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## **Official Report of Debates (Hansard)**

Wednesday 15 January 2014

## **Journal des débats (Hansard)**

Mercredi 15 janvier 2014

**Select Committee on  
Developmental Services**

Developmental services strategy

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

Stratégie de services  
aux personnes ayant  
une déficience intellectuelle

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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 15 January 2014

Mercredi 15 janvier 2014

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

**DEVELOPMENTAL SERVICES STRATEGY**

**MS. SUSAN THOMS**

**The Chair (Mrs. Laura Albanese):** Good morning, everyone. We are starting our second day of public hearings here in Thunder Bay. It's another beautiful morning.

We will start by hearing first from Susan Thoms. Good morning. Welcome to our committee.

**Ms. Susan Thoms:** Good morning to everyone here.

**The Chair (Mrs. Laura Albanese):** You will have up to 20 minutes for your presentation. If the presentation is any shorter than that, that will leave some time for comments or questions on behalf of the members of the committee. You may start any time.

**Ms. Susan Thoms:** Thank you for the opportunity to present. My name is Susan Thoms. I am 63. I am one of many mothers my age and older who care for our sons or daughters with special needs, who live at home.

I am here because my 27-year-old son who has multiple needs has experienced discrimination in the school system, and we currently struggle to maintain an adequate level of funding to allow us to purchase the supports that he needs to ensure any quality of life.

The experiences that Steven has had and continues to have directly affect me and my family. My experience due to his many needs ranges from fatigue to unbridled love. At nighttime I may go to bed feeling overwhelmed with all the things that I need to do for him, but every morning I am greeted with a smile that lights up his room. Despite the fact that he needs daily help with every facet of his life, somehow Steven's amazing personality keeps me going.

There are so many things I want to say that it is hard to slow down in order to be articulate. When I very recently learned about this committee, my thoughts were, "Do I want to retell my story? No, not really." I reasoned that if I could connect with one person on this committee, my experiences could possibly lend themselves to making some real change.

Although I want to discuss our current needs, I feel it is important to begin by revisiting my son's school experience and the period known as transition. Although the early years were emotionally and physically draining,

my most difficult experiences were with the school system. From the beginning, we experienced a system that was not eager or prepared for him.

When I went to register Steven in JK at our accessible neighbourhood school, I was politely but firmly directed to register him at a school in town. Due to the unwelcoming reception, I complied. I enrolled Steven at a school the board of education directed me to. After two years, it was suggested that he attend yet a different school because there was an elevator there. I felt as though Steven's continuity of education, friendships and familiarity with his present school were ignored. Due to this, I again felt unwelcome, and I complied. In the beginning of his time at the second school, we were fortunate to have wonderful teachers.

As my son grew, plans at the board of education office also grew. I heard through the grapevine that the board was planning a segregated class for students who required special assistance. After not being welcomed by our neighbourhood school and then being persuaded into relocating to yet another school, we subsequently received a letter advising us that our school board was constructing a segregated classroom and that they had selected Steven for attendance in it.

I was livid. I was forced to take a stand. All along I had simply wanted him included and learning in a regular classroom. At this point, I understood that the school board was not educated or equipped to accommodate children with my son's needs. They were scrambling to try to set up a segregated classroom in an attempt to honour their responsibility to accept my son and other children with special needs, but with little in the way of resources or the know-how to include him in a meaningful way. They were simply viewed as hard-to-serve students—to fit into their current system; not as children embarking on their life journey, children needing to learn and enjoy what the school system offers most children. So much for the slogan "lifelong learning," at least as demonstrated by the decision-makers at the school board.

In the book *Changing Canadian Schools*, Marcia H. Rioux writes in chapter 3 about her idea that the education system is a system of social disempowerment. Ms. Rioux writes about four myths that she believes people assume about education: the myth of universality in education; the myth of equitable education; the myth of meritocracy; and the final myth, "that the structure of

the education system results in a social and economic system that ensures equality based on ability.” I think my son’s experience with our school system would easily be an example of these myths.

I again draw your attention to an article entitled “School/Family/Community Partnerships: Caring for the Children We Share” by Joyce L. Epstein. In summary, Epstein states “the main reason to create such partnerships is to help all youngsters succeed in school and in later life.” Yes, they are students, but children first. School ends but life continues after the school door closes.

The point I am making is that partnerships are important at every level. None of us operate in isolation. In their decision to arbitrarily pull my son from his peers and isolate him, I was again not consulted. This time I reached out to the ARCH Disability Law Centre based in Toronto to help me. My gut feeling told me that my son needed the company of other children and that isolating him was not only not equitable but that it would be detrimental. Putting my non-verbal son in a classroom with other non-verbal students and/or children with behavioural issues would most certainly provide little in the way of growth opportunities for him or his peers.

During the tribunal hearing that ensued, due in large part to the help that ARCH provided, the board of education representative who attended the provincial hearing fell asleep during the hearing—a wonderful example of the board’s level of interest in my son’s placement.

Through ongoing advocacy, Steven was not placed in the segregated classroom. This does not mean he received an equitable time in school. Due to his multiple challenges, educational activities like being included in class outings did not routinely happen. Lessons were not routinely modified for him. Some teachers and some educational assistants were good about trying to ensure that my son was receiving modified instruction, but there was definitely no consistency.

I think I know my son pretty well. I know he loves people, he loves to be included and participating in activities. He brings out the best in those around him, given the chance for them to get to know him. He is not to be feared. He cannot harm anyone. He is an amazing listener—he’s non-verbal. He is patient and open-minded, and the list goes on.

My beliefs lie along these lines: All people can learn and need choices; that differences are good—in fact, life would be boring without them; that children learn from one another, as well as from adults; that by segregating children with special needs, you are denying them the opportunity to learn, and that the world includes a wide variety of people and abilities.

If in life we shunt our more difficult concerns off to the side, they somehow wait for us until we have some even more pressing issues to deal with. I think everybody can relate to that one.

Isolating children who are developmentally delayed is a system I believe that slows the growth of all children and adults. A system of education that would allow a child to be segregated from his peers is not one that I

support. Not consulted or offered choice about placement, not being open to even trying to include Steven in a classroom, dismissing him as unworthy of enjoying the classroom experience that most children enjoy is discrimination to me.

One incident stands out for me from Steven’s grade school time. Dropping off an item to his school one day, I discovered Steven sitting on a toilet unbelted and unattended. Keeping in mind that he is non-verbal, he has epilepsy and spastic quadriplegia, you might imagine my angst. I waited some time before the support person returned. Shortly after reporting this incident to the principal, I received a letter stating that if I wanted to visit the school I would have to request permission to come on school property—which I ignored, of course.

An incident like this would lend itself to questioning a system that would hire and keep on an employee who demonstrated this level of performance. This person was also responsible for assisting my son academically. Obviously, the expectation that my son learn to the best of his ability was not on the school board’s agenda. I note this incident to highlight the myth of universality and the myth that education is equitable. One just has to be the parent of a child with higher needs to know first-hand that they are indeed myths.

The level of instruction that a student receives varies with each teacher they have. If you are a child requiring support, your education really depends on the knowledge and skill that your support person and the teacher display. Teachers work for the school board. Segregating children who come into the school system with special needs starts at the top. It is the system that dictates what will happen and the level of funding to make it happen. If children with special needs are to truly be given the opportunity to learn to the best of their ability, they need educational assistants who are skilled at helping them with their specific support needs—people who take their responsibilities seriously.

#### **0910**

When grade school ended, it was again presumed that Steven would attend a large segregated classroom in a local high school and not attend the high school that the rest of his peers and friends were headed to. After some deliberation, he was granted permission to attend the high school that his peers and friends were going to attend. The stipulation was that he could not attend any science or music classes. Steven ended up experiencing the support of some wonderful educational assistants and teachers, a few of which stand out from each school that he attended.

There were many bumps in Steven’s school days. Despite them, I know that he misses all the people who took an interest in him, and there were many exceptional people. My thoughts are that in the end, Steven taught them, or at least allowed many people the opportunity to get to know him.

While these experiences are not current, I have been informed that the school system still operates on a deficit model, assuming that children are not competent.

We do not all aspire to be rocket scientists. I do not think we need that many. Everyone needs to have a meaningful place in society, and that starts with participating in the mainstream at school along with their peers and with the support to enable them to reach their potential, whatever that may be.

“Transition” is the term used to describe the move that students labelled as having special needs make from the education system out into the community. While the term “transition” generally denotes a smooth move, that is not generally the case, due to the very limited supports available to young people leaving the school system.

My son’s transition was abrupt and impersonal. One evening about a month before his exit from school, I received a telephone message advising me that Steven would be finishing school in June. I had been under the assumption that he had until the end of his 21st year to attend school. He was 20 when I received the message.

A number of major issues suddenly arose. Were we going to receive an increase in support dollars so I would be able to continue to work, and if so, how much and when? If increased funding were not forthcoming, and quickly, I would have to retire early.

Another very stressful time: I quickly discovered that I had to complete the paperwork required to access what was called Passport funding, and then I had to wait for a reply. I include this experience to show the level of preparedness that the school system demonstrated in our situation and to emphasize the amount of planning allocated to my son, who had been in the same school system since JK. It would have been extremely helpful to have had two ministries working together to help me plan a smooth transition for Steven.

Once we had the knowledge that Steven’s school years were ending, we were offered help by the Ministry of Community and Social Services to assist us in trying to obtain the funding that would allow us to purchase daytime supports.

I did not know if we would receive funding, or how much. I could not even begin to think about hiring anyone to cover the daytime hours that would allow me to continue working. I was forced to choose between financially supporting my son and my family or staying at home to do the daily support required to ensure that his health and well-being were met. I quit my job.

Funding was approved late in the fall. I immediately began looking for a suitable person to hire on as a daytime support for Steven so that I could return to work and financially support my family.

Since our initial receipt of Passport funding seven years ago, we have never received an increase in the amount allocated to Steven to purchase supports. As the years roll on, the need for some level of cost-of-living allowance to accompany the basic funding allocated for supports for Steven emerges loud and clear.

I currently have seven different people who do part-time support work with my son. I am confident that if I could offer a higher hourly wage, I would be able to attract and retain people on a more permanent basis.

Over the years, we have had dozens of people doing support work with Steve. Many people have stayed on only long enough to locate a full-time job with benefits and a higher hourly rate. Losing good people to agencies is an all-too-common occurrence.

When a scheduled support person is ill, moves on to take another position or is absent for any other reason, I must become the person who supports my son, which leads me to another issue that is a common situation for many of us who are caring for a son or daughter with special needs at home.

I recently received a letter from our Lutheran Community Care Centre, advising me that I had not used some or all of my son’s Passport funding. The letter went on to advise me that someone would be calling to offer us assistance around how this funding could be used.

I know how to use funding. I want my son engaged. If I have no one to do the support work, I have no one to spend the money on. I am the one to fill in. I am the person responsible for doing the administration work, but I cannot pay myself. I am grateful for the funding that we receive. I think that we use the funding wisely. I realize that many families do not have funding.

I can understand why this committee has been struck. There is an enormous need to overhaul the systems. I do not have many answers, but here are some ideas:

- (1) Stop the endless assessments and reassessments.
- (2) For people who have lifelong needs, grandfather funding for the supports that they require, and ideally ensure a cost-of-living allowance so they are able to retain their support system.
- (3) As an incentive for graduates of the PSW program who choose employment in a home-based setting, rebate a percentage of the PSW course for any individual who remains in a placement in a home setting for a minimum of a year.
- (4) Set up a benefit plan for PSW graduates who are employed in a home setting, allowing them to contribute to a choice of plans, i.e., dental, eye care etc. If the person pays for the entire plan, it could be tax deductible. This might attract more people into this occupation and help to keep them working in a home setting.
- (5) Set up some kind of a provincial pension plan for people who do PSW work and who are employed in a home setting—a plan that is portable and funded by what they put in. As a larger provincial plan, it would grow over time.
- (6) Set up a registry of qualified PSW graduates so that parents would have access to people interested in doing support work in a home setting. Set it up at the college.

(7) Incorporate a mandatory course on inclusion at the faculty of education, rather than an optional course on special education—and I’m not really current, so I don’t know if that’s taking place.

(8) Early on, establish and keep a circle of friends going for students who are developmentally challenged. This concept could be a priceless method to assist

countless young people throughout their school years and beyond.

(9) Consider subsidizing the private sector to build small housing units, the idea being that there could be some shared living space, some private space and shared support between the people sharing the building. Parents are willing to invest in housing for their children, but 24/7 care is prohibitive.

In conclusion, what happens when I am not physically able to take care of my son? Who will advocate on his behalf?

Steven was originally part—I don't know if I can read this—of a pilot project called Choices. Through this project, individualized funding was unavailable. I was not yet experienced enough to understand what a significant opportunity this was, or how important it could have been for my son. At that time, the request I made was for some help to connect my son with his peers, the children he was in school with. Steven's need for accessibility, combined with our location in the country, made connecting with his friends a challenge. If there's one thing I regret, it's not understanding the importance of individualized funding and requesting it for him.

At the end, I explain what meritocracy is, because I sure didn't know. The education system is structured and run in a way that is necessary for the continuation of the current economic and social systems.

Thank you for your time.

**The Chair (Mrs. Laura Albanese):** Thank you for this passionate presentation. There is no time left for questions from the committee, but we want to thank you for sharing with us so intimately the story of your family and your son. Thank you for your suggestions. They are very much appreciated, and we'll take them into consideration.

#### MS. DERYLE BOND

**The Chair (Mrs. Laura Albanese):** We will now ask Deryle Bond to come forward. Good morning. Welcome to our committee. Make yourself comfortable. As you have heard before, you will have up to 20 minutes for your presentation. You may start any time you feel comfortable.

**Ms. Deryle Bond:** Thank you for the opportunity to address the committee.

I wasn't going to get emotional, because I don't usually, but after listening to Susan—my name is Deryle Bond. I'm the sister-in-law, advocate and power of attorney for Maisie Bond. Maisie Bond is 62 years old. She's a senior citizen with a pervasive developmental disability. Mentally retarded with personality disorders, bipolar, manic, multi complex support needs—these are several titles that have been addressed to her situation over her 62 years.

0920

Excuse me. I'll get it together here.

In 1995, Maisie was chosen to be in the pilot project for Choices individualized funding. At this time she

moved into residential living at age 43, having lived at home with her widowed mother until her mother was 83 years old.

Until October 2012, for 17 years, Maisie has lived a very full, functioning and happy life. She has been served very well by the system under Choices individualized funding. With the help of a planner/broker, we navigated through the system as changes came and went. Maisie lived in a family environment, working during the day at ARC Industries/Monty Parks Centre and living a normal, routine, day-to-day life with a family which included family outings, camping, mini vacations and simple day-to-day routines.

As Maisie has aged, it has become more difficult for her to keep up with the daily work grind, and at age 60, she retired from Monty Parks Centre after working there for 30-plus years. This development caused her residential model to change, requiring 24-hour residential care as opposed to part community placement/block funding and part residential placement/individualized funding.

Unfortunately, at this time she had a bout of ill health that required her to become hospitalized. When her medical problem had improved and she became stabilized and able to return to the community, we were told that there was no suitable residential placement for her. There were no family home placements or group home vacancies at this time. She had to live in the hospital. This situation lasted for the next six months. This was one of the darker experiences of her life.

**The Chair (Mrs. Laura Albanese):** Take your time. Take a breath if you need to. We'll wait.

**Ms. Deryle Bond:** At the end of six months in the hospital, she was offered a bed in a seniors' long-term-care home, Lakehead Manor. Having no other options, Maisie and family agreed to her placement in a long-term-care home even though it is another medical model, not a model set up to support her developmental needs.

As a transition from the hospital to long-term care, Maisie received a personal support worker to assist her to adjust to this new residential model. Her individualized funding through Choices is now being called transition funds for 30 days. We then had to negotiate an extension to 60 days, then negotiate an extension to the end of March 2014, and now will be submitting a budget from March 2014 to April 2015. These dollars did not automatically follow Maisie. The family had to lobby the system for 30 days, then 60 days, then the end of March, and finally submit a budget to the end of March 2015. What happened to the individualized funding that she has had since 1995?

Maisie is receiving a personal support worker three hours per day Monday to Friday and 16 weekend hours per month for recreation. These hours allow Maisie to help maintain the lifestyle that she has experienced over her last 20-some years. The support hours allow a personal support worker to assist Maisie on a daily basis to partake in the in-house daily programs at the manor; community programs outside the manor; help to educate the manor staff in the strategies that work in assisting

Maisie to stay balanced; help her to keep her personal things—for example, keep clothing in order, organizing, replacing, and helping Maisie to make appropriate choices; her recreation, attendance at hockey games—of course, Christmas is just past, and she went to the Santa Claus parade—Parade of Lights, Christmas banquets, bowling banquets and Special Olympic bowling on the weekends.

These are the necessary activities that Maisie needs to be assisted with to keep her balanced to live a normal lifestyle. Maisie does not have the mental ability or cognitive skills to handle these necessary daily skills for herself.

The staff at the manor is highly challenged with their present hours to just complete their present long-term-care duties. They were not allotted extra hours to handle Maisie's personal developmental needs. Family and staff have observed this to be true over the last six months of her placement in a long-term-care facility. Family can also attest to the fact that long-term-care staff do not have the adequate hours to complete their own duties. Maisie's mother was in long-term care from 1998 until her passing in 2003. We observed the same timelines that were not adequate then, and the system has not improved in that respect. Therefore, these areas of Maisie's life will go unattended, and she will slide into an uncontrollable situation, making her a danger to herself and others, becoming a crisis situation for everyone.

There is no guarantee of Choices individualized funding continuing. Funding is always tentative: maybe, maybe not. We're told that individualized funding no longer exists. Aging family members will limit the possibility of lobbying and negotiating support on her behalf in the future. There is the possibility that the Ministry of Community and Social Services will not share Choices individualized funding with the Ministry of Health, where Maisie has been placed by the Ministry of Community and Social Services. A group home is not likely as a placement because of the cost of the group home. It could be up to \$300,000 a year, as opposed to her current individualized funding of \$35,000 a year.

In conclusion, Maisie's developmental handicap is not going to change for the better or go away; it is there to stay until the end. Without this assistance in Maisie's daily life, she will slowly slide into an uncontrollable situation, making her a danger to herself and others and becoming a crisis situation for everyone.

Why is her support funding always on the line and in jeopardy? Why is the system becoming harder to navigate? When the Minister of Community and Social Services stated that funding for developmental services has had a 63% increase since 2003, where did Maisie's \$35,000 go?

Our solution for Maisie would be to see Maisie's situation be grandfathered, with her individualized funding through Choices in the amount of \$35,000 per year until her death, or put her in a group home at \$300,000 per year.

Thank you.

**The Chair (Mrs. Laura Albanese):** Thank you very much for sharing such an emotional story with the members of the committee.

We do have about three and half minutes for each party to ask questions. Ms. Elliott?

**Mrs. Christine Elliott:** Thank you very much, Ms. Bond, for coming and speaking to us today about something that is obviously very personal and very difficult to talk about. We've heard similar stories from other families.

What I'd like to ask you about is, has Maisie articulated to you what she would like or, if not, what would be the ideal situation for her, as far as you and the family are concerned?

**Ms. Deryle Bond:** She would be fine where she is now with personal support, with what she has now, because it keeps her balanced. With the staff from the manor and her personal support, she would be fine.

**Mrs. Christine Elliott:** So as far as you're concerned, it's okay for her to be living in a long-term-care facility at this point?

**Ms. Deryle Bond:** As long as she has personal support dollars, yes.

**Mrs. Christine Elliott:** Okay. But yet you can't get that securely funded; you're constantly having to negotiate it.

**Ms. Deryle Bond:** Correct. It probably would be there, but you never know that. I'm over 70, and her other brother is over 80 and not well. I mean, pretty soon, she's going to have nobody to advocate for her, and so everything will just go down the tubes.

**Mrs. Christine Elliott:** That certainly has been a concern that has been expressed by many family members, about what's going to happen when they're not there any longer to be able to advocate. So in all fairness—

**Ms. Deryle Bond:** So it would be this or a group home, but, I mean, forget a group home. You're not going to get a group home in Thunder Bay in the next 25 years.

**Mrs. Christine Elliott:** Are there any group homes for more senior people with developmental disabilities in Thunder Bay?

**Ms. Deryle Bond:** I don't think for seniors specifically. I think they're integrated in with the other group homes.

**Mrs. Christine Elliott:** But as far as you're concerned, there's really nothing any more suitable for her than where she is right now?

**Ms. Deryle Bond:** She's fine where she is, with her funding, but without funding—no.

**Mrs. Christine Elliott:** Okay. There's a question about whether she'll lose it at 65. Has anybody said anything to you about that?

**Ms. Deryle Bond:** With the Choices individualized funding, there wasn't an age limit. We just assumed that's—I mean, it's not a pension; it's not ODSP. It's her personalized funding.

**Mrs. Christine Elliott:** Okay. Thank you very much for being here.

0930

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

**Ms. Cheri DiNovo:** Thank you very much. Certainly, I just want to assure you that this committee has been struck and we're here to make things better. We've heard similar stories from other folk who have come forward at hearings. Some themes emerge, one of them being that dealing with a system that's very discretionary instead of entitlement, like health—she should be entitled to what's necessary for her to have a healthy life, and clearly that's not working. So I want to assure you that we're committed to changing it. That's number one.

Just a question about the long-term care: She spent six months in the hospital. When you look at the cost of that to the government, to us all, that is outrageous. To your knowledge, is this happening fairly frequently in Thunder Bay, that people are spending long periods of time in hospitals because of want of a bed somewhere else?

**Ms. Deryle Bond:** Oh, definitely.

**Ms. Cheri DiNovo:** So that points me to research again. I would love to know about alternate levels of care in hospitals. I think we've asked this before: How many people are in hospitals who have developmental disabilities and who are waiting for beds? That would be a very important figure to have.

Thank you very much.

**Ms. Deryle Bond:** Thank you.

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

**Ms. Mitzi Hunter:** Thank you, Madam Chair. Ms. Bond, thank you so much for sharing Maisie's story and for all of the work and dedication that you've done on her behalf over the years. As others have said, the purpose of this Select Committee on Developmental Services is to look at how we provide that continuation of support across a person's lifetime at different points and stages of life. Very important, and it's really stated in the mandate of the committee, is the cross-ministry support and coordination. We've certainly heard that today and it is one of our core mandates that we are seeking to improve. You've actually, in your very well-presented documents, which we have, illustrated a need to have better coordination between the Ministry of Community and Social Services and the Ministry of Health. We heard earlier about the need for the same with the Ministry of Education. We've received that information, and the intent is to make sure that we have better coordination so that there is not that impact on the individual in terms of their quality of life. I just want to thank you for your presentation today and to assure you that the committee is here to listen and to act upon these recommendations.

**Ms. Deryle Bond:** Thank you very much.

**The Chair (Mrs. Laura Albanese):** Thank you once again for presenting to us.

Just a brief parenthesis for the committee members: We do have confirmation that the Lutheran Community Care Centre has accepted to come and present to the committee at 1 o'clock this afternoon. That's not on the agenda, but we will add them on if the committee agrees. We wanted to hear from them. They prefer to come and

see us rather than, I guess, us going to see them. We may be too many for the centre to handle. They'll be here at 1 o'clock.

MS. SANDI BOYES

**The Chair (Mrs. Laura Albanese):** We'll now call Sandra Boyes to come forward. Good morning and welcome to the committee.

**Ms. Sandi Boyes:** Good morning. Can you hear me?

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

**Ms. Sandi Boyes:** Okay. Thank you for giving me the opportunity as well to come and speak. My situation is a little bit different. We're all here for the same reason, I believe. Do you have my package in front of you, as well?

**The Chair (Mrs. Laura Albanese):** I think it's being distributed as you speak.

**Ms. Sandi Boyes:** Okay. In my package, I'm speaking on behalf of my son Thomas Boyes. He's intellectually disabled and he has low tone and balance. He's never been identified with a specific label, as we call them, which doesn't give him the opportunity for a lot of programming. I always have to advocate on his behalf. He's very high-functioning in certain areas—no label except for developmental disability. We've seen many doctors over his lifetime. He's 25 years old. He lives at home. He gets support through Passport funding only because he had Special Services at Home funding.

Thomas gets \$1,800 a year in support, which—I run out of funding. I don't ask for lots for him. I work full-time. I've worked in long-term care as a food service nutrition supervisor, and I've been in that position, working in long-term care, for 25 years. So I totally understand long-term care and the funding, because we never have enough for our seniors as well.

Going on with this, I did submit Thomas's wishes and goals, and they were done in 2008.

I don't have a problem with workers; I have a problem with funding. I used to pay my workers—I could do it for four hours a week.

Thomas likes to go swimming and bowling and to floor hockey. He competes a lot. We snowshoe. When he was younger, he was involved with Easter Seals; now it's Special Olympics. He has represented Ontario in snowshoeing competitions all the way to the nationals in 2011.

I like to keep him active. He works part-time and has been working three hours on a Wednesday afternoon for Petrie's Cycle and Sports, but he can't even ride a normal bike, even though he's not in a wheelchair or anything like that.

He's very outgoing. We go to all the hockey games. He knows a lot of people in Thunder Bay. I go to places—we were in Toronto at a Blue Jays game. Someone walked up to us: "Hey, Thomas. Thomas, right? You're from Thunder Bay." He walks up to everyone: "Hi, my name is Thomas." He's very social. I'm sure the people behind me know him very well.



I'm a very proud mother. I have another son who is 23 years old. He lives at home as well and has his own things that he does. He isn't as involved, so sometimes that takes away from other siblings at home. It's very difficult when you have a son who looks like you and I, until we have a conversation.

I have no private life. Everyone, I think, in Thunder Bay knows what I do, where I go, when I'm at bingo with my mom, when I'm at the grocery store, because when you phone, he tells you my number at work or wherever we are and what we're doing.

Anyway, onwards with this.

I have my own thing that I'm kind of saying. I wasn't even prepared to say all this stuff about Thomas, but with the help of the others who spoke before me, that gave me the courage to go on with that.

He also volunteers Thursday mornings at Lakehead University, at the field house. He knows all the Thunderwolves players, both the basketball and hockey players, and even the Staal brothers, when they come to work out in the summertime at the university. I mean, he knows a lot more things than I do in the community.

Anyway, to go on with this, I'm really disappointed in having to advocate all the time and be on the phone. Being that I work full-time, I'm burnt toast. I have an 82-year-old mother who comes to my house daily, because Thomas is at home during the day. He phones everyone. He needs the socialization. He needs somewhere to go daily. You know what? We don't want them playing games or watching TV and those kinds of things. That's what is putting kids in unhealthy situations: overweight, no exercise. Healthy living, socialization, all the things these young adults need—as soon as they turn 18, the system changes on them and we're fighting for every little thing.

In 2011, I had a two-day assessment saying, "We're going to provide funding for you for your son to be a normal 23-year-old." He's never going to be a normal 23-year-old, and, man, who am I fooling if I think he is going to be? I don't expect that of him. I just expect him to have his friends and to continue with that and be happy. He's very happy. He doesn't complain.

I just don't know where to go with this. Is there one go-to place? I have to phone and ask, "How am I going to get more funding? I ran out of funding." I have a continuous worker; I have lots of people who want to work with him, and I just can't. I used to pay my worker \$10 an hour, and she never even complained. In the past year and a half, I put it up to \$15, but that's to take him to swimming at night, because he goes swimming on Monday nights. Wednesday night is floor hockey. On Friday nights, it's either basketball that he wants to go see—the local Thunderwolves, ladies' and men's basketball—or it's hockey. I go to all the hockey games; I love hockey and stuff like that. But, jeez, I'm burnt toast. My social life is my son's social life. The time when I'm by myself is when I go to work as a supervisor in long-term care and I see all the long-term-care people that I'm trying to balance my budget for, to make sure I've got enough money to feed them.

Seeing these younger people going into long-term care—no, that's not the place for them. Yes, with the supports, because I see nursing staff, the PSWs—they don't have the funding to have the proper care for both our seniors and our special-needs children. For me, we need one go-to place that'll provide these services, whether it be dental, health care.

#### 0940

I found out from my podiatrist, or whatever you call her, that my son could go and see someone about his orthopaedic shoes. He's been off balance for 25 years, seeing a specialist, but this orthopaedist said he has high arches. We found where to get funding for him to get these special insoles. He loves them, and he's on balance. It just took that one thing—but it took 25 years?

I'm not ignorant about the health care—but it's just the communication. The dental, the health care, the one go-to place, the socialization—where can we go? I don't want to go from phone call to phone call about my funding: "I'll transfer you to her. I'll transfer you to him."

I knew about this committee through Jerry Woods because I had phoned him. I don't even know the man—if you're sitting here. I've never met him, but I spoke to him on the phone, and he said this committee was here and, "Would you like to speak?" I said, "I don't know." But I guess that if we become vocal as parents, then maybe we'll get somewhere. It's just really stressful.

Putting these kids in group homes? Is that the right answer? That's expensive. Putting them in long-term care? It's expensive. Health care? Expensive.

If these kids could exercise and have a go-to place, somewhere where they're safe—where I'm at, there's PR Cook Apartments. That's a safe, secure building. We have a little café. They have an exercise room downstairs. That's at Bethammi Nursing Home, where I'm at, the Heritage. They have all these supports there for the seniors before they're moved into long-term care—because that's where they normally go. They have their meals together in the café. It's not institutionalized. But the waiting list to go into PR Cook is huge. So where do our young people go, and who advocates for them?

I just want to have the services streamlined and have a go-to place for parents for information-sharing and finding out facts about where we can get funding. I just heard today about Choices. I'd never heard about it. It's by talking to other parents who have young adults or even children that we find out from one another. We'll have a phone call.

Even the RDSP for my son—I never knew about that. We can invest a few dollars in that and he'll have something. He can do this until he's 49. It's help from the government, and it's helping the government, and they're saving. That's a win-win. Do you know how many banks I had to go to in Thunder Bay? And then they transferred me to Toronto because they didn't have a clue about it. There is one bank in Thunder Bay, I must say—and the girl was ever so helpful. Still, there are a lot of people who don't know about that, and that's a really positive outcome for these young adults—if we can save any money and help them when we are gone.

I don't have the answers. I am a single parent, I work full-time, and I'm just speaking on behalf of my son, and also the ones who can't speak.

I snowshoe with young adults who have special needs on Sundays. I love it, but some of them will come with no snow pants—and they have workers or someone that the government has put in there for them. I'll say, "Well, where are your snow pants?" "They're in my closet." Do you know what I mean? The system is kind of broken, and we need to fix this.

Hopefully, I made some sense here.

I know that we do need the funding. I also included my Wesway. My funding has not changed. I've done many appeals since 2005, and now I have no funding till April for my son. That's one of my stories, and I'm sure there are other people who are in the same boat, who are different.

My son would be able to get up here and tell his own story. He wanted to come. He did the closing ceremony speech at the Thunder Bay auditorium for our winter games, so he's good at presenting, but he does not understand as totally as we do. His communication is very different. He can tell you all the stats in hockey and baseball and things like that, and he's very active in the community. I promote that, and I encourage it, and I love him for the way he is.

On behalf of my son, myself and the other people who can't speak for themselves, we need some help and some funding. Thank you.

**The Chair (Mrs. Laura Albanese):** Thank you for coming to speak to us this morning. I think we all appreciate the fact that you spoke spontaneously. We will get the rest of the information from your written submission, all the data part. So that, I think, was very welcome.

We do have a couple of minutes for each party to comment. Miss Taylor.

**Miss Monique Taylor:** Thank you, Chair. Good morning. Thank you so much for being here and for sharing your and Thomas's story with us, because it is important that we do hear from you. I'm glad that you made the decision to come and talk about Thomas and just to give us the other information.

You mentioned that you worked in a long-term-care facility, and it's something that we've been hearing quite often, that "we don't believe that young people belong in long-term-care facilities." In your experience, in Thunder Bay, how many young people are you seeing? Do you have an approximate—are there are a lot of young people in your long-term-care facilities?

**Ms. Sandi Boyes:** No. Actually, I know of one person—and this is one before I became a supervisor; it had to be at least 15 years ago. There was a girl—she was in her twenties. She hated it. She just hated long-term care. She just didn't want to eat. She said, "I don't belong here." I said, "No, you don't." And you know what? She just didn't want to be there. And long-term care, because everyone was older—a lot of them are ready for palliative care. They're there. They're not usually going anywhere else. So it took about three or four years, and

we always spoke about her in the nursing staff. She went to live in a group home. I see this girl now. I don't know if she comes for therapy or why she comes to Heritage—probably for therapy downstairs, because I see a lot of it. She's the happiest person I've ever met.

**Miss Monique Taylor:** That's wonderful.

**Ms. Sandi Boyes:** That was the best choice for her: to go into a group home. She would have just deteriorated so much in long-term care.

I know another person—I think he was in his forties—who came to where we were. He had a lot of mental disabilities, whereas people—and he was able to go into the community. I saw him at baseball, and someone had said to me, "Do you know he ate two packages of raw bacon?" I'm thinking, "Oh, no," because this person was a street person, because he didn't have the supports. So I phoned nursing, and I said, "When so-and-so comes back, if he's really sick, this is why." But there was no one to advocate for him. Someone had said they saw him do this at baseball. So how do these people fall through the cracks?

I did phone, and he was okay, but he didn't live for very long. He ended up falling when he was going to ride a bus. From then on, he deteriorated. I don't know if it's being a setting of long-term care, or if it's a mental illness, because in long-term care, we are not equipped to deal with mental illness, and it puts the safety at risk of the other residents and that client themselves. And you'll hear about that in Toronto, in long-term care, and then it goes to everything else—I just went through a big thing yesterday on ethics, too, in long-term care. It was—wow—an eye-opener, too.

**The Chair (Mrs. Laura Albanese):** Thank you. I believe that Mr. Mauro has some comments to make. Go ahead.

**Mr. Bill Mauro:** Thank you, Madam Chair, and thank you very much for your presentation, Ms. Boyes. I have just a couple of questions. The first one: Your words for Thomas were that they didn't have a label for him—

**Ms. Sandi Boyes:** Correct.

**Mr. Bill Mauro:** —and so there's been difficulty in applying a strict diagnosis definition to his condition.

**Ms. Sandi Boyes:** Correct.

**Mr. Bill Mauro:** I've never heard that before, and I'm wondering if, for you, it created any unique challenges in terms of accessing funding for your son, because of that inability to—

**Ms. Sandi Boyes:** It did, because I would go see one of the doctors here in Thunder Bay, a very well-known doctor, Dr. DeSa. He was for younger children. I said, "Can you give me a label?" And we don't want labels for our kids, when they're children and stuff like that. He said, "NYD." I said, "Well, what's that?" "Not yet diagnosed, and you can have that forever," he said.

But he is intellectual, and even in one of my papers here, they said, "We understand that your child has a very severe intellectual disability." But you know what? I was like, "Yes; I've lived with this my whole life." I don't even know when that letter was, but I thought I had included it.

0950

Those are kind of the weird things that we as parents have to go through through: do a lot of paperwork, and there's not a lot of transparency. That's why I put my things in there. I want my facts to be known, because \$1,800 a year for that is not very much. I don't know if you could do the math—I don't even think that's four hours a week.

I did put some facts in there also about the funding as well. Is my time up?

**The Chair (Mrs. Laura Albanese):** No, go ahead.

**Mr. Bill Mauro:** There's still time? Yes, thank you. The other question was, if you could expand for me this bit that you mentioned about the RDSP.

**Ms. Sandi Boyes:** It's a registered disability savings plan. I think someone probably has better facts than me, but if my son puts in \$500 per year, then the government matches up to I think \$1,500. Automatically, every year, there's \$1,000 put in there if you're investing in this. That's strictly for him after he's 49 years of age.

**Mr. Bill Mauro:** When did that start, do you know?

**Ms. Sandi Boyes:** At least—I want to say seven or five years ago.

**Mr. Bill Mauro:** Five years ago? Okay.

The 49 number—you said that was the—

**Ms. Sandi Boyes:** The cap.

**Mr. Bill Mauro:** That's the maximum allowable?

**The Chair (Mrs. Laura Albanese):** It's the age—49 years of age.

**Mr. Bill Mauro:** Yes. Thank you.

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

**Ms. Sylvia Jones:** Thank you for your presentation. You made mention of one place, one stop, to figure out what's available and what's out there for Thomas. You're not the first person that has made reference to that. We talked about the transitions and coordination that has to happen within ministries. If you could envision an individual, an advocate, who basically took you from diagnosis or understanding through the various stages—education, health care and ultimately residential options—could you see that being of benefit to you in your journey with Thomas?

**Ms. Sandi Boyes:** Definitely, definitely, and most parents as well. I shouldn't speak for everyone, but it seems that the only way we find out things is when we know that, "This change is going to come about. What are we going to do? How are we going to figure it out?" Then I'll say, "Did you hear anything? Did you know anything? What are you doing?" So it's parents speaking to other parents in how they're coping with things. But it would have been very beneficial. I never even knew my son was special needs until I sent him to George Jeffrey's when I had to go back to work—I think I went back to work six weeks after I had Thomas—and because he used to fall a lot. The only reason he went to George Jeffrey's was because a good friend of mine's mother-in-law worked there. I didn't want to put my son in daycare. That was my first child. To me, he seemed okay, but he

was later in walking and speaking—we didn't even know if he'd speak.

There are a lot of programs that I went through with that—understanding through George Jeffrey's and the Hanen program and educating myself as best as I could and looking through magazines and talking to people. Some people don't like to approach or they feel really nervous. I'm not the best at approaching but I think, "If I don't do it, how am I going to figure these things out?" So I've tried to be that way most of my life.

**Ms. Sylvia Jones:** And that type of navigator would be of assistance if you moved locations?

**Ms. Sandi Boyes:** Definitely.

**Ms. Sylvia Jones:** If there were changes in your circumstances—you talked about working full-time. The people who are presenting are the strong advocates, but we have to build a system that's going to help everyone with all different levels.

**Ms. Sandi Boyes:** It depends on what their needs are, how old their son or daughter is, their age group and their ability to do things. We want to have them included, but it also has to be very safe. I had people from an agency tell me they were going to take my son and teach him to ride the bus. Thomas has an awesome memory; he probably knows the whole bus route better than all of us in this room or someone from Thunder Bay. That's not it; it's the safety issue, you know? Going on the bus—if he was normal, I wouldn't even let him go on the bus. Are you kidding me? He talks to everybody. It's a safety thing that these people don't seem to understand. It's more that—and I really don't like saying this—they're book smart, instead of being in our shoes. That's all I can say. I'm not putting them down. I'm sure they're very smart, intelligent people, but they don't feel it in here and they don't live it. So when I'm saying, "I don't want my son to ride the bus," that was totally ignored. I thought, "Okay, you want to spend your day riding the bus with my son? Go ahead." Who am I to say? I'm only his mom. But you know what, you don't want to be on the bad side of these people either, because we're not going to get any money. So we're not in a good place sometimes.

I'm definitely not complaining; I'm just explaining.

**The Chair (Mrs. Laura Albanese):** Thank you for your openness. It's very much appreciated. It does help us in the work that we need to do. Thank you for being here this morning.

**Ms. Sandi Boyes:** Okay, and thank you for giving me the opportunity. I'm glad that I did find out about this. I'm sure there are lots of parents who didn't even know about this, as well, in Thunder Bay, because I wouldn't have known if I didn't make the phone call. So thank you.

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

#### NISHNAWBE ASKI NATION

**The Chair (Mrs. Laura Albanese):** I will now call on Nishnawbe Aski Nation to come forward.

Oh, Ms. Wong?

**Ms. Soo Wong:** Madam Chair, while we're waiting for the next witness, can I ask the researcher to look into additional stuff for the committee? In Ms. Boyes's presentation, in the written submission, she shared with us the goals of her child in terms of securing meaningful employment. My question here—and if the researcher can find information for this committee—is, can we get some data across the province with respect to the Ministry of Education for the students ages 19 to 21 who are still in an existing publicly funded school board, what resources and support they are providing both to the students and the family in terms of transition to the next stage?

Furthermore, I also want to know what kind of collaboration—each of these publicly funded school boards are working with MCSS, because very clearly, Ms. Boyes's concerns raised to us that something happened, because this goal, here, should have travelled from the time when her son was 18, 19, 20, 21 at that school board. If they are a publicly funded school board, I want to know about the collaboration from that district school board, working with MCSS, as the students are going to be transitioned out from that school board. So I want to know about that collaboration and what supports are there for students and the family.

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

We want to welcome the Deputy Grand Chief, and you may begin at any point in time. You have up to 20 minutes for your presentation.

**Deputy Grand Chief Goyce Kakegamic:** Nishnawbe Aski Nation appreciates the opportunity to speak to the select committee on developmental disabilities. I'm here on the behalf of 49 First Nation communities, not as an individual spokesperson. Our territory runs from the Manitoba border to Quebec and consists of 49 communities: 32 of them are isolated. The only way you can get there is by plane. It covers two thirds of the NAN territory.

My heart goes out to see the report of the urban people, of the challenges as they deal with those in their family who have disabilities. Our First Nations do have that challenge too in our communities. But if you see the need, which should be addressed in urban society, our status situation is worse.

**1000**

We take for granted to have physicians. I live in a city. I pay tax; I own a home. I don't even have a doctor. In our communities, there is no physician. There's a nursing station and a nurse. Our children, our youth, adults with developmental disabilities from the Nishnawbe Aski Nation face an alarming lack of services and support. This lack of support is very damaging to individuals with developmental disabilities and their families. All families that are supporting a family member with a developmental disability have a heavy load. But in the Nishnawbe Aski Nation, especially in the remote communities, the stress and the despair are incredible.

The high cost—I suppose you guys came from Ottawa or Toronto. You probably paid only \$300 for a return

trip. In our communities it's cheaper to go from here to Las Vegas than to go and see our medical services from our communities to Thunder Bay. The high cost is enormous. In some cases, this even results in children not being able to attend school, parents not being able to look after their own children, and adults with developmental disabilities getting caught up in the criminal justice system. This is not right. We need to do better. With the right tools and resources, I am sure we can.

The Nishnawbe Aski Nation has the capacity and willingness to work with the provincial government to address these issues in order to provide a better quality of life for all children, but also families living with developmental disability.

Again, I'm here on behalf of our chiefs, our communities. I am their spokesperson. We have the title—in Indian terminology, "Chief" means to be just a spokesperson doing the bidding of who elected you. A literal translation in the native language: You're a spokesperson. So I'm here to say that we are all citizens of Ontario. There are services in urban society; there's none in existence in our communities, and the high cost is enormous.

So it is a challenge, not a problem—a challenge. When we think of it as a challenge, a positive gear kicks in: What can we do for citizens who are part of Ontario, Canada, with developmental disability?

I'll turn it over to my colleague, to my staff.

**Mr. Bobby Narcisse:** Good morning, ladies and gentlemen. My name is Bobby Narcisse. I'm director of social services for Nishnawbe Aski Nation. I work under the portfolio of Deputy Grand Chief Goyce Kakegamic.

I've been there for close to eight months now. I'm originally from the Aroland First Nation, where I was sitting on council over there and working in social services within our particular communities. I had the great opportunity of working with the deputy grand chief on this portfolio, and I'd just like to briefly touch on some very important points that we've been working on and also different challenges that we wish to overcome with respect to disabilities in the Nishnawbe Aski Nation.

We appreciate this opportunity to speak with you all. We will provide you with a recommendation that is solution-focused. We've heard a lot of the heartfelt stories, and we really identify with many of the challenges faced within this sector, within the province, but the recommendation that we are putting forward to the provincial government is to provide Nishnawbe Aski Nation with adequate resources to conduct a comprehensive review of the current services and supports and the impacts on individuals and their families living with developmental disabilities. The review will provide a basis to develop a comprehensive strategy to ensure families are supported in Nishnawbe Aski Nation.

We would like to acknowledge that all families who are supporting a family member with a developmental disability have a very heavy load, but in the north, especially in our remote First Nation communities, the stress and despair is incredible.

Children, youth and adults with developmental disabilities from NAN territory face an alarming lack of support and services, as the deputy grand chief just said earlier in his opening remarks. It is estimated that the rates of developmental disabilities, learning disabilities and conditions such as fetal alcohol spectrum disorder are much higher in our First Nation communities, especially in the remote north. These disabilities are further exacerbated and complicated due to remoteness, social and health disparities, poverty and lack of services.

The deputy grand chief just also said that it costs more to go to one of our communities than to go to Mexico. It costs a couple grand just to go to our First Nations. With many of our population needing to go to urban centres, such as Thunder Bay or Winnipeg or Sioux Lookout, the amount of resources needed is quite exponential within our territories.

Challenges obtaining a diagnosis of developmental disabilities, including fetal alcohol spectrum disorder, are extremely magnified in our communities. Very few individuals receive disability-related diagnosis. Unfortunately, and only in some cases, these services kick in because of involvement with the justice system, or child welfare. As I'm sure you're aware, this is much too late.

In addition, this places a tremendous strain on the children's welfare system and the justice system. We need to start a little bit earlier. We need to start identifying these disabilities earlier. In our First Nations communities in the remote north, there is a severe lack of services to do so.

The First Nation community-based programs work very hard to address these high needs in their communities, but they're extremely overwhelmed, underfunded and often do not have the infrastructure or the training to carry out the needed support. They are placed in the position of delivering programs in isolation of the clinical supports that are available in other parts of the province and in urban settings.

Developmental support services in the communities are virtually unavailable to clients and their families. Mainstream agencies report that they are able to provide very little compared to what is needed in our remote communities. There are two Community Living agencies that exist on-reserve, and both are in southern Ontario, close to urban settings, whereas there is nothing in our remote communities to help our children and our adults and our youth with developmental disabilities.

Housing supports for adults with developmental disabilities are non-existent. As you know, many of our First Nation communities experience a wide range of challenges, such as poverty, lack of housing and lack of infrastructure. To think, to have somebody with developmental disabilities in our First Nation communities—there's nearly nothing to support them.

There's nowhere to go for specialized care and services on-reserve. First Nation community members frequently are not even referred to services due to the wait times and prohibitive costs. Again, this fact complicates our attempts to advocate for more service.

Many individuals fall through the cracks, and it results in their disability being further complicated, resulting in a poorer quality of life and a higher rate of secondary disabilities. Families experience stress and breakdown because they are not able to care for their child or adult with special needs and have to make choices of giving up their child to care or relocating to an urban setting. Schools are unable to work with many of our children, resulting in children just sitting at home or just left in the classroom, not getting the supports that they need.

#### 1010

Elderly parents caring for adult children with disabilities are under great stress, often dealing with adult children who are self-harming and behaviour that places the parents at physical risk. Elderly parents have to face the very difficult decision to not care for their adult child, resulting in the person with disabilities being turned over to the hospital, living in a long-term-care facility or becoming homeless, living on the street. In many cases, people have started to believe that it is not possible to get help in our First Nation remote communities. The result is lost opportunities for early intervention, and lifelong complications.

Other challenges in our area include jurisdictional issues that create serious problems for people to access service. I'll give you one example: The mechanism to cover travel costs for First Nations accessing health services is the federally funded Non-Insured Health Benefits Program. Non-Insured Health Benefits will only approve travel costs for an OHIP service.

Most assessment, developmental or rehabilitation services are not available in the hospitals that serve the NAN communities. These services are provided through the Ministry of Community and Social Services or the Ministry of Children and Youth Services' funded programs. This obstacle impedes the access to many services. Jurisdictional issues are very evident in our communities.

Many other barriers exist that result in people not accessing mainstream services. This situation has become so protracted that First Nations community members frequently are not referred to services due to the prohibitive costs of travel and the significant wait times.

Education: Here is another big barrier, and also obstacle, that we have. High-cost special education is a major issue that impacts the programs and services of students in the Nishnawbe Aski Nation on an ongoing basis. There are many instances where the identification rates range from 20% to 40% of the student population that require high-cost special education. There's no guarantee that there is funding to undertake high-cost special education assessments and that, if the assessment is undertaken, there is funding to ensure that the required services are in place.

Under the federal government's High-Cost Special Education Program, the funding is not based on need but rather on the distribution of available funds through an approved formula process. There is simply not enough funding to meet the needs of students, whether it's

through formal identification or teacher-based assessment and delivery of intervention strategies. We continue to participate in the Ontario First Nations Special Education Working Group to advocate for the needs of our students.

With respect to service providers, based on the experiences of organizations providing services in Nishnawbe Aski Nation territory, they have outlined the following key issues as predominant:

- individuals are often misdiagnosed, victimized or bullied;

- people with developmental disabilities live in isolation, with nothing to do;

- no respite services for families in remote communities of the Nishnawbe Aski Nation;

- clients served in First Nations communities are more likely than other northern clients to suffer from physical and mental abuse or to have attempted suicide—as you know, the suicide rates in our First Nations communities are very high. We see it in the media. With respect to many of our students, especially coming from their home communities and their parents to go to school in urban centres, it's quite a challenge; and

- many referrals from First Nations communities are complex, needing inter-ministerial intervention.

Ladies and gentlemen, in conclusion, the essential barriers to supports and services for people with developmental disabilities in Nishnawbe Aski Nation territory seem to be identification and diagnosis; adequate resources for both mainstream agencies and community-based services; a culturally relevant system linking support back to the community; and logistical and jurisdictional barriers.

Unfortunately, there is very limited information and data on the incidence of developmental disabilities in Nishnawbe Aski territory. This leads to gaps in identifying the number of people requiring services and support, and a poor overall systemic response.

The people in Nishnawbe Aski Nation territory are struggling in many areas: health, social, education, economic and housing. The general conditions of the communities, layered with an estimated higher rate of complicated disabilities, mean the most vulnerable people and their families are placed in unacceptable conditions. This needs to be addressed.

Again, the recommendation we are putting forward is for the provincial government to provide the Nishnawbe Aski Nation with adequate resources to conduct a review of current services and supports, and the development of a comprehensive strategy that will support individuals and their families living with developmental disabilities.

Further, the increased participation and co-operation of various ministries working to this end is also required—communication and co-operation, and also the inclusion of First Nations input as to finding the strategies with respect to this area.

With all the changes going through our province with respect to resource development and the Ring of Fire and many of the resources that are being accessed in our traditional territories, I think it is imperative that—First

Nations want to be a part of that. We want to get our citizens involved in that process as well. As treaty partners, we ask that the government also invest in our people. There are many challenges that are facing our First Nations communities in the remote north, and I think it's worth an investment in our region, within our families as well, to partake in this initiative.

I think I'm almost out of time, but I really thank you for having us and listening to our concerns. We look forward to working with you to come up with a mutually beneficial solution in this area of developmental disabilities.

**The Chair (Mrs. Laura Albanese):** We want to thank you for coming before our committee, and we want to thank the Deputy Grand Chief for being here as well, for helping us to shed some light on the challenges that you are facing in the community, and for giving us these very valuable suggestions. Unfortunately, as you pointed out, we are out of time, and I will have to move on to the next presenter. On behalf of all the committee members, thank you very much once again.

**Mr. Bobby Narcisse:** We'll be emailing you our information as well, so if you have any questions or comments, you can also contact us from there. Thank you very much.

**The Chair (Mrs. Laura Albanese):** That will be most welcome. Thank you.

Ms. Elliott?

**Mrs. Christine Elliott:** Madam Chair, while we are waiting for the next presenter to come forward, I'm wondering if we could get some information on the federal travel grant situation and the educational grants so that we can have a better understanding of what's funded and what's not funded.

**The Chair (Mrs. Laura Albanese):** Yes.

**Mrs. Christine Elliott:** Thank you.

**The Chair (Mrs. Laura Albanese):** That would be welcome.

Ms. Wong?

**Ms. Soo Wong:** Madam Chair, while we're waiting for the next witness to come forward, can we get more data on the new medical school up here and the relationship and support provided to these remote communities—because that was one of the goals for this new medical school: to address some of these rural communities. So if we can get some data and information, that would be really helpful.

**The Chair (Mrs. Laura Albanese):** That would be from training, colleges and universities?

**Ms. Soo Wong:** No, it would be MOH, Ministry of Health and Long-Term Care.

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

**Ms. Mitzi Hunter:** Yesterday we heard about identification being done through a community partnership, I believe, with Surrey Place. But in terms of diagnoses and services for individuals and families coping with developmental disabilities, are there currently any supports in place for this territory? Can we ask the ministry?

**The Chair (Mrs. Laura Albanese):** Is that fine? Thank you.

1020

#### COMMUNITY LIVING THUNDER BAY

**The Chair (Mrs. Laura Albanese):** Now we will welcome Community Living Thunder Bay. Please state your name and your title before you begin. You'll have up to 20 minutes for your presentation.

**Ms. Lisa Louttit:** Thank you. Good morning. My name is Lisa Louttit, and I am the executive director at Community Living Thunder Bay. With me is Jordan Pretchuk. He is a member of Community Living Thunder Bay's council and also a member of Community Living Ontario's council.

Jordan and I would like to thank the committee members for this opportunity to address the committee and share concerns on behalf of Community Living Thunder Bay this morning. We'd like to start off by lending our support to the presentation made by Community Living Ontario, which I'm sure you heard about. As a member of the federation, we are pleased with the concerns and recommendations that Community Living Ontario has put forward. But specifically, today, Community Living Thunder Bay would like to emphasize a couple of areas in which we believe some immediate change is needed.

The first is around inclusive education at an elementary, secondary and post-secondary level. If we are to be serious about people who experience disabilities attaining real jobs and contributing to community, there needs to be a real and shared vision around inclusive education in our province. Elementary, secondary and post-secondary education prepares students to enter the world as contributing members of society. There have been some great steps taken toward inclusion through policies such as regulation 181/98, which states that a regular classroom should be the first option as a placement for all students, but progress remains scattered and inconsistent across the province. The reality is that many students across the province are not fully included in typical classrooms. Many students are stuck in segregated classrooms and are not accessing the quality education they need to prepare them for the world of work and contribution to community.

Sadly, this reality continues often into post-secondary education as well. Opportunities for inclusive post-secondary education in Ontario are very limited. There are a number of colleges that currently offer opportunities through CICE programs, but there are not enough. Fortunately, there are some great resources that we can draw on that can assist the province in making the changes needed to right this situation.

I did bring a resource along. It's called A Promising Path to an Inclusive Life, which chronicles over 20 years of experience around post-secondary inclusive education opportunities for adults in the province of Alberta. A number of universities and colleges in Alberta offer opportunities where students can participate in classes

and programs of their interest, as well as participate in campus life. These opportunities are made possible through voluntary peer mentoring by non-disabled students and funding for facilitators that work with the students, the peer mentors and the professors to ensure that students are accommodated in the classroom and are participating as fully as they can in the course. Many of these students have been able to go on and get real jobs in their community due to this experience. In addition to enhanced employment opportunities, these students have also had the pleasure of building friendships and relationships within their networks of supports that are lasting. It is our hope that this can happen in Ontario for adults who experience disabilities.

Another positive example of leadership in the area of inclusive education is the state of Vermont. Vermont has been providing inclusive education for students at an elementary and secondary level for over 30 years. In 1987, the State Board of Education developed a document entitled Vermont Education Goals that articulated the restructuring of schools to support the high performance of every student, and no vision of special education as we know it, creating funding formulas that allowed resources for special services in the classroom—typical classrooms—with the student. It is essential that Ontario's education systems implement the changes needed to make full inclusion in typical classrooms with effective supports a reality.

Quality education at all levels that focuses on the students' gifts and capacities will open doors for students that experience disabilities and will ensure greater success in employment. It will also have a profound effect on organizations such as ours, Community Living Thunder Bay, as young adults growing up accustomed to fully inclusive experiences throughout their school years will demand more individualized and responsive services for living and employment and community participation. Young adults and their families will no longer be satisfied with the traditional congregated supports that many organizations still offer.

The other area that we'd like to touch on is the need for flexibility and creativity, for organizations to shift away from traditional support models. There are many associations, such as Community Living Thunder Bay, that still provide traditional congregated services such as group living, sheltered workshops and day services. Although these supports may make sense for some people, we're finding younger people coming into our service don't want these types of supports. Many people that we serve and that currently receive these types of supports want a better quality of life and want to explore other options.

Many organizations, like Community Living Thunder Bay, have a desire to move toward providing individualized supports that promote inclusion and self-determination for the people we serve. However, we need flexibility and the resources to move forward and make the needed changes in service delivery for people.

It's often challenging for organizations to maintain current supports while trying to unbundle resources and

provide new and innovative supports for people who want to try other things. Allowing for more flexibility in meeting service targets and control over vacancy management, even on a time-limited basis, will in the long run allow organizations to increase service capacity for people currently receiving services, improve quality of life, and create capacity for people on the wait-list. Short-term funding to maintain existing services while new and innovative options are explored will help organizations to make these transitions.

Resources for training around initiatives such as positive approaches, and connecting with organizations that have already successfully shifted away from traditional services and that are willing to share their stories and experiences, can enhance leadership within organizations and build confidence in organizations that want to make these changes.

We also need some flexibility and interpretation around compliance standards as well. It's our belief that the standards set in the quality assurance measures are well intended and are to set a foundation for minimum standards and safeguards around service delivery. The challenge is that some of these standards do not make sense, nor do they ensure a minimum standard.

An example of this would be the requirement for organizations to provide protection skills training to all direct staff. This is a huge waste of resources that could be better used for training around positive approaches, communication skills and many other areas of training that staff need within organizations. Many of the people we serve pose no threat to staff, and there is no need for protection skills training. Not only that, but there's lots of research to support that using restraints on people only further traumatizes people. We would like you to allow organizations the flexibility to determine the type and scope of training needed to ensure that people that we serve, who might engage in challenging behaviour, are supported more holistically, and that we can keep our staff safe.

Jordan would like to share his experience in finding work in our community.

**Mr. Jordan Pretchuk:** My mom became a member at the first self-advocate meeting she attended here. Parents expressed their concerns to Lisa, as director—and her skill and dedication to serve this very full position.

Mom, as a parent, found information necessary for help was by word of mouth, and through other parents. They were in the same position as her. Outside of these parents, information seemed little to non-existent.

Her first lead was Lutheran Community Care, which had me tested at Options. Through Lutheran Community Care, I was sent to the ministry director, to the March of Dimes, for job training.

After my job training, I was informed by word of mouth to go to Monty Parks, but there was a long wait-list of names I would be placed on. After my job training, I remained at the March of Dimes to join the activities out there. In the meantime, I tried to get employment, to no avail. It was suggested to go back to Lutheran Com-

munity Care, and they tested me again and put me on the list with Monty Parks. I gained a job through the March of Dimes through money funded. It opened the door for me to be on the March of Dimes work team.

As it happened, I was encountered by Marie Morrison, my worker at Monty Parks, to help me in a job search. Through Marie, I made connection with the activities of Monty Parks and the self-advocate group.

Directing me, Pat Tront and Morgan Austen have been most helpful in managing and directing me in self-advocacy group. I am very happy to receive this opportunity to help extend myself to community life and activities that have benefits for my special needs, living and working in the community.

**1030**

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

**Ms. Lisa Louttit:** Thank you very much.

**The Chair (Mrs. Laura Albanese):** Well, thank you for being here this morning and for presenting to us. We do have some time left for questioning. I believe it is the government's turn to start this time. Ms. Hunter?

**Ms. Mitzie Hunter:** Thank you so much for being here today and for sharing with us the ideas that you have from your years of experience on how to improve and strengthen the system.

I also particularly want to thank Jordan for sharing your experience with living and working in the community. It seems like it's a positive one for you, and I think that's the best outcome that we can seek.

You made a comment that having more control over vacancy management would be something that would be advantageous for you. Can you maybe talk a little bit about how you see that and why?

**Ms. Lisa Louttit:** Having more control over the vacancy management?

**Ms. Mitzie Hunter:** Yes.

**Ms. Lisa Louttit:** Okay. It's not that we don't agree that there should be vacancy management and a transparent system; it's that sometimes—if I could maybe walk through an example, that might be helpful. For instance, if we have a number of people that live in a particular home—say four people in a group home—that want to try an alternative living option, the challenge is that one or two of those people might want to move out temporarily and try this option, and it takes time to make sure that it works for them. It could be a family home or a shared living arrangement or it could be a more independent SIL-type option. It takes a long time sometimes for people to know that that's going to work for them, so we're not in a position to be able to declare a vacancy right away. We need a little bit of time to make sure that that situation is going to work with that person. It's not always easy, either—if there is a vacancy, sometimes it will give us an opportunity to look at that particular living situation, that group home or that location, and maybe create more movement for people to explore different options, but then we have the burden of the service target. There are just a lot of barriers in the way that prevent us from being able to be more flexible in moving



our resources around while still trying to maintain the core services while people want to experience other things. I don't know if that makes any sense or not.

**Ms. Mitzie Hunter:** I think it's very helpful, because we also have a waiting list that we've heard about as well.

**Ms. Lisa Louttit:** Yes, and we're very mindful of the waiting list and the pressures that are out there, but if we can have more flexibility to look at what we have and at where people want to go in terms of the people we're currently supporting, we're pretty confident we can free up more resources in the system to address the wait-list down the road. It's just that we need that time and sometimes we need the flexibility around our service targets and maybe a little more enhanced funding sometimes on a short-term basis until we can create those opportunities for people to try different things. Then we believe it can free more money up in the system, longer term.

**Ms. Mitzie Hunter:** Okay. Is there time for one more?

**The Chair (Mrs. Laura Albanese):** Yes.

**Ms. Mitzie Hunter:** Okay. You also talked about needing flexibility around the job training and having more choice based on the needs of your employees and the client group that you're serving. Can you talk a little bit about health and safety and how those standards are maintained throughout your facilities?

**Ms. Lisa Louttit:** The health and safety—

**Ms. Mitzie Hunter:** For employees.

**Ms. Lisa Louttit:** For employees. I referred to the protection skills training. Is that what you mean?

**Ms. Mitzie Hunter:** Yes.

**Ms. Lisa Louttit:** Okay. For instance, one of the pieces of the quality assurance measures requires us to train all of our direct support staff with one of three approved providers that do training around protection skills for staff. So that's a lot of money and, depending on the system that you use, you may be required to do that mandatory training with all your employees once a year.

Not everybody needs that. For instance, our organization wants to take a zero restraint approach. We don't want to use restraints. We believe that using restraints further harms people and causes them trauma. A lot of the people we support experience anxiety. There are lots of reasons why it doesn't make sense to use physical restraints on people. If we say, as an organization, that we are only going to use protection skills training or we want to try other approaches such as positive approaches, we will be in a non-compliant position with the current legislation, the way it's structured.

What we're asking for is to allow us to use some best practices, use more holistic ideas around supporting people who engage in difficult behaviours. Let us decide what staff and how many staff we need to train, and how often, and what methods we need to train them in so we can save money, and that money can go for training

around more meaningful things that can help the people we support and keep our staff safe.

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

**Mrs. Christine Elliott:** First of all, I'd like to thank you, Jordan, very much for being here today. This is what this committee is all about. The extent to which we can hear from people like yourselves with lived experience really helps us, in a very deep way, to understand what we need to do to continue to support you and allow as many opportunities as possible for you. So I really appreciate you being here.

Lisa, I have a few questions for you. First of all, can you tell me how many people you serve here in Thunder Bay?

**Ms. Lisa Louttit:** Community Living Thunder Bay serves around 300 people. I'm relatively new to my role, so I'm learning some of these statistics myself; sorry.

**Mrs. Christine Elliott:** Okay. We do have some information on education, particularly post-secondary education. I have some familiarity with the CICE program, and it is wonderful. First of all, it's offered at your local college, I'm assuming? Can you tell me how many students they take per year? Also, what is the job experience for those graduates, and how many are able to find employment?

**Ms. Lisa Louttit:** I'm actually still learning about the community of Thunder Bay. I just moved here. I am from Sault Ste. Marie, and we do have a CICE program in the Soo. I worked at Community Living Algoma, so I was very familiar with the CICE program there. I know a lot of the people we served attended that program and were able to get jobs.

I think the CICE program is an excellent example of inclusive post-secondary education, but I really would love the committee to turn their attention toward the work that is being done in Alberta. The beauty of the work that's being done in Alberta around post-secondary inclusive education is that it is not based on pay support; there are some resources that are focused on having a facilitator present on the university or the college campus, who coordinates things. To me, the real beauty of that program is that it's based on voluntary peer mentoring with students who don't experience a disability. It's a very natural connection, and they create, in some cases, lasting friendships. Although it's probably not a certificate program—some of the CICE programs offer a certificate at the end. The students who attend the universities and colleges in Alberta—there's no certificate; it's more like auditing a program. The benefit is that they're fully included in the course. It's accommodated at the level they need to be at, and they're experiencing and studying things that they're really passionate about that typically aren't available to people who experience disabilities. There are people enrolled in music, arts, psychology, literature and all kinds of courses that you and I might be interested in.

**Mrs. Christine Elliott:** Thank you.

**The Chair (Mrs. Laura Albanese):** Sorry, the time has already transferred into Ms. DiNovo's time.

**Ms. Cheri DiNovo:** Thank you, Jordan. You gave a wonderful presentation. Thank you very much for being here. It's important that you're here.

Lisa, I have some questions for you. One of the ongoing issues that we're trying to get our heads wrapped around in this committee is the wait-list numbers. We've had some numbers come forth from the ministry, ComSoc, but they're very, very at odds with the numbers we're hearing, for example, from Community Living. I'm really asking you to help our researcher out a bit here, for Community Living Ontario, if you have a sense of the number of people on wait-lists for your services across Ontario. Is there an idea? Because you've had experience with Community Living Ontario as well.

1040

**Ms. Lisa Louttit:** I'm not going to be able to quote you statistics today, but I know that we can get that information for you.

**Ms. Cheri DiNovo:** Yes, could you, because—

**Ms. Lisa Louttit:** Through email, absolutely.

**Ms. Cheri DiNovo:** That would be extremely useful. The other thing is, in terms of inclusive education—and we hear from you and have heard from the others. We also earlier heard somebody come forward as a witness who was touting her experience of, in a sense, exclusive education, which is a special-needs school that's set up. I'm wondering if you could comment on that because we've heard on this committee that there's no one solution for all. We really need to look at this as an individualized program. Could you comment maybe on your experience or your clients' experience with exclusive special-needs education or schools set up specifically for that?

**Ms. Lisa Louttit:** I think sometimes that what families really want is they want to make sure that their child is safe when they attend school and that they're not experiencing bullying. I certainly am not a parent and I can't speak for parents, but I think sometimes parents maybe default to segregated schooling or segregated classrooms because their hope is that their child will be safe from bullying and the kind of treatment that can go on. So I understand sometimes the desire for a segregated classroom or a school. But I think there is tremendous research to show the benefits of being able to go to school with your typical peers and classmates. It's not only the benefit to the child with the disability, but it's also the benefit to the children without the disability and to the whole social network of that school.

Those kids later go on into society and expect that people who experience disabilities will be fully included in society. Those students go on to own businesses and create employment opportunities and naturally assume that people who experience disabilities do have gifts and interests and passions to offer society. I really believe that inclusive education, if it can be something that can be required—typical classrooms, regular classrooms, no segregated classrooms—has the power to change how we do business as organizations. I think the more inclusive people are and the better the education they get and the

more our society understands the gifts and what people who experience disabilities have to offer—we will be compelled as organizations to offer individualized, creative and innovative supports that make sense for people, but at the same time address the concerns families have around needed resources. We'll be able to free up a lot of money in the system to support people the way they want to be supported.

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

#### RYERSON UNIVERSITY: REIMAGINING PARENTING

**The Chair (Mrs. Laura Albanese):** And now we'll call on Ryerson University, Reimagining Parenting, to come forward. As you're making your way up, I will remind you that you have up to 20 minutes for your presentation, and if you use less than 20 minutes, then we will have some time for comments and questions. If not, we're just very happy to hear from you and hear your comments and your input. If you could begin by stating your name, that would be wonderful. You may begin any time you feel comfortable.

**Ms. Pat Seed:** First of all, we'd like to thank the Select Committee on Developmental Services for allowing us the opportunity to present today. My name is Pat Seed, and I think I'll let Cher McCullough Monteleone introduce herself first.

**Ms. Cher McCullough Monteleone:** Hi, everyone. My name is Cher Monteleone. I'm married and a mother of two young children. I'm also a woman with a disability and a self-advocate and co-researcher for the Thunder Bay Reimagining Parenting project.

**Ms. Pat Seed:** Now, Reimagining Parenting possibilities is a very important project to me. My name is Pat Seed. I've been a volunteer in this community since 1980. I'm currently on many advisory boards and so forth for people with disabilities. I'm currently president of CWDO, which is Citizens With Disabilities—Ontario, which is an Ontario-wide organization of people with disabilities devoted to people with disabilities and things like the AODA. We're very much involved in public education and in watching the Accessibility for Ontarians with Disabilities Act to make sure that it gives all of the standards force so that they can be put into effect.

We also give input to the Council of Canadians with Disabilities. They are a Canada-wide organization. Both of us, actually, give information and input into the United Nations convention for the rights and so forth of people with disabilities.

Now, I learned about this presentation during the weekend of January 4 and 5. I had written a letter to our MPP, Michael Gravelle, and he called me, actually, at home and he was very interested in this project that you will see outlined in the handout that you will look at. There were three members of the group that were coming up last Monday, on January 6, and they came up from

Toronto. One of them was Esther Ignagni. You have her name there today. She's from Ryerson University. Melanie Moore came up here. She's from the Centre for Independent Living in Toronto. Also, Renee Morin, who is a self-advocate.

Michael wanted to meet with us about the project. We wanted to describe some of the information that we had. He also wanted to provide us the information on this committee. So we met at the Hagi building at 1201 Jasper Drive. Over persians and pizza, we discussed it for about an hour and had a very good meeting. Today we'll give you some of the information. I know that you've received a lot of information so far. You have also had a lot of historical information, so I'm going to scan over a lot of that, and give you specifics about the Reimagining Parenting project.

It's a collaboration of research which has the following organizations participating in it: Ryerson University is one of them, and I mentioned Esther Ignagni, who is the principal investigator; McMaster University is also part of it; Western University; Strength-Based Parenting Initiative, which is SPIN, and that involves Melanie Moore, who also is with the Centre for Independent Living. Actually, Esther and myself are also on that Strength-Based Parenting Initiative. As I said, I'm with the Citizens With Disabilities—Ontario and also involved with Springtide Resources.

The members of the collaborating committee really worked together. They've been working together for a little over a year now on this whole parenting project, and it has been really eye-opening and a learning experience for all of us. There are various sites in Ontario. There is one in southern Ontario; there's one in northern Ontario, which we are part of in Thunder Bay; there's eastern Ontario; central Ontario; and also there is a group in Ottawa who are parents of aboriginal culture, and they have developmental disabilities. They're taking part in the project as well.

#### 1050

The additional members of the group are self-advocates. There's about six of them in the Toronto group, as a matter of fact. I'm the site investigator for Thunder Bay, and Cher is one of our investigators, co-researchers and so forth, in Thunder Bay.

The Reimagining Parenting project—you know that it's a human right for people to be parents, and you've heard a lot of talk about the United Nations and so on and so forth. We like to build up the enjoyment of relationships and family life for people.

It's very important for the parenting project and SPIN to be able to public-educate and to do all those kinds of things that will help people understand more and help people get more information. We want people to be able to ask questions. We want people to be able to participate in the project.

To that end, we have people with developmental disabilities and intellectual disabilities who actually are part of the project. They're doing the interviewing. We team up with them, and it works out really, really well.

We're gathering stories across Ontario about parenting experiences, and we really know that this is going to enhance everyone's lives.

The long-term goal of the project is to develop materials for those who create policies, those who create educational materials and so on and so forth, so that they can be able to have the information they need and they'll know what more people need in addition to what you've heard today.

The project grew out of the work of the SPIN organization, as I said. SPIN is definitely an Ontario-wide organization.

What I'd like to do is go to the recommendations, because I really think that you have heard a great deal about the history and so forth. I'll give Cher a chance to find her page and I will have her explain to you the first six recommendations that we have.

**Ms. Cher McCullough Monteleone:** Our recommendations:

- Include, in a meaningful way, the voices of people with developmental disabilities in policy and program development and implementation in matters that affect them and their families.

- Ensure that all parenting, sexuality, relationships and reproductive health resources are developed and accessible to people with developmental disabilities and that these comply with the AODA—Accessibility for Ontarians with Disabilities Act—standards.

- ODSP rates must be at an amount that is enough to support dignified family life.

- Social and supported housing for people with developmental disabilities needs to be designed to support families led by those with developmental disabilities.

- Ontario child welfare agencies should receive training and education about developmental disabilities and should work together with developmental services to make sure that parents have adequate and appropriate supports.

- Developmental services, disability services and child welfare agencies should work with people with developmental disabilities to create and facilitate alternative parenting arrangements, including co-parenting, open adoption and family configurations that continue relationships between biological parents with developmental disabilities and their children and grandchildren.

**Ms. Pat Seed:** If you think about it, many people do not know people with developmental disabilities who are parents. So, to that end, we really feel that there needs to be also education for the general public and everyone, including politicians and all kinds of policy-makers and so on and so forth, to be able to have them know about developmental disabilities and intellectual disabilities.

We are all familiar with the term “handicapped accessible,” by the way, and we know that that means wheelchairs, ramps etc., etc. Well, the opportunity for us is right now, to show that we are very serious about accessibility for those with developmental disabilities. That's really why I thank you, as a committee, for coming today

and taking all the information that we have and, in fact, going across Ontario for these presentations.

You might also think of accessibility in other ways after this group of presentations. Very often, situations with people who are blind or visually impaired, and also situations with people who are deaf, hard of hearing or profoundly deaf are not addressed as far as accessibility. Again, I say that you really see most the people—the accessibility—with wheelchairs, ramps and so on and so forth, and I think a lot of eyes need to be opened.

I will allow you to read this presentation at your leisure, and I definitely can be contacted for questions. I also have more copies of the presentation, should there not be enough for media or for the public who want them.

Now I'll take your questions.

**The Chair (Mrs. Laura Albanese):** Well, thank you. Thank you for coming today and for your presentation. We don't have a lot of time for comments and questions, but I will turn it over to Ms. Elliott to start with.

**Mrs. Christine Elliott:** Thank you very much for being here today, Pat and Cher. You have really opened our eyes, as you said you wanted to do, to some of the issues around people with a developmental disability who are parents and have families.

I'm wondering, Cher—if you don't mind if we ask you a few questions, as much as you feel comfortable with—if you could tell us about any of the problems that you and your family had in terms of, say, for example, finding housing. Was that a difficult thing for you to do?

**Ms. Cher McCullough Monteleone:** Not really, because we had already found a place before we had the kids.

**Mrs. Christine Elliott:** Okay, so that wasn't a particular issue for you. I'm looking at some of the recommendations that you've made, and you've indicated that that's sometimes a problem and it's something that we need to look at.

Did you have any problems with any child welfare agencies, or with any organization, for that matter, with respect to parenting, specifically?

**Ms. Cher McCullough Monteleone:** I did when my first child was born. CAS was involved for a little bit, but they found no issues so they got uninvolved. But, yes, other than that—

**Mrs. Christine Elliott:** Okay. So they've pretty much left you alone to be a parent on your own.

**Ms. Cher McCullough Monteleone:** Yes.

**Mrs. Christine Elliott:** Okay. That's very good. Thank you very much for sharing that with us.

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

**Miss Monique Taylor:** Hi. Good morning. Thank you so much, Pat and Cher, for being here with us today and for bringing a different piece of the puzzle to the table.

Yes, one of the things that I was wondering about before I actually got to the recommendations was how the child welfare system was involved. Was it intrusive?

Was it helpful? What are the experiences that families are facing when it comes to having children?

**Ms. Pat Seed:** Very often, the children are taken away from the families, and that is done, so to speak, as a protective measure, instead of working with the families to be able to raise their own children and to be able to have the supports to do that.

I've seen Cher very much involved with her two little children. She has a little girl who's eight months and she has a little boy who's—four?

**Ms. Cher McCullough Monteleone:** Three.

**Ms. Pat Seed:** Three. She gives them boundaries; she gives them all those kinds of discipline things.

**1100**

Only by education is it going to be that people would be able to know—and this includes sexual education, information on marriage, information on parenting, information on child rearing and so on and so forth—child development etc. All of that is needed.

**Miss Monique Taylor:** It's fabulous—

**The Chair (Mrs. Laura Albanese):** Thank you. Sorry, Miss Taylor. I have to move to Ms. Hunter.

**Ms. Mitzie Hunter:** Thank you, Madam Chair. I want to thank you both for joining us here today and bringing your part of this forward, because it's a perspective that we need to consider.

Your first recommendation is to include, in a meaningful way, the voices of people with developmental disabilities in policy and program development and implementation, and I think that's a very important consideration—and as a committee, there have been many different ways that that is being done, and I think your contribution is helping to further that.

I also noted that the network of support around this project seems quite extensive, through the universities and through community-based programming. I really look forward to seeing the results of your work. Much of what you're attempting to do is to change attitudes and behaviours, and that will influence support policy and then the supports that are required.

I just want to say congratulations on your work, and I look forward to seeing more of it as it unfolds.

**Ms. Pat Seed:** We really appreciate your time, and we really appreciate the fact that Michael Gravelle took it upon himself, on his own time, to come over to us and meet with us. He was very interested in the project.

**The Chair (Mrs. Laura Albanese):** We will let him know. Thank you very much once again for presenting to our committee and bringing this different voice and different perspective to the table.

**Ms. Pat Seed:** By the way, if you need a phone number for contacting me, you can use 807-473-0909.

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

MS. DEBRA JOHNSEN

**The Chair (Mrs. Laura Albanese):** We'll get ready now for our next presenter, Ms. Debra Johnsen.

I see that you're getting ready for a video that you have for us.

**Ms. Debra Johnsen:** Yes. My name is Debra Johnsen. It's a pleasure to be here. This is my friend Tara Lennox.

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

**Ms. Debra Johnsen:** My son, Lindsey, is just sitting in the front row. He's comfortable where he is, so he'll just listen.

We've circulated the CD. I'm going to make sure there's no sound on it. When you're flying back to Toronto, you'll be able to put this in your laptops and listen to the terrific music, listen to the lyrics. It's a wonderful—

*Interjection.*

**Ms. Debra Johnsen:** We'll get you one, Tara. She wants the chocolate that's attached to it.

Welcome to Thunder Bay. You've brought some warm weather. I thank you for this opportunity. Good morning.

My name is Debra Johnsen. Firstly, I am a mom, one of many that you will likely be hearing from. Thirty-two years of learning much from my son, Lindsey—he has never spoken a word but has touched many lives.

When I chose to present, it was based on one of those personal experiences that I know are shared by many across not only this province but the country, and, I believe, like many of the challenges we collectively are facing, could quite easily be resolved.

I applaud this government's vision in seeing the urgent need for a comprehensive developmental services strategy.

A communication that I've circulated to the members here, coming from Ted McMeekin, Minister of MCSS, was quite shocking to me. It speaks of funding, and as a parent I was quite appalled by the numbers. When I read in this communication that there was \$42.5 million a year added to developmental services to help 1,000 adults and their families with new or additional supports and that there is \$620 million in new annual funding since 2003, a 63% increase, I want to say, "Where is it hitting the street?" We're not seeing it as individuals and families. The system is broken. These facts are impossible to grasp, knowing first-hand that there are few examples of where it is having successful effect. The stories you are hearing are testament to a complex system that needs to be unwound in many ways but that, in my opinion, starts at the community level.

As a family supporting our 32-year-old son, Lindsey, we have been extremely active in advocating for independent planning and facilitation, individualized funding, and allocation mechanisms that ensure access, fairness and equity. Lindsey has been extremely fortunate to be living with two other fellows who over the past 10 years have become family. One of them is Michael Gravelle's brother. We're very, very blessed. Mark Gravelle has become one of Lindsey's other brothers.

We are part of traditional services offered by Community Living, the dreaded group home that you're

hearing about. Sure, there have been challenges, but the bottom line is that Lindsey is in a loving and caring environment. He has a network of family around him that advocate and push and prod the system to be more inclusive and responsive to his needs.

My current most pressing issue is Lindsey's health. Over the past year, he has lost more than 30 pounds—I can only wish that would happen—likely due to dental hygiene issues. Many of the persons who require the specialized services of day surgery for simple dental cleanings know first-hand that of which I speak. The stories are horrific, the wait-list four years and longer.

I spoke with a mom a few years ago whose daughter was diabetic and couldn't eat and couldn't get time for an abscessed tooth. Our wonderful dentist, who is well known as an ardent advocate, has been hard-pressed to find solutions. He has told of having to stop a cleaning halfway through because he ran out of ODSF funding. I guess, similar to our group plans, there are limited units offered, and they're not cumulative from year to year—in my mind, a possible simple solution—despite waiting four years to get into that much-coveted OR space at Thunder Bay Regional. Can you imagine getting half of your teeth cleaned? Any of us would be outraged. Another issue, according to this dentist, is lack of OHIP coverage for the necessary anesthetic. This is unacceptable.

As parents, we've advocated, we've gone to Thunder Bay Regional hospital, we've talked to the head of that department, but still lots of discussion with no resolution. So here I am, a mom worried sick about a child whose weight loss is striking and very likely due to mal-absorption issues related to gum disease. We are on this wait-list to have all of his remaining teeth excised in the hopes that some of the wasting will abate. This is a guy who loves to eat, loves food, loves car rides, otherwise loves life. There are so many times that we wonder how much of his self-abusive behaviour might be related to a toothache. Once again, imagine yourself in this scenario.

I bring this forward hopefully to address some huge shortcomings. I've included a Globe and Mail article that was in a recent paper. The Canadian Dental Association's Peter Doig admits that people with special needs have limited access to dental care. He says that oral health has never been made a priority, and that "One of the problems is that it comes down to an issue of funding." There's that dirty word once again: "funding."

**1110**

So what are my recommendations to you? It's totally unrelated to dental care, but it fits, and I think it will resonate with you. Provide supports in a proactive manner. This will reduce the costs of having to provide supports in times of crisis. From my perspective, investing in circles of support or networks and nurturing their development through the early school years and beyond are key to transformation.

In my humble opinion, the failure of the Choices project in Thunder Bay was this missing link. Even though the development of networks was a critical piece

to the Choices project, which was that individual funding model, it was not seen as pivotal once that pilot project was finished.

I was part of a family-led advisory committee that pushed really hard. We tried really hard to say that this was a pivotal part, but unfortunately that vision got lost. It was consumed by the system, and the Lutheran Community Care Centre became another service provider. Creativity and innovation were thwarted by old thinking.

Loving relationships are key to well-being. Without social supports, health care suffers, choices diminish, vulnerability increases and there is a risk of being caught in an impersonal service delivery system. Whether we're developmentally challenged, whether we're quasi-normal or we're seniors, that is a truth.

Secondly, I'll call it the three Is: independent planning and facilitation, individualized funding, and innovation. Families have been underground for years. They continue to be jaded on many levels, without much to encourage their entry into this vortex. The funding facts articulated by Minister McMeekin should outrage all of those families supporting individuals.

Individualized planning, facilitation and funding, coupled with a vibrant network of support—as I suggested early on—at the grade-school level, would allow for a shift in power and control, where it should be: in the hands of the individual. Unbundling of existing services is necessary so that everyone receiving traditional services is aware of what fundings are allocated. This will lead to and will encourage accountability, innovation and creativity.

To have all employment in this sector tied directly to outcomes—how is your job producing a positive experience for that individual supported? I know, wishful thinking. Yet families are being told of a freeze to their support dollars and to be more creative, and we wonder why families are underground?

Lastly, creativity and innovation are the master key to managing fiscal realities. In order for this seed to be nurtured, there needs to be a breaking-down of barriers and silos. There needs to be a demonstration that there is political will to support families coming together to answer those needs, not just throwing more money at an already broken system.

We, the movers and shakers within our community, need this committee and our government to hear that we have the passion to set the stage for a new story. We just need support in the how-tos. Individuals and families need an unprecedented demonstration of “We hear you. What can we do? Here is our undivided attention. How can we make this work?”

Forgive me. I am an eternal optimist; I drive my husband absolutely batty. But when I become discouraged when not too many things are working these days, I know that I must step up to the plate and say, “Enough!”

I believe that there is a tipping point beginning to emerge, where this has begun to resonate amongst the community. I know that at government-level tables, things aren't working well federally or provincially.

Maybe it's time that we start thinking differently and acting differently. Who wants to be on a board of directors when it is not even a place that is effective any longer?

My last recommendation is dialogue. Talking about critical issues often leads to life-changing events—here's hoping, anyway. I know that my son Lindsey's well-being is a huge concern. There is an absolute need to address the basic and necessary dental care for individuals with special needs. Likely a national oral health strategy is necessary under the Charter of Rights, prior to a lawsuit being commenced. Let's begin the conversation and find a resolution for fair and equitable coverage available under ODSP.

In conclusion, I want to continue to be engaged. I want to support an emerging family movement. I want to see meaningful collaboration across sectors and an unbundling of resources that will enhance the lives of our children and will naturally build capacity within communities. Simple solutions often lie on the other side of complex problems.

I'm going to make sure that the sound is off on this. I'm part of a network of ICANers. Tara's an ICANer and Lindsey's an ICANer. What's been so cool about this: For very minimal dollars—I would probably say zero government dollars, sort of—this network was developed by families going, “Holy Hannah, we've been meeting since 1999, and none of us know each other's kids. For God's sakes, let's get together once per week and just network. Let's try and get those families out of the basement to come out and socialize.”

*Interjection.*

**Ms. Debra Johnsen:** You remember that—Tara's in a lot of these. There's Tara; there's Tara.

What has emerged from this very simple one-week-per-month informal network has been—Tara's gone camping with one of our volunteers. Two years in a row, a group of girls has gone camping. Right?

**Ms. Tara Lennox:** Yes.

**Ms. Debra Johnsen:** Tara's been invited out to dinner, just last week.

**Ms. Tara Lennox:** No, with Bob.

**Ms. Debra Johnsen:** With Bob, yes, just recently.

Take your time to look at these slides here because you know what? All the issues you've heard about across the province, there are the movers and shakers in Thunder Bay. Those issues articulated in that wallscape are exactly what you've been hearing across Ontario. I guess what I'm saying from this ICAN! network is that encouraging families somehow—the family network piece—is so important.

There's stories with our pumpkins. Don't do pumpkins too soon because they go mouldy.

**Ms. Tara Lennox:** And they fall apart.

**Ms. Debra Johnsen:** And they fall apart.

**Ms. Tara Lennox:** They do.

**Ms. Debra Johnsen:** We've seen people who are not normally engaged, engaging and having fun. We've got volunteers who had never been involved in the disability

sector come out and say, “I’m getting more back than I’m giving out.” It has become a perfect, perfect kicking-off point for us.

Anything you want to add? Thank you. I’ll just let that run, and answer any questions.

**The Chair (Mrs. Laura Albanese):** Thank you very much for your passionate presentation this morning. We do have less than a couple of minutes each for questions. We’ll start with the NDP.

**Ms. Cheri DiNovo:** Yes, thank you so much for your presentation, and thank you for being part of the solution as well. Circles of support are also operating in my riding. I’ve seen them effectively work through and with Community Living and all sorts of wonderful unique options for families once families are energized, so I want to thank you.

I want to contribute this to Tara because—I feel like I’m hurting the dental saga here—

**Ms. Tara Lennox:** I can’t have chocolates.

**Ms. Cheri DiNovo:** Certainly, in terms of the dental care, thank you for bringing that forward. It’s the first time that we’ve heard that piece, and it’s a very critical one. We absolutely need to act on that, I would say immediately. So thank you.

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

**Ms. Mitzie Hunter:** I too want to join in thanking you for sharing your passionate story. My colleague would like to comment.

**Mr. Bill Mauro:** Debra, thanks for the presentation. It’s a bit distressing, I must say, to hear the part about the dental. I’m trying to just figure out what’s going on here—not specifically here with us, I guess, as a government, because I know we’ve been part of at least a couple of announcements on expansion—significant expansions, as I came to understand it—on dental care programs.

1120

But maybe there’s a theme here, because you referenced at the beginning that the increases in funding in the sector, that were referenced in the minister’s letter, of \$63 million or whatever the numbers were—you weren’t feeling it on the ground. And the dental money as well, or programming that we’ve rolled out—or at least, I certainly was under the impression we had. There were two separate ones; I forget the names of them now. But you’re not able to find your way—I mean, I understand the piece of ODSF tied to the rates and what the dentists get paid and whether or not they still want to be in the game of providing the service—not “the game;” that’s a poor choice of words. But you know what I mean: being part of the system, in terms of providing the service.

But I even thought, through the public health units, that we had a second program that had expanded access—

**Ms. Debra Johnsen:** Not any knowledge to me.

**Mr. Bill Mauro:** Okay.

**Ms. Debra Johnsen:** I know personally of only one dentist who has the passion, I think, as an advocate—Dr. Mason is well known in Thunder Bay—that it has created such stress in his own personal life—because he’s had to

stop cleanings and whatnot—that he had shut his door, in fact.

The Globe and Mail article suggested possibly specialized clinics. Dr. Mason spoke about lack of being covered for anaesthetic. Well, could Lindsey access his normal office, with anaesthetic, without having to be in an OR room at day surgery at Thunder Bay Regional? I don’t know that answer. Dr. Hettenhausen at Thunder Bay Regional listened to it, and I wasn’t even given to believe that it was an issue of OR time.

It just seems like there’s a vortex of the left hand not knowing what the right hand’s doing. It’s not right. It wouldn’t happen amongst other circles. That’s where the strength of a family network—us coming out of the basement—stopped. It has got to be addressed.

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

**Ms. Sylvia Jones:** Debra, thank you for your passion. I loved your three I’s: independent planning and facilitation, individualized funding, and innovation.

I was involved when we were doing some of the transformation agenda. There were a number of us who pushed pretty aggressively for the circles of support, because we have seen anecdotally in our own community how well they have worked when you have that family and community engagement.

So we’re not giving up, and your story will just reinforce the value of what that brings to everyone. Thank you.

**Ms. Debra Johnsen:** Lindsey’s saying, “Good. Good, you hear.”

**Ms. Sylvia Jones:** Thank you, Lindsey.

**The Chair (Mrs. Laura Albanese):** Thank you for being here this morning and for bringing your voice to the table, to our committee.

**Ms. Debra Johnsen:** Thank you.

#### THUNDER BAY FAMILY NETWORK

**The Chair (Mrs. Laura Albanese):** Next we will have the Thunder Bay Family Network, which will do a presentation to the committee. Mr. Paul Meyer?

Yes, Ms. Wong, as we’re waiting for—

**Ms. Soo Wong:** Madam Chair, while we’re waiting for the next witness, can I ask the researcher to get some data for the committee with respect to the last announcement—it was so recent; I can’t remember the date—last fall, from the Ministry of Health and Long-Term Care, dealing with dental services, and where is the earmark of that, because it was supposed to be expanded programs. The administration of that particular program—my colleague Bill Mauro and I were just talking—my understanding is it was supposed to be administered through the local health unit.

So if we could get some more data on that expanded funding for dental services, and how does that address the last witness’s concern dealing with individuals with developmental disabilities and how they get access to those programs.

**The Chair (Mrs. Laura Albanese):** If I recall, there was an expansion to an extra 5,000 people, especially children and youth, but perhaps not adults. Thank you.

Welcome.

**Ms. Debra Johnsen:** Good morning. Here I am again. Not only am I a mom; I'm chair of Thunder Bay Family Network. Passion, passion, passion, 1999 forward.

Today at the table with me is Paul Meyer, one of our board members; and Bob Speer, who is part of one of those networking groups, called the Intentional Living Group. He's also a pretty passionate, cool guy who attends ICAN! with his granddaughter.

I'll do a quick blurb; then Bob Speer will bring up the Intentional Living Group that has emerged from Family Network, and then Paul Meyer will tie up.

We are a family-driven grassroots organization that is dedicated and committed to nurturing the strengths, dreams and enthusiasms of individuals with disabilities, their families and caregivers.

This mission has been constant since our 1999 inception. Over the years, passionate people have tirelessly pursued the goal of building relationships and enhancing community capacity, towards that ever-elusive need for peace of mind.

We've circulated not only our package but the Safe and Secure book that we helped to edit the Ontario version of. If you look closely at it, it provides the six steps. It answers the questions about RDSP. It provides opportunities for how creating a house—and central to all that is networks of support, the values and reasons why networks of support are so important.

The stories you've heard today, and likely in every other community, are based on those very real fears: "What will happen when I'm gone?"

The values guiding our work are simple. We know that families and individuals can best determine their own support needs and that innovative solutions can be discovered when families are engaged. Networks of families are stronger than one family in isolation.

We are continually seeking new and innovative ways to support and nurture families, individuals and communities. The book Safe and Secure is central to many of these discussions: tangible steps in how to plan a positive future, one that is built on solid relationships and real opportunity.

We've got various groups that have emerged, and I showcased the photo story of ICAN! because I didn't want to waste the time. I wanted the questions to come after.

Bob Speer will be speaking about the Intentional Living Group.

**Mr. Bob Speer:** Hello. I'm Bob Speer and I'm a volunteer with the Thunder Bay Family Network. I am a grandfather to a special-needs young lady who is now 18 years old.

Samantha was born weighing only one pound, four ounces. Within a few months, it was determined that she had cerebral palsy and Dandy-Walker. She has been in therapy for years at George Jeffrey Children's Centre

with great success, where she can now walk and attend school. The centre has enriched her life and many other children's who attend the centre. She cannot talk but uses sign language and an iPad to communicate. She will always require 24/7 support for her entire life and is subject to seizures at any given time, and this, hereby, is a big problem.

Imagine you see all around you the challenges that will be facing your son, your daughter, your grand-daughter, even many of your friends. Imagine you start exploring and digging a little deeper. You speak about your own wishes, about wanting to live in a setting that is inclusive, one where everyone is supported, their gifts recognized. Imagine what it would look like.

We've been asked by a committee to dream big. Well, this group has been, for the past six months, without knowing that there might be someone who might want to listen beyond the core group of passionate family members and friends.

We've developed a vision. We have imagined a new building with the main floor a buzz of social enterprise, the best club in the town for music and food, which is beyond fantastic. The tourists are even hearing about it as being the place to go. Or as—

**Ms. Debra Johnsen:** Excuse me, Bob. We would have suggested last night that that's where you would have gone for supper instead of the Prince Arthur. Sorry to interrupt.

**Mr. Bob Speer:** Or as simple as a coffee shop with various areas of support which complement our intentional living quarters on the upper floors. It could include the recycling shop, the delivery service and the community kitchen.

In order to live here, one must complete our application and agree to established criteria. It might be a mom with young children doing night support, ensuring that two units are tucked in safely, while one of them meets her children off the bus and keeps them occupied making muffins in the community kitchen.

**1130**

We have found many reports speaking about the crisis that is looming. Our local report by DSSAB on housing and their 12 initiatives and the Ministry of Community and Social Services' own Ending the Wait document all talk about housing.

We've seen where the government is supporting social enterprise. It seems as if everyone knows what is needed. We want to start speaking to others, professionals that might support an initiative, but then the word "funding," or lack thereof, stops us in our tracks.

Can a group such as ourselves get support to pull on threads that may challenge existing funding models towards something that is different? Can existing funding dollars be allocated in a different direction to support a concept that supports across age and ability? We are asking this committee to consider allocating resources that will support the growth of innovation that, over the long haul, will provide a community that is engaged in living with intention, supporting all of its citizens.



It is a known fact that many parents with special-needs children and young adults receiving their care and support at home are becoming older, with less energy to provide the proper care most need. Parents, grandparents and families are living with much stress and worry about the outcome of their children if and when they are no longer able to provide the necessary care.

It is important now that plans are made and implemented to provide special housing and care for our special-needs adults. It is time for helping individual groups who want to take the initiative to step up and then plan and implement the goals for intentional living. Groups need access to tools, resources and strategies, and to partner with government and community so dreams will be accomplished and our special people can count on their lives to be enriched.

I do believe this meeting here to listen and receive input from many concerned individuals is a great start, and look forward to the outcome and, hopefully, the necessary help needed to ensure our adult special needs are looked after in the future years.

Thank you.

**The Vice-Chair (Mrs. Christine Elliott):** Thank you. Yes, sir?

**Mr. Paul Meyer:** Hi. I'm Paul Meyer, and I'm a board member of the Family Network. I feed off Deb's passion.

I'm sure you're hearing an earful of problems in the systems. I want to talk about what I see as opportunity.

In our community some years ago, back in the 1990s, I was with the Ministry of Community and Social Services. We were closing a facility, and I was charged with helping find placements for people leaving the facility.

We began with the traditional approaches: more group homes and so on. As we came together as a group of agencies with the ministry and talked about it, we challenged each other: "Isn't there a better way?"

We'd heard about this concept of individualized funding which was emerging in BC, learned more about that, and took some of those ideas and adapted them at the community level to something we called the Choices Project. We made it bigger than just people coming out of the facility. With the monies that were moving into the community, we were able to generate a project that would include people from the facility as well as families who were ready for a move from traditional and some that were waiting and had no service. The whole concept was based on a fundamental premise that people plan their own needs before entering the service system.

We had independent facilitation, where the person's family and support network were involved in developing a plan and then negotiating, with the help of a facilitator, the funding for that plan. Thirty families, in that short period of time, were able to participate, and still do enjoy and manage their own support arrangements.

That initiative lost momentum for a variety of reasons that I don't have time to go into right now, but if we fast-forward to today, what I see is this new legislation that contains the nuggets of that same thinking: the key

elements of person-directed planning, the possibility of independent facilitation for those who want it, and even the possibility of direct funding to support the plan that the family and individual develop.

I see underlying this new legislation some fundamental principles that guide us, Deb and I, in our work with the Family Network, and I call it the three Cs. This is a result of a lot of thinking over a lot of years in retirement, when you actually have a chance to sit down and think about life.

We believe passionately that people should have control over their own lives and the lives of their beloved family members. That includes choice. It's even bigger than choice. We learned a lot with the Choices Project. Control, to the extent that any of us have control over our lives—that is fundamental.

Secondly, they have connection beyond paid staff. That's not to knock paid staff; we have many, many good staff in our community who are doing a great job. But there's more to life for these people than just being involved with paid staff. They need connection and opportunity for connection, such as Deb was talking about, with ICAN!, as a simple example.

Thirdly, competence: People are involved in some way, according to whatever ability they have, in something meaningful so that, at the end of the day, their lives have some meaning and they're not just existing and being managed.

When I look at the system, I think we're stuck. All of our resources are tied up in maintaining the current system. On the other hand, I think we have a really enlightened piece of legislation which guides the way to a new way of doing things, and it contains those elements of families having control in planning and arranging their own support systems. But I don't see anything happening. All of the pressure, it seems to me, is focused on the one element that was introduced, and that's the DSOs, where people are getting the assessments, but then the ball stops there; there's no movement. We have a lot of frustration. We've created a huge pressure point across the system, and we're seeing a lot of cynicism from families: "Why bother? It's not going to go anywhere."

It seems to me that the solution lies at the community level, and it begins with families. We need to rethink our whole model of service and supports for individuals with disabilities, using these guiding principles that I think are inherent in the legislation. How do we do that? On the one hand, with the current system, we need what I call—and these are some thoughts that were developed with the help of one of our members sitting in the audience today, from the university—a reinvestment strategy. Many of the points that Lisa raised in her comments from Community Living—rethinking how we provide supports based on this new way of thinking inherent in the legislation; to begin a shift to more individualized approaches.

I'm talking about change, but I'm not talking about chaos. We can't just turn the current system upside down and start all over again, although some of us would like to, including Deb. We start family by family. On a plan

basis, we begin changing the current system and moving to the new page, the new legislation. On that side of the page, I call it an investment strategy. I can't see the government coming up with enough money to maintain the current system and yet pour in a ton of additional funding for this new system that is going to emerge. If any monies do come, and I'm hopeful they will, they need to be focused on this side of the page and not just continue shoring up what we're doing now.

We need to see flexible funding that might be generated from the transformation in the current system moved over to the other side of the page, where it becomes available to more individuals. We need forums where families and communities can come together and talk about and develop their own plans, learn about this new system and how to engage it. That's what Deb's all about.

We need—and this is the tricky one—to move beyond this concept of entitlement: “The state will provide.” That's old thinking from institutional days.

**1140**

There are many families that are willing and able to bring family resources to the table to help develop a plan, to help their young adult children, much as we do with our own, to give them a hand up, a start, not to make them dependent on family for life. Certainly, we have a responsibility to support people with disability, but we're overlooking all of the huge, tremendous potential in communities and families and guys like Bob, who are there doing things with housing, looking at options. We're missing out on all of that.

So how do we start? We start with the community. I'm hearing that across the province there are already some good practices going on. We need to get some of these people together in the same room, at the same table, and talk about how we can develop a framework within whatever guidelines are coming down from the ministry, but we can't wait for this top-loaded plan to filter out. It's got to start at the community. I think we've got the kind of people in this province who have already demonstrated that it's doable and are already doing things, making things happen. We can make it happen.

Lastly, we need more forums for families. As I said, we need opportunities for families. We need to actively encourage it, not just invite a family to a conference or to be a participant at another planning table, but to actually create forums where families have their say and their voice can be heard. It all starts with families having control of the lives of their individuals, their loved ones. If we do anything less, I think we're just wallpapering the room again and I don't think anything is really going to change.

I really wish this committee well in their work and I hope you're hearing the same message but also that you're seeing that opportunity is there. Let's get moving. The train is ready to leave the station. We have communities that are ready to go. Let's get it moving.

Thanks for your time.

**Ms. Debra Johnsen:** If I can comment: This venue or this opportunity hopefully will help our Thunder Bay

families emerge and create a movement. I'm hopeful that a successful outcome of your work will be Family Network pulling the pieces to bring those families out of the woodwork. Thank you.

**The Chair (Mrs. Laura Albanese):** Thank you very much for your thorough presentation. That's something that our committee is also looking for—that input from people on the ground such as yourselves. You live it every day and you can teach us. We don't want to tell you what is needed. You have to communicate to us what the need is, so we thank you very much for that.

Unfortunately, we don't have any time left for questions. I just want to convey on behalf of all the members of the committee how much we appreciate your presentation. Thank you very much.

**Ms. Debra Johnsen:** Thank you.

MR. GEORGE SAARINEN

MS. CHERYL DUCE

**The Chair (Mrs. Laura Albanese):** We will now hear from George Saarinen and Cheryl Duce. Good morning, George and Cheryl. Welcome to our committee.

**Mr. George Saarinen:** Good morning. My name is George Saarinen and I'm a front-line worker with Options Northwest Personal Support Services. Cheryl Duce is the director of residential services. I know our time is brief, so I'm just going to get right into the report. I have a short session, and then Cheryl will carry on.

I have met with several MPPs through public consultations. My work with the Federation of Ontario Public Libraries—I know Ms. Albanese from there. I've done deputations with the budget process and I've met MPP Wong during that process.

Just to get into it, I'm a graduate of the developmental services program at Confederation College here in Thunder Bay. I was there from 1978 to 1980, and at that time we were called mental retardation counsellors. My, how terms have changed in the past 30 years.

As well, I am a publicly elected school board trustee with Lakehead Public Schools here in Thunder Bay. We are a school board that welcomes all students. I am not the director; I'm not the superintendent; I'm just one of the independent trustees.

I have concerns, as a trustee, with the lack of supports for individuals with support or special needs who are in our school system. These individuals are in the school system until the age of 21, at which time they are no longer supported by the education system in Ontario. In education, we see shortfalls in special education funding. This is an issue I talk about with MPPs every time I have an opportunity.

We try and offer supports for identified students with needs and have educational assistants work with these students. Unfortunately, the funding dollars do not meet the expectations or the needs, so many students are falling through the cracks and do not get the help they need.

There is a gap or a lack of services for individuals who reach the age of 21. There are few, if any, supports for

these individuals once they leave the school system and enter the community. When they are in school, they have supports, life skills and training opportunities, but these cease at the age of 21.

We have an aging population with our recipients of service. For many years, many of the individuals we supported lived in institutions and were moved in supportive living in the community. Many of the recipients are now in their fifties, sixties, seventies and eighties. Many individuals are dealing with loss of memory, motor skills, mobility and cognitive skills. They experience medical needs which may require hospitalization, and they require supervised supports in a hospital setting due to loss of skills and abilities due to aging issues.

Recipients of service may require 24-hour support in hospital, and many service agencies may not have been provided the funding for such supports. It may be necessary to place our recipients of service in long-term-care facilities, where the caregivers may not be aware of the individual's needs, wants and supports. Once again, the individual may be placed in a strange new environment, which may confuse the individual more.

We are expecting shortfalls of physicians, specialists and dentists in northern Ontario. Many recipients of service face long waits in getting a new doctor or dentist due to the shortages and availability of the professionals. The recipients have needs that need the attention of medical practitioners, as was mentioned earlier. Some of our recipients need to be hospitalized for dental work; for this to be done, long waits are incurred for the surgical time to open up for the dental cleaning and examinations, a simple process that has become complicated. With the shortages of family doctors, the recipients must go to walk-in clinics to get their prescriptions filled and forms for ODSP for equipment such as wheelchairs, devices for supported living, like mechanical lifts, or other supports.

With regard to infrastructure and capital funding, we require more for the operations of the group homes for the recipients. Many of the homes require updates for new roofs, windows, doors, furnaces and ventilation systems. Often, these costs can be astronomical; where do the agencies find the money to make these repairs?

An interesting point that I have experienced with my work is that ODSP ends for recipients of service at age 65. At that time, the individuals are entitled to old age security and the guaranteed income supplement, if the forms are filled out appropriately and in a timely manner, six months before turning 65. However, once ODSP does end, the individuals lose their dental support, dentures and eyes glasses which were previously there through ODSP. The individuals are now responsible to purchase these needs on their own. With the guaranteed income supplement, if the recipient is late in filing their tax return, the GIS is cut off as well.

Through the ODSP income support, we need support for household items such as furniture, bedding, winter clothing and personal items such as winter boots or even appropriate footwear. Often, when the rent and food

expenses are paid, there is very little left for personal needs. Support staff, families and individuals often may go buying clothes and other items in a thrift store or a Salvation Army—again, third-class citizens in Ontario.

We need to support the Special Diet Allowance for recipients of service. We know recipients who have been denied support for the Special Diet Allowance, and purchasing food to help them lead a healthy lifestyle becomes very expensive.

Indexing benefits to the cost of living so that benefits do not decline over time would benefit all recipients of service. Costs are going up everywhere. The base housing allowance needs to be indexed to the actual average cost of the rental accommodation in the community where they reside. Across the province, especially here in the great northwest, costs are higher for rent, hydro, heat, oil, natural gas, city water and sewer. We pay more for food, gas and other supplies, yet ODSP is the same throughout the province.

I would not call it racism, but I certainly see discrimination for the recipients of service, many of whom require specialized equipment such as form-fitting wheelchairs, standers, mechanical lifts and a variety of other supports. These supports come at a huge price, because they are specialized items; they can't be purchased at a Walmart or Target. They have to go to specialty stores such as Shoppers Home Health Care to purchase these medical devices. I appreciate that the Ontario Disability Support Program does support their programs for the wheelchairs or assistive devices once every five years. However, these waits can be longer than five years as well for these individuals.

#### 1150

Ontario public school boards led the initiative for mental health leads and successfully led work with all the ministries and parents' groups to work together for mental health issues across the province.

Others have mentioned the lack of support across the ministries: children and youth services, health, education, housing, and community and social services. The individuals with needs are supported by several ministries, and co-operation and a smooth flow or transition from one service to another would be most helpful to families, agencies and the individuals we support. Let's all talk from the same page and continue success for the individuals we support in their journey of life.

It would be advantageous to have a review panel set up of recipients of service, families, front-line staff and community members or agencies to make recommendations to better meet the financial, emotional, physical and social needs of the individuals we support. I sincerely appreciate the work that this committee is doing across the province and feel this consultation is well overdue but is now happening. Thank you.

Recipients of service have seen many changes in their lives from institutional care to supportive living opportunities. While living in institutions, they had day programs, workshops and recreational programs to enrich their lives. Upon transitioning into the community, many

of these programs have disappeared, and many individuals face long waiting lists to get community supports for recreational opportunities or community programs supporting recipients of service. We heard yesterday about the extensive wait-lists.

However, great gains have been made from the individuals we've supported in the past 50 years. There are reasons to celebrate these successes because the individuals have made the transition from institutions to group homes or Community Living settings. Governments have seen, listened and made changes for the individuals we continue to support. It is my hope that the Select Committee on Developmental Services will listen and act upon the recommendations that are brought up in these hearings to improve the daily life of the individuals we support 24 hours a day, seven days a week, 365 days a year. Thank you.

**Ms. Cheryl Duce:** Hi. My name is Cheryl Duce, and I'm the director of personal support services with Options Northwest. A lot of the issues that George just mentioned to you are some of the issues that we face. Our organization currently supports 76 adults with developmental disabilities throughout the city of Thunder Bay. We support them in 24-hour supported residential locations. But if you see my submission, the ideas that I present today are also the ideas of those from Superior Greenstone Association for Community Living. They support adults with developmental disabilities in the Greenstone district, which is Geraldton, Nipigon, Red Rock and Pic River.

I just want you to know that I kind of horned in on George's time here. I was just going to submit in writing, but he came to visit me and said he was giving this presentation. A lot of the issues that George has mentioned, because he does work for our organization, are the same issues that I will be presenting to you.

Options Northwest also has a clinical services component to our organization. Not only do we provide residential support, we also provide clinical support. The clinical support is provided to adults with a developmental disability. There's a small amount of funding to provide services to children with a developmental disability, but only those children who have a complex behavioural or medical issue or need.

That's where I kind of lead into my first concern: that there's a lack of group living locations for children with complex medical and behavioural needs. Because of this lack of residential support within the city of Thunder Bay, children with complex medical and behavioural needs are often sent out of town for residential support. We don't have any group living locations for these individuals, for children with developmental disabilities. As we are aware, this is very difficult for the individual and their family. While efforts are made for visits and calls, it isn't easy for some to go to southern Ontario to be with their children. The Residential Placement Advisory Committee, which is a committee that follows up with these children, says some are as young as 10, and they are crying on conference calls because they miss

home and their family. This community has very experienced service providers who can provide the support these children require, but we are told that the cost per day to send children away is more economical than keeping them in Thunder Bay. Once these individuals reach adulthood, many would like to return to their home community of Thunder Bay, but service providers and the community are not aware of their needs. The transition back to Thunder Bay, which we have done on a couple of occasions—transitioned those individuals back to group living residences within our organization—is very difficult due to the cost of travel, problems accessing required information and the time it involves putting the potential new support team in place.

In the end, when you look at the transition cost and the cost of visits for families, is it really more economical? What price do you put on the quality of life for a child and their family? We are all aware of the resulting emotional problems in adulthood when children attended residential schools. If residential locations or treatment centres were developed for children in Thunder Bay, emotional issues would be reduced for the individual and the family. Transitioning to the adult sector could begin at a much earlier age. The adult service provider would be able to get to know the individual by providing respite using purchased services until the child transitions into the adult system, and, I believe, at a much lower cost.

Number two: You said you haven't heard this one yet and now this is the third time you're going to be hearing it, related to ODSP dental benefits. I have actually spoken to dentists within our community who have said that within the city of Thunder Bay—I've talked to dentists within the city of Thunder Bay, who have mentioned that the amount of coverage provided by ODSP dental benefits does not cover the cost of procedures. In order for these dentists to cover their costs, they're required to bill the individual for the difference or—something that's unacceptable to them—to do the work for less. Because they find it very difficult—and this is what one dentist did mention to me: he finds it very difficult to recoup the money from this population for the difference of what the cost is for the ODSP coverage and what the actual cost of the procedure is—they're very reluctant and often refuse to take individuals who are covered on ODSP dental benefits. Our support staff spend a lot of time phoning around, trying to find a dentist, and as soon as they find out they're on ODSP, often they will not even accept the individual.

Others who are fortunate enough to have dentists but require anesthetic and surgery to have dental work done, are put on very long wait-lists waiting for surgery, and we have some that have been on a wait-list for as long as five years. We also have some whom the dentists take off their patient rosters because they haven't seen them in three years and the reason why is because they're waiting for dental surgery—just a real circle. We've even been told by some dentists, "Maybe you should look to Winnipeg to go and get dental surgery done." What would that cost be to the individual and for their support staff?

Also, there's a real lack of physicians available for recipients of service. Some individuals are unable to obtain a regular family physician and rely solely on walk-in clinics, nurse practitioner clinics and the hospital emergency room for health care. This is very difficult for most individuals due to a lack of consistent health care, but particularly difficult for those individuals with complex medical or behavioural issues. I'm sure you're all well aware that some of our individuals with complex behavioural issues require special medications in the controlled drug class. You have to get those medications renewed every three months, and you cannot go to a walk-in clinic. They're not within the scope of a nurse practitioner. They will not renew those prescriptions at any hospital emergency room. Believe me, we've tried all of them. Some individuals with complex behavioural issues also experience medical issues. Without a consistent physician involved in their care to work along with their support team, it is very difficult to try to do a functional assessment to determine the cause of behaviours, which is what we're required to do now under the new policy directives by the ministry.

**1200**

Many individuals living within the districts—this is for the Greenstone area—have to travel to Thunder Bay for medical care. The appropriate professionals, who are required to review behaviour support plans, as directed in MCSS policy directives, are also not available within this community.

Lack of supported day programs: Most of our recipients of service require support to access their community, many requiring one-on-one support. Because we have limited staffing resources, and because there are four to six individuals residing at each group-living location, individuals have limited access to their community, some less than once a week. There are funded day services available, but because these individuals are supported by an organization in group-living settings, they are on the bottom of the priority list for funded spots.

Purchased support services are available, but due to the cost of these services, which is approximately \$30 to \$36 per hour, very few individuals are able to access this type of support.

Passport funding is available to individuals living within the community. Those individuals, supported in 24-hour residential living locations, again are on the bottom of the priority list for this type of funding.

Aging population and providing palliative care: As individuals age, mobility is often decreased and individuals are faced with diseases of aging. The general population is able to access staffing support and equipment resources to live in their own home as their needs change, or during an acute illness, or at the end of their lives. These resources are not available to organizations. Organizations do not receive extra funding to provide appropriate lifts, accessible washrooms or to make the required renovations, nor do they have the funds to increase staffing, as is often required.

We do put extra staffing in; we go into a deficit because we do that. We have several homes that do support

individuals who have quite high medical needs. The homes are wheelchair-accessible; they have special lifts. But you can't move people around. All of a sudden, somebody in a home, where they were able to walk around their home, but now their mobility is reduced—you can't move them out of their location where they are. So we put extra staffing in to support these individuals when we have to.

Options currently supports an individual who is receiving palliative care in his group home, at the request of his family. This is not the first time we have supported individuals during the end of their life. Because of the age of our population, it is only the start of this type of care. It is in the best interest of those we support to age and receive end-of-life care in their group homes, where they and their families are familiar with staff and roommates, who have become like family.

This reduces funding pressures on the Ministry of Health, as it keeps individuals out of hospitals, long-term care and hospice, where staff are often unfamiliar with how to provide supports to people with developmental disabilities who have complex medical and behavioural needs.

Possibly partnerships can be created with the Ministry of Health to pay for extra staffing and the required equipment and renovations that we organizations put in place during these situations.

We currently have an agreement with the Regional Health Sciences Centre and, at their request, our staff are supporting our recipients of service at the hospital, when they're in the hospital or admitted to the hospital for an extended period of time—

*Interjection.*

**Ms. Cheryl Duce:** Oh, sorry. I'm not going to get through. That's okay.

**The Chair (Mrs. Laura Albanese):** Yes, I'm sorry to interrupt. It's just that we've already gone over the time that has been provided, and we're on a really tight timeline.

**Ms. Cheryl Duce:** Yes. Sorry.

**The Chair (Mrs. Laura Albanese):** But at the same time, I want to give you the opportunity to wrap up, at least, with some comments. We do have the presentation, so we can take the time to read it. Just some final comments.

**Mr. George Saarinen:** I have one comment, when she's done.

**The Chair (Mrs. Laura Albanese):** Sure.

**Ms. Cheryl Duce:** You know what? There are many more issues that I have down here, so I was going to submit it in a written submission as it was. Hopefully, you'll read the rest of it.

**The Chair (Mrs. Laura Albanese):** We will. That is our job.

**Mr. George Saarinen:** As a school board, we inherited the school of Armstrong when the remote school boards were terminated a few years back. We have a student population of 96 there: 60 are identified.

**The Chair (Mrs. Laura Albanese):** Okay. Thank you for the written presentation that we will read thoroughly.

It is all very interesting to learn more about the challenges that are faced by the community.

*Interjection.*

**The Chair (Mrs. Laura Albanese):** Yes, I know we have to check out of the hotel. All of us are under some time constraints. We are recessed till 1 o'clock. Thank you.

*The committee recessed from 1206 to 1300.*

#### LUTHERAN COMMUNITY CARE CENTRE

**The Chair (Mrs. Laura Albanese):** Our committee is back in session. We are calling on the Lutheran Community Care Centre to come forward. We welcome the executive director to make a presentation to the committee. We thank you for agreeing to come and speak to us. We have heard many people who made presentations here in Thunder Bay reference your centre, so the committee members are eager to find out more about it.

You may begin at any point in time. You have up to 20 minutes for the presentation.

**Mr. Michael Maunula:** Thank you very much. My name is Michael Maunula. I'm the executive director of the Lutheran Community Care Centre. Its head office is here in Thunder Bay. Our agency serves as the DSO for the northern region. We also administer the Passport program for the northern region and provide case management services for adults with developmental disabilities—that's known as adult protective service workers—for the city of Thunder Bay and along the north shore of Lake Superior to Marathon.

For the programs that cover the entire northern region, the geography is vast. Our southern boundary is the French River, our eastern boundary is around 50 kilometres east of Sudbury, our western boundary is the Manitoba border, and our northern boundary is Hudson Bay.

To serve such a vast region, the DSO, as we call it, short for Developmental Services Ontario, has offices in Dryden, Thunder Bay, Sault Ste. Marie and Sudbury. We utilize videoconferencing technology and Internet voice technology to be as efficient as possible when dealing with the vast distances of our offices and the beneficiaries of our services.

The nine DSOs across the province are fulfilling the role of the application entity as described in the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, its regulations and the policy directives put forth by the Ministry of Community and Social Services. As this legislation went through the committee process of the Legislature, I was impressed with the level of agreement by all the parties on what this legislation should accomplish. To me, there appeared to be agreement on providing a provincially consistent definition of who is eligible for services, the process that would be followed in confirming eligibility, the transformation to a system that was equitable, and the introduction of mechanisms to allow individuals and their

families to have greater involvement in how supports are delivered to them.

You and I know that not all parts of the legislation have been proclaimed; namely, the sections on direct funding and the funding entity. It could be argued that part of the tension we see right now in the service system is that the journey has been started, but part of the process to complete the journey has not been operationalized yet. Nevertheless, the Lutheran Community Care Centre has agreed to start on this journey, and I want to share a bit more on our approach.

We utilize the relationship model of governance and management, and as the name implies, the relationships that our organization has at various levels are given much focus to ensure that they are healthy. We have relationships with our funding ministry, our employees, the beneficiaries of our services and the other service agencies across the north. With our sparse and dispersed population, partnerships are an important part of getting things done. While we have three larger urban centres with larger, and in most cases multiple, agencies, we have many more communities where there is one developmental service provider, very often an association for community living.

As the DSO for the northern region, we need healthy working relationships with those agencies to connect with the individuals and families in need of services for the first time or those experiencing a change in their service needs. The DSOs help articulate the demand for developmental services, show where changes in approaches are needed to respond to new types of supports, and make sure access to a limited resource is done in a fair manner.

We cherish our partnerships with service providers that have good relations with remote First Nation communities so that we can, in culturally appropriate ways, explain the process that must be followed to become eligible for provincially funded developmental services. Because of the remoteness of many First Nation communities in the north, direct funding programs such as Passport are probably the most viable way of providing those supports.

The relationship model places a high importance on certain values. One is the value of affirmation. Affirmation acknowledges the worth and contribution that everyone brings to the achievement of a common goal. In a way, the select committee, through its hearings and invitation to a broad range of parties to present their ideas and concerns, is an act of affirmation. You are hearing multiple perspectives on how to best serve persons with a developmental disability.

Another value of the relationship model is involvement. Involvement allows people the freedom to express their ideas and feelings about matters that affect them. We listen. As the DSO, we may be responsible for performing certain functions in a prescribed fashion; where we can make adjustments based on feedback, we will. We listen to how our partner agencies and the individuals and families we interact with feel about these processes.

System change in an environment of financial constraint can make it hard to discern the issues. Is it the imbalance between the demand for services and resources that are available that is the issue? The DSOs are helping the government quantify the unmet need. Is it the loss of past roles in service delivery that are behind the complaints that the new access-to-service system is not working? There were flaws in the decentralized process of the past. There was inequity. A service system needs time to change, and with the slowdown in the proclamation of all parts of the legislation, all the tools to correct this inequity are not in place yet.

In human services, you can allow yourself to get pretty down about the people who are still waiting for services. I am by no means minimizing the anxiety and the difficulties that these individuals face, and I'm sure you have and will hear a lot about the impact on people's lives.

We and many service providers across this province are helping thousands of people utilize the resources that we have available. We seek out partnerships to be more effective and we challenge each other to be innovative and responsive, and this we will continue to do.

Within our vast northern region, we have what we call four planning tables. One is the Kenora–Rainy River area, the other is the district of Thunder Bay, another is the district of Algoma and the fourth one is the Sudbury–Manitoulin district. As the DSO, on a regular basis we meet with each of those planning tables, and at those planning tables are all the service providers for developmental services. That's one example of how we strive to work in partnership with all our various providers, to discuss the concerns that they have, to get feedback from them about what they perceive is not working well as far as what's in the best interests of the people they serve in their local community.

That is my presentation—rather brief, since I was briefly invited. But I'm certainly open to questions that you may have about the Lutheran Community Care Centre or developmental services, northern region.

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

**Ms. Sylvia Jones:** Thank you very much. I do appreciate that we didn't give you a lot of time to prepare, so thank you for appearing.

You also have group homes; is that correct?

**Mr. Michael Maunula:** No, we do not.

**Ms. Sylvia Jones:** Okay. Does Lutheran Community Care Centre offer any direct services?

**Mr. Michael Maunula:** The direct service would be our case management services, so the adult protective service worker.

**Ms. Sylvia Jones:** Okay. Essentially what you're trying to do is match people with opportunities and housing supports.

**Mr. Michael Maunula:** That's right. The DSO, when there's an identified vacancy or new resource by the service providers, then matches people who are on the waiting list to those resources.

**Ms. Sylvia Jones:** And so I'll ask the “elephant in the room” question: How many people are on your waiting list?

**Mr. Michael Maunula:** We organize the waiting list by what they're asking for—I'll have to refer to another document as far as numbers. For our residential waiting list in the northern region—and this is as of a couple of months ago—we had 657 people waiting for residential supports.

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*Interjection.*

**Mr. Michael Maunula:** Yes, 657.

For community participation supports, we had 593 people waiting for service in the northern region. For respite services, we had 213. So we have those three waiting lists.

Currently there are not waiting lists for case management services or for clinical services.

**Ms. Sylvia Jones:** Thank you. You mentioned that because of the nature of so many of your First Nations communities that you serve, the remote nature of them, that they are most often best able to use the Passport Program—which I get, in terms of their remoteness, but having visited, there's also not a lot of opportunity. So how do you match that?

**Mr. Michael Maunula:** With the Passport dollars that the individual and the family receive, they can engage or hire other people in the community. There may not be another agency that they can purchase a service from, but they could purchase it from a neighbour or someone else who has the ability to provide the various activation or support needs that their son or daughter is requiring. So they're able, in a sense, to act as the employer and purchase those services directly.

**Ms. Sylvia Jones:** Okay. Thank you.

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

**Mrs. Christine Elliott:** Thank you very much, as well, for coming here on such short notice. I just wanted to follow up on one of the questions my colleague just asked regarding services for First Nations people. What about the assessments? How do you deal with assessments for Passport? How are they conducted? In person? Do you go there? Do they come here? How does that work?

**Mr. Michael Maunula:** Very often they are done by videoconferencing. All of our four offices that I mentioned have the Ontario telemedicine videoconferencing equipment. Then we link in with—it may be the health clinic in the remote First Nation community that also has that connectivity to videoconferencing. So it's done by videoconferencing.

As you may know, to apply for developmental services, there's an application package, which is an application package as well as a supports intensity scale tool. Those are both done by videoconferencing.

There are times when, if they are coming to a larger community, say, like Sioux Lookout, flying into Sioux Lookout, that we could do it there. In the past, we've had situations where we've agreed to go to their community.

It all depends on whether the ice road is functional at the time, whether you get into that community or not. So you do have to have some flexibility in providing the DSO services in the remote locations.

**Mrs. Christine Elliott:** Thank you.

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

**Ms. Cheri DiNovo:** Yes. Thank you again for coming on short notice. Have you had an opportunity to read some of the testimony that has come before this committee?

**Mr. Michael Maunula:** Just very briefly.

**Ms. Cheri DiNovo:** I have to be frank: What we've heard about DSOs generally—not yours specifically, but DSOs generally—has been very, very negative. What we've heard from people who have come before us is that they see DSOs as simply a hurdle; that it's all about long assessments that aren't really necessary; that once the assessments are done, nothing is forthcoming, usually, in terms of services, except wait-lists, for most people. Some have been told by some folks, and some DSOs, things like, "You have to wait until somebody dies before you get service."

That's what we've been hearing. How would you respond to those concerns?

**Mr. Michael Maunula:** You have to, I guess, go back to the legislation and why the legislation wanted application entities and a standardized process across the province. Prior to that legislation, how people were determined to be eligible for service varied considerably. Who could sign off to say that that person had a developmental disability was quite different. Now it's very clear and precise as to who is eligible for services.

The identification of their support needs: Again, there would be various tools across the province that were used. The Ministry of Community and Social Services agreed upon a standardized tool, the supports intensity scale tool, for assessing that need. So now it doesn't matter whether you live in Sioux Lookout or Toronto or Ottawa or Kenora; when you are assessed for your needs, the same tool is being prescribed. That is improving the equity and the common knowledge of what people are waiting for. That information then helps the government identify, "Where do we want to redirect our resources"—knowing full well that the resources are limited. Is it more respite that we need as opposed to group living? Is it more direct funding, more Passport funding versus block funding to agencies? It's helping the system evolve.

You're correct: The notion that you go through the application process and in many communities you are then placed on a waiting list—that's not the fault of the DSO. It's just articulating that that is the situation that we are in right now. As those resources become available, the people on the waiting list are all equally measured, evaluated, and there's a standard prioritization process so that you know that those who are in most need or the best match for that service—that that is taking place, as opposed to the person who is the most vocal, the one who

gets their MPP to call the ministry offices and gets a side deal accomplished.

**Ms. Cheri DiNovo:** We've heard about other jurisdictions—for example, Saskatchewan—where they've eliminated wait-lists, where you cannot be on a wait-list, where services are mandated. Many of the parents that we've heard of have already gone through assessments by the time that they've reached the DSO position, and those assessments—nothing has changed. They can just submit those assessments. Presumably, if you had a system where it was seen as a right to have services rather than a luxury, then you would just take that one assessment that has already been done by a medical diagnostic person. I'm taking time up, but maybe just a quick comment—because I know my colleague has a question as well.

**Mr. Michael Maunula:** In the province of Ontario, developmental services are voluntary services. They're not mandated services. That's the current legislation.

**Miss Monique Taylor:** Thank you for the short notice in accommodating us.

How many clients are within your DSO? You have four satellite offices; correct?

**Mr. Michael Maunula:** Yes.

**Miss Monique Taylor:** Would you happen to have a number for the entire region?

**Mr. Michael Maunula:** As far as the number of adults with a developmental disability?

**Miss Monique Taylor:** Yes. How many clients are within your DSO?

**Mr. Michael Maunula:** The DSO northern region's target is to complete assessments on about 458 individuals per year. We've been meeting that target for the last few years. The total population in about four or five years' time that we have interacted with may be 3,000 to 4,000 individuals.

**Miss Monique Taylor:** You're telling me that you have a target of getting 458 new every year? So we still have people who are waiting who can't get to the DSO?

**Mr. Michael Maunula:** For the people that the DSO interacts with, there is a prioritization process to whom we interact with first, or whom we contact first. Those priorities are transition-aged youth who are turning 18 who have a developmental disability, those who have not received services yet, and those who have changing needs. The people who are already in service will go through the application process, but probably in future years.

**Miss Monique Taylor:** Thank you.

**The Chair (Mrs. Laura Albanese):** So my understanding is that you really don't know the overall number yet. We don't have sort of a census, let's say.

**Mr. Michael Maunula:** That is gradually being established—

**The Chair (Mrs. Laura Albanese):** We're gradually getting there.

**Mr. Michael Maunula:** There's a provincial database called DSCIS which all the DSOs use, which is currently being ensured that—there's a migration of all the clients



in service in the province of Ontario moving to that database. The migration is still taking place. The cleanup of the data is still in its completion phases, but the ministry is soon at a point to be able to say how many people are being served and what people are waiting for.

1320

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

**Ms. Mitzie Hunter:** Sure, I'll start, and I'm sure my colleagues will have questions as well. Can you talk a little more about the picture that you're gradually getting of the number of people in your region with a developmental disability, and what your role is in assessing the need? Once someone has been identified, it seems as if there is a priority basis in which they will interact with your services. Can you describe that a little bit, in terms of identification and service provision?

**Mr. Michael Maunula:** In the first two years that the DSOs have been in operation, because we're dealing with new people and often transition-age youth, we are getting a picture of the young people wanting to come into or receive developmental services. They are quite different from, say, the average client that has been with an association or Community Living for many years.

They and their families are used to being in a more integrated setting. They've gone through the school system in an integrated setting, so when they want services for their son or daughter—they want more inclusive settings; they want more generic settings. The group home setting doesn't come first in their mind. A sheltered workshop does not come first in their mind. They want something that's more integrated and inclusive, so you see that in a lot of the people who are coming through the system.

You're also seeing people who, besides their developmental disability, have concurrent issues. It may be a mental health issue. It may be traumatic events in their childhood that they are dealing with.

I think the new people who we are seeing come into the system are a challenge to our traditional service providers. They have to begin to modify their traditional services to respond to that. Hopefully I—

**Ms. Mitzie Hunter:** No, that's good. Can I ask another question, Ms. Wong?

**Ms. Soo Wong:** Yes, yes.

**Ms. Mitzie Hunter:** In the northern region, what are some of the unique conditions that you face, once you identify those needs, in matching those to the services that are available within the community?

**Mr. Michael Maunula:** I mentioned earlier that in a lot of the communities that we serve, there's just one service provider in town. So a family may come and want their son or daughter to receive residential services or participation supports in that community, and they don't have the luxury of saying, "Well, I'll go to the next community," when the next community is 150 kilometres away. The whole family has to move to receive services from another agency, so the notion of portability is constrained by that.

In small communities, we have fewer recreational and social opportunities for individuals, so you have to be much more creative as to what those community participation supports will be. We have a much higher First Nations population across the north than other parts of Ontario that we have to be cognizant of.

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

**Ms. Soo Wong:** How much time do I have, Madam Chair?

**The Chair (Mrs. Laura Albanese):** A couple of minutes.

**Ms. Soo Wong:** I have two quick questions, so maybe you can answer them. We've been consistently hearing concerns raised by families that there is fear and intimidation by DSO staff to these families. So my question to you as executive director for your DSO—I only want you to speak to your DSO—is, what support and resources is your agency providing—I'm not saying all the DSOs in Ontario; your particular agency—to make sure that families are not being intimidated and not being fearful when they come with express concerns? What mechanism is your agency providing to make sure that your staff are properly trained and not intimidating those who are recipients of this care?

**Mr. Michael Maunula:** As far as our staff, as I mentioned, we use the relationship model of governance and management, so all of our staff understand that process, that sense of affirming individuals and involving individuals as much as possible. We closely supervise our staff to make sure that the quality of service that is provided is at an acceptable standard. It's not only in implementing the various provincial tools but also in the way we approach the families. The families know that they can contact the program manager. They can contact myself, and they regularly do.

The other thing that we do as the DSO for the northern region is, when people go through the application process, and we realize that they're going to be placed on a waiting list for some period of time, we want to make sure that they're referred to a case management agency in their community. As I mentioned earlier when we were talking about the waiting list, there isn't a waiting list for case management services. So while they're waiting for, say, the hard service of a residential support from a developmental service agency, the case management agency can send out a social worker to meet with the family and identify, "What are some of the generic resources in our community right now that I can link my son or daughter to?" So things are happening for them to alleviate the stress and the tension of waiting for that eventual, formal service. They're being helped with looking at some more natural supports that are available. We have good linkages with the case management agencies across our region.

**Ms. Soo Wong:** Okay. My last question, Madam Chair, is that we have heard consistently that there's now an aging population, so what is your relationship with the CCAC and long-term-care facilities to make sure there's

a smooth transition from the DSO through long-term care or whatever services to support the aging needs?

**Mr. Michael Maunula:** I guess one of the advantages when Lutheran Community Care Centre was chosen as the DSO for the northern region is that we're a multi-service agency. In my introduction, I just mentioned that our services that are available are funded by the Ministry of Community and Social Services. We provide other services such as generic social services, pastoral care in hospitals and homes for the aged, and a street-reach ministry, so through some of our other programs we have quite regular contacts with both the CCAC and the long-term-care facilities. As an agency, we have 30 years of established relationships with those organizations. When you know them and they understand you, you're better able to call them up on the phone and say, "This is the particular client we're dealing with. Besides their developmental disability, they are experiencing health care needs that are rightly within the realm of long-term care." You use those relationships that you've developed over time to work in the best interests of the individual.

They call on us for our help as well, so it's a mutual relationship that you have to develop to make sure that when two service systems are at play and supporting an individual, you gain co-operation at the ground level.

I know that there are protocol agreements between our ministry and the Ministry of Health and Long-Term Care, but those are at a high level. If you have those good relationships on the front line, that often opens doors quicker.

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

**Ms. Mitzie Hunter:** I do have a question. A lot of what we've been hearing about from families directly is that they just didn't know. They didn't know what they were eligible for; they didn't know where to find the help and support. What is your organization doing about communicating to families and making them aware that there is this support available to them in the community that meets their specific need?

**Mr. Michael Maunula:** When the Lutheran Community Care Centre—in this, I can speak pretty well for all the DSOs—when they were first designated as a developmental service organization, there were tours across all communities within their region describing what the DSO does. That happened in the first six months of our operation, and we had considerable geography to cover. We don't have a massive advertising and marketing budget—and rightly so; our resources are put elsewhere—but there is a provincial DSO website. We also rely on our partner agencies, those ACLs that are in those communities. Naturally the person in Atikokan is going to knock on the association's door there; they're not going to first think of calling a Thunder Bay number or a toll-free number. So we make sure that our partner agencies also can communicate to those individuals and families what the new process is, how to contact the DSO, and we do our best to make sure that it's a seamless process, a toll-free process, and that we have staff

reasonably close to their community. So with the example of Atikokan, they would have someone coming from our Dryden office to meet with them.

1330

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

**Ms. Soo Wong:** I have a question, Madam Chair, for the researcher with regard to more data, not a question to the witness.

**The Chair (Mrs. Laura Albanese):** Any more questions for the witness?

**Ms. Soo Wong:** No.

**The Chair (Mrs. Laura Albanese):** I have one final one for the witness and then we can proceed to your question, if you don't mind, Ms. Wong.

I just wanted to know if you had any recommendations and any suggestions for the committee, especially for the region that you serve. If we're putting you on the spot and you prefer to put it in writing and write to us, that's fine as well.

**Mr. Michael Maunula:** I think that what we feel is most important—and I realize that the ministry is working on the background work that is required to proclaim the rest of the legislation. We would like to see the rest of that legislation proclaimed as soon as it can be proclaimed, because I think that will create the full picture of transformation and will help everyone understand that this is a transformational process. The original legislation was well-thought-out. When all the tools are available, then give it a fair chance to play out. But to criticize it when it's only halfway there and it doesn't have all the tools may be unfair.

**The Chair (Mrs. Laura Albanese):** What difference would it make to you? What difference would it make in this situation? Just concrete examples.

**Mr. Michael Maunula:** Well, I guess examples would be that when you have a funding entity and you have direct funding, then for the people who say, "Well, it doesn't make sense for me to send my son or daughter to Thunder Bay where there are more specialized services if I could purchase it with direct funding closer to home, where there will still be the natural supports," it will be of benefit to them. It will be of benefit to the families. They'll feel like they are being listened to and that they don't have to go to large urban centres to receive specialized services.

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

**Ms. Cheri DiNovo:** A question for research. I'm not sure what parts of this legislation our witness is referring to.

**The Chair (Mrs. Laura Albanese):** Direct funding.

**Ms. Cheri DiNovo:** Just more direct funding? There's a piece of legislation here that we're hearing hasn't been put into play, so I would like to hear what that piece is, what piece of legislation.

**The Chair (Mrs. Laura Albanese):** Yes. I'm going to—so thank you very much for your presentation today. We really appreciate the time that you took to come down and to talk to us very much. Thank you, and keep up the good work.

**Mr. Michael Maunula:** You're welcome.

**The Chair (Mrs. Laura Albanese):** Ms. Wong, I know you had a question of the researcher.

**Ms. Soo Wong:** Yes, thank you. We have consistently heard about the aging population, and today we heard about the need for palliative care. So through you, Madam Chair, to the researcher, I would think the committee would benefit in terms of getting some data from the CCAC in terms of their data on number of admissions, because they are the ones that control the admissions for the long-term-care beds in Ontario. Through the CCAC, by region, I'd like to know the data: How many individuals are currently on the wait-list or currently in long-term care with DD or intellectual disability? That's the first thing.

We also heard this morning, from the last witness, I think it was, about the need for palliative care. We will need data from the LHINs to get the hospice stuff and the funding earmarked for this particular sector.

I believe in one of my requests, Madam Chair, I asked about the concerns dealing with the individual with the capacity review board. Again, we heard this morning the concern raised about the cost for the assessment. So can we pull out that piece of legislation that drove this requirement of assessment?

I also want to hear—

**The Chair (Mrs. Laura Albanese):** I would believe that it's the same legislation that saw the creation of the DSOs.

**Ms. Soo Wong:** The DSO?

**The Chair (Mrs. Laura Albanese):** I would believe so.

**Mrs. Christine Elliott:** The entity, though, ended up being deemed—becoming a DSO.

**Ms. Sylvia Jones:** Yes. They didn't call it "DSO" in the legislation.

**Ms. Soo Wong:** No, no, for the public trustee's office, because the last witness in her presentation, from Options Northwest, talked about an individual without persons to act on their behalf. She talked about the escalating cost, and it's coming through the Office of the Public Guardian and Trustee. That's the AG's office, right?

So my question here is: If someone has a DD diagnosis at age four and now they are 45 and they need to have this reassessment—I mean, they're already financially limited and now have to consider spending \$2,000

to \$5,000. So my question here, Madam Chair, through you to the researcher, is what do we need to do in our deliberation? Because we consistently heard about too many assessments, too much cost, blah, blah, blah.

**The Chair (Mrs. Laura Albanese):** Too many forms.

**Ms. Soo Wong:** And now, we have some data here that was presented by one of the witnesses saying that this is a barrier. I want to validate this data. I want to know how we improve it, because very, very clearly the presentation from the AG's office—I know I didn't get too much out, and I certainly know we didn't hear about this piece.

**Ms. Erica Simmons:** Can I ask for clarification on your previous question? You're asking about funding earmarked for palliative care for people with developmental disabilities?

**Ms. Soo Wong:** As it relates to the presentation from Options Northwest, because in her written submission—the aging population and providing palliative care. I know hospice funding in Ontario is through the LHINs, so my question here is: What current resources are being earmarked for this growing, aging population? Or are there any?

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

**Ms. Cheri DiNovo:** Just further to what Ms. Wong said—I'm just clarifying—this is really similar to the question that we asked about alternative levels of care. How many people with developmental diagnoses or dual diagnoses are in alternative levels of care in hospitals? This directly relates to the other witness who was talking about doing palliative care in the group home rather than in the hospital. One is funded under Comsoc; one is funded under health—you're comparing apples to apples, in other words, so we know what it costs under health. It would be very interesting.

**The Chair (Mrs. Laura Albanese):** Okay. Well, thank you. This concludes our day here in Thunder Bay. We want to thank everyone who has taken the time to make a presentation, who has taken the time to participate personally in our committee, all the people who are here and who have followed the proceedings of the day. Thank you very much.

We will resume the committee tomorrow at 9:30 in the morning in Moosonee.

*The committee adjourned at 1338.*

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