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

**Wednesday 27 November 2013**

## **Journal des débats (Hansard)**

**Mercredi 27 novembre 2013**

**Select Committee on  
Developmental Services**

Developmental services strategy

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

Stratégie de services  
aux personnes ayant  
une déficience intellectuelle

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ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**SELECT COMMITTEE ON  
DEVELOPMENTAL SERVICES**

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

Wednesday 27 November 2013

Mercredi 27 novembre 2013

*The committee met at 1603 in committee room 1.*

**DEVELOPMENTAL SERVICES STRATEGY**

**The Chair (Mrs. Laura Albanese):** Good afternoon, everyone. The Select Committee on Developmental Services is called to order.

**MINISTRY OF ECONOMIC  
DEVELOPMENT,  
TRADE AND EMPLOYMENT**

**The Chair (Mrs. Laura Albanese):** This afternoon we will be hearing first from the Ministry of Economic Development, Trade and Employment. I would ask our guests to come forward and settle at the chairs here at the front. As usual, I would ask you to start by stating your name and title for the purposes of Hansard. You will have up to 30 minutes for your presentation, and that will be followed by questions by all three parties. You may start any time you feel ready to.

**Ms. Carrie Burd:** Good afternoon. Thank you for having us here today. My name is Carrie Burd. I'm the director of accessibility integration at the Ministry of Economic Development, Trade and Employment. With me today, I have Ann Hoy, who is the assistant deputy minister of the Accessibility Directorate of Ontario; I have Sam Boonstra, who is the director of our entrepreneurship branch; and I have Victor Severino, who is the assistant deputy minister of our policy and strategy division.

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

**Ms. Carrie Burd:** I'll be kicking off today's presentation, if you want to turn to slide 4. I just wanted to provide a little bit of context for today's presentation.

The overarching theme, of course, is greater social inclusion for all. The government of Ontario has made a commitment to improving opportunities for Ontarians with disabilities to engage in their communities, access gainful employment and contribute to the economic prosperity of our province.

To deliver on this, ministries are working together across the Ontario public service to ensure effective public policy development, coordination and implementation; to ensure strategic linkages with government, industry and community partners and stakeholders; ensur-

ing fully leveraged government funding, programs and services; and ensuring legislative and regulatory compliance with the ODA and the AODA, which are the Ontarians with Disabilities Act and the Accessibility for Ontarians with Disabilities Act. By shifting the Accessibility Directorate of Ontario, or as we call it, the ADO, from the Ministry of Community and Social Services to the Ministry of Economic Development, Trade and Employment, the government has also signalled a commitment to working with the private sector to increase the number of persons with disabilities, or PWDs, in the Ontario workforce.

So what does MEDTE do? MEDTE delivers a range of programs, services and tools to help businesses innovate and compete in today's fast-changing global economy, including business support and youth entrepreneurship programs, strategic investments, international trade and export expertise. Through the government's Open for Business initiative, the ministry helps make investing in Ontario more attractive for businesses while protecting the public interest. Through the Accessibility Directorate of Ontario, the ministry works with the disability, private and public sectors in the interest of promoting accessibility for all. The ministry is affiliated with six agencies, which are independent bodies established by the government, but not part of the ministry, and two operational enterprise agencies.

Reflecting on my role, and that's accessibility integration, to ensure the seamless integration of the ADO and its mandate into MEDTE, the ministry recently appointed a director of accessibility integration. In this role, I have responsibility for assisting in the identification of new opportunities to embed the principles of accessibility and inclusion into our business programs, services and supports and leverage key partnerships. I also have a role in assisting in the identification of new opportunities to promote the social and economic benefits of employing persons with disabilities, ensuring the strategic alignment and effective project management of key accessibility initiatives under way across the ministry and developing a work plan that will reflect that integration.

Slides 7 to 9 illustrate how the work of our ministry, MEDTE, intersects with and complements the work of the ministries that have preceded us here at the committee. Our next few speakers will provide the committee with an overview of the work they are leading in their

divisions and which may be of particular relevance to the committee's mandate; that is, Ontario's commitment to creating an accessible Ontario, including barrier-free employment, Ontario's youth job strategies and Ontario's employment strategy to increase employment opportunities for persons with disabilities, specifically providing support to businesses and leveraging the capabilities of persons with disabilities.

At this point, I'd like to hand it over to my colleague Ann.

**Ms. Ann Hoy:** Thank you, Carrie. I'm going to ask you to move to slide 10, which is where we're going to start a little bit of an overview of the Accessibility for Ontarians with Disabilities Act.

If you look at slide 11, accessibility makes sense and is important for Ontario because one in seven Ontarians has a disability. This number is expected to grow to one in five over the next 20 years. The number of seniors aged 64 and over will more than double, from 1.9 million in 2011 to 4.1 million by 2036. With a labour and skills shortage, Ontario may be increasingly dependent on a workforce that currently lives with a disability, including people with developmental disabilities; 39.1% of Ontarians with disabilities between 16 and 64 years of age were unemployed or not in the labour force in 2009, almost three times the rate for Ontarians without disabilities.

Accessibility requirements foster an inclusive society and accessible culture by helping to increase integration, independence and activity levels among persons with disabilities, including people with developmental disabilities.

The Accessibility for Ontarians with Disabilities Act became law in 2005 and made Ontario one of the first jurisdictions in the world to move from complaints-based legislation to a modern regulatory regime that mandates accessibility. The AODA establishes the goal of an accessible Ontario by 2025, to be achieved through the development, implementation and enforcement of accessibility standards that apply to the public, private and not-for-profit sectors. All organizations in Ontario with one or more employees have obligations under the AODA, including a wide range of organizations that serve people with developmental disabilities—including, for example, developmental services agencies, group homes, health care providers, specialized transportation service providers and so on.

The AODA adopts the same broad definition of "disability" as the Ontario Human Rights Code. It includes "a condition of mental impairment or developmental disability."

#### 1610

The AODA requires organizations to become more accessible to people with a wide range of disabilities, including physical, mobility, mental health, developmental and those with multiple disabilities.

Five accessibility standards are now law under the AODA: customer service; information and communications; employment; transportation; and the design of

public spaces. An estimated 360,000 organizations with one or more employees are required to comply with the AODA and its standards as they come into effect. Timelines for complying with accessibility standards are being phased in over several years based on organizational type and size. For example, public sector organizations are required to comply before small private businesses.

Compliance with accessibility standards is monitored through self-certified online compliance reporting, for companies and organizations of a certain size, and through file reviews. If an organization is found to be non-compliant, the Accessibility Directorate of Ontario offers assistance and support to help bring it into compliance. For example, we provide free guides, tools and templates to organizations. Failure to comply could result in director's orders and financial penalties.

The AODA will have an impact on people with developmental disabilities as the standards come into effect over the next number of years.

The customer service standard: Organizations are required to train their staff on providing accessible customer service to people with various types of disabilities, including people with developmental disabilities; for example, explaining how to use a product or helping somebody to get around a store. If a person with a developmental disability uses a support person, then organizations must allow the person with a disability to be accompanied by him or her.

Information and communications standard: Organizations are required to provide accessible formats and communications supports upon request; for example, using plain language or speaking slowly and clearly.

Organizations are required to make their websites accessible, making navigation easier and intuitive, using clear and plain language, and making them compatible with assistive technologies.

Under the employment standard, organizations are required to let people know that accommodations are available throughout the employment life cycle to support them; for example, providing more time to complete an interview assessment, offering a modified work schedule to attend medical appointments, or modifying work tasks.

Transportation standard: Transportation service providers are required to provide accessibility training to vehicle operators, including on how to use accessibility features and equipment—for example, ramps and lifting devices—and on emergency preparedness and response.

Organizations are required to meet a number of technical and physical accessibility requirements that will improve accessibility for people with a developmental disability or with multiple disabilities; for example, grab bars, non-slip surfaces, audio on-board announcements, storage space for mobility devices and courtesy seating.

The design of public spaces standard: Organizations are required to consult with people with disabilities on how to make outdoor play spaces accessible—by adding sensory/tactile or other features, for example, to enhance the play experience for people with developmental disabilities.

Organizations are required to make beach access trails, recreational trails and exterior paths of travel accessible. For example, they may have to have a minimum width, and they should be stable and have flat surfaces. This will enhance accessibility for people with developmental disabilities who may also have a physical or other disability.

We reach out to obligated organizations through public education and outreach. The Accessibility Directorate of Ontario reaches out to organizations to help them meet their customer service standard and the other standards, which are combined under the integrated accessibility service standards regulation, by developing and distributing compliance assistance information and resources through key channels such as the ministry's website, social media and online tools—we have something called the AODA wizard that allows organizations to see what the requirements are for them; participation at conferences and events; and also by forcing strategic partnerships with key provincial umbrella organizations through the EnAbling Change Program. So far, more than 50 partnerships have been established since 2005 through this program.

We have some examples of partnerships that would impact developmental services and clients, noted below. There was one with the Ontario March of Dimes that developed a tool for emergency management to support people with disabilities during emergency evacuations. We worked with Reena to develop tools and resources to help support social inclusion for persons with disabilities in their communities. And there was a partnership with the Ontario Community Support Association, developing tools and conducting training across Ontario to assist home and community support workers on meeting the requirements of the AODA.

With that, I will pass it over to my colleague Sam.

**Mr. Sam Boonstra:** Great. Thank you, Ann. Good afternoon. My name is Sam Boonstra, and I'm the director of the entrepreneurship branch with the ministry. I'm going to speak about some of the specific initiatives under the youth jobs strategy.

Slide 18 speaks about youth and unemployment with some data around unemployment rates. Obviously, it is a rate we would like to bring down. It's hovering around 16% to 17% right now in terms of the entire youth population, and when you drill into some of the vulnerable populations, and certainly youth with disabilities, that number goes up significantly.

The third bullet here touches on 2006 data that shows youth with disabilities aged 15 to 19 have an unemployment rate of 21.9, and for ages 20 to 24 it's 15.1%, so higher than the average youth unemployment, and obviously an imperative to bring that down.

The early labour market attachment is very important for all youth, and particularly for youth with disabilities. These are really foundational years in that first work experience is very important in terms of their longer-term attachment to the labour market.

Entrepreneurship and business formation is also a critical element that we've considered as part of the

youth jobs strategy, with over 100,000 new businesses created in Ontario each year. Youth are entering entrepreneurship and starting up their own businesses at almost three times the rate of entrepreneurs over the age of 45.

A recent study put out by BMO indicated that almost 50% of young people surveyed were actually interested in becoming entrepreneurs versus working for someone else—so clearly a trend, and something that we've really taken to heart in the design of programs under the youth jobs strategy. And almost a third of youth-owned enterprises are located here within the province of Ontario.

Slide 19 underscores some of the key themes related to the youth jobs strategy. This has been informed by some of the data that I just touched on, as well as a series of consultations that have taken place over the last number of months, where government met with over 20 stakeholder groups, at roughly 20 sessions held across the province, to really gather input and perspective on the challenge, but also on solutions that have proven effective or perhaps require further study to move them forward.

Work experience is obviously a key theme. Something around experiential learning and the important role that that experience plays to position young people for their careers is critical, and it's very important to eliminate barriers around providing that important work experience to young people. Ensuring that that work experience and the skills that are offered to young people are relevant to the 21st century and where there are opportunities has also been a critical thematic that has guided the creation of the strategy.

I've touched on the importance of entrepreneurship. Certainly supports available to help young people who are interested in pursuing entrepreneurship and becoming job creators themselves has been very important to us in the delivery of the jobs strategy. This ensures that the supports are available to help the companies that they are interested in starting—that they're viable and ultimately successful, whether they're in the high-tech space, innovation space or what we term "Main Street" businesses.

Having streamlined access to resources for young people is also critical, and that includes equipping young Ontarians of all abilities and all backgrounds with the right resources that they need to become employed or to start their own company. It's also making sure that government is very transparent and streamlined in the way in which we are communicating the programs and the services that are available to help young people in those pursuits.

The jobs strategy, overall, represents an investment of \$295 million over two years, this fiscal year and next fiscal year. It's really focused on training, mentorship and job opportunities, and our goal is to provide 30,000 of those opportunities to youth right across the province.

Slide 20 presents a summary of the four funds that are included as part of the strategy. The first two relate specifically to youth employment and the second two to youth entrepreneurship.

I'll speak first to the Ontario Youth Employment Fund. This is delivered by our colleagues at training, colleges and universities, and it's \$195 million that's been set aside here, which is to reach 25,000 young people and ensure that they're provided with employment opportunities. This fund does provide wage subsidies to employers who are able to bring youth into their workforce, and there's a specific focus on vulnerable youth and youth who are facing barriers within this fund.

#### 1620

The next element is Youth Skills Connections. This is \$25 million that has been identified, and this program is being managed by MEDTE. The intent is for industry to be very actively engaged in the identification of gaps that they have in their workforce where they're not able to find qualified individuals. Industry will partner with training institutions, post-secondary institutions, labour and not-for-profit organizations to design training interventions that will actually help to close the gaps and provide them with the qualified talent that they actually need to fill those vacant positions. We're asking for employers to actually put money on the table for those training programs in terms of their development and their delivery, and then also to provide hiring commitments so that they have skin in the game and they're committed to actually hiring the participants in the training programs that would be funded through that initiative.

There's also a stream under Youth Skills Connections called the community stream, which is very much tailored to youth who are facing barriers and youth who are in high-needs communities to make sure there are specific interventions that really respond to their individual requirements and that the government engages with delivery partners that have expertise in developing programming and training that will actually be effective and resonate with those populations.

The Ontario Youth Entrepreneurship Fund is the third element here. There's \$45 million set aside and this is being jointly delivered by both MEDTE and our colleagues at research and innovation. This is a series of programs that will focus on training, on mentorship and on start-up capital to help young people who are interested in pursuing entrepreneurial initiatives. The focus is both on students as well as young entrepreneurs, community partners and populations that are facing barriers.

Finally, the Ontario Youth Innovation Fund: \$30 million here being managed by the Ministry of Research and Innovation. It's really focused on providing skills and projects around industrial research and development that will allow for ideas to be brought to market through commercialization and by working with post-secondary institutions to ensure that there are accelerators and incubator spaces made available to young people, but also working with alumnae of those institutions and other community folks who are willing to invest in business ideas that are viable and have the potential to really bring wealth to the province.

Slide 21 speaks specifically to some of the efforts that we, as a ministry, have made to ensure that youth facing barriers, including youth with disabilities, are both aware

of the initiatives that are being put forward through the youth jobs strategy and also able to actively participate in those initiatives.

I've mentioned the community stream of Youth Skills Connections. That's an example of an initiative that has been specifically tailored to vulnerable populations, which includes youth with disabilities. At the top of the slide there's a list of all the populations that we're working with under the youth jobs strategy, including aboriginal youth, newcomer youth, racialized youth, youth who are in care, youth who are in or at risk of conflict with the law, youth in poverty or from low-income families, LGBTQ youth, youth with disabilities and special needs, and youth who are social assistance clients.

As I mentioned, there are some specific programs targeted specifically to those populations, but all of the programs of the youth jobs strategy have a requirement that they both conduct outreach to these populations and also report back to us on what the participation levels are.

The programs also acknowledge the realities of youth with disabilities, so we're allowing for costs related to accommodation, to transportation etc. to be included as eligible costs. We are in discussions with the Ministry of Community and Social Services to ensure that participants in the youth programs do not have their benefits clawed back as a result of their participation.

Finally, our delivery efforts are reaching youth with disabilities. We're working with ministries such as MCSS, children and youth services, the Ministry of Aboriginal Affairs and others to make sure that their front-line staff are aware of the programs and able to introduce them in the interactions that they have with young people. Based on what we're seeing in terms of early response to the calls for proposals that we've issued, this is resonating with the stakeholders working directly with youth with disabilities and the other vulnerable populations, based on the applications we've seen so far.

Thank you, and with that, I'll turn it to my colleague.

**Mr. Victor Severino:** Thank you. I'm Victor Severino. I'm the assistant deputy minister at the Ministry of Economic Development, Trade and Employment, as well as the Ministry of Research and Innovation.

As my colleague Sam indicated, interaction and co-ordination with businesses and employers is both key to resolving the youth unemployment issue and it is absolutely key to resolving underemployment within the community of persons with disabilities. We, at the division, have been working towards a strategy that engages employers and that leverages much of the untapped talent amongst persons with disabilities.

Our work would complement the existing programming that already supports persons with disabilities in becoming part of the labour force and helping them to find meaningful employment. In our work, we've been largely focusing on ensuring better access to jobs and entrepreneurial opportunities and, most importantly, improving the employment trajectory of persons with disabilities by valuing their talent, their skills and their capabilities.

Since the mid-2000s, the government has been committed to creating a barrier-free and accessible Ontario, as has already been indicated. In the 2013 budget, the government moved the accessibility directorate to the newly named Ministry of Economic Development, Trade and Employment, the purpose being to better work with Ontario's businesses and organizations and communities to improve employment opportunities. With the pending partnership council on employment opportunities for persons with disabilities, the government has made championing the hiring of people with disabilities a key priority.

It's important to recognize the size of the cohort that we are dealing with. People with disabilities make up about 1.85% of Ontarians—oh, sorry, 1.85 million Ontarians, which is about 15.5% of the population. This is a significant part of the population. So supporting persons with disabilities is important to Ontario's long-term economic potential, and the risk of not addressing the current barriers will likely result in continued lost productivity and economic independence for many Ontarians.

In addition, as makes the news often, Ontario is suffering from a skills deficit and talent development challenges. So if employers actively leverage the talents of persons with disabilities, significant economic benefits could accrue not just to employers, but to the province as a whole, and for the individuals as well. For example, the Martin Prosperity Institute has concluded that GDP per capita in Ontario could increase by about \$600 per year per person if greater participation of persons with disabilities in the labour force were realized.

A few key statistics to help understand the community a little bit better: Data show that, historically, persons with disabilities have had lower educational attainment than the general population. That is still the case, but the situation is improving. From 1986 to 2005, the proportion of post-secondary qualifications awarded to students with disabilities tripled. Overall, 43% of the persons with disabilities population in Ontario have some type of post-secondary credential as of 2008, which is the last year that we have data available. The problem, however, is that persons with disabilities still continue to have lower employment and earnings than persons without disabilities. That is what we are looking to address.

I'm now on slide—what slide am I on?

*Interjection.*

**Mr. Victor Severino:** Twenty-six. Sorry, I have a different slide numbering system than the rest of you.

What we know is that with respect to employment, persons with disabilities continue to have higher rates of unemployment; they have lower participation rates; they experience underemployment, such as more often resorting to part-time work, at a much higher rate than the general population; and they generally earn less overall.

What we've tried to do is undertake an exercise where we generally break the barriers up into two segments. What we've tried to do is identify what we refer to as demand side barriers and supply side barriers. The demand

side barriers are based on the employer's preparation for being able to leverage the diverse workforce. For example, there may be attitudinal barriers towards employing persons with disabilities. Employers often have misconceptions and biases about the accommodation needs or the competence or the productivity or the social skills of persons with disabilities. There may be perceived opportunity costs of being organizationally inclusive. There might be fears and questions about the costs of employing persons with disabilities. There may also be a tendency towards human resources practices and capacity that don't align very well with employing persons with disabilities. Many organizations simply lack the HR know-how to implement strategies, either in recruiting, in accommodating, or in retaining persons with disabilities. So those are some of the demand side barriers that the community faces.

**1630**

But there are also supply side barriers that keep members of the community from accessing employment. As Sam has noted, early attachment to the labour force is key for youth, and it's also key for persons with disabilities, so there may be a lack of work-related experience. New graduates with disabilities are often missing the vital experience necessary to compete on a level playing field. They simply may not have the work experience. They have education and skills attainment that are generally a little bit lower than the general population, notwithstanding that the trending is in a positive direction. There is generally an absence of transitional support to employment, so once leaving an academic setting, for example, the support services in terms of managing the labour force may just not be there for persons with disabilities.

What we are contemplating is generally a three-pronged approach. This would offer a high-level framework for a strategy and it's one that targets each one of the barriers that I've identified.

In the first instance, one element of a strategy would be to address the demand side issues, specifically to work with employers. We are focusing on developing a culture of inclusion. This includes dispelling many myths and misconceptions about the employability of persons with a disability. It means addressing attitudinal barriers and it means fostering partnerships to establish inclusive workplaces.

Additionally, on the supply side, we're focusing on the employability of people with disabilities. This is talent development based on educational attainment, skills training and early experiences with the labour market, particularly through experiential learning.

The third area of focus is the support system and environment, specifically to establish a provincial ecosystem that supports the employment of persons with disabilities. This could include a spectrum of supports, programs, metrics, services and solutions for persons with disabilities.

We are at the stage, at this point, of doing the policy work that is necessary to put together a coherent strategy. There will be consultations and opportunity, both

internally and externally, for stakeholders to advise us and to guide our work. When the appropriate time comes, we'll be seeking the necessary approvals, once we have the initiatives identified to move forward with some elements of this strategy.

**The Chair (Mrs. Laura Albanese):** Thank you. We'll now turn it over to Ms. Elliott for questions.

**Mrs. Christine Elliott:** Thank you very much, Chair, and good afternoon. Thank you very much for making the presentation today. I have a few questions on each of the sectors that you presented on.

First of all, with respect to the AODA, we've heard recently that compliance has been quite low and that there hasn't been a really coordinated approach to enforcement. Can you tell us what your plan is, moving forward, to make sure that the many, many businesses that are not in compliance with the customer service standard are going to be in compliance?

**Ms. Ann Hoy:** Thank you for the question. I want to be clear in my answer that businesses with 20 employees or more must report their compliance, and that's what you've been seeing low numbers for. But businesses with one employee or more must be compliant with the act. There are businesses that don't have to report that are compliant, as well as businesses that needed to report and haven't made their reports yet, just to be clear about the difference there.

You're right: The number of businesses that have reported their compliance, to date, is lower than what we would have hoped, but I can tell you that we're continuing to follow up with businesses that have not yet reported compliance to work with them to bring them into compliance with the act. There are measures outlined in the act that allow us to pursue various measures of enforcement, and we are working through that process as it's outlined in the act.

**Mrs. Christine Elliott:** Can you tell me what specific steps you've taken? Have you notified them that they have a deadline? What are you specifically doing to enforce compliance?

**Ms. Ann Hoy:** Yes. There were a number of notifications that went out to business before the end of last year. They were to have reported compliance by the end of last year. There have been reminders that have gone out to business since then. Relatively recently, this fall, we sent out a great many letters, 50,000 letters, to businesses to make sure that we were covering the waterfront of businesses to let them know that if they hadn't complied, they needed to do so, and we did receive a number of reports and a lot of phone calls and requests for support since then.

We are continuing to follow up with businesses that we haven't heard from in a measured way and will continue to do so over the next weeks and months.

**Mrs. Christine Elliott:** So can you assure us, then, that they will be followed up to make sure that they are in compliance within the near future?

**Ms. Ann Hoy:** Yes, we continue to follow up with businesses to look for them, absolutely, to come into compliance.

**Mrs. Christine Elliott:** My next question had to do with the youth jobs strategy. Just taking a look at what you're concentrating on—and I'll just pick two: work experience and skills for the 21st century—I'd suggest that maybe what you're aiming at here is not really attainable by the group that we're speaking about right now, young people with developmental disabilities. What we're hearing is that they can stay in high school until they're 21, and then they pretty much fall off the face of the earth—that there are very few job opportunities for them, there's very little post-secondary opportunities for them. So to concentrate on work experience—first of all, they're not able to get jobs because people aren't hiring them and, secondly, they aren't able to get the skills because there are very few programs like the CICE program, for example, in some of the community colleges that allows them to get those skills. There really aren't those opportunities for them. I think it's great that we have the jobs strategy, but I would suggest that it's not going to be that applicable to this group until we work on the other aspects of it that I think are the third part of your presentation today.

You had mentioned on slide 21 that you're constantly in contact with MCYS and MCSS to make sure that they're promoting it. What kind of feedback are you getting from them about the applicability of this strategy to their client population?

**Mr. Sam Boonstra:** Sure. Just quickly, on the first one around the 21st-century skills, that's an overarching goal for the strategy at large. One of the reasons we created the community stream of Youth Skills Connections was recognizing that specific interventions that were tailored to specific populations would be required and important. Those skills training programs will focus on skills where there are opportunities for their client base to actually move into positions.

In terms of the relationship with MCYS and MCSS, they've been very actively engaged in the design of the programs and they're very supportive of the strategies that we're moving forward under each of those, so much so that they're also sitting on our assessment committees to look at the proposals. They know a lot of those stakeholders better than we do, based on history and other relationships they've had with them, so that will be valuable as part of that. They've also been very active in terms of getting the word out through their own sort of localized networks, whether it's local staff, youth outreach workers or other partners that they have a relationship with at the community level.

As I say, based on the application information we've received back so far, we're currently setting up the delivery structure of the organizations that will deliver programs. It has been positive. Once we put that structure in place, it's actually doing the intake of young people. So we could sort of continue this outreach strategy to make sure that young people continue to be aware of the opportunities when we're also delivering the projects themselves.



**Mrs. Christine Elliott:** Are you working with the Ministry of Training, Colleges and Universities to help bridge that skills gap as well?

**Mr. Sam Boonstra:** Absolutely. They're also part of that same committee that I mentioned, along with correctional services, community safety, aboriginal affairs and a number of other ministries.

**Mrs. Christine Elliott:** Okay. That's great, because I see the statistics about the number of people with disabilities who are getting higher levels of education. I think there's a difference between the people who report themselves as having a disability and needing extra assistance in writing exams and so on and the people who actually need help to go to classrooms, who are not as immediately employable, perhaps, as some of the people who have a declared disability that might be just needing extra time, as I say, for an exam versus the students in the CICE program who need a lot more support, but who are employable once they have that skill. So I just urge that consideration be given to a greater emphasis on the latter group.

**Mr. Sam Boonstra:** All right. Thank you.

**Mrs. Christine Elliott:** And finally, with respect to the relationship with business, I think that's wonderful. I think it's really, really important to work with businesses to have them understand the importance and the business advantage of hiring someone with a disability. It's a good business practice as opposed to a charitable act. I think that's really critical, and there are some really good groups around Ontario that are advancing that.

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I'd just be interested in some of the specific work that you're doing in that respect and who you're meeting with—not specifically by name, but are you meeting with business groups and engaging them in conversations about how to advance opportunities for people with intellectual disabilities?

**Mr. Victor Severino:** Well, specifically through the partnership council is where a lot of that activity will be taking place; that is correct. I think there's still a meeting pending, but we are engaging businesses through that mechanism. What we know from the best literature and the best international experience is that without businesses being seized with the business opportunities, it's very difficult to actually get the employment to occur. It's our hope that the partnership council will be the key vehicle that helps us engage with businesses so that everyone recognizes the economic value of employing persons with disabilities.

**Mrs. Christine Elliott:** As I'm sure you know, the federal government came out with a report by a panel about a year ago now, I guess, that indicated that very few physical accommodations were necessary in order to hire someone with a disability, far less than what people would generally think of. I'm just wondering if you have a similar sort of panel that's going to be reporting or—

**Mr. Victor Severino:** Yes. As I indicated, some of the barriers are largely attitudinal. One of the easy steps is just to break down some of those attitudinal barriers.

Once again, that has been the experience internationally, that the accommodation needs are often—I mean, they're certainly not insurmountable; they're often quite negligible in terms of actually employing persons with disabilities.

**Mrs. Christine Elliott:** The chart that you have very near the end about the three-pronged approach—I think that's great. I would just like to know what the timelines are for narrowing this down and fully developing this strategy.

**Mr. Victor Severino:** I'm not sure I can be definitive on the timelines. What we've done at this point—the initiative is still relatively new in our ministry, so we are relying very much on our partners at MCSS and TCU who have—certainly MCSS—more of the history in terms of this. But we're doing the policy work, and the next stage is to vet some of the policy options that help address the barriers.

At this point, it's largely an internal process to government. I would say, making sure that we have all of the right alignments, in particular with all of the other programs that happen, not just in the youth program, but also at MCSS in particular, which has a big chunk of its budget devoted to supporting persons with disabilities. So making sure that that internal alignment—that there are no built-in disincentives or we cause something that we didn't intend to cause: That's going to be pretty critical work.

I guess I wouldn't want to place a bet in terms of what a strategy is until we have confidence that the internal work has been done at this point.

**The Chair (Mrs. Laura Albanese):** Thank you, MPP Elliott. The time allotted has elapsed.

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

**The Chair (Mrs. Laura Albanese):** I will turn it to Ms. DiNovo.

**Ms. Cheri DiNovo:** First of all, thank you for coming before us. Second of all, I'm going to be channelling AODA Alliance and people like David Lepofsky. You're very aware that I asked Minister Hoskins a question not too long ago about why AODA Alliance, a non-profit group of people, your stakeholders with disabilities, would have to pay over \$2,000 just to find out about compliance rates or any information about the AODA, the act, and its compliance. I was wondering why you were going to charge them that money. Why not just give them the information?

**Ms. Ann Hoy:** That's a difficult question for me to answer clearly. There is a freedom-of-information process, which I'm sure you're aware of, which includes a certain amount of funds being charged for searching records and so on. The work that was done in that process by the people who look after it did take that into account.

**Ms. Cheri DiNovo:** But these are presumably the stakeholders who should have your ear, and whose ear you should have, about the way these programs are operating. They found that quite distressing—not just I and they, but the Toronto Star in their editorial found it

quite distressing. Going on from there, once they did get some of the information—and it took a question in the House to the minister to get them that—then, of course, they discovered that the compliance is way behind, that the enforcement is woefully inadequate.

Again, we come back to it's your job to enforce and seek compliance with this, whatever way that may be, whether it's letters or a response. I realize you're the messenger about this, perhaps, and it maybe should be asked of the minister, whose ultimate responsibility it is, but clearly this isn't on track.

So I guess, to back up what my colleague Ms. Elliott said, when do you see compliance—how will you know that it's working, and how will you guarantee that the dates for compliance are met going forward?

**Ms. Ann Hoy:** This is a new area for particularly private sector organizations in Ontario. As you know, the act came into effect in 2005, and the customer service standard became effective for the first time for the private sector and not-for-profits at the end of last year. So I would just want to be clear with you that, for many businesses, it is still very new. It is not something that has been in place for a long time. As a result, it's taking us longer than we had hoped to make sure that we reach out to everybody to make them aware of everything that they need to be aware of.

As I had mentioned earlier, we do understand now that we need to continue to do some work along those lines. So in addition to the information that I was giving earlier about enforcement, per se, I do want to let you know that we continue to reach out to the private sector. We have done a lot of work, as I indicated in the presentation, with private sector organizations such as business umbrella organizations, and we continue to work with them to ask them as well to work with their constituents to make sure that businesses, first of all, are aware of what they need to do and can get the help they need to make sure they come into compliance, either through their organizations that we've worked with or with our tools and so on that are on our website. We continue to work with those organizations. We are more active now in social media than we have been before. We are continuing to use every avenue that we can, working through other ministries and making sure that businesses are aware of what they're doing.

What I can tell you that is perhaps encouraging is that when we are working with businesses, we are not finding that any of them are in any way refusing to comply. It sometimes takes them a little bit longer to understand what it is they need to do, because this is still a new process for business in Ontario.

We are right now still at the stage of following up on the compliance reporting that we expected to have in place by the end of last year. But there is another cycle that will also come up in 2014, so we will be continuing to work not just on 2012 but to make businesses aware of what they need to do coming up to the next set of compliance reporting deadlines as well.

**Ms. Cheri DiNovo:** Okay. This is an act that came into place in 2005, so we're 10 years in. I understand,

you know, that it's not all at once, but clearly whatever process you've been engaging in to try to get compliance isn't working.

So I suppose what I'm not hearing and what I would like to hear is, how are you going to do things differently so that there will be more compliance? I'm hearing a continuation of the same, with the addition of social media. But the reality for people in the AODA Alliance and the reality for people who we see in our constituency offices is that they're still denied service, that there are still problems getting in and out of businesses they need to get in and out of, and that even public sector employers and organizations are not compliant. This isn't anecdotal; this is pretty widespread. Once the information was released, it became pretty clear this was the case, so they do have a point.

I guess what I'd like to see—and I'm, again, channeling them; I'm not speaking from my own experience here—is something different and something better in terms of compliance for the AOD Act, because otherwise we'll be at 2025 and we'll still be in the same situation if there's not more enforcement.

What we would hope to see, certainly in the New Democratic Party and for those who are living with disabilities, is that if you don't have the tools at your disposal because of some inadequacy in the act, that that is brought forward, then, to the minister, who will then bring it forward to change it or to put in additions so that we can get the enforcement of the act if you don't have the tools at your disposal to do that. I guess I'll just leave that hope hanging, because right now, it's simply not working.

1650

**Ms. Ann Hoy:** If I may just add a little bit to your comment, I think the fact that the ADO is now with the Ministry of Economic Development, Trade and Employment is going to give us new avenues to work with business, and I have been working with my colleagues at the ministry to start tapping into their business networks. I think that puts us in the business conversation in a way that hasn't been possible before as easily when we were part of a different ministry.

I would also note for you that there is currently an independent review of the AODA that's just starting with Dean Mayo Moran. I know that she will be looking at the effectiveness of all of the legislation, so we continue with what we've been doing. We're certainly doing more working with our ministry colleagues, engaging new channels and looking at new ways of reaching out to businesses, and doing more marketing and so on, to raise awareness. At the same time, I think we also have an opportunity to see from a step back, through an independent reviewer, whether there's a need to do more in a different way than what we see at the moment.

**Ms. Cheri DiNovo:** Just picking up the phone and talking to the alliance and to people with disabilities might help, too.

Another efficacy question, and that is the youth jobs strategy for those youth with intellectual disabilities.

Again, I'm just wondering how you're going to measure the effectiveness. Is it number of jobs that you find for young people who have intellectual disabilities, and are those numbers available now? Or do you have a timeline at which point those numbers will be available?

**Mr. Sam Boonstra:** It is a two-year strategy and we've just embarked on those two years right now. There certainly is a performance management framework that will track a number of indicators. Jobs, and the sustainability of those jobs, is certainly paramount, although we're also tracking things around mentor hours that are conducted between young people and mentors. We're also looking at funding that we're leveraging from the private sector, and also participants in training programs and whatnot that better equip people to move into employment. We'll be tracking all of those things and certainly reporting back.

**Ms. Cheri DiNovo:** Okay, thank you for that.

**Ms. Carrie Burd:** [*inaudible*] office and Victor's shop, which is the policy and strategy division, to map out a set of performance measures that we can apply, not just against the three initiatives we're here talking with you about today, but across all of our divisions and all of the programs and services that we're delivering through business and umbrella organizations.

**Ms. Cheri DiNovo:** I would just recommend, really, that transparency's always the best bet, so that if we have to fight to get information, it makes one suspicious before you can get it. Thank you.

**The Chair (Mrs. Laura Albanese):** Thank you. Now we'll turn it over to the government side. Ms. Wong.

**Ms. Soo Wong:** Thank you very much, Madam Chair.

Thank you so much for the presentation. I've been reading this data for a long time, dealing with the relationship between individuals with disabilities and unemployment. So my next question that has to be asked is, what is your ministry doing? You recognize the data. I read that script—everybody in this House read the script about the youth employment fund. You had the four funds; you keep telling us there's \$295 million. So my next question has to be this: What efforts on each of those funds are you targeting specifically to help those young people with developmental disabilities to make sure they're successful? You're targeting First Nations communities, you're targeting certain populations, so for each of the funds, what strategy is your ministry doing to help these young people?

**Mr. Sam Boonstra:** What I will say for the programs that my ministry is delivering is that we're still in that phase of setting up the delivery structure, where we're really trying to bring the best of the best in terms of the stakeholders who have expertise and a track record in working with all of the populations that we've identified. And then we'll move into the intake phase, where it's actually those partners who will be managing projects, using tried and true methods in program delivery and effective interventions with those populations to actually do the intake and then manage them through the training

intervention or the innovation and entrepreneurship intervention to move them into more sustainable employment.

What I can say, though, on the employment fund that's already being delivered by training, colleges and universities, launched in September, is that there are already over 2,000 young people who have been placed into jobs as a result of that. So I think the momentum is starting to build as we now start to advance in the two-year strategy, but it's a little bit early, I think, for the programs that our ministry is delivering, to give you anything more tangible than that in terms of the outcomes, because it is a two-year program.

**Ms. Soo Wong:** I hear different numbers. You said 2,000; I heard this morning the minister say that it's over 3,000. It doesn't really matter. How many of those young people who apply are youth who are developmentally disabled and who are being aggressively—by your ministry and your service provider, wherever they are provided, working with your ministry, or MTCU—identified?

**Mr. Sam Boonstra:** I don't have the specifics on the TCU elements related to that population.

**Ms. Soo Wong:** The other thing is, we heard from different ministries that there is this committee at the ADM level called the ADM multi-ministry strategy. Are you part of that group?

**Mr. Sam Boonstra:** Yes.

**Ms. Soo Wong:** You are. Okay. So what are you, conversation-wise, in terms of addressing—because you shared with us just now that these are young people with the education; they do have the ability. They certainly are interested in being employed. So at that table, at the ADM level, what strategy are you guys sharing amongst yourselves to support this group, which has a higher incidence of youth unemployment than the other group?

**Mr. Sam Boonstra:** The conversation around that table to date has really been around program design and how we have effective linkages between the various programs as well. So if a youth is not eligible for one fund, they're not dropped, but rather streamed into a more appropriate fund if one exists. That's been really important.

We also wanted to leverage best practices that existed in other ministries, as well as expertise in terms of knowledge of the client population, who the stakeholders are and effective outreach strategies to make sure that we were being really meaningful and targeted in the way in which we were actually delivering the programs as well.

**Ms. Mitzie Hunter:** Thank you. My colleague Ms. Wong has asked the question that I had as well. I can appreciate the work that you're doing, and it's reaching a very important youth population, but I would ask that you, perhaps, turn some of your time and resources to the specific needs of our young people with intellectual developmental disabilities.

The focus of our work here at the select committee is to ensure that through a life cycle this group is not forgotten, that we work across ministries and we find solutions to the challenges that we face and that we support families who are looking to tap into those types of

support. So I can certainly appreciate the work that's being done and the funds that are being invested. We want to ensure that the needs of this group are met and are considered within the ministry.

My question is relating to the work being done with businesses, and I find it really quite hopeful that you've already thought about some of the ideas to build a culture within companies that embraces people with developmental disabilities. What role do you see governments playing to support people with developmental disabilities who want to find employment? That is their goal; that's something that they want to work towards. What role do you see governments playing in that?

**Mr. Victor Severino:** Well, I guess I should note that there are people with disabilities employed already, so it's not as though it's a cohort that always doesn't find employment; it is a cohort that does find employment. Part of the challenge is ferreting out where the best practices are and what exactly contributes to those conditions.

I'll rely on some of our experience with the UK, which is, in many respects, somewhat advanced on this issue. What they found is, there are a series of supports that businesses are not interested in providing, and it's really kind of determining which those are. They're not insurmountable, but there are certain types of simple things, like transit subsidies that simply allow somebody the ability to actually get to the place of employment, or a special transit subsidy where they might require an accessible vehicle, for example. So there are a range of employments that, in our research on this, are best provided by the state, are best provided by the public sector, because we know once those barriers are overcome, employers are actually quite willing, then, to kind of carry the load the rest of the way.

As has been noted already, the accommodation requirements are often not very expensive—or zero—at all. Lots of places are moving to universal design already, so lots of places are already accessible, even though they don't actually need to accommodate persons with disabilities. There is a trend towards workplaces that are already more amenable to employing persons with disabilities.

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All of that is encouraging. I guess I would say that, in the conversations that I have with business, the issue of employing persons with disabilities isn't always a feature of that conversation. Part of our challenge is to make that a feature of the conversation, because until we penetrate that worldview, that mindset, it will just be that much more difficult for us to make progress in this area.

**Ms. Ann Hoy:** May I add just a quick note to that? Under the Accessibility for Ontarians with Disabilities Act, there is an employment standard businesses will have to follow over the next couple of years. I think it helps to provide a level playing field for people of all abilities to be accommodated better into the employment life cycle. For example, organizations will be required to let people know that accommodations are available through the employment life cycle. There will be more accessible recruitment. They can have individual accommodation plans and a number of other things that

would support people. That is already in place under the AODA, but not fully in effect yet. But I think that will complement some of the things that Victor has been talking about.

**Ms. Carrie Burd:** And I would also add that in my role, I've had an opportunity—and we're just starting the conversation to sort of unpack some of the issues behind this and what's involved, especially with that particular slice of disabilities. One example is that PwC recently did an Industry Canada round table and had the president and CEO of Specialisterne, which is a Danish company that provides supportive employment for persons with autism and autism spectrum disorder. It was a fascinating conversation. We really learned quite a bit about what kind of accommodations are required for that type of situation.

I think those are the very conversations that we're interested in having with industry. So I'm actively working through the people who are out on the front lines of our organization and dealing daily with businesses to try and uncover those best practice examples and engage in conversations with them.

There's also a follow-up round table that's going to be hosted by PwC on disabilities and disability employment. They've invited me to join that table. We're certainly looking for referrals from anybody who is aware of people—and I hear Second Cup would be another example, and Ann and her team would be aware of employers who are ahead of the pack on that.

**The Chair (Mrs. Laura Albanese):** I'm sorry, but the time has elapsed. Thank you for your presentation. Perhaps, Mr. Balkissoon, you can ask them as they're leaving and just a brief question so—

**Mr. Bas Balkissoon:** Mine was quick—

**The Chair (Mrs. Laura Albanese):** No, no, I can't allow any time. We hear the bells ringing. We're going to get the next presenters up, if the committee is okay with that. We will continue going and maybe allow—is five minutes before the vote okay with everybody? Okay.

Thank you very much for your time today.

#### CENTRE FOR ADDICTION AND MENTAL HEALTH

**The Chair (Mrs. Laura Albanese):** We'll ask the Centre for Addiction and Mental Health, CAMH, representatives to please come up—and thank you to the ministry for the presentation. If we have any more questions, the committee, we will be contacting you. Thank you.

We welcome CAMH. I would ask you please to start by stating your name and your title before you start your presentation so that it can be recorded. You may start at any time.

**Dr. Peter Szatmari:** Thank you very much. My name is Dr. Peter Szatmari. I'm the chief of child and adolescent psychiatry at CAMH, but also at the Hospital for Sick Children and at the University of Toronto. I've worked in the field of autism spectrum disorders for more than 35 years, and developmental disabilities. Adults

with autism spectrum disorder is one of the things that I'm most passionate about and most concerned about, and I hope to share some of that information with you this afternoon.

**Dr. Pushpal Desarkar:** Hi. I am Dr. Pushpal Desarkar. I'm a staff psychiatrist with CAMH and assistant professor at the University of Toronto. I'm also trained in developmental psychiatry—but not 35 years; I'm just six years, and at CAMH for two years. So I'd like to talk about our experience as well.

**The Chair (Mrs. Laura Albanese):** I forgot to mention that you have up to 10 minutes to make any presentation you wish, and that will be followed by questions.

**Dr. Peter Szatmari:** I'll speak first and then my colleague will pick up where I leave off. We have a presentation for you. We're just basically going to follow the outline of the presentation.

We really have just two very simple messages to convey this afternoon. One is that specialized mental health services for adults with developmental disabilities, including autism spectrum disorders—and we're going to underline that—are essential. It's not optional. It must be inclusive to include the entire population, it must be provided early in order to be most effective, and it has to be personalized. In other words, every individual with a developmental disability is different, and the treatment plan that they require is also going to be different.

There's only one solution. It's simple: We need greater capacity, because in Ontario, we don't have enough capacity, and we need greater collaboration between community agencies and specialized services.

I want to, first of all, make a comment about the terminology, and I think this is an area where it's very confusing. There are what are called dual-diagnosis services, which refer to those individuals who have a developmental disability plus some kind of challenging behaviour and/or a mental health disorder. The term "dual diagnosis" is not a medical diagnosis. It's not one that's really used in the field of psychiatry. It is an administrative convenience to identify a particular service.

Autism spectrum disorder is the most common developmental disability. So when we're talking about developmental disabilities, that's a wide group. Probably the most important group within developmental disabilities in terms of morbidity and mortality is the autism spectrum disorder group. But it's also important to distinguish that from intellectual disability, which is defined as an IQ score below 70. Only 50% of adults with autism spectrum disorder who have a developmental disability also have intellectual disability; that is, an IQ below 70. So we have to distinguish developmental disability as a generic term, and autism spectrum disorder as one type that may or may not have intellectual disability, which is an IQ score.

Now, we know a fair bit about the adult outcomes of individuals with autism spectrum disorder. Some work has actually been done in Canada, and I've been involved in some of that work. We know that about 80% of adults

with autism spectrum disorder have a poor outcome across a variety of domains. I like to look on the positive side: That means 20% actually have a good outcome, and in fact some individuals are able to recover from their autism spectrum disorder. But look at some of these data: 40% of adults are still living with their aging parents. Only 8% are living independently outside a group home situation. Only 12% in Canada, in British Columbia, have an independent job without any kind of job support.

The two major factors associated with the poor outcome are an intellectual disability and a mental health challenge. So when I talk about challenging behaviours, what I refer to is really aggressive behaviour, irritability, non-compliance. Autism spectrum disorder is the developmental disability with the highest frequency of challenging behaviours, and these challenging behaviours can be part of the disorder itself or it can be part of a mental health condition, like an anxiety or a mood disorder.

A key finding is that challenging behaviours and mental health problems are not more common among developmental disability individuals with an IQ below 70. So there's a myth that an IQ below 70 identifies the greatest need, the highest severity. That's not true.

If we look specifically at psychiatric disorders amongst individuals with autism spectrum disorder—and this is work that I did here in Ontario—roughly 40% of adults with an autism spectrum disorder have an anxiety or a mood disorder. Over 50% have some form of a mental health disorder when they're adults. It starts in childhood, around nine to 12 years of age, and then continues through adolescence and then into adulthood. These comorbid psychiatric disorders are, in fact, more common in those who have an IQ score above 70, again underlining the point that this differentiation of service by IQ is an artificial barrier.

#### 1710

Individuals with developmental disabilities, including autism spectrum disorder, who have high IQ, for example, are often refused services by the developmental disability sector, and by the mental health sector, because they have a developmental disability. They're caught between these two tables and they fall between them, which is really unfortunate, because for the first time in the last five years, we have some really good, evidence-based interventions, well-documented and very effective, for adults with autism spectrum disorder, plus these comorbid mental health problems.

In the previous talk, there was some discussion about the transition into adulthood. Exiting high school is a key transition point. For most individuals with an autism spectrum disorder, it's in fact a disaster. They lose their school-based services. I've written here, to be polite, "a paucity" of services for adults. But for these individuals, any kind of transition is extremely stressful. There's now good evidence from data from the United States, for example, that there is a deterioration in functioning and an increase in mental health problems after the exit from high school, and that this is, in fact, worse among those who do not have an intellectual disability.

Let's think about what's going to happen in Ontario. Roughly 1% of the population has an autism spectrum disorder. I think I've emphasized that high need is not the same as having an intellectual disability. We would propose that Ontario is not really ready to deal with these new cases of autism spectrum disorder that have less cognitive impairment and more challenging behaviours.

**Dr. Pushpal Desarkar:** Continuing farther, I will talk about lessons for adult dual-diagnosis services. Here, I like to highlight two overarching priorities: one, prevention of hospitalization; and the second, supporting families before a crisis point is reached.

If you move on to the next slide, you will see on the right-hand column the photograph of the last Ontario institution being closed four years ago, and in the left column, you can see the current length of stay for DD inpatient clients at CAMH. The numbers are quite obvious: years and counting.

Eight out of nine of them have been declared alternative level of care. It's a technical level which means that the hospital has completed assessment and treatment, but still they are waiting, and waiting at a tremendous cost to society. So we are voicing concern here: Is the hospital the new home for DD clients?

In the next slide, in the right column, you will see what we are seeing at CAMH, and in the left column you'll see what we have shared the Canadian research data. You will see that we are mostly getting young males with autism, mostly coming from family homes. All of them displayed serious aggression or life-threatening self-injurious behaviour. All of them were over-medicated and then they were admitted after multiple emergency visits. You have seen that they continue to remain hospitalized, even though evidence indicates that a hospital environment is stressful for them.

If you look at the research data, you will see that what we are seeing here is consistent with research, so what we are seeing is not a CAMH phenomenon. It is happening everywhere in Canada.

In the next slide, I'll be talking about the experience of families. In the day-to-day practice, we have seen that parents, by the point of hospital admission, are no longer able to cope and to take care of their children. They report a high degree of long-term stress and burnout. They attribute this to the insufficient support that they receive in the community. I've given examples like deficient primary care support, lack of specialist assessment, poor planning, long waiting times, and poor coordination among services.

In the next slide, we have argued that the solutions are already known. We have given the example of the joint policy statement of the Ministry of Health and Long-Term Care and the Ministry of Community and Social Services that was published in 2008. That had all the key assumptions.

Then, moving to the next slide, in the left column you'll see the proposed levels of care—first line, intensive and specialized. In the right column, we have provided facts that we believe represent reality.

You'll see that only 20% receive care through inter-professional family health teams. Regarding the specialized services, families report that these are band-aid solutions. It means these are crisis-focused. There is no long-term planning.

The other thing is that with developmental conditions, response to medication and treatment is often sub-optimal. Experts believe that the standard of care is interdisciplinary care, but we know that this is lacking.

Talking about specialist care, we figured out that in Ontario, we have only 13 specialists serving 12 million, which means one specialist per million. Many of us regard our system as similar to the UK system. If you look at the UK figure, they have 250 developmental specialists serving one million, so it's a staggering 250 times higher than what we have. This indicates that the development of mental health services here is not informed by population demographics.

Then we'll talk about the solutions. What we are observing is an unfortunate legacy of missed opportunities. I can't emphasize more the fact that doing it early is the key. We have to invest upstream. I couldn't agree more with Peter in saying again that what we are looking at is early, personalized intervention.

I would like to propose two key priorities for us. We have to strengthen primary care. We have to improve knowledge and the attitude, and thus we can change practice. The second thing is that we have to create effective secondary care. This is conspicuously missing here, and this is what differentiates us and makes us look different from other services such as those in the UK. Here we are talking about secondary care having to be need-based and population-based. It means that it should work in smaller catchment areas.

We are emphasizing interdisciplinary services, not just a psychiatrist alone. Also, we are talking about how it has to be well linked with primary and tertiary care, so we are talking about shared care protocols. Also, it should allow step-up and step-down care, so we're talking about establishing clear pathways through which patients can move back and forth. This model is quite effective in the UK.

I'll end by saying that an effective social inclusion depends on sound health, and there is no health without mental health. Thank you.

**The Chair (Mrs. Laura Albanese):** Thank you very much. I first of all want to say that I did allow them to go over because the Clerk told me that they had half an hour at their disposal and could leave to the committee whatever time they saw fit. So why I was wrong in giving only the 10-minute mark off the top.

We're now 10 minutes away from our vote. We have five minutes, I guess, before we go up. I would say, let's use them. So I would give five minutes to the NDP—

*Interjection.*

**The Chair (Mrs. Laura Albanese):** No, I can't. Maybe you can start and then—

**Ms. Cheri DiNovo:** I just have a question on process, Madam Chair. Some of us are not going up to vote.

*Interjection.*

**Ms. Cheri DiNovo:** We have to? Okay.

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

**Miss Monique Taylor:** Thank you for your presentation. The problem I have with your presentation is that I agree with the lack of so many resources that we have for these folks. What are we going to do? This seems to be exactly what you were saying when we don't have enough doctors who are able to handle this. The numbers are absolutely astounding when we look at the number of specialists that we have to deal with the millions of people who are facing this. What is the solution for that?

**Dr. Peter Szatmari:** The solution is that if you build an attractive service that has good infrastructure and is interdisciplinary, people will be attracted to the field. This happened in the childhood autism field. There's now a huge influx of clinicians in the childhood autism field, but they're not moving into the adult field. We have the infrastructure for children and youth; we don't for adults. Build the infrastructure and they'll come.

**Miss Monique Taylor:** Okay. So this is specifically directed at adults.

Caregiver burnout is a major issue with families that I've heard from and families that I know will be before this body before long, because I've just actually seen some of their names on the list to come before us. They're dropping their children off and surrendering them. Do you have any ideas for a solution of what we do to help those families through?

**Dr. Pushpal Desarkar:** So that's why we talked about the development of need-based clinical services in the community. This is what we believe is conspicuously lacking here. If you compare our health care system to those of the UK and the US, we do not have enough clinical services that can support challenging behaviour and mental health presentation in the community. Here, what we are seeing is a direct jump from primary care to tertiary care; there's nothing in between. So we have to have support out there in the community. I think that's the key.

**Dr. Peter Szatmari:** And when those families come, ask them how many services have rejected them for one reason or another—have rejected providing them service either because they're too severe or they have a developmental disability or something. Because they're often excluded, and as a result, they just continue on a trajectory down.

**The Chair (Mrs. Laura Albanese):** Go ahead.

**Miss Monique Taylor:** I still have time? Okay.

**The Chair (Mrs. Laura Albanese):** Two more minutes.

**Miss Monique Taylor:** The impact of changing services for families: We know that's a major problem. We find that that is something that definitely happens once they reach the age of 18. What are your comments on that?

**Dr. Peter Szatmari:** Well, you know, we have a system for young people with schizophrenia. We have early intervention psychosis clinics. The Ministry of Health

supports these. If we could have the same model for adults with a developmental disability, we would be able to avoid a lot of these problems. So we have the ideas; it's just thinking of applying those ideas to another health condition like developmental disability and autism. The early intervention psychosis clinics provide that continuity of care, over school, into the transition into adulthood.

**Miss Monique Taylor:** Now, we know that the early intervention programs—IBI, ABA—are helping with children as they are young. So now they're allowed so much time and they're being thrown under those programs, too, because I believe the wait-lists are too long and they're just trying to shuffle them through—who gets the next little bit or piece. What happens after that point? How do we try to maintain some of the growth that they've had through that experience and take that into adulthood? How are we missing that piece?

**Dr. Peter Szatmari:** That's a wonderful question. I could talk for days. Basically—

**Miss Monique Taylor:** I wish you had days, because I would love to hear it.

**The Chair (Mrs. Laura Albanese):** Only 10 seconds.

**Dr. Peter Szatmari:** Sure. We can get together.

**Miss Monique Taylor:** Yes, great.

**Dr. Peter Szatmari:** We need a spectrum, a continuity of care, from the moment of diagnosis to old age, and we just need to be able to link a spectrum of care that's specialized and individualized.

**The Chair (Mrs. Laura Albanese):** I'm sorry to interrupt. We are suspended until the vote, and I urge members to come back as quickly as possible after the vote.

*The committee recessed from 1723 to 1732.*

**The Chair (Mrs. Laura Albanese):** Thank you for your patience. We will now move to the government. Ms. Wong, you'll have five minutes.

**Ms. Soo Wong:** Five minutes? Okay. I'm going to talk fast, fast, fast.

Thank you so much for your presentation, doctors. On page 7, you share with the committee a number of solutions or suggestions on how to improve the system. There's identification of the lack of specialists across Ontario to service this community with ASD. Am I correct in my reading of this? Given the government's commitment to family health care teams and nurse practitioner clinics, how can those groups help to support the limited number of specialists out there? There may be professionals who are not interested in working with the aging population; they're not interested in geriatric care. What are we doing with the family health care teams and the nurse practitioner clinics, given your identification that there are limited specialists who are working in this field? Can you give us some comments and suggestions on that, please?

**Dr. Peter Szatmari:** I think the concept of collaborative care with family practice is a really important initiative. Having specialists provide input towards those family health care teams is really key, and we need to

work with our colleagues in general psychiatry to teach them about developmental disabilities and ASD to work towards that. We are trying to do that at CAMH very vigorously. There's kind of a stigma about working with adults with autism spectrum disorder and developmental disabilities that we have to deal with and do something about.

**Ms. Soo Wong:** You also mentioned to us—

**Dr. Peter Szatmari:** Might I just make one other point?

**Ms. Soo Wong:** Yes.

**Dr. Peter Szatmari:** That is the number of residency slots. We need to have more residency slots open for psychiatry in general. They're frozen, I believe. In particular, we're trying to get child psychiatry specialists. Child psychiatrists are the ones who do most of the adult developmental disability work in Ontario. There are no funding slots for the extra year of training in child and adolescent psychiatry. We'd love to have some funding and train some of those new people to work in this area to provide the expertise.

**Ms. Soo Wong:** I know this is a national number; residency is a national number. What is the national number? You said it's frozen.

**Dr. Peter Szatmari:** Yes.

**Ms. Soo Wong:** So what is the number we're holding at right now?

**Dr. Peter Szatmari:** That, I don't know. Sorry.

**Ms. Soo Wong:** All right. So we'll ask that question.

*Interjections.*

**Dr. Pushpal Desarkar:** Very quickly, I refer to the recently published executive summary of the Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario. You'll see that only 20% are receiving care.

**Ms. Soo Wong:** Okay. That's great. Thank you. That's it.

**Ms. Mitzie Hunter:** Thank you so much for your presentation. You talked about how we need a spectrum of continuity of care from birth to old age and the fact that we have the structures in place for children; let's build it for the adults. If there was one thing that we could do as recommendations to this committee, which will be writing a report with some solutions, what would that be?

**Dr. Peter Szatmari:** One thing?

**Ms. Mitzie Hunter:** Your top three things.

**Dr. Peter Szatmari:** I think I'll do one and a half and I'll let my colleague do the other one and a half.

I think to reduce the barriers between institutions on the ground so that the two ministries involved make those agencies accountable for collaboration and working with people with ASD, so that the exclusions are no longer present. There has to be a sense of accountability, because currently, agencies can do what they want based on their own mandate, and that's an injustice.

**The Chair (Mrs. Laura Albanese):** In 20 seconds, did you want to add something?

**Dr. Pushpal Desarkar:** I think that Peter said what I was going to say as well. I think we have to reduce the

barriers as well. What we are seeing every day—admission is part of one ministry and discharge is part of another ministry.

**Ms. Mitzie Hunter:** So coordination of ministries.

**Dr. Pushpal Desarkar:** Coordination, yes.

**Ms. Mitzie Hunter:** Thank you.

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

**Ms. Sylvia Jones:** I'm going to continue on slide 7, where you say that only 20% receive their care through interprofessional family health teams. That is not a surprise to me, because I sat on the Select Committee on Mental Health and Addictions—very similar kinds of scenarios happening.

There's an issue: You can't separate the patient from the various illnesses, so how are we going to get the general practitioner buying into treating the whole patient? Help us.

**Dr. Peter Szatmari:** I think if the family doctor were supported by specialist care in a collaborative care model, he or she would be much more comfortable in learning. It's capacity building. Those family doctors need to be supported so that they can phone somebody up and say, "I've got this problem. What can I do? Should I try this or try that?", so that there's an access to information from a specialist. But we need more specialists. A specialist doesn't have to be an MD. It can be a nurse practitioner; it can be a psychologist; it can be a social worker who has expertise in adults with developmental disability. That's what we're talking about in terms of building within the gulf between the family doctor and the institution. We have a gulf there, and we need to build a continuum of services within that. We need to start with that.

**Ms. Sylvia Jones:** I would suggest that we also need to do something about the fact that a lot of these patients can't even get into the family health team. Right?

**Dr. Peter Szatmari:** Sure.

**Ms. Sylvia Jones:** Outside of the 20%, you have a problem before you even get to the 20%.

**Dr. Peter Szatmari:** Right.

**Ms. Sylvia Jones:** Absolutely some of the FHNs have a mental health practitioner of some description, but any kind of challenge or complication, then they need the support that you're referencing.

**Dr. Peter Szatmari:** Right. And if the individual has a developmental disability or autism, those family health teams with the mental health support say, "It's not our ballpark."

**Ms. Sylvia Jones:** Absolutely.

**Dr. Peter Szatmari:** And that's a mistake.

**Ms. Sylvia Jones:** Yes. I agree 100%.

**Mrs. Christine Elliott:** Thank you very much, doctors, for what is really an excellent presentation. You've validated a lot of what we've heard anecdotally in our communities.

1740

I was really interested in the information that you had on—I have to use my glasses here—slide 5 with respect to eight out of nine of your in-patient clients being



deemed ALC, and I'm assuming that's because suitable accommodation can't be found for them. Are you finding that many families and caregivers are really leaving their children with you, that they can't cope anymore and they need assistance? Is that the reason?

**Dr. Pushpal Desarkar:** Yes. That's why I shared it. This is pretty much the story that we are seeing every day, actually. As I said, seven out of nine cannot go back to the family because the family is completely burnt out. They are no longer able to cope with this kind of ongoing challenging behaviour. They have other issues as well. They have their own mental health issues as well.

**Mrs. Christine Elliott:** I'm assuming that's significantly affecting your ability to take new patients in, that there's a complete blockage in your system right now.

**Dr. Pushpal Desarkar:** Exactly. Totally agreed. You see, you cannot discharge eight out of nine clients. It's quite obvious that you cannot take new clients in.

**Mrs. Christine Elliott:** I would suspect then that one of the solutions would be to invest in more housing options, that there's an urgent need for them, that families are not able to cope and that we urgently need to deal with this. Would you agree with that?

**Dr. Pushpal Desarkar:** Yes, definitely. We have to invest in that, but we also have to invest early so that they don't come in. You have to prevent hospitalization, and I think that's the key. All of these families, we have seen, did not get the kinds of services they needed, and that's why I talked about this legacy of missed opportunities. Now they actually get the care but they have nowhere to go. The two problems are linked, actually, so we are seeing both.

**Mrs. Christine Elliott:** Several families in my own community have told me that they've been desperately seeking help, and it's only when something dramatic happens in the family that they're able to access help on an emergency basis. Then, of course, that bumps all the other people who are waiting down the line even further, and those families have to cope, so it's a pretty desperate situation out there right now.

**The Chair (Mrs. Laura Albanese):** Just a final comment.

**Dr. Pushpal Desarkar:** Yes, I agree. It's a band-aid solution. The families took this as a band-aid solution. It's a crisis-focused approach.

**The Chair (Mrs. Laura Albanese):** Thank you very much for your presentation and thank you for your time and your patience.

MS. MARILYN DOLMAGE

MS. MARIE SLARK

MS. PATRICIA SETH

MR. JIM DOLMAGE

**The Chair (Mrs. Laura Albanese):** We'll welcome the next presenter, Marilyn Dolmage. Again, I would ask you to start by stating your name for the purposes of our Hansard recording.

**Ms. Marilyn Dolmage:** Thank you very much. I am Marilyn Dolmage, and I will ask that my co-presenters introduce themselves.

**Ms. Marie Slark:** My name is Marie Slark.

**Ms. Patricia Seth:** And my name is Patricia Seth.

**Mr. Jim Dolmage:** I'm Jim Dolmage.

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

**Ms. Marilyn Dolmage:** Thank you. We're going to go through slides, which you have in front of you and can actually see on a screen, thanks to the wonders of technology.

We're presenting a picture of change, and I bring this empty picture frame with me because I think that there would not be a select committee if there wasn't a political commitment to change—that the status quo is not good enough, and you've been hearing many details about that. Really, the way I think of this is that we take the old picture or the current picture for people with developmental disabilities out of the frame and we look at a new picture and we frame that in ways that will improve lives for everyone in Ontario.

"You see things; and you say, 'Why?' But I dream things that never were; and I say, 'Why not?'" It's really that idea of going from the nightmare that is existing for people and that has happened in the past for people to a dream for a better future. Stubborn people always know what they're going to think tomorrow, so we're looking for open minds.

We think back to hundreds of years ago with Copernicus and Galileo. They had an idea about a different concept for the universe, and they were rejected. Those ideas were rejected partly by people who refused to look in the telescope and see what was there.

When we think about the Copernican model that was radical because the sun was in the middle and had all the power and the earth was on the outside, the people in the earth didn't want to lose the power. They didn't want to acknowledge that someone had more power, and that's exactly what we're talking about with a radical person-centred revolution. It's nothing short of a revolution to say that the individual with a developmental disability should be in the middle and have the control. The only reason for friends and family and associates and services at the outside circle is that the person wants them there, brings them there and tells them what to do, so that radical power shift and radical respect where the person is really at the centre and has the power—not just the direction but the power.

If we think about, "How do you frame that picture?", you may think of some people you know, your constituents and others in the news, whom you would want to be getting a new picture for.

I look at this picture, and this is my little brother, Robert. This is the only picture I have of Robert. It's this little, worn-out black-and-white photograph because I never met Robert until he had died. Because he was diagnosed at birth with Down syndrome, he was institutionalized for all of his short life. He was identified very early, and I think that's why we have to be really

careful what we ask for. Early identification doesn't always bring the right results, the right intervention. He was seen as "one of them" from the moment he was born. He was sent "over there." At the age he was in this photograph, he was admitted to Huronia Regional Centre in Orillia and, very far over there, removed from family. I think of that, and I hope you will remember his picture as to what segregation means. Whenever you talk about "one of them" and "over there," that's what it is. It needs to be called that.

At the time, that institution was called a "hospital school," but I have to tell you that Robert died at the age of eight of pneumonia and had not been treated, did not receive medication and treatment for pneumonia, so he was left to die. So I say, "Some hospital." and I found out that he had never attended school, at the age of eight. Some school; some hospital. Again, that's segregation.

I'll present you a different picture, and this is our children, Jim and I, a long time ago. They're all in their 30s now, but Matthew, in the middle, lived with a number of challenges and died almost 10 years ago at the age of 29. His sister, Leah, is on one side and his brother, Jay, on the other. So I think of this picture as: Here's our family. They're all individuals. It's that sense of us that a family provides. They're touching, as many family photographs are, close together and together. So where segregation is one of them over there, this is what inclusion is—us and together. It's essential for that change picture.

Here's a later picture of our family when Jay and Heather were married 10 years ago. Again, individuals, one of us touching, strong—they're doing the sign for "strong" there—and together and inclusive.

We can talk about the institution then—Huronia Regional Centre has closed, but there are many other institutions in the community. We can talk about school boards now. There's that one of them over there, but the whole school system in Ontario is putting a huge amount of resources into exactly the same thing—identification and placement—and not nearly as much attention on programming historically over the whole development of special education in Ontario. Where we could talk about, "Was it a hospital? Was it a school?", people with intellectual disabilities themselves say, "Is it special and is it education?"

We need to be looking at the outcomes of special education. I know there's a project in Ontario that only looks at how you measure outcomes, not how you improve them, for students who are not accessing the Ontario curriculum. Why are they not accessing the Ontario curriculum? Why are their goals not literacy, not just communication? Why are they therapeutic? And so on.

**1750**

Here's the picture of our family. It was very important for us to have all of our children going to the same neighbourhood school together, where Matthew became—after much advocacy—a member of the regular classroom, learning at his own rate alongside all the other students of his age in the courses he chose. It was very important for our family.

Here's a picture of Matthew, just before he died, at his brother's wedding. Just before Matthew died, I spoke at an individualized funding gathering 10 years ago; I was very frustrated at that time, because we'd been talking about individualized funding for about 10 years by then. We've been talking about it another 10 years now, and it's still not happening for people.

The theme of that gathering was citizenship, and I think we often don't know what we're talking about when we say "citizenship." I returned home, and Matthew died that very evening. I thought, "Why are we waiting so long for individualized funding to come to people?" Matthew had individualized funding in 1997.

There are many examples across the province of direct, individualized funding that happened under the old legislation; they're still not happening now under the new legislation. There's no money to provide to people, for Special Services at Home and Passport funding in particular.

After Matthew died, I realized that what citizenship really meant, the strength of his life, was that he had a lot of connections: many people to whom he was important, and who missed him when he was gone. They saw him for his contributions.

John O'Brien talks about how the five things missing from the old picture are these, and the way to improve people's lives is to have more people in the lives of people with intellectual disabilities—more places, more choices, more respect—and not to focus first on gaining skills, but on gaining connections in the community. Then the rest comes. If skills are the only focus, the rest may not come. Aiming higher, focusing on strength, respecting all, interdependence and inclusion: lots of things to think about.

People First of Ontario talks about the picture they want in very clear terms: real work for real pay, a real home, real school, real friends, real love, to see the strengths of everyone and to aim higher for their future. There was a presentation earlier this afternoon about career development and career support, and I really don't think that those supports are being made available to people with developmental disabilities who need additional supports. They need to piggyback different kinds of supports, but they can have access to real employment; Matthew did. Really, the replacement picture is to boldly go where everyone else has already been, but people with intellectual disabilities in Ontario have not been a priority.

I've talked about some supports to keep family together that were important to us: inclusive education, direct funding, career development and job creation. We're also motivated by the nightmare, by the way things have been. Here's an old picture of an institution, whose name I will not say, in Ontario; what it was called later, when it closed in 2009, was the Huronia Regional Centre.

Now Marie, Pat and Jim will talk a little bit about what the Huronia Regional Centre class action, in which we have all been involved, teaches us about what to stop doing and what to start doing.

**Mr. Jim Dolmage:** Thank you. Before this lawsuit took place, most people in Ontario didn't know that Huronia Regional Centre existed. Like all of these institutions across North America, it was hidden away. Thanks to the lawsuit and these two brave women, a lot of citizens in Ontario now do know what the institution was and what went on there.

I'm just going to talk very briefly, and then I'm going to ask Marie and Pat some questions, just to give you some context about how they think and what their lives are like now as adults outside of the institution. Both women were placed in Huronia as small children, six and seven years of age, primarily due to family circumstances.

Marie, could you just briefly describe the life with your family before you went to Huronia? You need to be fairly close to that mike, the one that's lit up.

**Ms. Marie Slark:** When I was living with my family I was neglected and not taken care of properly.

**Mr. Jim Dolmage:** Could you just pull the mike a little closer to your voice? Thank you. You're okay? All right. Great.

Pat, where do you live now?

**Ms. Patricia Seth:** I live in downtown Toronto and I have my own apartment. I live by myself. I really love downtown living.

**Mr. Jim Dolmage:** Both women were very unlucky to have been put in the institution, but they were also lucky to have gotten out as young adults, having now spent most of their lives out of the institution.

How long have you lived on your own, Pat?

**Ms. Patricia Seth:** I said "24 years" earlier, but that was in Orillia alone. If I was to add years after that up until now—I really never calculated.

**Mr. Jim Dolmage:** A long time. That's all we need to know.

**Ms. Patricia Seth:** A long time.

**Mr. Jim Dolmage:** Marie, who do you share your apartment with?

**Ms. Marie Slark:** I share my apartment with my cat Maggie.

**Mr. Jim Dolmage:** You live on your own as well?

**Ms. Marie Slark:** Yes, I live on my own.

**Mr. Jim Dolmage:** Thank you. Pat, are there still things affecting your life now, almost 40 years later, from the institution?

**Ms. Patricia Seth:** Yes.

**Mr. Jim Dolmage:** Could you tell us a little more?

**Ms. Patricia Seth:** I have problems with authority in my life. The people who help me—I look at them as authority figures. Authority figures scare me, and if they're mean to me or they talk in a sharp tone to me, sometimes I get my back up against them, even though sometimes I know some people are trying to help me. But I have problems with authority figures.

**Mr. Jim Dolmage:** Thanks, Pat. In a conversation—we were travelling; were we in the car at that time, the three of us. Was that on the trip to Barrie? It doesn't matter, but Marie came out with a statement about what she would do if she were to get any money from the

settlement in the lawsuit. To be perfectly clear, from the beginning of that lawsuit, money was important, but as a signifier, not as a bulk item. There were other things that were equally or more important; one was just getting people to know about Huronia, and that has been successful.

Marie, you told me what you would do if you were to get any money from the settlement. What was the first thing you said?

**Ms. Marie Slark:** I would pay for my funeral in advance because in the near future I may never get that amount of money ever again.

**Mr. Jim Dolmage:** Marie works at Winners down on Spadina, and this time of year she gets to work every day because they're very busy. Most of the rest of the year she doesn't get nearly as much work, but like most people in this situation living on ODSP, they don't get to accumulate savings, so a dream would be to be able to prepay her funeral expenses. They have strong feelings about looking after themselves and making their own decisions, and Marilyn and I have had some fun with that along the way at times.

How have you been treated at other jobs you've held, Marie? Tell us about Winners, to begin with.

**Ms. Marie Slark:** Winners is really great. They're really understanding. Nobody picks on me there. In other jobs I've had, unless I've worked alone, coworkers would give me a hard time and they would pick at every little thing I did every single day.

**Mr. Jim Dolmage:** Pat, there were times that you didn't want people to know that you had been in Huronia. Talk about that a bit.

**1800**

**Ms. Patricia Seth:** Well, when I was living in Orillia in the Georgian College apartments, there was a counsellor from Huronia who lived in the same building that I did. I met her in the laundry room one time, and I didn't know she was a counsellor at that time. I would just say hello and that. But then she found out that I had resided at Huronia Regional Centre. She had her little boy with her; I was on my way in the building, and I said hello to her and her little boy. She grabbed her kid away from me and said, "You don't talk to that Winkie." I got my back up against her, and I said, "You're supposed to be a counsellor who's supposed to care about people, and you're calling me a Winkie." I won't say what happened. I won't say any more of what happened after that, but I gave her a good tongue-lashing. I said, "You can't hurt me now."

**Mr. Jim Dolmage:** "Winkie" is a particularly pejorative, derogatory term that I think is limited to northern Simcoe county, but applied to people who have been in an institution.

Pat told me something on Saturday. We've been meeting very, very frequently, trying to come to terms with all of the issues in the lawsuit. This was a surprising announcement too, but you told me what you would do—you buy lottery tickets?

**Ms. Patricia Seth:** Yes, once in a while if the prize is big, regardless of the ticket. I would pay the government

all the money that they gave me on family benefits and then when it got switched over to ODSP, and then plus I would pay the subsidies all back if I came into a lot of money, but it would have to amount to a lot in order to do that. So that's—

**Mr. Jim Dolmage:** You're talking about your housing subsidy—sorry; I didn't meant to interrupt.

**Ms. Patricia Seth:** My housing subsidy. Just so that somebody else who needs it just as much as I used to—well, I need it now because I haven't won any money, but I'd like other people who could really use that help to get help. If I ended up coming into that amount—like \$50 million, for instance—then I'd be able to pay that all back out of it, you know.

**Mr. Jim Dolmage:** Different dreams.

**Ms. Patricia Seth:** Yes.

**Mr. Jim Dolmage:** Do you folks have any questions for either Marie or Pat?

**The Chair (Mrs. Laura Albanese):** First of all, thank you for your presentation. Any questions?

*Interjection.*

**Mr. Jim Dolmage:** You aren't on, Marilyn.

**Ms. Marilyn Dolmage:** —wanted to ask them questions about what they've said.

**The Chair (Mrs. Laura Albanese):** Well, if they're not finished, then I would like them first to finish. We have one challenge: We are really limited with the time, so I would ask that you finish your presentation. That's the most important thing to us right now.

**Ms. Marilyn Dolmage:** Just to recap some of what the class action is about, you can see in your PowerPoint the problems with institution and segregation. Here is Edgar Riel the day the class action settlement was announced. We are looking for the apology to come from the Premier herself because we think that would be the recognition people want, that they are citizens, not clients of services but real citizens of Ontario.

We think that the survivors of institutions need trauma-informed support. There's an overuse of drugs and behaviour management for people with developmental disabilities, whether or not they've been in institutions. We need to listen with more than our ears to those who do not use words to communicate—and we haven't done enough of that—see with more than our eyes and stop the ongoing segregation that exists. All the ills of the government institution are still happening in the community, and I ask you to look more closely at these points in your written presentation.

We discovered, in the documents prepared for trial, that the government kept admitting people to Huronia to relieve the burden on their parents, even though they knew how horrific the conditions were there. Here's a

picture that may be familiar to you: In Ottawa last spring, the government finally listened to his mother, but no one seems to know what happened to Philipp Telford after she left him at a DSO office.

To me, this is exactly the same thing: We're looking at people with developmental disabilities as burdens on their families, without caring about their lives and what happens to them. Underfunding is neglect. "Out of sight, out of mind" is exactly repeating the horrors of institution in communities and in people's own homes where there is not adequate political will to put the funding in place.

The real experts are Marie and Pat and others who live with disabilities. I hope that's who you're going to hear in this committee. Change will not be achieved by old minds with new programs but by new minds with no programs.

We have a policy of inclusive education and equity in Ontario, but it does not translate to all students. It is not happening for students with developmental disabilities, and it's not providing the tools that teachers need to teach students of all abilities together in regular classes.

The big issue is the lack of direct funding. I think most of the challenges that are going to come to you in this committee could be resolved if—at least a major part of resolving them would be to make adequate direct funding available to people so that those families that are waiting for autism services and so on can have some support at home while they're waiting. Without that, everything is the old picture, the nightmare; we're right back to the same thing.

Paul Nichol, who was one of our people who swore an affidavit, was responsible for leading the class action. Unfortunately, he died two and a half years ago in Gravenhurst after having lived for many, many years in the institution and being put out to do slave labour for years and years, not paid by the institution. But when Muskoka Centre closed in Gravenhurst, and I was part of that process, he challenged me and said, "Did everybody go and live in group homes?" And he said to me, "Then why did you close it?"

If we listen to Paul and others like him who have lived in institutions, they would be also critical of the service system as it exists. We need to keep people from going into group homes and segregated programs and support them right where they are, as citizens in their own communities.

**The Chair (Mrs. Laura Albanese):** Thank you for your presentation. Because of the time, I will need to adjourn. Members are free to talk to you after I adjourn, but as Chair, I need to adjourn. Thank you.

*The committee adjourned at 1807.*







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