son of one family has undergone another surgery. The father in the second family threw out his back and the mother must be home with her adult son.

I am the mother of a beautiful 29-year-old—her name is Robynne—who, at the age of three, was the 38th diagnosed case in the world with her particular developmental delay. There are currently 70 people in the world diagnosed with this delay. We were told that she would never walk, never talk and would invariably fall behind, but if we wanted to try and teach her—"Go ahead, blaze a trail."

So that's exactly what we did. She walks, talks, sings really badly, can read and spell a bit, can do simple math using a calculator, and is a known and loved volunteer in five communities.

Many of the things families take as commonplace now, we fought for. They were new and extreme for the time, but we were able to enlist the help of people along the way who saw the potential that sparkles from Robynne's eyes.

Robynne lives at home with her dad and me. She was granted a lump sum of money when the Passport Program was initially established. It was not based on a support budget and does not come close to meeting the actual support that would enable her to fully realize her dreams and meet the established goals. Still, we do the best we can with what we have, trusting that one day there will be a change in the system.

I am also the accountant at Community Living St. Marys and Area. Our agency provides individualized supports, creates individual budgets and produces individual income statements each month. When I speak to you today, it is backed by being the parent of someone receiving support and having worked for the agency providing that support for 20 years.

Mr. Harold Holland: Hello. My name is Harold Holland. My wife and I adopted two children, one at age 11 months, Aimee; and then three years later, we adopted a little boy named Thomas.

As the years went on, it turned out that both had special needs. Aimee is now 27, with borderline personality disorder. We've had to break communication with her. She became a ward of the court. She's now living in a group home in Exeter.

Thomas is now 23. He's been diagnosed with autism, Tourette's, developmental delay and anxiety disorder. He has full-time support 24 hours a day, seven days a week.

My wife didn't work when Thomas first arrived. She spent most of her time in the next 20 years running children to appointments, seeing specialists, therapists, school meetings, advocates and supports.

I may be at the wrong meeting, because we have funding. We've received funding and supports from Community Living St. Marys and Area, family services, CPRI, RSA, the Crest centre and numerous professional specialists—all this coming through crisis emergency intervention. I could go into telling you the story of Aimee and Thomas, but it would take a half a day for each child.

All this money that's been spent on Thomas alone is mind-boggling, but it's all been worth it. He's a happy guy, and for the most part, he's a lot of fun to be around. He got a job in November. He's got a purpose in life now. He's a happy guy. He's had a great year with his support staff.

But what I'm afraid of is, why do we always have to go to a crisis to get to this part? I know several families that are raising their children—and some of them are adults—at home, thinking that things will work out. I worked with Perth parents, and we sat down and wrote letters to the Ombudsman. It was amazing the people who didn't want to tell their story; it's amazing the people who couldn't write a story. We helped them with that.

As the parents age and the children become more difficult to handle, and there's no routine once school is over, it gets complicated. It takes a big physical and mental toll on the supportive parents, the staff and the child. What ever happens when the caregiver cannot give anymore? Is that, then, a crisis? I feel that these people who I know are all time bombs just waiting to go off.

Ms. Vickie Logan: The concerns raised by the families in St. Marys include the acceptance of waiting lists as being the norm; no affordable housing options; young people being placed in nursing homes; the cut to special services at home at 18; and the increasing disconnect between the system and the people it was established to support. Families are in crisis.

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The current system is deficit-based. We believe that a more positive system based on potential—their hopes, dreams, goals and achievements—would be far more valuable to the people using support services. A deficit-based system drives down the perceived value of people and creates the impression of handouts rather than hands up. Imagine how you would feel if every day of your life you were made to think negatively about your child, to see all that is wrong with him in order to secure the supports they need to connect to their communities—communities where they can make friends, have jobs, make real contributions to society and teach those around them about respect and acceptance.

Current access to funded developmental services is through the DSO, as you know, and involves a long application and assessment. We spent six hours doing a SIS assessment and received a useless multi-page document that provides no information about Robynne. It sits in a file drawer in our home, and a copy is housed in the DSO computer. There is nowhere for her to go because there is no funding entity established as part of the

transformed system and no hope of securing the funding to obtain support. We are wait-listed.

Some of us are being asked to have our children get further psychological testing to determine eligibility. This does not make sense for many people who have been identified with a lifelong disability. There is a huge cost both to families and to government. The Ballantyne family has had to make numerous inquiries and arrangements for testing their son Mac, when even the DSO assessor knows he is eligible. This has added huge amounts of stress to an already very stressful situation. Mac is turning 18 in August, and the funding received now for his support will not be available once he turns 18. Added to the threat of no support, Mac has just endured another surgery related to his physical disability due to cerebral palsy.

Wait-lists contribute to the feeling of scarcity and hopelessness. There are very real crises among aging parents with adult children still living at home. No one would argue the point that these situations must be addressed immediately. However, with the cut to SSAH funding at 18, the system has now created a greater base of crisis situations.

Often overlooked is the group of parents who are not in the aging category. We are in our forties and fifties, but our daily stresses are the same as everyone else's. Plus we fear for the future of our children, and we know that we limit their ability to connect to community. We can't work, be parents and be the support workers for our children. We also have elderly parents who are often our support network and provide the breaks we need to get through another year. Some of us are the sandwich generation in that we have elderly parents to support and adult children to support. Matthew lives outside of St. Marys on the farm with his parents. They provide for all but a few hours of support each week, and they provide a home and support for his 90-year-old grandma. There are no other families in the area, and Matthew's parents are tired.

There are few alternatives for families. If there is no support in communities, some people are forced to look at the health care system. A number of young adults have spent months in Perth county hospitals—not because of health-related issues, but because they had nowhere else to go.

As well, young adults are being placed into nursing homes. This is horrific. They will live out their days with no connection to their communities at all. While their base needs will be attended to, they will not have full lives. Once again, we are limiting their potential and neglecting all that they can contribute to society. There is a cost associated with young people living in nursing homes. Why can't this money be used to support them in their community?

Families are also turning to police services to support them in crisis. Often, as Harold mentioned, crisis can be avoided if adequate supports were in place for families. The Dunseith family feel little hope for their future and for their 36-year-old son who lives at home. Until some

secure funding for support is made available to their family, they fear for their safety.

Planning for life, including times of crisis, is key to supporting our children to live full and contributing lives in the community. Person-directed planning, and the facilitation and funding needed to implement those plans, will prove to be a smart investment. Our children, young or adult, and our families want to expand possibilities in the community, but we need help. New legislation allows for person-directed planning, but this service is not funded in our system, and it needs to be.

A person's life does not need to be divided into funding categories. If we are able to get some funding as a family, we end up trying to track it and keep it all straight, and it's really quite confusing. A life is a life, whatever support a person requires to live it in a dignified manner and to achieve their goals.

As parents, we're not looking to abuse the system by getting our hands on unreasonable support dollars. We all know what it's like to sit on a waiting list and how it feels to have no hope. We do not wish this on anyone. Providing lump sums of money not based on a real support plan does not solve the issue. You need to trust that we will use the funding as efficiently and as effectively as possible. We will do what we know is right for our children and continue to be creative and progressive.

By investing in the potential of people, helping them to be in their community, living, working, volunteering or joining groups, we provide them with the skills that they need. We help them to realize the importance of rising to what is acceptable behaviour, about their appearance and the rules of society. We give them the skills they need to live as independently as they possibly can so that, when it is time for them to move from their family home, they have already established the connections and the skills that they can build on to grow. They have people around them who already know them and care about them, so the transition is eased.

Robynne showed a window of time which would have been ideal for her to move out of our home, but we could not act on it, so she remains. With each passing day, that window closes more, because she becomes more comfortable and she is losing that drive for her independence from us. But what happens if she is still at home when my husband dies from the number of life-threatening physical problems he has? What happens when I die? Robynne's home will be sold out from under her. Her family will be gone. She will lose everything and have to try to begin a life during the very time she is grieving for all that she has lost, trying to understand something that none of us is good at understanding. As her parents, we fear that day, because we know that there is no money to provide the support she will need.

It is our hope that you will truly hear what we are trying to tell you today and that real, systemic change will result from the time that we have all taken.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. We have about two minutes for each

party. We will start with the NDP. Miss Taylor or Ms. DiNovo.

Miss Monique Taylor: Thank you so much for your presentation and thank you for the work that you're doing in the community and for being an advocate for so many families. We can tell by your presentation that you're definitely in touch with your community, and you see what's working and what's not working.

I would love to hear your opinion on the DSO and whether you think that it's something that should continue or something that should be changed into working for families.

Ms. Vickie Logan: I think that the DSO has got too much power. Without the funding entity, our transformation didn't really have an end plan. It just started throwing things into place without a global idea of how things were going to look in the end. The DSO says that there's no money, and they're right. There's no funding entity doling out money to anybody based on anything.

I think that it's a layer of infrastructure that could be better spent supporting people in the community.

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Miss Monique Taylor: Thank you. If you had a magic wand, what would it be used for?

Ms. Vickie Logan: I would invest in the people we are supporting. That's why we all have jobs in the first place. That's our reason for being. Our reason for being is not so that we can sit in nice offices and have the latest technology. We're here to support people. That is our only reason for being. To build an infrastructure that serves no purpose is kind of like—remember that analogy where the guy was hired to run the well, and he was the guy who got laid off, but all the infrastructure was above. I feel kind of like that.

Miss Monique Taylor: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. I will now ask Ms. Wong to take the microphone.

Ms. Soo Wong: Thank you very much for your presentation. I was reviewing your written submission to the committee. One of your recommendations—you asked to reconsider the lengthy application assessment process. Can you elaborate on what you said here, the collection of some of this information? What are examples of some of the information that can be less costly? Can you give us some examples of that?

Ms. Vickie Logan: I think that most of you—sorry. Do you want to answer?

Mr. Harold Holland: Go ahead. No.

Ms. Vickie Logan: I think that most of the people in the province have had every test available that they can have on their children. I don't think you need to do them again. You might need some updating, but I'm pretty sure the parents are going to be open and honest with you about how far along their kids have come.

I'm proud of everything that we've accomplished. We've worked hard. I think we've done a good job. I'm not going to undermine my daughter for an assessment. I think those types of things money doesn't need to be spent on, unless there are huge dramatic, changes in the person.

Ms. Mitzie Hunter: I'd just like to ask, in terms of providing her with the choice as an adult, what are the supports that would be required at that stage of her life?

Ms. Vickie Logan: Well, I'm hoping I've done as good a job as I think I have in getting her ready to live independently. My grand plan would be that she owns or rents a home in the community and somebody comes in and provides the overnight monitoring, maybe for a reduced rent or whatever—whatever can be arranged—that she actually becomes part of their life, part of their social structure and connections, but that it is her home. And if that person doesn't want to do this anymore, if they don't want to live with her, they leave. They take their stuff. But her house stays intact and she's in control of that. Because it's very hard to keep control over your life when everybody's telling you what to do and everybody's telling you when to do it; right? So that would be something for her to be in control of, to be responsible for, to be proud of.

Mr. Harold Holland: She wants what my son's got. And it wasn't easy for us to get it, either. The paperwork is over the top. It's way too complicated to get funding.

The Chair (Mrs. Laura Albanese): Ms. Elliott, do you have any questions, or Ms. Jones? I just saw both of you going towards microphones.

Mrs. Christine Elliott: Such a great presentation.

Ms. Sylvia Jones: Vickie, Harold, thank you for your presentation. Harold, you're not in the wrong room, because, to your point, the reason that your son has been able to thrive and survive in the community is because you had to go through the crisis. And that's wrong, and we have to change that. So thank you for coming.

Vickie, in your last recommendation, which is 12, "Value the relationships developed in communities between people with disabilities, families, neighbours and community-based organizations"—great recommendation. I don't want to put words in your mouth, but my perception, anecdotally, is the DSO can be a block to that and has become a block to that. Can you comment on that? I don't want to assume that that's happened or is happening. Can you share your experiences?

Ms. Vickie Logan: You know what? For me, I like the idea of the community-based organizations, because we've probably grown up together. We went to school together. We went to church together. Well, some people went to church together. They did all these things together. Their kids grew up together. There's comfort in that. There are long-standing relationships in that. You can walk through the door and know that the person on the other side is going to be friendly. They're going to understand. They probably know a chunk of your story, so you're not going to have to rehash all of that, and you're not going to have to demean yourself by having to put that story out there. It's private and it's personal, and who wants to do it, really—right?

Ms. Sylvia Jones: Or try to make it sound worse so that you get to the top of the list, which is ultimately not what you're trying to accomplish.

Ms. Vickie Logan: The race to the bottom is kind of what they call it. But I think if you had a vision, an idea and a goal, how empowering that would be to the person sitting across the table from you. Sell the vision, sell the idea, get them on board with you and everybody is happy, nobody is burnt out and everybody is working towards something positive.

The Chair (Mrs. Laura Albanese): Thank you. Sorry, I am the tyrant with the time. I let it go over but I have to be mindful of the next presenter. Thank you so much for your wonderful presentation.

Mr. Harold Holland: Thank you very much.

REGISTERED NURSES' ASSOCIATION OF ONTARIO

The Chair (Mrs. Laura Albanese): We'll call now on the Registered Nurses' Association of Ontario to come forward.

Miss Monique Taylor: Chair, while they're getting settled could we ask research to possibly provide us with a copy of the application that families have to go through? I've seen it. It's quite intense and it takes hours to fill out. I think it would be good if we had a copy and could actually sit and go through it ourselves.

The Chair (Mrs. Laura Albanese): Certainly.

Miss Monique Taylor: Thank you.

The Chair (Mrs. Laura Albanese): Welcome to our committee this morning. You may begin anytime you feel ready to.

Ms. Kathy Moreland Layte: I'm as ready as I'll be.

The Chair (Mrs. Laura Albanese): Please start by stating your names.

Ms. Kathy Moreland Layte: Yes. Good morning. My name is Kathy Moreland Layte. I'm a registered nurse and professor of nursing from Kitchener, Ontario. I'm here today representing the Registered Nurses' Association of Ontario, the RNAO, along with my colleague, Mary Mueller, to my left.

RNAO is a professional association representing registered nurses wherever they practise in Ontario. Since 1925, RNAO has advocated for healthy public policy, promoted excellence in nursing practice, increased nurses' contribution to shaping the health care system and influenced decisions that affect nurses and the public we serve.

On behalf of RNAO, I'd like to extend our thanks to the Select Committee on Developmental Services for hearing our presentation today. Committee members are to be commended for addressing the issues of developmental services, as they impact greatly on the health of many Ontarians, their families and our communities as a whole.

Through review of the minutes of your proceedings, it has been noted that the issues of children and adults with autism and other developmental disabilities are being well represented. Thus I'll focus RNAO's remarks on a group of individuals and their caregivers who too often fall through the cracks of the developmental services

grid. I'm here to speak to you specifically about children, youth, adults and caregivers living with fetal alcohol spectrum disorder, and to share recommendations from the RAO for you to consider. I will start by sharing some background information, which we have also included in the files before you.

Fetal alcohol spectrum disorder, or FASD, is a brain-based physical disability that is the most common type of developmental disorder in Canada. The brain damage developed in relation to FASD is permanent and cannot be cured. Because of their brain injury, people with FASD face a wide spectrum of lifetime challenges, from mild to very serious physical, mental and emotional disabilities.

Let me give you a sense of the disorder's key mental disabilities first. They include difficulty with assessment, judgment, impulse control and reasoning, poor memory and language processing, poor emotional regulation, an inability to generalize or think abstractly, and difficulty with planning and executive function.

The term FASD is in fact an umbrella acronym that encompasses four medical diagnoses, including fetal alcohol syndrome, or FAS; partial fetal alcohol syndrome, pFAS; alcohol-related neurodevelopmental disorder, ARND; and alcohol-related birth defects, ARBD.

This disability affects approximately 1% of the population. Equally alarming is the fact that FASD prevalence is only expected to rise. Statistics point to troubling trends. For example, binge drinking, defined as four or more drinks within a short period of time, is increasing. According to Health Canada, 20% of women of child-bearing age consume five or more drinks at a time once per month or more often. This is three times the rate of a decade ago.

Health Canada has determined that women at highest risk of binge drinking are 15 to 19 years of age, followed closely by those in the 20- to 24-year-old age bracket. Consider this: The Public Health Agency continues to state that no amount of alcohol at any time, of any kind, is considered safe for women thinking of becoming pregnant or for those who already are, yet the estimated overall rate of unplanned pregnancy in all women is 40%. The highest rate of unintended pregnancy is 82% among 15- to 19-year-olds.

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Let's get back to the disability itself, which is largely considered invisible. That's likely because those diagnosed with fetal alcohol syndrome, or FAS, are the only people under the FASD umbrella who bear the facial features so commonly associated with fetal alcohol exposure. A birth mother must binge-drink between days 7 and 15 of her pregnancy in order for those facial features to develop.

Others born with other forms of FASD go unnoticed until other symptoms appear. However, it is important to note that fetal alcohol syndrome is not indicative of greater or lesser brain injury than the other diagnoses in the spectrum.

Children and adults affected by FASD are at a higher risk of developing additional health challenges such as addiction and mental health issues, including anxiety and depression. They can have difficulties when it comes to learning and staying in school. Long-standing, unsupported attention to a child's FASD or lack of a diagnosis often progress into tertiary challenges such as trouble with the law, sexual promiscuity, unemployment, homelessness and other hardships associated with poverty.

In addition to the human cost of suffering for people living with FASD, there is great strain on health care, education, community and criminal justice services. Until people with FASD have serious behavioural or mental health issues, there are very few—if any—community supports available through the lifespan of those affected.

Let me now share the caregiver's perspective. There is a great deal of stigma associated with obtaining an FASD diagnosis, especially for a biological parent. Because of this, many children are instead diagnosed with attention deficit hyperactivity disorder, oppositional defiant disorder, attachment disorder or anxiety.

Getting an FASD diagnosis can take years. In Ontario—unlike Alberta, British Columbia and Manitoba—there are difficulties with obtaining a diagnosis, for three main reasons:

- There is limited diagnostic expertise. An FASD diagnosis requires psychometric testing—and a psychologist then interprets those tests—clinical expertise in management, a speech assessment and an occupational therapy assessment.

- The birth mother must admit to using alcohol while pregnant.

- Except for the medical services, a diagnosis of FASD is not covered under OHIP. This means an out-of-pocket expense for the caregiver, with the average amount of the cost of a complete assessment being approximately \$3,000 to \$5,000, compounded with the fact that it can take years to obtain.

Caregivers of children with FASD struggle, and often lose their children due to the aforementioned challenges. They have few options if they are living with an aggressive child, youth or adult at home; in fact, many caregivers often surrender their children suffering from FASD to family and children's services when they have no other support.

As the representatives from Peel shared in December, these parents are at the end of their rope. Children are also placed in section 23 schools not specifically geared to FASD issues, juvenile detention centres or group homes.

Because of funding cuts to regional and children's services, many group homes are closing under the auspices of inclusion and keeping families' children in their homes. As a result, many of those living with FASD are sadly lost to the streets, or families must continue to bear the burden of their child's aggression or needs.

Should their child stay with them, caregivers face a life of chronic stress and financial strain and grief as a

result of their child's disabilities and lack of educational and social support. Many caregivers report significant social isolation, exacerbated by a frequent lack of understanding of their child's issues from family members, health care professionals and educators. I would say that that's probably because these children look normal.

Many caregivers give up their jobs and face financial strain to stay home and care for their children, as they cannot be attended to at school. The high cost and lack of availability of trained caregivers, as well as the lack of respite opportunities, is a burden for many. Currently, families pay anywhere from \$15 to \$35 an hour for appropriately trained workers, and that's if they can find them.

Many of these children do not meet the threshold to qualify for supplemented care such as Extend-A-Family as they do not fall below the required IQ of 70 or the intellectual disability cut-off of 2% to qualify as intellectually disabled. Special Services at Home funding, while available, is limited to those who qualify. To make matters worse, caregivers of children with FASD have few financial resources available to them at all other than the disability tax credit—if, I would add, they're working.

Let me now address some of the issues related to education for people with FASD.

Many educators are ill-prepared to understand the needs and strategies to identify and assist those with FASD. While the Ministry of Education has already outlined the Education for All strategies, each school board must decide how their special-education funding is used. The funding formula is based on the 15% special-education criteria, I believe, set out by the Ministry of Education, but does not meet the needs of many communities. In my own community of Kitchener, over 20% of the children are identified with special needs. The board must deal with providing the best they can with the insufficient funds they have.

Cuts to educational assistant positions and child/youth worker jobs have made classrooms a difficult place for educators and for children with FASD to have their needs met. Inclusion philosophies have not considered the inability of many of these children to handle over-stimulating environments. Children with FASD are often removed from school under the Safe Schools Act because of aggression and/or inability to cope with the sensory inputs of a regular classroom. Because many of them look normal, educators have more difficulty recognizing that these issues are a part of the disability versus defiance. Consequence-based approaches to problematic behaviour rarely work with these children, and they have little ability to transfer learning from one context to another.

Individual education plans and the Identification, Placement, and Review Committee—or IPRC—processes have many loopholes that allow school boards to limit educational assistant help and support and promote the concept of modified school days and/or removal under the Safe Schools Act when behaviour problems become

an issue. This creates a great deal of stress and financial burden on the caregivers.

While removed from school, there is little or no tutoring provided. These children are left on long waiting lists for limited and often inappropriate mental health services or classrooms that are often effective but short-term. These waits can last anywhere from months to years. The children are then returned to their regular schools, often for one to two hours a day, and then the cycle becomes repeated. Many caregivers eventually remove their children from school permanently, resorting to home-schooling because of exasperation and frustration.

It's also important to discuss the transition to adulthood for people with FASD. It's estimated that those living with FASD may be developmentally one third to half their biological age in many functions, putting them at great risk during their teen and early adult years. As a result, people with FASD require lifelong care, often in the form of a person or people to negotiate situations and prevent them from getting into difficulties in school, their teens and adulthood. At 18, children who were fortunate enough to have gotten diagnosed with FASD are eligible for disability, but have few or no social service supports to help them through the processes of the DSO, to get their disability support, to find work or to become self-sufficient. If they are still living with their caregivers, there continue to be no support services available. As you've already heard, aging parents and grandparents fear for their children's future in a similar way to those with other developmental disabilities. Who will care for their children if they become ill or die?

There are ballooning costs associated with the FASD population. The cost of FASD to the public is difficult to determine but has been estimated to be anywhere between \$1 million and \$3 million per individual over their lifetime; \$5.3 billion to \$7.6 billion is spent annually in Canada to support those with FASD from birth to age 53.

I would be remiss if I discussed costs without talking about the impact that the lack of care of children with FASD has on the criminal justice system. Based on available Canadian data, it is estimated that youth with FASD are 19 times more likely to be incarcerated than youth without FASD in a given year. Research also indicates that there is a 10 times greater incidence of FASD in the correctional population than in the general population. The average cost for a federal inmate in this country is roughly \$360 a day, or about \$170 a day as a provincial or territorial inmate. Compare these costs to the average cost of an early intervention. A child youth worker costs \$164 a day on average for one student, or \$82 a day for two students. Finally, an education assistant costs about \$123 a day, or \$62 a day if they have two students. Investing early shows greater changes of self-sustainability in the future for this population. To keep them in school is important.

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Let me now give you a sense of what RAO is doing to help those affected by this devastating disability.

In 2012, at RNAO's annual general meeting, a resolution was unanimously passed to address the prevention, diagnosis and treatment of FASD in this province. You have in your package a copy of that resolution, that was co-authored by myself and my colleague Mary, as well as some of the follow-up activities that have taken place, including an article from RNAO's bimonthly journal, *Registered Nurse Journal*.

In February 2013, RNAO released its political platform called *Why Your Health Matters*, and many of you probably met with members.

In an attempt to begin a conversation and prompt a call to action to leaders such as yourselves to collaborate and focus your work on matters that will build an even stronger province, our presence here today is a part of that commitment to educate you, as decision-makers, about this vital gap in developmental services for those living with FASD, and to advance healthy public policy to serve them, their loved ones and our communities. Lack of attention to people with FASD impacts on two of RNAO's key health priorities: accessibility to health care, and the reduction of poverty.

What can you do as political leaders driving policy in Ontario? I'll outline three points.

(1) RNAO is calling for a provincial strategy. We are one of the only provinces without a provincial framework to address FASD through an integrated, interdisciplinary strategy for prevention and diagnosis, and the care of individuals and families living with FASD.

In 2005, the Public Health Agency of Canada developed a framework for action on FASD, calling on all provinces to develop an integrated, purposeful approach to FASD.

To address FASD and save costly resources, Ontario needs to develop an evidence-based, integrated strategy. Such a strategy is currently being drafted for presentation to the provincial government by FASD Ontario Network of Expertise, which is called FASD ONE. Such a strategy would reduce the harm created by continued use of alcohol in pregnancy, diagnose early those affected by prenatal alcohol exposure, and provide support to individuals and families living with FASD through their lifespan.

(2) We urge that accessible, affordable diagnostic services be available to children who suffer FASD, and their families.

(3) Caregivers should have the respite and other services they need to be able to work, stay well and have a healthy family life.

In conclusion, FASD is a preventable disability, and Ontario is not adequately addressing it. Spending \$150,000 on prevention would save \$1.6 million in treatment.

Prevention is more than just raising awareness about the dangers of drinking in pregnancy. Addressing the inequities that exist in our province with respect to the social determinants of health, such as poverty and social exclusion, would significantly decrease the incidence of FASD. We need to promote the low-risk drinking

guidelines for all people in their childbearing years, develop policies that limit the potential for alcohol abuse, and involve all health care providers in screening for risky alcohol use and in education about the dangers of drinking above the low-risk drinking guidelines.

FASD impacts the health of all Ontarians, their families and communities, across all determinants of health. It creates poverty and secondary health issues while increasing costs to associated social services, education, health care, community services and the criminal justice system. It breaks families and entire communities.

The time for an integrated provincial strategy is now. With the focus on prevention, early diagnosis and the right supports, we as a society can decrease the prevalence and help those living with FASD achieve their potential. Without a provincial strategy, people who suffer with FASD—and their caregivers also suffer. The cost to the system in human and financial terms becomes greater. Individuals with FASD, and their families, need and deserve better.

On behalf of RNAO, I thank you for your time, and welcome your questions.

The Chair (Mrs. Laura Albanese): Unfortunately, we don't have any time left for questioning, but I want to thank you for your presentation. I personally learned a lot about FASD through your presentation. I admit I was not aware, in detail, of all of this, and I think that all other members found it useful as well. So thank you for coming and presenting to us today.

Ms. Wong.

Ms. Soo Wong: Chair, before we adjourn for our break, can I ask—because a couple of the last witnesses, their presentations, I want to follow up with the legislative researcher. Can I ask those questions now instead of waiting until after lunch? Is that possible, Madam Chair?

The Chair (Mrs. Laura Albanese): Is that possible?

Ms. Erica Simmons: Sure.

Ms. Soo Wong: Okay, so first things first. With regard to the FASD file, given RNAO's comments—and I dealt with this when I was on the school board. I need to find out why is it, in the faculty of education curriculum, there is no discussion or curriculum for teachers, incoming teachers who are going to be trained at the faculty of education—there's nothing in the curriculum that talks about FASD. I know it's mandatory in the faculty of nursing, but it is not in the faculty of education, when given the data we just heard today from the RNAO—so I need some explanation of why is the College of Teachers not addressing this issue when they're in a classroom. That's the first question.

The second piece here is Councillor Hainer's presentation to the committee and her written submission on priorities. Can we get an estimated cost for one of her suggestions dealing with extending the Healthy Homes Renovation Tax Credit for eligibility for claiming the T2201 Disability Tax Credit? Can we get an estimated cost if the committee wishes to—

The Chair (Mrs. Laura Albanese): Make that recommendation.

Ms. Soo Wong: So I want to have a cost estimate.

The other piece here is on the presentation from Councillor Hainer to the committee—I don't know what page of the slides it is. She commented about SEAC, the parents not being eligible to sit on SEAC.

I know in the city of Toronto that is not true. I co-chaired SEAC.

The Chair (Mrs. Laura Albanese): It probably varies from board to board.

Ms. Soo Wong: Yes. So I need to know, because that is a legislated committee, why are certain school boards prohibiting parents' engagement in this provincially mandated committee and why only agencies can sit on SEAC. Why does the Toronto District School Board have parents sitting on the committee, yet here in Elgin county, the school board is different? When we have provincial legislation, isn't it supposed to be uniformly across? I just wanted some clarification about that piece. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. We have just received a package with ministry responses—

Ms. Mitzie Hunter: For the researcher as well, we've heard a lot of reference to the BC model. I was just wondering if you could share that with us as well.

The Chair (Mrs. Laura Albanese): If we could have some research done on that. Okay.

Thank you very much. We will adjourn, and we're adjourned until 1 p.m. We will return in the room at 1 p.m. Thank you.

The committee recessed from 1218 to 1302.

MS. SANDRA MOTHERSELL

MS. JILLIAN MOTHERSELL

The Chair (Mrs. Laura Albanese): The committee is called to order for the afternoon session. We welcome now Sandra Mothersell and Jillian.

Ms. Jillian Mothersell: Woohoo!

The Chair (Mrs. Laura Albanese): Thank you for being with us.

Interjection.

The Chair (Mrs. Laura Albanese): No problem. We welcome you to the committee and please, you can start your presentation any time you feel comfortable.

Ms. Sandra Mothersell: Okay. My turn first, Jillian.

Hello. My name is Sandra Mothersell. I am here with my youngest daughter, Jillian Mothersell. Jillian, her dad and I live in Grey county. Sue Near is present with Jillian to assist her with communication.

Jillian is 21 years old. She has a developmental disability. She has blue eyes and a beautiful smile.

Ms. Jillian Mothersell: Absolutely.

Ms. Sandra Mothersell: Jillian finished secondary school last June. In her first years of secondary school, she was fortunate to have Sue as a teacher. Sue continues to be a part of Jillian's life, and she assists Jillian to organize her thoughts with the use of a communication board.

Jillian is a strong advocate for facilitated communication because it has allowed her to share her deep thoughts—

Ms. Jillian Mothersell: And her deep breathing.

Ms. Sandra Mothersell: —and show her true potential.

Jillian is at risk of not being taken seriously by people who won't spend the time to understand her or allow her to pull her thoughts together.

Jillian really struggles with anxiety and lack of confidence. When she is feeling upset or nervous, her true personality is hidden. It is harder for her to communicate, to connect with other people and to stay present in conversations. She obviously feels very comfortable here today.

Ms. Jillian Mothersell: Yes, I do.

Ms. Sandra Mothersell: Jillian's preschool years were challenging. We were connected with a local Community Living behavioural expert to help with separation anxiety and issues with sleep and self-injury. The expert told us to continue loving her, and that was all that he could suggest.

We knew that Jillian needed more than love. We connected with CPRI in London. CPRI had a good outreach program at that time. The caseworker supported us and gave us the knowledge, tools and strategies to help us understand how important planning, routine, choice and control were for Jillian.

Skipping forward over the years of learning, planning, transitions, milestones and hurdles, as Jillian was coming to the end of her secondary school years, we realized that we needed to begin preparing Jillian for a future more independent of her family's supports.

Ms. Jillian Mothersell: Yes.

Ms. Sandra Mothersell: We began to read about the Passport Program and the plans to transform the developmental services system. The Passport Program was described as a program to assist students with a developmental disability who are preparing to transition to adult services and supports by promoting independence, fostering social, emotional and community participation skills. The transformation focused on promoting independence, dignity and self-reliance so that people can live and be included in their communities as full partners in society.

We were so hopeful and felt fortunate to live in a province that was creating programs and transforming to provide the future that we wanted for our daughter. We were willing to jump through all the hoops for the DSO assessment and the support intensity scale. We were emotionally drained by the end of this intrusive process that took 12 hours over two days, but we still had hope.

The Ministry of Community and Social Services started making announcements that were alarming. Although it did not affect Jillian, we were saddened by the announcement informing individuals and families that on April 1, 2012, Special Services at Home funding would end on the 18th birthday of those who turned 18 years of age after March 31, 2013. These young adults

would need to apply for adult developmental services and confirm eligibility. Many of these young adults were put on wait-lists instead of receiving the services and supports they previously received.

We thought about how important these formative years between 18 and 21 were for Jillian. We remembered how many new interests she developed in these years while she was supported in the community, interests that were not determined by the interests of her family. But we still had hope, and I argued that equitable supports and services would be provided based on the results of the DSO assessment. Other less naive and better-informed family advocates argued that no further assessments were necessary.

Over the past months we have realized that those advocates that argued against the assessment and SIS were absolutely right to do so. The realization came when we asked DSO the specific questions that the Ombudsman's office advised us to. The following reply from the DSO crushed our expectations. Here is their reply: "Jillian has been through the prioritization panel and would be considered to be in the moderate range. When there are available resources in the community in which she has applied, she will be given due consideration for resources meeting her needs."

We remembered all the assessments over the past 20 years that had assessed Jillian in the moderate range. How much money had been spent to come to the same result? As a toddler, planning, sequencing, organizing, problem-solving, reasoning, focus, fatigue, initiation, sensory processing and anxiety were identified as areas of difficulty for Jillian. As an adult, planning, sequencing, organizing, problem-solving, reasoning, focus, fatigue, initiation, sensory processing and anxiety are identified as areas of difficulty for Jillian.

It is time to realize that turning 18 years old does not make a developmental disability change. It is time to stop spending money on numerous assessments and end the wait-lists. It is time to further develop inter-ministerial co-operation that will provide seamless supports and services for health, education, housing, recreation, employment, transportation and community supports for life.

Each morning, Jillian wakes up and asks if she can go to Tim Hortons, swim—

Ms. Jillian Mothersell: And then—

Ms. Sandra Mothersell: —I'll just do mine and then you can do yours—or shop. She is so enthusiastic to help with breakfast club at the local school, keep her adopted road litter-free or support her great-aunt Lora on an outing. She needs one-on-one support to make all of these things happen. Without the natural supports of her family and the \$125 per week that she receives in Passport funding, she would simply watch TV all day.

I have been following along with the transcripts of these committee hearings. Many families have mentioned their fear for the future. One of the most influential people in my life is my aunt Lora. Aunt Lora is 83 years old. She has a developmental disability. I have the same

fears that my grandmother had many years ago. I saw my grandmother's fears become reality.

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After the loss of her parents, Aunt Lora struggled for many years, but she found a family home through the Family Home Program. Her family lived on a farm in a rural setting, similar to Lora's home in her younger years. Lora lived with her new family for 20 years.

You have had the opportunity to hear presentations from individuals and families. We will never all agree on one type of education, health care, support or residential option, because we are basing these decisions on our own unique lives and challenges. For example, some families self-administer direct funds, which they do efficiently and effectively. Others have found an agency that shares their values and philosophy. Our family self-administered Jillian's Special Services at Home and then Passport funds until very recently.

South-East Grey Support Services respects families and natural community connections. They welcome families to participate in supports and service decisions. They are now providing Jillian with opportunities to make choices and be supported as an individual.

Jillian has had the opportunity to have an independent facilitator and planner. We know that planning must be deliberate and independently facilitated to provide Jillian with the opportunity to have her choice in relationships, community participation, and volunteer and employment opportunities.

The outcomes of the independent facilitation and planning, with Jillian leading the way amongst the people of her choice, have given far more guidance and actions than the DSO assessment that has yet to serve a purpose.

With the adequate supports, Jillian has so much potential to be a contributing member of society. She advocates for a litter-free inclusive community with an increased understanding of acceptance and diversity.

And now it's your turn.

Ms. Jillian Mothersell: Oh, I—

Ms. Sue Near: I think my mom—

Ms. Jillian Mothersell: I think my mom is one great—

Ms. Sue Near: Woman.

Ms. Jillian Mothersell: —woman, and I really love her.

Ms. Sue Near: She has—

Ms. Jillian Mothersell: She has done something much—

Ms. Sue Near: Harder.

Ms. Jillian Mothersell: —harder than most parents have in the world.

Ms. Sue Near: That was spontaneous. Yesterday, Jillian wrote a piece using the same system, and she spoke out loud. We got it down in writing, so we're going to try to read it now.

Okay. But you can see, if she gets excited, it just causes some communication problems. So we'll just do the very best we can, right Jillian?

Ms. Jillian Mothersell: Yes.

Ms. Sue Near: Because I never—

Ms. Jillian Mothersell: Give up.

Ms. Sue Near: Okay. All right. Are you ready?

Ms. Jillian Mothersell: Yes.

I think my mom explains things better than I ever could.

Ms. Sue Near: I think my mom explains things better than I ever could.

But—

Ms. Jillian Mothersell: But she missed some things that I would like to do.

Ms. Sue Near: She missed some things you'd like to do, right? We came up with that.

Ms. Jillian Mothersell: Yes. I would like to continue to learn and to improve my communication.

Ms. Sue Near: She was my student. I've retired; I could not leave. We could not leave each other. I have a few students that I work with; it's incredible how hard she works and how well she does, so you can see why I couldn't ever let go.

Ms. Jillian Mothersell: I would never give up and I hope that the ministry appreciates how hard I try. I will not waste your funding, and neither will my friends.

Ms. Sue Near: Is that the truth?

Ms. Jillian Mothersell: Yeah.

Ms. Sue Near: This was her word coming up. I hope you can wrap your tongue around it. I was just so shocked when she said this yesterday.

Ms. Jillian Mothersell: My esteemed—

Ms. Sue Near: "Esteemed." I love—

Ms. Jillian Mothersell: Life.

Ms. Sue Near: And I love—

Ms. Jillian Mothersell: Language.

Ms. Sue Near: She loves language. She loves vocabulary.

Ms. Jillian Mothersell: My esteemed friend Christopher—

Ms. Sue Near: Christopher Wrigley.

Ms. Jillian Mothersell: —has shown me how important our work is—

Ms. Sue Near: How important our work is. He also said "world."

Ms. Jillian Mothersell: World.

Ms. Sue Near: I think she meant "world" when she was writing it: how important our world is.

Ms. Jillian Mothersell: We must show people that though we are different people, we are all intelligent. Am I doing—

Ms. Sue Near: Is she doing okay?

Interjections.

Ms. Sue Near: Okay. You're doing great.

Ms. Jillian Mothersell: We all wish to make this a better world for all of us. Each of us will do it in our own special way. It will be a great time when all people can be heard.

Ms. Sue Near: It's okay. You're doing fine.

Ms. Jillian Mothersell: I think Christopher would be happy if I read his words.

Ms. Sue Near: Did you hear her self-correct? Did anybody hear her self-correct there? She was reading along—okay. "I think Christopher would be happy if I read his words."

Ms. Jillian Mothersell: Thank you for getting—

Ms. Sue Near: It's okay. Mistakes are good. They can tell that you caught yourself.

Ms. Jillian Mothersell: —listening to all my dreams.

Ms. Sue Near: Jillian—

Ms. Jillian Mothersell: Mothersell.

Ms. Sandra Mothersell: Good work.

Ms. Sue Near: Christopher is a friend of ours and a member of—

Ms. Jillian Mothersell: The family network.

Ms. Sue Near: The family network. He is older than you are. He's 37 years old and he has been involved in adult services for a while now. I see him on a fairly weekly basis, and he tried so hard to be here. He wanted to be here, to be present. He's non-speaking, largely. He also uses a similar form of communication; he does it on a computer. He's eloquent. I would just love to share him with you. He's just a wonderful man, but I think it's captured in his writing. He has written oodles of things. He wrote this specifically for today.

"Dear committee members"—help me when I get stuck, will you, Jillian? Okay?

Ms. Jillian Mothersell: Yeah.

Ms. Sue Near: "I appreciate being able to add my thoughts to others representing self-advocates in Ontario. I have made a good effort to live on provincial allowances over the years. My mother is an excellent manager but has made huge sacrifices in order for me to live a healthy and stimulating life. In order for her to work, our only option was for me to attend a day program with others like myself. It had been adequate for many years, but services have not been maintained, with resulting loss of opportunity for community involvement. I would like my community funding to be released from Meaford Community Living. I would hire a facilitator to assist me and my family to develop a plan. This, I believe, is the expressed intent of the new legislation.

"Respectfully submitted,

"Christopher Wrigley."

Thank you.

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Ms. Sandra Mothersell: And in closing, I would just like you to keep in mind the value of the contributions of self-advocates, families and others that care when you make your recommendations. We ask that you make recommendations that allow us to be present and involved in decision-making at a provincial and local level, not as token representation but with honest respect for the crucial perspective we bring to the table. Please keep in mind that individuals and those that they choose to be present continue to be barred from meetings and decisions that determine employment and volunteer options, where they live and who they live with, how and by whom their health care will be provided, and how they

will participate in their community and who will support them.

In closing, I would like to thank the members of this committee for your respect for people with developmental disabilities and your dedication to an improved system. We have hope for an improved developmental service system because we know Jillian needs more than love.

The Chair (Mrs. Laura Albanese): Thank you for your amazing presentation, Jillian, and thank you to your wonderful mom and your wonderful teacher.

Ms. Jillian Mothersell: And thank you for all your hard work.

The Chair (Mrs. Laura Albanese): Thank you so much. You did great. Never give up.

COMMUNITY LIVING TILLSONBURG

The Chair (Mrs. Laura Albanese): Now we'll call Community Living Tillsonburg to come up. We have, I believe, three representatives here in the room. As you make your way to your seat, I just would like you to start by stating your name and your title when you begin your presentation for the purposes of the Hansard recording. Thank you.

Mr. Urbain Demaiter: Good afternoon, everyone. My name is Urbain Demaiter. I'm a semi-retired dentist. I've served on the Community Living board for a number of years, presently as treasurer. On behalf of Community Living Tillsonburg, we thank the select committee for the opportunity today to provide you with recommendations for the developmental sector.

Our organization has over 58 years of experience working with children with special needs and their families. Initially, we were organized by both parents and friends so that children with special needs would be able to remain in their communities rather than leaving to go to an institution. It is interesting to note that the government finally closed the last institution in March 2009. Through the years, we've continued to work with children through child care and child development programs. As the children grew into adults, we began to develop our supports and services to include adults. Our package provides you with our last annual general meeting report and brochures about our services.

We would like to make reference to the data report that we have provided in our briefing to you. This data has been provided by Developmental Services Ontario South West Region. The data shows that for the past year there were 1,098 requests for group living and 928 requests for supported independent living in the South West Region. Of those requests, 33 people were able to get group living supports and 42 people were able to get supported independent living supports. In Oxford county, there were 56 requests for group living and 79 requests for supported independent living. In Oxford county, one person received group living and eight people received supported independent living supports. Today in the South West Region, there are 1,457 families with children with special needs who are receiving Special

Services at Home funding. There are 942 families on the wait-list.

It was not that long ago that we used to see the wait-lists for supportive services at home eliminated or considerably reduced. We know that families are healthier when they get the supports they require and the respite they need. In our business case, we alerted you to the concern about growing wait-lists. We are prepared to take them on with you. You need to unleash the creativity of the community to address this crisis.

You provided us with a poster regarding employment a few years ago: "Don't Waste Talent." When people are placed on wait-lists and cannot access the supports they need, we are wasting their talents. We are placing people and families at risk when we, as a community, do not provide the supports we know they require. We are placing those families at risk.

We recommend that the government of Ontario recognize the dire need to address all service requests in a timely manner and seek the funding to meet the required needs.

As an agency, we experienced the strikes of 2007. We also saw what the strikes did to the individuals, and we have provided you with a copy of the booklet Behind Closed Curtains, which captured their feelings about the strikes. We recommend that the government not waste valuable resources by forcing strikes on our sectors.

In 2010, we were directed by government to negotiate reasonable contracts. Later, we were advised that these contracts would not be funded, as a wage freeze was being introduced. We have been managing these costs by reducing our staff. We cannot provide wage increases without government funding.

Unfortunately, our agency and our sectors get thrown into the broader public sector mix. There's a misconception that we have full pension plans and wages that reflect current pay standards in our society. We continue to be sectors that are still undervalued. We may achieve pay equity only if we self-fund it by eliminating positions and more services. This is not acceptable.

We watch as government tells us that the Ministry of Education needs new legislation to support the negotiation process between the three parties of school boards, unions and the government, yet we do not see the same concern with regard to our sectors. We remind you that over 100 contracts are coming due during the fiscal year 2014-15. Our past two experiences were not helpful, and we wonder what the experiences of 2014-15 will be.

We want to express to this select committee the need to rethink whether these homes are the homes of individuals or just workplaces. Yes, people work there, but the first priority is, these are people's homes; these people pay rent. We have worked hard at helping our staff recognize that it is the home of the individual. We have tried to ensure it as a home first and foremost and a workplace secondarily. We have seen the private member's bill around picketing at homes, and this might be one of the answers. We firmly believe that people should not have to experience strikes at their homes.

We also firmly believe that individuals need to have the right to choose who they live with. We cannot and should not become a system of counting and filling beds.

The quality assurance measures introduced by the government do not have the support of the community. It is our opinion that there are many other measures of quality assurance that get to the quality-of-life issues, and it would be much better to utilize these tools. We recommend that government work with the community to redevelop these tools so that they are in line with the perspective of the community.

I pass now to Michael.

Mr. Michael Kadey: Hi, I am Michael Kadey. I'm on the board of directors for Community Living Tillsonburg, and I'm also the vice-president of People First Tillsonburg.

Poverty issues: We have been trying to influence the social assistance review recommendations and poverty reduction strategies. We still struggle with our budgets, with the current levels of income support. We know that when we do have jobs, we have more income, but it's still pretty confusing. We have to submit what we earn each month and see our income supports go up and down, based on what we earn. We want to work more, but jobs are hard to find.

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We recommend moving to a quarterly report or like taxes, an annual report. We recommend higher amounts of earnings to be kept before clawbacks. Again, a private member's bill was proposed this last year.

We also contribute to our community in many ways. When we have the right supports to have a job and participate in our community, we help just like anyone else. We raise money for the Relay for Life. We volunteer in nursing homes, Meals on Wheels, child care centres. We help the BIA decorate our downtown, and we help keep it clean.

We do not believe that people should use their income support for paying for staff supports. We struggle with just having the basics on our incomes. We are active with the ODSP Action Coalition and have included a document of theirs in the package. We are generally concerned that people with disabilities have been seeing their benefits reduced.

Marty?

Mr. Marty Graf: I'm Marty Graf and I'm the chief executive officer for Community Living Tillsonburg.

Society does need to recognize the value of including people with disabilities in the workforce, and we have seen efforts to promote employment by both the federal and provincial governments. ODEN has also developed a Champions League of business leaders who promote the hiring of people with disabilities. We are proud members of ODEN and have provided you with some recommendations on employment. We recommend that Ontario consider an employment-first strategy, as explored at the recent ODEN conference. When the labour shortage hits, people with disabilities will be seen as one of the

solutions. We believe that people's lives are enriched when they are able to participate in the workforce.

With children's services: Families with children with special needs do best when they have access to the supports they require. We see the value of respite and have developed effective strategies with families. We develop funding from many sources to ensure that families get the breaks they need over the summer and during school breaks.

We're now into our third ministry for our children's services over the last 15 years. There is instability in the child care system as the full JK-SK system continues to unfold. As a government, you need to stabilize the remaining child care system. There is concern that as we shift into our third ministry, no one will know or understand what we do at the community level to help sustain families. Our children's services has provided you with recommendations on supports to children with special needs and their families.

On the application and assessment: These tools don't fit well with community beliefs and values. The tools need to be adjusted so they can fit with community beliefs and values. We know of people not willing to be put through such a process. They drop out and will require more services later.

In regard to housing: Many Community Living organizations have developed the capacity for property management through partner corporations. We provide a mix of housing options that include specialized housing and accessible housing. We ensure that the rental rates are affordable, and it is done under the not-for-profit model. We also see that landlords in general also seek out people we support as tenants, as they know they have a history of being good tenants. We also see the benefits when people have access to affordable, subsidized housing options in their community. We recommend the government work with us to expand the housing options required. We have worked with financial institutions over the years to develop our housing options, and they need to be included as part of the plan.

Supported decision-making: We recommend that Ontario take the lead in entrenching supported decision-making into the legal system in Ontario and Canada.

We've been trying to keep up with all that you are hearing from the community. You are hearing much wisdom and compassion and determination from the community. You need to unleash the talents of our sector so that we can solve these problems with you.

We thank you for the opportunity to present and look forward to your questions. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation. We have about a minute for each party to ask a question, so if there are any, they should be very brief.

Mrs. Christine Elliott: Thank you very much for coming and making a presentation to the committee. You've raised a number of excellent points.

We don't have a lot of time, so I was wondering if you could expand a little bit on some of the innovative

housing solutions that you've been able to develop, because we've consistently heard that that is an urgent need, and that's why we're here: to hear about some of the prospective solutions.

Mr. Marty Graf: Years ago, we had a big residence where 20 people used to live together. We learned that people don't like to live in that kind of setting and with that many people, and over the years we've been able to transition out of those larger environments. Our agency took risks: "Let's pull together the down payment and start buying some housing," and we've been in that business for close to 30 years now. So you can have a triplex where somebody who requires a lot of supports is getting that. People on the second floor are getting the benefit of access to those supports, but they're not needing 24-hour supports. The person in that top-floor apartment just needs a checkup once a day or two times a week. They are accessing supports that are there 24 hours, but they don't require that. So we've changed from trying to have everybody in group-living situations to trying to figure out the best way to individualize. A lot of people can't live with four or five other people, and so they're better off when they can share access to supports, but not necessarily having 24-hour supports.

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

Miss Monique Taylor: Thank you for being here and for presenting to us today. You brought up something that I hadn't heard of before: It was called ODEN. Could you speak on that a little bit further? It's under "Employment."

Mr. Marty Graf: You'll see that they have developed some recommendations. It's a collective of us who have been around for years. Joe Dale is the executive director. We used to be big in developing sheltered workshops, and then we realized that employment is the best way to go. So there's a collection of us throughout Ontario. We have really focused on employment programs, and we strongly believe that is the best way for a lot of people to gain independence.

Miss Monique Taylor: So is it members by employers?

Mr. Marty Graf: We are connected to a lot of employers. They have developed this Champions League with us. It has the support of the Lieutenant Governor. But first and foremost, the members are the agencies who provide employment services for people with disabilities.

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

Ms. Soo Wong: Because of time constraints, can you forward to the Clerk—one of your recommendations is about supported decision-making. So can you elaborate on that statement and share with the committee what you mean when you ask that Ontario take a lead in entrenching supported decision-making into the legal system in Ontario and in Canada? If you could submit something to us, that would be really helpful.

Mr. Marty Graf: Yes, we'll make sure to submit that to you.

Ms. Mitzie Hunter: I would also ask for your recommendation on the quality assurance model. You sug-

gested that there were best and good practices that you're familiar with, and I was wondering if you could share that with the Chair as well.

Mr. Marty Graf: Yes. There are a number of accreditation programs available that are possible options for agencies like ours. So I can get that information.

Ms. Mitzie Hunter: Thank you.

The Chair (Mrs. Laura Albanese): We thank you very much for presenting before the committee today.

Mr. Marty Graf: Okay. Thank you.

The Chair (Mrs. Laura Albanese): Continue the good work.

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MS. MARY JO WINKLER-CALLIGHEN

The Chair (Mrs. Laura Albanese): Our next presenter, Mary Jo Winkler-Callighen, is actually not here. She wasn't able to come and present to the committee. She has sent her presentation, though, and we have now Joyce Balaz, who will read it into the record. So just to be clear, we won't have any questions. The presentation will be read into the record on behalf of Mary Jo Winkler-Callighen.

You may begin.

Ms. Joyce Balaz: Thank you for your indulgence in this. She tried very hard to get volunteers. She's on a ventilator and she needs to travel with two people. She also could not get Paratransit to pick her up, and her technology also broke down, so all three strikes against her. I'm passing along a picture of her so that people know who she is.

"We have created a great divide. We put the temporarily able-bodied on one side and the rest of us on the other. All my life, I've been on the privileged side, the temporarily able-bodied. Very luckily for me, I met a man who, with extraordinary effort and against social norms and bypassing the structure of well-intentioned, supportive governmental programming, integrated into community across the great divide.

"I have the great good fortune to call him my friend. About four years after we met, I began to lose the use of my legs and feet, then my arms and hands, then my voice and neck, and now, some of my intellectual capacity. Without my good friend to show me the way, I could never have imagined remaining active in community. He opened my mind to possibilities that would have been closed to me by my own assumptions. He gave me hope; he taught me how to negotiate my way through relationships and through life. I would not have found this vital guidance without him.

"If he hadn't been integrated into community, our paths would never have crossed.

"When we bridge that great divide, we regain the wholeness of our humanity. When we are making full integration real, we begin to heal the rift, and mend the old and cruel great divide. We learn to value one another and accept our bodies and our minds. We cannot do this without full integration.

“I had much more to say, but my technology has failed me, and this kernel will have to say it all for me.

“Thank you.

“Mary Jo Winkler-Callighen.”

The Chair (Mrs. Laura Albanese): Thank you very much for reading that into the record, and give our best to Mary Jo.

SPECIAL SERVICES AT HOME/PASSPORT COALITION

The Chair (Mrs. Laura Albanese): We now have as our next presenters the Special Services at Home/Passport Coalition. Good afternoon and welcome to our committee. Just make yourself comfortable, and whenever you feel ready, we can start. Please identify yourself before you start your presentation so that we know who everyone is.

Ms. Susann Palmiere: Hello. My name is Sue Palmiere, and this is my colleague Janice Strickland and my daughter, Alexis Palmiere.

We’ve done four handouts. One is a brief, and I’ve done a point-form outline of it that you can just follow along with as I read it. Another one is a handout about one of our committee members’ sons, Dave, who had a full life with direct funding. And the other one is called Social Exclusion, which is a paper we did in response to some of the problems that have been coming up. We did that in June.

I’d like to introduce our coalition. The Special Services at Home/Passport Coalition is a volunteer group of families, individuals, organizations and agencies that are dedicated to ensuring that people with developmental disabilities and their families in Ontario receive the meaningful support they require through direct funding. Our coalition believes that all people have the right to self-determination, and therefore a right to choice and control over the supports that so affect their lives. We believe direct funding ensures supports that are flexible, responsive, individualized and self-directed and that result in relationships that are meaningful in community, and should be the support options of first choice.

I’d like to just go over a quick history of the Special Services at Home and Passport programs.

Direct funding was introduced by the government in 1982. It was introduced as a way to assist families and prevent the admission of children with developmental disabilities into provincial institutions. At the time, it was defined as a program of last resort, to be used when all other options of support had been exhausted. The program was immediately very successful with families, so much so that in 1987 there were many more applications than there was funding. In 1989, which is the year that our organization started, they expanded the program, in fact, to cover children with physical disabilities and adults with developmental disabilities.

If you see the chart on the point-form outline—I’ll just address that. In 1993, there were 9,000 families who were covered by a \$28-million budget. In that same year,

actually, the family groups, including ourselves, made recommendations to the government that program funding be doubled. We also made some other recommendations for improving the efficiency and effectiveness of the program, but I don’t know if they were adopted.

In 1995, the government increased the budget of SSAH by \$6 million. I should mention that the government always told families that they could apply for as much as \$10,000 annually per person. The average allocation for someone with SSAH is around \$4,200, and that has not changed. We’ll talk about that later.

In 2001, the budget increased to \$56 million and it served 16,900 families; in 2002, 18,500; in 2003, 17,200. The only point to note with this is that as the demand for the program increased, which it did, so did the wait-list.

In 2008, the ministry funded absolutely no new applications. However, they continued to encourage families to apply to the program so that they could gauge demand.

Then, in response to the growing wait-list—and you’ll see that by 2012 the wait-list is almost 9,600—in 2011 they put \$11 million into the program, which I believe funded 950 more families, but it only reduced the wait-list by 20%.

Finally, in April 2012, the government announced that SSAH would no longer be available for people over the age of 18. You’ll notice, in 2012, that the people served were 27,000 and the people waiting were 9,600.

Then, in April 2013, people over the age of 18 with developmental disabilities were cut off SSAH funding.

We’ll just go on to Passport. I’m hurrying; I want to get through this so we can answer questions. Passport is a very recent program. It was introduced in 2005 to assist young people with developmental disabilities who are transitioning from high school to community life by fostering skill development towards independence and autonomous decision-making. Funds were used for community participation, continuing education and personal growth.

You’ll notice the chart, and that’s page 3: In 2010, the budget for Passport was \$31 million; people served was 2,492; people on the wait-list, 3,959. In the next year, 2011, with the same budget, 2,700 people served; the wait-list was 4,500 people. So throughout the entire time that Passport has been in existence, the wait-list has exceeded the number of people served.

We have asked for recent statistics for 2012-13 from the ministry a couple of times and we haven’t received any.

As far as our last statistics, in 2012, there are now, to this day, 4,500 young people waiting for Passport funding and 9,600 families and children waiting to be funded through SSAH.

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This brings us to our next heading, which is that direct funding is a have-not program. You see our graphic; we call it our teeter-totter graphic. These are from information from the ministry. In March 2012, 9% of the developmental services budget went to SSAH and Passport; 91% went to everything else, from maintenance of the

system to supporting those individuals on government care and to building the bureaucracy needed to implement the new social inclusion act. Community Living Ontario estimates that as little as 15% of the new funding announced in the past seven years has gone to address the needs of people on wait-lists.

I really want to get to what the benefits of direct funding are. I did want to mention, however, transition. As you can see, there are problems in the developmental services sector today resulting from the years of underfunding—also now, from the manner in which the social inclusion act is being implemented: in effect, institutionalizing wait-lists and denying support to thousands of people.

One of the most urgent problems that has come out lately from the implementation of the act concerns transition of children from children's services to adult services, and how it coincides with a number of other difficult transitions. At 18, SSAH funding ends and families must take their young person—they apply to DSO, who do a SIS assessment. That's their very intensive and intrusive supports intensity scale assessment. Then they're placed on a wait-list.

If there's a significant time lag from losing their funding to getting new funding through Passport—which there usually is—or a significant difference in the amount, the person loses the support worker they've had for many years, as well as, at that time, losing the school community that they've known for many years as they transition from school to the community at 18 or 21.

Also, there is, at 18, a significant transition for our young people. Many of the people with developmental disabilities have associated psychiatric, medical and physical disabilities—and I know that you're looking also at dual diagnosis—and they are served as children within the children's hospitals or the children's treatment centres. Both of these institutions absolutely discharge at 18. So all of the services—OT, speech, physiotherapy, vision services, psychological services, and all the pediatric medical specialists—all access to those services ends, and the families have to find these services within the adult sector.

You've heard from H-CARDD, I believe, and Surrey Place. People with developmental disabilities are a very marginalized group in the medical community. There is very little expertise on, certainly, dual-diagnosis developmental disability, and there's very little expertise on the quite rare disabilities of childhood onset. They're usually rare, and it's very, very difficult to find service. The system is structured to precipitate crisis and family breakdown at transition.

It has often been said by families and ministry staff together that SSAH has been one of the most successful programs that the ministry has ever introduced. The reasons for it are fivefold.

Direct funding is cost-effective. I know you're familiar with the Drummond report. He observed that the recent legislation recognizes that people want life in the community, and they want choice and control over the kind of supports that allow them to live in the com-

munity, so he recommended moving towards consolidating developmental services funding for community-based support programs into a single direct-funding program. Certainly, what we as families can comment on with regard to that recommendation is that as families we are very, very skilled at obtaining value for very little funds.

Secondly, direct funding allows for flexibility in the use of funding to respond to specific situations and changing needs. I'm going to use personal examples on the next board, because I'm most familiar—keeping in mind that people with developmental disabilities are extremely varied in their needs and so we use direct funding in differing ways to meet those needs.

My children seemed fine, if a little bit unsteady on their feet, at one and three, but they were diagnosed with a progressive neurological and immune system disorder that involved progressive loss of the cerebellum, which is the back portion of the brain. The cerebellum controls all motor movement. It controls fine and gross motor movement, coordination, balance, vision, speech, swallowing and digestion. The cerebellum also has inputs into cognitive processes; in particular, information processing.

Very quickly, we were seeing all sorts of specialists, and then therapists in the children's treatment centres, with various therapies and what have you at home. I was pretty well required to leave work to meet all these needs, and that entailed my husband taking on more work travel and in fact work outside the country in order to compensate for the lost income. So I was alone, and we were trying to meet all of these needs.

Now, home care was available in our area. It was VON and Red Cross, but the workers in a rural area were often unavailable. They were constantly changing. They couldn't do the therapies and procedures we needed them to do. They couldn't come with us to appointments—that was a biggie. But the biggest thing was that they weren't trained in the care of children. They were trained in the care of the elderly.

I really feel that, for children with a progressive disability, building emotional resilience is of utmost importance. Building a sense of competence and agency and a sense of self in the presence of this is vital, but to do that, you need to know something about child development. So the SSAH coordinator found a young woman from the University of Guelph studying family studies, and she knew quite a bit about child development. She was able to grasp quite quickly values around disability and empowerment, and she was with us for five years. I'm just using this as an example of how SSAH can respond quickly to the needs of a family, whereas the Ministry of Health was unresponsive, inflexible and very expensive.

The other thing about direct funding is that it does encourage creativity and the use of available resources to achieve desired outcomes. By the time my son—my son also has this same disability—was nine, he was beginning to lose the ability to walk and was resisting going into a power wheelchair. Now, at school, the boys would be out on the field playing, or they'd be riding bikes after school. As a result, he wasn't able to keep up, and he was

losing his friends. He responded by withdrawing into about two video games. It's all he would do, these two video games, and we were getting really concerned about his behaviour.

So we hired a young man—again, a student from Guelph, a poli-sci student—who would come every day after school, sit on the floor and play these two video games. He did this for weeks, but gradually he persuaded Sam to try some more challenging video games. Following that, then, was Ryan's favourite activity, canoeing. This was followed by disabled sailing, then disabled skiing, then power wheelchair hockey. And so, with time, Sam became pretty proficient in his chair and a good goalie, and started defining himself as a sports guy in a chair.

Eventually, after six years, Ryan left. He was replaced by Curtis, another student. He was a YMCA day camp counsellor, so Sam became a summer day camp counsellor volunteer.

By the time Sam got into his early twenties, he finally admitted to Curtis that he really hated disabled skiing and he wanted to scuba dive. He and Curtis found a program out of Ottawa that teaches people with disabilities to scuba dive and snorkel, and he's been an avid participant ever since.

We all discover who we are by trying new things and meeting new people. Direct funding allows people with developmental disabilities to do this as well. Direct funding also helps people achieve personal growth and realize self-determination.

When Alexis was eight, we took her to an educational psychologist, and he more or less said, "Well, her scores are really low but it's difficult to test her because she's visually impaired and the physical disabilities, but she has a remarkable memory, and you just build on that strength and forget all the rest of it."

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In fact, her EAs at school more or less gave up on the technology anyway. They just read to her all the way through her school. As a result of this, she developed just an incredible auditory memory.

At 21, Alexis graduated with a diploma, supported and accommodated. She wanted to go to college with her classmates. After a few false starts, we found a college without entrance exams and they said she could take a course. Then we found April. April was as fiercely dedicated to Alexis and her abilities as Alexis was dedicated to education. She spent months training Alexis in an on-screen keyboard, use of a joystick, word-predictive software, reading software. Alexis took the course, but she found it agonizingly difficult, and she didn't do terribly well and she hated it and she was crushed because she had dreamed of being a teacher of young children, like her grandmother.

With nothing else to lose, we said, "You should really do what you're interested in," so we went back to the college and talked to the early childhood education program. They allowed her into a course. She took the one course, loved it, and she has been doing them ever since. The material that she reads and memorizes gives

great meaning to her volunteer work in daycares and also greater depth to her relationships with the children of caregivers. So I say that direct funding has helped her realize some of her dreams.

Finally, direct funding helps build informal networks of support in the community. All of us are part of a network of relationships through work and school and recreation and community involvement, and they give us identity and belonging and some fun and they give us assistance. This, of course, is our informal network of support. People with developmental disabilities have very fragile informal networks of support. They have formal networks of support that are changeable and often compromised. What has to be done for people with disabilities is, they need informal networks of friendships and support built intentionally.

Sam and Alexis, as you can tell, have had a lot of really terrific workers, who all move on. They come as students and they move on to adult life. They go on to graduate school and professions and marriages, but many of them have wanted to stay involved. It's difficult for Sam and Alexis to sustain relationships. What we've done is we have formalized their engagement with the kids' lives by starting planning circles. The circles help with decision-making—you don't want your parents helping you with decisions all your life—and problem-solving around school, work and recreation. They provide social opportunities. Each circle is eight members. They meet every six weeks, and they've been meeting now for seven years. It's funny, but the workers now come back with all the skills they've gained in their professions. One guy has a master's in education. He's a fabulous group facilitator. Another girl, because of the kids, became an autism specialist and so she's very good in educational accommodations.

The Chair (Mrs. Laura Albanese): Sorry; I have to let you know your time is up. We've actually exceeded the 20 minutes.

Ms. Susann Palmiere: Can I say one more thing?

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

Ms. Susann Palmiere: It's to do with family mentoring, and perhaps you can read the brief there. Families are central to the lives of people with developmental disabilities and are key, actually, to making the system work. I made a couple of points as to how what's going on right now has really made families unable to continue helping their family members achieve a meaningful life in the community. Perhaps you could read that.

Do we have any time for questions?

The Chair (Mrs. Laura Albanese): No. It has been exceeded; I'm sorry. But it's important that we hear from you, so we thank you so much for the presentation and for being here with us today.

Ms. Susann Palmiere: Thank you.

MS. JOYCE BALAZ

The Chair (Mrs. Laura Albanese): We'll now call Joyce Balaz back for her own presentation this time. Joyce is accompanied by two people.

Ms. Joyce Balaz: Sorry for the time delay. I'm Joyce Balaz. I'm from London. I'm accompanied by Bill Hiltz and his intervenor, Arn.

With the indulgence of the committee, I would like to ask you a few questions—turn things around a little. Do you have friends who are not paid to be with you? Were those friendships developed through your interaction in the community, be it your workplace, your place of worship, from the time you were in school, maybe a service club? If you are in a relationship with a significant other, how did you meet that person? I'm sure that it didn't happen when you were out in the community with your mother, right? How many people would you like to have provide very intimate care for you? Are you able to choose the group of people you spend a lot of time with? Do you think that your role in society is a valued one? I ask these questions to provide you with an opportunity to understand a little bit better why an individualized approach that allows for choice is so important.

Because you've chosen to sit on this committee, I believe you feel that the current system is quite badly broken, and I believe that what you've heard thus far supports that notion. I believe that the root of the problem is that the system is built and continues to be built to support the system and not the individual.

When I say "individual," I mean an individual living with a developmental disability. When I say "family," that includes family, friends and advocates.

I am a family home provider for this gentleman, Bill Hiltz. To most eyes, Bill is a broken-down individual who is most often pitied, but certainly for the most part, he is not valued for the contribution to society that he has made.

While Bill is not the usual candidate for a family home placement, I can tell you unequivocally that this is the best place for Bill. Having been his educational assistant, I knew that Bill had many gifts to share. Because of the relationship Bill and I had developed, when he needed a new home, I offered to have him come and live with me. It was then, in 1996, that I became his family home provider.

After Bill left the education system in 1998, once again he fell through the cracks in between systems, and his intervention needs were not met. It took us six long, hard years of advocacy to obtain these supports. During this hard advocacy, I was effectively silenced and Bill's rights as a citizen were trampled upon. It took the support of many individuals for us to maintain the strength and advocacy to ensure that Bill's rights were upheld. I cannot begin to explain to you the enormous stress that we endured. I wish I had time to explain all of these things more fully, but there are more important things to discuss with you.

I paused here to illustrate what many individuals who have lost or have no supports are subject to for many hours in the day: They can do nothing.

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Bill and I are very active politically because we feel that if one wishes to complain about a situation, one must

be ready to roll up one's sleeves and bring about change. That is what brings us here today.

We are involved in many organizations that advocate for individualized supports. We have experienced the benefits of independent facilitation, without which Bill and I would no longer be together. We have lived through the harsh intimidation of the powers wielded by the system, but with the strength of Bill's support circle and the support of the facilitator, we survived an ordeal I hope no one else ever has to endure.

I only mention this because it is important for you to understand that power can destroy wonderful relationships and truly harm individuals and families. But on a positive note, seeing a vulnerable individual become empowered through the support of others is so inspiring.

Bill's accomplishments are many, far more than those of many of us in the room put together. He inspires me to higher heights. He is an inspiration to many. We have distributed posters of Bill's accomplishments as well as a snippet of his community participation.

All of this would not be possible if Bill's supporting agency did not believe in individualized supports, and it would not be possible if I did not provide the level of care and support that I do for Bill.

I said that we are here to bring about change. It is time that MCSS recognizes and values the unpaid supports of the many people who provide support day in and day out. Over the past 18 years, I have done the math, and I have saved the ministry over \$1 million by providing 16 hours a day of support and then some. The ministry refuses to acknowledge the savings because they believe it is not a savings, because they didn't have to pay it out first. I receive a per diem of \$47, from which I must also provide for Bill's housing and meals and anything else he needs. I have not had an increase in that per diem in four years.

The most probable placement for Bill, if he were not living with me, would be a group home for individuals who are deaf-blind. I did a cost analysis about 10 years ago, and at that time, Bill's supports would have been at least \$150,000 a year. I am quite certain that the amount is probably higher today, and those supports would not provide for the one-on-one support that Bill requires.

I must point out here that for a significantly lower cost, Bill has a much better quality of life, individualized to his needs, and one that acknowledges his gifts and talents.

I also want to point out that, contrary to the beliefs of CUPE and OPSEU, the same level of support is possible through an individualized approach. However, there is an inherent danger, and that is that historically, individualized supports remain stagnant, and therefore people begin to fall behind those individuals supported through a transfer payment agency.

I also wish to point out that there has been no increase to Bill's intervention funding since it was secured in 2002. This presents a challenge because in order to retain good workers, we have to pay the same rate as people working in agencies or else we lose those workers to the

agency positions, which provide benefits and job security.

One important change we see for individuals is to immediately implement an entitlement to independent facilitation and planning prior to the assessment process so that individuals who require supports to lead an everyday, ordinary life can, at the very least, have an opportunity to dream and experience the value of developing relationships within community. With this experience, individuals will be better able to identify what supports and services they need in order to be a valued, contributing member in their community.

The second important change is to develop a method so that dollars that are allocated for CCAC care be individualized so individuals can add those dollars to other funding to allow for supports which better meet the needs of the individual. I provide more details about this in my written submission.

By allowing funding to be combined, we could hire another full-time intervenor, giving Bill more direct support. Bill would then be able to choose which worker would provide the best supports for each activity he's involved in. Not only would this provide for optimum supports for Bill; it would also provide more dignity, as there would not have to be six people providing intimate care for Bill in a week. As in the MasterCard commercial, this is priceless.

Another very important change that would make things much better for everyone is to work across the various ministries to develop a registry for individuals with developmental disabilities. Since developmental disabilities usually emerge at an early age, there should be no need to reapply for services and supports at age 18. If a child is entered into the registry upon diagnosis, it would be easier to plan for the future and to provide numbers with which to advocate for more funding.

The transformation process is moving too slowly. It began in 2004, and people were hopeful. Now, 10 years later, things have gotten worse for a lot of people. People have lost hope and trust in the process. Part of the problem is that the transformation is based on bad legislation. Once the legislation was crafted and passed through debate to the final committee process, many advocates were absolutely disgusted by the process. Even sound transformative amendments were shoved aside and not considered because they originated with the opposition. This highlights that the process served only the government and not the people that this legislation is intended to serve.

Currently, the DSO process, which was developed to be a single access point for service, is an unwieldy process. It is not responsive to individuals and their families. It is another bureaucratic layer that has taken in excess of \$12 million away from the direct support of individuals. It does not allow for the immediate call to action in times of crisis. Alternately, the application process should be as easy as applying for an accessible parking permit or the disability tax credit, which can be completed by the family physician. It would not be difficult to develop a

simple questionnaire to determine whether there is a developmental disability. Once the simplified application form is completed, an individual and/or family could present the form to a ServiceOntario office—which is already an existing entity—and provide proof of residency in Ontario and then proof of age. The personnel would accept the application, electronically add the individual to a registry and things could proceed from there.

Provide a six-month deadline for everyone currently receiving supports through ACSO, Special Services at Home, Developmental Services, ADP and wherever other people get some services from, to apply as explained above. As well, put out a call through family networks, various community organizations, ODSO and OSO offices, subsidized housing, CCACs etc. to connect with those individuals who haven't bothered to apply because they know there are no resources available. In this way, the government would have the required data of a number of people who currently require supports and services. While this would not have the information on the level of support that the individuals need, it begins the process.

From there, everyone who is deemed eligible through this process must be entitled to independent facilitation and planning to begin the dream of what life looks like for each person. At least everyone gets a start. This independent facilitation and planning must take place before individuals enter into the assessment stage to determine the supports they need. The facilitator can also help them navigate through the system.

Independent facilitation saved our life together; without it, Bill would no longer be living with me and, in the opinion of his neurologist, he would not be alive today. I can tell you, that would be a real crime. Bill inspires so many people. To illustrate how important change is to Bill, he has opted to not use his energy to enjoy his life but has instead decided that he will only work on his advocacy role to help those who have no supports, to help others understand that they have a voice and that they can do whatever it is they want. His words to fellow classmates when he left school were, "Great things are there for you if you choose to work for them."

Investment in community development is needed to help break down the enormous attitudinal barriers for people living with disability. An example of some basic community development that would reduce the financial burden on the ministry is to ensure that all parks and recreation staff are fully trained in assisting people with developmental disabilities who require minimal support. There is always apprehension when people first begin to interact with individuals. But, over time, when it is commonplace for people to be active in the community, that apprehension melts away and makes room for some very honest relationships.

I witnessed this with Bill in the environmental studies class one year. The mix of students in the class was such that after Bill and I had joined the class for their yearly Cyprus Lake camping trip, once back at school, Bill

would lead me out to their class and the students included him in whatever they were doing as if it was commonplace. At other times, if we came across one student in particular at the cafeteria, Bill would choose to spend time with the group of students that she was with at the time. I left Bill in their care and backed off with my support. It turns out that the summer after that, Bill hired one of those students to be his intervenor for the summer. This was a wonderful example of building relationships in society. This is true inclusion.

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Another issue which needs to be addressed immediately is one of inequity. The program being a discretionary one breeds inequity. "Discretionary," by definition, identifies choice, but whose choice? Funding is allocated at the whim of the government, and unfortunately, our most vulnerable population is not seen as a priority. For about 25 years, advocates for individualized supports have been asking, through many forums, avenues and meetings with the ministry, to allocate 25% of any new monies added to the developmental services budget to be put towards individualized supports. A quarter of a century later, 10 years into the transformation process, and the ministry, despite its vision of social inclusion, has seen fit to allocate only 9% of the budget for individualized supports. There is a huge inequity here.

Despite the large proportion of funding being held by the transfer payment agencies, wait-lists for day programs and residential supports continue to grow. Bill has been sitting on a waiting list for a group home placement for at least 20 years. I keep him on that list because I do not know what will happen to him when I can no longer provide supports. We came very close to that point last year when I lost a lot of my mobility due to a deteriorating hip caused by osteoarthritis. Luckily, I was able to continue to provide support for Bill. It was rough after my hip surgery, but we managed—not without struggle and stress, but we managed.

In the statements already presented by others, including CUPE, OPSEU and various service agencies, you are hearing that the chronic underfunding is eroding their ability to provide the services that individuals need, yet they are quick to point fingers at the individualized supports as not being able to maintain supports and eroding the services sector. If the system moves to personalized budgets, there is no need to develop separate programs, as individuals will find what works best for them. For this reason, it is important that, moving forward, all budgets of people in service be personalized.

We acknowledge the fact that not all individuals want to strike out on their own with individualized supports. However, if budgets are personalized and fully portable and individuals find that they are successful in the community, they can move to individualized supports, and, depending on the other supports that they require, perhaps more direct service dollars can be found to better support the individual with community participation and community capacity building.

Another very important issue which we have not yet touched upon is the re-institutionalization of individuals

whose needs cannot be met with the maximum level of support in the community. Young people, because there are no alternatives, are being placed in long-term-care facilities. Ask yourselves this: Would you want to be living in a long-term-care facility at the age of 24? By keeping the system woefully underfunded, people are being forced back into institutions—this upon the heels of a very impassioned public apology to the residents of the Huronia Regional Centre on December 9. In that apology, the Premier told Ontarians, "Today, we strive to support people with developmental disabilities so that they can live as independently as possible and be more fully included in all aspects of their community. As a society, we seek to learn from the mistakes of the past, and that process continues."

The reality is that today we ship people off to nursing homes, mental health units, treatment centres and jail, depending upon the circumstances. Where are the community supports that were to be reinvested in the community when the Huronia Regional Centre, Rideau Regional Centre and Southwestern Regional Centre were closed? No one seems to know where that money went.

This brings us to a major problem with trust. The ministry is all too happy to trust families to care for their sons and daughters without providing any supports and services, but that trust really disappears when funding is attached to the support.

But what about the trust that people placed in the ministry? During the early stages of transformation, people were worried that individuals would lose their current level of funding. We were assured time and time again that this was not the intention of the transformation. Then what happens on April 1, 2013? Anyone who turns 18 loses the funding that they were receiving through SSAH because it has been converted solely to children's programs so that they can address the children's wait-list.

In the MCSS presentation you were told that there were no cutbacks. What is it called when funding is taken away under the guise of having to reapply to the adult sector to retrieve this funding? Individuals who had funding lost it, because there was no seamless transition between the child and adult service delivery.

Another issue of trust rose up early last week. We received a disturbing communication about a recent ministry publication entitled Hiring a Support Worker. The first statement is, "Are you a person with a developmental disability in Ontario? Do you get money from a job, a direct funding program, the Ontario Disability Support Program (ODSP) or another source? Would you like to use some of that money to hire someone to support you and your life in the community? Are you a friend or family member of someone who wants to hire their own worker?"

People have been identifying to advocacy organizations that the DSO, and even staff at the Ombudsman's office, are suggesting that if individuals do not have funding to pay for supports for community participation, they should use their ODSP income support to do so.

With the woefully inadequate ODSP, which is meant to provide for housing and food with a small pittance for other personal items, how can they even look to using this support to pay a wage to someone else? Not only is this unreasonable, it is probably illegal.

Individuals are being counselled to use one social assistance benefit to pay for something that it's not really meant to be used for. This is outrageous, as these are two totally different support programs.

When questioned about this, David Carter-Whitney told representatives at the partnership table that his earlier comments had been misunderstood, and that was never the intent, yet people are being counselled to do so, and now it is even written in a ministry document. How is anyone to trust anything that they are being told?

In summary, my recommendations to enable individuals to fully participate in their community and bring about substantive change to developmental services are:

- invest in community development as a way to move from a model of providing charitable supports to one that supports economic growth;

- move from a discretionary support program to one of entitlement, as our most vulnerable citizens have the right to participate in the community of their choice;

- ensure that individuals deemed eligible for supports and services are entitled to independent facilitation and planning;

- move to a system that supports the individual and not the system;

- implement personalized budgets;

- ensure that supports are whole-life based;

- develop effective inter-ministerial coordination to allow blending of budgets to provide for more meaningful supports for individuals; and

- last, but by no means least, it is time that people really listen to the individual. All they want is an everyday ordinary life, like everybody else. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your very thorough presentation. I believe that Bill now follows.

Ms. Joyce Balaz: Yes.

The Chair (Mrs. Laura Albanese): We don't have any time for questions for this first one.

MR. BILL HILTZ

Ms. Joyce Balaz: Bill has had some seizures this morning and this afternoon, so bear with us. We'll try to get him to do what he's supposed to do.

Mr. Bill Hiltz: Good afternoon. My name is Bill Hiltz. I do not speak with voice. I use facilitated communication, which takes a lot of time and effort, so my intervenor, Arn, will speak for me.

The Chair (Mrs. Laura Albanese): It automatically turns on as you start speaking. We have our attentive team here.

Mr. Arn Row: This is Bill's poem. It is called *Understanding People*.

A set of standards by which to judge,
to their friends, they give a nudge.
When they see me come their way,
they stop and walk the other way,
Or even worse, they stop and stare
as if I'm stupid and unaware.
If only they could know that I care;
how people view me—it's just not fair!
I feel the very same as others do,
they should try and walk in my shoe.
Life's not easy, when the body that you own
was given to you broken-down.
They may be mean; they may be cruel; they may be
bad;
but most of all ... they just don't understand.

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With some time and special guidance,
we can have a great alliance.
For an hour or for a day,
we all need friends along the way.
So when you see me come along,
try not to focus on what is wrong.
I am a person just like you,
who needs and deserves a good friend too.
Just walk beside me straight and tall
and be the friend that I can call
when I am lonely and afraid.
Just remember what I've said:
All you need is to understand;
do not judge, just take my hand.

I ask you now to open the bags that you were given and put on the items that are in there, just so you can get the experience of what it's like to live in Bill's world.

Ms. Joyce Balaz: Bill has graciously offered to give someone else his wheelchair for a time.

Mr. Arn Row: While Bill was working on this presentation, he was plagued by seizure activity as frequently as every two minutes. Despite this, he pressed on. The text in italics are Bill's actual words using facilitated communication. Anything not in italics was developed with Bill presenting the main idea, and then together with Joyce's skilled intervention, Bill was able to provide more detail and has approved if not the actual words, at least the content of the statement:

"I am not a client; I am a person first and foremost. I am a person who faces many challenges. I was not miraculously cured at age 18. My needs have not lessened. My seizures are getting worse as I get older, so I need more support to keep me safe.

"Does an expert need to tell you that I need 24-hour care, seven days a week? For many people like me, an expert opinion is not necessary; it is quite evident. So why the added expense for an expert opinion? Is it really necessary to spend scarce dollars unnecessarily on a full SIS assessment, when a simple questionnaire could easily determine the level of supports I need?

"It is important that families have the support to allow their sons or daughters to grow and truly blossom. That

support was not there for me and my family. I spent a lot of time in hospitals and foster homes. At one and a half, I became a crown ward and spent time in various foster homes before being sent to the Christopher Robin Home in Ajax. I spent a number of years there until I was rescued by a wonderful foster family when I was 8. I lost a lot of my childhood there.

“It was important for me to support the survivors of Huronia Regional Centre because they lost so much too. It is important for everyone to have a life in the community. It is very important to me to be able to continue my advocacy work to help others have the same opportunity as I do.

“These five guiding principles, which I helped develop with other board members of Family Alliance Ontario, will help everyone to have an everyday, ordinary life.

“An everyday, ordinary life: Having a developmental disability does not diminish the right to a life like anyone else in the community; it just means that people need varying levels of support to achieve many of the things that happen naturally for those who do not have a disability. By having an everyday, ordinary life in the community, people will be better able to develop the relationships that are an integral part of society.

“Whole-life-based supports: Supports must enable people to live a full life in the community from birth to the end of life. Individuals must be seen as a person, not as a sum of the parts of life: health, housing, recreation, transportation, education etc. Supports must be flexible to provide assistance as necessary through the various transition times in life because necessary supports at these different times in life are varied according to the challenges which emerge. Therefore, having the ability to draw from a whole-life-based budget for supports will allow for that flexibility to provide the supports necessary at any given time.

“Independent planning and facilitation: They are integral supports necessary to fully integrate individuals into their community based on their strengths and abilities. Planning must be more deliberate for people with disabilities, and facilitation provides for the relationship-building and the building of capacity in the community to allow for positive inclusion and a more caring community. Every individual deemed eligible for supports and services through development services must be entitled to independent planning and facilitation before starting the assessment process.

“Economic growth: Providing supports for a person with disabilities must no longer be seen as a charity. By providing adequate supports, individuals are providing employment opportunities for support workers. Family members who would otherwise be forced to stay home to provide supports to individuals are able to participate in the workforce, bringing more financial stability to the family unit. Individuals who become employed contribute to the economy. Individuals who become part of the volunteer network contribute to the community and to the humanity of that community. Families of individuals who are full participating members of society are faced

with less stressful situations and therefore enjoy a healthier life, reducing the cost on the health care system.

“Inter-ministerial co-operation: Developmental disabilities do not start when a person reaches adulthood, yet currently, the developmental services system only serves people 18 years of age and older. Developmental disabilities are generally recognized before the age of 2. Supports and services must be ongoing from the time of diagnosis to the end of life; therefore, there must be inter-ministerial co-operation to provide for seamless services and supports. It is ludicrous for people to lose services and supports when they turn 18 simply because it falls to another ministry. Disability affects all aspects of one’s life, and as such, supports and services must be available to assist with life.

“It is time to stop studying what it is that people need and to start providing the supports and services necessary to enable a full life in the community, no matter what those may be, whether it be personal care, health care, physical and/or occupational therapy, housing, employment, mental health supports, community participation supports, transportation, issues with regard to the justice system and the legal system etc.

“The simulation was an important part of my presentation. It was my hope that you would better understand my life and why I need someone to help me with all parts of my life. I must trust those who help me to keep me healthy and safe. That is why it is really important that I choose those who support me. Choice in life is very important. Everyone must have the same opportunity to be a part of their community. Please make sure no one is left behind.

“If you have any questions, please ask the member sitting near you to read out what you silently say using the communication board supplied to you for at least one question. Thank you.”

The Chair (Mrs. Laura Albanese): Thank you for providing us an insight into Bill’s life.

We have two and a half minutes each, and it starts with the NDP, so Miss Taylor or maybe Ms. DiNovo.

Ms. Cheri DiNovo: Joyce and Bill, thank you so much for your presentations. Joyce, thank you for your advocacy; that goes beyond this committee, and we probably all had experience with that advocacy over the months and years.

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Just a question: I think we’ve heard from a number of families about individualized funding and individualized plans, and that the system is broken. I’m starting from there. My question, I guess, is for those families. Bill and Joyce, you’re very lucky people to have each other. You’re very lucky, all of you, to exist as a family.

There are, of course, those that aren’t as lucky. They don’t have family, so we are always going to need places for those folks too. I just wonder if you could speak a little bit about that, because that segues into some of the other presentations from Community Living about the cuts to funding for beds etc., so if you could talk about that.

Ms. Joyce Balaz: Absolutely. One of the things that we do like to let people know is that only about 30% of the population wants to have individualized funding, so we will never destabilize the system. The system still needs to be there. All we're asking is if the payment transfer agencies that are not as progressive as some of the ones that do provide the individualized funding and supports could see their way to making some changes so that there are not so many congregate living situations. I'm sure that, if you take a look, a lot of the people who are living in group homes were never asked if those are the people they want to live with.

The Chair (Mrs. Laura Albanese): Is it Ms. Hunter or Ms. Wong? Okay. Ms. Wong.

Interjections.

The Chair (Mrs. Laura Albanese): Oh, okay. I'm trying to understand which one is going to speak.

Ms. Soo Wong: She's pointing and I'm trying to speak. "Hello. I love—a great presentation. We need help to try to make the system better. Thank you."

Ms. Joyce Balaz: That just gives you an example of how difficult it is to communicate in a different way. Thank you for being brave to do that.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Jones, do you have any comments?

Ms. Sylvia Jones: Yes. Thank you, Bill, Joyce and Arn. My question is actually more of a comment about the challenges that we are now seeing in the system as a result of Bill 77 and that transformation, because some of us were involved in that process.

I'm pleased that you talked about the need for the individualized planning. I think that that's a step that would have helped a lot of families and a lot of individuals. We missed an opportunity there, but maybe we'll get it right this time.

You mentioned that only about 30% of individuals are looking for individualized funding. Do you find, in your experience as an advocate, that that relates more to the stage in life—that we all experience different needs, desires and motivations as we go through—or is it just that 30% is the average?

Ms. Joyce Balaz: I don't think it really depends on age, demographics or stage of life. I think it depends on the advocacy of the family. I think it really depends on what kind of supports the individual has. If there is a support circle in place, those people are probably more likely to want to have individualized funding, because they have supports behind them. Does that help?

Ms. Sylvia Jones: Yes, absolutely. It's the opportunity, essentially.

Ms. Joyce Balaz: Right.

The Chair (Mrs. Laura Albanese): That makes sense. Thank you.

Thank you very much, not only for being here and for presenting to us but for giving us the opportunity to really have an insight, as I said before, into what Bill's life is like, and for all the work that you're doing. We'll do our best to get it right.

Ms. Joyce Balaz: Thank you, and thank you for all being so brave to sit through that piece, because it's not easy. Thank you.

The Chair (Mrs. Laura Albanese): Yes?

Mrs. Christine Elliott: If I might, while we're waiting for the next presenter to come forward—

Ms. Joyce Balaz: Can I just mention that one of Bill's accomplishments is that he was an Olympic torch bearer? Should anybody wish to hold the torch after, one of the things he likes to do is share that with people.

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

Mrs. Christine Elliott: Madam Chair, one of the issues that came up in Ms. Balaz's presentation was the communication about hiring a support worker that came from the ministry. I'm wondering if we could ask research to get a copy of that pamphlet or presentation and also to get clarification from the ministry with respect to the intention behind it.

The Chair (Mrs. Laura Albanese): That's very good. Yes, we will ask for that.

CROSSING ALL BRIDGES LEARNING CENTRE

The Chair (Mrs. Laura Albanese): We'll now ask the Crossing All Bridges Learning Centre to come forward. Good afternoon, and welcome.

Ms. Debbie Brown: Thank you for having us.

The Chair (Mrs. Laura Albanese): You may start at any time. Please state your name and your title before you begin your presentation so that we can record those in our Hansard proceedings.

I believe you know you have up to 20 minutes for your presentation. Should it be shorter, we'll try to divide the time if there are any questions.

Ms. Debbie Brown: Thank you. My name is Debbie Brown. I'm executive director of Crossing All Bridges Learning Centre. I am one of the founding mothers of Crossing All Bridges. I have a daughter who is autistic, and she's 32 years old.

Ms. Nancy Gowing: I'm Nancy Gowing. I'm the board treasurer. I'm one of the founding mothers also. I have a son, Scott, who is 31 years old, and he has Down syndrome.

Crossing All Bridges Learning Centre would like to take this opportunity to thank the select committee for taking a major role in trying to improve the quality of life for people living with a developmental challenge.

Crossing All Bridges was founded by four mothers, two of which you see today, who were very concerned about the future of their adult sons and daughters, who were getting ready to graduate from the high school system. That was 11 years ago.

In looking at the options available at the time, it was discovered that there were few choices and opportunities in our community to provide purpose and meaning to their day. We believed that our developmentally chal-

lenged adults should have the same options as our other sons and daughters.

In our search to fill a gap in opportunities, we looked to what made our sons and daughters happy and what they felt was important for their life plan. They believed that keeping friendships with their peers is very important. They wanted to continue to learn so they could contribute to their community, and they wanted opportunities to be available to them. Crossing All Bridges opened in 2003 to fill these needs.

We are a not-for-profit registered charity that operates on a tuition basis. Tuition fees represent 54% of our revenue. The rest is raised by funds from grants, fundraising and donations. Crossing All Bridges does not directly receive government funding, but we have searched out partnerships with the federal programs—the jobs creation program and Canada Summer Jobs—and Employment Ontario.

We currently service 52 people with developmental challenges, of which many have dual issues. The age range of our students is 18 to 58 years of age. Over our 11 years, we have serviced almost 100 individuals. We have a staff of seven full-time employees, connections with Mohawk College, Wilfrid Laurier University, Medix school and local high schools where we provide co-op student placements. Crossing All Bridges has several volunteers who contribute approximately 3,000 hours yearly.

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Our students come from a service radius of 60 kilometres. Our mission: provide dynamic programs and opportunities to maximize the individual potential of adults with intellectual challenges. Our daily offered programs continue to evolve to meet the needs of the students. In the beginning, we were perceived to be a post-secondary option for students leaving high school. Many of Crossing All Bridges students watched their brothers and sisters go off to college or university, so they wanted the same option.

To date, Crossing All Bridges Learning Centre has been a model for several other communities in the province of Ontario. We have had North Bay, Kingston, Windsor, Guelph, Hamilton and Amherstburg visit our site. Three of these now offer similar programs in their communities. Recently, we had staff members from Yarmouth Life Skills for Disabled Adults from Nova Scotia come and visit our model.

Ms. Debbie Brown: We are at a stage in our development where many of our students have been with us since we opened our doors. Crossing All Bridges is investigating and developing social enterprise as a viable employment option for adults with intellectual disabilities. In our 11 years of experience, only 7% who participate in our day programming have been able to successfully transition into and maintain part-time employment at local businesses, using a variety of the supports currently available in our region. CAB would like to see that number increase.

This is where social enterprise comes in. Social enterprise is simply a newly branded term for the ways in

which non-profits and charitable organizations have been making money through business ventures. As a business model, social enterprises often have a dual or triple purpose that involves generating income, delivering an organization's mission or meeting social and/or environmental aims. CAB is primarily interested in considering social enterprise as a model that would generate stable employment and income for the individuals with disabilities who face barriers in attaining and maintaining employment.

In a perfect world, there would be no need for social enterprise. However, the statistics that CAB has gathered suggest that some individuals are not able to transition into mainstream employment. Social enterprise provides another option for individuals who are not able to successfully transition into mainstream employment with non-disabled individuals.

This initiative strengthens CAB's organizational capacity and encourages it to further meet its mission to provide continual, meaningful opportunities for individuals with intellectual disabilities. Currently, CAB is servicing individuals between the ages of 18 and 58 because there are few opportunities provided for adults living with intellectual disabilities. Social enterprise would provide another avenue of choice, enabling these individuals to meet their life goals. CAB requests that support be made available for social enterprise as a distinct option for employment supports, especially to start-ups beyond the major urban centres in this province. With the government's acknowledgement and support of social enterprise, CAB and other organizations across the province can help more adults to succeed in employment.

Crossing All Bridges Learning Centre recently hired a full-time person to research social enterprise to begin the process to address the employment needs for the people faced with developmental challenges who live in the Brantford and surrounding areas. We are currently writing grants for funding to support the feasibility study, followed by a business plan and move into start-up for two social enterprises.

Employment can be exciting for young people just leaving the high school system, especially so for those who have had training or co-op experience while attending high school. It appears that some special education students have had success with co-op programs while many in the segregated special education classrooms have not had employment options. Special education students who have not had any training or co-operative employment opportunities would benefit from the ODSP Employment Supports program, but families are not educated or informed of the services offered by the Ontario government. More communication and knowledge is needed to further this option. High school transitional plans should be inclusive of all options for students and their families.

The government of Ontario could play a more active role in the social enterprise opportunities for people with developmental challenges. Pots of funding should be available for calls of proposals.

Crossing All Bridges made recent calls around the Brantford area to inquire about employment training opportunities for adults with developmental disabilities. We found very little that pertains specifically for adults with developmental challenges. We are here today to discuss our model and the positive impact we have had for the people we service and their families, along with the risks that face us going forward. We are here to talk about the future for adults with developmental challenges who have completed their secondary education and now live within the community.

Ms. Nancy Gowing: Here are some of the challenges that we are currently facing.

Tuition fees: Crossing All Bridges operates on a fee for service. The students of Crossing All Bridges have been utilizing their Passport funding, formerly known as Special Services at Home, as a means to meet the tuition costs. Since the conception of Crossing All Bridges, the organization has endeavoured to keep the fees as affordable to students as possible. However, Crossing All Bridges is now looking at heavy increases to support the growing costs of operating the organization. In the beginning, the fee structure was \$25 per day, but over the last year the rate has been increased to \$30 per day. The current fee structure breaks down to cost each student \$3.75 per hour for an eight-hour day's service.

Based on Crossing All Bridges' fiscal year end at the end of July 2013, the true operational cost of the program is close to \$54 per day. Through our grant writing, fundraising and donations received, Crossing All Bridges subsidizes the tuition costs to balance out the shortfall on tuition. This has potential risk factors for the organization as it continues to grow, putting straining workloads on all the efforts of the organization to subsidize the program.

In the beginning development of the organization, it was hoped that tuition would cover the basic operational costs and other revenue generated through fundraising would eventually go to costs associated with maintenance and the purchase of a facility. We've grown and we've expanded. Now we need more space. We've already fundraised to our maximum. Ideally, to continue, we need to increase tuition, but if we do so we know that families will cut back because they can't afford it. The lack of appropriate financial support to families is crippling our organization.

We will see many students reducing the number of days serviced. Again, it would result in less service for people with developmental challenges, when our goal is to increase services. We're in a Catch-22. There are potential new students who would benefit greatly from the program but face the financial barrier of the tuition fees due to a lack of sufficient funding. Students who started 11 years ago receive the same funding levels today, yet the cost of living has increased steadily every year, requiring families to sacrifice valuable service for their sons and daughters. Some students attending Crossing All Bridges have even had their funds decreased. Five of our students were fortunate to receive Passport funding when it was introduced.

Families are faced with daunting decisions to come up with dollars to continue to pay the fees, especially the families that now live on their Canada pension or retirement funds. As family caregivers age and continue to provide care for their loved one at home, they are finding that the costs to keep them are increasing while their sources of income are decreasing. Many families do not plan their retirement incomes to include the cost of care for a developmentally challenged dependent. An increase in Passport dollars would benefit many people living with developmental challenges.

Our staffing: Crossing All Bridges understands that our best asset to a success is through the people we hire. Over the past 11 years we have found that well-educated and trained employees bring a wealth of knowledge, understanding and passion to their job. The students respond to staff members faster and seem to retain what they have learned. With the overflow of young teachers who have not been successful at getting positions in local school boards, Crossing All Bridges has been privileged to have their talents in our classrooms. The challenge Crossing All Bridges is having is keeping them. We can't compete with teachers' salaries and the salaries of transfer agencies with government funding. We're not able to provide benefits, so we're only able to keep our teachers for a limited time until they can find better jobs elsewhere. They've all got families, debts and things to pay. CABLC feels we do not have a level playing field for offering wages to our employees unless the increase in tuition fees is addressed.

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Families that receive government-funded programs are not aware of the cost of their government-funded programs, such as literacy programs or respite. They can't compare a fee-for-service program and a government-funded service that they don't really know the actual cost of, so they're not really sure they're getting the most bang for their buck. The introduction of Passport funding has introduced cost for service, but families are unaware of fair market rates, so to them government-operated programs are free. Families have not had to manage money for service in the past. Passport is a new concept that is taking some time for families to adjust to. Again, they're not really sure what the cost of government-funded programs is. They know that our program costs \$30 a day, and it seems like a lot. An investment in more dollars for Passport would assist with organizations being able to manage the costs of service.

Marketing and training: Crossing All Bridges has made many attempts to reach local high schools in both the public and Catholic systems in regard to transitional planning. There have been small gains in the last couple of years where we have finally been allowed to share our information with graduating students and have been asked to make presentations to graduating students transitioning into the community. More effort on transitional plans by high schools would reduce the anxiety for families and the student moving into life after school.

Being invited to attend community developmental round tables would provide a means for all organizations

that provide services to adults with developmental challenges to be kept informed of current issues. It may also foster partnerships for sharing services. Currently only government-funded agencies sit at round table meetings.

Crossing All Bridges would welcome the opportunity to have members of the government of Ontario come and witness what we offer the adults in Brantford and surrounding areas and show that there is great value in every dollar invested in our program. This could be considered an alternative to college or university for the people we service, while at the same time working to engage adults with developmental challenges in social enterprise employment opportunities.

The need to provide social, recreational and inclusive opportunities for children, youth and adults: Crossing All Bridges believes heavily in this. Our experience is that peer friendships are extremely important for the wellness of all people, regardless of age, race and diagnoses. We all value our peers for friendship and support. We have witnessed a friendship between two Down's syndrome young adults at our learning centre that turned into romance and then to marriage. A young Down's syndrome woman who stopped talking for many years now tries to sing and speak. A 40-year-old Down's syndrome woman, after graduating from high school, stayed at home with her mom for 20 years and became withdrawn, shy and timid, but once registered with the program, she learned to cook, made friends and eventually became the caregiver for her aging mom of 94. This vulnerable population is no different than anyone else. They need social stimulation and they need to feel a part of a group and community to stay healthy. The government can choose to support organizations such as ours.

The elementary and secondary school education needs of children and youth: Students need tools and training to do the job. Classrooms designed for developmentally challenged people require teachers that understand the needs of the students. They need teachers who are committed to keeping informed of current information on the spectrum of developmental findings. Constant attention needs to be given to technology that can assist developmentally challenged people to learn. Schools need to be equipped with these tools, and teachers need to be trained on their operations so students can benefit. In the years that my daughter attended high school, her classroom was filled with whatever was left over from all the department needs, so I highly believe in investing heavily into the current technology that's available.

Teachers who are committed to educating people with disabilities: The special educational hiring policies need to be specific so teachers entering the teaching profession understand that it's just not a backdoor entry system into the teaching profession nor is it an easy last few years to retirement. Teaching a special-ed student should carry a full university course. We could follow cases such as medical doctors and how they go through their training.

The need for a range of available and affordable housing options for youth and adults: Crossing All

Bridges is aware there are needs for group home living models, supported living models and independent living, and that it would be daunting to consider changing the current funding system. We are aware that the government of Ontario has built considerations for innovative models that are based on good business plans with sustainable futures. Living models are as diverse as people's needs and circumstances. In CABLC's strategic plan, completed in 2013, the establishment of a living model solution was considered by virtually all board members to be the initiative that would have the most benefit for members and their families. Wait-lists for the Brantford area are on a crisis basis only, and by that, I mean one of us would die and then my daughter might reach service. She has been on the wait-list since she was 13 years old. We've never been called.

Our health is shaped by how income and wealth is distributed, whether or not we are employed and, if so, the working conditions we experience. Furthermore, our well-being is also determined by the health and social services we receive and our ability to obtain quality education, food and housing, among other factors. These living conditions are often imposed upon us by the quality of the communities, housing situations, our work settings, health and social service agencies and the educational institutions with which we interact.

The Canada Mortgage and Housing Corp. completed a study between 2004 and 2006 that found that family members are the main source of support for almost 80% of adults with developmental challenges. I would assume that's much higher now. They found that individuals with developmental challenges are living longer and that the demand for housing would double over the next 25 years. The study reported a significant gap between the housing needed and the housing available. When families are forced to make the decision to place their loved one in a home, many families are presented with options that do not support the lifestyles of choice. This has forced many families to continue to care for their loved one in their home setting, leaving caregivers the responsibilities well into their 80s.

The Chair (Mrs. Laura Albanese): I have to advise you that you have reached the 20-minute mark, but if you want to make some concluding remarks, please go ahead.

Ms. Debbie Brown: We just hope that you consider our model. Thank you.

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

MS. DARLENE SMITH

The Chair (Mrs. Laura Albanese): Our next presenter is Darlene Smith. Our Clerk just indicated that she's in the hallway, so she should be here in a second or two. I had no idea she wasn't present; otherwise we could have heard a minute or two longer from Crossing All Bridges Learning Centre. Here they come.

Darlene, please come forward. Thank you for being with us this afternoon. As you settle in, I just want you to

know you have up to 20 minutes for your presentation. If you take less than that, then we'll have time for some questions; if not, we'll be very pleased to hear you.

Ms. Darlene Smith: Thank you.

The Chair (Mrs. Laura Albanese): Go ahead. Catch your breath. If you need some water, go ahead.

Ms. Darlene Smith: Yes, I might just take a little sip before I start because my throat is dry.

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My name is Darlene. Thank you for allowing me to come and speak with you today. I am here today to share with you our personal story of raising a child with fetal alcohol spectrum disorder and some of our suggestions that would help other families in Ontario who are also raising children with FASD.

I am an early childhood educator and a home-schooling mom. I have worked in the field with children for the past 24 years, both in formal child care settings and most currently in home child care. In this time, I have worked with a lot of children. Probably hundreds have been through my care. I have seen many children over the years diagnosed with ADHD, ADD, autism and various other developmental disabilities. I have the skills to work effectively with both the children and their families, giving them skills to help them in their journey as families who are raising children with special needs.

With my background, becoming a foster home for newborn babies was natural for us. Helping the little ones who come into this world drug-addicted and alcohol-affected was both challenging and rewarding.

We were blessed to be able to adopt one of our foster babies, and she is now six and a half years old. She is our life, a joy, and full of enthusiasm. What I was not prepared for was the challenge of parenting this little dolly. I figured with my background, my skills, my personality and an amazing, supportive family, this would be no problem. I've worked with lots of children with special needs.

Up until she was five, I was using all my skills to help her as she struggled with social interactions, hyperactivity, impulsivity and emotional outbursts. Nothing I tried was working. My skills were useless. I was starting to feel like a failure to this child. What was I doing wrong? Society and those watching, I'm sure, were thinking the same things: "Look at that ECE mom. She can't even parent her own little one."

In January of just last year, I was Googling, trying to find out what possibly could be happening for our little one. We knew that her birth mother had made some bad choices when she was pregnant, but I guess we were naive. I then came across an online assessment for FASD. I printed it and filled it out, and my heart sank. I answered yes to every question. The light bulb went on.

Trying to find out how to have her diagnosed was my next challenge. Off we went to the pediatrician, who listened to our concerns, then referred us to a local agency, knowing that there was a new diagnostic clinic in our city. We were turned down and told we had to exhaust all other resources in the city before this agency would take her case. Now where do we turn?

I called another family and children's centre here in London in February of last year when I was finally hitting a crisis point, not knowing what to do. Who do I turn to for support? We finally had an appointment with an intake team. They gave us behaviour techniques that I had already tried and knew would not work for her. Cause and effect, reward charts and stickers are all things I had tried in the past, but because of her organic brain damage, these techniques do not work.

Back to Google I went for how to get a proper diagnosis of FASD in Ontario. I did find a list of clinics, but with most of them you had to live in the region where the clinic was offered. The waiting list in London was much too long, as it is a pilot project.

There was one exception, and that was a clinic being run out of St. Michael's Hospital in Toronto. I made the call and was told that if we had a pediatrician fax a referral, we could be seen as early as June of last year: 12 weeks. Wow. I thought that was amazing. So we got the referral and the appointment booked.

Our daughter does not do well in the car for any length of time, so we chose to take the train to Toronto. We had two appointments, one in June and one in July, two train trips, two days off of work, and we came home with a diagnosis of alcohol-related neuro defect.

FASD is the umbrella term, and under that are levels on the spectrum based on facial features alone. We all assume that if there are no facial features, it cannot be FASD. Did you know that the facial features that we commonly associate with fetal alcohol spectrum disorder are only affected in the first 21 days in utero? After that, any drinking that happens causes all this brain damage to these little ones without the facial features. So now we have a population of children living in our communities who look very, very normal but have a very serious brain injury. It is completely invisible.

So now where do we turn? There are resources for autism, for children with physical or intellectual disabilities, but at this point, FASD is not recognized by most of these agencies, and therefore we're not able to tap into their resources. This goes for children, youth and adults in our communities who are living with this brain damage.

We have navigated our way, trying to learn as much as we can through online resources, webinars, and most importantly, I have connected with adults who are successfully living with FASD. These are the people who have lived it, and I have learned so much from them, more than any book, article or video could ever teach me. I am urging you, as a committee, to find these people in our communities and connect with them. They are the ones who can help us figure out the services that they need.

Now my family is on this journey, a very lonely journey at times. No one really understands what our day-to-day life is like. They see a beautiful, blonde, blue-eyed little girl who is full of life. We see the same, but what others don't see is the constant, behind-the-scenes managing of her behaviour, emotions, sensory dysfunction and social interactions. Our lives revolve around

supporting our daughter 24 hours a day, seven days a week, as we are home-schooling her.

We are her external brain. The cognitive impairments in children and adults with FASD can cause them to have poor memory, lack of impulse control, poor judgment, and difficulty with cause-and-effect reasoning. This means they often need support from others to help them think through their decisions, behaviours and consequences, as well as help them remember their routine, schedule, and how to complete tasks assigned to them. In other words, those living with FASD need a trusted person to act as their external brain 24/7 through their complete lifespan.

As a family in this situation, finding respite and support is almost non-existent in our communities in Ontario. Wait-lists of upwards of three years—and even then, getting the right fit for our child is a tough one. People are not educated about FASD to really understand how to work with them.

I am urging you to step up to the plate to educate our communities, medical teams, professionals and even parents about the horrible effects of drinking during pregnancy. No amount is safe. It sickens me to read articles as recently as last week in our local paper stating that drinking 15 drinks in a pregnancy is okay. I am telling you, as a parent raising a child who is affected by alcohol, that this is unacceptable. The labelling of alcohol bottles, advertisements promoting zero drinking, commercials—anything that gets the word out there that drinking in pregnancy is damaging these babies in utero. It is the most preventable disability in our communities.

I am also asking that this committee take a look at the diagnostics for FASD. We need these clinics in our communities to receive full funding, not just pilot projects to see if they can stay. They need full funding now so they can carry out this very important role.

We need to educate our medical professionals, teachers, social workers and anyone working with these children. Just because there are no facial features does not mean a child is not suffering from FASD. FASD needs to be added to all the warning sign checklists and diagnostic tools. ADHD is the first thing people see in our little one; when they see her, it's what they think she has. Yes, she's high energy and can appear to be very defiant, but the impulsivity, hyperactivity and defiance are symptoms of her FASD, and are symptoms that signify that she is not able to cope without her external brain.

She does not process our words. Her auditory processing is impaired and therefore she hears one out of every four words we speak. So this speech, to her, would be: "I'm ... you ... go ... now"; that was: "I'm asking you to go to the bathroom now." She hears one in every four words, so communicating with these children, these adults, is very specific on how we can communicate with them.

Her concept of time is pretty much non-existent. Five minutes, one hour, one day, one week, are all very abstract to her, no matter how much I've worked with

her, and therefore make our interactions quite difficult. Her short-term memory is affected. Each day, the same teachable moments, the same things—she does not remember from day to day. That's why she needs her external brain. For these reasons, we have chosen to home-school her, in order to give her an environment that she can be successful in, but not all families are as blessed and lucky to offer that environment.

I have heard from so many parents in our FASD support group that trying to get the proper support in school is not possible. There is not enough of an understanding of FASD and how it impacts these children from day to day. There are very specific strategies that can be used to help them, but teachers and school systems are not aware and/or are not able to provide the time and resources needed for these children. Now is the time to invest in them. Now is the time to put money into early diagnosis and keep these clinics open so that they can get properly diagnosed, making sure they are in homes that are trained to help them be successful, in school programs that understand and support the primary disabilities of FASD, and in communities that will support them 100% just like any other child who has a disability. By having these things in place, secondary disabilities like frustration, acting out, irritability, mental health disorders, homelessness, alcohol and drug addictions, disrupted school experiences, trouble with the law, incarceration, inappropriate sexual behaviour, problems with employment and dependent living can be prevented, if they are given supports and external brains to help them.

1520

Go to the adults who are living with FASD. They are our best teachers and educators on this. Find out what life has been like. Most of them have been through the trenches because they were never diagnosed when they were young. They have dealt with drug addiction and alcohol addiction but have come through and got proper diagnoses, finally. Some of them are 40, and the light bulb went on for them, and they are now able to get those supports in place. How sad that it took that long. We are in a time when we can find these supports early and get these children diagnosed.

These children as well as adults in our communities really do have a serious disability that none of us can see, and it needs to be acknowledged. There are many children in foster care and adoptive homes, which do break down because of these behaviours, and the parents just don't know what to do with them, and adults living in our communities who are either misdiagnosed or diagnosed and not being given proper supports to help them live a successful life. It's time for agencies and government to take a hard look at what we can change to help make this invisible group of people in our communities live supported and successful lives.

A child will not grow out of fetal alcohol spectrum disorder. However, early diagnosis and intensive intervention can make an enormous difference in the lifetime prognosis.

Do I have a few minutes?

The Chair (Mrs. Laura Albanese): Yes, you do.

Ms. Darlene Smith: Okay. I'd like to introduce to you Emma.

"My name is Emma, and I am six years old. Can you believe that? Six already.

"Don't you think I'm cute? On the outside, I looked just like any other baby: tiny, sweet, and oh, so snuggly. I was adopted when I was a baby because my birth mom was too sick to take care of me. She wanted me to have a loving home, and I'm so glad I was adopted. I have the best mom, dad and big brother.

"I am loving life. We are a home-schooling family, which means I get to spend a lot of time with my family doing really cool things. We have a home-school group, too, that we do field trips with. It is a lot of fun.

"I love to dance and sing. You can usually hear me humming and singing even when I'm playing or doing school work. I love to colour, paint and make amazing creative messes.

"But there's something about me that you don't know. When my birth mom was pregnant with me, she made some not-so-great choices. She didn't take very good care of herself and did some things that mommies are not supposed to do when they are pregnant. Because of these choices, I have something called FASD; you pronounce it just the way the letters are said. That stands for fetal alcohol spectrum disorder. It sounds pretty confusing, but I'm going to tell you what it means.

"I know I look just like any other little six-year-old girl, but there's something about me on the inside that you can't see: how my brain was damaged before birth by my birth mom drinking alcohol. You can't see the tangled connections and all the little empty spaces in my brain. Unless you can see inside my head, you can't see that I have FASD. It is an invisible disability.

"But I do know what you can see, and that is how silly I act when I am out in public, like visiting with family or friends, at church or at the mall. You can see that I have a hard time controlling myself and I appear to be misbehaving. You may notice when I get out of control and lose it, and that happens when things get to be too much for me to handle. Some people think that my behaviour is a problem and I'm just being a bad kid. The truth is I have FASD. The doctors told me that what that means is my brain damage won't get any worse, but it won't get any better either; it's forever. I need a great team of people in my life to help me be the best that I can be.

"You can always hear me because I talk a lot to anybody who will listen. When you ask me a question, an answer pops out, whether it's true or not. I have a really hard time understanding what others are telling me. I really need you to help me and to be super patient with me when I am like this. I'm not doing it to be rude; I usually do it when I feel overwhelmed and cannot handle the situation.

"There are some things you can do to help me: take my hand, talk with me. If I interrupt you, please do not get frustrated and walk away; gently tell me you have

something really neat to tell me. I love hearing funny stories. If you distract me with something new, I can usually pull myself together.

"Because of my FASD, I can't remember a lot of things from day to day. I know my mom and dad say it feels like every day we go over the same things. They probably think I should learn from my mistakes, but I can't. It's not that I don't know the rules; I do. It's not that I don't understand consequences; I do. I just can't make myself do what I know I should do. I don't know why; I just can't. That is the part of the brain that is damaged, the part that links the left and the right side together. For me it is so frustrating because I so badly want to make good choices, but when I feel overwhelmed, I can't.

"Everybody can see that I'm friendly and affectionate. I love people and I love making them smile, but nobody can actually see how lonely I really am. I have lots of friends, but they never come over or call for play dates. I don't have a best friend, but I pretend like I do. If someone just smiles at me, they are my friend. I have a hard time understanding how to behave in social situations like play dates or when I bump into people I know. If I see you, I get excited really quickly. Please hug me, love me and be happy to see me too. I need you to be super patient and kind in order to make me feel safe.

"I have a very free spirit. I do not understand my personal safety. If my parents let me, I would just go off and explore the world without them. They know that is not a safe choice for me and they need to supervise me at all times. Please do not be hard on them. They know me best and need to watch out for me because I will make silly, unsafe choices. The job they've been given is a huge job but I'm so thankful they're patient with me. It's going to help me a lot to have the support of family.

"I sometimes have trouble remembering things. I've heard my mom call me Dory, like in Finding Nemo. She has short-term memory loss. Even when people tell me things over and over, I still forget. I have a problem processing information, especially when it's busy around me, and then it may look like I'm being a bad kid again. This is where I need you to help me too. I need people to give me reminders and guide me through some of the busy times.

"My parents and brother have a pretty hard job. They need to be my coaches in life and need to be with me wherever we are. I do not understand safety and would just run if left to do that. They are going to take turns helping me when we are out, helping me to stay in control. They're not being over-protective; they're being supportive and helpful to me. I do not try to make people mad. I don't want to be seen as being bad. I just need help to interact and behave in different situations. Please encourage them, as they have been given this lifelong task of helping me. I am so thankful to have them.

"I want to be appreciated for the good things I do and who I am. Do you notice those—my smile, my friendly personality and my helpful nature, the compliments I give out graciously, my singing, my dancing and my love

for everyone? I just want to be accepted and understood. I hope that you knowing about FASD will help you know more about who I am. I need you to care even when I act like I don't. I want to be respected and I need you to be a good role model for me so I can learn to be respectful too. I need lots of love and patience as I grow, so if you see me having a hard time, please help by being with me instead of walking away. Hold my hand, sing with me, laugh with me, and let's make great memories."

We put this book together for family and friends and those who come in contact with Emma to have a better understanding. Like I say, it's completely invisible, and she's one of thousands. If you saw her in here, you'd think, "She's a little out of control." She's not; she just needs help to be in control, and there are thousands of them. This little one is blessed; we're able to do this for her. But there are families and supports that are not in place, and then we have adoption breakdowns and we've got children suffering and adults going into their adult life.

So keep those clinics open and fund them completely, please. It will pay off.

Any questions?

The Chair (Mrs. Laura Albanese): Thank you. Unfortunately, we're out of time for questions, but it was so much more interesting to be introduced to Emma and to hear her story, and you read through that booklet. It's really amazing what you are doing. Thank you for presenting to us and for making us aware of this. We really, truly appreciate it.

Mr. Mitzie Hunter: A very quick question: Your book is just for your personal family and friends, or is it—

Ms. Darlene Smith: What I can do—is there a way I can email this to your committee?

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

Ms. Darlene Smith: Okay. I can email you, because I just want to take out a couple of her pictures because of her face at the front. I shall email you an electronic copy of it.

The Chair (Mrs. Laura Albanese): Yes, you could email our Clerk, Trevor Day.

Ms. Darlene Smith: Okay, perfect. You can purchase them for \$150 each, just to add to your collection. We'll raise money for the clinics.

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

COMMUNITY LIVING LONDON

The Chair (Mrs. Laura Albanese): We now call on Community Living London to come forward. We have three people who are moving up. Good afternoon; welcome. We look forward to your presentation. If you've been sitting in the back, you know you'll have up to 20 minutes to do that. Please introduce yourselves, starting with your names and your titles. Thank you.

1530

Mr. Jim Hewett: Thank you very much for inviting us today. My name is Jim Hewett. I'm the chair of

Community Living London's advocacy committee, and I'm a member of the CLL board of directors. I'm also the parent of Kevin, who was born with Down's syndrome. He is in the room today.

I'd also like to introduce two other members here today. Murray Hamilton, on my right, is also a member of Community Living London's advocacy committee, and Michelle Palmer is our executive director.

We commend the select committee for its commitment to examine the urgent need for a comprehensive developmental services strategy to address the needs of children, youth and adults in Ontario with an intellectual disability. We look forward to contributing to the development of a comprehensive plan for the developmental services sector, and we're here on behalf of people with an intellectual disability and their families.

As you are aware, there are over 19,000 people with an intellectual disability waiting for service in Ontario. The developmental services sector is in a state of crisis. This sector has been underfunded for far too long, and this has created the critical situations that you have heard about from families who are facing a lack of residential options, limited community participation opportunities after graduation, limited resources to secure employment for long-term success, lack of transitional supports from childhood to adulthood, and aging parents who are no longer able to care for family members who live with them. We could go on.

As you are aware, based on statistics from Developmental Services Ontario, South West Region, there are over 12,000 people in Ontario waiting for residential supports. In this region alone, London-Middlesex, we have over 300 waiting for group living supports and over 200 waiting for supported living arrangements. In London-Middlesex, there are over 190 waiting for in-home community participation supports and 150 waiting for social and recreational supports. As well, there are 100 waiting for employment training supports. In Ontario, people with an intellectual disability are 70% unemployed, even though 80% of people with an intellectual disability can and want to work competitively.

Today we will focus on solutions so that people with an intellectual disability and their families will begin to receive the supports and services needed to meet the significant challenges that they face.

We'll keep our presentation short to allow the maximum time for questions.

We would like to suggest the following five actions that would go a long way to resolving the issues confronting families and people with an intellectual disability.

Mr. Murray Hamilton: The first action that we would like to recommend is that the government formally recognize the legal rights of people with intellectual disabilities.

It is generally recognized that government has a responsibility to protect the rights of and to provide services to all its citizens. One of the values inherent in Canadian society is the belief that it is important to

collectively care for people who are unable to care for themselves and that elected politicians are expected to carry out the will of the Canadian people in this regard. A society is judged by how well it deals with its most vulnerable members.

We are asking that the select committee recommend to the government that it formally acknowledge its responsibilities to vulnerable citizens by amending the Ontarians with Disabilities Act, to grant them the legal right of access to the services that they require.

De facto, these needs were recognized by the government of Ontario more than 170 years ago when they established facilities for people with intellectual disabilities in Orillia, Ontario. Over a hundred years later, they recognized that facilities were not the place for people to live, and co-operated with community agencies and families to create a broad network of support services for people with disabilities.

Regrettably, in the last 15 or 20 years, the government seems to have forgotten its responsibility to citizens living in our community. Our community network is virtually stalled.

We urge the government to rebuild this partnership between the government, families and community agencies, to create a service system that responds in a timely manner to the particular needs of individuals and families.

Secondly, we're recommending the development of a multi-year plan for the developmental sector, to develop a long-term plan to address all of the service needs that have been identified throughout the course of your hearings. This plan would necessarily require a commitment of hundreds of millions of dollars over the next decade to meet the critical needs of people for residential support, day service options, in-home support and employment.

As an immediate priority, we're supporting the recommendation from the initial report entitled Ending the Wait that the critical needs of adults whose parental caregivers are over the age of 70 be addressed within the next 12 months. Now this government has had a good track record in developing multi-year plans to address very serious and long-term issues. Between 1982 and 2010, there were a number of multi-year plans in which governments and agencies and families worked together to close facilities. This was an initiative that took 40 years. The problems confronting us today are just as great, if not greater. So we recommend that the government take the long view here and develop a number of multi-year plans to address these issues over time.

Continuity of supports from birth to death: to reinstate immediately the services to young adults who reach the age of 18 which were recently arbitrarily suspended, thus leaving families without the necessary resources upon which they have become dependent for in-home support and respite care. This decision reflects the lack of coordination of services between the Ministry of Children and Youth Services and the Ministry of Community and Social Services. We recommend a reversion to the

time when a single ministry would be responsible for the provision of community support services for all people with intellectual disabilities from birth to death.

Our fourth point is fair compensation for workers. We applaud the fact that in recent years, the Ministry of Community and Social Services has participated in a human resource strategy that is focused on agency-based training requirements, core competencies and shared interests. However, in order to maintain a high standard of service, employees in this sector must be compensated fairly. The sector cannot have good services without skilled employees and positive employee relations. It is interesting to note that direct care professionals in this sector today are earning a similar wage to what government workers who performed the same duties earned 10 years ago. We recommend that the government commit itself to providing annual compensation consistent with increases to municipalities, school boards and hospitals—informally known as the MUSH sector.

Our final point is that we work to break the cycle of poverty for people with intellectual disabilities, as most people are living well below the poverty line as defined by LICO, the low income cut-off, now pegged at \$16,753 for a single person living in London, Ontario. It is not well understood that people with intellectual disabilities are dependent on their ODSP for all of their personal needs: for food, clothing, shelter and transportation. These allowances over the past 20 years have consistently lagged behind the rate of inflation. Currently, ODSP recipients have lost 18% of their purchasing power relative to inflation since 1995. Consistent with the recommendation of the social assistance review, we are recommending an immediate increase to ODSP income support to reach LICO levels and a commitment to link further ODSP allowances to the rate of inflation.

With respect to employment, we strongly encourage the government to develop strategies to increase employment for people with intellectual disabilities. We have provided a link in your package that will take you to a video that demonstrates the impact that strong relationships with business and the provision of relevant training for people has on long-term employment success for people with intellectual disabilities. We recommend that the first \$700 of earnings be exempt from clawbacks and, beyond that, ODSP benefits be reduced by only 50% of earned income, and that this exemption keep pace with inflation. The government must make sure that its most vulnerable citizens at least meet the LICO cut-off before reducing any further earned income.

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Mr. Jim Hewett: In closing, we wish to emphasize the government's responsibility to acknowledge the inherent rights of citizens with intellectual disabilities and to provide the necessary supports and services to enable these persons to live full and meaningful lives.

We want to acknowledge that this ministry has a track record of developing a series of successful multi-year plans over the three decades that resulted in the closure of all Ontario institutions. These plans were developed in

consultation with families, community agencies and government.

We would like to remind government that their responsibility for people with intellectual disabilities did not end with the closure, and encourage them to honour the commitment that was made during the closure of institutions by providing adequate funding for community service and support options.

We also strongly encourage the re-commitment to a multi-year planning process that consults broadly with families and agencies to achieve mutually determined goals.

Thank you. We're willing to take any questions.

The Chair (Mrs. Laura Albanese): Thank you, and we have about three minutes for each party for questions. We will start with the government side.

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you very much for your presentation.

The focus of our committee is to develop a comprehensive strategy that will provide the necessary supports for people with developmental disabilities across a lifetime and across ministries. You have put forward a number of very solid and well-thought-through recommendations. If you were to prioritize, what would you put as your most important recommendation for us to consider?

Mr. Jim Hewett: The very first thing is the wait-list. The wait-list has to be dealt with. There's no question about that. It's huge.

The second thing is funding for the sector. The sector has been underfunded for many, many years without the financial support of government to this sector. Working with the families, working with the local community and working with government together, we hope that we can move forward on this.

But those are just a couple of things. We've given you five things that we really are very strongly endorsing here. But the wait-list and the funding—they're critical. They're critical to do anything by any organization within this province.

Ms. Mitzie Hunter: One of the challenges that we're hearing from people presenting today and as we're listening through these hearings is the transition moments, in particular, transitioning from the services from the children's programs into adult services.

Mr. Jim Hewett: So from Special Services at Home to Passport funding—we call it "falling off the cliff." That's basically what it is.

Ms. Mitzie Hunter: And it could even be, just beyond that—I guess what I'm looking at, in terms of your experience over many decades working with people with disabilities, is, what are some of the things that we can do to strengthen the system and make that transition a much more successful one in the areas of employment, in the areas of community inclusion and some of the things that we're hearing?

Mr. Jim Hewett: Well, I think the first thing is they don't need to drop off the list once they turn 18. If there are supports in place for that individual, the individual

has been identified, then it should transition from Special Services at Home directly into Passport funding. That's one of the first things.

Then, when we get into the person leaving school, once again, they drop off another cliff, because the supports are no longer there. So we have to be able to transition from that school environment into either an employment environment, a community access program environment or some type of supports for the individual so that they can meet their goals in life.

Ms. Mitzie Hunter: Thank you.

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

Mr. Jack MacLaren: Your five ideas are great. I think here we all understand that everything kind of hits the wall, and the inevitable question is, "How do we pay for all this?" So I want to ask you on that part, because that's a question that we have to answer, or all of this is just academic exercising.

So do you have any idea—and that might be a tough one—how much money we would need to fix these five things, and how should we and where should we access that money? Would it be increase taxes, cut other programs, look for private money or what?

Mr. Murray Hamilton: It's very difficult for us to put a concrete number on it, but we feel that it's pretty simple for the ministry to be able to do that. They know currently how many people they're supporting; they know how many people are on the waiting list. Take the average cost of the persons that they are supporting today and add that number to the corresponding waiting list number. It is hundreds of millions of dollars. This problem has been allowed to languish now for 15 years.

Frankly, as we have said, we believe that these are legal rights; these are legal entitlements that people have. I believe the government has a responsibility, out of its tax base, to fund these services. The fact that they have not done so for 15 years just has made the problem more difficult, but it is not going to go away. As we have pointed out, there are people in their seventies and eighties looking after their disabled children. It is important that the government acknowledge that this is a role and then put a long-term plan in place to fix it.

Mr. Jack MacLaren: Well, I agree with you and I think most of us do acknowledge it's a problem. We've neglected this area for a long time, and the falling off the cliff is a classic example of a huge problem—aging parents etc. But at the same time, most of us also understand that the general population is kind of taxed out with hydro bills rising and taxes rising and property taxes rising. To raise taxes, as a straight answer, is not just a real happy solution either, because often you're taxing the same people we're talking about here today, plus everybody else as well.

Mr. Murray Hamilton: It's not for us to discuss how the government has spent its money over the last few years—

Mr. Jack MacLaren: That's too easy.

Mr. Murray Hamilton: It's not for us to discuss that. However, we know that money can be found when the government wants to do stuff. These are legal rights that people have. The government has to find this money. If it has to raise taxes to do it, so be it.

Mr. Jim Hewett: We need to make it very clear that there's a huge bubble brewing. All the adults and children being supported by parents at home right now are aging. You've got a huge baby boomer population that is supporting these individuals at home. They are between 50 and about 66 years of age. They're getting to the point where they can no longer do this. This bubble is going to break at some point in time, and it's going to break in the not-too-distant future.

Ms. Michelle Palmer: If I could just also talk a little bit about pre-planning, I think right now the response is governments reacting based on crisis. When families just can't do it anymore, then all of a sudden somebody becomes a priority.

Any kind of emergency plan costs more money. If we can do concrete plans with families in advance, then you can look at, for example—and this is not the only option; I want to be clear that we're supportive of family options, any options on the table. But if I have to plan for one person today, it's going to cost a lot more money, because that one person may still need 24-hour support. If they have three friends that they'd like to live with as well, four people supported together could cost the same amount. Right now it's a knee-jerk reaction based on crisis response, which costs more money.

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

Ms. Cheri DiNovo: That leads me to another question for research. We have questions where we haven't yet received a response from MCSS. They haven't given us wait-list numbers. You folk kindly have, but we haven't gotten that from MCSS.

Number two, we've asked for the number of people with developmental disabilities that are in long-term-care homes, in prisons and in hospitals. The reason we asked for those figures is that that's ridiculously expensive care, as you've said, that shouldn't be happening. What should be happening, of course, is the kind of care that you've advocated here. So again, I ask for these figures from MCSS or health or somebody. I mean, we just haven't got them, and without them it's hard to do our work.

The only other question I have for you is the DSO. You hadn't talked about that in your presentation. What's your experience of it?

Mr. Murray Hamilton: Well, our experience basically is that we have created a planning mechanism but there's no money to plan. So it's easy to get very angry at the DSO, and like everybody else, we are, but until such a time as this body has some money to actually create services, it has just become kind of a bureaucratic nightmare.

I would say that the one mandate they do have is to provide good, solid information; we're not getting it. We're not getting good waiting list information. We're

not getting any rolled-up information, as you have just said.

I just want to end up on one positive note. We've talked about how big this problem is, and it is huge. However, we do believe that at a certain point you are going to max out. We will reach the point where we can support all individuals with intellectual disabilities and the system will be self-sustaining.

1550

Unlike the Ministry of Health, which will never stop asking for money, this service sector, if everybody is served—we're at the point where the number of people who are dying is going to be equal to the number of people who are coming into that system. We're virtually there now, except that we've got this great bubble of people who aren't getting any service at all.

I think that when the government is doing its planning, sometimes they get nervous because they think this will never end. This will end if it's funded properly.

Ms. Michelle Palmer: Can I just jump in about the DSO? I just want to really stress that the problem in our sector was here before the DSO, and the problem will be here without the DSO. So I just want to clarify: The DSO is not the problem.

Ms. Cheri DiNovo: But it takes money to—

Ms. Michelle Palmer: Correct.

Mr. Jim Hewett: You were mentioning, too, the number of people who are in long-term care. Actually, in the Ministry of Health presentation, 4,500 residents in the province who have a developmental disability are currently living in long-term care.

I wouldn't look at the Ministry of Health as the solution to the problem. This is from the Toronto Star last June: "The number of people waiting for beds jumped by almost 85% between 2005 and 2012, when there were 19,000 waiting for placement, according to the provincial auditor. But the number of beds increased by only 3% during that time."

We had 2,000 Ontarians in hospital beds, waiting for LTC placement, in March of last year. Some 90% were placed within 495 days, with waiting lists being the longest for the hardest-to-serve patients, including those with dementia.

So the Ministry of Health is not going to be the answer to this. They have their own problems. But it can be solved with a single ministry, from birth to death, dealing with developmental and intellectual disabilities.

The Chair (Mrs. Laura Albanese): Thank you for presenting to us. We also have received some answers from the ministries to date. Some are included.

Interjections.

The Chair (Mrs. Laura Albanese): The researchers told me that some of them are included—

Interjection: In the back.

The Chair (Mrs. Laura Albanese): —in the back. Yes, I went by the front as well, but in the back, they are included—not all of them, but some.

Mrs. Christine Elliott: Madam Chair, I'd just ask for a little bit more research to be done on the basis of some

of the excellent information that we got from this presentation. We probably have this information in one of the presentations we've already received, but if we could get some indication about the number of people who are receiving ODSP in Ontario—because there was an indication in the presentation that there's a 70% unemployment rate, even though 80% of people have indicated that they are willing and able to work competitively. I think if we take a look at that and figure out the number of people who potentially could be working but who, through no fault of their own, aren't working right now, we could probably find the savings from a lifelong time on ODSP that isn't perhaps necessary for some people—to put it into the supports and services for people who truly need them.

The same thing—we could probably quantify by taking a look at the number of people who are inappropriately placed in hospitals and long-term-care facilities right now. By sorting people into where they should be economically and socially, we could also achieve, I believe, significant savings to put into the supports for those people who are truly vulnerable and really need help.

The Chair (Mrs. Laura Albanese): As you said, it's more about planning and doing it right.

Ms. Michelle Palmer: None of us want to live in long-term care for our entire life.

The Chair (Mrs. Laura Albanese): Yes. Thank you very much for coming this afternoon and for the information you provided. It's very valuable to us, as a committee. We appreciate it.

MS. KATHLEEN GIFFORD

The Chair (Mrs. Laura Albanese): We'll now call on Kathleen Gifford. You can choose the chair you like best.

Ms. Kathleen Gifford: Thanks.

The Chair (Mrs. Laura Albanese): Good afternoon, and welcome. You may begin any time you feel ready.

Ms. Kathleen Gifford: My name is Kathleen Gifford. I'm employed with Ingersoll Support Services as a social network facilitator. I am also an independent facilitator, hired by families, and am currently working with two families. I am passionate about this work because I have a son with complex autism.

We use the phrase “complex autism” where others would use “low-functioning autism.” Our son has a developmental disability and is non-verbal. However, he does have a lot to say. With these labels and a strong desire to communicate, he is often frustrated. The combination breeds a severe anxiety resulting most often in self-injury. So I thank you for the privilege and honour to present and introduce my son to you today. I am very grateful.

The story that I'm going to be telling you is from my son's point of view. He has indicated with his iPad things that he wanted me to mention and chose the many pictures and artwork that we have in this. I wish he could

sit here beside me but he cannot tolerate that at this point in his life.

David John Lane Gifford: He wanted his full name in there and he wanted to let you know that his mom would be speaking for him. He is 18.

“I am 18 years old and the youngest in my family. I have two sisters. The best part of having older sisters is I have two brothers-in-law. I am an uncle”—He wanted pictures of his niece and nephew in there—“Genevieve is five and is going to be a big sister in about a week”—so I promise not to procrastinate here. Rowan Matthew is two and “is going to be a big brother in the summer.

“I communicate in many different ways. I use an iPad with Proloquo2Go and some sign language. Here I am pointing to tell my father which way I want to exit the park.”

And of course, he wanted me to talk about McDonald's. This is a new skill that he has just developed, to be able to go into McDonald's and place his own order. Sometimes he can even sit inside to eat it.

“When I was a little boy my dad taught me to use songs and nursery rhymes to teach me sign language. I was inspired by the Helen Keller movie to learn sign.

“Communication has always been difficult for me and lots of times my message would be misinterpreted or completely missed all together. The mistakes quickly led to self-injury. Self-injury became so commonplace that people at school would ignore the message completely. People began to think the self-injury was just the makeup of my disability. School was a lonely, painful place. This is where depression and anxiety moved in.

“My family always believed in me. Here I am with my sister. We love to walk together. Walking unlocked my anxiety the same way music unlocked my expressive communication. I began to walk every day. On these walks, I started to learn about life. More importantly, my community started to learn about me. My vulnerability began to fall away and was replaced with people who knew me and liked me. I learned to trust people.

“I began to enjoy life, and my parents invested in my abilities. I began to advocate for myself. It is important to define your own day, your own life.” As his parents, this is something that we weren't sure that David would ever be able to do, so we're thrilled that now he's able to access some things for himself that we weren't able to access for him just by exerting his power.

“These walks have shown people how much I know and they trust me that I know it—things like personal safety. I know I have to wait for trains, look both ways before I cross the street, how to operate the stop lights and what they mean.

“I have learned that my walks are more enjoyable if I can make purchases, so I learned to carry a wallet, to make a financial transaction, to look for a checkout in any store. I opened a bank account and learned to use a bank machine.”

Here's a picture of him using his iPad to order some French fries, operate the stop light, wait and know what it means. These sound like mundane tasks but up until this

point, a lot of people in his life didn't believe that he had any abilities whatsoever.

"People in the education system believed I had nothing to contribute. My existence became meeting criteria to remain in a behaviour classroom. My self-injury soared to above 600 blows in a half a school day. My parents hired an educational assistant over the summer months, and she witnessed the story that my parents were saying. Finally, someone who was not family believed I had a contribution to make." When she returned to school in September, she "began telling everyone what I could do. I still had to remain in a classroom for half the day and could do co-op every afternoon."

1600

The classroom that my son was placed in was a behaviour classroom that had only four people in it, none of them verbal.

"This is where I began teaching my parents. Life had to be real, and I would rise to the challenge to learn. They learned that I need certain things to feel safe and supported. I need a lot of physical activity to keep the anxiety at bay, I need two people with me to feel supported, and I need to have real relationships in my life. It turns out what I need is what everyone needs: an everyday, ordinary life where we can experience and participate in full citizenship.

"My schooling now is full-time in the community." That's at risk. The board is still trying to figure out a way that that can happen. Right now we have an application in to the Thames Valley District School Board for supported alternative learning, and we should hear next week if this schooling can continue for him. He meets the support outside of the school, and they leave the school from there. He's able to do that without self-injury. If he needs to go inside the school, he simply cannot do that anymore.

"I took everything I learned and went to Canada's Wonderland." Again, this sounds like nothing earth-shattering, except he could make it relatable and function in it—without going on any of the rides; that didn't interest him anyway. But he was able to do all the skills that he learned in his hometown: making purchases and eating in restaurants. He was able to do that in a new place, and that was thrilling for us.

What has been happening after almost a year and a half now of the walking and the co-op is, he's now showing us that he has more capabilities and more interests. He's now learning to read, which sounds a little bit ridiculous since he's 18 and almost finished school, but we're thrilled that it has shown up now. The picture of the dragon gate is just an example of his very unique interests. This is a literacy project that he was doing.

What's next is employment possibilities. He always notices garbage on his 12-kilometre walks, so we are approaching parks and recreation in the spring to find employment for him.

We hired an artist to spend time with him. "Nelle ... walks with me every Tuesday morning and photographs everything that catches my eye.

"I look at the photos and choose the ones I want reproduced.

"Nelle paints them with oil or watercolour." She does stone carving as well. Here's a process of the photograph that he chose and the reproduction of the art. There are a couple of examples of that.

This is all to show you that we rely heavily on self-administered individualized funding. We have a complex needs budget of \$29,000 a year, which is a nice amount to do a little bit with, but it's really only the tip of the iceberg. David aged out of Special Services at Home last month, and we lost \$10,000 in his budget there. Since we adopted our son at the age of three—we had a subsidized adoption, and in June he lost \$12,000 to his budget there.

David is a man who requires supports, education and all of his resources to be customized. He requires two support workers to be with him. We hope that this will change. This has been a development that came up in the last two years, where we had to add the second support person. We hope that it's only for a time while this massive learning is happening. He's a pretty big guy and he has huge impulses, so to be safe right now, we need the two people and that costs a lot of money. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for sharing all of this with us. We have about three minutes for each party for questions. We're back at the PC Party.

Mrs. Christine Elliott: Thank you very much for coming forward and telling us David's story. I'm just wondering where you are in funding right now. Are you in that transition phase where you're applying now to get back the \$10,000 that you immediately lost? How is that being dealt with?

Ms. Kathleen Gifford: I don't really know where to go to fight for the funding that is lost. Thankfully, David has the complex needs funding. That stayed with him, so the \$29,000 will stay with him, but we're just going to need so much more than that. It's fairly evident that David is going to require 24-hour support into the remainder of his adult years. So, yes, the fight would continue for more funding, even to recover some of what was lost. We tried to get children's aid to stay committed to him until he was 25, but that was a very firm, fast "no."

Mrs. Christine Elliott: Can you tell me what other supports are available in your community if, for example, you are not able to continue to support David at home?

Ms. Kathleen Gifford: Well, we're in the wonderful process right now of DSO. We're halfway through the process. It's fairly dehumanizing. I guess you become part of the huge wait-list that was just talked about prior to that. Thankfully, David has family members with him. It's not really a plan to go to a group home. David is going to do much better on his own. We are in the process of setting up a micro board around him—I'm not sure if people are aware of what that is—just to protect his voice and keep it strong. He has a lot to say, has a strong way to say it but at the same time, with being non-verbal, it's very easily stifled.

Mrs. Christine Elliott: Would that be similar to a circle of support—the micro board that you’re speaking of?

Ms. Kathleen Gifford: Yes.

Mrs. Christine Elliott: That seems to be very helpful in terms of putting together supports, both—because they don’t all have to be paid supports, of course—lots of unpaid, informal supports that are also extremely important in a person’s life and allow them to be able to articulate their needs, and for other people to help them achieve their goals.

Ms. Kathleen Gifford: Right, and probably the best way to have those natural supports around them, around David, is with the independent facilitation, which really isn’t something that’s normally offered at this point.

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

Miss Monique Taylor: Thank you so much for your presentation today. This caught my attention here: David was adopted.

Ms. Kathleen Gifford: Yes.

Miss Monique Taylor: Did you continue to keep other people within the children’s aid society that are dealing with special needs children in your network, by any chance?

Ms. Kathleen Gifford: Well, we kept his foster parents. He luckily only had one foster parent. We tried networking a little bit with other family members—

Miss Monique Taylor: But I mean, like other families that have other children with special needs—did you stay in any of those kinds of networking groups?

Ms. Kathleen Gifford: No, I didn’t really know of any when we adopted him.

Miss Monique Taylor: Okay, it was just a curiosity that would have led me into another direction.

So when he turned 18, you lost \$10,000 for your Special Services at Home that you’re hoping you’ll get somewhere in the Passport world, I’m sure. It says, “July 2013 we lost \$12,000.” Where was that from? Was that from the children’s aid for the special needs?

Ms. Kathleen Gifford: That was from children’s aid. That was the subsidy, yes.

Miss Monique Taylor: It was brought to my attention earlier through this process—I believe that families who had children through children’s aid, and when those children aged out—children with special needs—they were then asked to move on and not keep those children anymore because they had aged out of the system. I had wondered if you had any contact with families who had been through that kind of situation, but you had adopted David so I guess that would have put you in a different position.

1610

Ms. Kathleen Gifford: Right. I have met families from this province who were at risk of losing their individualized funding. Thankfully, that hasn’t happened to David; I hope it never does. A friend of mine in Chatham, her son is the same age as Dave, the very same

capabilities, and he’s living in a psychiatric hospital right now.

I did want to point out that having real experiences around David, as opposed to getting him ready for real life—the self-injury that was so high in the classroom is less than six on a bad day. Most days, he’s functioning without self-injury. So there’s something to that whole programming aspect, that it’s just not good for people. People can’t thrive there.

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

From the Liberal side, are there any questions?

Ms. Mitzie Hunter: Thank you so much for sharing David’s story. I was curious to find out what was happening in his co-op program, because you were saying that it was such a good experience for him and he was learning new skills. Could you share a little bit more about that?

Ms. Kathleen Gifford: Yes. Some of the things—people didn’t think Dave was capable of learning around numbers and safety awareness. Basically, his 12-kilometre walk is six kilometres in the morning, he comes home for lunch, and then does another six in the afternoon. It is just walking through his community, going into and out of businesses, making purchases, learning how to use a bank, so anything that is going to help him learn for existing as an adult: things he couldn’t learn in the classroom, things that were attempted to be taught to him. Basically, it’s these journeys that he goes on. I didn’t know that he would understand the concept of money, and he has proven us wrong on that. The next step is teaching him value—so basically the academics of a classroom that he just couldn’t stop the self-injury enough to learn. He really needs to be on his feet.

Ms. Mitzie Hunter: Experiential learning.

Ms. Kathleen Gifford: Yes.

Ms. Mitzie Hunter: And you’re seeking to get that recognized as a course credit?

Ms. Kathleen Gifford: Definitely, yes. He’s 18 and legally needs to be in school until he’s 21, so that’s a big fear. I just don’t know what will happen if the option is to go back into a classroom.

The Chair (Mrs. Laura Albanese): Thank you very much for being here today and sharing your story with us.

Ms. DiNovo.

Ms. Cheri DiNovo: Madam Chair, another question of research that has come up, and thank you, research, for directing me to page 511 of the MCSS report. There it says 2,300 adults are on the wait-list. I have a couple of questions about that figure. If you compare that to the 4,500 residents with developmental disabilities who are currently living in long-term-care homes, clearly that figure is not being counted into the wait-list, the 4,500. That was one of our presenters who raised that before. So add another 4,500 to that 2,300, I assume, because I assume the first choice of parents is not long-term care for their children with developmental disabilities.

There’s that, and then—I haven’t totalled it up, but if I’ve got time on the flight tonight, I will—there seems to

be a real discrepancy in wait-list figures between the presenters here, if you add them all up, and the 2,300. Maybe somebody could add up those figures of the presenters here that actually have wait-list figures and the MCSS figures, because I suspect there is a discrepancy. It seems like way more from what we've heard from presenters, Community Living primarily.

Thank you.

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

FASD-ELMO NETWORK

The Chair (Mrs. Laura Albanese): We'll go on to our next presenters, the Fetal Alcohol Spectrum Disorder network of Elgin, London, Middlesex and Oxford.

Good afternoon and welcome.

Ms. Juanita St. Croix: I'll just introduce myself and my colleagues here before we start. I am Juanita St. Croix. I am the co-chair of FASD-ELMO Network. I am also a facilitator with the Southern Network of Specialized Care. Directly to my right here is Angela Geddes, who is the assessment coordinator for our regional FASD assessment clinic, and on my far—this is my left; I'm sorry—left is Tracey Ashby, who is a public health nurse with the Middlesex-London Health Unit, and we are all members of the FASD-ELMO committee.

To start, we would like to thank the select committee for the opportunity to share information about fetal alcohol spectrum disorder and its impact on individuals, family and human services across the lifespan. We will be speaking from a regional needs assessment that was completed in 2010, published works on FASD and the FASD-ELMO Network's priority statement that was developed through consultation with parents and professionals in the region. We are providing copies of our full documentation for your review and consideration, as well.

Ms. Tracey Ashby: The FASD-ELMO Network is an unfounded, grassroots network of parents and professionals that was established in 2009 to raise awareness and improve practice related to FASD in the Thames Valley region. Current membership includes 57 parents and professionals from 23 groups and human service organizations in the area.

FASD is a permanent, largely preventable neurodevelopmental condition that impacts every aspect of life for individuals and families. Primary disabilities related to the physical impact of the teratogen—the alcohol—on a developing fetus can include neurodevelopmental damage, physical deformities and intellectual challenges.

The top three priorities for the FASD-ELMO Network are to promote and support interagency, inter-ministry and intergovernmental efforts in the areas of prevention, neurodevelopmental assessments and lifelong family-focused supports and interventions.

It was heartening to see a reference to FASD in MCYS Deputy Minister Alex Bezzina's presentation in October. Individuals who are affected by prenatal alcohol exposure face a lifetime of struggle, and are often missed

in service provision models because of a lack of diagnostic capacity and awareness.

Secondary disabilities are the disabilities that occur after birth, when there is a mismatch between the person and his or her environment. Early diagnosis and appropriate interventions can reduce the effect of lifelong deficiencies caused by this brain damage. These are some examples of secondary disabilities that can be lessened or eliminated through appropriate intervention: mental health problems, repeated school failures, trouble with the law, inappropriate sexual behaviour, and drug and alcohol problems.

The numbers related to FASD are daunting, and our capacity to serve individuals and families across systems requires education, collaboration and a change in paradigm. We know from our experiences in local capacity-building that this is not easy, but without a coordinated, systemic understanding, the loss of potential and the human devastation are unconscionable.

Ontario is behind other Canadian jurisdictions in identifying and serving FASD, but well-established models of identification and support in other provinces and territories are replicable and can be improved upon with a growing knowledge base. An FASD-informed approach, accurate assessments and appropriate services are important at any age.

In 2009, the cost of FASD annually to Canada of those from the day of birth to 53 years old was determined to be \$5.3 billion. From our experiences in the field, much of that is being spent on services and interventions that are not FASD-informed and lead to frustration and marginalization.

The importance of a systemic approach to prevention and harm reduction cannot be overstated. In spite of awareness campaigns, the rates of drinking have increased over the past 20 years. This increase was especially prominent among women and drinkers aged 18 to 29. It is from 1.3% in the year 2000 to 7.2% in 2009.

In just one study, and it talked about just one exposure—this was a 2013 study which showed widespread acute apoptotic death of cells in both grey- and white-matter regions of a monkey or macaque fetal brain, just from one exposure in the third trimester. Therefore, the importance of clear prevention messaging to prevent brain and neurodevelopmental damage cannot be overstated.

1620

Ms. Angela Geddes: Statistically, there would be more than 700 FASD-affected students in the Thames Valley District School Board alone, most of whom are not diagnosed or are misdiagnosed, leading to ineffective interventions or no interventions at all. Early diagnosis is critical in order to identify needs and necessary supports to assist students as they move through their education system.

Obviously, increased and dedicated funding is required to facilitate diagnosis. Staff and administrator education is also critical so that these students can access the education and support services that they deserve. This

education needs to be provided to all staff in all schools and all support workers, not just those who may have contact with an individual student.

Currently, 89% of children identified with FASD are in the care of agencies or are being raised by people other than their biological parents. This statistic speaks to both the hopes of families who welcome our community's children into their homes and the repeated disruption, which creates a further negative impact on the child's development. There is also the potential for this figure to hide the magnitude of the problem as there is significant mother blame, judgment and stigma currently when considering the diagnosis of FASD.

The estimated 1% of our population who suffer from FASD contribute to at least 60% of the prison population.

In a recent Alberta study, early diagnosis, a supportive environment and early intervention have been identified as crucial factors to optimize outcomes for affected individuals. The results of this 2006 Alberta study truly highlight the inappropriate cost and the importance of implementing positive structures and supports. Ontario needs to establish supportive interventions for transitional-age individuals and adults who are affected by FASD. We cannot assume that our incarceration rates, with our current lack of FASD-informed services and diagnoses, are any lower than those in Alberta.

Tragic stories of individuals who are impulsive, reactive, marginalized and who have committed random crimes are frequently reported in the news. Incarceration is a very costly and ineffective intervention for individuals who lack impulse control and cannot understand cause and effect. These are two primary impacts of prenatal exposure on the brain.

In London, we are fortunate to have a youth therapeutic court where youth who have committed a criminal offence and who have been diagnosed or suspected of having a mental health issue can be diverted from the usual criminal justice process. Dedicated cross-ministerial funding would ensure that these youth receive the support and services they require as they navigate our court system. We also know that not all youth who could qualify receive the therapeutic court services.

The current lack of understanding among practitioners places a great deal of pressure on the individual and the family. Family-focus supports and interventions, which are guided by a clear understanding of FASD and the strengths and the needs of the individual, as well as the abilities and needs of the caregivers, are urgently needed in a deliberate, coordinated approach over the lifespan.

Many adults who have FASD have either not been diagnosed or were incorrectly diagnosed as children. This leads to the development of secondary disabilities and tragic effects on their quality of life and life trajectories. Without appropriate dedicated supports, secondary disabilities associated with FASD can lead to high rates of mental health problems, including trouble with the law, confinement for treatment of the mental health issues or addictions, inappropriate sexual behaviour, homelessness, victimization, unplanned pregnancies, and

problems with employment. There are currently no specific adult diagnostic services in our region. Once transition from childhood to adulthood is complete, people with FASD cannot receive the appropriate supports and services to help them lead successful lives.

Ms. Juanita St. Croix: As the situation currently stands, the many kinds of service providers involved in supporting individuals with FASD and the level of the support provided demonstrate the complex nature of this disorder. But without designated funding specific to FASD, service providers are attaching funding from alternate sources in order to work with clients with an FASD. This results in fragmented delivery of services and supports that often do not meet the needs of the person.

Current service provision is costly and resource-intensive. There is an urgent need to increase supports across the lifespan, but also to target resource allocation further upstream in FASD prevention and support of affected children and youth to ameliorate resource allocation further downstream.

Current levels of service provision are not adequately addressing the needs of affected individuals. FASD requires a coordinated approach, with all service sectors working in a coordinated manner. When different sectors are not able to work with clients appropriately due to workloads, wait-lists, lack of funding etc., this impacts on the ability and effectiveness of other service providers. This is in addition to impacting outcomes for affected individuals and families.

A cross-ministerial approach to funding supports and services for a person with an FASD across a lifespan is needed to avoid the issues of transitions to adulthood, diversion when appropriate from the criminal justice system, and effective community mental health supports.

Planning for lifelong interdependent supports is also critical. The person may always need some level of supervision and support and multiple service provider involvement.

As previously indicated, there is a significant over-representation of FASD in the prison population. Court diversion programs such as the one in London's adult therapeutic court clinic are unique, given that there are varying levels of awareness of FASD within the judicial system in general.

However, FASD is not well understood, or is perceived as a non-issue for the judicial system, which leads to ongoing recidivism and punitive outcomes for a person with an FASD. Effective prevention of recidivism requires understanding FASD and supports and services tailored to the person's needs.

Caregivers of adult children with FASD express significant concerns for their affected children long-term with respect to planning for supports for care for their child when they are no longer able to do so, and the children's quality of life long-term.

Less than 10% of individuals who are diagnosed are able to live or work independently in adulthood, so supports based on functional ability are required for

success in all aspects of life, work and relationships. Because of a serious lack of diagnostic capacity in Ontario, often the level of support required is not recognized, and many affected individuals fail at behavioural attempts, which are contraindicated for FASD, to assist them and force them to levels of independence that are unrealistic for their functional ability. This results in the development of secondary disabilities.

The last point I would like to hit is not actually in a written statement. I would like to repeat the point that \$5.3 billion are already currently being spent federally annually across the lifespan to age 53. This resource allocation is not dedicated specifically to informed approaches and strategies around FASD and therefore is excessively costly and intensive. A cross-ministerial strategy acknowledging FASD strategies and supports is really recommended from a provincial level, which we currently do not have.

I just wanted to thank the committee for your time today and to open any questions that you might like to have.

The Chair (Mrs. Laura Albanese): And we want to thank you. We appreciate your presentation very much.

I believe it's the NDP's turn. Ms. DiNovo?

Ms. Cheri DiNovo: Thank you very much for your presentation. I'm just looking here: There's about one in 100 people in Canada—I know it's difficult because we don't have the diagnostic ability and people aren't getting diagnosed in Ontario, but do you have any idea of approximately how many folk are probably affected by FASD in Ontario?

Ms. Juanita St. Croix: In Ontario? We're probably looking at about 1% of the population of Ontario. If we can apply that same statistic, we're looking at about 1% of the population that we are aware of.

Ms. Cheri DiNovo: I was shocked to hear, for the first time, that OHIP doesn't cover diagnosis, and now I'm hearing that there are very few people who can do it anyway. So those are two very clear things that come through—to me, very obvious moves. What would be another obvious move that you would think that would be top of the list for this committee to go in the direction of?

Ms. Tracey Ashby: If you're looking at a prevention model—actually, in Edmonton in the fall, in September, there was the first international convention on the prevention of FASD. Many people from Ontario were there.

When we look at one of the key pieces of prevention, it is around screening and intervention, so looking at all primary practitioners, screening for problematic substance use, specific in this case to alcohol. If we did that—we know from research that a brief intervention, some motivational questioning, is enough to effect change in some of those women, to reduce the amount of alcohol, and, therefore, the incidence of FASD would be reduced.

1630

Ms. Cheri DiNovo: Now, a lot of that, of course, is in the schools as well, because we're talking about the first

few weeks, when women don't know they're pregnant as well.

Ms. Tracey Ashby: Exactly.

Ms. Cheri DiNovo: Binge-drinking behaviour—this was presented earlier—that kind of educational component. Thank you.

Ms. Juanita St. Croix: And I think, if we're looking at lifespan issues, if we look at the resources that are already spent—which I think is not a fact that is well known—funding is already going to services and supports. That is being misdirected. We think of a number of cases of parents of a child with an FASD who are in maybe five different mental health supports programs, where one would be quite effective and adequate if it were dedicated with an FASD strategy in mind.

I think the inter-ministerial piece is key, looking at it from the perspective of how we can look at what resources are already being spent and how we could streamline that with a directed strategy around FASD.

Ms. Angela Geddes: Again, with the FASD approach, I think that if we were better able to recognize it—some of the symptoms that we're seeing in the kids who are entering the school system, for example, or even going to our physicians—if we asked the question earlier about alcohol use prenatally, we would be able to assess more appropriately.

These kids are being seen by our system. They're seen at the school level. They're seen everywhere, but they're just not seen in a coordinated fashion that's FASD-specific. I think education and awareness throughout would be really helpful.

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

Ms. Soo Wong: Thank you very much for your presentation. I think your group is not the first group today to talk about FASD.

I want to drill down. Ms. Ashby, you are a public health nurse. In your report here, you talked about the statistic of about 700 FASD-affected students at Thames Valley District School Board. How much resource or collaboration is there between the public health department and the school board? Can you share that with the committee?

Ms. Tracey Ashby: We are bound by Ontario public health standards. Within those standards it states, around healthy pregnancy, preconception issues. Our health unit has chosen, in this area, to devote time, as into FTE, public health nurses as well as some budget, to look at FASD. That is a choice of our health unit, though not mandated across the province.

We've been very fortunate to have that wisdom of our board of health. As well, Thames Valley District School Board has been very supportive of this issue around FASD and has been supportive of bringing together all our professionals for this network: bringing people together, looking at professional development and increasing awareness around that.

As far as the prevention piece, we have public health nurses who are in all the high schools, so there can be

work done if the teachers are agreeable to it and if it is within the curriculum to look at alcohol use during pregnancy.

One of our initiatives is also looking at college-level and university-level students and doing some initiatives around that, as far as mass-media campaigns around alcohol use.

Lots of movement is happening, though not mandated by any governmental body. It's the choice of what our health unit is doing.

Ms. Soo Wong: So can I ask a further question? Do I have time, Madam Chair?

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

Ms. Soo Wong: One more minute. Quickly, is your health department the only health department putting dedicated resources to address FASD? Do you know of other health units?

Ms. Tracey Ashby: There are other health units that are putting money towards that, but again, it's not a set amount or a set expectation, so it would be depending on what priorities have been determined within those health units.

Nine of our health units in southwestern Ontario have gotten together and have put together an FASD poster and fact sheet to augment the Rethink Your Drinking campaign. That was around alcohol in generality. We saw that there was nothing with FASD involved. We pulled that together.

Again, it is not mandated. It is just the choice of the priorities of the health units. There are other health units that are working on this as well.

Ms. Soo Wong: Great. Thank you.

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

Mrs. Christine Elliott: I'd also like to thank you for your excellent presentation. One of the things that you focused on was the high percentage of people with FASD who get caught up in our criminal justice system. The adult therapeutic court that's here in London, I believe, is one of only very few in Ontario. I think there's one in Toronto and one in Ottawa, if I'm not mistaken. It sounds like you think it's a good concept, but maybe they're not specifically informed about issues around FASD to be as effective as they might be. Is that fair to say?

Ms. Juanita St. Croix: I think that's very fair to say. Without a mandate or some sort of a provincial strategy around it, it will not receive the attention that is required. It's still very poorly understood, regardless of efforts to educate the judicial system. There has to be interest.

Ms. Tracey Ashby: Through our local therapeutic court, we do have representation on our network around FASD. I think, of the ones that are in Ontario, we probably have a better view of that. We do have some lawyers who sit on the committee. We're getting that groundswell of information around this, and I think people are starting to see that this is an issue with people who are coming through, say, health or through developmental services. I think we're starting to build that knowledge base.

Ms. Angela Geddes: But without a diagnosis, it's difficult to determine for certain that it's not just a mental health issue.

Mrs. Christine Elliott: And it's a very different approach. With mental health issues, you can perhaps do more to work with people. With FASD, there is sort of a hard-wiring problem, so to speak, that makes provision of those services more difficult.

Ms. Juanita St. Croix: In other court systems that don't have a dedicated therapeutic court, they are looking very much for a concrete diagnosis to be able to do some diversion. There is diversion happening in other courts as well, just not a formalized service.

Thank you very much for your time.

The Chair (Mrs. Laura Albanese): Thank you, on behalf of all the members of our committee, for being with us.

MS. PATRICIA GALLIN

MS. DANA LOWRY

MS. WENDY RICHARDSON

The Chair (Mrs. Laura Albanese): We'll now call on the very last presenters of the day in London: Patricia Gallin, Dana Lowry and Wendy Richardson. Good afternoon. Please take your seats and make yourselves comfortable. When you're ready, you may begin.

Ms. Patricia Gallin: Thank you very much for this opportunity, and thank you very much for coming to London. It made things a lot easier.

My name is Patricia Gallin. While I am sure you have been hearing a broad range of concerns, I'm focusing on a very specific thing related to the recent transformation by MCSS of developmental services. My eldest son, John, is 28 years old, and has Asperger syndrome, an autism spectrum disorder; thus my involvement with developmental services over the past two decades.

Autism Ontario has already presented to the select committee, so you've heard about the unique challenges of ASD, and they've given you the broad picture. Our family is one of the thousands across Ontario that has been living with our own version of the challenges of ASD. Our son has a developmental disability. He has a social communication disorder that is going to challenge him for his whole life. He also has an IQ over 70.

John had to drop out of high school in grade 11, despite being in a special high school program for students with high-functioning autism. He was hospitalized for mental health concerns: depression, rage, self-injurious behaviour and suicidal issues—common complications of high-functioning autism.

During that time of crisis, John got some individualized funding; not a huge amount, but enough to make a big difference in his life. With that direct funding, we were able to customize John's support, since the few existing generic programs in our community weren't a fit. We hired people who worked well with him and his ever-evolving needs.

Over the last decade, with this ongoing support, John has regained his health, successfully gained his high school diploma and audited classes at both Western and Fanshawe. He has had some competitive employment and is working to gain future employment. John lived semi-independently with a roommate for two years but is back home until we can figure out something else in this climate of minimal residential support. He actively volunteers and is learning, in a more natural way, appropriate social communication with support staff who are his peers, even some who are female, which could not have been possible a few years ago.

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It's not perfect. This has been a slow and mostly progressive path. John is a contributing member to his community and, with more specialized supports, could likely contribute even more. With this support in place, even I have been able to finally work part-time outside of the home, though I remain the key person facilitating John's support and activities and worry about who will do this when I am gone—if only independent facilitation was an established option for families.

I'm telling you our story because right now, in 2014, I am thankful every single day that John is 28 years old and went through his hell when there was some support available. I fear for all of the families of teenagers with high-functioning autism today. Most will very likely be getting some form of support at school, only to be informed by DSO that at age 18 they will be ineligible for support. How is it that the very people with a social communication disorder, who, with just a small amount of individualized support, can make big gains, are now being discriminated against on the basis of IQ by the very act that is supposed to be promoting social inclusion?

One does not grow out of an autism spectrum disorder, and prevalence rates have only been increasing. Is this a convenient cost-cutting approach by MCSS? If there is no support from MCSS for these folks, where is it to come from? What in the world have we transformed the system into?

Ms. Wendy Richardson: My name is Wendy Richardson. We appreciate the opportunity to present to this select committee. My son Nathan is 27 years old, the third of four boys, and he has high-functioning autism. He does have an IQ above 70. He has an average to above-average intelligence but with many of the adaptive functioning deficits that people with this disorder suffer. He was not diagnosed until he was 13, even though I was telling the doctor I felt that he had autism.

In 2007, he suffered a complete mental breakdown as a result of circumstances at school related to a lack of understanding surrounding the disability. He was in a psychiatric ward here in London for two weeks. Because of this breakdown, he was not able to finish high school and did not receive his high school diploma. The doctors were not confident that he would recover and also told us that they did not know how to treat people with autism.

He did recover, and out of that crisis situation we received individualized funding that has allowed us to

create a somewhat meaningful life for Nathan. We have the help of support workers and various other supports paid for by this funding, which we are extremely thankful for. Without it, I believe that Nathan would either be in an institution of some sort or in some other horrendous situation and even possibly incarcerated, as he does have aggressive tendencies when he is anxious, stressed and fearful. This would cost the government far more than the small amount of funding that he receives, which allows him to contribute to the community rather than be a burden on it.

With the cueing and support of his workers, he is able to be in the community and now, because of their coaching, has been able to go out successfully on his own for short periods.

Nathan wants to live on his own and we would like to make that possible, given the right circumstances and environment. There is not any type of housing in London at present for this population. They do not do well in group homes, and also, the wait-list for those homes is 10 to 15 years. Those with an IQ over 70 are ineligible for service, so they would not qualify for this type of housing.

There is also a need for some type of meaningful work for this population. This would include having people who are educated in high-functioning autism and Asperger's who could do job coaching and job carving and be able to convince employers that having people from this population would be a valuable asset to their workforce.

There's a great deal of misunderstanding and lack of education surrounding the Asperger's and high-functioning area of the autism spectrum. This has led to the idea that if you have an IQ of 70 or over, you do not need any supports. This is simply not true, as this population has many and diverse areas of deficits. But with the proper supports and funding, they can be the functioning and contributing members of society that they want to be.

I will cite the example of a brilliant university professor who has Asperger's. He goes on speaking tours and must take a support person with him, as he does not like to be touched. His support person will make sure that people understand this and keep them from touching him, which could totally throw him into a meltdown. Also, when he is out of his regular environment, he cannot remember how to dress himself. Yet, this is a man who can speak to hundreds of people and teach high-level university courses without a problem.

In closing, I would like to say that if the ministry feels they spoke to families and were listening to their input, I would have to say they didn't listen very closely. I have been very involved with Autism Ontario for many years and also facilitate the parent support group. Not once have I heard a family say that people with an IQ over 70 do not need supports. Thank you.

Ms. Dana Lowry: My name is Dana Lowry and I am a sole-support single parent to a high-functioning adult on the autism spectrum. Thank you for your time.

My son Devon is 20 years old, in his last legally entitled year at high school, and was diagnosed when he was 18 during a three-year battle with severe anxiety. Poverty, mental health issues, social reclusiveness and a decreased access to education and employment are all issues that will plague him in the future unless we do something about it now.

I would like to talk to you about school, Developmental Services Ontario and some of the implications of the DSO.

On the subject of education, my son and I have had to fight for his legal entitlement for an education. My son's story includes him not attending his much-beloved school for three years while he hid in our house, missing his teachers and staff at the school and eating \$200 in groceries per week. His school was extremely happy to help him stay out, and when my son hit 19, his vice-principal talked him into signing documents to remove him from the registrar. It wasn't until they realized that we were going to the tribunal that the fight became a little less intense.

The exclusion of services that began in high school continued in earnest with the DSO once he hit 18. Because the DSO refused to accept any documents from his psychiatrist, I had to take him to a psychologist for an assessment—food for thought. The cost of an assessment is more than \$2,000. This is not refundable by most health care insurance providers. After we submitted our documents, we were told that my son “does not fall within the definition of developmental disability because his IQ is over 70%.” They referenced the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008, section 3(1) to prove that he did not fit within this definition. But it is interesting to note that the act itself does not mention a specific percentile for cognitive ability.

The DSO has a chokehold on access to 18 out of the 21 relevant community services here in London. This kind of exclusion has disastrous ramifications for him and affects his charter rights. I struggled to find money to pay for much-needed services, and I know that there's so much more that he needs that I can't provide. Just a little bit of support would go so far for him: more time with his support worker, educational supports and social opportunities.

To conclude my presentation, I had mentioned at the start of my speech that poverty, mental health issues, social reclusiveness and decreased access to education and employment would haunt my son if we don't start to address the issues that face this population. As it stands, his future is bleak without support. It's not a lot of support—just a little bit could make the difference between being a hermit living beneath the poverty line and a successfully contributing member of society. I'm asking that you review the current state of the educational landscape for this population and modify the DSO's eligibility criteria to review the IQ and to recognize the adaptive functioning needs. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for presenting to us. We have two and half minutes for each

party. I've lost track; I believe it's the Liberals. I'm going on good faith.

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Ms. Soo Wong: Thank you very much, Madam Chair. Thank you to each one of you for sharing your child's story with the committee.

I heard issues about the assessment, the DSO, the housing, the meaningful work—in terms of priorities, which one of these issues and challenges all of you experienced should be a priority for our committee?

Ms. Wendy Richardson: I'll address that. We talked about it beforehand and we would say, have them remove the criteria of the 70 points for the IQ. Then, other people who need this funding would have an opportunity to receive it.

Ms. Soo Wong: Okay, that's good. Thank you. Do I have more time?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Soo Wong: You talked about the challenges your son and you experienced dealing with the school board, in terms of not being in the school for a number of years. In terms of the accountability of the school board and their follow-up—for the three years that your son was not in school, which school board was it that didn't follow up? I'm just curious.

Ms. Dana Lowry: That would be the Thames Valley District School Board.

Ms. Soo Wong: Okay. During this period of time when your child wasn't in school, was there any call either from the principal, the area superintendent—

Ms. Dana Lowry: Every day.

Ms. Soo Wong: So what were the reasons for not dragging your son back into the school?

Ms. Dana Lowry: Their belief was that this was a behaviour issue and that punishment was the way to get him back to school. If it was uncomfortable for him not to attend school—so if he would be punished, threatened with suspension or expulsion—then maybe he would come to school.

Ms. Soo Wong: My last question is, what kind of support was provided to you, as the mother, so that he would be properly home-schooled, since he was not in school? What kind of support was given to you?

Ms. Dana Lowry: None. Home-schooling was never an option.

Ms. Soo Wong: Thank you.

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

Ms. Sylvia Jones: I'll try not to make this a rant. My first question is—and this number keeps changing—what percentage of the Ontario population has ASD?

Ms. Patricia Gallin: The prevalence is one in 94 right now.

Ms. Sylvia Jones: Okay. So, because of this magic eligibility 70 IQ, you guys aren't even on the waiting list?

Ms. Wendy Richardson: We were grandfathered in—

Ms. Sylvia Jones: Because of age.

Ms. Wendy Richardson: Yes, because of our children's age. But anyone, as of last April 1, who turned 18 after that date is not eligible if they have an IQ over 70.

Ms. Sylvia Jones: And it's your understanding that this is not by legislation; that this is some magic rule the DSO has implemented?

Ms. Dana Lowry: It's not listed within the act at all. There is no number listed in there. It's the DSO that has magically—my understanding, in attending a conference, was that the DSO and another entity had negotiated the 70.

Ms. Sylvia Jones: That's a heck of a way to keep the waiting lists down.

Mrs. Christine Elliott: Having served on the committee with Ms. Jones on the transformation of Bill 77, I specifically recall that we discussed that. We concluded that that 70 eligibility line was not appropriate; it was more a question of functionality that we should be considering. So this is something that we specifically tried to deal with with Bill 77 that somehow has come back at us.

Ms. Patricia Gallin: I went to all of those meetings and that's what kept coming up: that it should be adaptive functioning. But that's not what's happening.

Mrs. Christine Elliott: Thank you for letting us know about that.

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

Miss Monique Taylor: Thank you so much for your presentation today and for bringing this aspect to the table. Did I hear you say that your son wasn't diagnosed until 18?

Ms. Dana Lowry: Yes.

Miss Monique Taylor: What were the challenges that you faced throughout his life in trying to get that diagnosis?

Ms. Dana Lowry: We had multiple diagnoses ranging from, initially, a speech and language delay/communication disorder to, the latest and greatest before his final diagnosis with autism: schizophrenia. Most of these professionals were actually through the school board, because the wait time is less if you go through the school board.

Miss Monique Taylor: So, after struggling his entire life to finally get him a diagnosis, you're just being left in the cold because he has an IQ over 70? That's wonderful. That is absolutely horrifying, and the struggles obviously will continue. We've been hearing on a regular basis how people in that state are finding themselves in correctional facilities and places where they absolutely don't belong. I really hope that isn't the path that your son finds himself on.

All the best wishes for you. You were so lucky with the grandfathering and fighting those struggles through the years, so thank you again for being here.

Ms. Patricia Gallin: Thank you.

The Chair (Mrs. Laura Albanese): Thank you for appearing before the committee.

I want to thank, actually, everybody who came to present and to speak to us today here in the city of London. Thank you for the time that you have taken to be here. We usually say "for taking the time out of your busy schedule," but it's often an unpredictable schedule, as we heard very often today, so it's very much appreciated. It helps us to hopefully do a good job. That's what we're hoping for. Thank you.

I just wanted to say to the members of the committee as just a note, a parenthesis, that some of us are allergic to perfume, and today it's been a little bit challenging. We don't know whether it's that or it's the room, but if we as members of the committee could perhaps avoid wearing perfume or creams that are scented, that would help others out.

Interjection.

The Chair (Mrs. Laura Albanese): Yes, less use of Kleenex.

Mrs. Elliott?

Mrs. Christine Elliott: Madam Chair, if I could make one more request of research, just based on what we heard about the cut-off at 70 points for IQ: If we could find out how that came to be—whether it's by legislation, regulation, proclamation or whatever—I think we would like to get some more information on that.

The Chair (Mrs. Laura Albanese): Yes, I completely agree.

Ms. Wong?

Ms. Soo Wong: I was going to ask the same question as Mrs. Elliott.

Madam Chair, through you to the researcher: With respect to the school board issue, I also want to ask for more information from the Ministry of Education on how we deal with high-functioning autistic students. Given what we heard about one particular school board, I want to see data with respect to school withdrawal, home-schooling, expulsions and suspension of intellectually and developmentally disabled students in our system, because it's very, very disheartening for me as a member here to listen to a mother, a constituent in this area—that there was no support. So I want to know what happened and where the accountability is. I want to get more information about that, Madam Chair.

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

Ms. Mitzie Hunter: I have a question for the researcher as well. There was a reference to a study in Alberta that looked at incarceration rates that were based on fetal alcohol spectrum disorder, and I wondered if there were any similar studies in Ontario and if those numbers could be made available to us.

The Chair (Mrs. Laura Albanese): Any further comments, questions?

We are therefore adjourned until 9 o'clock tomorrow morning in Thunder Bay.

The committee adjourned at 1659.

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