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Wednesday 11 December 2013

Select Committee on Developmental Services

Developmental services strategy

### Journal des débats (Hansard)

Mercredi 11 décembre 2013

Comité spécial sur les services aux personnes ayant une déficience intellectuelle

Stratégie de services aux personnes ayant une déficience intellectuelle

Chair: Laura Albanese

Clerk: Trevor Day

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#### LEGISLATIVE ASSEMBLY OF ONTARIO

#### ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

#### SELECT COMMITTEE ON DEVELOPMENTAL SERVICES

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

Wednesday 11 December 2013

Mercredi 11 décembre 2013

The committee met at 1631 in committee room 1.

#### DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Good afternoon, everyone. We can finally start our meeting. All members will see in front of them a letter that we have received from MCSS, the Auditor General's report regarding developmental services and some submissions.

Also, we have received our approval from the House to travel, and we will be having a conversation about that after we hear from our deputants. I believe it's eight days in total.

#### THE OTTAWA ROTARY HOME

**The Chair (Mrs. Laura Albanese):** Therefore, I would ask the Ottawa Rotary Home to come forward.

Good afternoon. You may take a seat. If you could kindly state your name and title before you begin for the purposes of Hansard. After that, you may begin your presentation, which will be followed by questions from all three parties.

Ms. Maria Contreras: Perfect. Thank you very much. My name is Maria Contreras, and I'm the director of client services at the Ottawa Rotary Home. I'm here on behalf of Gina St. Amour, who is our executive director and who unfortunately, at the last minute, had to send her regrets. So I will also ask your indulgence, because it was a last-minute switchover. But thank you very much for inviting us to present here today.

I'll start with a little bit of background. I have two primary goals for my presentation today. The first is just to acquaint you guys a little bit with who we are, what we do as an organization and what our vision is for a comprehensive developmental strategy in Ontario and in the Ottawa area. My second goal is to focus on some of the ongoing challenges that families are facing in our area and some of the ideas and recommendations that we have for improving that situation.

The Ottawa Rotary Home: We were founded in 1982. It was a collaborative effort between the Rotarians in Ottawa; the social workers from one of our key allies to this day, the Ottawa Children's Treatment Centre; and some local physicians. The idea was to fill a gap that had been identified in our community, which was respite services for children who had physical disabilities affecting

mobility. So this was something that they had identified as lacking in the area.

Since our inception, creating and leveraging community partnerships has been a fundamental element of what you could call our modus operandi. In fact, the conception of the home, as I mentioned, was, in itself, a huge collaborative effort.

Over the past four years, we have expanded our services to include overnight respite services for youth and young adults with severe disabilities, a population that is chronically underserved in our community. The expansion to incorporate adult respite services was based on the recognized needs in our community. The children that we had started off serving were aging, their parents were aging, but the needs weren't going away.

In order to remain true to our mission of keeping families healthy and keeping them strong and allowing them to remain in the community, we could not simply withdraw our support when these children became adults.

At this point, the Ottawa Rotary Home is one of the only organizations in the region that is providing specialized respite services to adults with developmental disabilities as well as the medical complexities that come along with some of the conditions that they have.

So just to reiterate a little bit what the values of the Rotary home are: What we aim to do is to empower families to maintain the care of their loved ones in the home by developing strong relationships of trust and by recognizing, respecting and responding to the unique individual needs of each of the individuals that we serve, recognizing that throughout their lifetime, these needs may change.

In the late 1990s, it was becoming apparent that the need for respite services from families in our community was starting to exceed the capacity of what we were able to provide. In 2001, we applied for and were granted funding from the Ministry of Children and Youth Services to add three additional beds to our respite home, focused primarily on children who were MFTD—medically fragile, technology dependent. At that time, we were able to hire nurses to work alongside our developmental services workers, staying true to our original service model, but now able to provide for some of those medical complexities.

We first began working with adults back in 2005, and this was really an effort at maximizing efficiencies. We were serving children at the time, most of whom were in school during the day, so we had staff on site, but no clients. At that point, we started offering a day program from 9 to 3 to serve these adults, most of whom were what we like to call "graduates" from our children's program. Once high school was finished, they found themselves without any sort of day supports or day programs to attend.

Over the years, several attempts have been made to secure both funding and a location to provide adult respite services. We were unsuccessful until, many years back, they announced the closure of all of the facilities in our area, the institutions. At that point, we were able to come to a mutually beneficial agreement with MCSS, MCYS and the Rotary Clubs of eastern Ontario.

By March 2009, our original children's respite bungalow had been converted into a residential space, and a new building had been constructed with facilities for both child and adult respite. This was, again, another example of a big partnership. The funding for the building was comprised of a lot of different things: a \$2-million federal grant; \$600,000 from the Ministry of Community and Social Services; a \$2-million public capital campaign; and a \$1-million land donation of five acres of land in south Ottawa. Though the Ottawa Rotary Home is a small organization with a very specific and targeted population, we did manage to engage a variety of stakeholders to build on some of the solid foundations that we had set up.

At this point, I'd like to step away from the history and start with a bit of a story. It's a story about a boy—a young man, actually, at this point; his name is Jonathan—and his adopted mother, Doris. Jonathan started coming to the Ottawa Rotary Home as a young boy. He has cerebral palsy and epilepsy, and he's also blind.

Aside from the complexity of his medical needs, Jonathan has a developmental disability and several behavioural issues, including aggression. All of this in combination made it very difficult for his family to find services when he was a child. Now that Jonathan is an adult, it's almost impossible. Even if the family could afford to pay out of pocket for day services, finding an agency that could adequately meet Jonathan's needs would be very difficult in our community.

At this point, Jonathan is now 21. High school is over and children's services have ended. Doris, Jonathan's mom, is absolutely dedicated and determined to keep Jonathan at home, but recognizes that in order to do this, she's going to have to look outside of the existing system and processes to get the services that she needs to maintain that reality.

Doris is a very strong advocate. She has put herself out there quite a lot. She has talked to local politicians, she has contacted the media, she's been engaged with the Ombudsman—all of this in an effort to advocate for the services that she needs to keep her son at home, where he belongs.

To provide a little bit of context, if Jonathan were to be placed in residential care, it would cost approximately \$120,000 a year to keep him there. One week of respite a month for the year would cost \$30,000, and Jonathan could stay at home where he belongs.

This story is one example. Unfortunately, it's fairly common. We see it a lot in our community: families who want to keep their loved ones at home, but don't feel they have the support to maintain that long term.

Children approaching the age of 18—it's been likened to falling off a cliff, approaching the edge of a cliff. The absence of services once your child is an adult makes it extremely hard for families to cope, and we can see that. It's evidenced by the fact that waiting lists for residential services are long and getting longer every year. The alarming increase in heart-wrenching abandonment situations could also potentially be avoided and prevented if we can reach families early and provide services early before they reach that cliff.

#### 1640

To provide a little bit more context about respite services for adults: The Ottawa Rotary Home does continue to pursue our goal of a consistent and planned—and I'll refer back to this a lot, this idea of "consistent and planned." I think that this is one of the most important things that we like to emphasize when talking about respite services, the need for consistent and planned respite services for adults in the community. Unfortunately, at the moment, these services remain unfunded from an ongoing, annualized perspective, and we continue to piecemeal our funding together from a variety of different sources. The fact is, the cost of providing overnight respite care in a group setting is only a fraction of the cost for full residential care for individuals with total care needs.

Our vision has always been to focus on the strength of people and their families to create direct connections with clients and families so that transfer payment agencies can evolve and respond to those needs, and ensure that families are able to maintain their loved ones at home in their community. Consistent and planned respite service is an essential component of a proactive system of care, which supports individuals and families throughout their lifetime, avoiding crisis and family breakdown and the need for reactionary services on an emergency basis.

I want to talk just for a moment about some of the pressures that our system is experiencing. Over time, our system has shifted into one that is primarily reactive. Even the most recent DS investments that have come through focus entirely on respite as a temporary, unplanned response to emergencies, part of a crisis management strategy which only comes into play once the crisis has started; in other words, after families have hit a wall and are no longer able to cope. We need to start to focus on respite as a proactive mechanism, a preventive tool that helps us to reach families sooner and avoid the traumatic experience of hitting that proverbial wall in the first place. By focusing on this emergency response ap-

proach, we also send the message to families that the best way to get services is ongoing crises.

With respect to some of the pressures in the community, we are consistently hearing that families and agencies are still confused by the process of accessing services through Developmental Services Ontario and the resulting disconnect with the agencies themselves that this can create. The fact of the matter is that not everyone is a Doris, the mother whom I described: capable of advocating on her behalf and navigating through a highly complex system to obtain the services, and just the basic information, that she needs.

Our board of directors is well aware of the ongoing transformation towards a direct funding approach and fee-for-service programming, and they're onboard with this; however, families and agencies are not receiving any guidance surrounding fee-for-service options in their community, and are feeling lost and overwhelmed by the choice and discrepancy in costs between fee-for-service and funded programs.

Resource management and allocation at the level of the local community service planning table also remains a struggle, particularly in the Ottawa area, where the volume of requests far exceeds the resources that exist. This reality presents a constant struggle to our local transfer payment agencies in our community who are trying to do more in an already taxed system. A key example is the influx of abandonment cases that we have seen recently in our area.

At CSPT, Community Services Planning Table, we are struggling with, on the one hand, staying true to the processes that have been put in place with regard to accessing services, while at the same time facing the harsh reality of individuals being left behind in homeless shelters, in ALC beds at the hospital and in all kinds of inappropriate care settings.

The last area I wanted to talk about was with regard to financial pressures; that's always going to be one of the things that comes up. Increasing costs and eroding budgets clearly have a negative impact on the agency's ability to maintain services and provide innovative solutions. Just to give you an example of what I'm talking about: The medically complex program that we received funding for since 2001 hasn't received a single cent in budget increases. So trying to maintain quality nursing staff at a budget that hasn't increased since 2001 is proving particularly challenging. This lack of base funding increase negatively impacts recruitment and retention of quality staff, as well as contributing to labour instability and impacting the quality and consistency of the care that we're able to provide. There is great value, both economically and socially, to supporting the establishment of strong agencies in the community with established standards of care and existing trust relationships with the clients and families.

The story of the Ottawa Rotary Home is like many other transfer payment agencies. We continue to work to find innovative ways to do more and serve more in an ever more constrained fiscal environment. In spite of the constant financial struggles, the system has evolved greatly over the years and continues to demonstrate its willingness to adapt to the needs of the clients we serve, to look for partners and to explore ways of doing things differently.

Some of the other recommendations that we have are a focus on person-centred planning. The focus on a person-centred approach to services is central to the shift from a crisis-response approach to one that is proactive and responsive to the needs of the individual. It acknowledges that there is not one solution, but rather a whole spectrum of solutions, of which people may need different solutions at different points in their life. At this time, the system we work in is primarily focused, again, on crisis response and on the immediate needs of the system. Unfortunately, this does not take into account long-term, sustainable system development and efficiency. We need to start focusing on the unique strengths of individual families and start to implement strategies and services early, before families are in crisis.

Another area that we, personally, as well are focusing on is cross-sectorial participation. A clear first step is to encourage cross-sectorial collaboration between ministries, for example, working particularly in the environment we work in, where we cross sectors from developmental to medical. Strategies in place between MCSS and the Ministry of Health and other health services to facilitate that would make it a lot easier at the agency level

A common provincial approach: Given the system navigation issues that families are facing, transfer payment agencies need to work more closely with the Developmental Services Ontario offices across Ontario to ensure that they are, on the one hand, honouring those processes that have been put in place with regard to accessing services, while on the other hand still making an effort to listen to families and developing those relationships of trust that are so important. This will help to avoid the perception that abandonment or placement in a residential setting is the only option and the only way to obtain services.

Referring back to the continuing move towards direct funding—another area that would be beneficial for both agencies and families if consistent strategies were implemented across the province. For example, if Developmental Services Ontario were to implement a tool kit for agencies and families regarding the development and use of fee-for-service programming.

Flexible funding: While there's no doubt that the system could certainly use more money, there's also no expectation that that money is coming at the moment. It's proven that transfer payment agencies can be very creative at times in terms of finding innovative ways to do more with less. It's a bit of a catchphrase right now, "Do more with less." That said, one way to reduce the financial pressures on agencies would be to increase agency flexibility with respect to funding allocations, clearly within set parameters. A simple example of this, which would likely have little to no cost to the govern-

ment, would be to allow a change in service contracts from one year to three years. This would allow for increased innovation with respect to financial planning and increased flexibility with respect to quickly responding to family needs and emerging trends.

The last example I wanted to point to in terms of areas where we could focus is inter-agency collaboration. This, as I had mentioned before, has always been a key area of focus for the Ottawa Rotary Home. For example, a recent initiative that we came through is the development of a community nurse consultant. This position was created in collaboration with several other developmental service agencies in our region that were noticing a trend of increasing medical complexity in the clients they were serving in group homes. The result was often people unnecessarily going to emergency or having to wait an extended period of time before they could get an appointment with their family physician for very simple procedures, whether it was a catheterization, whether it was an injection—lots of different things that could potentially be done on site if they had appropriate staffing. Our community nurse consultant does both advocacy—she'll do assessments and she will do in-home training for group homes to be able to provide those services on site in a way that they've never really been able to do before. So that's another key area of focus for us in terms of inter-agency collaboration.

#### 1650

That's a bit of the spiel that I wanted to share with you guys today. Thank you very much. Absolutely, I'm open to any questions.

The Chair (Mrs. Laura Albanese): Thank you for your thorough presentation. We will start with the Conservative Party: Ms. Jones.

**Ms. Sylvia Jones:** Thank you, Maria. Excellent presentation. I have so many questions, and I'm not going to get to them all, but I'll start with, can you tell me how many respite beds does Ottawa Rotary Home currently have?

Ms. Maria Contreras: For children or adults?

Ms. Sylvia Jones: You can split it up.

Ms. Maria Contreras: We have 11 funded beds for children, and we have eight beds available for adults. They're not funded on an annualized basis. We do get pockets of funding every now and then, and our foundation is able to fundraise so that we're able to provide some periods of respite throughout the year, but it's not consistent.

**Ms. Sylvia Jones:** Okay. Good segue, because my next question is going to be, what is your annual operating budget, and how much of it is coming as a transfer agency partner?

**Ms. Maria Contreras:** Our annualized operating budget for respite for children—I don't have the exact figure, but I can tell you that it's funded in conjunction—MCSS and MCYS—and it's about 97%.

**Ms. Sylvia Jones:** And the 3% is from your foundation—

**Ms. Maria Contreras:** From the foundation, exactly.

**Ms. Sylvia Jones:** —or fundraising. Okay. The rest of them I'm going to save for the researcher.

Do you have a question?

Mrs. Christine Elliott: Sure. Thank you very much for coming to make the presentation today. It was an excellent presentation. It really highlights some of the needs that we've been hearing about in the sector. One of my questions was with respect to the day program. You mentioned that briefly at the beginning of your presentation. Could you tell us a little bit more about what you do in that and how many people you're able to serve?

Ms. Maria Contreras: Sure. It depends on the day. It's a different number of people each day, but we serve up to 11 clients in the day programming. It is specifically focused on—there's an element of skills development and providing programming as opposed to the respite, which is more about the short break for the individual and the families. This one focuses a lot more on programming, skills development and activities like that. We have a number—it's fee-for-service, and we have some funded spots. So it's a mixture of the clients who attend, and it runs Monday to Friday from 9 to 3 still.

Mrs. Christine Elliott: And are the parents finding that to be helpful in terms of both giving them some day respite, and also are they seeing any mitigation of any aggressive behaviours as a result of that? Because we certainly know that it is like falling off a cliff once you finish school at age 21. Are you getting hopeful signs from that?

**Ms.** Maria Contreras: I absolutely think so. I think most of the families that we serve would say if they didn't have that, they'd be in big trouble, because it also allows most of the parents that we serve to work. Without it, one, at least, of the parents would not be able to do that.

In terms of aggressive behaviours, I couldn't comment necessarily on that. I don't know that I've heard anything to that effect. Generally, the clients we see aren't particularly aggressive because we have the combination of medically complex and developmentally disabled. We have to maintain a certain element of safety for those medically complex clients, so we don't serve many people with aggressive behaviours.

Mrs. Christine Elliott: Now, you mentioned that you're one of the only agencies in the Ottawa area that provides respite services. Do you know what happens to the many families that aren't able to access your services? What do they do?

Ms. Maria Contreras: That's a very good question, and I don't know that there's a clear answer. Just to clarify, we're one of the only agencies that is able to provide such specialized respite services. There are a number of agencies that can provide—I shouldn't say "a number." There are a few agencies that are able to provide respite services to individuals with developmental disabilities, but they're not able to provide the same level of medical expertise. Essentially, they don't have nurses on staff, most of them, so they are not able to

attend to those who have accompanying complex medical conditions.

Mrs. Christine Elliott: My other question just is on housing, which is not, I know, the business that you're in, but in the Ottawa area, are you finding, because the lists are so long, that a number of young people are being placed in long-term-care homes because there's no other place to go?

Ms. Maria Contreras: Yes, very much so; very much so. Long-term care is used a lot as what is called temporary solutions that end up being a lot more longterm than they are temporary. We're seeing a lot of individuals who are placed in environments that are really not suitable, who are not getting the stimulation, the level of activity, the level of engagement that they would otherwise be getting if they were in a proper environment.

The Chair (Mrs. Laura Albanese): Thank you. We have about four minutes for each party. Miss Taylor.

Miss Monique Taylor: Great. Thank you so much for your presentation. You did a great job.

A lot of my questions were taken up already, about long-term care, but you mentioned that there was an influx of abandonments. Do you have any idea of what those numbers would actually look like?

Ms. Maria Contreras: I think we've seen roughly seven since April.

Miss Monique Taylor: Seven since April. And you talked about financial pressures: no budget increase since 2001 for critical needs-

Ms. Maria Contreras: For the medically complex children's program.

Miss Monique Taylor: Yes. What exactly does that look like for your financial deficit? How much would it cost to actually bring you up to speed on that?

Ms. Maria Contreras: We've been pretty lucky so far in terms of not having too much of a deficit, but one of the main reasons we were able to do that is that we've actually had to switch from registered nurse personnel to registered practical nurses. The wage differential has allowed us to continue. There has actually recently been a big expansion in terms of the scope of practice of the RPNs, so we're able to do that safely, but that's one of the ways that we've managed.

Miss Monique Taylor: Being creative.

Ms. Maria Contreras: Being creative. Exactly.

Miss Monique Taylor: Absolutely. In your sector, I think most facilities definitely have to learn how to be creative to be able to get through.

Do you have any questions?

Ms. Cheri DiNovo: My question takes up where they left off. Thank you for your presentation.

How many should be served? When we asked the ministry here, they seemed to be very vague about waitlists; you have a more direct knowledge of that. How many are being turned away from your services, do you think? I know you—maybe you do keep statistics. I don't know.

Ms. Maria Contreras: It's hard to keep statistics with respect to that, because we've never had a permanently funded program so we're able to sort of piecemeal it together. If I were to look, for example, at our community service planning table and at how many people are waiting for services, whether it's respite or whether it's day program, we are looking in the hundreds of individuals who are waiting for service.

When we're looking at residential, then it gets very serious in terms of how many people are waiting and how long they will be waiting, because the places just don't come up that often in terms of—

Ms. Cheri DiNovo: Right. So hundreds for the day services and more than that for residential—and a long time being a year? Two years? Longer?

Ms. Maria Contreras: I'd say there are some people who are on that list who will be there for tens or twenties of years before they find a placement—if, I should say, they find a placement.

Ms. Cheri DiNovo: Yes. The other suggestion you made about cross-sectoral coordination between ministries: Can you give us an example of how that might look in some instance? What would that look like if it worked better?

Ms. Maria Contreras: Absolutely. So, for the community nurse consultant position that I mentioned, her job is to go into group homes and assess individuals who are living there. A developmental support worker can do some controlled acts—in other words, injections, catheters, enemas, suppositories and things like that-if that act has been deemed to be an act of daily living, something that is regularly done with foreseeable out-

Her job is to go in and assess and see if some of the individuals there can be trained to provide those services, but what we're finding is that a lot of people will have things like an injection that is PRN, so "as needed." You might need it once a year, and it's not feasible—it's not legal—to train a DSW to provide that service.

One of the things we're working on is developing stronger relationships with the CCAC in Ottawa to see how we can work together, to see if they can help us support those individuals so that they're not having to go to emerg, so that they are not having to wait weekswhich is sometimes quite dangerous—to see their family physician to get a procedure done, or to go to a walk-in clinic where you have about five minutes and the individual isn't known to that person. It's very different working with an individual with a developmental disability who is not able, necessarily, to provide the symptoms, to provide the background that is needed by the physician.

The Chair (Mrs. Laura Albanese): Thank you. And now to the government side. Ms. Wong?

Ms. Soo Wong: Thanks very much for your presentation. I just wanted to get some clarification. Who holds the wait time lists that I just heard you respond to my colleague Ms. DiNovo about? Does your agency hold it?

Ms. Maria Contreras: It's the DSO.

Ms. Soo Wong: The DSO? Okay.

1700

**Ms.** Maria Contreras: The DSO in Ottawa has the wait-list. That's the access to services. Any government-funded services for adults are accessed through the DSO, so they'll have the wait-list.

**Ms. Soo Wong:** Okay. Now, I want you to share with the committee in terms of the staffing ratio. I want to hear a little bit more, because you have complex medical care being provided, on the type of staffing and support for these staff. So I want you share with the committee what the staff ratio is for your clients in those homes.

Ms. Maria Contreras: We provide a 2-to-1 staffing ratio. That's two clients per staff. I think in Ottawa we actually have the lowest, so we're able to offer the best in terms of client-to-staff ratios. The reason that we are able to do that is because of the medical fragility of a lot of our clients. In some cases, we are able to provide a 1-to-1, but that's in very extreme cases—and we're looking at individuals who have a tracheostomy who need regular suctioning and things like that. But typically, we provide a 2-to-1 ratio.

**Ms. Soo Wong:** Now, I heard you mention hiring RPNs versus RNs in terms of the cost. Where is the support and where is the training for the RPN to be certified to do those procedures?

Ms. Maria Contreras: Well, they'll get most of that training in school—it's part of the designation of being a registered practical nurse—but we also have the support in terms of the supervisory levels. Our director of operations and client care is a registered nurse. The clinical nurse educator that we have on site is also a registered nurse, and she provides a lot of the regular training and supervision that happens directly on the floor. The program manager of our children services is also a registered nurse, so it's in the oversight.

**Ms. Soo Wong:** My last question here is, how much support is your agency getting from the Ottawa CCAC?

Ms. Maria Contreras: At this point, we don't have a formal collaborative relationship. We are working towards it, as I mentioned, with the community nurse consultant, but that would be with community clients, so not clients that we see in our organization. The reason for that primarily is that we do have nursing supports on site.

**Ms. Soo Wong:** Okay. Thank you.

**The Chair (Mrs. Laura Albanese):** Ms. Hunter, it's just one question. Please be quick.

**Ms. Mitzie Hunter:** Okay. Oh, boy—just in terms of the medical expertise and what prompted that combination in this type of home?

Ms. Maria Contreras: That was really a response to what we were seeing. A lot of people were being turned away from care because the agencies were not able to provide that level of medical support and were not willing to take the risk of having someone who could potentially have, let's say, a very severe seizure and need certain medications, or someone who—a case that recently came up was someone who was denied services because they were diabetic and they had a sliding-scale insulin injection, which means that it's something that

cannot be taught; it needs to be administered by a nurse. As a result, they were not able to access services. So it's something that we see regularly, but a lot of agencies are not equipped or legally able to deal with and provide some of those services.

The Chair (Mrs. Laura Albanese): Thank you very much. Unfortunately, the time has expired, but we thank you very much for your presentation and for answering our questions—and for your patience in waiting until the committee started today.

Ms. Maria Contreras: Thank you very much.

#### MS. WILMA ARTHURS

The Chair (Mrs. Laura Albanese): We'll ask our next deputant to come up. Ms. Wilma Arthurs, welcome. Please take a seat. Again, I need for you, yourself, to state your name.

**Ms. Wilma Arthurs:** Okay. I'm Wilma Arthurs and I'm a parent. I'd like to start—I have some portraits of families I'd like to pass around, if that's okay?

The Chair (Mrs. Laura Albanese): Sure, that would be great. The Clerk will assist you with that.

Ms. Wilma Arthurs: These are portraits of families right across our province with children with intellectual disabilities. There's quite a cross-section of them there—older parents, young parents, young children, older children with varying types of disabilities. But all struggle with intellectual disabilities.

First of all, thank you very much for allowing me to come to speak to you. I'm really happy about this committee. I think it's a very important committee. I've been reading the transcripts, and I think you're all looking at the right topics and asking the right questions.

My topic today is families in crisis. When we, as parents, raise our children—I'm assuming that many of us here are parents—we do so in the hopes that they will make a place for themselves in the community. When we, as parents, raise children with disabilities, we do so in the hopes that the community will make a place for them.

I'd like to focus on three families: mine, who was in crisis last year; Mark's family, who is currently in crisis; and Ryan's, who, without help, is moving toward crisis.

In my family, I have four daughters. The three older daughters are in their thirties and all have families of their own, making me a grandma. My fourth daughter is Emilia. She's 23 years old. She's the light of my life. She was born normal but had viral encephalitis as a baby, and it left her with brain damage. Her diagnosis now is that she has autism, epilepsy and cortical deafness.

Over the years, our family has had to advocate for everything for her, from therapy to education to transportation to supports. She functions at the level of a two- to three-year-old. She is non-verbal, unable to understand spoken language and limited sign.

Because of this, she experiences severe frustration, which comes out in self-abuse. She smears feces, she has some destructive behaviour and occasionally she lashes

out at others, usually her caregivers. She's hyperactive and in constant motion. She rarely sits. She uses her incredible strength to get what she wants, and she has no sense of danger. She'll run right out into traffic. She loves to be outside and just run away.

She has extreme sensory needs. She throws herself into walls and onto the floor. Transferring from a vehicle to a building and vice versa is a very difficult task, because she always tries to take that opportunity to just run, and it can be quite dangerous. She doesn't sleep much, because she has nighttime seizures. She can't be left alone for a moment. She gets herself into all kinds of trouble, which she thinks is fun.

My late husband Chris and I cared for Emilia together. I left our photo out; you can pass it around. We shared the load. As she became older, it became tougher. Chris and I were a team when caring for her. He would take her for a drive or play with her in her playroom while I prepared meals.

Preparing meals was a difficult task to do in our home, because she had no patience to wait for it. She would be pulling at whoever was preparing the meal. She would roll around on the floor at our feet. It was kind of dangerous, so we worked out a routine where Chris would look after her, and after the meal, I would look after her and he did the dishes. On the days when Chris was working, I would have prepared meals ahead of time to prepare in the microwave to speed the process and lessen the behaviour.

This was only one small part of the day where challenging behaviours would keep us hopping. We were sleep-deprived, suffering from joint and back pain from the physicalness of caring for Emilia.

Chris and I gained respite by taking her for long drives, sometimes three times a day. It was the only way we could sit down for a break, and Emilia loved her drives. The few hours of other respite we received from the community were taken up with chores and other responsibilities. We also received a weekend or so every four to six weeks in a specialized respite home for people who have behavioural challenges.

How we went into crisis: In the summer of 2010, Chris was diagnosed with cancer and, following surgery, began treatment. In the fall of 2011, the diagnosis became terminal. As Chris's illness progressed, I was increasingly left on my own to care for Emilia. I contacted the ministry to ask for help, and we were given some extra respite.

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Emilia's behaviours grew increasingly worse, and almost impossible to cope with. Our safety for the three of us—Chris, myself, and Emilia, most especially—became a huge issue. I was trying to prepare meals with her, trying just to move a hot pot from the stove to the sink almost was impossible with her at my feet. Trying to chop vegetables with her flinging herself around was difficult.

Emilia couldn't grasp her dad's illness. She didn't understand. She would pull at him and didn't know—you

know, "How come you're not doing stuff with me, Dad? Come on, let's go," and she would physically try to pull him off the couch, which, at a later point in his illness, caused him great pain. He ended up having to lock himself up in our bedroom because he couldn't cope. If Emilia knew that he was in our bedroom—we would have the door locked, but she would lay on the floor outside the door and kick at the door, trying to—"Come on out, Dad." That was difficult for Chris, too, because he saw the turmoil that I was in with Emilia. It was tough for him to see that and not be able to respond, and, at the same time, he knew that he was dying.

I begged the ministry to help us. The answer was always, "No, there's no funding. There are no options." Our family came to the horrendous decision to surrender care of Emilia, and the way we did it was that I booked Emilia into the respite home for a five-day stay and on September 17, dropped her off there. The next day, I informed Community Living that we would not be picking her up. It was heartbreaking, painful and unthinkable, but it was all we could do to cope with the situation. What we did got out, and the word "abandonment" was used. It was devastating. It is my belief that our family was abandoned, and it forced us to surrender care.

Our story became public. We were in the local and national papers. Eventually, the CBC, The National, did a story about us for the national news on TV. During this time, Chris continued to deteriorate. I was in constant communication with the ministry, which kept informing me that Emilia could not stay where she was and there was nothing they could do. We were told that they were considering approaching the public guardian's office so that Emilia could be placed in either a psychiatric facility or a nursing home. We were terrified of that. Finally, near the end of November, I received a call from the ministry, stating that Emilia could stay where she was and that permanent funding had been put in place to support her needs outside of our home.

Three weeks later, Chris passed away in peace, knowing Emilia and I were going to be okay. Tomorrow is the first anniversary of his death.

What has transpired since? Emilia remains in the respite home, where a bedroom has been added. The home is now designated a group/respite home. Emilia is the only resident there, but she has many of her friends who have behavioural challenges come and stay for respite. It's a big party there all the time. Emilia has two caregivers at all times. She is happy, and her caregivers from Community Living have found unique ways to fill her life and enjoy being out in the community. I visit her often at her home. She is still the light of my life. I wish I could have kept her with me and been able to care for her, but the reality is that I am unable to.

I just want to show you—she likes getting me to help her take selfies on my iPhone. This was just taken a few days ago, and you can see she is a happy girl.

The next family is Mark's. Mark is a friend of Emilia's who comes to her home for respite. He is 25, non-verbal, and is a very sweet young man. Three

months ago, Mark's behaviour escalated and he ended up in the psychiatric ward of our local hospital. He is still there. His father, a single dad, can no longer cope with his son. He visits Mark every day, but is heartbroken about the situation. There is no place for Mark to live because there is no funding.

The staff at the hospital don't know how to cope with a person with an intellectual disability as well as mental illness. The only thing they can do is heavily medicate him and keep him in isolation. His dad told me recently that Mark is eating his meals off the floor in his room, as he only has a bed in it.

There is a dual diagnosis team in our community that could help Mark to stabilize back to a happy person again, but it needs to be done within the team's temporary specialized treatment home. The trouble is, when Mark is stabilized, he needs to have somewhere to go. The hospital will not allow him to come back to live, and he can't safely go back to his dad's home. The dual diagnosis team cannot help until he has a place to go after. So Mark is stuck in limbo, where his life continues to deteriorate. His dad says that all he wants for Mark is for him to be safe and happy. As in Emilia's case, Mark's dad was also informed that they wanted to approach the public guardian to make decisions for Mark.

This family situation is not unique. This kind of thing happens all the time in our communities. I have personally known two other families over the years, where their adult sons live in hospitals for almost three years before proper community homes could be arranged. By that time, these young men had deteriorated so much that now, years later, they are still coping with the fallout.

The last family I would like to tell you about is another friend of Emilia's, Ryan. I also have a picture of his family. Ryan's family was also featured in the CBC news along with ours.

I've brought my only copy of the clips shown on TV. Trevor has them, and he's going to copy them and share them with you. There are two clips; they are each about eight to nine minutes long. I recommend that you have a look. It really shows clearly what families in crisis look like.

Ryan lives with his mom and dad out in the country. He's almost 30 years old. He is also non-verbal and has challenging behaviours. His dad took early retirement a little while ago as he saw his wife deteriorating in trying to cope with Ryan. So now they both have devoted their lives to caring for him. It's a very difficult life for them, and I know that they would dearly love for Ryan to have his own place to live. This is a family that's heading for crisis.

In our province, families who have children with disabilities can no longer make a plan for their futures, other than to plan for a crisis, to hope that when that crisis comes, something can be done outside of psychiatric facilities, hospitals and nursing homes.

In 2009, we saw the closure of the institutions for people with disabilities in our province. It was a wonderful thing. But, sadly, we are now seeing the reinstitutionalization of people into hospitals and nursing homes. It comes down to funding—more funding for families and agencies who can plan and enact more meaningful lives before families go into crisis.

Our communities know who the families are, and it's clear when a family heads for crisis. We need to do something to prevent the crisis from happening. It is clear that crisis is expensive. It is much better financially and morally to head crisis off.

People with disabilities look to their parents and families. Parents and families look to their advocates. Advocates look to their government for the help that is so desperately needed to properly look after and support people with disabilities. We need a clear, concise, enduring funding program to make life better for our most vulnerable citizens. Mahatma Gandhi said that a nation's greatness is measured by how it treats its weakest members.

That's my presentation.

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The Chair (Mrs. Laura Albanese): Thank you very much for your presentation. I will pass it on to Ms. DiNovo.

Ms. Cheri DiNovo: Thank you so much for your presentation. I think we're probably all in shock to hear—and personally, I just want to say my prayers are with you. Our hearts go out to you. Thank you so much for being the person you clearly are, for caring, for loving, for being a parent and for being here. So thank you.

You're right, the system abandoned you: You're absolutely right. You were treated horrendously and your family was, as were the other families that you have detailed to us. I guess my question starts there, with those assumptions. How do we make this better? What would have helped your family? What did you need that wasn't there?

Ms. Wilma Arthurs: I think we needed to begin planning sooner for Emilia's future. It was very obvious and clear to people in our lives—agencies, support people in the community—that we were heading for a crisis, even before Chris became ill. We wanted to keep her with us for as long as possible, but I think we needed help with planning and, obviously, funding.

**Ms. Cheri DiNovo:** So the ideal situation for you at that point would have been funding for someone to help, funding for respite care? Or what would that have looked like in your situation?

Ms. Wilma Arthurs: Well, before Chris became ill, we had already begun planning, and what our plan looked like was to renovate a section of our home into an apartment and have enough funding in place to bring staff in for a good part of the day. We would take over the other parts, but it never came to be.

**Ms. Cheri DiNovo:** Clearly, you're detailing and you've drawn a very clear picture of children who are going into psychiatric institutions, going into hospitals—the most expensive possible care—

Ms. Wilma Arthurs: Yes.

**Ms. Cheri DiNovo:** —astoundingly more expensive than what would have helped. Does that sound like an accurate assessment to you?

Ms. Wilma Arthurs: It's very accurate, yes, I agree—and totally inappropriate, also. Do any of us want to live in a psychiatric hospital, a hospital or a nursing home when we're young? People with disabilities want the same things as the rest of us—not to live in a nursing home, but to live in a home where they're supported to be able to live a meaningful, happy, productive life.

Ms. Cheri DiNovo: Thank you.

Miss Monique Taylor: Thank you for being here. Thank you for coming to share your story with us. It kills me every time I hear it, and I think of your family often, so I'm always with you for that.

I know that you do a lot of advocacy work for people in your area. I know you reach out to them through websites and all of that. How many families are you actually dealing with right now? Do you have any idea?

**Ms. Wilma Arthurs:** Myself? In the past year, just a couple, because—

Miss Monique Taylor: It's been a rough year for you.

Ms. Wilma Arthurs: —it's been a difficult year for
me. I really don't know. I speak to families all the time. I
have families call me, I have agencies call me, I have
schools call me and say, "There's a family that just needs
to learn about the system, and can you speak to them?"
"Of course." So I really don't know how many families.

**Miss Monique Taylor:** But you're touching a lot of families with the work that you do, I'm quite sure.

You've brought one family, for sure, that's already in crisis.

Ms. Wilma Arthurs: Yes.

**Miss Monique Taylor:** Do you know of other families that are in crisis right now?

Ms. Wilma Arthurs: No, but in speaking to some of our community leaders, I asked how many families are what they call "bed blockers" in hospitals. I found out that in our local hospital, there are at any given time three or four people with intellectual disabilities who sit in the hospital, waiting for something.

Miss Monique Taylor: Right. Those numbers are quite astounding for an area as small as your own, right?

How much time do I have, Chair? Nothing?

The Chair (Mrs. Laura Albanese): You're almost there

**Miss Monique Taylor:** All right. Well, again, thank you for the work that you do. I look forward to hearing from you often, and all of the wonderful work that you're doing.

Ms. Wilma Arthurs: Thank you.

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

**Ms. Soo Wong:** Thank you very much for your presentation. I have just one question; I know my colleague will probably have more.

I'm particularly interested to hear more of your comments and your suggestions about the whole issue of preventing families from going through crisis, if you could elaborate a little bit more in terms of the support that they currently have and how we improve it. I also want to hear about the different ministries, because I suspect that's one of the gaps. If you could share that with us, that would be really, really helpful.

Ms. Wilma Arthurs: Okay. I think you all know that children are allowed to attend school until they're 21, and I think that's when the crisis begins to happen, when families begin to fall into crisis. A lot of the services fall off the plate for us. Children end up sitting at home, behaviours increase, and parents become overwhelmed. It's a constant falling down.

If more emphasis were put on supports—respite, day support programs—for people once they graduate from high school, I think that would do a lot to prevent crisis. It keeps people with disabilities engaged in the community. The behaviours decrease. Families can continue to hold down their jobs and have some kind of life rather than trying to be at home caring for their children. I think respite is a big thing, and planning.

Also, recognizing families that really are overwhelmed—there are families with children out there whose disabilities are so severe that it really is extremely difficult for parents to care for them. I think that when that's recognized, if some funding were put into place, that would help.

**Ms. Mitzie Hunter:** Thank you so much for your courage, just expressing your story and on behalf of the other families.

I couldn't help but notice the shift in terms of when you had a partner versus being a single mom. I wonder if there are some lessons there that you could share with our committee, perhaps in terms of those unique considerations.

**Ms. Wilma Arthurs:** Do you mean in how our family's life changed and what we could have—

**Ms. Mitzie Hunter:** Yes, and your ability to address the needs that Emilia had.

Ms. Wilma Arthurs: It was difficult. I remember thinking, "I can do this. I can do this. I can look after her," but I couldn't. I couldn't physically. I couldn't mentally or emotionally. I was exhausted. That was a difficult thing, to come to that realization. It was really difficult.

Ms. Mitzie Hunter: I can appreciate that. Just building on my colleague's comment about the system, you've interacted with the system across a spectrum at different ages and stages. I'm wondering if you could offer any lessons learned from interacting with the system.

**Ms. Wilma Arthurs:** I think that the government funds very good programs and good agencies. I'm really happy about the change in the new act that looks after developmental services, and the agencies that are funded all do amazingly good work.

That comes down to our communities. Our communities know what's needed. They really do. Everything is there. All we need is—it always comes down to the same thing—more funding so that agencies can expand their programs.

I've said before that our young children, our regular children, are allowed to go to school. Nobody is turned away from school. Everybody gets to go to school. There is no such thing as a child standing at the window going, "Gee, I wish I could be in there. I wish I could go to school," and I think we need to think about that for people in our province with disabilities. I think that there needs to be priority for funding to look after everybody with a disability.

If I could just add something—

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

Ms. Wilma Arthurs: A number of years ago, I had a conversation with Madeleine Meilleur, then-Minister of Community and Social Services. She told me that the government works by the will of the people, which is very true. I've mulled that over many times since she said that. I always thought that people in a disability world needed to make more noise.

But I'm feeling differently now. I'm thinking that the long wait-lists that have been created and the underfunding have created an acceptable level of discrimination in our province. Because of that, the issues facing people with disabilities never become an election platform, because of that level of discrimination. That comes from the wait-list, that it's okay to let people with disabilities sit on wait-lists and wait until they go into crisis.

So families can't make noise. They're tied down, looking after their children. I think what I said earlier about families—our children look to us, we look to our advocates, the advocates look to the government, and I really believe that the government needs to make that noise for us.

The Chair (Mrs. Laura Albanese): Thank you for that talk. Now I'll pass it to Mr. Bailey.

Mr. Robert Bailey: I'd like to thank Mrs. Arthurs, Wilma, for being here. She's a tireless advocate in her community and across Ontario for people with disabilities. I had the privilege to know her late husband, Chris; I worked with him. I know how much he loved Emilia, as well. I'd just like to commend the work you've done. You're the face of people with disabilities and the children that these families are raising. So I want to commend you, again, for the work you've done and for putting a face on something that doesn't get enough attention probably in this province and especially in this place here.

I'll turn the rest of my time over.

**Ms. Sylvia Jones:** Thank you for coming. It's great to see you again, Mrs. Arthurs. I very much appreciate that you have continued to advocate this past year in what must have been a very challenging year.

I wanted to ask you your thoughts on the DSO. I understand that for your own daughter, it has not been an impact, but you do an awful lot of work for an awful lot of families, and I wonder if you can provide the committee with any insight into how have they found that process.

Ms. Wilma Arthurs: I have mixed feelings about the DSO. On one hand, I'm glad that they have developed assessment tools to help families gauge the levels of support that are needed and that that's identified for individuals. But having regional places to allot funding and go through the process—it's not community-based.

Before the DSO was put in place, communities did a good job. It was done through collaboration with agencies, and the community knew the people with disabilities, so that when funds came or a placement became open, all those placements were done within our community. So I do see the DSO as a little bit of a waste of money, another level of bureaucracy. That money could be better spent going directly to the communities and doing the same kinds of things.

In my case—I can tell you my own experience with the DSO—I was able to get an assessment for Emilia, and we were able to document through that her high level of needs, but when we went into crisis, the DSO couldn't really steer me anywhere. They couldn't really answer any questions. In fact, about three months after funding came through for Emilia, I received a letter from the DSO saying, "Congratulations, you have Passport funding." It was clear to me that they did not know what was happening—especially with us being such a public family and being out there.

So maybe there's more work to be done. I don't know. **Ms. Sylvia Jones:** Well, to your point, not only does the community understand the individuals whom they're trying to assist, but they also know what services are and are not available.

**Ms. Wilma Arthurs:** That's right.

Ms. Sylvia Jones: I'm not sure that regional DSOs have that kind of detail.

Ms. Wilma Arthurs: No. And within our community, and I'm sure this is the same across the province, different agencies are able to collaborate with each other too to help support individuals—I've seen that happen many times—whereas that just doesn't happen if it's in a regional office. That community aspect just isn't there.

**Ms. Sylvia Jones:** Thank you. I'll pass it over to my colleague.

Mrs. Christine Elliott: Thank you, Wilma. I can't thank you enough for being here today and for all that you've done and are continuing to do, especially under such difficult personal circumstances in the last year.

I'd just like to make a comment about your last comment in speaking with the minister and government serving the will of the people. I firmly believe that government does have a very large role to play here, that it is incumbent on government to provide leadership to make working with people with disabilities a priority and to educate the general population about the difficulties that people experience in all aspects of their lives.

I think what we need to do—and hopefully we can achieve that somewhat through this committee, but there are other ways that we need to work on it—is to shift the paradigm in people's thinking, to make sure that we include everyone in our decision-making about things like

housing, education, employment opportunities, social and recreational opportunities, so that everyone in Ontario is included and has the opportunity to live a life of purpose and dignity. I can assure you that that's what we're striving for in this committee, and I thank you so much for being here today.

Ms. Wilma Arthurs: Thank you, Christine.

The Chair (Mrs. Laura Albanese): Thank you for sharing your personal story with us and your suggestions. Your story has touched all of us.

**Ms. Wilma Arthurs:** Thank you very much. I appreciate this very much.

The Chair (Mrs. Laura Albanese): Okay, so we—Ms. Sylvia Jones: Chair?

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

**Ms. Sylvia Jones:** Before we delve off into other areas of interest, can I make a couple of requests of the researcher?

The Chair (Mrs. Laura Albanese): Absolutely. Please go ahead.

Ms. Sylvia Jones: Does any ministry have a list of the residential respite beds that are available across Ontario and what kinds of waiting lists are there? And is anyone tracking the numbers—and I'll use Ms. Arthurs's line—of where we have abandoned individuals and families in crisis?

The Chair (Mrs. Laura Albanese): It would also be great to know if there are any beds available that are not being utilized because of underfunding.

Any other requests? Okay, so we may move forward.

#### COMMITTEE BUSINESS

The Chair (Mrs. Laura Albanese): As we mentioned at the beginning of our meeting, we have had the approval to travel. We have eight days, and I would ask our Clerk to—well, you have the calendar at hand, right? Yes.

The Clerk of the Committee (Mr. Trevor Day): The committee has eight days over the winter recess with which it can meet and travel within Ontario. The committee has decided that it will be meeting next week, on the 18th, which currently falls within that recess, so we are down to seven days with which to travel.

So I'm looking for a little bit of direction. The committee had previously spoken of the week of January 13 potentially being a week when the committee would like to travel. There was also talk of five locations: London, Thunder Bay, Sandy Lake, Moosonee and Ottawa. I wanted to check if that's still the committee's intention, but that's where we're at right now.

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

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**Ms. Sylvia Jones:** Just to clarify, the week of January 13, you're actually looking at using five of our seven days?

The Clerk of the Committee (Mr. Trevor Day): It would be up to the committee, but that would be the intention, to meet at those five locations.

Ms. Sylvia Jones: Thank you.

**Mrs. Christine Elliott:** This is all in accordance with what we have previously discussed, isn't it?

The Clerk of the Committee (Mr. Trevor Day): Yes.

Mrs. Christine Elliott: Okay, it's fine.

The Chair (Mrs. Laura Albanese): So do we agree to finalize that as the week we will travel?

Ms. Cheri DiNovo: Sure.

**The Chair (Mrs. Laura Albanese):** Ms. DiNovo? Yes? Okay. I believe that the Clerk had mentioned that we probably would leave on the Sunday, the 12th.

The Clerk of the Committee (Mr. Trevor Day): We'll look at the availability of locations. It would be our intention to get a charter and do a loop, but we will be back in touch now that we have the go-ahead from the House. We can start looking at that, and we'll have more detail for you by next week at the soonest.

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

**Ms. Sylvia Jones:** I was just going to suggest that perhaps we should be looking at booking those last two days—

The Chair (Mrs. Laura Albanese): Yes, that's where I was heading.

**Ms. Sylvia Jones:** —keeping our constituency office happy.

The Chair (Mrs. Laura Albanese): Yes. So we do have another two days that the committee is allowed to meet during our break, and we want to identify those two days. Any preferences?

The Clerk of the Committee (Mr. Trevor Day): All that I would like to add to that is this committee has to have its interim report tabled by the 26th, which is a Wednesday—

**The Chair (Mrs. Laura Albanese):** The 26th of February.

The Clerk of the Committee (Mr. Trevor Day): The 26th of February. Taking into account translation and printing, it would be ideal if we could have it signed off by the 12th of February. We'll start there and see where we can go, but that would be best for us. We will do whatever the committee needs us to do, but if we could have it signed off by the 12th or somewhere in that week, it would give us ample time to get it translated and printed.

The Chair (Mrs. Laura Albanese): Well, to have it signed off on the 12th means that we would have to write it before then.

Mr. Bas Balkissoon: That's right. I was just going to

Mrs. Christine Elliott: I'm assuming that we'll probably do it in the same way that we did with the Select Committee on Mental Health and Addictions. Basically, the interim report was mostly an organized summary of what we had heard.

The Chair (Mrs. Laura Albanese): Okay.

**Mrs. Christine Elliott:** So we should be able to do that with the assistance of legislative research, if that's all right with you?

Ms. Karen Hindle: Yes, that's fine.

The Chair (Mrs. Laura Albanese): Okay, so we're back at choosing the two dates. Do we want those two days to be back to back or do we want them separate?

**Ms. Sylvia Jones:** I, personally, would like them back to back, for what it's worth.

Mrs. Christine Elliott: The only other thing to bear in mind is that there's also, I think—Bas, you're also travelling, doing the LHIN travel as well for social policy. I forget which days we're travelling with that, but I think we just have to organize it with those travel days.

**Mr. Bas Balkissoon:** I think we're starting January 27.

Mrs. Christine Elliott: The 27th, okay.

**Mr. Bas Balkissoon:** And we're going to February 11 or something.

Mrs. Christine Elliott: Yes, that's the last day.

Mr. Bas Balkissoon: We go four, two and two.

Mrs. Christine Elliott: Right.

Mr. Bas Balkissoon: So it's pretty hectic.

**Mrs. Christine Elliott:** So we should probably think about the next week of January, then, after we travel for two days?

The Clerk of the Committee (Mr. Trevor Day): So do we want something in the week of the 20th?

Mrs. Christine Elliott: That's probably best.

Mr. Bas Balkissoon: Or before.

**Ms. Cheri DiNovo:** So we're looking at two days in the week of the 20th? Is that what I hear people want?

**Mr. Bas Balkissoon:** I don't think I'll be travelling all the days. I'm sure there will be other people having to sub in because it's going to be impossible.

**Ms.** Cheri DiNovo: I thought I heard the week of the 20th for two days.

The Clerk of the Committee (Mr. Trevor Day): We've got five days. The week of January 13 is agreed to. It's really just the two additional—

Ms. Cheri DiNovo: The two other days, right.

The Chair (Mrs. Laura Albanese): It's the two additional days that we're looking for.

Ms. Cheri DiNovo: Yes.

The Chair (Mrs. Laura Albanese): And they would have to be anywhere between, let's say, January 20 and February—the 12th?

The Clerk of the Committee (Mr. Trevor Day): Or that week, somewhere in there, now that it doesn't have to be a Wednesday.

**The Chair (Mrs. Laura Albanese):** Well, the 12th is the day we would like to have the report ready.

**Ms. Cheri DiNovo:** So what about that week of the 20th?

**Mrs. Christine Elliott:** Is the 20th and 21st a possibility for everyone else? I think it's a Monday, Tuesday.

Ms. Cheri DiNovo: Yes, just let me get there.

The Chair (Mrs. Laura Albanese): We just want to hear something from Karen.

**Ms. Karen Hindle:** My understanding with respect to the 20th and the 21st is that because we will be travelling the immediate week before, it's going to be difficult for us to turn around all of the summaries of the witness testimony for those five days by the next Monday.

**Ms. Sylvia Jones:** You can say "impossible." That's okay.

**Mrs. Christine Elliott:** Yes, but we don't need to have that to hear from more witnesses.

**Ms. Karen Hindle:** Oh, I thought that we would be discussing the draft report.

**Mrs.** Christine Elliott: No, no, no. Two more hearing days.

Ms. Karen Hindle: Okay. That's fine.

Mrs. Christine Elliott: Breathe, breathe.

**Miss Monique Taylor:** That's okay, Karen. You're off the hook.

The Chair (Mrs. Laura Albanese): So that's a good point. We don't have two more hearing days; we have two more days to adopt the report. So it could be one for hearing and one to adopt; we don't need the whole day to adopt the report if it's going to be just the summary of everything we've heard. So let's say that that is February 12 for half a day.

The Clerk of the Committee (Mr. Trevor Day): So basically what we have is that the House will return on the 18th of February, which is a week before the report needs to be in the House. So the week turnaround is too little for translation and printing. We can push it but it's tight, which means that somewhere in the remaining two days I need all of you to say, "We agree to this. It's okay. Send it off." I don't need a full day.

The Chair (Mrs. Laura Albanese): So the Clerk has identified the 12th as that possible day.

The Clerk of the Committee (Mr. Trevor Day): Well, the reason I said the 12th was I thought we had all Wednesdays. At this point, because we're not all Wednesdays, you can put it anywhere before the House returns, but somewhere in there just to say, "What we have in front of us, we agree to it." It could be our interim, and you can present it to the House.

The Chair (Mrs. Laura Albanese): So it could be anytime; however, we're hearing that we don't want it to be back to back with our travelling week.

**Ms. Sylvia Jones:** No, we've resolved that. It can be back to back if we so choose, right?

The Chair (Mrs. Laura Albanese): Okay.

**Ms. Sylvia Jones:** So I can't do February 12, for what it's worth.

The Clerk of the Committee (Mr. Trevor Day): It doesn't have to be the 12th. That was just one of the Wednesdays, the last Wednesday—

The Chair (Mrs. Laura Albanese): So we'll go back to Ms. DiNovo's suggestion, which was the 20th and the 21st?

**Ms.** Cheri DiNovo: That's what I heard. It's close to the other hearings, so it might be fresh—I don't know.

The Clerk of the Committee (Mr. Trevor Day): So I think what Karen was bringing up and the issue there is,

you will hear from people throughout that week for five days; you will hear from people the following two days, potentially here. Research will go off and put together a wonderful interim report. At some point, this committee has to say, while it's sitting, "Yes, we're adopting that, and that's what you're going to present to the House."

**Ms. Cheri DiNovo:** Well, now, sorry, I'm hearing from Christine, who is the expert here, that the interim report is a summary of what we've heard. But then the report writing itself to the House is a different piece of work entirely.

Mrs. Christine Elliott: Correct.

**Ms. Cheri DiNovo:** So, is that not correct?

The Clerk of the Committee (Mr. Trevor Day): It's basically going to be—if you're tabling it as your interim report, this committee has to say, "We agree with it," whether it's verbatim, what's there. At some point, it has to say, "We agree. Chair, present it to the House."

Mrs. Christine Elliott: And we can do whatever we decide to do. That's just what we did with the Select Committee on Mental Health and Addictions. Given the tight time frame that we have and our desire to hear from as many witnesses as possible, I would suggest that we do our interim report in that format because it's relatively straightforward; we don't have to spend hours deliberating with each other.

**Ms. Soo Wong:** No recommendations.

Mrs. Christine Elliott: No recommendations; it's just a summary. Then we can choose our direction from there. We have that next window of time. So that's why I would suggest that we sit on the 20th and 21st, hear the rest of the evidence and then pick another day where we can go through a draft, because I don't think we would need more than a day.

The Chair (Mrs. Laura Albanese): Or can the draft be sent to us individually in an electronic form, and we send our comments back?

**Mr. Bas Balkissoon:** But if you send comments back, we may have disagreeing comments that we need to wordsmith, so we would have to meet to wordsmith.

**Ms. Sylvia Jones:** But just keep in mind that there are no recommendations; there's no editorializing in this interim report, if we use mental health and addictions as the model.

**Mr. Bas Balkissoon:** But we may not agree on the wording unless we're here in person. Otherwise you'll be sending one comment and I'll be sending a different one; what does research modify it to be? We have to agree on any modifications.

Ms. Sylvia Jones: Could we get the interim report on mental health and addictions circulated so people get a concept of what—it was very benign is what I'm trying to say.

**Mr. Bas Balkissoon:** Yes, but we did meet on all of it; we didn't do it electronically.

The Clerk of the Committee (Mr. Trevor Day): Can I suggest that—we can do those days the following week, research puts together an interim report/witness summary of what was heard and we circulate it. If we're allowed to

take that first base document and send it off for translation, which is where all the time is really spent, and have that translated, if there is a slight word change to that, when we meet—at this point, I'm going to say the 19th; the House is back—the translation won't take as long. We're talking about small bits of words. So we'll get it translated. If the committee authorizes us to go ahead and do that, at the authority of the Chair to translate that without the committee meeting, on the 19th the committee will be able to make changes—minor, I hope—and then we can get those changed and printing shouldn't be a problem for the next week.

The Chair (Mrs. Laura Albanese): Is that agreeable to everyone?

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Mr. Bas Balkissoon: We're going to try.

The Chair (Mrs. Laura Albanese): Okay.

The Clerk of the Committee (Mr. Trevor Day): Okay. So the two dates are going to be—
Interjections.

The Clerk of the Committee (Mr. Trevor Day): Which dates were they?

Mr. Bas Balkissoon: The 20th and 21st. Isn't that—

The Clerk of the Committee (Mr. Trevor Day): The 20th and 21st?

**Miss Monique Taylor:** Are they all day?

The Chair (Mrs. Laura Albanese): Yes.

The Clerk of the Committee (Mr. Trevor Day): Yes.

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

Mr. Jack MacLaren: Can I ask a question of clarification, because I have no experience with this kind of thing? If this is an interim report, when would the final report be? I assume there's a final report.

The Clerk of the Committee (Mr. Trevor Day): It's due May 15.

The Chair (Mrs. Laura Albanese): It's due May 15.

**Mr. Jack MacLaren:** May 15? Oh. And that would be where, if there are recommendations that come out of all this input—

Mrs. Christine Elliott: We'll have to spend a lot of time together talking about what our recommendations are going to be.

Mr. Jack MacLaren: Okay.

Ms. Cheri DiNovo: That's a whole other thing.

The Chair (Mrs. Laura Albanese): So that's good? January 20 and 21?

The Clerk of the Committee (Mr. Trevor Day): We're going to advertise, get our stuff out there. We already have basic authorization, so it'll just be consultation with you.

Ms. Mitzie Hunter: And those are in Toronto—

**Mr. Bas Balkissoon:** No, all over the place.

**Ms. Mitzie Hunter:** —or we don't know yet? The 20th and 21st.

The Chair (Mrs. Laura Albanese): No. The 20th and 21st would be in Toronto.

Interjections.

**The Chair (Mrs. Laura Albanese):** The other ones are not.

The Clerk of the Committee (Mr. Trevor Day): The other ones are currently London, Thunder Bay, Sandy Lake, Moosonee and Ottawa. They are the other five.

**Mr. Bas Balkissoon:** You're going to email us the schedule when you have it set? Okay. As soon as possible.

The Clerk of the Committee (Mr. Trevor Day): As soon as we get locations, we'll—

The Chair (Mrs. Laura Albanese): Yes, and we will be advertising, as agreed, in all the different locations that we will be travelling to, and in the Toronto area as well.

Interjection.

The Clerk of the Committee (Mr. Trevor Day): The 13th will be 9 until 12, 1 until 5.

**Miss Monique Taylor:** Oh, we're here on the 13th, 9 until 12, 1 until 5?

Interjections.

The Clerk of the Committee (Mr. Trevor Day): Sorry. Not the 13th. Sorry. That was the 18th.

Interjections.

**Miss Monique Taylor:** So we leave the 13th, and we come back when?

The Clerk of the Committee (Mr. Trevor Day): We'll probably leave the evening of the 12th.

The Chair (Mrs. Laura Albanese): We'll probably leave on the 12th.

**Miss Monique Taylor:** Yes, but I just kind of want to have a—the 12th until the—

The Clerk of the Committee (Mr. Trevor Day): At this point, the 12th until the 17th.

Miss Monique Taylor: Okay.

The Chair (Mrs. Laura Albanese): The evening of the 12th to the evening of the 17th of January.

The Clerk of the Committee (Mr. Trevor Day): We'll send out an itinerary as soon as we have some information on it. It will most likely be a charter loop that we take throughout the province.

**The Chair (Mrs. Laura Albanese):** And then January 20 and 21 in Toronto, 9 to 12, 1 to 6.

Interiections.

The Chair (Mrs. Laura Albanese): Oh, 1 to 5. Sorry. Mr. Bas Balkissoon: I'm on two committees. I can't travel every day.

Interjections.

**Mr. Bas Balkissoon:** Soo knows my daughter is expecting. My wife won't let me go.

Interjections.

**Mr. Bas Balkissoon:** My daughter is not going to be pleased.

The Chair (Mrs. Laura Albanese): Order. Ms. Hunter has a question.

**Ms. Mitzie Hunter:** Just for the travelling, the scheduling of the hearings, with the advertising, is it the same process that we've been following, that people send in a request to appear before the committee and then that's how—

The Clerk of the Committee (Mr. Trevor Day): We have had some questions about locations. I've been able to relay what the conversation has been in the committee. At this point now, with us actually having dates, we'll be able to put an ad out. I think what you'll find in the requests that have been given to the members of the subcommittee—the locations will start to fill up. You'll see a lot more. We put in the locations they requested—

Ms. Mitzie Hunter: I see. So it's the same list.

The Clerk of the Committee (Mr. Trevor Day): You'll get the same list. What we'll be able to do is set up lists for each location, so that—

**Ms. Mitzie Hunter:** That would great. That would be helpful.

The Clerk of the Committee (Mr. Trevor Day): It's a little better that way. It's not just one big list.

Ms. Mitzie Hunter: Thank you.

The Chair (Mrs. Laura Albanese): Yes, and the researcher, Karen, has something that she would like to bring to the committee's attention.

Ms. Karen Hindle: I'm sorry. I know that you all want to head out the door, but there's an issue that's come up with respect to a request from the committee. On December 4, Ms. Hunter asked, on behalf of the committee, for a detailed map of the DSO structure, including community agency partnerships from MCSS. The ministry has written back to us asking for some additional information. You can find a copy of the letter in your package.

They have indicated to us that they are happy to provide whatever information the committee is requesting, but they need additional detail or additional information as to what exactly the committee would like the ministry to provide. So any—

**Mr. Bas Balkissoon:** I guess it was a DSO location, the agencies and what age group the agencies are serving, and the disability, if they specialize. At least give us a list, so we know what kind of services they're providing.

**Ms. Cheri DiNovo:** You made it pretty clear. It should be an organizational map, showing what agencies are reporting to DSOs etc.

Ms. Karen Hindle: So is it an organizational—

Mr. Bas Balkissoon: But we would need some background information on the agencies, saying these are the services they deliver, so like a quarter-pager or a halfpager on each agency, because that will give us an idea of where there are gaps. If we don't know what these agencies are doing, we will have no idea what the gaps are.

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

**Ms. Sylvia Jones:** I'm a little disturbed that they're having trouble fulfilling this request.

**Mr. Bas Balkissoon:** The letter says they are willing to do it; they just need more clarification on what we need

**Ms. Sylvia Jones:** So it's the 13 DSOs, and then within each of those DSOs, what agencies are they referring their individuals that they are attempting to serve?

Mr. Bas Balkissoon: Right.

The Chair (Mrs. Laura Albanese): Ms. Hunter, it was your request originally, so let's hear from you, as well.

**Ms. Mitzie Hunter:** It was my request, and I have to say, and I can understand if it needs to be more specific. I do think that Ms. DiNovo's sort of visual system, DSO—

The Chair (Mrs. Laura Albanese): Organizational chart.

Ms. Mitzie Hunter: —organizational structure—how does it interact with the agencies? I just want to get a flow of what's coming into the DSO and how they're interacting with the partners. It's just simply so that we can have a one-page placemat of the DSO structure. That was my intention, and I'm also—if the committee would allow—happy to convey this to the ministry as well, if that's helpful.

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

Ms. Cheri DiNovo: Yes, I would say this is a pretty straightforward request that all organizations should have at their fingertips, one would think, of their organizational structure and who reports to whom. That's really what

we're asking about here. It would be great to have a halfpage on everybody, but I would be happy if we just knew what the services are and a word or two about what they provide. It should be able to fit on a placemat, or maybe a very big placemat; I don't know.

The Chair (Mrs. Laura Albanese): A foldable placemat.

**Ms. Cheri DiNovo:** I'm also a little disturbed that it's not readily available—

Interjection.

The Chair (Mrs. Laura Albanese): Maybe they misunderstood us.

Ms. Karen Hindle: They have indicated that they intend to provide a response to the committee by December 18, which will be the next committee meeting. In the event that we get it in advance of December 18, we will circulate it through the Clerk, but otherwise we will make copies available to committee members next Wednesday.

The Chair (Mrs. Laura Albanese): Thank you very much. We are adjourned for the day.

The committee adjourned at 1758.

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#### Also taking part / Autres participants et participantes

Mr. Robert Bailey (Sarnia-Lambton PC)

Clerk / Greffier Mr. Trevor Day

#### Staff / Personnel

Ms. Karen Hindle, research officer, Research Services