DS-15 DS-15

ISSN 2292-1087

Legislative Assembly
of Ontario

Second Session, 40th Parliament

Assemblée législative
de l'Ontario

Deuxième session, 40e législature

Official Report of Debates (Hansard)

Tuesday 21 January 2014

Journal des débats (Hansard)

Mardi 21 janvier 2014

Select Committee on Developmental Services

Comité spécial sur les services aux personnes ayant une déficience intellectuelle

Developmental services strategy

Stratégie de services
aux personnes ayant
une déficience intellectuelle

Chair: Laura Albanese
Clerk: Trevor Day

Présidente : Laura Albanese
Greffier : Trevor Day

Hansard on the Internet

Hansard and other documents of the Legislative Assembly can be on your personal computer within hours after each sitting. The address is:

Le Journal des débats sur Internet

L'adresse pour faire paraître sur votre ordinateur personnel le Journal et d'autres documents de l'Assemblée législative en quelques heures seulement après la séance est :

http://www.ontla.on.ca/

Index inquiries

Reference to a cumulative index of previous issues may be obtained by calling the Hansard Reporting Service indexing staff at 416-325-7410 or 325-3708.

Renseignements sur l'index

Adressez vos questions portant sur des numéros précédents du Journal des débats au personnel de l'index, qui vous fourniront des références aux pages dans l'index cumulatif, en composant le 416-325-7410 ou le 325-3708.

Hansard Reporting and Interpretation Services
Room 500, West Wing, Legislative Building
111 Wellesley Street West, Queen's Park
Toronto ON M7A 1A2
Telephone 416-325-7400; fax 416-325-7430
Published by the Legislative Assembly of Ontario

Service du Journal des débats et d'interprétation
Salle 500, aile ouest, Édifice du Parlement
111, rue Wellesley ouest, Queen's Park
Toronto ON M7A 1A2
Téléphone, 416-325-7400; télécopieur, 416-325-7430
Publié par l'Assemblée législative de l'Ontario

LEGISLATIVE ASSEMBLY OF ONTARIO

SELECT COMMITTEE ON DEVELOPMENTAL SERVICES

Tuesday 21 January 2014

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ SPÉCIAL SUR LES SERVICES AUX PERSONNES AYANT UNE DÉFICIENCE INTELLECTUELLE

Mardi 21 janvier 2014

The committee met at 0901 in committee room 1.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Good morning, everyone. I call the Select Committee on Developmental Services to order. It is the last day of public hearings here in Toronto before the interim report.

FAMILIES FOR A SECURE FUTURE

The Chair (Mrs. Laura Albanese): We will hear first this morning from Families for a Secure Future. Good morning.

Ms. Judith McGill: Good morning.

The Chair (Mrs. Laura Albanese): How are you? Thank you for making it down bright and early on this very cold morning.

Ms. Judith McGill: We sledded down.

The Chair (Mrs. Laura Albanese): You will have up to 20 minutes for your presentation. If you could please start by identifying yourselves with name, last name and title, that would be appreciated. You may start.

Ms. Judith McGill: Hello. My name is Judith McGill. I am the executive director of Families for a Secure Future.

Ms. Maureen Emmons: My name is Maureen Emmons and I am the chair of Families for a Secure Future. I'm also a parent of a wonderful daughter who is 31 and lives at home with me.

Ms. Judith McGill: We'd like to begin by thanking and acknowledging Christine Elliott for her perseverance and determination in calling for this select committee. Our families are putting their faith in the ability of this three-party committee to make strident and coherent recommendations to MCSS that will better the lives of individuals who live with a developmental disability and their families. These hearings are incredibly timely for families across the province who feel disheartened by the transformation agenda.

In reading through the committee transcripts, we couldn't help but feel that many alarm bells have already been rung by other groups, representing many different constituents. André Marin himself, of the Ombudsman office, has been ringing alarm bells about the state of crisis that families find themselves in as caregivers, and he describes his investigation by saying that it is like a leaking dam, and you're trying to hold back the rush of water. It can't hold water and there are plugs in the holes. Basically, the government has to go in and plug the hole as another one is pegged out of the wall and begins leaking.

He went on further to describe that the complaints coming into his office—more than 900 over a short period of time—were dealing with more complexity than his staff had ever met before and required more than a simple fix. The fact is that families today are in more crisis than ever before. Families need far more support than they're being given. There is also an ever-present worry about losing the support they already have. We are days, maybe weeks, from the filing of the Ombudsman report on the state of affairs for families. Families feel they've been heard and they feel that the complexity of their situation has been comprehended. Now, they wait to see if anything will be done.

As one of the oldest independent facilitation organizations across Ontario—we've been around now for over 13 years—we've learned a number of key things. Essentially, it is this: People need each other. They need to hold one another during difficult times, to celebrate with each other, to inspire one another, to help each other re-imagine their lives and imagine better, to problem-solve together, to pause and seriously listen to one another, and to have each other's back. If their lives are to transform and if they are to experience belonging in a sense that they are being seen as someone who contributes, they need others to be in their lives. They need others to believe in them.

Ms. Maureen Emmons: As an organization, I want to share with you a little bit about what we stand for. First of all, relationships are a significant safeguard for the future. People need support to participate and build relationships in their lives. We set out to build, over time, relational safeguards for both the individual and their family, safeguards with our facilitator who gets to know us over time, who gets to know my daughter and our children over time, and can support us in the way that we need to be supported and our children need to be supported.

We are committed to assisting individuals to build a supportive decision-making context in their lives where they are helped to make key decisions, those day-by-day decisions, so that people have more say in their lives within the family context. That's a really important thing to support. We said from the beginning, when we were forming Families for a Secure Future, that the individual is the one who comes first and the family second, so we're always looking to what is best for the individual and with the individual.

We are committed to supporting individuals to re-imagine their lives and to rethink what is possible. We support individuals to hold a dream for their lives and make it known to others, so that it can happen.

We are committed to helping each other and helping each individual to develop their voice. We believe that everyone has a voice by indicating their preferences and their will. We assist the individual to find or develop their voice and, in so doing, begin to shape and direct their lives.

My daughter, Jessica, isn't able to speak very well. She has very few words. However, through time, we've been able to figure out and have other people figure out what it is that she likes, what she wants and what she wants to do, and we've been very successful in supporting her to be out in the community, to volunteer, to have her presence known and to make a difference in the lives of others. That wouldn't have happened without the facilitator, through time, figuring it all out with her support circle and others.

We are committed to doing whatever it takes for the individuals to become contributing members of their community and to take up their adult roles, and we are committed to building capacity. Our primary role is to help individuals and their families figure out what is the most pressing need at any one time and what their next step is in addressing that need.

We help families foster resilience and build capacity. We believe that personal transformation and change involve families, not just individuals.

Ms. Judith McGill: We believe there are significant concerns facing families at this time, not only ours but those whom we connect with and network with across the province. One is the response to crisis. Families are put under immense strain, emotionally and financially, to care for their sons and daughters, and these same families are often in the position of caring for frail parents as well. These strains increase the incidence of poor health among parents. Parental illness compounds the complexity of the caregiving situation.

Family respite services are inadequate in relation to the needs of families. Providing crisis respite beds cannot be the primary response to individuals and their families. When it's the only response, it is likely to only exacerbate the situation.

Being part of a family group helps to avert crisis. We have seven family groups across the province who come together on a regular monthly basis to have each other's back, to be there for one another over time and to provide mutual support. The intentionality matters. It offers emotional support as well as tangible help by expanding awareness of local resources and through collective problem-solving and co-inspiring one another. Having access to planning and facilitation support also aids significantly to prevent family crisis. Families need to be consulted about how crisis is portrayed, imagined and resolved. We cannot expect regional crisis protocols to go anywhere far enough to reach what families need in order to understand how to get through a family crisis.

0910

Planning and facilitation must be linked to be effective. We can no longer have planning be the focus and facilitation be put to the side. Independent facilitation is equally about facilitation as it is about planning. They cannot be delinked. They are integral to good support.

Facilitators help create custom-fit supports, negotiate the service system and understand how to use resources that are allocated. When people are getting so few resources, there is a real need for facilitation support to make the most of what people have.

Another concern is that relationships, as Maureen has said, really are the only safeguard, and people need others in their life to assist with supported decision-making. We have for far too long accepted the best-interests argument for people; we've accepted guardianship and substitute decision-making. We now, with the UN declaration, understand that supported decision-making is the way that we all make decisions, and so we need others to be around us, to hear the voices of the most vulnerable people in our culture at this time and to help strengthen that voice and help people have some say-so and practice having some say-so in their lives. We call that supported decision-making. We want to know what this province is going to do to ensure and presume capacity when it comes to decision-making.

The other concern is that individualized residential options offer security over the long term. Families for a Secure Future knows this to be true. We've helped people design and custom fit individualized residential options that are good not only for the family having a sustainable model going forward but the individual actually becoming part of their community and being truly seen.

We need broader access to Passport funding and more investment in individualized options. We need core funding for independent facilitation and planning organizations across the province.

We want to end with this and try to explain to the committee how important it is and has been over the last 17 years in the province to have some examples of good practice in the province about what it takes to be alongside an individual within the context of their family to actually have both planning and facilitation support. We have substantive concerns, as you'll see in the report, about the need for this to be funded across the province.

As an organization, for the first eight years, from 2000, we had solid funding through our own efforts at fundraising. We suddenly lost our funding and have found since then that fee-for-service as a model, which we had to adopt in 2009, is a model that isn't sustainable organizationally for a number of reasons, which you can read in the report. It's not a reliable enough source of income to lead an organization, to maintain and retain staff, and we ask that the province of Ontario, through MCSS, take seriously the need for this kind of support that's indicated in the social inclusion act to help organizations become able to offer this across the board without the burden of cost to families.

I think we'll end it at that. You can read in the report what we suggest in terms of that. We'll take questions.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation this morning. We have about two minutes for each party to ask questions. Mrs. Elliott.

Mrs. Christine Elliott: Thank you, Chair. Judith and Maureen, thank you very much for being here today and thank you for the great work that you're doing assisting families across the province.

I do have three quick questions for you. The first one is—and this is something that came up during the context of the Bill 77 discussions a few years ago about when the planning function should be started. It was suggested that you should do the planning with the individuals in the family before you do anything else, because a lot of people might choose independent funding or individualized funding, but they just don't know how to go about it. Has that been your experience and is that what you would recommend?

Ms. Judith McGill: Certainly, you don't know what you don't know, and families haven't been offered this before. We believe that it should be a real offer when people start considering their adult roles, which would be around 16, way before they leave high school, so that they can leave high school with confidence that they're going to have a life.

Mrs. Christine Elliott: You also talk about how important facilitation is as part of the whole process. We've heard a lot of people say that they would like to have the assistance of system navigators. Would you equate the two in terms of the general roles that they would be doing?

Ms. Judith McGill: We believe that system navigation belongs with independent facilitation, where it's unencumbered, with no conflict of interest, and that system navigation, sorting things through, sourcing resources is part of the facilitation role.

Ms. Maureen Emmons: But I don't feel that that's the major role. The major role is having someone standing by you, and when you're trying to figure things out for your son or daughter and with our sons or daughters, that they get to make those decisions, and if it doesn't work, we'll figure something else out. You can't just have a plan and you can't just know where to go. You need someone to help with hiring the right support workers and training the right support workers, who will stay then and do what it is that we need to do. That's one of the things that our facilitators do.

Mrs. Christine Elliott: Okay. The final one has to do with the concept of supported decision-making. We've heard a little bit about that and that it is important. Can you tell us how it actually works on the ground, how you support someone to be able to make their own decisions in this context?

Ms. Judith McGill: Well, we have a lot of our families supported through gathering people around intentionally and helping them start to discern how to understand the individual more comprehensively: how to understand when they're communicating "yes" reasonably, "no" reasonably; how they communicate their will, their preferences. We do that sometimes in a support circle, where people gather regularly and come to know his or her story and what his vision of the future is. Supported decision-making means beginning with the individual and taking direction from him as much as possible, helping somebody have some say-so over their lives and honouring that to the extent possible—so, being collaborative, having other people speak to the issue, but trying to help the individual more and more have control over their lives by expressing their desires.

Mrs. Christine Elliott: Thank you very much.

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

Miss Monique Taylor: Good morning. Thanks so much for your presentation. Thank you for being here today. I'm sorry, where is it that you come from? Is it the Whitby-Oshawa area?

Ms. Judith McGill: We're provincial, and we have six family groups in Guelph, Wellington, in Brampton and in Pickering, Ajax, Whitby—

Ms. Maureen Emmons: And Oshawa.

Ms. Judith McGill: Oshawa, Durham region.

Miss Monique Taylor: So just in different pockets across the province. And you talked about a funding model and that you used to receive funding. How much was that funding? How much does it cost?

Ms. Maureen Emmons: When we had our funding from a private source, we were up to almost $100,000 a year from a private source.

Miss Monique Taylor: To run all six models?

Ms. Maureen Emmons: Yes.

Miss Monique Taylor: And currently you're doing a fee-for-service, which is a cost of how much?

Ms. Judith McGill: We have a mixed funding base. We have some raised dollars to keep the office and my position available, at a minimum, and then support the family groups on a monthly basis. We do some fundraising, but the rest is fee-for-service.

Miss Monique Taylor: And I'm just curious on what your thoughts on the DSO are?

Ms. Judith McGill: Do you want me to answer that?

Ms. Maureen Emmons: Yes.

Miss Monique Taylor: Be honest.

0920

Ms. Judith McGill: I think when Christine asked the question about who should be doing systems navigation, I'm not certain that it belongs there. They're a resource, but I think that the systems navigation belongs outside of that. In the Bill 77 hearings, we talked about the separation of some of the functions, and we feel that the DSO has now doubled up on many of the functions, where "an assessor is a systems navigator and is a this," and we're concerned about the redundancies, the expense of the DSO. All the things that contribute to making it a one-stop place make it more difficult for families to actually have some autonomy.

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

Miss Monique Taylor: Thank you very much.

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

Ms. Mitzie Hunter: I just have one question, and then I'll pass it over to my colleague Mr. Balkissoon. I wondered about what you were seeing in terms of any changes in adults with developmental disabilities and what services they're asking for.

Ms. Judith McGill: One of the problems that we have with the DSO is that we feel that there's a bias in what happens when they go into an assessment, and that is that many, many families would say that they would prefer independent facilitation. Our families are finding that it's not being offered right at the point of contact during the assessment, during the intake, during that initial part of the assessment. Families say that they're not being asked if they would like individualized residential options, and we know that those two things are available and should be spoken to and addressed—

Interruption.

Ms. Judith McGill: —our 20 minutes is up, I guess—and yet it hasn't been offered. So we're concerned about there being an inherent bias. In families whose sons and daughters have led inclusive lives until they leave school, they get into the process and find that the options that they're being offered are agency-based options, so they don't have the support or even think that it's an option to think outside of the box. That, for us, is a real problem.

The Chair (Mrs. Laura Albanese): As you heard, the time has expired, but if you need to ask a question—

Mr. Bas Balkissoon: No, it's okay.

The Chair (Mrs. Laura Albanese): Okay.

Thank you very much, then, for your presentation this morning and for your recommendations. The committee will keep those in due consideration. Thank you so much.

Ms. Maureen Emmons: Thank you.

Ms. Judith McGill: Thank you.

ADULT PROTECTIVE SERVICE ASSOCIATION OF ONTARIO

The Chair (Mrs. Laura Albanese): We have a slight change in our agenda. We will hear from presenter number three before we hear from number two, because they're setting up for a PowerPoint presentation. Therefore, we call up the Adult Protective Service Association of Ontario, APSAO.

Ms. Dasha Choitova: Hi. How are you today?

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

Ms. Dasha Choitova: I'm just going to grab a glass of water first, before we start.

The Chair (Mrs. Laura Albanese): Sure. Please go ahead. Grab a glass of water. Make yourself comfortable. You may start whenever you're ready. The presentation is 20 minutes at the longest, and if it's any shorter, that will give us time for questions.

Ms. Dasha Choitova: Excellent; excellent. First I want to start off by saying thank you for having us here. It's quite a treat to be in front of you and to let you know a little bit about who the adult protective service workers are, what we do and some of the pressures that we're facing right now.

To tell you a little bit about us: The program started in Hamilton in 1974, and the goal was to support adults with developmental disabilities who live independently in the community and who have no family or other significant supports.

Over the last 40 years, adult protective services have provided support and guidance to these adults who live independently. We advocate on behalf of the people with developmental disabilities to help them manage their day-to-day lives and their personal issues.

There are approximately 165 adult protective service workers across the province, and we serve over 6,000 people. Some APSW programs are funded by ministry-run organizations, while others are funded as transfer payments to agencies. Some examples are given in my written report.

To tell you a little bit about the client, the adult protective service workers work directly to support adults with a developmental disability who are living on their own in the community. The workers assist them in strengthening their capacity to manage and acquire the skills necessary for daily living, and to help them enhance their community supports, as well as access generic-based supports and government-funded supports and services. In many cases, our clients also have co-existing mental health disorders, although they're not always diagnosed formally. These individuals are the most vulnerable in the community.

A perfect example that comes to mind is door-to-door salespeople. They're friendly, they're engaging, but they often force our clients to sign on the dotted line, and without knowing it, the clients are taken advantage of. This is where they need the APSW's support and plain-language interpretation.

To access APSW programs, an individual must contact and register with their local DSO, Developmental Services Ontario.

To tell you about the worker and what we actually do, the adult protective service worker facilitates an individual's involvement primarily with generic community supports whenever possible, but also with government-funded programs such as ODSP, the Ontario Disability Support Program, and legal aid, just to name two. The adult protective service worker assists the person to develop a network of supports that will foster greater personal independence and social inclusion. With the consent and direction of the capable adult who has a developmental disability, the worker will provide assistance with planning and accessing these supports based upon individual strengths, needs and goals.

The relationship between the adult protective service worker and the client is strictly voluntary, which means that the person is not compelled to accept the services of the adult protective service worker and is not mandated to take their advice. The adult protective service worker is expected to provide the services within their mandate to people with a developmental disability who seek their help. The adult protective service worker does not have guardianship or legal custodial authority over the individuals they support.

I'll tell you about some of the limitations that exist within the role of the adult protective service worker. Participation in the APSW program is strictly voluntary. The adult protective service worker cannot compel an unwilling or disinterested individual to accept the services of the program from the APSW. The adult protective service worker does not have a mandate to provide or compel compliance to treatment or other recommended support services. While the APSW can assist people in making healthy and safe decisions, ultimately the final decision belongs to the adult who has a developmental disability and who is capable of making such decisions.

Situations that require direct observation of an individual after medical treatment or care, assistance with medical treatment, enforced treatment or guidelines or orders, or other more intrusive or intensive means fall beyond the scope of what the APSW is mandated to provide. The adult protective service worker does not serve in a guardianship or power-of-attorney capacity for the individuals they support and does not make personal care or property decisions on the clients' behalf. In addition, the adult protective service worker cannot assume legal responsibility for the adult or supervise their children.

There are a number of issues that the APSW and the individuals we support face that are unique to the program. Vast regional differences and inter-ministerial co-operation tend to be the running themes in presenting critical issues.

The first point I'd like to talk about is the transition from education to employment. As youth prepare to leave the school system, they often want to pursue paid employment but are often not prepared to handle the day-to-day routines of the workplace. Their inability to successfully retain employment results in a lack of self-esteem and increased social isolation. As the ODSP becomes their only income and financial source, it places these individuals well below the poverty line.

There is a need for more specialized pre-employment training and education, and on-the-job training.

0930

The APS clients are concrete; they require first-hand experience in the culture of the workplace. Many young people simply do not know how to work. Their expectations of the workplace are unrealistic. Skills such as attendance, hygiene, peer relations and supervisory relationships are simply not there. The ODSP Employment Supports program, as it is now, is unsuccessful in preparing these individuals for the workplace. In the experience of the APSWs, there is also little incentive for employers to hire adults with developmental disabilities.

Another point I'd like to talk about is around the alleged, suspected and witnessed abuse-reporting in adult protective services. As you may know, quality assurance measures were implemented in 2011 and are part of the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008. It talks about the rules that agencies and Developmental Services Ontario, or application entities, must follow.

Quality assurance measures are rules that help the agencies and local DSOs provide high quality of service and supports, and meet set standards. Organizations funded by the Ministry of Community and Social Services that provide services and supports to people with developmental disabilities are required to be in compliance with quality assurance measures.

The adult protective service program establishes a voluntary working relationship based upon mutual accountability between the adult who has a developmental disability and the adult protective service worker. Adults who have a developmental disability are active participants in all steps of the working relationship.

This relationship becomes strained when quality assurance measures mandating the reporting of alleged, suspected or witnessed abuse are applied. As adults who live independently in the community, the APSW clients have the right to self-determination, a right that is compromised when their adult protective service worker is obligated to report to the police without the client's consent. The rapport is deteriorated as trust between the client and the worker diminishes. In many cases, the adult protective service worker may be the only support person in that client's life.

In the experiences of the APSWs, when situations of abuse are reported to the police, not all police divisions across the province are successful at addressing the issue. Many times, an individual is contacted, the alleged abuser is interviewed and the case is then closed. The APSW client many times has no other choice but to return to the abusive situation, where the abuse then escalates. As the rapport with the adult protective service worker has been compromised, the client is likely to avoid the worker and less likely to report anything ever again.

Another issue is around inter-ministerial co-operation. Often, health care professionals—a doctor, a physician, a nurse or a personal support worker through a community care access centre—are the first people who will observe physical abuse in a client. When a situation of physical abuse is observed by the physician who is treating an individual with a developmental disability who lives independently in the community, that physician is not mandated to contact the police.

While the abuse-reporting mandate is quite relevant and applies well to residential and day programs where the clients may not have the capacity or voice to speak out about experiencing abuse, the APSW clients' right to self-determination is eroded by the workers' mandate to report.

I'd also like to talk about aging in the APSW population. APS clients face another set of unique challenges as they begin to age. For most clients, aging is accelerated by a number of factors, from poor nutrition that results from living below the poverty line and lack of a healthy lifestyle to lifelong use of medications that are prescribed for mental health or physical health issues. These clients deteriorate and age a lot faster. As workers, a situation we often encounter is a mature adult of 50 to 60 years of age whose health is rapidly declining and who is in need of enhanced supports and services. These clients do not qualify for generic seniors' supports, as they do not meet the age requirement.

The APS aging clients' health is medically complex, and the requirements that are placed upon them by their physicians and health care professionals in many cases are elaborate and need support to follow through with. While local CCACs, community care access centres, may offer personal support worker assistance that becomes instrumental in the clients' lives, these supports are limited and in many cases fall short. Our rapidly aging clients require assistance with daily upkeep—personal care, activities of daily living, medication reminders and assistance. While their physical abilities decline, the APSW clients also heavily rely on the systems that are around them, and these systems become strained as a result of these complex needs.

As workers, we often hear, "He shouldn't be living on his own. He needs to go somewhere else." As workers, we often say, "There's nowhere for him to go." Wait-lists for group homes and other residential services will in most cases outlive the aging APSW client. While some regions offer creative solutions like youth wards in nursing homes, those spaces are very limited and they don't exist province-wide. What happens is that the APSW client is left to deteriorate on their own, with limited supports, or, worse than that, placed inappropriately into a long-term-care facility.

In closing, I'd like to say that adult protective service workers and their clients face a unique set of challenges as the program allows unique supports to these individuals so that they can remain independent in the community. The underlying intent of the program of the adult protective service worker is to work directly alongside individuals who have a developmental disability to develop a trusting and respectful working relationship in order for them to understand the person's strengths, needs and goals. This partnership needs to encourage active participation and self-determination on the part of the person who has a developmental disability in setting and working towards these goals.

Across the province, the DSOs and networks of specialized care are working together and beginning to work well to support these clients in accessing services when in crisis. The involvement of the adult protective service worker plays an advocacy role of speaking on behalf of the individual in their relationships with the community and the systems around them.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for appearing before our committee this morning. We do have about a minute and a half for each party to make comments or a quick question. I will start with Ms. Taylor.

Miss Monique Taylor: Thank you for appearing before us today. Thank you for the work that you do. I have to say it's the first I've heard of it, but I'm learning every single day as I sit at this table.

I believe you said there were a number of clients that—

Ms. Dasha Choitova: Over 6,000 across the province.

Miss Monique Taylor: So in a day, how many clients would an individual worker serve?

Ms. Dasha Choitova: In a day or as a caseload?

Miss Monique Taylor: As a caseload.

Ms. Dasha Choitova: As a caseload, again, depending on what the needs of the individual are, it can be from 14 to 28 clients in a caseload. When we're going into, for example, the northern chapter, which is quite vast, the caseload increases because there are fewer workers and a greater number of clients. The 14 to 28, I would say, is in the Toronto region, because I'm from Toronto and I can speak quite well about that, but I know that, for example, in rural Ontario, a worker can juggle 40 clients.

Miss Monique Taylor: So—

The Chair (Mrs. Laura Albanese): Thank you. Sorry; I can't. Ms. Hunter.

Miss Monique Taylor: Sure.

Ms. Mitzie Hunter: Just in terms of the inter-ministerial co-operation, can you talk about what your workers are seeing that's needed there and where greater supports are required?

0940

Ms. Dasha Choitova: There are a number of gaps that we're noticing. Some of the ones that I presented were around the transition from the Ministry of Children and Youth Services to the Ministry of Community and Social Services, for example, around preparedness of the client. In plain language, I can say that when a client becomes an adult by the ministry's standards, they're not prepared. ODSP is not in place, assessments are not in place, IDs are not there and things like preparation for employment are not there.

Other inter-ministerial co-operation themes around that would be, again, in regard to abuse reporting. A physician is not mandated to report, but we are. That doesn't make sense to me, and that's just to name a few.

Ms. Mitzie Hunter: Okay.

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

Ms. Sylvia Jones: Yes, thank you. You are new to us, because I am not familiar with your organization. I know we have a brief amount of time. I wonder if you could provide to the committee an overview of where your clients are and where you're operating within Ontario, because honestly, in Dufferin–Caledon? Never heard of you. I don't know if it's the case that there are no APSWs in my community or you're operating under the radar; something's going on.

Ms. Dasha Choitova: We're there.

Ms. Sylvia Jones: Okay.

Ms. Dasha Choitova: Oh, we're there. Part of the reason—sorry; I hope I'm not interrupting. Part of the reason that we're here is so that you guys do know about us.

Ms. Sylvia Jones: Okay. If you could provide to us where you are and specifically what you do—you've raised some of the stuff about how you don't attend doctors' appointments and what you don't do; I'd like to know what you do do. Would these be primarily clients who are SIL—supported independent living?

Ms. Dasha Choitova: Yes.

Ms. Sylvia Jones: Okay. So, if you could provide that to us—

Ms. Dasha Choitova: Absolutely.

Ms. Sylvia Jones: I'd appreciate it. Thanks so much.

Ms. Dasha Choitova: Not a problem. Again, this is why I'm really grateful to be here on behalf of the association, so that you are aware of our presence. We are everywhere. We are in rural Ontario and we are in urban centres. We work in the community, and we work directly with the clients in terms of assisting the clients to achieve their goals.

A goal may be, "I want to keep my housing," and we're there to help them plan to take the steps to support the client, so that the client can achieve that goal. A goal may be, "I want to go swimming. I want to be able to attend my doctor's appointment, because I live in rural Ontario and I may need to fly to my doctor's appointment."

We work on reserves. There are a lot of interesting issues that come out of there, of course. Our main goal, as we state in the presentation, is to support and encourage the client to be independent, so that they can stay living in the community and they don't become SIL—supported independent living. These are clients who have a developmental disability but manage to live in the community because of APSW supports.

I hope that answers your question. I can speak volumes on this.

Ms. Sylvia Jones: Thank you.

The Chair (Mrs. Laura Albanese): Yes, thank you. The time is almost expired. I just wanted to specify: These are adults with developmental disabilities who live in the community without a family or a support network close by. Is that right?

Ms. Dasha Choitova: Yes, that's right. Some may very well have families, but the families may not be in a supportive role.

The Chair (Mrs. Laura Albanese): But they're not close. Okay.

Ms. Dasha Choitova: As you know, family relationships may not always be perfect. Families tend to often be burned out by caring for the child as the child becomes the adult. These are adults who want to be independent and who are very proud of being independent and living in the community, just as you and I are.

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

Ms. Dasha Choitova: Thanks so much for having us.

The Chair (Mrs. Laura Albanese): Please make sure to send that information, perhaps through the Clerk.

Ms. Dasha Choitova: Absolutely.

WOODVIEW MENTAL HEALTH AND AUTISM SERVICES

The Chair (Mrs. Laura Albanese): We'll now welcome the Woodview children's centre. Good morning.

Ms. Cindy I'Anson: Morning.

Ms. Robin Brennan: Good morning.

The Chair (Mrs. Laura Albanese): We understand that you have a PowerPoint presentation for us.

Ms. Cindy I'Anson: We do. We're hoping it's going to work.

The Chair (Mrs. Laura Albanese): Yes, of course. When technology is involved, it's always an issue.

Ms. Cindy I'Anson: Yes.

Thank you so much for having us. "Woodview children's centre" is a bit of a misnomer. We actually refer to ourselves as Woodview Mental Health and Autism Services. My name is Cindy I'Anson. I'm the executive director. Robin Brennan is with me, and she is our director of autism services.

We're going to talk today about the issue of eligibility for adults with autism spectrum disorder and the need for lifelong supports. We have a very brief PowerPoint, and then we have four brief video clips of some of the people we support that will give you a really good snapshot of what we're talking about.

Ms. Robin Brennan: I just wanted to start by explaining very briefly about our services. Woodview Mental Health and Autism Services serves over 2,000 children, youth and adults in the communities of Hamilton, Halton and Brant. Woodview, along with Kerry's Place, is one of the few specialized agencies that offers ASD-specific programs for adults in the province and across Canada. Of the 2,000 children, youth and adults we serve within our agency, over 300 of those are served yearly with ASD—including ABA, IBI, respite camps, transition at high school and our varied adult programs.

Woodview's autism program in Hamilton is very unique in the province. It was specifically designed with Dr. Peter Szatmari and originally funded for higher-functioning adults. It's a very well-regarded and highly sought-after program that once was able to serve people across the province as a provincial resource, and then only the Hamilton, Niagara, Brant regions, and now we're only able to serve people in Hamilton.

We regularly get inquiries from across the province and Canada about wanting to duplicate our model. We offer a range of services that is a seamless, cost-effective, community-based alternative for individuals and families.

Specifically, I'm now going to focus on our Hamilton autism programs because that's where most of our adult programs are based. We provide comprehensive and consistent specialized ASD services and supports across the lifespan—so beginning at age seven and through to adulthood, including the key transition times of transitioning to high school and transitioning to adulthood. In Hamilton specifically, we provide services to 67 adults and 70 children a year.

We're a community within the community. We have a unique system of support, which includes developing extensive peer networks, which we have found greatly decreases the incidence of mental health concerns over time, including depression.

We focus on skill-building and use ABA-based ASD supports extensively. We focus on the core deficit areas in ASD: social life skills, communication strategies and supports, executive functioning supports, problem-solving and emotional regulation.

Our ultimate goal is, and has always been, to prepare individuals for life as adults and to be able to be as independent as possible, which allows individuals to reach their potential, as should be every person's right in our great country.

Ms. Cindy I'Anson: I'm going to talk briefly about the need for lifelong supports and the issue of eligibility.

ASD, autism spectrum disorder, is a lifelong neurodevelopmental disability that does not end at the age of 18. Extensive supports are available during childhood, and that includes IBI, which is intensive behavioural intervention, and ABA, which is applied behavioural analysis. They also have access to speech and language services, respite and Special Services at Home.

It should be noted that in Halton region alone, which is one of the three areas that we serve, there is a wait-list for ABA services of over 300 children under the age of nine. What will happen to these children when they reach adulthood?

Children used to be able to seamlessly transition into our adult services—and that's certainly the strength of what we provide: a lifelong service delivery model. Now they are often ineligible for adult services, and it's because of their IQ. They're high-functioning adults who have an IQ over 70, which I'm sure you've heard by now.

Eligibility is determined at a time when extensive supports are in place, which is problematic. Mental health and behavioural concerns escalate when supports are removed. An adult at 25 with no supports presents significantly different than a youth at 18 with supports in place.

0950

The regulation in the act has criteria that is too narrow and discriminates against people with ASD based solely on their IQ. The severity of core communication, social and executive functioning deficits, which are inherent in ASD, as well as adaptive skills deficits, do not carry the same weight as IQ in determining eligibility.

Measurement tools do not reflect the unique profile of people with ASD, and an individual's functioning in the real world cannot be predicted by their performance on pen-and-paper tests in a controlled environment.

We're going to show you four very short video clips of individuals that we support that have either just transitioned into adulthood or have been with us for a while. Hopefully this works.

Video presentation.

Ms. Robin Brennan: I'm just going to pause after each one.

The Chair (Mrs. Laura Albanese): We can't really hear it. Is the volume of your computer at max?

Ms. Robin Brennan: We did bring speakers because we weren't sure if—we might be able to put that in, if we've got some time.

I'll just speak briefly about this individual before, and maybe they can try to put the speakers in.

This is Ryan; Ryan is 20. He recently went through, at age 18, the eligibility criteria process through the DSO. He met two out of the three criteria required, but not IQ. He's presented with a full-scale IQ of 85, so above 70. He presented with a very scattered profile. His subtest ranged from below the first percentile to the 63rd percentile, which is very typical in autism.

The Chair (Mrs. Laura Albanese): Could you place the microphone close to your—the one that is in the back?

Ms. Robin Brennan: Sorry.

Miss Monique Taylor: Technology.

Ms. Robin Brennan: Yes.

So Ryan presents with quite a scattered profile. He ranges from the first percentile to the 63rd percentile. It's interesting to note that some of the higher scores that he got were in things like spelling, which really don't relate to successful functioning in everyday life.

It's also interesting to note with Ryan that during his two full childhood assessments that were done by different psychologists, they both strongly cautioned—due to such variation between his verbal and non-verbal domains—that his overall level of functioning needed to be interpreted with great caution. Unfortunately, when the assessment was done at age 18 through the DSO, those kinds of factors were not taken into account. All that was looked at was the final number of 85, and he was deemed ineligible.

Now his family has decided that they can't leave him without supports, so they have decided that they will pay a fee to keep him in a weekly social and life skills group so he can continue to develop and learn skills.

Video presentation.

Ms. Robin Brennan: So this is Michael. Michael severely struggles with social interaction, communication, and has extensive sensory needs. He has had significant involvement with the law. Michael is 39, so he has been grandfathered from the previous system. It's very interesting to note that Michael's IQ is 90, so he is considered to have an average IQ. If he was to go through the system today, he would not be eligible for developmental services.

Video presentation.

Ms. Robin Brennan: So that was John. John is 44 years old. He struggles with regulating his emotions. You can see him starting to get a bit upset towards the end. He perseverates on topics which upset him. His father is in a nursing home and his mother passed away last year. John's IQ is considered to be near average, so he's in the high 80s. Again, John has been grandfathered, but today he wouldn't be eligible, so it is a question of where would he be.

Video presentation.

Ms. Robin Brennan: Okay, and that's Katie. This is our last clip. As you can see, Katie has really nice social skills. She keeps a record of her schedule and checks it in her memory. She has excellent life skills. Katie is in her early 20s and was one of the first individuals in our program who went through the eligibility procedure with the DSO. Katie's IQ is under 70, so she was deemed eligible.

1000

I think it's really important for you to see the faces, that a number on these IQ tests does not reflect accurately how individuals with ASD function and it doesn't reflect accurately the things that they struggle with and the challenges they struggle with every day.

Ms. Cindy I'Anson: Just in closing, we'd like to say that adults with ASD who used to be eligible for funded services are now not meeting eligibility criteria for the most part. Many parents are self-selecting out of the process, which makes the need seem less, and that is because they feel that there is really no point in going through what is quite an extensive process, because they keep hearing that people are being deemed ineligible.

We're saying, do the extensive supports needs really disappear at age 18? We think not. We have some good examples that they don't. Autism is clearly a lifelong neurodevelopmental disability, and individuals with ASD need services and supports throughout their lifespan.

What can be done? We think there needs to be serious consideration given to addressing the eligibility criteria under the new act for individuals with ASD. When the new act was proclaimed and the regulation came out, we were quite hopeful. It seemed that it would allow the people we support to be eligible for services, but it hasn't turned out to be that way.

Thank you.

The Chair (Mrs. Laura Albanese): And we want to thank you for your presentation to us this morning. Unfortunately, the time doesn't allow for any questions, but the presentation was quite insightful and thorough. Should we have any other questions, we will make sure to get them to you. But thank you very much.

Ms. Robin Brennan: Thank you.

Ms. Cindy I'Anson: Thank you.

OPPORTUNITIES MISSISSAUGA FOR 21 PLUS

The Chair (Mrs. Laura Albanese): I'll now call on Opportunities Mississauga for 21 plus. Please take a seat. You'll have up to 20 minutes for your presentation. Should it be any shorter than that, we'll allow questions and comments.

Mr. Ross MacHattie: Thank you. Good morning, ladies and gentlemen. Thank you very much for the opportunity to address the Select Committee on Developmental Services.

Ron Pruessen and myself, Ross MacHattie, are first and foremost parents. We're also active board members of Opportunities Mississauga for 21 plus, an organization representing 180 families in Mississauga. Each of those families has an adult or a young adult with developmental disabilities.

Ron has acted in many roles for our organization, including past chair, and he sits on many different committees representing us. As a matter of fact, you probably recognize Ron from yesterday, when he was presenting on the Housing Study Group for us. I, myself, sit on the DSO for the Central West Region's advisory committee.

We're pleased to be able to present you some written materials that provide you our essential mandate, some background material and a priority program for us at the moment called Step by Step. This is a creative program that's able to offer services to a dozen families for the cost associated normally with just four families.

Generally speaking, we are the people that you have been hearing about over the last several months of testimony from the agencies and the ministry. We are the people living with the problems 24/7, year after year, decade after decade. We are the ones feeling the frustration, experiencing the challenges and feeling the despair that's actually endangering mental and physical health for us.

Mr. Ronald Pruessen: I guess one of the things we wanted to point out is that although we are those people that Ross was mentioning, we are not people asking you, the government, to solve all of our problems, any more than we have asked you to solve those problems over the past 20 or 30 or 40 years. We are parents from families with a powerful sense of responsibility that we have demonstrated over 20, 30 and 40 years in the past, and we want to be involved in finding and developing solutions for the critical problems confronting Ontario adults with developmental disabilities. We do not, for a moment, want to turn over the keys to our children's lives to you. We want to work in and with our communities and our children to develop solutions.

We also want and need to work with you, the government. Government has responsibilities in modern life: health care and education, road construction and public transportation—an endless list, as you all know perfectly well. Government uses tax revenues to provide vital social services, public goods, especially, it seems to us, for those who are most vulnerable in our society: at-risk children, seniors and those with disabilities. It's on the latter front, I think, that the government has fallen down so badly in recent times with respect to those with developmental disabilities. Those of you serving on this committee deserve to be applauded for recognizing the record of tragic failure here and for devoting your recent efforts to developing recommendations designed to produce what you have called a comprehensive developmental services strategy.

For our part as concerned parents and leaders of a large grassroots family group, we want to share with you our insights and recommendations. These emerge, by the way, from many years of round-the-clock, hands-on experience, far more than might be the case for many of those who have testified before you representing agencies and various public services. If you do even a minimal mathematic exercise for our particular group, for instance: We have 180 families. Even if you imagine just one parent in each of those families and take an average length of time in which we have worked with our children and on behalf of our children of 30 years—and in many cases, it's more than 30 years—you have, in our organization alone, in one community alone, more than 5,000 years of experience that we bring to the table. That's an important contribution available to you at this point.

Mr. Ross MacHattie: Our sense of priorities is embedded in this report, in the package that you have before you. The Step by Step program is, of course, not our only creative idea, but it is one concrete example that is able to express the principles and approaches that we hope you will be able to embody in your report.

Mr. Ronald Pruessen: A bit of background on this Step by Step proposal: We designed it originally in mind to create what we call a transitional respite and residential program as a creative and cost-effective response to the long-neglected needs of adults with developmental disabilities and their families. It was presented to the Ministry of Community and Social Services in 2011 with the endorsement of all of Mississauga's MPPs. As many of you all know, one of those MPPs is now Minister of Finance. I don't know why I thought to mention that.

We were not even given the courtesy of a meeting with the minister to discuss the proposal, much less the funding needed to make the initiative a reality. This is an example of the past experience that has generated the kind of frustration and despair and alienation and anger that you have been hearing about over the past months. Funded or not, however, we remain convinced that the Step by Step proposal would provide one example of the ways in which valuable services can be provided. We know, from many conversations around the province, that it is the kind of proposal that would be greeted enthusiastically by many other communities.

Mr. Ross MacHattie: One of the key principles of this proposal is the concept of partnership. We believe that this creative, transitional, respite residential program embodies the co-operation that's required between government, between agencies, between family-run groups, between the whole community at large.

1010

The Step by Step initiative starts off as a partnership between a parent community group and a seasoned service provider, but it can then extend into the community through faith-based organizations, service clubs, local businesses. The entire community is going to become part of the solution with this approach.

We certainly do not expect government to be able to do this on their own. It's not reasonable; it's not practical. It's really key to understand that all of these other members of our community have a stake in the game here. They have interests. They have ideas. They have resources. We need to be able to leverage that to make sure their interests help enrich these programs we are trying to launch.

Mr. Ronald Pruessen: The community component of this partnership principle is especially important to us. There are social connection and relationship opportunities within our communities that can dramatically enrich the quality of life of adults with developmental disabilities. These opportunities have been inadequately tapped to date. Families can play a huge role in changing this, since they live and work in their communities, and we believe that they are anxious to do so if baseline supports for residential programs and opportunities are provided by government and agencies.

Those baseline supports are crucial. Our emphasis on partnerships and community is not intended to give the provincial government an excuse to say, "Ah, well. This crisis will be solved by the families who have been doing the heavy lifting for 12,000 people on the residential waiting lists for the past decades."

Families want to play a vital role in solving the crisis, but adequate government funding will be needed to enable those family efforts to fuel the creative forces and energies that are waiting to be utilized more effectively in communities across the province.

With this in mind, we urge you to recommend that the provincial government make a dramatic and immediate start on what will inevitably have to be a long-term effort to solve a long-term problem. As much as we might wish for an overnight solution, no one seriously expects that to happen. But a beginning must be made to prove sincerity and determination.

You heard about the Housing Study Group's action agenda yesterday, for instance—I remember it—and the kind of recommendation contained in that about immediate and ongoing funding increases seems to us, as a family group on the front lines, extremely important.

From our point of view, a minimum of $10 million a year of new and then ongoing funding for residential supports and initiatives in each of the next five to 10 years would make a powerful difference in the lives of adults with developmental disabilities and their families if those funds went into genuine front-line services, as opposed to process investments involving revised forms of administration.

Mr. Ross MacHattie: This committee can make a powerful contribution by taking a leadership role and helping to make up for the years of provincial neglect that have been demonstrated. We hope that your recommendations will be able to incorporate the views that we are trying to emphasize in today's presentation, emphasizing the vital contributions of partnerships, of communities, of parent organizations, of individual parents.

As Ron said, new government investment is needed now, but it's also needed for the long term, to ensure that any great strides forward this committee is able to start are able to be sustained to provide the meaningful response that we're after.

You have an opportunity to lay the groundwork for a new era, where Ontarians can be proud, as opposed to embarrassed, about the way we've treated the most vulnerable people in our society. As a large, grassroots organization, we urge you to think boldly and caringly about the leadership role that you have to play. We hope that your recommendations will be informed by our experience and our willingness to work with you and other partners.

We thank you very much for your attention to this extraordinarily serious issue. We welcome any questions or comments you might have at this time.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. We will have about two minutes per each party for questions. Ms. Wong.

Ms. Soo Wong: Thank you very much for your presentation. I'm particularly interested to know—because we have heard now from a number of families and organizations before this committee—in terms of best practices across Canada and beyond, looking at your Step by Step model, do you consider your program to be a best practice within this sector?

Mr. Ronald Pruessen: At this point, we would like it to be a best practice in the sector. I think what you have heard is almost surely enough to suggest that, in Ontario at least, this is hardly a unique province in that respect. In Ontario, at least, we have too few best practices. We wouldn't have these enormous waiting lists, particularly for residential services.

At the moment, we have a very limited menu of practices at all. We believe that this kind of proposal, thoroughly endorsed and welcomed by many other communities across the province, would actually expand the menu of best practices in a very valuable way.

Ms. Mitzie Hunter: How do you suggest that we scale this across Ontario? There are varying needs in urban centres and in rural communities, and we would have that responsibility to have that—

Mr. Ronald Pruessen: I think this particular proposal, actually, would be very adaptable to communities of many different sizes. Keep in mind that we wouldn't for a moment suggest that this is the all-purpose solution to this problem. We think it is an extremely valuable solution for large numbers of people, but lots of other kinds of programs and services are going to be necessary as well.

For us, the transitional component of this would be extremely important for many families who don't want to create a situation where their adult children are being thrown into the deep end of a pool in a crisis situation. This allows a gradual transition that will develop life skills as well as allow the individuals to get used to being away from their families 24/7 around the clock. I think it's very adaptable, but it would need to be part of a long list of alternative models or best practices that could be developed in the province.

Mr. Ross MacHattie: Maybe I can pick up on just a couple of points there. The concept of a menu for us to choose from—as I'm sure you're being very well sensitized to—the issues that people have to deal with are grand in the breadth of the issues, and so there is no one particular solution that's going to help. That's point number one: We need many solutions to be able to draw from to meet the needs around the province.

The other aspect, I think, is that this is a relatively small scale we're talking about, addressing the needs of a dozen families. So it does scale quite nicely across the smaller communities around the province, I believe.

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

Mrs. Christine Elliott: Thank you. This is a really intriguing proposal because it covers off a lot of the issues that we're really grappling with: the issues of respite, the immediate needs of families to provide housing, and also, it really looks at the individual and what their needs are and how they can best be met—as you say, throwing somebody into the deep end and all of a sudden moving them into another location is very stressful. It's stressful for anybody. I really like the concept of that as well as working in partnership with communities, too.

We know that government can't be all things to all people, and I think we really need to look at how we can provide the most service for the most people, working in partnership with communities, with service clubs and so on, and letting them know what the needs are. I think there's a lack of awareness on the part of some people about what the needs are in this sector, so one of the things that we want to do is to be able to help, let people know about that, and I'm sure you're doing your best in your area as well.

Can you tell me if there has been any movement on this particular proposal for Step by Step since it was, I guess, rejected in 2009? Are you moving forward with it independently, are you still in contact with government, or where is the proposal now?

Mr. Ronald Pruessen: First of all, amen to everything you said to begin with.

We continue to have discussions with Christian Horizons, which is the agency partner for us at this point, and we continue to make efforts to communicate with the Central West Region office of the ministry at this point, and with the ministry itself—no positive response, as far as the needed funding is concerned, which is, hardly surprisingly, a continuing source of frustration since we do see it as a valuable opportunity.

1020

We were hoping, for instance, that the $42 million of new funding that went into the MCSS budget last year would provide an envelope of resources for just these kinds of initiatives. It didn't. At this point, virtually nothing was done to meet the critical needs on the residential front, which strikes us as the most powerful need within the province at this point. Some of the easier things have been done; the hardest thing of all remains untouched at this point, and our proposal and the lack of response to it is one example of that.

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

Mr. Ross MacHattie: Our children have taught us great patience, and that's helped us work with this effort of trying to tease out some funding.

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

Miss Monique Taylor: Thank you so much for the work that you're doing and for the initiatives that you're bringing forward, because you've definitely been creative, from what I've been able to try to understand of the concept of how it all works.

My understanding is that it's a transition kind of learning with respite. Is that correct? A respite home for a month and then two months in the family—is that what I'm—

Mr. Ronald Pruessen: Yes, exactly.

Mr. Ross MacHattie: That's precisely it.

Mr. Ronald Pruessen: So four months in the course of a year, but with two months at home each quarter as well. So it's respite, particularly for the family, that would delay, hopefully, the burnout crisis situations that you've all been hearing about that lead to things like abandonment—relinquishment of care cases, to use the formal terminology—but also allow the development of life skills and social experiences, so that at the end of a period of three or four or five years of this, the ways in which the individuals who have been going through that experience would be able to move into other kinds of programs might be very different from what was imagined. I think it's very easy for us to imagine, in some cases, for instance, that the opportunity for a supported independent living arrangement would become obvious; that wouldn't have seemed so at the beginning. Though it's also perfectly clear that in many cases, you'd still be talking about the need to move into a full-time, 24/7 kind of—

Miss Monique Taylor: So it's pretty much in the way of and working towards that scenario.

For the levels of care, what would this model be looking at? Would it be a moderate level of care, or a high critical level of care would be able to be facilitated? What would this model—

Mr. Ronald Pruessen: I think the discussions with Christian Horizons at this point have suggested that the way to begin would be with moderate to low-needs levels of care—moderate, in particular. With low levels of care, supported independent living options already exist. As you've probably heard, in any number of regions, the funds available for supported independent living arrangements go unspent at the end of the year. It's moving up the spectrum, across the spectrum toward higher needs. But to begin with, probably a moderate level of care, but there's no reason at all why this could not be adapted to higher levels of care as it got up and running.

The Chair (Mrs. Laura Albanese): We thank you for presenting to our committee and for enlightening us into your project. We now know more about it. Thank you so much.

Mr. Ross MacHattie: Thank you for the opportunity.

Mr. Ronald Pruessen: And sorry for any confusion that I may have caused with this sense of déjà vu. Your heads must be spinning a little at this point in the process.

Miss Monique Taylor: We've had a few of you who keep reoccurring.

Mr. Ronald Pruessen: I'm not the only one; good to know.

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

Mrs. Christine Elliott: Chair, if I could ask a question: We may already have requested this from research, I just can't recall, but could we find out what has happened to that $42.5 million, $43 million that was allocated in last year's budget to reduce the wait-list for housing—where that stands right now?

The Chair (Mrs. Laura Albanese): I believe we had asked the ministry for a breakdown, but I don't think we've received it yet.

Mrs. Christine Elliott: Thank you.

Mr. Bas Balkissoon: Chair?

The Chair (Mrs. Laura Albanese): Yes, Mr. Balkissoon?

Mr. Bas Balkissoon: I wonder if we could get some background also on the assessment process, when it was started and this 70 figure—what's the scientific research behind it, or is it just an arbitrary number?

Ms. Sylvia Jones: The 70 IQ?

Mr. Bas Balkissoon: Yes.

The Chair (Mrs. Laura Albanese): How it was determined and—

Mr. Bas Balkissoon: How did the ministry arrive at that cut-off?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Soo Wong: And you know what, Madam Chair? Why don't we look across provinces? What are the other provinces' cut-offs in terms of eligibility? Are they using IQ as one of their criteria?

The Chair (Mrs. Laura Albanese): Okay. Interesting question.

Ms. Cheri DiNovo: Madam Chair, since we're on the research topic, I was just wondering—there have been a number of questions asked of research; when will we be getting the responses to those?

Ms. Heather Webb: Well, we are doing them as they come in, so we're certainly dealing with them as soon as we can. In terms of waiting for responses from ministries, we are unfortunately in the hands of that ministry to provide that information.

Ms. Cheri DiNovo: This is something we need to know. If the ministries aren't forthcoming with the information, we need to know that. We need to know why we're not hearing, essentially, is what I'm asking.

The Chair (Mrs. Laura Albanese): Would we be able to get a quick list, let's say, of questions—

Mr. Bas Balkissoon: Maybe a list of what requests we made and the status.

The Chair (Mrs. Laura Albanese): Yes, of questions that we've asked and which ministries have responded and which ones have not. And if we could get a date so that we get a sense of if it's a question asked two days ago or a month ago. Thank you.

TORONTO DEVELOPMENTAL SERVICES ALLIANCE

The Chair (Mrs. Laura Albanese): We'll now welcome Toronto Developmental Services Alliance. Good morning. Nice to see you, Robert.

Mr. Robert Morassutti: Yes, it's nice to see you.

The Chair (Mrs. Laura Albanese): I know you've been sitting in the back for a while, so you know you have up to 20 minutes for your presentation. Should that be any shorter, that will leave time for comments and questions. You may begin any time. Please state your name and title before you do so.

Mr. Colin Hamilton: My name is Colin Hamilton. I'm the executive director of Surex Community Services, which is a transfer payment agency with the Ministry of Community and Social Services here in Toronto.

Mr. Robert Morassutti: And I'm Robert Morassutti with Montage Support Services, another transfer payment agency here in Toronto. We tend to support individuals that have complex care needs in addition to their physical disability, developmental handicap, and we offer residential and day services for them.

Mr. Colin Hamilton: We're here today representing the Toronto Developmental Services Alliance. The alliance is brand new. Formerly, our name was MARC, which stood for Member Agency Representative Council. That was established in 1985. We have a long history in Toronto. The alliance currently includes about a little over 20 transfer payment agencies in the city of Toronto. We represent probably about 20% of the provincial budget in developmental services in Toronto.

We have a lot of experience in this area. The collaboration is one whereby agencies are coming together on a monthly basis to really discuss our issues and work together. We work closely with our regional office; we have a good working relationship with our regional office. We, as an alliance, also sit on the provincial network and the other provincial tables. We're here today to talk a little bit about what we see are some of the issues across Toronto and in the province, and also to make some recommendations to you.

Mr. Robert Morassutti: Thank you. We know that the committee has heard a lot of presentations, and we don't want to belabour a lot of the information because I'm sure you've had personal experiences shared with you, as well as overall presentations.

The alliance, as Colin mentioned, is a collective group of transfer payment organizations, and we came together and tried to narrow down our presentation to three main points.

The first point we wanted to look at is Developmental Services Ontario. We know that the committee has heard a number of presentations with respect to Developmental Services Ontario, but we want to add our voice. We understand that the DSOs are legislated, that they do have a regulated, legislated mandate, but given what the intentions of the DSOs were set out to achieve, we feel that it hasn't really assisted families and individuals with the opportunity to access services any more easily or any more immediately. That's certainly a concern of ours, that we hear, as organizations, the frustrations of families in trying to access services and the obstacles that many of them encounter. So I certainly would recommend that there be some review of the DSOs as they currently exist.

1030

Secondly, another issue that I'm sure the committee has heard is that of children moving into adult services. Most families who have children with some disability are able to enjoy a number of inclusive and supportive services and programs in the community while their children are children. Unfortunately, when they reach the age of 18—in some cases 16—most families are really not prepared for what they encounter. We hear this over and over and over again.

Children's services, such as education or child welfare, are mandated services by the government. As such, there's a real wealth of services and resources and funding available for children. That all changes when someone turns 18. We always say in the adult sector that children's has them for 18 years; we have them for the rest of their lives. The funding that seems to go towards children's services is certainly not comparable to what we experience in the adult sector. Families are continuously being, I guess, shocked and surprised by the way they're led to a cliff, as many have said to me, and then pushed off the edge, because what they enjoyed with children's services is not there in adult services.

The third point we want to focus on is the concept of "most in need." The ministry has adopted a stance where, because it's not able to provide services in the same way that they may be provided under children's or mandated or entitled services, there is that concept or that approach of most in need. As transfer payment organizations, we spend a lot of time trying to meet a lot of the regulated requirements, reporting requirements. We tend to be spending, I guess, an inordinate amount of time in terms of the administration and maintenance of a lot of these requirements.

The government is very good at providing short-term crisis management, but when we look at long-term planning, long-term funding, there certainly is a little bit of a gap there. We don't have a good sense of the vision for the future: where we're going and how we're going to get there.

As I said, we spend a lot of time in administration. That includes things like the quality assurance regulations, risk assessments, policy directives from the ministry, health and safety directives from the province, fire safety regulations, mandatory training and quarterly reporting. This all cuts into the available resources—limited resources—that we have as organizations, non-profit groups, and takes away some of the energy from the program or service development that we could establish. Rather, we are spending a lot of time meeting those regulated and reporting requirements.

Finally, under "most in need," we also have the issue of labour costs. We're sure that each person around this table here understands that area. We're looking at things like pay equity obligations, regulatory requirements under quality assurance measures. Now with the Regulated Health Professions Act, in our case especially, any kinds of activities for daily living will require added training from medical personnel.

As we continue to provide these supports, these services, it certainly impacts on our ability to provide quality support to the people we are there to serve. Stretching those scarce resources is really going to erode our capacity.

Mr. Colin Hamilton: We've also included some recommendations for you to consider in your deliberations.

The first recommendation we'd like to make is around a multi-year funding approach. As you probably are aware, agencies in our business are funded on a year-to-year basis. At the end of each year, we do a reconciliation with the province. If we've lost money during that year, that is our board's problem and our agency's problem. If we have an excess at the end of the year, that's returned back to the provincial government.

What we'd like to see is a three- to five-year type of planning process where, within that time frame, agencies and boards have more flexibility on a year-to-year basis in dealing with ongoing funding issues and expenses that happen, oftentimes completely out of our control. So that's one thing we'd like to suggest, that multi-year funding idea.

Secondly, we feel that it's important for the government to go back to its original principles, where every citizen is guaranteed their right to work, housing, income, food and shelter. The needs of all citizens, especially Ontario's most vulnerable, should drive society's approaches.

Lastly, hitting on Robert's last point around the co-ordination between ministries and regulatory bodies, we really feel that our ministry needs to take the lead in looking at working with other ministries around regulatory issues. One would certainly be the issue around modifying the proxy pay equity obligations that many of us face.

When proxy pay equity first came in, the comparator that we were expected to use by the legislation was hospitals, so we now have groups of our staff who are on target to eventually make $35, $40 or $50 an hour. If you are not a proxy employer, the gap that is going to exist down the road is going to be enormous. We think it's a regulatory change that could help fix the issue for us and take some of the pressure off of us on an ongoing basis.

Again, the new regulations that are coming out regarding QAM, fire safety and the Regulated Health Professions Act—there's no funding that comes along with these, and again, those are added pressures on agencies to deal with those. We're dealing with them within the existing budgets that we have.

As you're well aware, I'm sure, 80% of our budgets go towards staffing. When we want to make cuts, it's fairly obvious where we need to make cuts, and that's in staffing. Although we continue to provide service, we're not continuing to provide service at the level that we really should be. As I've said on occasion, how much lower can you go than one staff on shift? You really can't, but many of us are doing that.

Lastly, we feel that employers need legislated incentives to hire citizens with developmental handicaps in Ontario. That certainly would provide opportunities for many of our adults who have those capabilities and abilities to work in their communities.

Thank you very much for listening to us. We hope that you'll take our comments and recommendations in your deliberations, and hopefully we can see some of those integrated in your work at the end of your period.

We know that this is a very complex field. Just sitting here and listening to some of the questions earlier around intellectual ability at 70 and why that is a cut-off, issues around where money has gone around residential support, and the complexity of our system in terms of dealing with people who have very little ability to look after themselves and manage, to the other end of people who are living in supported independent living—it's a complex system. I really, quite honestly, don't envy the work that you've got to go through and the arguments that you're going to end up having to hopefully come up with some good recommendations for all of us.

But we're with you, and we are really committed to what we're doing. We really need to feel that there's a fix here somewhere. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. We're really committed to trying to find some solutions as a committee. We're working very hard. Ms. Jones?

Ms. Sylvia Jones: Thank you, gentlemen; excellent presentation. I understand that you're an alliance, so this may be a little more challenging because of your umbrella role, but you are not the first presenter who has made reference to the regulations and the impact that they have on time and cost in your organization.

However, many of the other organizations—I'm talking specifically about the health and safety component of training for violence intervention—say, "We practise complete non-physical intervention, and so this training has no value for our staff. We don't do confinement. We don't do any of that, and yet we're basically forced to train our staff within the first 30 days." Can you comment on that?

1040

Mr. Colin Hamilton: Well, I won't comment on that one specifically. I will comment on the fact that I think we understand that having qualified and trained staff on shift is really, really important. I don't think that any of us in an administrative capacity would sneer at any kind of training that comes along, quite honestly. We really want the training as well. The difficulty is that there isn't the funding to go along with it.

Ms. Sylvia Jones: But shouldn't the training be appropriate for the circumstances that your employees are involved in?

Mr. Colin Hamilton: Yes, but again, those circumstances change from time to time. You may have an admission of someone who is more aggressive, who is more self-injurious. Then you may be in a position of going, “Oh. Well, we didn’t train any staff on violence interventions. Now maybe we’d better do that.” It changes all the time.

Mr. Robert Morassutti: And in our instance, specifically with Montage, most of the individuals that we support are non-ambulatory. They don’t communicate with words, most of them; there’s other kinds of gestures and indications. They’re not going to be the aggressive crowd that some people associate them with. In our instance, again, there are good de-escalating techniques. There are good situations that can be, I guess, modified in some way with the training. Generally speaking, a lot of what you’re saying in terms of the training being appropriate to the people being served is very true, but as Colin says, we also want to be sure that the staff that we have working are able to deal with whatever situation comes up. It really is one of saying, “What is the most appropriate manner in which to support people in that particular location?”

Ms. Sylvia Jones: Thank you.

Mr. Colin Hamilton: The only other comment, Sylvia, is that the other thing with the violence intervention training is also attitudinal. There are a lot of attitudinal things that go on with that training which are really important for staff as well.

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

Ms. Cheri DiNovo: Thank you so much for this presentation. It really, in a succinct way, picks up all the themes that we’ve heard, as of course you know, because you’ve followed along. I think overarchingly, what’s coming through for us, in a sense—and I want to reaffirm that we’re all here to make something happen. We hope this doesn’t become an argument; we hope this becomes a collaborative effort to actually see some change. It’s not an impossibility. Other jurisdictions do it better, so we know that we can do it better, too.

But overarchingly, entitlement versus discretionary keeps coming through over and over and over again, and that’s an attitudinal shift in the way one delivers services. You mentioned that as well. I particularly kind of ring with that. We need to be shifting our mind frame, and all things would flow from that, in a sense, in terms of how we approach the sector.

Any other comments on that shift, if you have them?

Mr. Colin Hamilton: Looking after someone with a developmental disability is expensive, period. It’s expensive. There’s no way around it.

The gentlemen who were here just previously talked about their project, their idea. Again, the issue is sustainability. If you’re going to fund something, it has to be sustainable. Having four or five family groups come together and buy a house and staff it themselves and keep it going: After a while, they’re going to be turning to agencies to say, “We need your help,” which is quite appropriate, and we really do enjoy working with families. But sustainability is the issue.

One of the questions that came up earlier was around that $42 million that went into the residential supports piece. I can tell you that in Toronto, we got X amount of money for that, a little over $1 million for hard-to-serve. That little over $1 million went to serve five individuals in Toronto—five. For one of those individuals, the price tag was roughly half a million dollars on an annual basis, to support one person. It’s a huge amount of money. Those are the exceptions to the rule, but nevertheless they are there in the province.

Again, when Bob was addressing the hardest to serve, that is the push, but what it also means is that families who were up here before us kind of get left behind—the thousands and thousands of families that are just looking for, “When am I getting some relief in this situation?” Again, it makes it a very complex situation, I know, for you.

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

Ms. Soo Wong: Thank you very much for your presentation and for your passion about this issue. I’m particularly interested to hear more on your last recommendation. You talked about employers needing legislative incentives. Can you elaborate a little bit more about these incentives, and can you share with us some best practices?

Mr. Colin Hamilton: I think the idea here is that there are a lot of individuals who would like to be working in the community. It’s expensive in that many individuals need to be shadowed by a worker before the employer can really assess, I think, “Can the person do it by themselves, or am I always going to need a person shadowing that person?”

So what we’re really looking at, then, is this idea of how we help employers to think about hiring someone with a developmental disability who can do a good job. Their training period is going to be longer. The support they need is going to be longer. That’s where we feel some incentives for employers, on a cash basis, would be really, really helpful.

Ms. Soo Wong: Thank you.

Ms. Mitzie Hunter: Thank you. That makes it clearer. So you’re looking at offsetting wages, more like a transitional employment-type model, and where there’s also paid staff support, job developers, that sort of thing, to help, and also to be there if something does change and needs to be re-explained or settled back down.

Interjection: Right.

Ms. Mitzie Hunter: Okay.

The Chair (Mrs. Laura Albanese): Very quickly, please.

Ms. Mitzie Hunter: That’s it. Thank you.

The Chair (Mrs. Laura Albanese): That’s it?

Ms. Mitzie Hunter: Yes.

The Chair (Mrs. Laura Albanese): Okay. Thank you. I apologize. I have to try to stick to the times, but I want to thank you for coming here this morning, for presenting to the committee. We appreciate, as agencies working on the ground, in the sector, your opinions and your recommendations. They’re very valuable to our committee.

Mr. Colin Hamilton: Thanks very much.

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

FAITH AND CULTURE INCLUSION NETWORK

The Chair (Mrs. Laura Albanese): We will hear now from Faith and Culture Inclusion Network.

Ms. Soo Wong: Chair, while we're waiting for the next witness, I understand the Ministry of Education is currently working with local school boards as it relates to the Focus on Youth summer employment opportunity to hire summer students. So can we get some direction, through the research department, to find out if there is any focus on the Youth Challenge Fund or the Focus on Youth fund to make sure some of the DD and ID students currently in the various school boards have priority to be hired for the summer program? Because these are provincially funded dollars, is there ear-marking that every school board must—you know, we give every opportunity to every kid, right? So this is a priority we're talking about in developmental services. Is the Ministry of Education—since they're giving funding to hire young people every summer, are there directions or criteria to encourage school boards to hire these exceptional special-needs students so they will have employment opportunities?

The Chair (Mrs. Laura Albanese): Thank you. We'll ask that.

Ms. Mitzie Hunter: In addition to that, while we're looking at the Ministry of Education, the Ministry of Training, Colleges and Universities oversees the youth employment fund, and we do know that a portion of that fund is set aside for people with disabilities. I think we need to ask the specific question about people with developmental disabilities and if there is an opportunity for them to tap into that fund as well for employment opportunities.

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

Good morning. You now may begin your presentation. You've heard that you have up to 20 minutes, and if it's less than that, we'll allow questions.

Mr. Paul Burston: Absolutely. Yes, and I do thank the committee for this opportunity to present this morning. I'm going to apologize in advance, because you're probably going to hear some similar themes from our presentation and those of others this morning. Hopefully, though, there will be nuggets of something new that you will have to think about.

Also, I apologize for coming by myself. The two people who were to come with me have joined Prime Minister Harper in Israel, so I'm here alone.

Anyway, I'll get right into this, because I do believe that the timing is perfect for addressing the crisis in the developmental service system. There is a crisis.

Faith and Culture Inclusion Network thanks the committee on developmental services for this opportunity to vision together with us to address the concerns and the struggles that families face every day.

1050

It's our intention, through this document presented today, to focus on actions that are critical to the viability of the sector and the support that is needed from our government to recover from years of underfunding at a base level comparative to other sectors. We have been hit harder than most.

Our priorities: Our goal is to modernize and improve our services and supports to people who are in the greatest need, especially those children and youth who have completed their secondary school studies. Our focus is on continuing education to prepare people for the workplace.

Our member agencies consistently strive to develop new approaches to services and supports that move us beyond the group home model wherever possible. We believe that that's an area that we don't give enough attention to. Group homes are extremely expensive. Other options are less expensive.

We will identify systems that inhibit us in achieving these priorities.

It is our intention to keep our comments focused on issues and actions that are critical to keep the sector healthy and the support needed from the select committee in its mandate.

We will provide information that will enable the select committee to make informed and timely recommendations to the government, which address the crisis not only for persons with a disability and families, but also for agencies that provide those services.

You've heard this morning a little bit about the financial pressures regarding the pay equity issue, the proxy method. I don't want to be repetitive, but I have had the opportunity to present to many, many of the finance minister's briefings and have brought this issue forward. It is a flawed method of trying to establish fair and equitable salaries. In fact, what it does is it actually begins to build within our sector inequity, because of the proxy method, as you've heard already this morning, based on hospital workers. What it amounts to is—for example, at the agency that I work for, it is almost $1 million a year that comes out of our operating budget to address this, which is mandated. It's legal; we have to do it. This affects agencies right across the province. What it amounts to is that with the proxy method, the spread, when we looked at this years ago, was a salary of between $18 an hour and $38 an hour. Of course, within our sector, there really wasn't any major inequity between a female worker and a male worker. We were simply all poor. Although pay equity has helped in improving salaries for people, it is, as I say, a flawed method and it really needs to be looked at in terms of what is a reasonable salary within our sector for our professional support people.

The simple solution—and we've heard a lot about things being complex, and very often things are complex because we make them that way. What I would suggest is that the select committee recommend that the government rescind the proxy method of determining pay equity and establish a reasonable sector norm of pay equity, and develop a multi-year funding plan to achieve it. Then we can put this thing to bed, because it's just been going on for years and years. In fact, some organizations are going to be doing this pay equity stuff for another 10 or 15 years. It's ridiculous.

We have been doing our part to work within significant financial restraints while at the same time coping with increased regulatory requirements that demand of our staff and leaders that they spend considerable time away from supporting people to supporting administrative duties.

It is imperative that the government recalibrate its priorities for the developmental services sector and accomplish this without endangering the fragile economic recovery, and free up agencies to manage what they do best without extensive bureaucratic requirements.

It is also important that our comments are not received as member agencies pointing a finger or playing the blame game. It is, however, reasonable to say that when the government and a non-partisan committee asks for input from the sector, it will do so with active listening and a real commitment to work together to resolve the crisis. I've heard that that's your agenda, and I was happy to hear that this morning.

Operational systems: The challenge families and agencies face is the impact of operational systems that add little or no value to the people in need of services and support. Our collective goals are frustrated due to forced long-term budget restraints, misguided priorities, inappropriate systems and a lack of vision for the sector.

Our current systems of operation have, in fact, not only complicated our work but are pushing us into a system that is not functional. Instead of facilitating needed changes, we are continually forced into restrictive processes that are achieving nothing to reduce the current crisis in the system or to modernize it. This is particularly true with the implementation of Developmental Services Ontario, the DSO. Their mandate has no resemblance to the reality of our work or the services that families require. Often, families do not feel supported by them. The DSO model has resulted in significant burdens on agencies within the sector. Restrictive, prescriptive requirements have been implemented. These requirements were intended to establish accountability for service delivery, as well as equity, but are in fact constraining the performance of both the DSO and agencies engaged in the delivery of services, resulting in diminished results for those we support.

We support the ongoing need to modernize our system. What the sector requires, though, is the development of clear and agreed-upon service delivery outcomes and the flexibility for agencies to collaborate on the appropriate means by which those outcomes are met. Again, restrictive, prescriptive bureaucratic systems leave no room for flexibility and innovation, which is needed to respond to service delivery demands. Sustaining these approaches inevitably leads to a focus on the systems themselves and detracts from the needs of those who need to be served.

The DSO goals also include that vacancies are to be filled by those most in need. The inconvenient truth is that those most in need are often inappropriate for the vacancies that are declared by agencies, due to their high needs and the lack of adequate funding, or their incompatibility with the persons that they're being asked to live with.

Following the process required through the DSO leaves agencies absolutely no room for creativity or for the modernization of services. We are simply recreating current services. This is a major issue, in that an agency will declare—we're looking at almost a health system mentality: There's a vacancy; get that bed filled as quickly as you can. What it does is it just recreates what's already there, and we know that's not working. It's not working properly, anyway.

Ontario has experienced great transformation in its view of its citizens who have developmental disabilities, often society's most vulnerable. History tends to repeat itself. Much effort is needed in order to help Ontario to continue to transform the image of its most vulnerable citizens, and we believe the following actions will help in this endeavour: that the government, in partnership with agencies, determine targeted reductions in the waiting lists as a first priority and, together, commit to eliminating the waiting lists within 10 years. This multi-year plan was used to close institutions in Ontario and was successful because of a shared vision and outcome by all stakeholders. I was part of that system. I've worked in the system for 43 years, starting in the institutions. The only reason the institutions were closed is because all parties got together and said, "This is not acceptable. People with disabilities need to be part of their community." So when we say that government can't be all things to all people, what we're really saying is that people with developmental disabilities are not deserving of the care that they need and the support that they need. I think that's a wrong focus to have because all the time that we plan from scarcity will always lead to inadequacies within our sector. We need to understand that.

1100

I've talked about the need for multi-year funding within the sector each year until the wait-list is eliminated, and I will add that that needs to be done while we modernize services. We can't just keep recreating what is already there. You've just heard that group homes should be the last priority, not the first, for families. Group homes are really there for people who have significant needs and need a safe environment in which to live, but many people, many on a waiting list, are people who can live more independently and be supported far more efficiently than a group home will ever be able to do.

Review the mandate of Developmental Services Ontario, the DSO. The intent of the DSO is good; it's the implementation and the focus that they bring, based on inadequate and wrong priorities within the regulatory piece of that. One of the things that this committee can do is say, "We need someone to look at how DSOs operate in the province to make them more effective."

Failing that, we would be better off with a collaborative system that was enjoyed here in Toronto for many years and worked really well, and it didn't cost any money, as opposed to $20 million right now.

The Select Committee on Developmental Services should convey to the Minister of Finance, as I've been doing for a number of years, that government-funded services target the financial gap accumulated over five years of zero increases to our sector.

This is another important element: continued support for creating real employment solutions for people with developmental disabilities to find gainful employment and reduce the amount of people relying on Ontario's disability support.

The lessons learned from Huronia: The recent court action regarding abuse in the Huronia institution and the subsequent settlement should inform all of us of our social responsibility and our collective duty to protect and support our most vulnerable citizens. We believe we can agree that the history of past abuses is not one we would want to repeat, and this should be the driving force that informs us all of our responsibility and which should, in fact, direct government policy.

In conclusion, we believe that there is an opportunity to be more fully engaged with the agencies and in the sector planning process to develop accountability mechanisms that focus on developmental services outcomes and principle-based approaches to ensuring continuity of service delivery while maximizing flexibility and innovation in a citizen-centric model focused on the needs of those being served and not having to serve unnecessary bureaucratic systems.

The question each of us as leaders needs to ask ourselves today is: Do current funding levels for the developmental services sector reflect the value we place on people with disabilities in Ontario?

Although a lack of adequate funding for the sector may not be a conscious action on our collective part, we need to reflect on this question, as it will help all of us re-evaluate our priorities in support of funding needed services for the most vulnerable.

Respectfully, members of the Faith and Culture Inclusion Network request that members of the select committee note that although there are seven recommendations, which I've just given you, many do not require significant additional funding. However, some do require re-allocation of funds and the elimination of wasteful bureaucracy and an outdated process for establishing pay equity within the developmental services sector.

The long-term strategy that the government must have is a vision that would see the elimination of wait-lists over 10 years and the courage to promote a social responsibility tax for that purpose. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much. We have about a minute each, so one question each, starting with the NDP. Ms. DiNovo?

Ms. Cheri DiNovo: Yes, thank you very much. Again, of course, as you're aware, we're hearing themes here, and you've just buttressed those themes, so thank you for doing that.

I have a question, actually, for research. I heard you quote $20 million for the DSO; I've heard others say $12 million, so that raises the issue: How much does the DSO cost us every year? I'd like an answer to that. Thank you.

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

Ms. Mitzie Hunter: Thank you so much for your presentation. One of the things you pointed out was the DSO's role in vacancy management. The intent is to have this sort of aggregated and that prioritization is dealt with as efficiently as possible. But sometimes there's a mismatch between the person's specific needs, particularly those that are most complex, and the available residential space.

Mr. Paul Burston: That's usually the case, because the way it operates is the most in need get that first opportunity for any vacancies. The most in need are more than often people with very complex and challenging needs. So what happens is the vacancies that are declared, they do not fit, and it would be inappropriate for those to be placed there. So there's a certain level of disconnect with agencies and families and filling spaces appropriately, and the lack of flexibility as well in terms of looking at existing housing stock. We've heard about the fire regulations, the building regulations, the accessibility, making some of our housing obsolete.

This is a great opportunity to work with the DSOs, if they were permitted, and with the ministry, to say, "What do we do?" How do we change our housing options so that we don't have to be worrying over every little thing around fire regs and accessibility, when we can probably inhabit buildings or have buildings that meet all those requirements? The group home is so expensive.

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

Mrs. Christine Elliott: Thank you. There are many questions I'd like to ask you because you've raised some really important new ideas here. But I will ask you about the DSOs, because we have spent a lot of time on them in your presentation. I guess my basic question is, do you think it's enough just to revisit what the DSOs are doing, or do you think that there is another way that we could deliver the same services without costing as much money, in another form?

Mr. Paul Burston: I believe that we had a system in place prior to the development of DSOs—the principles of one entry into the service system were already there. I know agencies in our group were a part of lead agencies that dealt with that. What that did for us was it allowed us to get to know the families more intimately. It's not just a piece of paper and filling out a form. It's about getting to know people. It's about building relationships. It's about the ability to offer other options. It's about the ability to know that what might work for this family might be respite for the next few years, before they enter into any more intrusive type of care. Families are just looking sometimes for a break, and all they can think of is group homes. That's part of the problem.

There was a system; it was working well. In fact, the minister at the time—I begged, "Please don't do that. It's costly.” We had an experience in Ottawa where—this is a number of years ago—several millions of dollars were spent every year, but not another single person was served in the system. We’re faced with the same thing today, really. The creativity that agencies have been good at is actually being stifled because we’ve got to follow this bureaucratic system. Unless the DSOs can be asked to recalibrate their approach and given some of the freedom to make decisions that we used to make as a collective, I don’t know how that will happen.

If I may, just very quickly, we had an experience where we planned for a person, and it took three months to fill this vacancy through the DSO process, which contravenes everything that they were put in place for. The weekend that the person was to move in, the family decided, “Well, that’s just too far for us to drive.” What that says to me is that we did not have the kind of information and the kind of relationship with that family that would have facilitated that change, so there’s a problem.

There are several options that are before us. One is the collaborative approach, which is less expensive or not a cost to the government. There is continuing to build into a bureaucratic system that’s not actually reflecting the needs of families. Families are coming back to agencies right now, asking for help, because they can’t get it at DSO.

1110

The Chair (Mrs. Laura Albanese): Thank you very much. We really appreciate your presentation this morning.

Mr. Paul Burston: Thank you so much for your patience and listening. I appreciate it so much.

MR. HAROLD BRENNAN

MS. DEBBIE BRENNAN

The Chair (Mrs. Laura Albanese): We’ll now ask Debbie Brennan and Harold Brennan to come forward. Good morning. Welcome to our committee. You may start the presentation any time you feel ready.

Mr. Harold Brennan: Good morning, honourable members Albanese, Elliott, Balkissoon, Hunter, Jackson, Jones, Taylor, Wong, Clerk Day and any other members of the committee. First of all, thank you very much for the opportunity to be here today. We’re Harold and Debbie Brennan of Belleville, Ontario, and we’re here today as advocates for our 24-year-old son. As I read this the other night, I thought, “That sounds an awful lot like an intro to Dragons’ Den,” but I believe this is a much more friendly environment here today.

Today we’re going to bring you a very personal story, a very grassroots story. But before we launch into that, the stated mandate of this committee—I’m sure you all know, but it’s also important for you to know that we have read the mandate of your committee and read the objectives, and congratulate you on tackling such a momentous issue.

Your strategy lists six issues that you’re going to take a hard look at. Based on our son’s age, we’ve already gone through the first two of your issues, to do with education and early years. We’re going to deal with the remaining four—they certainly are very relevant—and we’re going to revisit all four in our presentation later.

To help you understand our focus and some of the reasons we’re here, we’d like to read you a letter that we sent to six elected officials—I see some of them around this table—in September. We completed a follow-up in December. I want to take a bit of time and just have that letter read to you, because it helps frame the perspective from which we come.

Debbie, my right hand in everything for the last 30-some-odd years, is going to read the letter. She’s the author of the letter, and she also is the primary caregiver for our son.

Ms. Debbie Brennan: “Our 23-year-old son was a year old when our fears were first confirmed. We learned that my dream of having a child who I could dote upon and my interest in children with special needs had collided to present us with a child who, despite our best efforts and devotion, for 23 years would ever remain like a toddler.

“He was born with a chromosomal deletion named 1p−, and he bears the pain, anguish, complications and effects of severe global developmental delays, autistic tendencies, seizures, awkward gait, skeletal deformities, feeding challenges complicated by choking incidences, incontinence of bowel and bladder, anxiety, aphasia, behavioural and intellectual challenges.

“As I told his grandparents after he was diagnosed, ‘He will be okay. Harold and I are prepared. We will handle this. We are in a better position than many families, and I am very thankful’”—to this day, I can even say that—“‘that he is in this one.’ I assured them that the world had changed and that, with proper planning, he would and could have options and an enriched life.

“As a unit, our family rallied and devoted time, effort, expense and made huge emotional, physical investments in making him part of the family and community, while doing our best to provide a safe, healthy and enriched life for him.

“We began responsible planning for his future with Community Living Belleville and Area in 2004 with great confidence and hope, and participated in numerous meetings to discuss long-term placements, housing, community support, parental and financial responsibilities and the necessity of involvement of professionals to ensure a safe, fulfilled environment for our son, beginning at age 21, until their services were no longer needed.

“Until recently, I believed that we had been successful in achieving this plan. At 23”—he’s 24 now; I wrote this letter a few months ago—“our son still resides with us. His physical and intellectual disability result in him having the skill set and receptive language level comparable to that of a toddler. For the most part, his condition remains unchanged.

“I wish I could say the same for Harold and I. We are heartbroken, disappointed, exhausted and fearful that we and he are in the very position that we had planned and worked so desperately to avoid. We are seniors who have faced those associated challenges and have little hope for his future. Despite our efforts, both professionally and personally and by Community Living over nine years, we have been unable to secure a safe, suitable and long-term placement that meets his physical, safety, community support, intellectual and supervisory needs.

"It was hoped and planned that a recent respite placement would evolve into a long-term home. After two agonizing years of observation and assessment, it has proven a failure with respect to meeting his needs. It is our understanding that occasional funded spots that become available are not suitable due to elevated safety risks from others living in those homes and grave infringements on the rights of him and others in those homes.

"Many years ago, we were participants with a group of five families who shared the challenges and hope of suitable housing for our children. For a variety of reasons, such as family transfers and the health concerns of families and children, the group disbanded.

"Temporary housing options such as basement apartments outside of town were ruled out due to safety issues and community isolation. Extensive efforts by managers at Community Living have been unable to secure temporary support options such as those provided by the associate family program and reverse planning options.

"We have contacted other families on our own who share our concerns, have similar needs and have discussed options outside those provided by service agencies. No options are seemingly possible without secured and adequate funding.

"Concerns have been voiced by professionals involved with our son regarding his ability to transition. The longer he waits, the older he gets when he is faced with a transition to a permanent home, thus adding to the urgency of this situation.

"Our son is now a 23-year-old man with a severe developmental disability. We've grown older and are faced with fears for our future as well as his, and we can no longer imagine a retirement whereby we can look forward to visits from all our children, our son included. Now in our late 50s, we struggle with sleepless nights wherein he might be up for the day at 3 a.m., leaving me irritable, teary and less able to make sound decisions. On occasions, I have struggled to remember if I have even properly followed his medical protocol.

"Harold is working. Such nights interfere with his sleep, as he takes his shift when I am no longer able to cope. We are both awaiting appointments for day surgery; while we should be focused on our health, it is his safety, health and future well-being that dominate and dictate our thoughts, our leisure, our appointments, our financial fears and decisions, and our ability to fulfill our commitments to our daughters and aging parents.

"For the most part, our lives involve a tag-team, turn-taking approach as to who is watching or staying home with him. We do not attend family events with him, as he's unable to handle the commotion. Some events can be accommodated in advance, but spontaneous events such as the onset of illness become a challenge for us to manage because of his high needs.

"If I'm home alone with a migraine, I hesitate to take the proper medication for fear of becoming drowsy and unable to provide proper care. I take medication for high blood pressure and recognize the signs of its elevation, but have no choice but to power through tough times when I have no options or alternatives.

"Our physical health is reflective of our plight. Harold has two herniated discs and has given up some sports as a result of pain management, but it is difficult to avoid the physical needs of a toddler. Every night, Harold stays up later than I do to change our son before we settle for night. Our son is groggy at that point, requiring him being lifted onto our custom-made change table.

"Because of his limitations, needs and behaviours, there are huge amounts of laundry, household tasks and meal preparation to be completed. At an ODSP tribunal last year, I gave testimony regarding the work and effort involved in caring for him, his physical environment and his activities of daily living. When the judgment was handed down, it was acknowledged that the activities required for adequate care for him resembled those of an institution.

"It goes without saying that, after 23 years of lifting, excess stair-climbing and changing beds, my sore shoulder and hips are symptomatic of our parental responsibilities and complicated by our age. We struggle to but are trying to accept and manage the physical and custodial aspects of caring for our son.

1120

"But it is the mental torment, worry and fear for his future that we can no longer live with or cope with. When lying awake at night, I struggle to see how we would have done things differently, how things would have changed for him and his future. We accepted his plight, ours and those of his devoted sisters many years ago.

"When we began responsible planning for his future with the respectable, capable advocating agency with whom we worked to secure long-term care that was safe and properly staffed and that shared our goal of a happy, enriched life for him that recognized his strengths and weaknesses, we met with their managers as well as other professionals in the community, which included lawyers and accountants, to make sure we were on the right track when planning for him. It has become painfully clear that we are at a dead end and that there is no track and, quite frankly, no hope.

"I am disillusioned and have no confidence in a system that does not have or seems unable to have the best interests of our son in mind or often in their sight. It turns out that the fears of my parents, who I reassured years ago that the world and society had changed for the better, were realistic and accurate after all.

"We are willing and expect to continue to fulfill our responsibilities as his parents, but in the absence of adequate sustained funding, he will be sentenced to a life that agencies and officials with decision-making power can and have ignored and denied. As his mother, I refuse to accept that reality.

"Over the years, I have read about the plight of parents who, in their desperation, went public with their story. I wondered why they had been unable to plan, to organize, to meet with officials to discuss their responsibilities in creating an enriched life for their child, as we had done and as we were doing. It turns out that our work, our efforts, as well as those at Community Living, over a period of nine years have proven futile and were in vain, as we are at the same dead end and share the same feelings as those people who I once thought were desperate, deserving of insight, financial support and peace of mind."

Mr. Harold Brennan: Now that you have a clear understanding of our perspective, we would like to reflect on where we are now as well as have some dialogue around the four focus points mentioned earlier. We also want to talk about what we have accomplished for our son's planning and some of the ideas around viable solutions that we feel would be positive not only for our son but for many others in Ontario who suffer from a disability.

The perspective we're bringing to this is that we are dealing with a 60-year problem here because of our son's natural life expectancy, so it's not something that's going to go away short-term.

The committee focus points: The first one that we're going to deal with is the need to provide social, recreational and inclusionary opportunities. We obviously fully agree with the focus, and we have in fact been able to establish all three of those criteria. We've got them in place in his community. The problem is the sustainability of these objectives. We have opened the doors and laid the groundwork. We have that in place, clearly, all those items, but we need the staff to provide the care, support, guidance and delivery to sustain these objectives. Formerly, a lot of this delivery was through the school system and through his siblings, but because of his age and because his sisters are older and have now moved on to their own lives, that support system no longer is there. So the issue is the absence of perpetual funding to maintain what we have built.

The second one we talk about is the need for a range of affordable housing options. Again, we fully agree with the focus, and we believe that the population we are talking about, really, regardless of personal income level, should have similar housing environments as any other single Ontarian would. There should be no more than one to three people living in a home. That's what most people would expect, so why would we look at this sector and say, "Well, no. Because you're this way, you get to live with six or seven"? I think the perspective should be the same as if they didn't have an intellectual disability.

We feel that publicly funded homes in our communities should be made available, maintained and staffed as sustainable and safe homes. Our attempts to ensure such housing for our son have been in vain so far. We worked, as Deb mentioned, for the last nine years. So we have personally purchased a home. It's an appropriate house that can meet the structural, social, environmental and inclusive needs either permanently or temporarily. We're flexible to go either way; it depends on the future availability of safe and sustainable publicly funded homes.

We feel we should not have to, but are willing to, provide the physical environment at well below market rate. The problem is the sustainability. Now, if we look at the cost of staffing on the publicly funded model—and we've used the numbers from a transfer agency—you're looking at about $280,000 for one-to-one funding. We feel that the funding can be done for about 60% of that on a one-to-one. If we look at more of a private-sector type cost structure as opposed to a public cost structure, it runs at about 60% to 64.5%. To basically make this more efficient, we're willing to work with other families that are like-minded and compatible. In addition, we need the support of public agencies that have rid themselves of old-world, inefficient thinking; so they've got to change. We need the agencies to provide services such as staffing rosters, human resource management, payroll management, staff screening, med training, liaison with related agencies, continuing education etc. That's what we see we need them for.

The next focus: the respite and support needs of families. This focus, from our point of view and experience, goes hand in glove with the previous focus. The primary difference, of course, is that respite and support, on average, is a need that increases from childhood to adulthood.

If there is adequate, proper, quality housing and, more importantly, adequate, quality staff based on needs, not budget, then both of the above focuses will be met.

The next focus: how governments should most appropriately support these needs and provide these opportunities. First of all, we do not envy you, as our government, trying to balance the wishes and needs of such a diverse population like in Ontario. Our sense is that the answer to this focus is very personal, and we've given this a lot of thought. Our single most important thought is that those with disabilities should be treated with no less respect than other publicly funded stakeholders.

We haven't figured out the answer, so we don't get to be your last speaker. We didn't bring the magic bullet with us today. If we had it, we would have forewarned you.

Again, we hope not to offend anyone with our thoughts here today, but we feel we need to take a look at some things. Primarily, we have to have a philosophical change and refocus in the public sector workplace. We need to engage outside-the-box thinking from sector benefactors and their advocates. We need to employ models that encourage private sector engagement.

We feel the number one priority must be that people in need must be the number one benefactor of every decision and every dollar, and the rest of us have to take a second seat. And by "the rest of us," I mean the rest of us: I'm talking about politicians, taxpayers, parents, siblings, public employees, private employees—everybody else but those we serve.

The way we have supported people with disabilities in the past is not how we feel they should be supported in the future. We must take vision and mission statements off the walls of agencies and turn them into practice. We have to accept the sacrifice that it takes to do that, and you will get to the benefactor being the person with the disability.

We need to refocus from the present, whereby employers and employees are being beneficiaries of the system ahead of those we serve. It's an unfortunate reality that we see. The individuals with disabilities have to be number one, not number two, three, four or five.

We realize these are very heady objectives, and some thoughts that we hope may have some merit and in some small way improve the system of support for those we're all trying to support—it ended up being a total of eight:

The funding, we feel, must attach to the individual, not an organization.

Organizations should consider a modernized employee model, not a continuation of the current model, as it has proven financially non-sustainable. When I hear math up here about 80%, 85% into staffing—I'm in private business, and that's about 20% to 30% above what would be seen in the private sector. We think that having more private sector support in this area is going to really free up a lot of dollars to get available to provide service to more people at a higher level.

Government ministries need to work together, and I'm sure you are, to efficiently deliver to the individual needs. Ministries, in our opinion, that were coming into play here are social services, the health ministry, the finance ministry, children and youth services and, to a lesser extent, colleges and universities.

Advocates need to be revenue-neutral-to-negative, and when involved with financial management of public funds, we need to be fully accountable and audit-ready.

1130

Government ministries should take a look at making it attractive for the private sector to participate at a much higher level than current. I think this is an area of opportunity for additional funding in an efficient manner. An example here would be for the Ministry of Finance to fast-track applications for small micro-boards as non-profits. It would be able to make it viable for local organizations, individuals and charitable foundations to contribute to local needs.

The new world model would embrace in action, not just in word, the tools that are out there. They'd actually be more ready to use behavioural consultants, occupational therapists, technology and dietary specialists. Those services are out there and there's a lot of chatter about them, but our experience has been they don't get applied as much as they get talked about. We need to make sure that there are no impairments to services.

Last but not least, we have to revisit the budget process. Unfortunately, it is always about the money. We feel, based on the current environment, that the vulnerable of our province are getting less money than some other sectors.

We're running out of time here, so I want to give you at least a minute or two to ask us a question.

The Chair (Mrs. Laura Albanese): Unfortunately—

Mr. Harold Brennan: We're all out?

The Chair (Mrs. Laura Albanese): We're over the time and we won't be able to ask any questions. First of all, I want to thank you for your compelling and frank presentation. I want to commend you for all that you're doing thus far for your son. I just want to assure you that we will be taking all your recommendations into account. We thank you for being here today.

Mr. Harold Brennan: Thank you very much. We appreciate the opportunity.

Ms. Debbie Brennan: Thank you.

MS. ROSANNE RENZETTI

The Chair (Mrs. Laura Albanese): I'll now call on Rosanne Renzetti to come forward. Good morning. Welcome to our committee.

Ms. Rosanne Renzetti: Good morning. Thank you for having me. I just have a really simple handout today, so I hope you all have that.

The Chair (Mrs. Laura Albanese): It's being distributed; we'll get it momentarily. You may start in the meantime.

Ms. Rosanne Renzetti: Thank you. I'd just like to thank the committee for allowing myself and other parents an opportunity to share our experiences, and I'd like to particularly thank Ms. Elliott for introducing the resolution that created this committee.

I'll largely be focusing on the needs of children and youth with autism from personal experience. My daughter is eight. She is on the autism spectrum. She is a cheerful, sweet, affectionate girl who is extraordinarily active. I sympathize with our last speakers about staying up all night; we do that a lot, too. She also has a number of challenges, including language limitations and social impairments, as well as the anxiety, cognitive delays and sensory processing issues that many children with autism face.

I recognize that you've heard from and will continue to hear from many parents who have children with severe or multiple disabilities, parents who are struggling to cope with incredible challenges, and that in comparison, our situation may seem less dire and may not seem to warrant the same urgency as others. However, our story is not unique. It's one that I've heard anecdotally from many other parents, and the fact that so many of us have had similar experiences makes me think that it is a story worth hearing once more. That's what compelled me to come here today.

I'd like to make some very general recommendations, just based on our experiences in the last six years, and the supports and services that would have improved our experience and our daughter's outcomes. My focus today will be on diagnosis and early intervention and what I call ongoing and inclusive support. I will get into more detail as I go on.

Starting with diagnosis and early intervention, this is our story: My daughter was diagnosed as being on the autism spectrum shortly after her third birthday. It was not an easy diagnosis to obtain. Her former pediatrician refused to believe that any of her symptoms were cause for concern, and it took six months of persistent lobbying on our part to convince him to examine her situation more closely.

After admitting she likely had autism, he would not give us a diagnosis but insisted that we receive a formal diagnosis through a local autism services agency. When we called and found out that the waiting list for diagnosis was at least a year, we called the pediatrician back and asked for other options to speed up the diagnosis process, thinking that a diagnosis would help us get her services. He told us to just get on the wait-list and wait.

Thus began the first of many typical encounters with government services. Whether a doctor, a staff member from an autism agency, or a school principal, each one understood their role in my daughter's life in the narrowest and most strictly defined terms possible and no more. If their role was to refer, they referred. If their role was to redirect us to other services, they redirected. If their role was to apply the Education Act as narrowly as possible, they did so. If there was anyone with a comprehensive view of the system whose role it was to guide us through the complexities of autism services in this province and ensure my child's best interests were being served, that person did not exist for us. We became that person.

As parents, more often than not, we were left to put the pieces together on our own: to make the endless phone calls, fill out the same information on numerous application forms, to advocate tirelessly with multiple levels of government on behalf of our child. More often than not, we simply had to resort to privately funding interventions for lack of any other option. My husband and I are both university-educated, English is our first language, we are trained researchers both, and my husband has a law degree. And yet, with all these strengths, we could barely cope with the strain of finding services, understanding the larger system, including the education system—just understanding it—and struggling to pay for private services when we could not bear the thought of wasting precious time on wait-lists.

To this day, we wonder: What happens to the families who do not speak English or French as their first language, who are not familiar with the inner workings of government and simply cannot make the financial sacrifices required to go beyond the system when it fails them? This goes back to my first point of diagnosis and early intervention. I don't make a lot of detailed points; I'm thinking broad strokes here. We need to ensure that there is an abundance of centralized caseworkers. I didn't even know what a caseworker was until probably three or four years after my daughter was diagnosed and someone asked me if I had one. I had no clue what that was because we were simply never offered that option. There simply—whatever the system of delivery—has to be more support for parents from the moment an issue with developmental delay is suspected. I'd like to see a definite reduced wait time for diagnoses.

I ask a few broad questions: Can we empower our family doctors and regulated health professionals to deliver more initial diagnoses if that speeds up the process? Have we made it as easy as possible for these individuals, as well as teachers and early childhood educators, to make referrals for diagnosis? Can we envision a system where we provide interventions and recommend them to parents while parents are still waiting for an official diagnosis? In many cases, children with developmental delays could benefit from interventions from day one. There are general ones that could benefit many, many children in many different situations. We can start providing those even before we start to stream them towards one specific group of funding or another.

Ongoing and inclusive support is the next area I want to focus on as my second bullet point. Here I'm proposing something a little whacky maybe. I'm looking for something that's ministry-neutral. If we're going to have caseworkers or agencies, I'd like to see them work more effectively across ministries to help guide parents and children through the system, regardless of who is providing the services.

I'd also like to see a vision where these same agencies and/or caseworkers are working through broader time periods. Those of you who have children with disabilities or developmental delays know that it just sometimes takes longer to get to different points in their life. We feel that sometimes it's rather arbitrary. You get funding for a certain period in their life, and then it's cut off and then you're moved to another period. You're not ready for that period, necessarily. If I had a caseworker who could follow my child, let's say, from infancy through preschool, and then perhaps a different caseworker who works her through her primary and junior years, that would make a lot more sense in the development of the child and the child's specific needs.

I'd like to see agencies and caseworkers who can respond to the changing needs of children as they grow and progress and they require different supports or therapeutic interventions, not just one, whatever they need at that point in their life, which is constantly going to be changing, as they change and grow.

I'd like to see interventions and therapy as part of the classroom experience. Let's stop dividing our educational supports from the therapeutic ones. In her short life, my child has undergone speech therapy, occupational therapy, physical therapy, behavioural interventions and social skills therapy. That's not even getting into the medical stuff. We had to carve out the time and funding to pursue these therapies outside of her regular school day, or cut them out entirely and watch our child regress.

In a daycare setting, I found that daycares were generally more open to allowing private therapists to come in. This was generally not allowed in a school setting.

Ideally, we should provide a school system that has a holistic approach, very similar to the child and family-centred approach that the Bloorview School Authority here in Toronto has, for example. If that's impossible, then we need a means by which private therapists can be approved by the ministry and/or school boards to provide interventions and supports. I get that this is a Pandora's box in terms of regulation and monitoring and providing a two-tiered system; I'm certainly not a proponent of it. But the reality is, we have parents who are giving up paid employment to volunteer in their child's classrooms or who are paying therapists to volunteer in classrooms in order to get around the limitations of the system.

1140

In my bullet point about ongoing and inclusive support, I'm using the term "inclusive" a little differently than it's usually used in the disability community. It usually refers to integration. I'm talking about it in a slightly different way, and I'll explain why. At the time of my daughter's diagnosis, most funding for autism services was aimed at children under the age of six. This was in the form of applied behaviour analysis, ABA, or intensive behavioural intervention, IBI. This is what was approved by the province. It was believed to be most effective when started early. In order to receive funding for this therapy, you had to bring your child to an assessment centre to see if they qualified. So having a diagnosis in hand wasn't enough; you had to be assessed at an approved centre.

While there was no doubt on the part of the team who assessed my child that she was on the autism spectrum, she was well behaved at her assessment and spoke one or two words—not directed to anyone or not in anything that would indicate an understanding of communication, but she spoke. Based on this one-time, 10-minute observation where she spoke once and the fact that she did not scream, cry or trash the room, she was deemed to be too high-functioning to receive funding.

Fast forward to two years later: She's finishing kindergarten at our local school. We are struggling through an IPRC with the Toronto school board. We have a child who still has the same autism diagnosis and who clearly will not be able to cope in a regular classroom without support. While we have accepted that integration has benefits, we know that she would benefit academically from being in a classroom with autism supports. The school board requires an assessment from their own psychologist before placement. Why? She has a diagnosis. Well, in Toronto, the autism special education program is limited to children with average or above-average intelligence, despite the fact that 75% of people on the autism spectrum have some sort of cognitive delay.

To put it bluntly, my child was too bright to receive financial support for autism therapy and too dumb to receive the autism-specific educational supports she desperately required in school. It is in many ways difficult enough to cope with your child's limitations, but it is insensitive at best and, frankly, discriminatory at worst, to use these cognitive deficits to determine whether she deserves supports. We need to stop discriminating on the basis of diagnosis and intellectual ability.

The Auditor General of Ontario did a very comprehensive report this year as part of the 2013 audit. "Reports on Value-for-Money Audits," section 3.01, focused on autism services. It's an excellent review of the issues around wait-lists and lack of consistency across the province. The Auditor General points out that clinical research demonstrates that children with mild forms of autism would enormously benefit from IBI, but they are presently being denied the service because it is only available to children deemed more severe, who in some cases do not benefit as much. The Auditor General goes on to note, "According to experts, early diagnosis and treatment ... might reduce the need for more supports and services later on in life." This has been proven over and over again. So it stands to reason that we're reducing long-term costs by extending these services to all children, regardless of severity.

I would like to extend what the Auditor General says and say that we need to calculate another hidden cost, that borne by the health care system—and I think the previous speakers have demonstrated that amply. I can't speak for them, but I can certainly say that many of the parents I have met seem to deal with an inordinate amount of stress, part of which comes from coping with the actual situation, but a great deal of which comes from the very preventable stresses of navigating the system. It is very difficult to be constantly reminded by every government agency of the urgent need for intervention before the age of six, while simultaneously being presented with every obstacle possible to receiving that intervention. This takes a toll on your physical and mental health. Other parents and I also have to cope with the financial stresses of providing therapies, as well as setting aside funds for future support.

I was somewhat concerned to read a recent University of Calgary study from their School of Public Policy. They did a cross-Canada study, across many provinces, which reported that lifetime autism costs, including the actual expenses plus the cost of caregiver time and caregiver lost potential earnings, ranged from $1.2 million to $4.7 million for a typical person with ASD.

Once again, going to my point on ongoing and inclusive support, we need to provide a range of services regardless of the specificity of the diagnosis or the severity of the disability. It's not about the diagnosis or the severity; it's about the access to consistent, frequent and appropriate intervention and support for your children.

That's all I have to say today. Hopefully I shaved a bit of time off. I know everybody has run over.

The Chair (Mrs. Laura Albanese): Thank you. There are about two minutes for each party, and please do not go over. We're already running late. Ms. Hunter?

Ms. Mitzie Hunter: Thank you so much for sharing your story. It definitely reflects what we have been hearing as we've been conducting these hearings across the province. The issue of diagnoses, the issue of treatment—and appropriate treatment and intervention at the right time is a particular theme that has emerged. I think that you've very much given us additional ideas, such as teacher referrals, the roles that doctors could play, and relaxing the system so that we can get to the business of providing assistance to the children, so I want to thank you for that.

I've also noted the holistic approach as a new thought that we can think about in terms of, what are the other wraparound supports that people need?

I'm also hearing—as a parent; as we've heard from all of the families—the need for relief, and for the system to be working with you and not against you.

So I want to say thank you for giving us this very simple one-pager and for so eloquently expanding on it.

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

Mrs. Christine Elliott: Thank you very much, Ms. Renzetti, for being here and for your continued advocacy on this issue.

Ms. Rosanne Renzetti: May I say, Ms. Elliott, that I hate the word "advocacy"?

Mrs. Christine Elliott: Okay.

Ms. Rosanne Renzetti: I just want that to go into Hansard. I really think that in an ideal system, I wouldn't have to advocate for my child's basic rights. Sorry. I'm sure you had something more important to say than that—but I'm never going to be on the record again, so I might as well.

Mrs. Christine Elliott: Well, I quite agree with you that you need to. I think that's the situation most parents find themselves in: that you have to do that in order to get the services you need for your child. So the concept of system navigators just to help you get through the system, and even to inform you about some of the services that are available, is so important.

Ms. Rosanne Renzetti: Absolutely.

Mrs. Christine Elliott: I'd like to ask you a question, actually, on another point that you made, and that was about not dividing therapeutic and educational supports. We've heard that from other parents—parents whose children may have been involved with a children's treatment centre, and then when they're school age, of course, those supports are cut off. The therapists can't come into the classroom, and families find that extremely disruptive, and then they don't get systems and services picked up when they go into the school system. I'm wondering if you could comment just a bit more on that, and what it meant to you and your daughter.

Ms. Rosanne Renzetti: Absolutely. I think it's a bit of a fallacy that we've somehow spun—in the autism community, at least—that you get to them before the age of six and then they're miraculously cured. I think everyone knows that while you make great gains in the primary years, there are certainly things that still need to be worked on. My daughter still required a great deal of occupational therapy for sensory integration issues. Her speech had improved somewhat, but she certainly hasn't made enormous leaps, and she could have benefited from having those things

Because we could not do it in the school system, my husband and I basically had an impossible work schedule, where we'd pick her up from school, drive her halfway across the city, engage in therapy, come home, vaguely remember that we had another child somewhere, pick that child up, come home and go through our regular day. We could do that two or three days a week, plus huge chunks of the weekend—to try to cram all of that therapy in while continuing with a regular school day. At a certain point, we realized that it was just taking a very detrimental toll on our mental and physical health, because we couldn't sustain that pace. But we still feel that she needed those interventions.

In the school system in Toronto, at least, their model has been to provide consulting. So you might get an occupational therapist, five months after you ask for one, to come in and spend 10 minutes in the classroom and provide the teacher with some supports. It's simply not enough. I think we know that teachers are quite burdened at the moment. They have more than enough on their plate, and they can't become occupational therapists or speech therapists on top of that.

So if the school system can't provide the therapy, then we need to start thinking outside the box about how we can loosen things up and perhaps find more ways to provide that.

1150

I pointed out Bloorview as an example. Although they only go to grade 1, that's an example of an environment where it is inclusive. There is some integration, but there is a lot of support by those alternative regulated health professions. They have speech therapists on staff; they have occupational therapists on staff. They work very closely with the teaching staff to implement things that each child needs. I'm not quite sure that that need really ends at six. I really think we need to see that continue forward and to develop programs that are closely modelled on that. That would be a huge benefit.

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

Ms. Cheri DiNovo: Thank you so much, and I'm so sorry for what you've gone through. We're here to change that, we hope.

Ms. Rosanne Renzetti: I believe that.

Ms. Cheri DiNovo: Just very quickly, I particularly loved your suggestion—not the first, of course, that we've heard of a system navigator or caseworker, call it what you may, but someone who will walk with you from cradle to grave, as it were, develop plans along the way, that there be consistency rather than bureaucratic aspects of government that just administer assessment tests and then administer wait-lists. We don't need more of that. We need more direct help, and you have pointed toward that, so I thank you for that.

Ms. Rosanne Renzetti: Thank you.

The Chair (Mrs. Laura Albanese): And I want to thank you as well. We recognize and are fully aware of the frustrations you have been through. We want to try to improve that, and thank you for bringing forward really important suggestions.

Ms. Rosanne Renzetti: Thank you for your work on this matter. We do appreciate it.

FETAL ALCOHOL SPECTRUM DISORDER ONTARIO NETWORK OF EXPERTISE

The Chair (Mrs. Laura Albanese): Now we'll hear from the Fetal Alcohol Spectrum Disorder Ontario Network of Expertise, FASD ONE. Please take a seat.

Ms. Sharron Richards: Good morning, and thank you for allowing time for us to speak to you today. I'd like to just acknowledge our appreciation that we're in a tough time slot here. We're just following the very moving and powerful presentations of parents and we're in the pre-lunch spot, so we'll do our best to keep your attention.

I'm Sharron Richards. I'm the chair of Fetal Alcohol Spectrum Disorder Ontario Network of Expertise, which we're going to refer to as FASD ONE. A few years ago, I retired from close to 38 years working in child welfare and now I am involved as a community volunteer. I'm accompanied by my esteemed colleague Nancy Hall, who is the lead of our support and intervention action group. In her other life, she's a facilitator with the Southern Network of Specialized Care.

FASD ONE is a volunteer collaborative of caregivers, practitioners and specialists committed to the prevention of FASD and the development and dissemination of information that will support individuals affected by FASD and their families. Our members come from communities across Ontario, including First Nations, Métis and Inuit communities. I know that some of our members have appeared before this committee in other parts of the province.

Our presentation is going to speak to three aspects for your consideration: We're going to provide you with some background on FASD, which may be a repeat of what you've heard, and we apologize for that; we're going to talk about the human and economic costs of FASD; and then we're going to talk about the recommendations.

I'm going to ask my colleague Nancy to speak to the first two sections and I will speak to the recommendations.

Ms. Nancy Hall: Thank you, Sharron.

Background: As you may know, FASD is a brain-based physical disability with developmental impacts resulting from prenatal exposure to alcohol. It is an umbrella term used to describe the range of effects that may include physical, mental, behavioural and/or learning disabilities. You may also know that it's preventable. Because it is incurable, those affected will require a range of supports across their lifespan.

The Public Health Agency of Canada estimates that this disability affects approximately 1% of the population. While there have been no prevalence studies conducted yet in Ontario, it is estimated that it currently affects over 130,000 children, youth and adults living in our province. It is believed that the prevalence is underestimated. Three studies presented at the last international conference on FASD identified the prevalence rate as 2% to 5%.

Contributing factors to underestimating prevalence include the fact that FASD is often invisible, not understood and misdiagnosed, and for which there are few diagnostic services across the province that are accessible and affordable and, I would like to add, knowledgeable. An additional factor is the stigma associated with women drinking while pregnant, which prevents women from confirming prenatal alcohol use, a requirement for a diagnostic referral.

An increase in the prevalence of FASD can be anticipated with the development of increased diagnostic services and training for caregivers and service providers to understand, assess and screen for FASD, and because, according to Health Canada, 20% of women of child-bearing age consume five or more drinks at a time once per month or more often, a rate three times higher than a decade ago. Women at the highest risk of binge-drinking are 15 to 19 years of age, followed closely by those in the 20- to 24-year-old age bracket, all of child-bearing age. Health Canada estimates the overall rate of unplanned pregnancy to be 40%, with the highest rate, 82%, of unintended pregnancies among 15- to 19-year-old women.

FASD impacts the cognitive, mental, social, adaptive and executive functioning of those affected. As a result of their brain injury, people with FASD face a wide spectrum of lifetime challenges, from mild to very serious physical, mental and emotional disabilities. Throughout their lives, individuals affected by FASD will experience challenges such as:

—delays in meeting developmental milestones;

—memory problems;

—language comprehension, both verbal and written. They may have good articulation skills, but they may often not understand what they are saying;

—difficulties processing information, filing and retrieving it when needed;

—difficulties with abstract thinking and reasoning, so they hear, think and reason literally and concretely;

—inability to understand cause and effect, so they can't transfer learning from one situation to another;

—not picking up on social cues, causing them to relate inappropriately;

—poor regulation of their emotions and behaviour;

—poor decision-making, including in the relationships that they develop;

—poor time and money management skills;

—difficulties with planning, organizing and other executive functions;

—trouble maintaining appropriate attention and focus; and

—daily living difficulties.

A significant challenge for most individuals affected by FASD relates to the discrepancy between their chronological age and the age at which they function. We call this dysmaturity. In other words, they will function at a younger age than their chronological age in most areas of their lives. The exceptions are in their communications skills and their sexual development. As a result, they appear more competent than their actual abilities, leading to high expectations from others and subsequent failure in meeting those expectations.

If not diagnosed early and followed by access to appropriate supports and interventions, individuals with FASD are at a high risk of experiencing additional challenges, including poor family planning.

When we look at human and economic costs, without an informed system of care providing appropriate supports and accommodations, the human cost for people affected by FASD and their families is substantial. Ninety-five per cent will experience mental health issues; 82% will not be able to live independently; 80% will be raised by someone other than their biological parent; 70% will have problems with employment; 68% will have disrupted school experiences; 68% will come into contact with the law; 52% will exhibit inappropriate sexual behavior.

For individuals affected by FASD, they experience a pervasive and persistent sense of failure and frustration, believing that no one understands their lived experience, that they are constantly a disappointment when unable to live up to expectations and because they are aware that others consider them to be different, stupid, weird, unwanted and difficult. They are the people who are socially isolated and disenfranchised from the civic life of our communities.

The burden borne by individuals affected by FASD should alarm us all and rally us to proclaim that these costs are unacceptable in a province as resource-rich as Ontario.

All Ontarians bear the economic costs of FASD when those affected significantly strain publicly funded systems of health care, child welfare, education, mental health, addictions, justice and social assistance. While the cost of FASD to the public is difficult to determine, it has been estimated as anywhere from $1 million to $3 million per individual over a lifetime, while $5.3 billion to $7.6 billion is estimated to be spent annually in Canada to support those with FASD from birth to age 53.

1200

Despite the considerable money being spent on services intended to support children, youth and adults affected by FASD, it is not producing optimal outcomes. They are often referred to as the service users for whom nothing works, but it will work when the disability is understood and when services are planned and delivered collaboratively to accommodate the disability. Service systems need to operate on the basis that service delivery must accommodate the disability, rather than expecting those living with the disability to accommodate the service providers or service systems. We have attached the FASD Peterborough key findings report, as it further addresses the accommodation issue.

It also needs to be noted that when service provision does not understand and accommodate the disability, the result is harmful and not simply benign, as it sets up expectations for those living with the disability that they cannot meet. It results in everyone involved feeling like failures. I want to speak on the side: As a mother, I can certainly confirm that you definitely feel like a failure. You feel like you can’t do anything right until you understand this disability, and it’s the same for service providers. It’s really critical. It results in everyone feeling like failures, which for those living with the disability becomes destructive and debilitating over the course of a lifetime. Understanding and accommodating FASD is about working differently and not necessarily harder, and it’s about making better use of existing services and resources to achieve better outcomes.

Finally, approximately 10% to 25% of this population will meet criteria for developmental services. Given the mandate for developmental services to provide service to provincial crown wards before all others, along with what is estimated to be a significant prevalence of FASD-affected crown wards, it’s important for the Ministry of Community and Social Services to recognize that the impact of FASD on developmental services is growing, and it needs to be addressed

Ms. Sharron Richards: Our recommendations are founded on two critical factors: (1) that FASD is a preventable disability; and (2) that improved outcomes can be realized through early diagnosis and interventions that accommodate the disability and result in realistic expectations and optimal outcomes.

Our first recommendation is that the province of Ontario must engage with community stakeholders in the development of a provincial framework to address FASD. Ontario is one of the few provinces yet to develop an integrated approach to addressing FASD. Our network, FASD ONE, is in the final stages of preparing a document that we hope will contribute to the development of a provincial framework on FASD. Once completed, it will be presented to the provincial government for possible approval and implementation. We ask that this committee urge the government receiving the FASD ONE framework document to give serious consideration to its adoption, along with dedicated funding to implement the framework.

Second is that the province of Ontario dedicate resources to the prevention of FASD through public awareness, education and timely access to services for pregnant women using alcohol. FASD is a preventable disability. It is estimated that for every dollar dedicated to prevention, $6 will be saved on reduced call on services that frequently go from the least expensive to the most expensive services. All Ontarians, but especially women of child-bearing age and pregnant women, must receive accurate information regarding the risks of alcohol use during pregnancy and have access to the services required to abstain from or limit alcohol use in pregnancy.

Our third recommendation is that every person in Ontario who is affected by FASD have equitable access to the range of supports and services they require to live successful and productive lives. Every Ontario resident living with FASD and their families will require lifelong supports such as diagnostic services, respite, educational support, supportive housing, employment support, family planning, opportunities to become part of the social fabric of their communities, service providers in all sectors who understand their disability and lifelong case management services.

A recent study of youth with FASD living in Ontario found that 86% of youth had never been referred to or received any FASD-specific intervention or services, despite high levels of functional impairment across domains. Moreover, the majority of youth who had received specialized interventions or services had done so when participating in research.

Accessing needed resources and services shouldn't depend on where those affected live, in which service system they are being served, or whether their family can afford to purchase services for them. Eligibility criteria must be based on adaptive functioning and not just IQ in order to be inclusive of individuals affected by FASD. Equitable access to services should be considered their right.

The fourth recommendation: Capacity must be developed for the delivery of FASD-informed services in all systems and across all sectors. Regardless of which service sector one works in, an understanding of FASD as a brain injury with developmental impacts should be a practice prerequisite. Once FASD is understood as a brain-based neurodevelopmental disability, it should lead to two things: (1) an appreciation for the prevention of the disability through a message of no alcohol use while planning to become pregnant and when pregnant, and (2) for those currently affected, the critical need for early screening, assessment and diagnosis accompanied by early and appropriate interventions and supports.

Recommendation 5: It is critical that the Ministry of Community and Social Services prioritize identification of individuals with FASD as well as training and education in effective intervention approaches to create an informed system of care within developmental services.

Research clearly indicates that informed understanding and accommodation create positive outcomes for persons with FASD; therefore, screening, identification and training for all staff within the developmental sector is imperative for long-term success. The prevalence of this disability within the sector demands the development of expertise and specialization.

Number 6: Service system philosophies must make a paradigm shift from a goal of independence to interdependence. Many people living with FASD will not be able to live independently. Throughout their lives they will require support to help them manage the challenges associated with their brain injury. When they are served by systems whose goal it is to help them become independent, they will always fail to meet that expectation. For service systems to continue to have that as a service goal, it inadvertently places those affected by FASD in harm's way. It is in everyone's best interest to aim for interdependence with lifelong supports as a realistic, achievable goal.

Number 7: The child and youth service systems and the adult service systems must work to provide an integrated, seamless transition from one system to the other. We know that transitions for those affected by FASD are difficult and challenging. When the transition from the child-youth system to the adult system is not smooth and integrated, as is currently the case, too many young people affected by FASD aging into adulthood fail to make that transition.

They also go from a system in which they may have received significant support to one that expects a level of independence they cannot achieve. Case management services for those affected by FASD, especially transitioning-aged youth and adults, are frequently identified by caregivers and service providers alike as a critical but almost non-existent service.

Navigating our systems of service is not easy for most of us, but is almost impossible for a person living with an injured brain that significantly impairs their functioning.

Number 8 and our last recommendation is that a lead ministry be identified to coordinate an inter-ministerial approach to addressing FASD. FASD involves several provincial government ministries: health and long-term care; children and youth services; community and social services; education; colleges and universities; community and public safety; and the Attorney General. Yet, there is no one ministry assigned the lead responsibility. This needs to change in order to move forward to better address FASD at the provincial level.

We thank you for your time and your attention. On behalf of FASD ONE and all those in our province who are affected by FASD, we applaud your committee for addressing the issue of improving services for residents living with a developmental disability. We look forward to seeing our recommendations, as well as those of all the parents and caregivers who have appeared before you, reflected in your final report.

Thank you.

The Chair (Mrs. Laura Albanese): And we thank you for your presentation—very insightful. There's no time for questions, unfortunately, but we really appreciate everything that you brought forward. Thank you.

Ms. Sharron Richards: Thank you and good luck.

Ms. Nancy Hall: Thank you.

The Chair (Mrs. Laura Albanese): Thanks.

We're recessed until 1 p.m.

The committee recessed from 1210 to 1300.

MS. FRANKE JAMES

The Vice-Chair (Mrs. Christine Elliott): Good afternoon. I'd like to call the committee back into session this afternoon. Our first presenter is Franke James. Thank you very much for being here. You have 20 minutes for your presentation, and you can start whenever you're ready.

Ms. Franke James: Wonderful. Thank you very much. I have a really, I think, shocking story to tell you, but we're hoping that it has a happy ending. The role that you can play is to help make that happy ending. I've got specific suggestions at the end of my talk.

This is Teresa's story. It's about crisis, capacity and courage. I'm her sister Franke James. This is my sister Teresa. She's 49 years old and has Down syndrome. Teresa lived with my parents all of her life. After my mother died in 1999, she moved with my father to a condo in north Toronto.

On November 27, Teresa was admitted to a nursing home. We found this very odd because Teresa is an active, strong-willed and able-bodied adult. Teresa should never have been admitted to a nursing home. You can see in this picture her fellow patients, residents, at the Rekai Centre are in wheelchairs, and Teresa is doing her power walk.

The admission was done against her wishes. Let me just go back to that. I've blurred out the people for privacy reasons, but you can see that they're actually being fed. Teresa doesn't need anybody to feed her.

It was also done against the wishes of her father and me. How could this happen? The system did not protect Teresa. We're talking about the Griffin Centre, the CCAC, the Rekai Centre, Surrey Place, the DSO, the Toronto police and Family Service Toronto. In fact, the system actually worked against Teresa. Her human rights were taken away. Teresa's father lost his rights to protect his daughter. The CCAC crisis list was manipulated to put Teresa into a long-term-care home. Teresa's human rights were taken away.

When we look at this picture, we've got three bubbles: my father's, my sister's and a sibling's voice. Whose voice would you listen to? My dad says, "I do not want Teresa in a nursing home." Teresa says, "I want to stay in the condo." A sibling says, "Teresa should be placed in a nursing home."

On September 4, the CCAC assessed Teresa as not capable. They used Teresa's statements about her independence—"I shower myself"; "I dress myself"—as evidence of cognitive decline. The staffer Mark Weitz wrote, "The client has no insight into her dependency on others to shower her and dress." The client said, 'I shower myself'; 'I dress myself.'" So obviously they're believing the caregivers, and they're not believing Teresa.

The CCAC repeatedly ignored Teresa's stated wishes: "I like the condo. I want to stay in the condo. I like it here. I can play computer and watch TV." This is from actual files that we've obtained from the CCAC, and they were very difficult to obtain.

The CCAC ignored their own observations about Teresa. This is how the CCAC worker described Teresa: "a pleasant, calm and quiet client with Down syndrome who enjoys close relationships with her family members and at her day program at Addus."

Teresa's father lost his rights to protect his daughter. How can that be? The CCAC learned from my siblings that Teresa's dad, the senior power of attorney, would oppose Teresa's placement in a long-term-care home.

I'm just going to read this little bit to you that's highlighted in yellow: "Joseph, who is likely primary on the power of attorney document, would be upset regarding the client being placed in a long-term-care home. The DCC agreed to meet the client at Joanne's address"—that's one of my siblings—"so as not to upset Joseph. Joanne said she's pretty certain Joseph would not challenge the authority of secondary attorneys, and the DCC has suggested that the client could possibly make another POA document, though this will need to be discussed in more detail later."

The CCAC suggested on September 6 that Teresa's dad could have his rights removed. So, as a sibling, I am just shocked that the CCAC is advising how to remove my dad's rights. It's unbelievable. This is probably one of the most difficult and horrific episodes in my life.

"The DCC said that if Joseph asserts his right to be primary attorney for PC and will not address the issues involved in the client's increasing need for care, this shows inability to respond in clients' best interests and that a form G submission to the CCRB may be necessary." So they're giving advice on how to remove my dad's authority. My dad is a former lawyer, a QC, and a war veteran.

On September 10, CCAC interviews Teresa's dad and notes that he very clearly does not want Teresa put in a long-term-care home. "Joseph is adamant he does not want Teresa placed in a long-term-care home and became somewhat litigious, saying, 'I stopped practising law a few years ago, but I'm able to get a lawyer if I need one,' and that he would fight attempts to place client in a long-term-care home."

On September 11, the CCAC receives revocation documents removing Joseph Pocock's power of attorney. So my siblings, without telling me, without telling Teresa, without it becoming a known family issue, removed his rights as power of attorney over Teresa.

"DCC received a copy of a letter showing client's father Joseph Pocock has resigned as of 2013 September 8 as attorney for personal care. Now the siblings William and Patsy will take over care."

The CCAC, interestingly, did not question the revocation document. It's really curious that they didn't, because it was legally invalid, because it was signed by the spouses of the attorneys. So as Teresa's sibling, I am furious that my brother-in-law and my sister-in-law signed this document without my knowledge that took away my dad's rights to protect my sister.

That's another shot of it.

The CCAC crisis list was manipulated over and over again to put Teresa at the top and into a long-term-care home. On August 23, Teresa was falsely described as incapable of taking care of herself. It says that she needs physical assistance for bathing, for personal hygiene. She even needs physical assistance for the toilet, to wipe herself. She needs physical assistance to dress her lower body. This is not the sister that I know, and I am shocked that this would be in the CCAC's records.

1310

On October 5, Teresa was described as having insidious cognitive problems and decline: "Client has

Down syndrome, insidious onset over past year of short-term memory and procedural memory loss with accelerating STM loss/confusion over the past three to six months." Personally, I think that this was engineered in order to qualify her for a long-term-care home and it was a figment of my siblings' and the CCAC's imagination.

On October 5, Teresa was reported to have had wandering events: three, possibly more, wandering events in the past six months. So they're stacking the deck to make her qualify for a long-term-care home.

Mr. William James: Like Alzheimer's.

Ms. Franke James: Like Alzheimer's.

On November 21 and 22—so we had emails going back and forth amongst the siblings. When I really realized that they were serious about putting Teresa in a nursing home, I went, "Well, this is ridiculous. You can't put her in a nursing home. We are willing to take responsibility for her. Teresa's happiness is the most important issue here. We will be contacting the DSO to let them know we are willing to take Teresa and require further information about her health."

However, my siblings refused to give us any information about her health, and on November 27, Teresa was admitted as a long-term placement to the Rekai Centre. This was done with deceit and trickery. Teresa was taken out for a nice breakfast and then, instead of going to her program at Addus, she was taken to the Rekai Centre.

This is my brother speaking: "Colleen," his wife, "and I met Teresa this morning at the condo, went out for a nice breakfast and then went to the Rekai Centre at 10 a.m. Patsy," another sibling, "and her husband, Gerry, packed up what Teresa needed and met us there on our arrival." This was done without Teresa's consent and without my father's knowledge and without my knowledge.

"Patsy and I went over to the condo this afternoon to let Dad know what was happening. Dad was not pleased. He said he no longer has a reason to live on," and we'll see more of this.

November 28: CCAC was informed about my offer to take Teresa. On November 28, my lawyer contacted the CCAC. So they knew that I had offered to take Teresa. That should have taken Teresa off the crisis list and that should have taken her out of the long-term-care home, but it didn't.

On November 30, my dad, my husband and myself went down to the Rekai Centre and Teresa was discharged under the authority of my father, who was senior power of attorney. We had not seen the revocation document and they didn't have it on file. We didn't know anything about it.

On November 30, I spoke with the CEO of the Rekai Centre, Mary Hoare, and told her about my offer to care for Teresa. On November 30, the CCAC, unbeknownst to me, suggested calling the police to return Teresa to the Rekai Centre. What is going on? I mean, how could they be doing this in good conscience?

The CCAC writes, "If the client is at risk, the daughter," meaning my sibling, "can call the police to see if there is anything they can do to assist."

That night, the police arrived at my dad's home and took him, against his wishes, to Sunnybrook Hospital under a form 2, Mental Health Act, allegedly for being suicidal. I don't think it was anything to do with being suicidal. I think it had to do with the fact that my dad was threatening to change his will, and he was taken to the hospital instead of having the opportunity to meet with a lawyer. He was released later, in the early morning hours of December 1.

On December 1, the Rekai Centre was informed again about my offer to take Teresa. I wrote to Mary Hoare, and I said, "Thank you for speaking with me yesterday about my sister Teresa Pocock and her discharge from the Rekai Centre." I can give you copies of all of this, so you can read it in detail. I'm just going to read this quickly. I put this in writing to my siblings again—December 1. We had Teresa at our house, and I said, "Bill and I want Teresa to live with us. We feel it would be ideal for many reasons. We have an extra bedroom. We work at home. Our schedules are flexible. She will be close to family members, and she will be in the same neighbourhood she grew up in. We feel we can help Teresa to grow and develop to her full potential, as we have helped Teresa to develop her ability to do walks, such as the eight-kilometre Terry Fox walk. Our ultimate goal will be to have Teresa at a group home, if that is eventually what she wants and is in her best interests. But we are in no rush. We would be honoured to have Teresa live with us. Please let us know if you support our decision."

On December 4, we got a knock at the door. Three big policemen had arrived, after a missing persons report from the Rekai Centre, to take Teresa back to the nursing home. It makes me angry and upset to go through this again. So there I was, showing the policeman the documents, the photographs—I am a photographer, I'm a videographer; we documented all of this. We worked with a lawyer throughout this whole process. Fortunately, the police agreed—and I think it was an hour and a half I had to go through all of the documents and show them the video that we had taken, that Teresa was safe. They allowed her to stay with us.

On January 6, the CCAC, Surrey Place, refused to release Teresa's medical records, saying that Teresa's capacity was in question.

On January 11, Teresa had a new capacity assessment and was found to be capable. This is so important. Teresa Pocock is capable of granting a power of attorney for personal care. Kathy Sullivan, who has been a capacity assessor for 40 years, met with Teresa in our home on two occasions. She could see that Teresa wanted to live with us and wanted us to help her make her personal care decisions.

On January 15, Teresa signed a new power of attorney for personal care, and this was with her lawyer, Jane Martin. Teresa had never had a lawyer before, but she does now, and it's not my lawyer; it's her lawyer.

On January 18, Teresa got her CCAC records, and you're seeing some of them here.

Now I'm going to show you some photos of how Teresa is thriving at our house. You see she's wearing oven mitts and holding a lasagna that she has helped to make. She's at a Christmas party at Addus. Teresa is doing her happy dance. Teresa is thriving.

Even during the power blackout in Toronto, we managed to get away to a family's place that had power, up in Collingwood.

We are honoured and happy to have Teresa live with us, but it has been a horrible, horrible experience that brought me here today to tell you what has been happening.

I just want to go through our recommendations.

(1) The consent and capacity law is easily abused, so we need to change it. It appears that we have no recourse to hold our siblings, but most importantly, all of the organizations that worked against Teresa, accountable. We'll be exploring that in more detail, and maybe you can advise us. But our lawyer has told us the consent and capacity law needs to be updated.

1320

(2) The crisis list is broken; we need to fix it. If you go through all of the documents and the emails leading up to this, you will see how the description of Teresa was manipulated and changed in order to make it sound like she couldn't take care of herself and she had to be in a long-term-care home. I have never helped Teresa in the toilet. I have never helped dress her. She does not need help bathing, but I do supervise her to make sure she gets in and out of the tub safely.

(3) The disabled and the disadvantaged people are getting hurt in Ontario's care system, and we need protection for them. Nobody would know about this; Teresa would still be at the Rekai Centre if I had not stepped forward, with my husband's help, to get her out of there, and it is really, really shocking.

That's my presentation. Thank you very much.

The Vice-Chair (Mrs. Christine Elliott): Thank you very much, Ms. James. I think I can speak for all of us on the committee when I say that this is a truly shocking story that you have told us today. I'm so sorry that you and Teresa and your family have had to go through this. We absolutely will take everything that you've said into consideration.

I'm wondering, if it's all right with Teresa—because they're her records—if she would consent to your allowing us to have a copy of them. I think we'd all like to really understand a little bit better what went on here so that we can make the necessary moves to effect change.

Ms. Franke James: That would be great. As her power of attorney—and my husband is now power of attorney—Teresa, is that okay?

Interjection.

Ms. Franke James: Okay. The other thing I'd like to say is that if you would like a printed copy or a digital copy of my presentation, you're welcome to it. There are other background documents that I can provide, as well, which substantiate everything I've said.

The Vice-Chair (Mrs. Christine Elliott): Yes, if you could provide us with all of that information, I think we would all be most interested in receiving it and reviewing it.

Unfortunately, we don't have any time left for questions, but I'd like to thank you very, very much for being here today and sharing your story.

Mr. Bas Balkissoon: Just a quick request: If your lawyer can send us any information on the law and a suggestion—because we heard the same complaint with the mental health review. Three of us who were on the committee would love to hear his opinion.

Ms. Franke James: Our lawyer is Brendon Pooran, whom you may be familiar with. He's on the Consent and Capacity Board. He has been a tremendous help for us throughout this.

Mr. Bas Balkissoon: We'd love to hear what he would suggest.

Ms. Franke James: That's great. Thank you very much for this opportunity to present.

The Vice-Chair (Mrs. Christine Elliott): Thank you very much. I'm glad this story had a happy ending, at least.

The Vice-Chair (Mrs. Christine Elliott): Ms. Wong?

Ms. Soo Wong: I just want to say thank you for sharing your story and thank you for fighting for Teresa. This is what it's all about.

I do have a question, Madam Chair, for the researcher.

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

Ms. Soo Wong: I am in shock right now to hear about the CCAC.

Is it the Central CCAC?

Ms. Franke James: It's CCAC Toronto.

Ms. Soo Wong: Okay. I want to know whether it is the Toronto LHIN—because the CCAC reports to the LHINs—I want to know the rights and abilities. Because if it happens in the Toronto CCAC, how many other CCACs are currently in a similar situation? I want an explanation, given the consent we just received from Teresa as well as the POA, of how this could happen.

Coming from the health care sector, the rights of the POA are supposed to be respected, and the law is there to protect those rights.

I need some clarification from the LHINs—because very, very clearly, there's a chain of command here, and I'm concerned. If it happens at the Toronto CCAC, other CCACs across the province are in a similar situation, where the wishes and the choices of the POA are not being respected. I just want to ask the researcher to go back and find out about the CCAC and get some information for the committee.

The Vice-Chair (Mrs. Christine Elliott): Ms. Wong, we should probably review the background first, so that we really understand the issues, and then we can go back with very specific questions to the CCAC, if that's all right with you.

Ms. Soo Wong: Yes, okay.

Mr. William James: Can I make a simple comment on that? I think the problem with the CCAC is that there is a conflict of interest with the people who are serving the clients and the powers of attorney. The client was

Teresa, and another client was Joseph Pocock, her father, but the person working for the CCAC was serving the powers of attorney—

Ms. Franke James: The secondary ones.

Mr. William James: —the secondary powers of attorney, and was working to serve their needs. Because of that, they didn't really think about Teresa's needs or her father's needs, so that's the conflict of interest there. There needs to be something to help people separate who they should be taking care of, because, certainly if you read all of the documentation, the primary directive is always to serve the client first. That is the official policy, but it just wasn't done.

The Vice-Chair (Mrs. Christine Elliott): Clearly not. There is a clear delineation of legal authority there that, it appears, was undermined significantly in this case. We will certainly look into this, and we will look forward to hearing from your lawyer with respect to specific suggestions.

Yes, Ms. DiNovo?

Ms. Cheri DiNovo: Yes, just quickly: We heard in Ottawa from a group called People First. Their slogan is "Nothing about us without us," so I would definitely suggest that you hook up with them, because with that slogan, that says it all. It's got to be Teresa's wishes first.

Ms. Franke James: That's right. That's why Teresa is here today.

The Vice-Chair (Mrs. Christine Elliott): Thank you very much again for joining us.

Ms. Franke James: Thank you. And I will follow up—I suppose with Trevor—to find out how to submit those documents to you.

The Vice-Chair (Mrs. Christine Elliott): Great. Thank you.

MR. MITCHELL FEINMAN

The Vice-Chair (Mrs. Christine Elliott): All right. Our next presenter is Mitchell Feinman. I'd like to ask you to come forward, please, Mr. Feinman.

Mr. Mitchell Feinman: Does it matter where I sit?

The Vice-Chair (Mrs. Christine Elliott): Anywhere on this end, please. Thank you, Mr. Feinman. As you've probably heard, you have 20 minutes for your presentation. If you don't take up the entire time, we will have time for questions, so please start whenever you're ready.

Mr. Mitchell Feinman: Great. Thank you, everybody, for inviting me today. I'm so excited to be here. I thought what I'd start with is the letter that I wrote to the committee to get me the invitation today.

"Dear Mr. Day,

"I have been teaching students with developmental disabilities, including autism, in the Toronto District School Board the past 33 years, and I am so pleased to read about your upcoming meeting of the Select Committee on Developmental Services.

"I would certainly like to make an oral presentation to the committee in regard to the urgent need for day programs for young adults ... that reach the school-leaving age of 21 and are in dire need of services.

"The problems encountered by parents of young adults with developmental disabilities ... are complex and difficult to resolve. Difficulties faced by the families are increased rather than diminished by the physical maturing of their children. Parent respite and day programs could help alleviate some of the more serious problems observed: stress, fatigue, and irritability as a result of the strain involved in caring for their children.

"Many parents have their children on waiting lists for group homes, however, in the interim, need community support to help cope with the pressures of daily life.

"I have taught and know many students with developmental disabilities who have left the school system at age 21 and are now languishing at home with no available services while waiting for scarce placement openings to become available.

"Many of the achievements and gains my students have made over the years during their school career fade away due to the lack of further training, stimulation, retention and review once they transition from the school system.

"Young adults with developmental disabilities ... need to continue their education and gain more independence.

"Countless reports and recommendations have been presented over many decades by various ministries highlighting the shortage of services for adults with developmental disabilities.... There have been many recommendations in the past calling for innovative funding mechanisms such as public-private partnerships to be developed in order to create much-needed day programs for students who reach 21 years of age and must now leave the school system.

1330

"I am rapidly approaching my retirement and plan to intensify my efforts in securing and providing high-quality low-cost effective programs to individuals who are difficult to serve.

"I was previously granted a leave of absence," with pay, "from the Metropolitan Toronto School Board … to undertake a study of the need for and the development of a highly specialized recreation-vocational-socialization learning centre for adolescents and adults affected by pervasive developmental disorders, particularly autism.

"I would love this opportunity to meet with the committee to discuss my project ideas and plans and how we may proceed to provide top-quality cost-effective services for individuals who require a high level of care and supervision....

"Thank you very much for your consideration.

"Sincerely yours."

That was the background for the invitation today, and now I'd like to say—sorry for my over-reliance on the use of cue cards and a script, but when I found out my every word and action was going to be recorded, I thought that this would be the best way for me to proceed.

The parents of students graduating, as has been said, have had an extremely difficult time in the past accessing services that are appropriate for their children. The Toronto Star wrote quite a series of touching articles last year highlighting the problem. It totally inspired me to start working on the Bridging the Gap project again.

Over the years, I've been developing ideas to improve the coordination of services regarding the transition of graduating students. I've also served as a volunteer on the board of directors for the local Toronto chapter and the provincial branch of Autism Ontario, a provincial parent organization. I've attended eight annual information fairs that the DSO operated for families in Toronto, and this past May it was announced to families that Passport funding has been frozen at the current time, leaving some parents in tears.

I'm here today to talk for the thousands of students who can't speak for themselves. I thought I would talk a little bit about what is happening to my particular students who have graduated and have left school—regression, in most cases. Many of my students have become aggressive again: hurting, scratching, pulling hair, biting. Some are running away in the community from their caregivers. Some have lost their ability to speak or copy sign language words through a lack of practice. Some are no longer following instructions from their parents; they've become very non-compliant. Many have no access to computers or to tablets like an iPad, which is being used in classrooms so successfully. Many individuals at home today have never used or benefited from one of these devices. Some of my children no longer have use of or access to a voice output communication aid or a mobility therapy ball for physical exercise that they would have in a structured program like a school.

No longer having opportunities for appropriate social interactions, some of my students have become very obese from sitting on the couch and eating and watching TV all day. We've had increased rates of self-stimulation: repetitive behaviour such as rocking, watching finger movements, bouncing up and down on their couches all day, breaking them. Some of my children rip fabric at home all day. They are no longer going out in the community. They're not going to supermarkets and parks. The parents are embarrassed by their unpredictable behaviours. They are sometimes not able to deal with the behaviour. They may have to call their siblings to help deal with the temper tantrums, the terrible problems they have, while the parents are getting older at the same time.

I sat on identification/placement/review committees for 10 years at McCordic school when I was starting out, and I knew I had to do something to try to help get services at that time. I can't help but wonder why we spend so much time as a society educating these children if we don't care what happens to them when they reach 21. Parents and children need more support.

Ideally, I would now like to see the position of a transition coordinator created in the school boards in Ontario to help, and that's the page in the package that I gave out on the left-hand side. Also, I was thinking that perhaps a case coordinator should be appointed for each student, to be responsible for their transition. As well, I think we need to follow up on the many students who have already graduated and are, as I say, languishing at home with nothing to do to occupy themselves. There are thousands of people in this province like that now.

I would hope that sufficient funding is allocated to the DSO agencies so they never have to tell a parent that the government money is frozen and they aren't able to help right now. I think, as a society and local community, we should feel fairly disappointed in the way we've been treating this population for so many years and continue to do so, although with meetings like this yesterday and today, hopefully we're getting better. I've researched and read many reports and articles written over the past 30 years indicating the same lack of resources for students with autism and other developmental disabilities once they leave the school system. Now, after all these years, we find ourselves in an "urgent" situation. I hate to tell you, but it's been urgent for more than 30 years.

Hopefully, something positive and wonderful will come from these meetings, I'm sure. I want to hope that things are going to improve and I want to give hope back to the families who may have lost theirs. So I feel a little different today, coming here. Most times, people approach the government for money and other assistance, but I'm here today to offer my assistance to the government. I don't want anything other than a chance to make some of these plans happen.

We have to learn how to manoeuver the government system for parents; it's too unwieldy. I look at the trouble I have as a professional, and I just wonder how parents ever deal with it. You know what happens? They don't. They quietly endure and suffer rather than complain and fight. It's especially difficult for many of my families who have English as a second language to advocate successfully.

So I'm here today to share my plans that I've done over the past 29 years that will hopefully improve the lives of many individuals and their caretakers. I was granted, as I said, a half-time leave of absence with pay by the board to undertake a study on the need for and the development of a highly specialized recreational-vocational-socialization learning centre for adolescents and adults affected by pervasive developmental disorders, particularly autism. I decided to wait until I was ready to retire before leaving my teaching career to do this, and now that time is approaching. Hopefully, the benefits of such a program will be self-evident and people will support it so that it will grow. My plan is to continue building up my network of individuals and eventually bring them together.

So those are my prepared notes.

You have a sheet, "Proposed Summary of Duties for a Transition Coordinator for School Boards." They would be to support the team to facilitate the development, implementation and monitoring of transition plans for students with complex behavioural needs. I was thinking it would be great to have a transition office where the parents can come and find out about what services are available from the school board perspective, working in conjunction with the DSO, which does some of this work. Right now, the school boards give a pamphlet saying, “These are the agencies that will look after over-21. Contact them and get your child on a waiting list many years in advance.” But I was thinking it would help families if we had an office and maybe had videotapes where they could see some of the centres that are out there without having to go to the trouble of visiting all of them, so they could see which ones are of interest, narrow down their selection and maybe save some time and help them.

You can read most of the duties yourself on here.

As well, one of my ideas: While we know there are so many children waiting, why can’t the school boards open up a classroom where people could drop in and have some socialization? We had that many years ago. The Toronto board did it for two years for 21- to 23-year-olds. But they found out the funding was a problem. The space was a problem: If we don’t let the children leave the schools, where will the new ones go? So it was discontinued after a couple of years, but again, I would like to see a place where families could just bring their child in for a few hours to get them out of the house.

1340

That was my idea for the transition coordinator.

I prepared two pages. On the right-hand side of one is a summary of some of my original BridgeGap goals and objectives for the centre. I have a much more detailed binder that I didn’t photocopy, but I could provide that to the committee if you’re interested in seeing that.

As well, on the other sheet I have an overview of the different organizations, ministries and people that I’m now targeting to help me try to come up with the centre. Again, I’m just approaching them as an individual. This will be my approach to trying to get services.

I thank the committee so much for having me here today.

The Chair (Mrs. Laura Albanese): Thank you. We have about a minute of questions each. Ms. Jones?

Ms. Sylvia Jones: Thank you for your presentation. I have to say that we are told that the school board is actually in charge of transitions. With what you’re presenting to us today, from working in the system, you’re reinforcing what we’ve already heard, which is that we’re doing a pretty crappy job of the transition, post-21.

I’m wondering if, instead of a transition coordinator, you have thought about a system navigator which would not be age-specific—so it’s about navigating right from diagnosis, as opposed to this hiving off where we say, “The educational system is going to look after you from five to 21, maybe, and then someone else after that.”

Mr. Mitchell Feinman: I wonder if a person would have the skills to know enough about the post-21 programs to advise the parents, if they have to know all the services right from nursery school on—to be such a generalist. Certainly, there is a need for that.

Ms. Sylvia Jones: Right now, there isn’t much available post-21, so there isn’t a lot to learn, but I hear you.

Mr. Mitchell Feinman: No, but there are so many people who are trying so hard, with the few agencies out there, to give them continued support and to expand their support—it’s a fabulous job, in most cases.

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

Miss Monique Taylor: Thank you so much for all of the efforts that you put into this sector, and we can definitely see that you do that with a lot of heart and compassion. It’s important, because we can never have enough—the last presenter hated the word “advocates.” It’s true; it’s unfortunate that we need advocates, but without them, we would definitely not even be as far as we are, which isn’t very far at all.

A system navigator is something that we’ve heard about quite often at this table—people who need to be in those transition roles to make sure that families have smooth transitions to get through difficult times in life. We’ve heard it quite often that families are getting over one hurdle, almost having time to catch their breath, before they’re heading into the next hurdle of life, so we do really need to see those transition pieces in place.

Thank you for the work that you’re doing, and keep up the good work.

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

Ms. Soo Wong: Thank you very much for your presentation.

One quick question: Can you share with the committee, maybe not in the presentation—you can follow up with a submission to us: What is the TDSB doing with respect to the transitions for those—planning work with the parents of those who are currently between 17 and 21 years old, preparing them for the world outside the TDSB? If the TDSB is responsible for transitions, what programs, what services—who is leading that transition? I’d like to hear back from you, to this committee.

Mr. Mitchell Feinman: Okay.

The Chair (Mrs. Laura Albanese): Thank you for presenting to us this afternoon. It was very interesting.

Mr. Mitchell Feinman: Thanks again for having me. It’s my honour.

CANADIAN ASSOCIATION OF MUSLIMS WITH DISABILITIES

The Chair (Mrs. Laura Albanese): We’ll now welcome the Canadian Association of Muslims with Disabilities. Good afternoon. Please take a seat and make yourself comfortable.

Ms. Rabia Khedr: Thank you. My name is Rabia Khedr. I’m the executive director of the Canadian Association of Muslims with Disabilities. I am a person with a disability, who is also a sibling of adults with intellectual disabilities, as well as somebody who has been heavily involved from multiple directions—as a researcher and a trainer—in the developmental services section around diversity and inclusion etc., and, of course, as an advocate.

I appreciate the opportunity to have these 20 minutes to speak to you. I’m hoping that I leave you with something—now, why isn't my computer talking to me? Give me one second. I'm wired, just in case you're wondering. I have to have this little voice talking to me so I know what I'm talking about here.

What I'm hopefully coming with today is, I've provided you a five-page document there which has the key discussion points outlined, which I will go through, as well as an article attached as an anecdotal piece, a case narrative of a news article that was produced in the Ottawa Citizen on July 15, 2012. There is still no place for Mohamed. He sits in an ER today in Toronto, in fact.

Let me start by saying that families are generally very grateful. We appreciate the fact that there are so many services available to us in Ontario. We acknowledge the fact that there is no better place for people with disabilities to live a full lifestyle in any other part of the world but right here at home in Ontario.

Given that fact, we're grateful. We thank the system. We certainly value the efforts of the province to address gaps and appreciate the fact that this committee has been set up, and the fact that the Ombudsman's office has been investigating the sector. We are certainly looking forward to how transformation fully comes to fruition.

We appreciated the DSO when it was implemented. I actually even provided training around cultural responsiveness to one of the DSOs as it was developing, before opening its doors, and reviewed the support intensity scale application process to ensure that it was, in fact, addressing culture and spirituality and looking at an individual from a holistic perspective.

We really want to see consistency across the board in the sector. We want to see improvements because, as the population ages, as we've gone through these 30-plus years—as the teacher earlier was remarking on—between deinstitutionalization being finalized and community-based service being experimented with, we've come full circle through a generation of people's lives that have in fact fallen through the cracks.

My brothers are two of those individuals, today 36 and 38, who have certainly fallen through the cracks when education was just beginning to include them and the community was not ready to include them after age 21. I was told, "There's a big black hole," and I'm surprised that 20 years later I still sit here and there's a big black hole for people with developmental disabilities. That was the lingo we had out in Peel region: After 21, there's a black hole. There's nothing out there for these young men and women.

When I sat with a number of people, including ministry and service providers, and I said, "Really?", they said, "Yes." I said, "Does that mean I have to create something?", and they said, "Yes." I said, "Okay, I will." I formed a family group called Opportunities Mississauga for 21 plus. That's what they call themselves right now, but originally they were called—coined in my basement—925421+, because what else do adults want? They want something to do between 9 and 5, whether it's paid or unpaid.

Not much has changed. I'm basing some of the talking points here on case narratives and, like I said, the case in point that I've attached. We really need to work toward improving the quality of life for Ontario's most vulnerable citizens. People with developmental disabilities are in fact the most vulnerable because they cannot voice their needs for themselves. Every one of us, including myself, will manipulate or play around with their interests, whether we like it or not, because we're all impacted through facilitating support, so we will always try to get the upper hand. One sibling, one parent, the other parent, community will always have their own agenda behind the provision of care, so I'm really not even sure how we can guarantee absolute justice to this particular population.

1350

However, looking at navigating the developmental services system, certainly, diverse families lack service literacy, face language barriers and have challenges accessing the system. When somebody like myself, who has participated in the system from many different perspectives, has challenges navigating it, I can just imagine if people have barriers.

Case loads and burnout certainly limit the quality of service that is provided to families by front-line workers. Some of them have grown up in the system. Enough is enough—okay, my sarcasm is kicking in; I apologize. But in all fairness, after a while, when you have nothing to offer, it becomes very difficult to serve families, when all you can say is, "We have nothing to offer." Unfortunately, what ends up happening is when families are presented with options that don't meet their criteria, families like mine are made to feel like, "Oh, well, we're giving you something. You should be grateful."

The DSO layer, in fact, we had great hopes and dreams for, but it has complicated the system at present, and we're not sure exactly why that is. It has added an extra layer, which really hasn't brought about sufficient change. Perhaps, case in point mentioned previously, frozen resources are part of that problem.

Service gaps: A big, huge part of what families need that has not been present from the get-go is access to some sort of counselling or intervention through social workers to help them truly understand the nature of their child's disability, to bereave through it, because there is a bereavement dimension. Let's be honest: I don't want to have a blind child or a developmentally delayed child. I will feel badly for that. As somebody who's an activist, I can very confidently say that. We don't pray for that. If it happens, okay, thank God, I'll do my best. But it's not our first choice. Every parent, every human being looks forward to a healthy, "normal" child, whatever normal means. So there is a bereavement dimension to that that families usually don't even have an opportunity to cope with over a lifetime. They need to develop coping mechanisms; they need to feel that they're not alone. They need to really learn to put that into context and then move to the planning stage, because there is a lifetime of planning that needs to happen in order to ensure appropriate care—self-care and care for the person receiving care.

We certainly see that service providers lack competence in serving diverse families and addressing their spiritual and cultural expectations. There are regional disparities from city to city and town to town in terms of how services and programs are actually delivered at the front line. An inclusion philosophy is not implemented in practice, although agencies are bound by it in essence. Families in crisis find inadequate supports although there are crisis networks. Again, there's conflict of interest on those crisis networks because they're made up of the very agencies that the families might be challenging in terms of service delivery to intervene in a crisis situation.

Individuals with complex needs and dual diagnoses fall through the cracks. They have limited access to appropriate supports, and that includes the whole range of supports required, from medical to social to recreational to educational—the whole gamut of services, whether it means even down the criminal stream. Often they are falling through the cracks. If developmental services isn't prepared to pay for the services that they need, the government is paying for services through either the criminal stream or the health stream. Somebody is paying when people fall through the cracks because there is a need in crisis situations for intervention, and people are turning to EMS etc.

These streams of health, EMS, emergency rooms and hospitals are inadequately equipped to support people with developmental disabilities and, in fact, violate their human dignity.

The example I can give you is: My brother was taken, time and time again, by police to the local hospital. In the mental health room, he would be kept in ER to the extent that, because he wasn't comfortable there, he was acting out, his drugs were out of whack, they had him sleeping on the floor on a mat and stripped down to nothing. That's not human dignity, as far as I'm concerned. Every human being deserves dignity, no matter what kind of situation they find themselves in.

A two-tier system provides inequities across the board between families and individuals in terms of supports, whether families are accessing residential services versus families in the community providing care.

A series of recommendations to put forward:

We need to reframe provincial and national values to balance fiscal responsibility with our moral and ethical obligations to provide basic human dignity to our communities' most vulnerable.

We need to ensure that we are, in fact, complying with provincial, federal and international law, when it comes to our legal obligations, through a range of flexible services.

We need to do a province-wide review of the implementation of the DSO model through a third party to really see where we're at three years later.

We need to also pursue new and innovative partnerships and invest in initiatives with family and community groups, with new and emerging groups with new ideas, to foster creative solutions and involve everybody to invest and share and put hand in hand to ensure that there are programs and services, day programs etc. available to people with developmental disabilities in their local communities. That can be done through, again, asset-mapping etc. We need to bring new assets to the table, with government support.

We need to review layers of bureaucracy within the sector in order to ensure that dollars are applied to direct service delivery, not just invested in top-heavy processes.

We need to redefine the case management function to provide greater support to families. We need to mandate system-wide training to ensure that service delivery is culturally responsive and develop anti-racist, anti-oppressive practices throughout the sector.

We need to promote system-wide recognition of family caregivers.

We need a comprehensive aging and developmental disability strategy, given some of the issues that we've already heard and I'm sure you've heard around people being placed in nursing homes etc. age-inappropriately and needs-inappropriately.

We need to break down barriers between ministries. The anecdotal piece, again, around this that I can use is access to CCAC services versus developmental services. My 36-year-old brother was grandfathered into the CCAC program because he received home care and respite through them. This service has been accessed by him for a good 12 to 15 years now, I think.

There are multiple layers. You have the Ministry of Health, you have the LHIN, then you have the CCAC, and then you have the service agency. But the real relationship is between his family, his worker and him. Really, I think there's just so much streamlining that can happen there. I think you get my point. So we need to break down barriers and provide flexible services.

We need a provincial task force to address service gaps for individuals dually diagnosed, and do an environmental scan of successful models. One of the most successful models, in my experience, has been CWSDS—their STATE program and their dual diagnosis team and their one neurodevelopmental psychiatrist, Dr. Jay Rao, in Ontario, who is the only medical professional who actually understands developmental disabilities with the utmost dignity, coupled with any other issues, whether it's mental health or behavioural etc.

1400

We are, as an organization, as individuals, committed to building capacity through diverse communities to ensure that we develop new support models, and we welcome further engagement to address service gaps.

I've also provided you the story of Mohamed. The headline was "No Place for Mohamed." Mohamed catches headlines, I guess. He's a high-needs gentleman who has fallen through the cracks, with a developmental disability, with other multiple issues. He was hospitalized; $1,000 a day was the price tag pinned to that. He still has no permanent placement. Since then, he relocated to Peel and was inadequately served at the local hospital and was sent down to Toronto Western. He is presently again in complex care.

His behaviours are criminalized because when he has seizures, because they're unresolved, he acts up in the situation of a seizure. He is a black man who is often charged with being aggressive, so mom has to fight multiple battles, not only trying to access appropriate health care to save her son's life at the moment, but to deal with the criminal justice system to try to explain why he is not criminally responsible for his behaviours, that his behaviours are the outcome of a crisis situation coupled with mental health, brain injury and seizure disorder.

I don't know what else I can say. I can talk for a day to you folks with my lived experience and advocacy work that I do. All I can emphasize is that the system is badly broken. We have the best of intentions, we are doing our best to patchwork, but families are falling through the cracks. People are struggling in their day-to-day lives, they're feeling isolated, they're feeling alone. We really need to invest in bringing families together, communities together, trying a new way of doing and knowing what needs to be done in the system and engaging new and emerging communities and groups and individuals who have new drive and passion. Thank you very much for your time.

The Chair (Mrs. Laura Albanese): Thank you for your thorough and passionate presentation. You bring forward some different points of view. Unfortunately, we don't have time left over for questions. However, we will take this into serious account, and should we have any further questions, we will make sure to contact you. Thank you very much for coming here today and presenting to us. We really appreciate it.

Ms. Rabia Khedr: Thank you.

Ms. Angela Bach: If you wanted to ask questions—I'm next in line—I don't mind if she encroaches on some of my time.

The Chair (Mrs. Laura Albanese): Are there any questions from the members? Ms. Jones.

Ms. Sylvia Jones: I'm going to ask one question because you're the only presenter so far who has said don't get rid of the DSO; study it for three years. I guess my concern is—

Ms. Rabia Khedr: Not study it for three years, no, no, no. It's been three years.

Ms. Sylvia Jones: My question is, if we review it, that money can't be diverted, channelled somewhere else. What do you see in the DSO that you think could work that is not working?

Ms. Rabia Khedr: When I was first introduced to the DSO, the support intensity scale etc., I found it very helpful. I know many families find it very frustrating but I found it very helpful to go through that kind of assessment process because we had never been assessed. We had never done these kinds of comprehensive assessments before, so I really appreciated the opportunity to be able to think through many of those details of where these guys need support and what level of support they need and what our dreams for the future are and what supports they will need for the future etc. So it was a really, really helpful snapshot, after a rigorous process, of who they are, what their needs are and what their dreams are. I do see value in that.

The problem I see is that, again, how it's being done province-wide. There are some disparities. There are pay equity disparities, in fact. I can suggest there are disparities in the sense that the vast region that people are serving—again, resources aren't available to back up what people are identifying. So we got everybody's hopes up but we didn't put our money where our mouth is, attached to it. That's part of the problem, and then another bit of that issue is also that we took the same old people who were used to doing the same old things the same old way and put them in a new brand, and it's really difficult to do something new when you have an old mindset.

Ms. Sylvia Jones: Fair enough. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. DiNovo, you wanted to add to that?

Ms. Cheri DiNovo: Yes. I'd just very quickly thank you for your presentation. I guess I'll segue off of Ms. Jones. You started off by saying that there's no better place to live for somebody with developmental disabilities than Ontario, and then proceeded to talk about how awful it is.

Ms. Rabia Khedr: And I've been taught to be able to do that.

Ms. Cheri DiNovo: I agree with the latter, not the former. I certainly would suggest—we've heard that there are many other jurisdictions that do do things better, and that's good, because we don't have to reinvent the wheel here. We can actually look at best practices in other jurisdictions. We might not take everything from one, but we can certainly take some things from others.

Again, just a thought that there are some—for example, we've heard some good things about Saskatchewan, Australia, the UK etc. But I really thank you for your presentation. You develop themes that are certainly consistent with other presenters, so I thank you for that.

Ms. Rabia Khedr: Thank you. When I say that Ontario is the best, there are worse places in the world. I'm not necessarily—

Ms. Cheri DiNovo: There certainly are worse.

Ms. Rabia Khedr: If I grew up where I was born, I wouldn't be sitting here talking, let alone talking to you.

Ms. Cheri DiNovo: I hear you.

The Chair (Mrs. Laura Albanese): One second. We also have Ms. Hunter. One last question.

Ms. Mitzie Hunter: Thank you so much for your presentation. I believe you did bring a unique perspective to our hearings today.

When you talk about how the system itself needs to ensure that it is culturally and spiritually responsive in terms of anti-racist and anti-oppressive processes, can you expand on that in terms of what you might have seen or what others might have seen?

Ms. Rabia Khedr: We have new and emerging populations, and I've said this to the sector time and time again. The average Canadian experience has been built on the fact that when your child turns 18, the dominant social value is that they move out, or there's an expectation that they will, and you dread it that they remain behind for years.

That value doesn't necessarily ring true for people coming from other lands and cultures and calling Canada their home today. For example, in many eastern and southern traditions, from Muslim countries, from south Asian cultures, regardless of the faith, it's womb-to-tomb unless you get married and move out. Particularly for a child with a disability, mom and dad will take care of that child until death do them part, or extended family members are expected to. That's just a given.

They're not looking for residential services. They don't want to be put on wait-lists. They want alternative residential models. The only time we seek residential services is in crisis, in absolute crisis, when there have been no other services. As the teacher mentioned earlier, for people with developmental disabilities, their skills and abilities stagnate after leaving school, and eventually, from what I hear in the sector, 50% to 70% of young adults into their thirties develop mental health issues because of that social isolation.

The Chair (Mrs. Laura Albanese): Thank you so much, once again.

Ms. Rabia Khedr: Thank you.

MS. ANGELA BACH

The Chair (Mrs. Laura Albanese): Now we'll hear from Angela Bach, who kindly gave up some of her own time so that the committee could ask questions.

Ms. Angela Bach: That's okay. Good afternoon, everyone.

The Chair (Mrs. Laura Albanese): Good afternoon.

Ms. Angela Bach: My name is Angela Bach, and I actually grew up in the Dufferin–Caledon area, just south of Caledon East, but I consider Toronto my home now.

Those of you who are in Toronto probably last week received a little box of turnovers from me at your constituency office, with a little note attached highlighting the high rate of turnover for people who work in this field, as I work in this field as well. In addition to high rates of turnover, the burnout rate is also quite high as well. And sorry, Cheri; I got to your office after they closed, so I kind of stuffed them in your mailbox.

Ms. Cheri DiNovo: I'm sure they enjoyed them.

Ms. Angela Bach: If the raccoons didn't get them first.

I'm here today because I enjoy my job. I want to enjoy it even more, and I want to encourage more people to come and join me in working in this field. I work front line as a developmental service worker in a residential program. I never introduce myself the way that I just did, because developmental services are not well known or well understood. If you say that you work in developmental services, most people don't know what that means. I usually have to describe it a bit more. I say I work in a group home with adults with developmental disabilities, some of whom also have physical disabilities or mental health issues.

1410

Once people understand what I do for a living, they're rarely excited about it. I tend to get one of two reactions. It's either a look of aversion like, "Oh, that must be hard work; yeah, I could never do that"; or I get a look of sympathy, like, "Ah, it takes a special person to do the kind of work you do. You must be so kind-hearted." Well, thank you. Yes, having a kind heart goes a long way in this field, but I don't do this work out of the kindness of my heart.

I'm not a volunteer. The reality is that I've chosen this as a career. This is my profession. No one would ever say to a psychologist, "Oh, you must be a very kind-hearted person to do that kind of work," because they are respected as professionals. People with developmental disabilities shouldn't be marginalized, but neither should the people who choose to work with them.

How do we entice more people to enter this field of work? If a student chooses to enrol in a developmental service worker program at a community college and get their diploma, they'll have no problem finding a job upon graduation. This is what students want, right? With so many unemployed recent graduates out there, students want to choose a field of study where there will be job opportunities upon graduation.

So why is the enrolment in these programs decreasing? Why do half of the community colleges in Ontario not even offer this program at all? Because graduates don't just want to have a job; graduates want to have a good job. What makes a good job? I don't mind if you talk. What makes a good job?

Miss Monique Taylor: A decent wage.

Ms. Angela Bach: Yes. So what do you do for a living? "Oh, actually, I'm a member of provincial Parliament." Really—wow. That's a good job, a decent wage, benefits, pension, job security—

Ms. Mitzie Hunter: No pension.

The Chair (Mrs. Laura Albanese): No pension.

Miss Monique Taylor: No, no pension.

Mr. Bas Balkissoon: We'll recruit you to help us.

Laughter.

Ms. Angela Bach: If we look at people who have good jobs—my partner works in construction. He's an iron worker. He talks about the work that he does and things that he builds and the places he travels to. People are actually excited that he's worked in a power plant or built a bridge. I'm like, "Really? You know, I think my work is valuable, too." But he's got a good pension, and not all of us do.

Those are the kinds of things that make a job a good job. Firefighters, police officers—those are good jobs. Those are good jobs and they're also dangerous jobs. They're well paid because there's a risk involved. Developmental services is also a risky field of work to be in, with little protections in place.

I've been to your constituency offices, and I've had to buzz to enter or the doors were locked; Ms. Hunter, there's a bit of Plexiglas in there. That's all great; I'm all in favour of people being safe in their workplace.

In many fields, if someone becomes violent, they're barred from the program. All of these precautions are good, but they don't lend themselves to this specific kind of work.

The people that I care for often lack impulse control, due to no fault of their own, and they also may be unable to express themselves verbally, so they express themselves physically instead.

Last October, a co-worker of mine received a minor concussion after being hit in the head from behind. She's still experiencing chronic headaches and is in the process of trying to return to her full duties.

You might think that people with developmental disabilities are slow, but I can assure you that they are pretty quick and pretty strong, too.

My co-worker is fortunate that she is a full-time employee and therefore has some benefits coverage. Our employer also provides WSIB coverage. But several employers in developmental services don't provide WSIB coverage.

With the limited funding that's available to developmental service agencies, employers are often forced to choose between providing good care for their clients or providing good care for their employees. They're forced to either cut back on services for their clients or cut back on services for their staff. It's not fair to make them choose. They should be able to provide for both.

Another colleague of mine was recently hit in the face by someone in his care, and his glasses were broken in the process. He's a part-time employee, as many of my colleagues are, and therefore, he doesn't receive benefits coverage. So he's stuck with the bill for replacing the eyeglasses that were damaged while he was performing his job duties. That doesn't seem fair.

The most common injuries that we encounter at my workplace are temporary muscular issues, from either lifting and bending or from being manipulated by a grab, a pull, a twist, a bite, or having your hair pulled and jarring your neck a bit. Your doctor may prescribe some prescription-strength painkillers or muscle relaxants until you heal. The majority of the people I work with are hired as part-time employees or on a relief basis and therefore have no benefits. So if their doctor gives them a prescription, it's my co-workers with the lowest wages who have to pay out of pocket for the damages that were done while they were at work.

We use temporary agencies where I work, like many developmental service agencies, to provide coverage when needed. The employees who come from temporary agencies are generally very kind-hearted people, but they lack education in the field, and they often require a lot of on-the-job training.

Families who receive Passport funding are also put in the position of trying to maximize their funding dollars by hiring contract care providers who may not have the qualifications to provide the best care for their loved ones. This individualized type of funding is a quick fix for desperate families. What families need are good public services. There are too many instances where families are so desperate to find care for their child that they resort to drastic means. I'm sure you've seen the articles in the newspapers:

Emilia Arthurs, in Sarnia, was dropped off at a respite home in September 2012. Her parents surrendered her at that point and didn't return to pick her up. That's desperation.

Phillip Telford, in Ottawa, was dropped off at a government office last spring. His family had been receiving Passport funding, but it's not enough.

Qyzra Walji was a happy teenager living in London with her parents. In addition to the demands of caring for Qyzra, her parents were facing deportation, and she passed away with her parents in an apparent murder-suicide. This is why I do the work I do, because I can't handle hearing another story of families so desperate and resorting to such drastic measures.

1420

In 2007, Keith Croteau was a very small man with a developmental disability and he was living in a nursing home, as many are placed in nursing homes when there's just nowhere else to go. Keith passed away due to injuries following an attack by his roommate in the nursing home because Keith was hard-of-hearing and needed the TV loud. He usually had headphones, but they were broken. His roommate didn't like the noise of the TV, and Keith is no longer with us.

On one occasion at the group home where I work, one of the residents obtained a knife from the kitchen when it wasn't locked, and threatened another resident with it. Now we had the staffing ratio in place, and my skilled co-workers were able to separate the two and to de-escalate the situation until police arrived. Those two no longer live together, but both are still healthy and live well in their separate homes. So there's an example of the difference between adequate care and inadequate care.

I'm going to be mindful of my time and skip over a couple of other stories.

It's widely acknowledged that Ontario must create new jobs, so here's an opportunity to create these jobs. I know and trust that the formation of this select committee is going to result in a shrinking wait-list. But once these people on the waiting list have services, who's going to work with these people? Literally, who is going to do these jobs? I already have two jobs, and a lot of my colleagues also are juggling two or three different jobs. Who wants to enter a field of work where most of the jobs are part-time or casual, without benefits, limited vacation time if any vacation time, where they're being exposed to physical and verbal aggression which is known to be an inherent part of the job, where your employer may not be able to provide WSIB coverage and where the wages are so-so? The most rewarding part of the job comes from within, when I think, where would these people that I work with be without the services that people like me provide? Would they be like Emilia or Phillip? Would they be like Qyzra or Keith?

Taking care of the community's most vulnerable people must be a part of the larger plan to improve the economy. Until developmental services is a respected field with decent wages, it's not likely to be a career of choice attracting new workers. In my job as a developmental service worker, sometimes I feel like I wear the hat of a nurse, a counsellor, a teacher, a family therapist, a recreational coach and a behavioural interventionist. It's a complex job requiring multi-tasking, patience and a high level of responsibility. Workers in comparable fields have decent wages and pensions, and we don't receive a pension and we often live paycheque to paycheque.

About two years ago, the agency that I work for was faced with the serious possibility of closing its doors—eight group homes and a large day program, over 100 employees, and they were looking at closing. In spite of the growing wait-list and so many families desperate for services, the lack of funding meant that they really had to consider keeping the services that they currently offered. Is this the future of developmental services in Ontario?

Thank you for the opportunity to share my story and some of my concerns.

The Chair (Mrs. Laura Albanese): Well, thank you. It's too bad that we can't ask you any questions.

Ms. Angela Bach: That's okay. I was a little bit nervous for the questions and stuff, too. That's all right. The person before me spoke very well, and I was glad to let her have the question time.

The Chair (Mrs. Laura Albanese): She did, but so did you, and you can really tell that you do what you do with a heart. You've described in a very adequate manner what adequate care is and how it can be provided by passionate people, but they need to be paid well.

Ms. Angela Bach: Thank you, everyone.

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

INCLUSION INITIATIVES CORP.

The Chair (Mrs. Laura Albanese): We'll now call on Inclusion Initiatives Corp. Good afternoon.

Mr. Don Hill: My name is Don Hill. I am the executive director of a fledgling charity called Inclusion Initiatives Corp. Our mandate is to create job opportunities and programming for developmentally and intellectually disabled individuals. I'm here today to add a voice, or perhaps an additional voice, for the idea of social enterprise and what it can bring to this issue that we're here discussing today.

I don't think anyone would argue with the point that we have a significant problem before us, that typically there's probably not enough money to satisfy all the demands that are being put on the system. I would like to advocate for growing that pie and finding ways to look at this problem in a new light.

For instance, we are starting two initiatives as a social enterprise. We are a charity, so any money that is derived from what we do goes back into programming for the people we serve, along with wages. We are in the midst of opening a recycling effort, and we are starting a gourmet cookie effort. Our job is to bring innovative business practices and marketing to the table in these efforts and find ways to satisfy needs in society that we know currently exist and that we're capable of delivering on and using this money to solve this problem, or to help solve this problem.

There were a couple of points that were made that I just wanted to comment on. The DSOs so far have taken a lot of flak from the way that things have worked out so far, and you were asking if you thought there was a place for the DSO and what role that might be. Clearly it would seem that the DSO is just a service delivery mechanism. I think it could be a lot more than that.

Many of these individuals, once they leave the public school system—developmentally disabled, for instance—at the age of 21 really have very little as far as a place to go, somewhere to attach themselves. The DSOs may find it very easy to develop a new perspective on creating entrepreneurial efforts like the one that we are in the midst of creating, sponsoring these efforts, and standing up and being a focal point for people who are trying to solve this problem.

For instance, I would ask you to recall—what was it? Once upon a time, we had a Bill 30 that created a school system where no school system existed. The government stood up and created a bill, and assets were diverted from the existing system. All of a sudden, we had an additional school system.

Currently in the Education Act we have regulation 444. Regulation 444 says—this is me giving you my short rendition of it—that the school board can dispose of properties, but it has to go to certain organizations first to see if they have a need for them. This community could sorely use those assets but has no one to stand up for them, and they are not included in that argument or in that equation.

1430

If we could take public schools that were closing and use them as economic centres—just perhaps to put out a thought—where we could have classrooms turn into small businesses, have social areas, have service areas where we can run community-based organizations for people in a community with assets that we've already invested in, that are already there—and to run these businesses, all we have to start doing is, the government needs to have a new policy that if you want a government contract, perhaps one of your scorecard points that determines whether you get it or not will be: Do you do business with social enterprises?

For instance, it's not a big deal for us to collect cardboard from an organization like Walmart. They've got it in a place. We need a truck; we need a driver that can drive that truck. But to bring that back to a centralized depot and process that cardboard is something that a lot of these individuals could be involved with in a meaningful way and give them participation. You're probably aware of the Aspiring Workforce document that was recently put out, where they talk about the importance of a job, and I think that is very true for all people. People need to have dignity, and work helps provide that.

Just in case there are any questions, I'll try to cut this short, but I would encourage you to think about social enterprise. Social enterprise is a very broad subject. There are a lot of different structures within that, but I can suggest to you that social enterprise done under the auspices of a charitable designation where there is accountability to the government in following what your objectives are, once they've been stated and approved, is a fairly safe way of bringing in new people to provide services not just to this community but to the community at large, and finding ways to bring in new revenues that will be used to satisfy the needs of these individuals, instead of continually coming back to the government well that often has difficulty meeting all the needs. That's it.

The Chair (Mrs. Laura Albanese): Wow. That's very interesting. We do have time for some questions. It is Cheri's turn. Ms. DiNovo.

Ms. Cheri DiNovo: Yes, thank you very much for coming before us and speaking to us—very interesting. We have heard from a number of presenters, actually, about social enterprises, and I think we probably are all in agreement: They're wonderful initiatives. We've heard of laundries, restaurants, cookies and other things—everyone needs to have a job that they feel some sense of pride in; everybody needs some place to go, I think the presenters today said, 9 to 5. That's so important, so I thank you for highlighting that.

And your other suggestions, you should know that you're not alone. They represent themes that we've heard, so thank you for adding and augmenting those.

Mr. Don Hill: Thank you.

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

Ms. Soo Wong: Thank you very much for your presentation. I'm particularly interested in your organization working closely with the school board and local community with respect to your social enterprises, because regulation 444 allows organizations like yours to work with local council to then pick up, through reg 444—to build a system. I'm not sure you're aware of that.

Mr. Don Hill: Well, to be honest with you, I'm pleased to hear that. I don't consider myself an expert on that. I'll have to go home and research that. We would love to pursue that sort of activity.

Ms. Soo Wong: So working with the local school board, that's one suggestion, working with the local school trustee—

Mr. Don Hill: Yes.

Ms. Soo Wong: —and most importantly, with one of those 10 groups that you just mentioned, under reg 444, and they will then leverage your ability to pick up that empty school. It has been done here in Toronto. I've seen it done in Toronto. I'm going to encourage you because I think it's a really innovative opportunity and provides employment opportunities for this particular sector. So keep up the good work. I think there are lots of good things coming out.

Mr. Don Hill: Thank you.

Ms. Mitzie Hunter: I also want to add to that. We have recently announced our youth employment fund. A portion of that is for social enterprises and social entrepreneurship. The Ministry of Economic Development and Trade also has initiatives targeted at social enterprises, and there are assistants out there to help scale the projects and support people in getting their own projects going, so I would definitely encourage you along this path. It's not only job creation, but it's job creation that has a good social outcome, and you're adding the additional lens of people with developmental disabilities, so I think that's excellent.

Mr. Don Hill: Thank you.

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

Mrs. Christine Elliott: Thank you very much, Mr. Hill, for coming before the committee today. The concept of social enterprise is something that we have heard a little bit about. I'm wondering if you could tell us, in your particular case, how it works, how you got your organization up and running, and—I guess the recycling business is the one that you've got launched already—

Mr. Don Hill: That's right.

Mrs. Christine Elliott: —how that operates.

Mr. Don Hill: In essence, it's very simple. We have a couple of individuals, we have a van, and we'll go out and look for—our initial foray is into metals and then we would like to get into paper fibre. But with metals, we're currently negotiating some deals with people like Direct Energy and other people who are replacing furnaces, water heaters and refrigerators, where we can take these large amounts of metal—where we're not hunting for this metal but we've got a pre-organized location we're picking up from. Then we can take it, disassemble it and get it into its highest form, and we just sell that on the open market.

We hire people with disabilities to do that. Our mandate from the government is that we're allowed to hire anyone with a disability, but our heart is with developmental and intellectual disabilities, so we want to make as many opportunities in that area as we can. Not all of these people are capable of driving a truck, whereas someone with lupus might be able to drive a truck. So we can meet our obligation to the CRA and we can create opportunities for these individuals who may be able to use a screwdriver or a drill and take screws out of a furnace to strip it down, with proper supervision.

That's what we do. How we started: I started this to help my daughter, who does not have a developmental disability. She does have a disability, but her goal in life is to work with people with developmental disabilities. That's what she would like to do. Unfortunately, she had to drop out of university because of her disability this past fall, but if we can create this opportunity to serve people, there will always be a place for her to participate. That was the driving force, along with a niece who has Down syndrome.

I just think that, with good business practices—Gateway did their laundry centre, and they've done a phenomenal job. It just shows you what people are capable of. The market was there for the product, and they went out and got the contracts from the people they were working alongside. Now they've created tremendous opportunities for people who otherwise wouldn't have had them.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for appearing before the committee and for advocating in favour of social enterprises.

Mr. Don Hill: Thank you very much for the opportunity.

1440

MS. CHRISTINA BUCZEK

The Chair (Mrs. Laura Albanese): Next we will hear from Christina Buczek. Good afternoon.

Ms. Christina Buczek: Hello. I've asked that an article be passed around. This is an article from Prime Minister David Cameron, who is the father of a severely disabled child, and what he shares, with his own experiences, is what he sees as the five main lessons he learned that he would like to see implemented, as a father. I just wanted to share that with you.

I think that probably from what I've seen of the testimonies that you've heard, you've pretty much heard the gamut. It seems to me that you've got many, many people who've said a great deal. So I don't really feel I could probably do as much justice or say it as eloquently as many of them have. But I do have a few points that I think are important from my perspective.

One of them is directly related to the article, which is the issue of direct funding. I think that direct funding just makes the most sense of anything, especially when we look at the fact that funding has not been increased, and the number of families is increasing monthly. If we want to really make the best of it, direct funding is the easiest way to minimize the administration, the bureaucracy and the processes that are involved, which I think if you spoke to most families, they would tell you that the processes that we are put through are humiliating and demeaning. They require us to be totally without privacy. We have to give a lot of personal information, we have to talk about the most difficult aspects about our children, and we're made to feel like we're begging. It is not something people would want to have to go through. I think you'll see in the article, it says pretty much the same thing.

Direct funding also stops treating us like we're incompetent people who don't know how to spend money wisely. It seems like we're nickel-and-dimed to death because there seems to be this fear that we're somehow frauds who are going to spend it on drugs and booze or something. You really get to feeling like you're constantly having to defend yourself. You have to prove everything. There is no sense that there's any trust or thinking that you're doing the right thing.

I've also seen programs that have started out well-intentioned, but when they fold out, what's really interesting, is that they start reverting to the same old practices. What was supposed to be a direct funding option for parents quickly became one where the parent, in fact, could not submit their own plan. They had to sit down with somebody, arrange an appointment, sit down with a social worker, and that person had to write it all down and had to basically justify and verify whether or not they even agreed with the parent that this was an appropriate plan. Without their seal of approval, the parent couldn't have the plan. This is supposedly a family-directed plan. Then, the plan said, "Well, you know, we've come to realize that some parents don't have transportation and their child can't go on a bus, so we're willing to say it's not unreasonable to pay for a taxi so that the caregiver and the respite provider and the child could be taken to a program." Well, that was one of the fundamental positives about this program: finally recognizing that these are some of the basic hurdles people have—and they took it away. They said, "No, you can't use that for a taxi." So a lot of families are basically out of luck. I really do find that that's problematic.

Now one of the parents I know said, "You know, the problem we have is too much system and not enough service." That's very obvious. I hate to say it, but the road to hell is paved with good intentions. I'm sure everyone here has really good intentions, but, believe me, you're doomed to failure unless you do two things. Fundamentally, you're doomed to failure if the families that you're supposed to serve are not involved at every step. This is because you may think you are doing something that looks really great on paper, everyone in your meeting agrees that this is great, but nobody has thought to bring a couple of parents in to say, "That won't work," and explain to you what might be a simple reason why it won't work. But if you don't do it that way, and you think it's going to roll out just the way you've planned, it's not going to work. Anybody who invents something—it's like inventing a machine and expecting it to work perfectly the first time. It's not going to work. You're going to have to tool with the machine; you're going to need to understand what our lives are like and what hurdles we have that are preventing us from accessing the things that we need. To me, that's where—we really need to say that parents have to be involved.

The other reason I'd say it's doomed to failure is if you're working at the planning stage of it and the nuts and bolts to make it actually function and work are returned to the public service bureaucracy that you have. It's that very system that keeps being duplicated over and over that is the very thing that is problematic. We've got silos of different ministries. Parents can't move funds from one silo to another. Even though their child is supposed to get certain services in one location, they can't move it to another location.

My daughter was actually developmentally delayed, severely autistic, non-verbal. She requires two one-on-one assistants. She's under what's called a SIP grant. You're talking the most high-risk, most vulnerable, most developmentally delayed of anyone in the system.

She attends a school here in Toronto. I bet most of you never even heard of it and I'm sure none of you have ever been there. I can tell you, because whenever we've invited anyone to come to that school, not one has shown up—not one.

The school is fantastic. It's called Lucy McCormick. It's with the Toronto school board and I—

Ms. Cheri DiNovo: I've been there many times.

Ms. Christina Buczek: Well, probably because it's in your vicinity. But in all honesty, we've invited Ministers of Education to come and they have not come. The reason I say that I believe everyone who is on this committee needs to go to Lucy McCormick is because if you don't go there, you don't know your client; if you don't go there, you don't know what they're really all about.

We had a meeting last week there. Parents talked about how they don't really have a command of English, they don't use computers, they don't know about this meeting. A lot of people had never heard about this meeting happening.

The children who attend there: It could be a six-foot guy, 250 pounds, physical, the mentality of maybe a two-year-old. But you've got people dedicated to working with them who know what they're doing. That's few and far between, because when we have people graduate from teaching college, they have the minimum training in special ed; they were required to take one general course in special ed. Our children are the guinea pigs of people coming in with no training and they're learning on my child, who doesn't have a voice, who cannot speak, who barely communicates. That's not fair to my child.

Every year, my child, if she gets a new teacher—it's like starting at square one for them to have to learn her language, her way of communicating, and it can result in all kinds of complications. So to me, a fundamental problem we've got is an education system for teachers that says, "You go for one year. In that one year, you'll get maybe two placements out in the community, and then the next year, you're a teacher." We need some form of a mentoring program within the system that takes the teachers who really know what they're doing, with the staff who know what they're doing, and they have to learn. I shouldn't have a person assigned to my child who has never worked with autistic people before, doing things that are fundamentally wrong with her. Okay? They really have no idea what they're doing. I am trusting my child, who cannot tell me, "Mom, I've had a rotten day. This is what happened me," or "That's what happened to me"—I have to rely 100% on how she comes home.

I'm even lucky I got here today, because my daughter is a teenager and she's decided there are some days she doesn't want to go to school. She's physical. She has nearly thrown me down the stairs. My husband and I together cannot physically get her out the door unless my son happens to be home and can help us get her to the vehicle, where she is then strapped in in a harness to get her to school. I'm reaching the point where I physically cannot deal with it.

So yes, there's a crisis here, and I think if you go to that school and you really get to know your client, then maybe you'll get a real picture of what you're dealing with. It's almost like having a bunch of doctors sitting in a room talking about patients and their family life, never having gone in and visited that particular family. To me, it's fundamental. You really do need to go in there and meet these people.

1450

I even talked to other parents of autistic children. It's funny; we're talking at cross-purposes. They tell me to just tell my daughter to do this or that. When I tell my daughter's assistant this, they crack up laughing, because my daughter cannot be reasoned with in this way. There's a huge difference between talking to a two-year-old, who you cannot reason with, who doesn't hear what you're saying, who doesn't get it, versus talking to a child who can actually speak and be reasoned with. It's night and day. To me, that's fundamental.

The other thing I was going to mention is, the system really is set up with inertia—it's there to preserve itself. No employee is going to find a way to save money by getting rid of their own job. No unit is going to say, "I know how we can save money; I can get rid of three of my staff." The system just keeps perpetuating itself.

I hate to use it as an example, but there were a lot of people who saw real value in creating an IBI program, and I can tell you, the way in which it is actually maintained and how it functions is so ineffective. It is lining a lot of people's pockets, for their careers and their jobs. The amount that actually gets to our children—I hate to think what a small percentage it really is. Those people are not going to tell you that they're not needed. No one is going to say to you, "You can cut me by half; you can easily cut me out." That's how they make their income. They're not going to tell you that.

I even had people say to me, when I was showing concern about something they were doing that was, in my view, detracting from my child's services because of how they were spending money, "What do you care? It's not your money." I actually had someone say that to me.

I'll tell you, when it's my money and I go out looking for services, I get the respect I need and I get to set what I need them to do for me. It's very different. Putting the money in the hands of the parents directly cuts out a lot of the bureaucracy; it stops creating all the hurdles that we're expected to jump over—and it will actually put money where it's needed.

A lot of families with special needs—you've probably heard that between 50% and 80% are divorced. You've got single-income families, so the need for respite is very high. You also have a lot of families where one person is staying at home; one is a non-working spouse.

When we see that the community is aging and we've got people who are having dementia, Alzheimer's etc., a lot of families are now going to end up having to have a person at home being a full-time caregiver. If we look at that same person and put them in a facility, that's 24/7 care.

Amanda Telford was right when she said that 24/7 means three full-time jobs, seven days a week. Do we ever look at that and say, "What does it actually cost us, as taxpayers, to provide some of the services that we're doing out there right now"? Only when you get a real handle on what those expenses are—and those are strictly concrete expenses.

Why is it that funding for parents who are doing the job at home and trying to keep the family member at home—why are they going through so much difficulty for every penny they get? Why is it not increasing?

The cost of me getting a respite service has really increased. I've only ever been able to get people who are professionally trained. I often need two people—or I need to ensure that my son is there—because of my daughter's physical behaviours. That costs a lot of money, but I've not had any increase in any funding. In fact, I've taken an 80% decrease—because I have two special-needs children. One of them turned 18, and I thought it might be cut in half. I lost 80%—80%. So I don't know what's going on with funding. I just got another letter in the mail saying, "Based on your income—$60 less a month." That was it; no explanation. My income didn't go up, but I suddenly have $60 less a month. I need every dollar—80% gone.

What I really think makes a great deal of sense is, instead of constantly looking for more dollars to make available—we have so many families living at poverty level who are paying income tax. They're at poverty level, but they're paying taxes. Why are we not creating a process where it's put right on our taxes? Then I don't need to create a big administrative system; people just need to claim on their income tax, which already has paperwork indicating from a doctor that, yes, there is a severely developmentally delayed child in this home, and give us the bigger tax break so that parents will be able to retain more of their own income to use for this purpose. It makes just too much sense to me to do it this way that it obviously defies the logic of government.

I also believe in income-splitting, since so many of us have a stay-at-home spouse. Income-splitting would make a huge difference. We are taxed right now—I actually would be better off divorced than I am now as a married woman with respect to how my income tax is affected by my child. As I said, I have two developmentally delayed children—two children, that is, with disabilities. Something is wrong when the government is saying to me, basically, "You would pay less if you divorced your husband." That doesn't make sense. Income-splitting makes sense because we, as a society, keep espousing values, such as wanting the family to be able to stay together.

We know that the most important thing about a caregiver is that they actually have a love of the person they're caring for. Pediatrician Penelope Leach said that the most significant factor in any caregiver relationship is that the caregiver must fundamentally love the person they care for. Instead, we're putting them in various forms of institutions because families can't cope at home. If we really believe that we should create a society where people are able to care for them at home to the best of their ability, or to make it work, then let's create an income tax system that reflects that.

Let's say that the spouse who stays at home is taking care of either a disabled adult or disabled children—that they get some form of a tax break to enable them to continue to do this. I know myself, I would prefer to keep my child at home, my adult child. I don't like the idea that I have to go and drop her off at some facility and say, "I'm not coming back," as a way of getting her in the system. But the system is now being run on a crisis basis.

There aren't a lot of services once the child becomes 18. We've already been told that for a lot of the services, there are huge wait-lists and we may never access them. We say, "Be careful. It's not a wait-list." It's not a wait-list; it's a priority list, which means that whoever is considered a priority—in other words, who is in the most crisis—is going to get the service, which means that pits us parents against each other in going forward and trying to explain why my case as a crisis is more significant than someone else's. Can you imagine that? We're in crisis if we have to give up our kid, period.

The last thing I'd say is, any of us being told, or learning in the newspaper that a parent has killed their child and then committed suicide—it's not a shock to me, and that's scary to know, because I know that people have reached the end of their ropes. There are no services. I have seen it happen where they are told, "There is nothing we can do for you," and the parent is supposed to go home. They might get some counselling as an option for the parent, but no services for the child, because there aren't any to be given.

That's all I have to say. If you have any questions, I would be happy to take any questions.

The Chair (Mrs. Laura Albanese): Thank you. We really don't have much time for questions—if anyone wants to make a closing comment. Otherwise, I shall—Miss Taylor.

Miss Monique Taylor: I just want to say that I'm sorry for everything that you're going through and that your family is going through. It's absolutely horrific. Nobody should have to feel the way that you feel.

Thank you for coming here and being brave enough and taking the time out of your very busy life to come and share that with us today.

Ms. Christina Buczek: I really had not wanted to be so upset when I came. I knew that, unfortunately, I'd get emotional about it regardless.

I do honestly want people here to please, please go to Lucy McCormick Senior Public School to see what is ideal. Lucy McCormick is the only school that has all developmentally delayed students. It is the only school that has developmentally delayed with other multiple-needs children. It's the only one in the board. There are others that have both MID and DD students—mild intellectual delay and developmentally delayed students.

1500

The reason it's such a great school is that the people who are there are phenomenal. If my child could stay in the same school for the next 10 years, I'd be thrilled. But she can only stay there till she's 21. When I look at everything that's done at the school, every parent there would say, if this could be duplicated, this would be phenomenal. To me it's really worthwhile looking at because all the students are DD.

What I've discovered is that the staff look at everyone as having the opportunity to do something there; whereas at other schools, I found there was a real tendency not to include the DD students. In this instance, you'll see they're all included. Despite all the ups and downs that we've gone through, we now have my daughter in what I'd consider the best solution for her at this point in time.

The only small comment I'd make is that what's interesting is that the Ontario government has introduced a lot of mentorship programs and apprenticeship programming for regular students, and they do have some for MID students even. But there are none—nothing—for DD students with respect to actually using whatever they can learn at the school and having it apply so they can go out and actually work somewhere, even as a temporary thing to do with their school. It doesn't exist. The Ontario government has created a document called Education for All, and it was based on the concept of equity, so the idea is equity for all. But in this particular aspect of creating a way of bridging between going to school and then getting a job, the DD group is the only group that has nothing.

The Chair (Mrs. Laura Albanese): Thank you for coming here today. On behalf of us, we really do feel your frustration, but you've illustrated everything very clearly.

Ms. Christina Buczek: You're welcome.

The Chair (Mrs. Laura Albanese): We won't forget it. Thank you.

Ms. Mitzie Hunter: Madam Chair.

The Chair (Mrs. Laura Albanese): Yes?

Ms. Mitzie Hunter: With the last comment about the mentorship and co-op programs, can we get from the ministry what is available for students with developmental disabilities by way of those types of supports?

Mr. Bas Balkissoon: Maybe we should ask about the Ministry of Education's guidelines for providing—

Ms. Mitzie Hunter: What is the Ministry of Education's guideline on providing students with developmental disabilities with options for mentorship and co-op?

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

MS. CINDY MITCHELL

The Chair (Mrs. Laura Albanese): We're going to call now Cindy Mitchell to come forward. Good afternoon.

Ms. Cindy Mitchell: Good afternoon. Hello, everybody. We meet again. Today I come before you, though, as a mom. Last week I came as a mom, too, but I went to Ottawa with my daughter, and I was representing Family Alliance Ontario.

Karen was supposed to be here today, too, but when I talked to her this morning about it again, she made the decision that this wasn't the best place for her to be, so she declined coming here. She would sooner do what most people would do; she would prefer to participate in valued, meaningful kinds of activities within our community. That's exactly what she's doing today.

Karen felt it was much more important for her to go to her job, to go to her volunteer role, at a local community school. It's actually right in my neighbourhood in Whitby. She went there instead.

It's a very valued role for Karen. Actually, a year ago, she was nominated for an Ontario Volunteer Service Award by that school. She's been there for seven years now in the capacity of a volunteer. The principal from that school moved a year ago and gave my family a call and said, "You know what? Karen is such a great volunteer. She could teach people at this brand new school, called Chris Hadfield school, what it means to volunteer." So she now works there one day a week, too. Karen takes her volunteer roles and her work roles very, very seriously, and she's absolutely one of the best volunteers and workers this school has. That's clear because of that award. You've heard that about people with developmental disabilities from many, many presenters besides myself.

Karen is aware that I'm speaking about her today. She has given me permission to do that. She knows that I'm speaking about the experiences of my family, and the impact that systems in Ontario have had on our families.

I thank you for this opportunity—it's always hard to talk about your own family—on behalf of my family and my very wonderful daughter, Karen Inwood, to be here. I'm really pleased to speak to you today, in part because this committee is very inclusive. It encompasses all political parties, and all of you have chosen to sit here.

I think this is well worth the cost to me—my effort, my time and the emotional cost of sharing my family's story, because I think there is a greater potential that your recommendations could actually go somewhere, and possibly even be helpful to other families, and especially to our vulnerable sector of people with developmental disabilities.

I think this is so because you are working together. All parties are working together. I believe that you feel that the current system is not working, and I believe that what you have heard thus far supports this statement entirely.

I believe that the root problem is that the system is built, and continues to be built, to support the system. You just heard from this wonderful, eloquent mother about that. It's built to support the system, not the person, and especially not their family.

This problem crosses all systems, so I'm going to start with my story and our interaction with the first system, and that was the educational system. Karen started school in a small northern community: Hermon, Ontario. The public school was the very public school that I went to as a child.

The school board in that area had a special education class in Bancroft, Ontario. That was a one-hour bus ride away from the Hermon school. They informed me when Karen started school that she and two other kids at the school were going to be bused together—one hour away, one hour back—to this special education class.

The two other families and I, who happened to know each other, got together, and we tried to challenge the logic of this idea and the cost of this. Ultimately, all three of us pushed back, and our children remained in our local school. We pushed back against the system because we believed that our children were better off and safer in their neighbourhood schools.

We three parents then pushed our local Community Living association to do what it stated its job was. We said, "You need to stand up for us. You need to take a position with our families, and you need to support our children's inclusion in our local schools." This was my first experience of the power of a small group of families—in this case, just three of us—coming together to effect change at a local level in our communities.

If Karen was here right now, I know what she would tell you. She would tell you that she remembers riding on the bus. She remembers attending that school in Hermon. She would say she was very happy and was not afraid, because her big brother Kyle and her friends also took that same bus. Coincidentally, the bus driver who drove Karen and Kyle also drove me and my husband, at the time, as a child. This is what keeps my daughter happy and safe: people who know her, real, authentic relationships—not paid relationships—and real community inclusion.

I moved to Whitby when Karen was seven years old. We lived three blocks from E.A. Fairman Public School in Whitby. At our first meeting with the school, to introduce them to our beautiful daughter, they suggested that she be bused to a segregated school at the other end of Whitby, away from her new friends on the street, away from me as a mother and away from her brother who she adored.

We challenged that recommendation. We challenged that process, and that process—for me, as a young mother—took us right to a regional IPRC committee. It shouldn't have done that. It was emotionally draining. This challenge was not as easy as I had thought, because one teacher at that meeting suggested that I was a very abusive parent. She suggested that I was abusive because I was putting Karen in a situation of possible future bullying by others.

Thank goodness that, at that time, I was then connected to an organization called Family Supports Institute, which was a precursor and would eventually become Family Alliance Ontario, which I spoke to you in Ottawa about. Again, the power of families coming together with other families, supporting each other, standing beside each other, helping each other withstand the pressure of systems, helped me to not allow my daughter—my beautiful, wonderful, self-confident daughter—to be segregated, to be marginalized, to be devalued, to be sent to the back of the bus or the other end of the community.

1510

I'd like to point out that actually I have a wonderful supporter in the room. She has left—oh, there she is. Dawn Roper. She was actually one of the first moms I met when I moved to Durham—one of the very first moms. She was a catalyst of starting Family Support Institute, which is now Family Alliance Ontario. Dawn will be sending a presentation to this committee. I hope they will take time to read it because I am absolutely confident it will be filled with the history of this system, which you need to understand. You need to understand how we got here so that we don't keep doing the same stupid things over and over again.

Back to my family story: For the next several years, up until high school, Karen walked or rode her bike to a regular class at her neighbourhood school like all the other kids in our Whitby, Ontario, neighbourhood. I fought for that, though. Again, at the start of a major transition, when it should be easy for families, it wasn't. When Karen started high school, again the education system and I bumped heads. They were very unsupportive and didn't have the imagination to imagine how someone like Karen, whom you guys all met the other day, could be included in her regular school.

With zero knowledge of unions and this process in the system, I watched—sorry, I've missed my spot here. In grade 8, Karen had this wonderful EA. This is what relationships are about. She had this wonderful EA and she had a circle of friends in grade 8 because she was alongside the kids in our neighbourhood attending a regular school. With zero knowledge about unions and the process in the system, I asked this wonderful EA if she could move with Karen, and I asked the secondary school system if she could move with Karen. I was advised that she would have to apply for the new position. The EA and our family were advised that this EA would essentially have to leave her position in the elementary system—leave her job—and apply for the new position in the secondary system. Effectively she would risk ending up not having a job, potentially, if she didn't get hired. I'm happy to say that this wonderful, brave EA took that significant risk. She got the job and she supported Karen's inclusion throughout high school.

My point in telling you this story is to help you understand that it's people and relationships that move us toward our goal of social inclusion—the right people, the right relationships. That wonderful EA, Wanda Sharp, still contacts Karen; she's still in Karen's life. The grade 8 friends remained friends throughout high school. This, of course, was supported by a good EA, who understood inclusion. In their graduating year, these friends from grade 8 were instrumental in lobbying the whole school for Karen to be voted prom queen. Karen taught a lesson to all those girls about the value of all people being together.

I wish I could tell you that Karen went from that glorious high school experience of prom queen to her wonderful role as a highly valued elementary school volunteer, but I cannot because that is not the case. The thing about life is, things happen, life happens, and when it happens, it happens to the whole family. In our case, a few of the major things that happened were marriage breakdown—that happens a lot, you heard earlier, and I can attest to that. The second thing that happened in our family was that I was diagnosed with stage 4 cancer. And then Karen's best friends from high school went off to college and university. Karen had no place to go off to. She went directly to our couch and mom went to a stem cell transplant. This experience was extremely sad for Karen, and she suffered a significant depression during it.

We heard about and we applied for the new CICE program at Durham College, but Karen was not accepted. We would apply two years in a row for that program until Karen said, "Stop." This personal rejection she felt during the interview and the application process was too painful for her to endure a third time in her life.

As a mom, I got very excited—I was even actually somewhat hopeful—when I heard about this new program called the Passport Program. Of course, I gathered up my energy and my bald head and I applied for it. Given that I was ill and there was nothing available in the community, I thought for sure I would be approved. That was in 2006. Just like thousands of other families in Ontario, I'm still waiting for that to happen. However, on a positive note, our SSAH increased in 2005. Certainly, I believe this increase was due largely to the fact that everyone thought I was going to die. The flexibility of SSAH funding was helpful and supportive to my family and to Karen during this crisis in my family, a situation that I am certain would not be the case with the Passport Program and the new rules.

Cancer care and treatment doesn't end in six months. The new rule is six months—you can have some flexibility. Well, I'm standing here today, or I'm sitting here today, before you, so you can see I managed to elude death, and with a clinical trial high-risk treatment, I went into remission and I'm still in remission. In 2007, I was able to come off CPP disability and join a wonderful local organization that actually is in the DS system sector. At the same time, I joined a local family group of parents who wanted something different and imagined a better life for their kids. Through that group—not through my employment in the DS sector or having any knowledge about that sector, but through that group—I was able to access independent facilitation and planning.

Our facilitator, for a short time—because money ran out eventually—was able to help some of us develop plans for our sons and daughters. Access to independent planning and facilitation, along with being with a group of another, of other families—I get tongue-tied. It's really emotional when you have to sit before you and bare your family's soul, but I think it's important. So this access to independent planning and facilitation, along with being connected with a group of other families, really assisted me and, I'm sure, the other families in this group to learn and grow together. Together, we're able to dream; together, we're able to imagine a better life for our sons and daughters. By being witness to each other's stories and being present in each other's lives, and through our relationships, each of us was able to take concrete steps in better directions for our kids. I believe that families have to be in the company of other families if we here in Ontario are ever going to be at a place where more people with developmental disabilities get to experience authentic social inclusion—not a program, not a service, but being present and valued and contributing in their community, like my daughter Karen is today.

I was supposed to bring with me today a video called In the Company of Others. It was actually produced by Durham Family Network, which I'm part of. I wanted to encourage you to view it, so I'm going to have to courier it down. It is a really good little short video, produced by tax dollars, that really will demonstrate to you the importance of families coming together, being in the company of other families, and that through relationships and capacity-building among families, things can change, that we can actually move down a path and move towards real, authentic social inclusion for people with developmental disabilities.

Families coming together with families really doesn't just naturally happen, especially in groups of more than two or three. This intentional networking work is not really happening here in Ontario right now. It's actually quite prevalent in Durham region, but across Ontario it's not something that happens quite naturally. It certainly is not something that is supported by the developmental service system or is even on the radar of the transformation plans and ideas; I can't see it anywhere out there.

This committee has heard from other family groups; I know you have because I read them. They are telling you that is so, too. Some of those family groups—I think Deohaeko presented yesterday and probably told you about how, as a group, through families coming together, they were able to figure out and build good lives for their sons and daughters. This is over 25 years ago, so I can't believe we're still knocking ourselves across the head trying to figure this out. These families, 25 years ago, were figuring this out, and continue to figure it out together. With little money, they have sustained themselves, and their sons and daughters still have good lives in our community.

1520

I remain a single parent. I'm a caregiver. Now, I'm also a caregiver of two elderly parents, who I moved to Whitby two years ago. Five weeks ago, they moved into my sister's home. So I spend many hours supporting my parents to give my sister a break.

Ontario continues to fail caregivers, to recognize our lost earnings, to recognize our lost pension, to recognize the time and effort we contribute. The vast majority of us—the high vast majority of us—do this willingly and lovingly, but we are deeply afraid of the cost of this: the cost to our health, the cost to our future, the cost to our children's future, especially as we age.

Up until a year ago, I was spending in excess of $7,000 of my income to ensure my daughter had good support while I went to work. Not many women share their age, but I will: I'm 56 years old. For six years, I was certainly unable to save for my daughter's and my senior years. My income level was not enough to sustain this personal financial contribution, so I was deeply grateful when someone I know suggested I should teach in the DSW program at Centennial College, seven years ago.

At first—

The Chair (Mrs. Laura Albanese): Ms. Mitchell, I just want you to know you have about a minute left.

Ms. Cindy Mitchell: Okay; I'm nearly done. At first, this additional role on top of my already full-time job helped me to save for old age, so this past year, I've been able to save. But I still continue to work there because old age is coming faster than I can save. I jokingly tell this to parents, "I'm going to work till I'm 70." But it really isn't a joking matter; it's my life, and it's my daughter's and my family's life.

I know it is similar to the life experiences of many Ontario families. In telling my story and giving you a short glimpse into my life and my daughter's life, I hope you will think about what you will eventually recommend to Ontario and think about some of the things I would suggest. First—

The Chair (Mrs. Laura Albanese): Thank you. I'm sorry to—

Ms. Cindy Mitchell: I always run out of time. I've got a history here at this table of running out of time.

The Chair (Mrs. Laura Albanese): Maybe you can submit it to us? Would that be okay?

Ms. Cindy Mitchell: All right. But I've got a point to make, though.

The Chair (Mrs. Laura Albanese): Time has finished, and we're going to have an issue at the end of the day if we don't—

Ms. Cindy Mitchell: Can I make one last statement? I'm going to tell you there's a reason why you didn't get a printed copy of my presentation. It's because I wanted to take a stand for families, including my own, and tell you that there is an emotional and financial cost for us to come here. Most families, mine included, who come here cannot afford to pay for 35 copies for each of you, for this committee, as well as lose a day's work, as well as pay for support for their kids while they're here. So I will email you an electronic copy. Thanks.

The Chair (Mrs. Laura Albanese): We appreciate your deputation today.

ONTARIO ASSOCIATION OF CHILDREN'S REHABILITATION SERVICES

The Chair (Mrs. Laura Albanese): We will call on the Ontario Association of Children's Rehabilitation Services to come forward. Good afternoon. You may start as soon as you're ready.

Ms. Siu Mee Cheng: Hi. Thank you. Good afternoon. My name is Siu Mee Cheng, and I'm the chief executive officer of the Ontario Association of Children's Rehabilitation Services.

Ms. Louise Paul: I'm Louise Paul. I'm the chair of the board of directors with the Ontario Association of Children's Rehabilitation Services. From now on, we'll just refer to ourselves as OACRS. It's a little less of a mouthful for all of you to manage, and for us.

In my day job, I'm also the chief executive officer of the Children's Treatment Network of Simcoe York, which provides CTC-funded services to children, youth and their families in Simcoe county and the regional municipality of York.

Ms. Siu Mee Cheng: Thank you for the opportunity to make a presentation before this committee. Our presentation will hopefully be within time. We have three parts to this presentation. We'd like to introduce ourselves as an association; and then spend a bit of time just talking to you a little bit about the views and concerns of our members, our stakeholders, and the clients and families who our members serve, in terms of their concerns with regard to the current system; and then provide you with five recommendations on what needs to be done in order to address these concerns.

To begin, the association has been the united provincial voice for the 21 treatment centres across Ontario for about 35 years, since 1978. Our aim is to ensure that children and youth reach their full potential. Together, OACRS members serve approximately 70,000 children and youth with special needs and their families on an annual basis, and half of these are children who have developmental disabilities.

The CTCs are a really cohesive group of service providers who provide a fairly comprehensive set of pediatric rehabilitation services within Ontario. They provide approximately $275 million worth of publicly funded pediatric rehabilitation services, and they work both intersectorally and intrasectorally; that is, they work in partnership with education, health, municipal, social services and community-sector partners on interprovincial teams and interprofessional teams to meet the needs of children with disabilities, by providing integrated, inclusive and family-centred services.

On slide 4, you'll see a fairly comprehensive list of services that the children's treatment centres provide. Physiotherapy, occupational therapy, speech and language are some of the common services—also social work, as well as psychology, recreational therapy and other services, including some school health services and preschool speech and language. I will not go through the entire list.

That is the sum of OACRS and its members.

I'll let Louise talk about the current landscape and the concerns reflected by our members and stakeholders.

Ms. Louise Paul: I'm not going to go through an exhaustive list of what many of the issues are; I'm sure you've heard different perspectives on a number of the ones that I'll be referring to. I'm just going to highlight the key ones that were identified by our members.

Before I do that, I just want to pause to say, having listened to the amazing presentations from family members who came before us—I've worked in this field for 35-plus years, and what still continues to puzzle me in many ways, and also sadden me, is that when I started 35 years ago, and continuing up to today—and I think I'll continue for a while longer—if there's one issue that families continually raise with us, it is the lack of simplified and coordinated access to a comprehensive range of services for their children and youth. It seems like something that we should have been able to figure out by now. Certainly that view of families was reflected in the fairly recent report that the then parliamentary assistant, Tracy MacCharles, presented to Minister Piruzza—certainly a very strong voice from families, and that was one of the key issues that they raised with her.

I don't think that having coordinated services solves all the problems. It certainly doesn't address all of the issues of caregiver burden, and other issues that we have around coordination amongst different service providers. But it will go a long way, I think, to helping families feel more comfortable moving through a system, being able to know what services are available, and having key individuals—whether you call them service coordinators or service navigators—as families need them, and identify the need to assist them in moving through this system.

1530

I just wanted to flag that one. It's not flagged in our slide deck but it's one that resonated for me when I was listening to the two previous presenters and one that our members have raised as well.

In terms of some specific concerns in terms of the lack of access to services, Siu Mee mentioned the range of rehabilitation services that the 21 CTCs in Ontario provide. We have a real issue, and continue to have an issue, around long, long wait times. That is obviously for children with developmental disabilities, who, as Siu Mee mentioned, make up 50% of our population that we serve, but also for the other 50% of the children we serve.

We have, particularly for areas like diagnostic assessments—I can speak to my own centre—a 12- to 14-month wait. That's for a child to get an assessment about what their diagnosis is. When you're dealing with children with developmental disabilities, which includes autism, that's an incredibly long wait time.

There are equally long wait times for essential services that are needed in a child's developmental years around speech and language, occupational and physiotherapy, and other services.

I'm sure the committee knows about the situation with residential services for children, and that is that historically the residential service places, or beds, for children with developmental disabilities have been, and continue to be, funded by MCSS. Children who have been in those beds as children have continued to age in place, and they are now adults. But the funding for those beds continues to come from the children's side of the MCSS funding envelope for developmental services. So when we have more children coming in through our system, primarily children with developmental disabilities—and as they become preteens and teenagers, they often have sometimes very challenging behavioural and anti-social behavioural issues to manage, and families can't care for them anymore—the lack of residential beds is really exacerbated by the fact that a percentage of that funding continues to provide residential supports for adults. Within the children's sector we have, yet again, long, long wait times for essential residential services for children.

In terms of diagnosis, I referred to that in a previous slide around the long wait times for getting specifically a diagnosis of developmental disability for a child. There becomes a huge issue for families when they get to the other end of that continuum and they're wanting to move into the adult system.

If you're a family and you have either had a fairly recent diagnostic assessment by a psychologist for your child, and that assessment covers both the cognitive and functional areas that are criteria for an eligibility assessment by the DSO, then you can begin planning with the DSO at age 16 or earlier for your child's transition into adult services. Once your child turns 18, you can hopefully get some access to direct service right away, but you will then go on to wait-lists for adult services, but as of the moment you turn 18.

However, for many families, they're in a different situation. Either they had a diagnosis a number of years ago, when the child first went into school, identified as having a developmental delay, identified what supports were needed around the educational system—for many children, that's the only kind of formal diagnosis they've had around a developmental disability. When they get to that age of 16 and they're looking at wanting to move into the planning for adult services, the previous diagnosis is either too old, not done by the appropriate individual—it has to be a psychologist—or it doesn't cover both cognitive and functional areas.

If those families have the ability to pay for a private psychological assessment—for the eligibility assessment—they will do that, and then they will be able to begin that planning process. If, however—and this is a situation for many of the families we work with—you do not have that funding capacity, you have to wait until your child turns 18, and then the regional DSO, if they still have funding available in that envelope for assessments, will put you on a list for assessment—for that functional assessment, that eligibility assessment. There could be a wait for that assessment, there's then a wait for the report, and then you can get on the list for services. So there is a bit of a two-tiered system here and certainly a real disadvantage for families who do not have the capacity to fund a private eligibility assessment to enter into the adult system. The DSO inadvertently becomes a real roadblock, not through intent, and it's not all their doing, because they are restricted from providing funding for that assessment until that individual turns 18.

One of the considerations could be that if they could move that age back to age 16, then that would allow those families and those children to start that planning process sooner. But at this point, they are restricted because of the regulations, so they have no choice on that. That is obviously a major concern for us in terms of a roadblock to a really smooth transition into adult services for this population.

In terms of other parts of the fragmentation, we do want to highlight as well intersectoral fragmentation. I do want to preface this by saying that I think in the last two to three years, under the leadership of the Ministry of Children and Youth Services, we have seen much more interministerial collaboration and work. We work very closely with the Ministry of Health and the Ministry of Children and Youth Services, who fund us, and the Ministry of Education, obviously, during the years that children are in the educational system. We have seen a lot of movement around better coordination amongst the different sectors. However, there is still a long way to go, and there is no one provincial ministry that has direct, cohesive and comprehensive responsibility for all the policy and program service delivery for children and youth with developmental disabilities. I spoke to that a minute ago around the funding that still remains with MCSS for services for children with developmental disabilities, and then the funding and policy for children with developmental disabilities that falls under MCYS. So all the funding for the primary rehab provider for children's services for kids with developmental disabilities comes under MCYS, but a number of other services that those families access and that our service providers try to work in collaboration with are in a different sector, the developmental sector, which is primarily focused on adults, and tend to be within a different planning and service sector within local communities. It's inconsistent across the province, but they are not well integrated.

We want to also highlight family and caregiver issues. I will just hit on two.

In terms of dual diagnosis, one of the areas that we do want to flag for the committee is that—and I'm sure you've heard this from other presenters as well—the current service delivery system is really fragmented for children and youth with a dual diagnosis. Parents have to learn to navigate not only the children's rehab system and the school system, but they also need to learn how to navigate the children's mental health system. Because many of us have worked closely with our colleagues there, we know that within the children's mental health system there is often a reticence to serve children with a dual diagnosis because a lot of children's mental health providers don't feel like they have the skills and the competency to do that.

In terms of access to Special Services at Home and respite funding, I honestly don't think I could add much to the conversation, particularly from the speaker two speakers ago, who I think very eloquently addressed what the issues are around being able to access that type of funding. I would just say, though, that we do know that there is lots of evidence that shows that low-cost programs like Special Services at Home and respite funding can really, really help maintain families' quality of life and their resiliency and can in many cases avoid the need for out-of-home placement.

Caregiver burden: I think I, as well, am going to say that we would echo what has been said by the past two speakers and don't have anything to add at this point. We do have some recommendations, but I think that they said all that really needs to be said about that issue.

1540

In terms of transitional support for families and caregivers, there's a great quote on this slide from Ivan, who's a parent, who says, "I don't understand why my child (who is 17) has to get an assessment again to determine a developmental disability diagnosis for adult services if my child already was told by the school and others (i.e., CTC) that my child has a developmental disability." And we all know that. It just reinforces the comment I made earlier about the challenge with assessments at the point of transfer into the adult system through the DSO.

We know that children and youth with disabilities require supports to seamlessly transition between developmental stages, including stages throughout childhood and from the children's system into the adult system. I've spoken to this point really around the transition into the adult system. There is also a gap when children transition from preschool and community-based care into the school system. Children's treatment centres are the primary provider of rehab services up until a child turns age four or five, depending on when they go into school. Then, the funding and the authority to provide in-school rehab services shifts to the Ministry of Health and the community care access centres, which provide services through contracted providers, and those individuals provide the rehab services: OT, physio, speech and language, feeding—if that support is needed—in the school setting.

At this point, only five of the 21 children's treatment centres have those contracts or provide services within the school setting under the auspices of the local CCAC. So what happens is, a family who has been having pretty good service for the most part—coordinated, comprehensive service delivery through the children's treatment centres—moves into the school environment, and that therapist or those therapists don't follow that child through the school, with the exception of the five CTCs that provide those services. They have to establish new relationships. It's a different type of service that is provided. It's much more time-driven. There is no capacity for the therapist providing that service in the school to go and see the child in the home environment and in other community environments, like they can when they're with the CTC. So there's a huge disruption and rupture for families. They're not only trying to adjust to a new setting for their child, but they also do not have that continuity of service delivery in the rehab area. That's a huge concern for us in terms of continuity of coordinated and appropriate rehab services.

The Chair (Mrs. Laura Albanese): You have about a minute—

Ms. Louise Paul: Oh, gosh.

The Chair (Mrs. Laura Albanese): Sorry.

Ms. Louise Paul: You know what? I think I've covered most of this stuff. I didn't realize I'd wandered on for so long. I'm just going to turn it over to Siu Mee for a summary of our recommendations.

Ms. Siu Mee Cheng: All right. Thank you. A minute left; I will gallop along then.

We do have five recommendations. The first is ensuring that there is a whole-of-government approach to addressing the needs of children and youth with developmental disabilities—so the Ministries of Children and Youth Services, Community and Social Services, Municipal Affairs and Housing, Health and Long-Term Care, Education, and Training, Colleges and Universities—to build a comprehensive framework and approach to addressing the needs and service needs. This includes addressing moving relevant policy development and funding of relevant services over to the Ministry of Children and Youth Services. As well, the Minister of Children and Youth Services should, when they're advancing the mental health transformation agenda, include the rehabilitation services sector in their discussion tables.

The second recommendation is investment in services for those with developmental disabilities, so greater investments for rehabilitation services and other services for children and youth. This includes considering investments in integrated rehab services in the school setting, for instance, in the full-day kindergarten learning environment.

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

Ms. Siu Mee Cheng: I'm up? All right.

The Chair (Mrs. Laura Albanese): Sorry.

Ms. Louise Paul: No, I was the one that went on too long.

Ms. Siu Mee Cheng: Well, we are making a written submission. Thank you.

The Chair (Mrs. Laura Albanese): But we do have your deck, and we will make sure to read it.

Ms. Louise Paul: Yes, thank you.

Ms. Siu Mee Cheng: Thank you.

The Chair (Mrs. Laura Albanese): Thank you so much for coming here today and presenting before the committee.

JUSTICE FOR CHILDREN AND YOUTH

The Chair (Mrs. Laura Albanese): Now we call on Justice for Children and Youth to come forward. Good afternoon and welcome.

Ms. Mary Birdsell: Good afternoon. Thank you.

The Chair (Mrs. Laura Albanese): If you could please state your names and titles before you begin your presentation for the purposes of Hansard recording.

Ms. Mary Birdsell: Absolutely. Thank you. My name is Mary Birdsell and I am the executive director of the legal clinic Justice for Children and Youth.

Ms. Samira Ahmed: My name is Samira Ahmed and I am a staff lawyer at Justice for Children and Youth.

Ms. Mary Birdsell: We very much appreciate the opportunity to come and to speak with you today. We apologize; we don't have written submissions for you at this point. We were informed of the timing on Friday, and although it would have been ideal for us to have been prepared much ahead of time, we were not and we had to rearrange our schedules to be here, but we really wanted to do that in recognition of the significance and importance of the issues that you are addressing.

We know that you will have heard from many knowledgeable and extremely well-informed parties, and we want to try and focus our submissions today on things that are relatively connected to the legal issues that we see.

While we appreciate the opportunity to be here and we know that you've had many professional people here, we hope that in the creation of your strategy, recommendations and report and in any planning and strategizing that you do, you will commit some resources, including time, to consult directly with young people who are affected by the issues that you're considering and who are living through the subject matter of your inquiry.

I'm going to ask Samira to introduce Justice for Children and Youth to you briefly, and then we'll address our submissions.

Ms. Samira Ahmed: Justice for Children and Youth is the only organization in Canada, and one of a few in the world, that is exclusively focused on the legal rights of children and youth. This allows our clinic to offer a highly specialized voice on the issues affecting youth and their legal rights.

We strive to promote youth dignity and the rights of children and youth. Voice and empowerment are important tenets of our mission, and this is the most effective way, in our opinion, to protect and preserve the rights of children and youth, and allows youth, with the tools and context, to speak for themselves as individual rights holders in society.

At Justice for Children and Youth, we have lawyers who represent and advocate for youth who are under the age of 18, as well as for homeless youth who are under the age of 25. We are a specialty legal clinic that is funded to provide services to youth across the province. We regularly and routinely have contact with youth or parents of youth who are struggling with mental illness or developmental disabilities. We receive phone calls from youth who are experiencing educational issues, criminal issues and child protection situations. These situations are often as a direct result of their vulnerabilities due to their mental health issues or their developmental disabilities and, at times, both.

These youth are contacting our office for assistance and are often not receiving adequate support and/or treatment for their mental health issues or developmental difficulties.

Ms. Mary Birdsell: I just wanted to echo something that you heard from the previous speaker with respect to the simplified and comprehensive access to supports and services for families across Ontario. I would agree that in the almost 20 years that I have been working in the field, it does seem to be a perennially frustrating issue that there isn't a simplified place to go to get comprehensive access. I often think that if we seem, as a broader society, to be able to coordinate services to analyze the rocks on Mars, surely to heaven we can create coordinated and simplified access for these vulnerable people in our communities.

I wanted to recognize as a general matter that the young people to whom we offer services fall across a very broad range of their needs with respect to mental health services and developmental needs and the complexities that come with dual diagnosis, and that services need to be responsive and aware about the range of needs so that they can adapt to individualized circumstances. I would say that as a general matter the ability to individualize services and supports is an important part of any comprehensive strategy.

1550

I would say also that, generally speaking, the questions of mental health and developmental disabilities are very, very common in our client population. They are issues that affect almost every young person that we come into contact with.

We wanted to address four specific areas that persistently arise in the intersection between social and legal contexts for these young people. One is the child protection gap, and I will talk about that in a little bit more detail. The other is education issues. The third is transitional issues. Fourth, I just want to touch very briefly on the criminal justice system issues.

With respect to child protection, one of the areas of debate, not only inside our office but with many people with whom we come into contact, is the question of special-needs agreements under the Child and Family Services Act. As you may or may not be aware, there is a context in child protection where special-needs agreements are available in the legislation.

In 2001, there was a ministerial directive essentially putting an end to the provision of special-needs agreements where there are no other child protection concerns. Really, what this creates is a circumstance where a family can care, wants to care and has personal resources to care for their children who have mental health or developmental disabilities, but they don't have the other resources that they need to provide adequate services, so they're coming to child welfare to say, "I can't do it without your help." What child welfare has said now is, "Well, you don't present a protection concern; you're a loving, caring parent," but the reality is families cannot cope with the layers and layers of needs that might be available. Yet, what the ministry has said is, "We are not going to offer special-needs agreements in these circumstances."

I'm going to offer you just a very small vignette to illustrate this. We're trying to assist a family who had a newborn baby who was on a ventilation tube and whose health needs meant that they needed to have 24-hour, eyes-on observation. The person who was caring for this baby was a single mother with very few social connections in the community. She was really, really stuck. The children's hospital didn't want to discharge this baby because they felt that the parent couldn't care for them. Child welfare was unwilling to provide special-needs agreements and supports, and through the other kinds of access to services that this parent could access, there wasn't sufficient support to enable that baby to have 24-hour, eyes-on services. One of the commentaries was, "Well, we don't know whether this baby has developmental needs or not." That's just a simple example of a huge gap that's created in part by this question of child protection. There are many, many other examples that I'm sure you can imagine with respect to older children.

In our submission: Ontario must be able to provide adequate, appropriate and accessible services that are designed to keep families together, even in circumstances where we don't fully understand the nature of the disabilities that children are experiencing. I think that when you've got severe, complex special needs in the health context, those kinds of children need to be addressed in any comprehensive service. We understand the ministry directive, but we think that this removal of child welfare services really leaves an enormous gap for families who, while they want to provide care, may not have the resources that they need to have. Perhaps the answer is to create an individualized special-needs agreement model that is inter-ministerial between health, education, MCYS and MCSS, and perhaps there are other ministries as well that might be involved. Our proposal would be that they be mandated to ensure that there are appropriate educational services and supports, appropriate care and treatment resources available and appropriate supports for families, and that all of these together ensure the optimal health of young people.

I'm going to come back to this later, but we'd like to identify that, in fact, Canada and Ontario, who are signatories to the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities, are mandated to attend to these issues.

This is somewhat repetitive, but there needs to be one place for families to go where members at the table are empowered to make decisions. If there is an inter-ministerial service coordinator, they have to be empowered to make decisions, including financial decisions, and they need to have access to the various resources that the various ministries have at their disposal.

The other comment I'd like to make with respect to the Child and Family Services Act and child welfare services is that recently the Legislature is considering—it will go to third reading, we hope, when the Legislature is up again—Bill 88, which will provide some voluntary services to 16- and 17-year-olds.

One of the things that we see, especially in the homeless young people whom we offer services to, is what really would amount to child protection needs. Definitely mental health needs are very extreme, and developmental disabilities are also very present in the street youth population. Bill 88 will go some distance, we hope, to offering voluntary services to these young folks who have really fallen through the cracks in the most obvious ways, but we're still concerned about what happens to them when they turn 18 and what the quality and nature of these services will be. So I think these issues are still very much on your platter, even if that bill passes.

I'd like to move now, as the clock ticks by, to talk briefly about education issues and in particular special education issues, which are routinely engaged for the young people with whom you are concerned. As you know, special education supports are a matter of human rights. We are obligated to provide special education supports to young people who need them, but I would say that children, young people and their families are at the mercy of limited resources. In particular, smaller boards of education in more remote and rural communities, and their students, are disadvantaged by the small size of their boards.

Of course, this is a massive problem—and I'm glad that you are the brain trust who need to struggle with the details—but this can't be the reality in Ontario: that if you live in a place where you are in the midst of a large board of education, you might have access to services, but if you are in a smaller or more finely dispersed board you can't access services at all.

One of the difficulties that arises in this context is that school boards and school administrators wind up using disciplinary tactics as a fallback for a lack of services, so that young people who struggle with developmental issues and behavioural issues that arise in that context are left suspended, expelled and excluded from school for the very reasons that make them worthy of the human rights supports that they need.

Again, to use a somewhat mundane example, if you have a young person with a developmental delay, maybe autism, or many other kinds of things, who struggles with the management of simple behavioural things—outbursts, anger or frustration—when they act out, they wind up getting suspended or even expelled, even at the elementary school level, when what they really need are the supports to help them to learn to cope in the school context. These are fairly serious human rights violations, in our view, and they're massive weights to leave on families who are already struggling with the realities of children who are struggling.

The other thing I would say in this regard that I think is important to recognize is that school disruption only serves to further disadvantage students who are already struggling in the system, and that the societal costs of this are unacceptable and avoidable. Of course, while providing school resources may mean money, I think that, in the overall analysis, we are certainly much better off to provide those kinds of resources when children are young and still in school, and save ourselves the sad outcomes for young people who are excluded from schools.

One of the solutions that I would offer to this—and this is a small solution, but I think it is very important—is that school boards and school administrators must be educated about their human rights obligations and their Education Act obligations so that they understand the difference between disciplinary responses and human rights responses to children with special needs. One of the things that might be difficult to do in some ways but would be fantastic in other ways is if there were mobile services to support remote and rural communities in terms of the kinds of things and special education supports that young people need.

1600

Another education issue that is distinct but is very important is the issue of assessments. I'm sure it has come up for you repeatedly, but it is a huge problem across the province. Even large school boards struggle with one-, two- or even three-year waiting lists to get psycho-educational assessments for students. The previous speaker spoke about assessments more generally for developmental needs, and of course those are very important issues. But even just to get a psycho-educational assessment might be a huge, long wait, if not near-impossible. This cannot be, because we can't provide appropriate and meaningful supports unless we have a good sense of what's going on. It's an area that needs to be remedied immediately.

I wanted to speak to you about transition services. Again, as the previous speaker noted, there are a number of transitions that occur for children and youth from infancy to adulthood in the context of developmental disabilities and mental health. I want to speak specifically to the question of transitioning from youth to adulthood. I would say that, in our experience, it's a terrible stage for young people and their families and that we need to eliminate the age-based bright lines that exist from services and supports in one context to services and supports in another context, so that there's always an overlap in services and supports that we provide and so that no family or young person is left hearing, “The day you turn 18 is the day you have to jump into this next ether that you haven't been able to access at all prior to that moment when you arrive there.” It creates an impossible situation where you wind up being potentially homeless with developmental disabilities and mental health issues and suddenly being cut off from all of the supports that you may have had up until that time. In our view, we need to plan for and coordinate the overlap of services so that there's actually a full-on expectation that services and supports will overlap and that one set will not end until the other one has already been implemented and working and functioning. We would suggest that there be a legislated duty to implement smooth transitions.

The other thing that I would say in support of this, and I realize my time is probably running short, is that we have not always known the depth and extent to which brain development does not magically change and that in fact childhood and adolescence, in terms of brain development, continue definitely into your 20s and probably into your mid-20s, and that this is multiplied as an important issue for young people with mental health and developmental disabilities.

I wanted to speak very, very briefly about the criminal justice system. I would say that in our experience, the criminal justice system is often used as a mechanism for addressing the behaviour of young people with developmental disabilities and mental health issues. I couldn't try and express to you more strongly how inappropriate I think this is and how ill-equipped it is to deal with the complexity of the issues that these young people face. I think people turn to it when they feel frustrated and at a loss for what to do, but it's like going from one place where people are knowledgeable, educated and steeped in the issues to another place where people are not knowledgeable, are not educated and are not steeped in the issues. Not to sound like a terrible cynic, but the criminal justice system is designed to be responsive by executing—pardon the use of that word—by implementing punishment for wrong deeds done to people who understand the nature of their behaviour. It's not really designed to address developmental and mental health issues. Of course, it works hard to try and address those realities because the criminal justice system as a system knows that those things exist and that they're important, but that is not the place for young people with developmental delay and mental health issues.

The Chair (Mrs. Laura Albanese): You have about 30 seconds.

Ms. Mary Birdsell: The other thing that we would like to commend to you in terms of strategizing and going forward is that a coordinated approach to researching the needs of young people with developmental disability and mental health issues across the province would be a very fruitful task for the government to take the lead on. They have many resources at their disposal, and, of course, access to brilliant academics who I'm sure could provide fruitful commentary.

Thank you very much for your time.

The Chair (Mrs. Laura Albanese): Well, thank you for this thorough presentation. I apologize that I have to be so draconian with the times, but that's what I need to do as Chair.

Ms. Mary Birdsell: We understand.

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

ARCH DISABILITY LAW CENTRE

The Chair (Mrs. Laura Albanese): We'll now welcome ARCH Disability Law Centre. Good afternoon. Welcome to our committee.

Ms. Kerri Joffe: Thank you very much.

The Chair (Mrs. Laura Albanese): If you could please state your name and title before you begin your presentation, that would be much appreciated.

Ms. Kerri Joffe: My name is Kerri Joffe. I'm a staff lawyer at ARCH Disability Law Centre, which is a legal clinic, like Justice for Children and Youth, but ARCH is dedicated to providing services specifically to people with disabilities in Ontario.

With me today are Tebasum Durrani and Maija-lisa Robinson. They are both law students at Osgoode Hall Law School, and they are both completing internships at ARCH. They've come to assist me in presenting to you today.

I'll just tell you very briefly a little bit about ARCH, for those committee members who don't know us.

As I said, we're a legal clinic. Our mandate is to defend and advance the equality rights of persons with disabilities in Ontario. We do this in a variety of ways. We provide legal information and advice directly to people with disabilities throughout the province, including people who have developmental disabilities. We also represent people with disabilities, including people with developmental disabilities, in litigation at all levels of tribunals and courts.

We regularly work with people with developmental disabilities, their families and support agencies to conduct community development initiatives to support the community, and we do quite a bit of public legal education around human rights and disability rights for people with intellectual and developmental disabilities.

The submissions that we are going to make to you today are based on and draw upon that body of work and the context that we have very regularly with the community. We have prepared a written submission, which has been emailed to the Clerk this afternoon; it's not here, but you'll have it, I'm sure, to consider.

This afternoon, we'd like to focus on three key issues that we see as really important for strengthening and improving the developmental services sector.

The first is the need to include substantive rights for people with developmental disabilities in the law that governs developmental services and in the sector more generally.

The second issue is the need to promote and strengthen the right of persons with developmental disabilities to make their own decisions. We also refer to that as the right to legal capacity.

The third is the need to establish an accessible and independent complaint mechanism to ensure that developmental services and supports—and hopefully direct funding as well—are accountable to people with developmental disabilities.

I'm going to turn it over now to Tebasum and Maija-lisa to flesh out those three points.

Ms. Maija-lisa Robinson: Hello. Since 2008, ARCH has made several submissions regarding the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act and its accompanying regulations. I'm going to simply refer to that as the social inclusion act.

It continues to be ARCH's position that the legislation should include a clear statutory framework establishing substantive rights for people with intellectual disabilities who receive developmental services. The obligations on service providers set out in the quality assurance measures are designed to ensure that service agencies are accountable to the ministry for the quality of services and supports that they provide to people with disabilities. However, there is little in the regulation to make services and supports accountable to the individuals who receive them.

1610

In drafting the social inclusion act, it was the government's intention to transform the developmental services sector. Six years later, this committee is hearing from service providers and other organizations, as well as from families, about the serious problems that they face and the current crisis within the system.

It is ARCH's position that, in order to fulfill the government's stated objective of transforming the developmental services sector, people who receive developmental services must have rights. Enshrining rights in legislation sends a strong message that the government is committed to upholding the dignity and full participation of people with intellectual disabilities as equal citizens in society.

The provision of rights is empowering. It enables people who receive developmental services to access legal tools to address concerns they may have about services, instead of relying solely on the government to ensure that service providers comply with the act. The inclusion of rights is a fundamental step towards transforming the role of people with disabilities in the developmental services sector from passive recipients of care to active consumers of services who are accountable to them.

The unique circumstances of people with disabilities who receive developmental services are not addressed under Ontario's Human Rights Code or the Canadian Charter of Rights and Freedoms, which provide fundamental rights and protections but not rights specific to the developmental services sector. While people with disabilities are protected against discrimination and have the right to equal protection and benefit under the law, they have no rights regarding the quality and types of services and supports they are entitled to.

Let me give you an example of the type of situation that ARCH has dealt with. A woman who has lived in the same group home for more than 20 years is told that she will be moving to another home in a different part of town, far away from her family and her community. She has no input and no role in the decision-making process regarding a fundamental right that we take for granted: where and with whom she will live.

Some examples of the types of service rights that could be included in the legislation are:

—freedom of choice regarding activities of daily living, including decisions about food, clothing, personal appearance and participation in activities;

—the right to enjoy personal privacy, including expectations of daily living such as the right to have a private telephone conversation and the right to receive visitors of the person's choosing;

—the right to legal capacity; and

—the right to have personal decisions respected.

Including rights in the social inclusion act is important for several reasons. Symbolically, it demonstrates that the humanity and dignity of people with intellectual disabilities is not merely recognized in words but in substantive rights that people can use to improve the quality of their daily lives. This is linked to quality assurance measures, as the provision and enforcement of rights for people with intellectual disabilities will undoubtedly lead to an improved quality of developmental services.

Practically, including rights in the legislation is the first step toward creating a culture of rights within the developmental services sector, thereby increasing the possibility that people with disabilities will have more autonomy, control and self-determination over their lives.

Finally, the inclusion of service rights in the legislation will ensure that people with disabilities and service providers have similar expectations and standards. Adopting rights in the legislation would provide much-needed uniformity, ensuring that these rights apply to everyone who receives developmental services, regardless of which agency or support worker provides the service.

An important and related rights-based issue that I would like to draw your attention to today is legal capacity and the right to make one's own decisions. Under the law, capacity is presumed. Capacity is both issue-specific and dynamic. A person may be capable of making one kind of decision and not another, or may be capable at one point in time and not another.

Unless an adult is found to be incapable, they have the right to be informed and to make their own decisions in regard to every aspect of their life. This includes the right to make their own choices about everyday matters and matters related to developmental services.

The social inclusion act attempts to recognize that people with intellectual disabilities are entitled to live in communities of their choosing and participate as equal citizens in community life, yet there continue to be barriers that impede the realization of these entitlements. One of these barriers is the difficulty establishing a culture in which service providers and community members respect the right of people with intellectual disabilities to self-determination. ARCH regularly hears about and deals with situations in which service providers, family members and others assume that a person lacks capacity to make his or her own decisions simply because he or she has an intellectual disability or uses developmental services. Service providers may require family members to provide written consent to allow a person with a disability to participate in an outing or a community activity. Service providers insist on getting this permission even though the person with the disability is an adult who can and is entitled to make his or her own decision about participating in the outing. This is just one example of the way in which people with intellectual disabilities are denied the right to make their own decisions.

The social inclusion act is silent on the issue of capacity and does not protect autonomy of persons with intellectual disabilities. I would refer you to ARCH's written submissions for specific provisions and recommended amendments to the legislation.

A key change that can be made to strengthen Ontario's developmental services system is to ensure that laws and policies promote and protect individuals' right to make their own decisions. The legal presumption of capacity should be reflected and incorporated into the social inclusion act. Those who work in service agencies, DSOs and other developmental service providers must receive training on capacity law, the importance of supporting individual autonomy and how to accommodate individuals with disabilities to enhance their ability to make their own decisions. Thank you.

Ms. Tebasum Durrani: Good afternoon. Just as clearly articulating rights in the social inclusion act is crucial to promoting the empowerment of individuals with disabilities, so too is the addition of a process that ensures accountability and enforcement of those rights. Rights would be meaningless without a transparent and independent process to ensure that they are protected.

As such, ARCH recommends that the strategy for developmental services incorporate a rights-enforcement framework that is external from the service provider complaints process. The lack of such a mechanism within the legislation as it stands is problematic because there is no defined process for individuals to make additional complaints about the services that they receive to a neutral body that is external from the service provider.

People with developmental disabilities should have the right to a process that can be used to raise concerns about the service provision they receive and to recommend changes to promote enhanced accountability and quality assurance for those services. This is essential in order to ensure that individuals are provided with an avenue to assert their rights to receive developmental services in a safe and respectful manner.

At present, service agencies are mandated by the social inclusion act to have procedures to address complaints. Section 26 of the act requires agencies to have written procedures for initiating complaints to the agency and how they will handle those complaints. However, ARCH submits that there are challenges associated with the effectiveness of such internal mechanisms. While the existence of these processes is important, they should not be the last step for individuals in terms of asserting their rights as recipients of developmental services.

Due to the nature of supports that some people require and the environment in which those services are delivered, many individuals with disabilities fear abuse or being threatened or retaliated against if they file a complaint about the services they receive. Depending on their unique needs, people with intellectual disabilities may require support for activities of daily living, and this dependence can often enhance the inherent power imbalance that exists within the relationship between the person with a disability and his or her support worker. Individuals must work hard to maintain good relationships with their service providers and others upon whom they rely for daily assistance. Making a complaint about a support worker or raising concerns about services received can threaten these key relationships.

Further, individuals may fear being reprimanded by their support worker or being threatened with cuts to their benefits or privileges. Some agencies may require that individuals first raise their complaints with their support worker, against whom the complaint is being made. Again, fear of jeopardizing the relationship means that many individuals choose to stay silent.

1620

Finally, the neutrality of the process should be a priority given that current complaints processes are internal to a service provider agency. While the development of these internal mechanisms is important, ARCH submits that an additional layer of oversight is necessary to promote greater accountability and ultimate transparency.

In order to address these concerns, ARCH recommends that the strategy for developmental services includes the creation of an independent body that would receive and evaluate complaints. The objective is to give individuals a voice in terms of the services they are receiving and to ultimately enforce their rights to quality services. Ideally, its membership would be comprised of individuals who have expertise and experience in the developmental services sector and an understanding of the legislative framework surrounding service provision.

Any model will need to consider the necessary level of support that complainants would require in order to effectively pursue a complaint. ARCH recommends that consultations be conducted with persons with intellectual disabilities on what model would be most appropriate and what supports they may require to navigate such a process. This may include examining an advocate's office model, an ombudsman model or a more adversarial process with appropriate supports for individuals with developmental disabilities.

Finally, individuals who receive developmental services should be provided with information about the complaints mechanisms in a way that is accessible to them. The human rights principle of accessibility mandates that complaints mechanisms be designed to ensure that people with disabilities can access them and engage with them effectively. If the processes are too complex or legalistic, this will create additional barriers to accessibility, thereby undercutting the very purpose of these mechanisms. To remedy this, ARCH recommends developing resources that explain the complaint body's role in clear language, as well as promoting public education about the existence of this body and its purposes throughout the community.

The provision of ongoing support for the duration of the process of filing a complaint is also essential to maximizing accessibility and ultimately enhancing the effectiveness of any such process.

Any procedures that would require the drafting or filing of complex documents and the presentation of cumbersome legal arguments should also be modified with the goal of enhanced accessibility and ultimate flexibility for individuals. Thank you.

Ms. Kerri Joffe: How much time do we have?

The Chair (Mrs. Laura Albanese): You still have two minutes.

Ms. Kerri Joffe: Great, okay.

Before we ask you if you have any questions for us, I just want to echo the submissions of Justice for Children and Youth on the issue of the committee making time to consult with people who are actually affected by developmental services, people who receive developmental services. I know they work primarily with children and youth. We work with children and youth with disabilities, but also adults with disabilities. I would comment to the committee to really think about a meaningful consultation process for people who receive developmental services, which likely would look quite different from the hearings that have been held to date. We, at ARCH, are happy to consult with the committee on what that process may look like if that's something that people are interested in.

The Chair (Mrs. Laura Albanese): I want to consult with the committee members, but we have had some present to us as well in the course of our hearings, and we have visited some centres, just to let you know.

In any case, I would say it's more a comment more than a question. If it's a question, it's really brief. We're down to a minute and a half. Ms. Hunter.

Ms. Mitzie Hunter: Mr. Balkissoon.

Mr. Bas Balkissoon: Thank you for being here and thank you for your presentation. It's well prepared. Thanks a lot.

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

Mrs. Christine Elliott: Thank you for being here, and thank you for the work that you do on behalf of people with disabilities. It's really, really important, and we have taken note of the legal issues you've presented to us and look forward to your presentation in written form. So thank you very much.

Ms. Kerri Joffe: Thank you.

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

Ms. Cheri DiNovo: I looked up the Ontario Human Rights Code as we were speaking and saw disability there, so I'd be very interested in a presentation about why that process isn't sufficient, because I know that Huronia is a classic example. The Ontario government has been sued, and successfully. So if in your presentation you've got more information about that, I would be very interested.

Ms. Kerri Joffe: We do have a bit more in our written submission. Do I have a minute to address the comment?

The Chair (Mrs. Laura Albanese): You have 30 seconds.

Ms. Kerri Joffe: Thirty seconds. Okay. I'll try to address it very briefly. The Ontario Human Rights Code and the charter both address the legal issue of discrimination, so discrimination on the basis of disability. The kinds of issues that we see people coming to us with, people who receive developmental services, would not be able to be presented in an Ontario human rights tribunal process or in a charter challenge before a court, because those issues—it's very difficult to characterize them under the legal rubric of discrimination. They are issues that are related more to quality of services and complaints about the types of services that are received, lack of services, lack of choice, people's rights to make their own decisions not being respected. Those are quite different from our legal understanding of what constitutes discrimination, which is essentially being treated differently or negatively on the basis of your disability.

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

Ms. Kerri Joffe: Thank you.

MR. BARRY STANLEY

The Chair (Mrs. Laura Albanese): Now we call on Barry Stanley to come forward. Barry Stanley? Good afternoon.

Mr. Barry Stanley: Good afternoon, Madam Chair.

The Chair (Mrs. Laura Albanese): Welcome to our committee. You will have up to 20 minutes for your presentation.

Mr. Barry Stanley: I'm sorry. How long?

The Chair (Mrs. Laura Albanese): You will have up to 20 minutes for your presentation. If it's any shorter, that will leave time for questions and comments.

Mr. Barry Stanley: Thank you, Madam Chair. I'd like to thank you and the committee members for allowing me to make this submission.

The actual written submission, which I think you have in front of you, is quite extensive, so I don't intend to go through it all, because that would take up too much time. So the relevant points that you've asked for in your mandate are what I'm going to stress.

I'm speaking, basically, on behalf of those who are afflicted with fetal alcohol spectrum disorder and the families who support them. As you'll see, I am a parent myself, and I've been very actively involved in treatment and diagnosis prior to retiring at the age of 71 three years ago.

So I'm going to start on what is actually—I regret they're not numbered, but it's the seventh page. I'll read it and, if I have time, make comments. I hope there's time for questions.

Prenatal alcohol exposure to the developing fetus results in varying degrees of impaired brain function that are measured by neuropsychological testing. These neurodevelopmental disabilities are permanent and result in involvement by the individual with all the government agencies that you are considering here today.

Each assessment is a unique profile of the intellectual abilities of the individual and is essentially valid throughout their lifetime. There are some exceptions, but essentially that's true. We have in Canada the Canadian guidelines for the diagnosis of FASD, FAS and ARND, and you have a copy of those guidelines. These terms are designations given by the Canadian guidelines for the neurodevelopmental disabilities due to prenatal alcohol exposure. These guidelines include the set of psychological tests and the results required to make the diagnosis. I would refer them to you. As I say, you have a copy of the guidelines there.

It has been known since 1996 that if the diagnosis of FASD is made in early childhood and the appropriate measures taken, then the child will have less issues with schooling, the law, addictions, work and social interactions, most of which you are addressing today. The appropriate measures require recognition and understanding of FASD by all the agencies that you are considering.

1630

In Ontario, assessments are difficult to obtain due to poor funding and lack of appreciation of their importance. Consequently, FASD is underdiagnosed, with often tragic consequences to the individual and great expense to the province.

FASD—and I would like to emphasize this, please—is the only medical diagnosis that is denied in Ontario because of lack of access to the required psychological assessments and the paucity of diagnostic facilities. There is no medical condition that I'm aware of as a physician where the diagnosis is denied, in distinction, of course, to certain treatments, which are expensive and there is issue about. But the actual diagnosis is not denied except if you're FASD.

Since 1996, it has been apparent to those researching FASD that the IQ is inadequate and misleading as a tool for measuring the abilities of children who have been exposed to alcohol prenatally, yet to a varying extent, Ontario's public agencies rely on the IQ as a measure of intellectual ability. This results in the exclusion of many who need assistance, especially those with FASD.

The human brain is the most complex system known. The effect of prenatal alcohol exposure on the developing brain is ubiquitous and variable, within the range—and again, I stress this—of the IQ from extremely low to superior. Yet even the intelligent, as measured by the IQ, have chaotic lives, with various combinations of cognitive, information processing, memory and adaptive and executive functioning disabilities.

Sadly, most of those with FASD—children and adults—are seen as selfish, wilful, defiant and even evil, as stated to me by a crown prosecutor recently, when in fact they are desperately doing their best to make sense of their environment and the circumstances they find themselves in. In addition, their caregivers are usually blamed for the behaviour of the affected children. This often results in loss of the child and sometimes criminal charges against the caregiver, again with tragic consequences and hidden costs to the province.

Some 94% of those diagnosed will receive other diagnoses from the DSM, often multiple diagnoses; I've seen as many as six. It is important that the role of the DSM-5, which is the recent edition, is fully understood by our legislators. The Diagnostic and Statistical Manual is published by the American Psychiatric Association and is used throughout Canada by psychiatrists, pediatricians and psychologists. It includes mental health, developmental and behavioural diagnoses—diagnoses that enable access to government, public and private agencies for relief, awards and compensation. It's a vital document or book—they call it the bible of psychiatry. It's vital in the administration of all or most of your agencies. But the DSM-5, as in previous editions, does not include FASD, FAS or ARND.

This is one of the reasons why those with FASD and the families that support them have been denied what is rightfully theirs. The only way this gross deficiency can be rectified is for legislation to specifically include FASD as meeting the requirements for funding etc. by all government agencies that are involved.

I'm now going to go on to the items that you specified—suggestions and issues that you identified etc.

The elementary and secondary educational needs of children and youth—and I'm mostly referring, of course, to FASD, but I should say that it applies to all cases of intellectual disabilities. It's just that FASD is excluded so often. Children diagnosed with FASD need to be designated as exceptional, as in the acts governing education in Ontario. Children diagnosed with FASD need to be included in special education services.

The screening tools for FASD should be part of the training and the diagnosis pursued when appropriate.

All teaching and support staff should have training in FASD and be familiar with the psychological profile of the individual child.

Funding for psychological assessments should be a priority for all children with developmental disabilities of FASD. This is important in terms of costs, because the psychological assessments are one of the most expensive parts of the diagnosis and one of the reasons why the diagnosis often cannot be verified or pursued. What I maintain is that if this psychological assessment is passed and used by different agencies, then the virtual cost, of course, goes down, right? If it's only used in one agency and then repeated as necessary, then the cost goes up. So I say the psychological assessments from other sources, if adequate, should be used when available.

Behavioral issues need to be seen for what they are: a consequence of neurodevelopmental disabilities and not willful choices.

Programs for FASD need to be implemented universally. They should be based upon current research and be regularly updated.

A big issue is multiple schools, or schooling. FASD families are prone to move a lot. This means the children will often attend numerous schools over short periods. In addition, those children diagnosed FASD in CAS care—and there are many of them—often have multiple foster placements, resulting in a changing of schools. This, again, is due to lack of training and understanding of FASD and compounds the problems of education. Every effort should be made to keep the child in a stable school and home environment for optimum results.

Another important point: Other diagnoses from the DSM-5 should not exclude awareness, screening and diagnosis of FASD. On the contrary, such diagnoses should be a red flag for the diagnosis of FASD. Unfortunately, the opposite usually occurs once another diagnosis is made or efforts to explore the possibility of FASD are abandoned with, again, very negative results, as my case study at the end, which you may not have time to go through, illustrates.

Continuous two-way communication between the school and the caregiver is needed for the child to make optimal progress.

Moving on to the next issue, the educational and workplace needs of youth upon completion of secondary school: All transitions are difficult for those with FASD. While many do not complete school, for those who do the transition into the workplace can be especially difficult. Many will not be able to maintain employment—don't say they don't want to work, which is the usual thing—my son had 20 jobs in the first 10 years after leaving school.

Ontario Works needs to screen for FASD and refer for diagnosis when required. Work guidelines need to be developed by Ontario Works and shared with employers. I've got some suggestions here; I just don't want to run out of time. The complexity of the work and the degree to which it is multi-tasking depends on the intelligence of the individual. An intelligent FASD person can do a complex job; however, the following need to be in place, as a reflection of their disabilities:

—consistency: no significant variations, no unexpected changes or interruptions to the routine. Hours should be consistent. It may be best to avoid shift work. Part-time work may be preferable; no overtime, although some flexibility in terms of starting time could be best;

—no increase in the responsibility or workload, no matter how efficient they may be. Depending on the sleep patterns, night work may be best;

—no team work. FASD individuals certainly can, and may work around others; however, the work that they do should not require input from others. Likewise, other persons' work should not require input from the individual with FASD.

1640

They should only have to report to one person who has an understanding of FASD.

Depending on the type and degree of attention problems that the individual with FASD has, they may need to be in an environment that is not distracting, that is not busy or overstimulating.

Now here's an interesting one—I don't know whether it's appropriate to have interaction with the committee. Is that appropriate, Madam Chair? Okay. Payment should be on a weekly basis. This was told to me by an adult with FASD. I invite you to suggest why that should be, just to wake you up—and I realize this is the end and I fully understand what you've been through.

The Chair (Mrs. Laura Albanese): You're saying payment should be on a weekly basis?

Mr. Barry Stanley: On a weekly basis, and I might add, I didn't get it straight myself. He had to explain it to me. So if you don't get it, don't feel too bad. Any suggestions?

Ms. Mitzie Hunter: I think if it's anything longer, it might be forgotten, it might be—

Mr. Barry Stanley: Well done. I am so impressed. You did better than I did. I'm very impressed; I'm very encouraged.

He said to me, "Look, I can get out of bed when it's next Friday that I get my money, but way down the road—what's a month?" Time is very difficult for him.

In simple terms, they get distracted. It's, in fact, a much more complex thing than that, but persisting with an aim and a goal is very hard. They live in the moment. So to get up every day for a month is tough. They'll get distracted, they'll sleep in and they'll lose their job and many other things. Well done, I say; I'm very impressed.

Ms. Mitzie Hunter: To be fair, I worked at Goodwill Industries for seven years, so I have a little bit of knowledge.

Mr. Barry Stanley: Okay, very good.

The employer and supervisors need to be very precise with instructions—there's so much we could discuss, but we don't have the time—and they may be best given visually rather than verbally.

In terms of further education, some of those with FASD can certainly go to further education, college and so on. Many who do, do not complete it, in my experience, but there are no statistics. It has not been looked into; it needs to be looked into. Those that do complete—I have seen that, as well—unfortunately, they often cannot apply their education that they've gotten to a job, and a consistent job.

Moving on to the next issue that you raised: the need for a range of available and affordable housing options for youth and adults. Many of the homeless have FASD. Because of their adaptive and executive disabilities, those with FASD lead chaotic lives and are often in conflict with others. This results in them moving to the streets.

There is a great need for accommodation that is supervised with an understanding of FASD. In my experience, group homes are not the best because of the likelihood of conflict, and I should add, unfortunately—hopefully it's changing—the lack of understanding and the rigidity to, what I would call, old-fashioned programs creates great difficulties for those with FASD who end up in group homes. The less the domestic facilities are shared, the less the conflict. So the environment needs to be adapted to the individual, not the individual to the environment. That is a consistent and persistent need throughout all of the situations we're talking about.

The need to provide social, recreational and inclusionary opportunities for children, youth and adults with FASD: Those with FASD feel different. It's very significant and not very much known, but actually very consistent. They feel different and they are often lonely. Their unaffected peers often reject them. Consequently, they tend to associate with the disaffected and disadvantaged, by whom they are easily misled and exploited.

Provisions for social, recreational and inclusionary activities and programs are important for the well-being of those with FASD. However, such situations are fraught with unexpected consequences, and even dangers. Consequently, supervision by those knowledgeable about FASD is advised, indeed is necessary. Non-affected peers in those situations need to be advised about the disabilities of the person so as to avoid misunderstandings.

The respite and support needs of families: Respite is desperately needed for the natural, adoptive and foster parents of children with FASD, yet it is so rarely provided. This results in divorce, failed adoptions and multiple placements, all of which, of course, are exactly what the child does not need.

A provincial respite program is required for FASD families. This should list the public and private respite services, their location, means of access and cost. The cost of respite can be a major deterrent, and government aid is needed in many cases.

For respite to be successful, it is imperative that the temporary caregiver understand FASD and be familiar with the child's needs, as indicated by the psychological assessments. If not, the child's behaviour will be aggravated on return to the home.

Policy on FASD has to include regular respite on a scheduled basis. In my experience, frequent short periods are more effective than infrequent longer periods.

The alternate caregiver should be the same person as often as possible.

The Chair (Mrs. Laura Albanese): You have just a little over a minute left.

Mr. Barry Stanley: Okay. So I'll finish with how government should most appropriately support those needs and provide those opportunities.

Future legislation should include provisions for an overall comprehensive policy on FASD that applies to all government ministries, departments and agencies. The IQ needs to be abandoned as a criterion for the provision of developmental services.

A full psychological assessment should be recognized as the intellectual profile of the individual that can and should be used by all departments and agencies throughout the life of the individual. Means should be provided for the individual's psychological assessment profile to be used by all government ministries, departments and agencies—education, justice, ODSP, housing, respite—throughout the life of the individual, so as to provide co-operative, comprehensive and continuous services, thereby significantly reducing the virtual cost of the assessments.

The committee's present definition of intellectual disability, which I will not go through, needs to be extended to include the psychological assessments required and the criteria as in the Canadian guidelines for the diagnosis.

FASD needs to be specifically recognized in any future legislation, since they will fulfill the requirements as in the above. It should be mandatory for all public employees who provide services to those with developmental-intellectual disabilities and the families that support them to have training in FASD and always refer to the psychological assessments of the individuals in order to understand the needs of the individual.

Thank you.

The Chair (Mrs. Laura Albanese): Well, thank you for your comprehensive and thorough presentation. I apologize that there is no time for any questions.

I want to thank you also for all the different articles that you've added to your presentation. I was just looking at them, glancing at them, and they look very, very interesting, especially for the work of the committee.

Mr. Barry Stanley: Thank you.

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

Ms. Mitzie Hunter: Madam Chair, I would like to ask the researcher to please pull the definition that was referred to on the guidelines for diagnosis of FASD, because I think that would be interesting for us to think about, expanding our own definition to include it.

The Chair (Mrs. Laura Albanese): So thank you very much for presenting to us this afternoon.

MS. YVETTE FIALA

MS. BETTY MIDGLEY

The Chair (Mrs. Laura Albanese): We now welcome Yvette Fiala and Betty Midgley.

Ms. Betty Midgley: Yes. We're together.

Ms. Yvette Fiala: Good afternoon. I will take about 10 minutes, and my friend Betty, who was not originally on the list, will say a few words as well.

My name is Yvette Fiala, and I am a 50-year-old divorced mother of two boys living in Ajax, Ontario, in Durham region. My18-year-old has autism, Tourette's and oppositional defiance disorder. My 14-year-old is perfectly healthy, normal—no problem. He helps me, actually, with the 18-year-old.

My biggest issue and concern is respite care for the immediate future and possible placement in a group home care for later.

1650

When my autistic son became an adult last year, I lost a lot of funding. On top of that, his behaviours became even more challenging. He has frequent meltdowns at home and in public, screaming profanities—that's the Tourette's—stomping his feet and spitting around. I find it extremely stressful; so does my younger son, who tries to help a lot. The screaming fits are so loud that even though we live in a detached house, even with closed windows, people walking on the street are stopping and wondering, "What is that?" My neighbour can hear it, and that's two detached houses, his and mine, with closed windows.

I actually brought a couple of short one-minute-in-length video clips I'd like to show you, because nobody can imagine what it really is like unless you live it in the moment.

Maybe I'll have to revive it; I'm sorry. It's frozen. I will just continue and it will come back on. I'm sorry. It was important to me. I spent some time filming it because I live with that every single day.

The Chair (Mrs. Laura Albanese): Can't make it work?

Ms. Yvette Fiala: It just froze, so I'm trying to start it up again.

Mr. Bas Balkissoon: Did you try F7? Sometimes it will unfreeze it. Then just restart the computer and it will probably kick in.

Ms. Yvette Fiala: Okay.

The Chair (Mrs. Laura Albanese): So maybe you could go on with the presentation and then we can come back to that.

Ms. Yvette Fiala: Yes, certainly. I often feel like a nurse at a psychiatric facility when I come home from work. It is harder and more exhausting than my day job. Respite care is important for me. I need it so that I can go occasionally on a mental vacation myself. But there is no respite available. I spent weeks and weeks last year contacting agencies in Durham region, only to find out that there is one adult respite home run by Community Living and quite a distance away. The wait-list is of 100 families-plus, and just a few spots available, if they're available.

There is private respite care; however, at a cost of $22 to $35 an hour. This is more than I make per hour when I work, so it is not really an option for me. I would be stressing about how I would save money for that kind of respite care.

Also, I'm afraid for the future. In two to three years, the boy is out of school, and then what? What to do with him? Even now when he's at school, it's a major struggle—like summer vacation: 10 weeks from late June to early September, when school is out. Just an example: The cost of two weeks at a residential summer camp is $2,450. If I do that, that's two weeks out of 10 weeks I have to cover and I still have eight weeks to stress about how to find care for the boy during the day.

I tried to seek help from a specialist. I have seen two highly recommended psychiatrists in 2013. The last one told me, "Why is it that you came to see me, Mrs. Fiala? We psychiatrists cannot help because we simply don't know what is going on in the autistic mind. We just don't know." The doctor gave me a card with referral that I go and see a psychologist myself. I need counselling so as to come to terms with that that's how the boy is and he is not going to change.

For me, what would work the best is if there was maybe one spot at a group home that could be shared, something like: have the boy at a group home for three days weekly, then between me and my ex-husband we can do the remaining four days. Share one spot with somebody—for example, they can have four days; we have three days. I don't think such an option is available, and that would accommodate a lot of people, if they would like to share.

Right now, I am at a point where I feel like I need to give up the boy to the state. There have been moments in the past year where I really felt like I just have to drop him off somewhere at a hospital and tell them I can't handle it anymore. If I could get some reprieve, I'm still fine caring for the boy, because I love him, but not on a full-time, 24/7 basis. The toll that it's taking on me and my younger son is enormous. Just as an aside, last week, after one of those horrible screaming fits, my younger son actually looked up at me and said, "Mama, when are we going to get rid of him?" He was a bit sarcastic, but I knew exactly what he meant.

I have seen so many agencies, asking for help, and I have been turned away everywhere almost. I can tell you that it's extremely humiliating, because I feel like I am begging for services. Sometimes I don't even get a phone call back.

When I was thinking, let's say, of last year's—it was hotly debated in the media—cancelled contract to build some gas plant in Mississauga, I think, and the penalty cost of $300 million, up to $1 billion—when I think of how many group homes or respite homes could be built with that money, I would immediately put that in place.

Also, there is one agency called Family Alliance, I think. They really are against big institutions. But I was thinking of something in a format like a nursing home, an old age home: a bigger building where everyone's happy, where there is staff, there are recreational activities, but there are not old people living there, but maybe people with developmental disabilities. It doesn't have to be just small group homes, small place settings. I can say I was very happy with the Community Living children's respite house that was available in Whitby last year, but ever since he was cut after turning 18, I have had no respite whatsoever and it's just been brutal.

I am very disappointed because I wanted you to see something that I live with every day. I have it on a USB stick, but this thing just froze on me. It worked all the time before; I tested it. I would like to leave this as an exhibit. Please, if you can have a look at even one of those video clips, it's ear-piercing screaming. The boy is hitting his head like that. He's damaging furniture. He looks like he's hurting very much inside. I did seek help from psychiatrists, and they just don't know.

It's extremely embarrassing to even go with him in public. It can just come out of nowhere. A dog barking can set him off, or a little baby screaming, and he starts stomping his feet, screaming, "You fucking bitch, I'm going to fucking kill you!" at the top of his lungs, just like that. I can tell you, after each of those fits, it's like a piece of my soul is ripped right out from inside me, because it's extremely taxing on me.

Thank you very much for listening. If you could please watch at your convenience what I tried to put on the USB stick. Thank you.

Ms. Betty Midgley: I know it's the end of the day, so I won't take long, but I'm very excited about being here. We're very thrilled that this committee has been struck, because it has been a long time coming, but it's not easy for the two of us to even do something like this. We have to make arrangements for our sons; they can't be left alone. Bringing them would have been difficult, but leaving them at home is also difficult. We either have to hire a worker or we have to phone in sick or whatever.

1700

Anyway, I sent each of you an email earlier today, and it's essentially this seven-page document. I hope everybody reads it because it's filled with great suggestions and ideas. We have major challenges in our lives that most people don't have, so it's a little illumination on what we go through. But also, it's not just complaining; there are a lot of really excellent suggestions and ways to get to our suggestions.

So, yes, that was the main thing. It's mainly about the crisis with adults with special needs—like, where are our sons going to live? That's the big thing. Long-term care, day programs, respite and then—I have 12 suggestions which I won't even get into here. I just really, really urge you all to read your emails today, because otherwise I'm just going to be reading this out, and it's the end of the day. I've even got ideas on how to raise funds and all that. You'll love it; you just will. You'll be totally into it, and you're my heroes for putting this together, so thank you. That's the main thing. I just really wanted to thank you guys for putting this together.

The Chair (Mrs. Laura Albanese): I want to thank you both for coming here today, for presenting to the committee.

Ms. Fiala, I'm so sorry—

Ms. Yvette Fiala: Can I—I just remembered. Just one minute or less. I remember there was a report issued called Ending the Wait. I was reading through it, and it just put me into deeper depression. If they say "ending the wait," when it's, in fact—in year one, we will target those whose parents are 75 or 80 and longer. Year number two will be parents maybe five years younger, and year number three will be parents 70 and plus. So the whole title "Ending the Wait" is almost ironic. It's not really ending the wait, especially for me, who is too young. But at the same time, I am exhausted, and I am just shaking sometimes, with my son at home with no services available at all. Thank you.

The Chair (Mrs. Laura Albanese): I'm so sorry for what you're going through.

I will allow for any questions that you may have, or any comments you would like to make. I know it's the end of the day and we all want to go, but I will allow that. Ms. Elliott?

Mrs. Christine Elliott: Thank you very much. Thank you both for being here today. Betty, it's great to actually meet you in person. We've corresponded so much, so thank you very much. I look forward to reading your recommendations with great interest. We want to work together with parents and families to make sure we can come up with some good suggestions.

Ms. Fiala, I can't even tell you how sorry I am for all that you're going through. I would like to talk to you as a fellow Durham region resident with some suggestions I have offline, so perhaps if you could stay a little bit later.

Ms. Yvette Fiala: I have emailed Joe Dickson, and even you, I think, and he sends me—they are very nice. They have their staff do research, and they send me what I already have and who I have already contacted. So it's not really good, but they are trying. But I have contacted every single of those let's say seven agencies, and everywhere they say, "No, sorry." And if yes, for respite, "It's for who is 75 years old, not you. You are too young." Thank you.

Mrs. Christine Elliott: Perhaps we can chat afterwards. Thank you.

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

Ms. Cheri DiNovo: Yes. I just want to thank you and again express just our deep concern for you and your health and for your children, obviously. This is an untenable situation. The systems that are set up in the government currently are what are producing it. We've struck this committee to try to deal with that, to try to change that. That's the important part. Again, thank you for coming forward—

Ms. Yvette Fiala: If you can change anything—

Ms. Cheri DiNovo: Yes, well, that's what we hope to do: that we're not bringing you here for no reason.

I'm particularly interested when you were talking about Ending the Wait, because they were also here and presented to us. I don't think they even understood what that sounds like to you.

Ms. Yvette Fiala: Yes. It sounds like a joke.

Ms. Cheri DiNovo: What it sounds like to you is, "I'm going to have to wait 20 years to get some help." That's unacceptable. Thank you.

Ms. Yvette Fiala: Because I was at a point three times in the last year—this close to driving him somewhere, to emergency, and just telling them, "I can't handle him anymore. Just have him, please." I can't go through another tantrum. I can't go through any more of him yelling at me, "You fucking bitch; I'm going to kill you," and whatnot. There is a limit to what I can do.

Ms. Cheri DiNovo: Of course.

Ms. Yvette Fiala: Thank you so much.

Miss Monique Taylor: How are there not respite dollars for this family? It's unbelievable that there are no dollars to help this family for respite. There has to be emergency funding money. How is this family supposed to deal with this? I don't get it.

Ms. Cheri DiNovo: It's ridiculous.

Ms. Betty Midgley: Even when there's money available, that's not always the answer. There has to be a system in place for us. We are at the end of our ropes on many, many days. I'm just excited to be here, so I'm a little up, but it is very stressful. But it's not always a money situation either.

Ms. Yvette Fiala: I did contact Durham Mental Health Services. I work in a courthouse, and they have a mental health office. I was at my wits' end, so I went there. They put me in contact with somebody, and I got $500 for emergency respite. That put me through the month of October, I think. I was hearing of something—but it ends, and then you have to think of what is next.

I am working with Community Living on something called DSNAP. I need to de-snap from my moment when I am close to a nervous breakdown. I think something will come out of that. However, they stress that I have to have a solution to my problem, because if they give me something, it's going to end again. In two months, it's going to end. And I don't have anything, because I just don't know what to have—something like a day off, or a week, a couple of days a month, and, yes, I can just tune out my stresses and whatever.

It's nothing compared to what I am saying here. If you watch the video clips—and he is like that sometimes at school—it's like watching a horror movie. I can tell you, I get sick to my stomach. My younger son often says, after he has a fit in public, "Mom, I have to go home. I have a tummy ache," because he is embarrassed. He loves his brother, but it's super difficult.

Thank you so much. I think it was Christine Elliott who put this together—at least, so Betty tells me. We work together, and we spend our lunch breaks talking and brainstorming about services for our kids. That's all we talk about, eh?

Ms. Betty Midgley: That's all we talk about, yes.

The Chair (Mrs. Laura Albanese): Before you go, I want to give the opportunity also to Mitzie Hunter to say something.

Ms. Mitzie Hunter: Betty and Yvette, thank you for being here, for being so open and transparent with your story, because it is hearing from the families and individuals that is really most impressive upon us, as a non-partisan committee that has come together. We recognize that the system needs to be fixed, and I think that's what you pointed out, Betty, that it needs to be a system-wide approach, a cross-ministry approach.

I see here in your story that there is a role for health, and perhaps even more specialized and intensive health interventions than what is readily available. We also know that families need respite solutions and programs that are there for them on a consistent basis.

This is just really to let you know that that's why we're set up. Our next task is to draft the report and to begin to look at recommendations.

Ms. Betty Midgley: That's good, because it doesn't just affect the child; it's the whole family.

Ms. Mitzie Hunter: That's right.

Ms. Betty Midgley: My daughter has anxiety. I have high blood pressure. My husband had a mini-stroke. My son is wonderfully, blissfully unaware of all of that, and in a way, that's great. We are always worried about him, every single day. We cannot just dash over here to Toronto without moving heaven and earth to make arrangements. We have jobs and we have other kids, and it's just a major undertaking. I think that people just are not aware.

The Chair (Mrs. Laura Albanese): I want to thank you once again for taking the time and arranging your life so that you could come here and present to us.

Ms. Betty Midgley: Thank you.

Ms. Yvette Fiala: Thank you.

The Chair (Mrs. Laura Albanese): Is there any further committee business? Ms. Jones.

Ms. Sylvia Jones: Just briefly, Chair. I think it was Cindy Mitchell who made reference to the need for 35 copies, and she's not the first presenter who has made reference to it. Is that a rule, or can we suggest to people that they can bring 15 and we'll figure it out?

The Chair (Mrs. Laura Albanese): They can also just send an email. I think we should be able to take care of the printing, just for the committee members—

Ms. Sylvia Jones: Maybe we need to reinforce that so that any further presenters who appear understand that there isn't an obligation to bring 35 copies of their presentation.

The Chair (Mrs. Laura Albanese): Good observation.

Thank you, and we are adjourned until February 19, 2014.

The committee adjourned at 1711.

SELECT COMMITTEE ON DEVELOPMENTAL SERVICES

Chair / Présidente
Mrs. Laura Albanese (York South–Weston / York-Sud–Weston L)

Vice-Chair / Vice-Présidente
Mrs. Christine Elliott (Whitby–Oshawa PC)

Mrs. Laura Albanese (York South–Weston / York-Sud–Weston L)
Mr. Bas Balkissoon (Scarborough–Rouge River L)
Ms. Cheri DiNovo (Parkdale–High Park ND)
Mrs. Christine Elliott (Whitby–Oshawa PC)
Ms. Mitzie Hunter (Scarborough–Guildwood L)
Mr. Rod Jackson (Barrie PC)
Ms. Sylvia Jones (Dufferin–Caledon PC)
Miss Monique Taylor (Hamilton Mountain ND)
Ms. Soo Wong (Scarborough–Agincourt L)

Substitutions / Membres remplaçants
Mr. Jack MacLaren (Carleton–Mississippi Mills PC)

Clerk / Greffier
Mr. Trevor Day

Staff / Personnel
Ms. Karen Hindle, research officer,
Research Services
Ms. Heather Webb, research officer,
Research Services

CONTENTS

Tuesday 21 January 2014