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**Official Report
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Tuesday 5 August 2008

**Journal
des débats
(Hansard)**

Mardi 5 août 2008

**Standing Committee on
Social Policy**

Services for Persons
with Developmental
Disabilities Act, 2008

**Comité permanent de
la politique sociale**

Loi de 2008 sur les services
aux personnes ayant
une déficience intellectuelle

Chair: Shafiq Qadri
Clerk: Katch Koch

Président : Shafiq Qadri
Greffier : Katch Koch

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

STANDING COMMITTEE ON
SOCIAL POLICYCOMITÉ PERMANENT DE
LA POLITIQUE SOCIALE

Tuesday 5 August 2008

Mardi 5 août 2008

The committee met at 0904 in committee room 1.

The Chair (Mr. Shafiq Qadri): Ladies and gentlemen, colleagues, I'd like to officially call this meeting of the Standing Committee on Social Policy to order. As you know, we're here to meet for a province-wide consultation on Bill 77, An Act to provide services to persons with developmental disabilities, to repeal the Developmental Services Act and to amend certain other statutes.

SUBCOMMITTEE REPORTS

The Chair (Mr. Shafiq Qadri): To begin with, I'd invite members of the subcommittee to please enter into the record the two subcommittee reports, for which purpose I will call upon Mr. Levac.

Mr. Dave Levac: This is a report of the subcommittee.

Your subcommittee on committee business met on Wednesday, June 25, 2008, to consider the method of proceeding on Bill 77, An Act to provide services to persons with developmental disabilities, to repeal the Developmental Services Act and to amend certain other statutes, and recommends the following:

(1) That the committee meet for the purpose of holding public hearings on August 5, 6, 7 and 8, 2008.

(2) That the committee meet in London, Ottawa, Timmins and Toronto.

(3) That the clerk of the committee, in consultation with the Chair, place an advertisement about the public hearings in the major English and French newspapers across the province, as well as in a major English and French newspaper of each of the cities where the committee intends to meet.

(4) That the clerk of the committee broadcast the advertisement about the public hearings on VoicePrint in English and French.

(5) That the clerk of the committee post information regarding the hearings on the Ontario parliamentary channel and the Legislative Assembly website.

(6) That interested people who wish to be considered to make an oral presentation on the bill should contact the clerk of the committee by July 30, 2008, at 5 p.m.

(7) That the clerk of the committee provide a list of all interested presenters to the subcommittee following the deadline for requests.

(8) That, if necessary, each caucus provide the names of eight proposed witnesses and five alternates from the list of interested presenters to the clerk of the committee for the location that is oversubscribed.

(9) That each presenter be given 15 minutes in which to make a statement and answer questions.

(10) That the deadline for written submissions be August 12, 2008, at 5 p.m.

(11) That amendments to the bill be filed with the clerk of the committee by September 3, 2008, at 5 p.m.

(12) That the committee meet on September 8 and 9, 2008, for clause-by-clause consideration of the bill.

When I turn my paper over I'll read numbers 13 and 14.

(13) That the research officer provide a summary of the presentations to the committee by August 27, 2008.

(14) That the clerk of the committee, in consultation with the Chair, be authorized prior to the adoption of the report of the subcommittee to commence making any preliminary arrangements to facilitate the committee's proceedings.

So read into the record.

The Chair (Mr. Shafiq Qadri): Thank you, Mr. Levac, for reading the entire report. I now invite any questions or comments. Seeing none, I'd ask for a vote for the report to be adopted, as read. Carried.

I'll invite Mr. Levac to now please read the second subcommittee report.

Mr. Dave Levac: Standing Committee on Social Policy, subcommittee on committee business, draft report of the subcommittee:

Your subcommittee on committee business met further on Thursday, July 31, 2008, following the deadline for requests to appear, to consider the method of proceeding on Bill 77, An Act to provide services to persons with developmental disabilities, to repeal the Developmental Services Act and to amend certain other statutes, and recommends the following:

(1) That the meeting times for the committee be from 9 a.m. to 4 p.m.

(2) That the agendas for London and Ottawa be adjusted to accommodate all requests received at the deadline.

(3) That each caucus provide the clerk of the committee a prioritized list of eight presenters and seven alternates chosen from Toronto requests.

(4) That the potential presenters not chosen to appear before the committee in Toronto be offered the opportunity to make a presentation to the committee via teleconference on August 7, 2008, in Timmins.

(5) That the clerk of the committee, in consultation with the Chair, be authorized prior to the adoption of the report of the subcommittee to commence making any preliminary arrangements to facilitate the committee's proceedings.

There are no words on the other side of the page, so I can proceed to say that that's your report, Mr. Chair.

The Chair (Mr. Shafiq Qaadri): Thank you, Mr. Levac, for reading the report and the verification that you've just provided. I now invite comments or questions from any members of the committee. Seeing none, those in favour of adopting the report, as read? Those opposed? The report is adopted, as read.

SERVICES FOR PERSONS
WITH DEVELOPMENTAL
DISABILITIES ACT, 2008

LOI DE 2008 SUR LES SERVICES
AUX PERSONNES AYANT
UNE DÉFICIENCE INTELLECTUELLE

Consideration of Bill 77, An Act to provide services to persons with developmental disabilities, to repeal the Developmental Services Act and to amend certain other statutes / Projet de loi 77, Loi visant à prévoir des services pour les personnes ayant une déficience intellectuelle, à abroger la Loi sur les services aux personnes ayant une déficience intellectuelle et à modifier d'autres lois.

DUAL DIAGNOSIS IMPLEMENTATION
COMMITTEE OF TORONTO
NATIONAL ASSOCIATION
FOR THE DUALY DIAGNOSED,
ONTARIO CHAPTER

The Chair (Mr. Shafiq Qaadri): We'll now proceed to our first deputation. I would remind all of those who are listening, both in person and elsewhere, that the format is that 15 minutes will be offered to each presenter, whether they're individuals or representing organizations, and they can use that time as they wish. Any time remaining will be distributed strictly evenly amongst the parties for questions, comments, debates and rebuttals.

0910

We'll now move to our first presenter. I hope that they are both present, as we are just changing the order a bit. They are representing Dual Diagnosis Implementation Committee of Toronto and the National Association for the Dually Diagnosed, Ontario chapter, represented very ably by Mary Jane Cripps, who is co-chair of the Dual Diagnosis Implementation Committee of Toronto, as well as, I may add, director of Reconnect Mental Health Services in the extraordinarily great riding of Etobicoke

North; as well as Susan Morris, president of the National Association for the Dually Diagnosed, Ontario chapter. I would invite you both, Ms. Cripps and Ms. Morris, to please come forward. Please have a seat and, incidentally, introduce yourselves just for the purposes of Hansard recording for entering into the permanent record of the proceedings here at Queen's Park. Your time officially begins now.

Ms. Mary Jane Cripps: All right; thank you. Good morning. As Dr. Qaadri has so eloquently introduced me, I am here from that wonderful riding in north Etobicoke. My work position is executive director of Reconnect Mental Health Services, but today I'm presenting in front of your committee in my position as co-chair of the Dual Diagnosis Implementation Committee of Toronto, or the DDICT.

To tell you about the DDICT, our role is to monitor policy developments and work plans related to system design and implementation undertaken by the Ministry of Community and Social Services, the Ministry of Health and Long-Term Care and the community network of specialized services. Our committee also supports and encourages cross-sector system and service delivery integration at a local, regional and provincial level. I'll speak more to the integration of services in working with the specialized population of those with dual diagnosis later in our presentation. Thank you.

Ms. Susan Morris: My name is Susan Morris. In my work role, I am the clinical director of the dual diagnosis program at the Centre for Addiction and Mental Health. I am here today on behalf of the Ontario chapter of the National Association of the Dually Diagnosed.

NADD is a voluntary association representing families and service providers who work in the health and developmental service sectors. We're particularly concerned about the mental health of individuals with developmental disabilities. Our advocacy activities focus on service excellence through initiatives that support education and training directed to staff and families.

I'm just going to proceed with a bit of an introduction about the health and mental health needs of individuals with developmental disabilities, and then we have two points that we'll pick up on with respect to the bill.

Individuals with developmental disabilities experience higher rates of mental and physical illnesses than the average Ontarian. Of the approximately 300,000 individuals living with developmental disabilities in Ontario, 38%, over 100,000, will experience a mental health problem during their lifetime. This includes emotional difficulties, and/or psychiatric illnesses including mood disorders, depression, anxiety and schizophrenia.

The Ontario government recognized the significance of mental health issues in 1997, when the Ministries of Health and Community and Social Services established a joint policy that defines this population as individuals with a dual diagnosis. Dual diagnosis affects all individuals with developmental disabilities, from the range of mild, moderate to severe cognitive disabilities, as well as individuals with a diagnosis related to Down's syndrome or autism.

In addition to mental health difficulties, individuals with developmental disabilities experience higher rates of certain health problems and illnesses than the general population. Here, we're talking about physical disabilities at about 30%, communication and seizure disorders at around 30%. Amazingly, dental disease occurs in upwards of 90% of individuals with developmental disabilities. A large portion experience gastroesophageal reflux, usual problems that you and I have, and osteoporosis.

The introduction of Bill 77 is a significant milestone in Ontario's history, given the distance that we have come since 1974. Our social values have changed significantly since then, and the bill represents Ontario's commitment to integration of individuals with disabilities into the fabric of our lives and also provides a means for more choice to individuals and families in terms of how they receive supports and services.

Given the 34 years that have transpired since the original act, there are, however, two crucial areas that we want to speak to today. I'm going to speak to the first one and Mary Jane to the second.

In regard to the first one, the lack of any reference in the bill to the protection of personal health information is a startling gap, particularly given what we know about the health and mental health needs as I've just described. With this omission in the legislation, one might presume that Ontarians in 2008 continue to believe that our most marginalized and vulnerable citizens are not entitled to the same rights and protections as the rest of the population. We know, of course, that that's not true. Unfortunately, however, in practice, the abuse of rights of this nature occurs quite frequently for two reasons: in part because professionals working in the developmental and mental health sectors either aren't aware of these laws or, more concerning, don't think that these laws apply to individuals with developmental disabilities.

In my experience, we have examples of treatment being provided, such as the prescribing of psychotropic medications, without the assessment of the individual's capacity to understand that treatment, or the provider looking to the group home worker who happened to accompany the individual on that day to explain the side effects and also to provide consent for that treatment.

In a different example, Bill 77 provides for individualized funding to go to the person with a developmental disability or a person acting on their behalf with no reference to establishing the legal standing of that individual or the other person. In regard to financial competence, we know that the Health Care Consent Act is very clear about how rights of an adult 18 years of age and older are to be protected in this regard, or when a substitute decision-maker is to be appointed. As a health care provider, I have seen a number of examples of financial abuse of competent individuals with developmental disabilities by well-meaning families and by not so well-meaning other people who step in, including landlords.

With regard to the application centres, by their very nature and their role under the Personal Health Infor-

mation Protection Act, they will be considered to be health information recipients, and thus should be subject to the restrictions related to the collection, use and disclosure of health information.

Finally, the unfettered access by ministry staff to agency records which include personal health information without consent would also violate the privacy rules that we all must abide by in Ontario. So, therefore, we strongly urge this committee to ensure that, where relevant, Bill 77 reflect the rights that are ascribed to all Ontario citizens by including references to the Personal Health Information Protection Act, the Health Care Consent Act and the Substitute Decisions Act. Only in this way will it be ensured that the appropriate legal protections are available to individuals with developmental disabilities.

I'll turn it over to Mary Jane.

Ms. Mary Jane Cripps: Thank you. I would like to speak to the section of Bill 77 as it relates to qualifications of persons undertaking assessments and reassessments and the definition of professional and specialized services. Again, I would comment that, working in the health sector with individuals who are dually diagnosed, that is the special lens in which I was reading, interpreting and commenting on the legislation.

Throughout the legislation, "prescribed" is used with frequency. For example, in relation to administrative requirements, there are prescribed types of services, prescribed quality assurance measures that comply with reporting requirements as prescribed, financial records to be made available in the prescribed manner. Bill 77 describes "prescribed" as meaning "prescribed by regulation." Thus, many important details of how Bill 77 will actually operate in the real world are unknown and have to be specified in regulations and/or policy. A particular problem is the stipulation that applicants will be assessed by persons with prescribed qualifications, using such methods of assessment or criteria as may be prescribed. The qualifications of persons conducting assessments and reassessments and the methods and criteria they employ are of immense concern to families and to the professionals and paraprofessionals who provide services to individuals with developmental disabilities and/or dual diagnosis.

0920

In addition, the definition of professional and specialized services is too narrow. It neglects the full range of professionals and paraprofessionals required to provide services under Bill 77 and the breadth of services currently provided to individuals with developmental disabilities and/or dual diagnosis. For example, the definition needs to be specific and clear in what it's saying, but it must also be broad enough to allow for developments in technologies and assessment tools and for those professionals who can be properly trained to administer the assessment tools. While it is clear in the legislation that physicians and psychologists can conduct assessments, the profession of nurse practitioner has evolved tremendously and they have been able to take over some diagnostic

responsibilities. So the question arises, is the category of physicians and psychologists, as it's spelled out, too narrow; does it truly reflect the best use of professionals in our system today; could it be expanded? And, of course, we would like to see an openness to future developments in technologies, tools and professions.

We would propose that the bill should not encumber those emerging new areas of information and growth. Of course, regardless of professional designation, all assessors must have basic and, we would even propose, specified training in the area required to conduct the assessments.

We therefore suggest to the committee and recommend that the qualifications of persons conducting assessments and reassessments and the methods and criteria they employ must be spelled out in the legislation. We additionally recommend that the definition of professional and specialized services be broadened in the legislation to include not only those services that may be purchased by all those necessary health, mental health and community services required by people with developmental disabilities—here again, specifically those with dual diagnosis. For example, the bill must recognize that individuals with dual diagnosis receive a range of specialized services that are currently not listed. As an executive director of a mental health organization, we work with individuals with dual diagnosis in numerous programs. We have several specialized programs working with the dually diagnosed, including day treatment, vocational programs and, of course, we work with people with dual diagnosis through our ACTT team, the assertive community treatment team, which includes nurses, OTs, physicians, social workers, vocational specialists and also people with an addiction specialty. We also, in our housing programs, house individuals with dual diagnosis and we provide the support to them to maintain their housing and live successfully. We also have a continuum of mental health and justice programs and we certainly are seeing a number of people with dual diagnosis coming through those programs.

We are not governed by the Mental Health Act but we comply completely with the Mental Health Act and we would not want to see Bill 77 set up unnecessary steps that a person must go through in order to continue to receive services within the health care community. It's a challenging population; they're vulnerable, and we believe that services must be completely accessible and available.

The Chair (Mr. Shafiq Qaadri): Thank you, Ms. Cripps. We have a firm 30 seconds per side, with the Conservatives to lead.

Mrs. Christine Elliott: Thank you for an excellent presentation. I think you've raised some very good points with respect to the issue of consent and capacity. Would you recommend that there be an actual formal capacity assessment done whenever someone is coming in to service to—

Ms. Susan Morris: We think it's necessary. I think one of the issues is accessibility to a capacity assessment.

Mrs. Christine Elliott: Yes. I think it's very important, in the protection of these vulnerable people, to make sure that someone acting on their behalf is qualified and acting properly. It's a very good point.

The Chair (Mr. Shafiq Qaadri): Mr. Prue.

Mr. Michael Prue: Do you have any specific wording around your qualifications comments, something that we could insert in the act, or are you leaving that to our lawyers?

Ms. Susan Morris: We're leaving it to you.

Ms. Mary Jane Cripps: Although we are presenting a written submission—

Ms. Susan Morris: We will present a written submission, but I'm not sure that it'll satisfy—

Ms. Mary Jane Cripps: The lawyers.

Ms. Susan Morris: We'll look at it.

The Chair (Mr. Shafiq Qaadri): To the government side. Dr. Ramal.

Mr. Khalil Ramal: Thank you very much for your presentation. As you mentioned, the aim of Bill 77 is to strengthen, to enhance, the situation of people with a disability. I want to thank you very much for raising many different issues. I'm looking forward to reading your submissions about the issues Mr. Prue raised.

The Chair (Mr. Shafiq Qaadri): I'd like to thank you, on behalf of the committee, for your presence and representation on behalf of the organizations that you represent: Dual Diagnosis Implementation Committee of Toronto, and National Association for the Dually Diagnosed, Ontario chapter.

METRO AGENCIES REPRESENTATIVES COUNCIL

The Chair (Mr. Shafiq Qaadri): As there is some rescheduling going on, I'd just like to know if Mr. Colin Hamilton and Don Walker are present. Are you ready to begin your deputation?

Mr. Don Walker: Sure.

The Chair (Mr. Shafiq Qaadri): Are you Mr. Hamilton or Mr. Walker?

Mr. Don Walker: Mr. Walker.

The Chair (Mr. Shafiq Qaadri): That's great. Please come forward. We are actually having you appear about half an hour earlier than scheduled because of some cancellations and so on. I'd now invite Mr. Walker, who is a member of MARC, the Metro Agencies Representatives Council, and the executive director of New Visions Toronto. Mr. Walker, as you've seen, you have a firm 15 minutes in which to make your deputation, and time remaining will be distributed as you've just seen. I invite you to begin now.

Mr. Don Walker: As was indicated, my name is Don Walker. I represent MARC, Metro Agencies Representatives Council, whose members are 21 Toronto-based developmental agencies that provide a wide selection of supports and services to people with a variety of needs. MARC believes that all people should have the supports and services they need to live with dignity and to assist

people to reach their maximum potential as contributing citizens.

I'd like to begin by recognizing the Ontario government for its efforts in transforming developmental services and working to create a more inclusive society for all citizens. I would also like to thank the government for bringing forward this important legislation, which will likely serve our society for decades to come. The proposed legislation looks to address a number of important issues of significance to the developmental services sector.

MARC supports many of the positive changes that have been proposed and is eager to work with its partners and with government to make sure that this bill creates a progressive vision and framework for the transformation of developmental services. We support the government's attempt to develop better tools for understanding resource needs in the sector.

We believe that some changes to Bill 77 will enhance the ability of all to create a truly inclusive society. I would like to address proposed changes on areas we, at MARC, feel will help ensure that people who have an intellectual/physical disability have full control over the decisions and activities that shape their lives and that they are afforded the support they need to live as full citizens.

While there are a number of issues, I respect the process and the other presenters and will limit my comments to the following matters: inspections and operations, application centres, and community development.

With respect to our first issue, we believe that people with disabilities must be afforded the same rights and responsibilities as other citizens with respect to their dwelling. A home is a place where one must feel a sense of control, safety and respect. In order to protect the very essence of home, we believe that an official entering one's home must secure a warrant based on reasonable assumptions of wrongdoing in the home. This would apply equally to all types of residences, including supported group living residences and intensive support residences.

It is our recommendation that this matter can be addressed in the legislation by considering the following: that under subsection 27(3), the words "unless the residence is a supported group living residence, an intensive support residence or a prescribed type of residence" should be deleted and the following words utilized: "unless with the consent of the occupier of the place or under authority of a warrant." The amended section would read, "The power to enter premises under subsection (2) shall not be exercised with respect to a residence for persons with developmental disabilities that is owned or operated by a service agency unless with the consent of the occupier of the residence or under the authority of a warrant."

0930

In 27(4)(d), delete the words "a residence referred to in subsection (3) or of other" and "residents or other." The amended subsection 4(d) would read: "in the case of

an inspection of premises in which services are provided to persons with developmental disabilities, examine the condition of the premises and its equipment and inquire from any person in the premises, including persons receiving services from a service agency, about," and then continue with the rest of the wording.

We must all recognize that this matter has been successfully addressed elsewhere. As you are no doubt aware, Ontario's new Long Term Care Homes Act, section 143(2), "Dwellings," states: "No inspector shall enter a place that is not in a long-term care home and that is being used as a dwelling, except with the consent of the occupier of the place or under the authority of a warrant." This protection of a person's residence/home is common to other legislation that includes powers of inspection. Upon consultation with our members, we have not been able to identify a situation where a warrant was issued due to a request for access to something that was denied.

Recommendation 2, application centres: With respect to our second matter, in order to address potential conflicts within the application processes and to build on effective processes currently being used, the legislation should make clear that the various elements might be delivered by different bodies within a given region. The various bodies responsible for the administration of the application process must be connected in such a way as to ensure easy access for people applying for support, while eliminating any potential for conflicts. To this end, the legislation should refer to an "application process" rather than "application centres." The responsibility for allocations of funding should remain a direct responsibility of the government.

We request that consideration be given to addressing the following revisions in the legislation:

Part III, section 7(2), should read, "A director may issue policy directives related to the application process with respect to the following matters."

Section 8(3) should read, "Every application process shall provide a single point of access to services funded under this act for persons with developmental disabilities residing in the geographic area prescribed in the application process' designation." Other references to application centres should be changed accordingly to reflect the idea of an application process rather than an application centre.

Over the past 10 years, MARC, its partners and other community agencies delivering developmental services within the region of Toronto have invested significant effort and resources to develop a collaborative approach to access and delivery of service. The success of this collaborative partnership, which we believe is also true of other collaborative systems across Ontario, should serve as a foundation on which to build coordinated access to services and an integrated approach to service delivery. When agencies operate as a system, the capacity of each agency to meet the needs of individuals and families is enhanced. Individuals and families are the beneficiaries of a coordinated system dedicated to improvement, quality, system planning, innovation and accountability.

In this regard, the current Toronto collaborative model's successes are compelling. We believe that the success of transformation in this legislation is contingent upon a framework that builds on the successes and strengths of the current system and current collaborative approaches while emphasizing accountability to individuals and families. We strongly recommend that Bill 77 recognize the value of a collaborative approach in moving toward transformation.

For example, a proposed function of the application centres that would be best monitored by community agencies and their collaborative systems is the management of waiting lists. Waiting lists are significant across the province, and in Toronto, more than 2,700 people are currently without the community needs (day) or residential supports they require.

At agencies across Toronto, waiting on a list doesn't have to mean that the individual or family cannot receive some level of support. Agencies have extensive knowledge of resources available in the community that an individual can access while waiting for paid supports and services. In addition, community agencies provide services that are not funded by the government that may be accessed by individuals waiting for support.

Our final area of focus today is in respect to community development. Bill 77 provides mechanisms through which dramatic and positive changes could occur with respect to the inclusion in community life of people who have an intellectual or physical disability. Such change will not occur without the necessary support needed to prepare for and carry out these changes. Bill 77 should provide for funding in the following four areas in order to ensure that the gains envisioned by the act are realized.

First, agency supports for innovation: As people who have an intellectual or physical disability become increasingly aware of their rights as citizens, demands and expectations are changing with respect to the types of support people are seeking. Further, given the implementation of direct funding mechanisms in the sector, the relationships that people have with agencies are also changing. To ensure that service agencies can continue to evolve and respond positively to changing demands, investments must be made to support the development and sharing of innovative approaches. Bill 77 should make provisions for such investments.

Second, support for direct funding: Bill 77 makes no direct provision for the creation and development of supports to assist individuals who choose direct funding to administer their funds or to coordinate supports they purchase to ensure that they are receiving the best quality possible. While Bill 77 would allow for people to purchase such support using a portion of their direct funding, few such services currently exist and investment is needed to establish them. Bill 77 should include provisions for funding to create and develop such supports.

Third, community development: True transformation of developmental services will come from our continuing ability and commitment to connect with the community

and to assist people in taking part in community life. While Bill 77 makes provisions for the individual support that people will need to take part in the community, there is no provision made for the funding of innovative community development initiatives that would open doors to the community or build community capacities for social inclusion of persons who have an intellectual or physical disability. Bill 77 should make provision for funding of innovative community development initiatives that can enhance the outcomes achieved through the provision of direct supports and funding.

The final point, advocacy: Prior to 1995, the government of Ontario provided small seed grants to community advocacy groups to assist them in organizing for the purposes of community education, bringing a voice to the issues that concerned them and identifying barriers that excluded them. The developmental services sector would be served well by ensuring that self-advocacy, family and other groups are able to organize in a fashion that allows them to play an effective role in the public discourse related to the inclusion of people who have an intellectual or physical disability. We recommend that Bill 77 make provision for such advocacy groups.

We recognize that it may be the government's intent to clarify a great deal about Bill 77 within the future development of regulations. However, we believe that over the history of developmental services, language such as the word "centre" in "application centres" can conjure up an image of a rigid, formal structure in which one must fit versus a more progressive and relevant approach to support as is intended by Bill 77, and therefore it should be reflected within the actual bill as opposed to being clarified within the regulations.

I, on behalf of MARC, strongly urge the committee to address the issues of inspections and operations, application centres and community supports in order to ensure that the legislation is effective in addressing the needs of people who have an intellectual or physical disability in Ontario. Thank you.

The Chair (Mr. Shafiq Qadri): Thank you, Mr. Walker. It will be a firm one minute per side. Mr. Prue.

Mr. Michael Prue: In terms of the finances, you dealt with finances in four areas. Do you think that should be confirmed before the bill proceeds?

Mr. Don Walker: It would certainly be important that there be a strong indicator that if it couldn't be in place before the bill proceeds, it will be coming shortly thereafter.

Mr. Michael Prue: Have you heard anything from the government at all that the monies will be forthcoming to make this bill a reality? It's part of what the opposition is worried about.

Mr. Don Walker: Right. Not in the detail that we would like to see.

The Chair (Mr. Shafiq Qadri): To the government side.

Mr. Khalil Ramal: Thank you very much for your presentation. I know you mentioned many different things. First, I want to thank you very much for your

support for the bill. I was listening to you when you were raising your many different concerns and issues that you wish the government to address. One of them, the most important thing, was about entering and inspecting a place without a warrant. As you know, the aim of the bill is to make sure all the people who are receiving the money are using it in the interests of the person with a disability and it's not being abused. There's also a section in the bill to make sure that private homes are not subject to inspections—only businesses which receive money from the government.

0940

Mr. Don Walker: The concern, sir, with respect to when you talk about businesses, is it's really indicating that the people who get the support from those businesses are not looked at in the same manner as other people, and that's the concern. That, in their eyes and our eyes, is their home as well. That should be respected.

The Chair (Mr. Shafiq Qaadri): Thank you, Mr. Ramal. To Ms. Jones.

Ms. Sylvia Jones: Thank you, Mr. Walker. I wanted to get you to expand a bit on the application centres—a comparison with application centres and the application process. Can you share with the committee why you want that changed and, specifically, how you think it would improve the process?

Mr. Don Walker: As we indicated, in Toronto, for example, and certainly among other regions in Ontario, there has been a large amount of resources already contributed to setting up collaborative processes. That's the main focus. These processes are in place, and we would like to see them continue as opposed to being under the roof of one organization, so to speak, which concerns us because of the fact that it doesn't include the other partners.

Ms. Sylvia Jones: So you're concerned that the collaborative process would actually be hurt with the way it's—

Mr. Don Walker: There's the potential.

The Chair (Mr. Shafiq Qaadri): Thank you, Ms. Jones, and thank you, Mr. Walker, for your deputation today as well as going earlier.

I'd also just like to announce on behalf of the committee that we will be setting up the room next door for the overflow participants and members of the audience.

SHEILA LAREDO

The Chair (Mr. Shafiq Qaadri): I'd now invite, if she is present, Sheila Laredo. Is she present? Wonderful. Please do come forward. Sheila Laredo is here in her own personal capacity, I understand, and you'll have, as you've seen, 15 minutes in which to make your deputation. I invite you to be seated. Please begin.

Dr. Sheila Laredo: Thank you for allowing me to speak today. I'm here as a parent of two children with autism, and also on behalf of Friends of Children with Autism, which is a non-profit organization that advocates on behalf of children with autism. I'm speaking as a

parent of two children who are aged 12 and 10, as a physician and also as an advocate.

I'm specifically speaking today because of my experience with the autism intervention program, which is a Ministry of Children and Youth Services program that provided services in many ways analogous to the services that are contemplated under Bill 77. What I mean by that, specifically, is that there are two funding mechanisms under the autism intervention program called DFO for direct funding option and DSO for direct service option. Those are very much analogous to what's proposed in Bill 77.

Let me say first of all that families are very pleased to see this kind of program going forward, and also that with respect to the autism intervention program, for those children who have been able to access the services, there has been a profound positive impact on the children and on their families. I encourage this bill to go forward, and to go forward with substantial support so that all individuals can benefit from it.

What is the direct funding option versus the direct service option? As you would expect, the direct funding option provides a funding envelope for families to purchase services for their family members with autism, to receive ABA, or applied behavioural analysis, which is an intensive therapy shown to be effective. Direct service option involves a situation where no money changes hands, but the government contracts with regional providers to then provide those services on behalf of those children.

Clearly, neither of those programs is perfect for every individual in every circumstance, but there are some important differences that I want to point out to you. First of all, flexibility: Under direct funding option, parents are able to individualize programs for their children. Families have been able to provide services 24/7, whereas under direct service, service agencies have typically provided service Monday to Friday, 9 a.m. to 3 p.m. Very often, it is centre-based so that families have to go to the centre, which can involve a lot of driving and, in the context of looking after other children, of having jobs and so on, it can be quite onerous. They tend to provide one-size-fits-all options, whereas under direct funding families can really create a program that works best for their children. Families can obtain training through direct funding, which allows them to also provide intervention for their children at other times when the service isn't otherwise taking place, and this is parallel with what is considered best practices for autism intervention programs.

It might surprise you to know that while families have consistently provided more hours of therapy per week for their children, it has cost them far less. In the Auditor General's report of 2004 on the autism intervention program, the Auditor General found that the cost of providing service by families when they were funded was \$27 per hour, as compared to, on average, \$109 per hour through direct funding. There are a number of reasons for that, which are perhaps beyond the scope of my pres-

entation, but I think that's a really relevant point when we're looking at the fact that there are approximately 1,500 children receiving service and 1,100 children on the wait list.

Along those same lines, direct service providers have been put in a significant conflict of interest in that they are the gatekeepers for direct funding. We know from our experience that they have prevented families and disincented families from receiving the direct funding option, and that's in direct contravention of what the government mandated for them: to provide both options to all families.

There has also been conflict in that their decisions regarding when to start service and when to discontinue service are to some extent predicated on the fact that they experience a lot of pressure based on the fact that there are these wait lists of children waiting to be served. So it's very important that there be a clear separation between service provision and service decision-making processes.

Finally, there has been an inequity between what was funded under direct funding and under direct service. Direct service provided a complete umbrella of services, whereas under direct funding a number of items were missing which families then had to dig into their pockets to get. I want to make a few points around that and propose that funding for programs like direct funding be entirely equitable with funding for direct service so that there's no disincentive to families who want direct funding to approach it, so that they can design programs that best meet their loved ones' needs.

We recognize that there are a number of families who have not chosen direct funding notwithstanding, and the reason for that in many situations is because families feel overwhelmed. It's overwhelming enough to look after a child with autism—to also have to manage and oversee a program of intensive applied behaviour analysis. So we would recommend that there be processes and supports in place for families to get infrastructure support: things like peer-to-peer networks; Web services that can provide full listings of agencies that are available to them; expansion of current websites such as ABACUS and respiteservices.com; and finally, that there be a clear, distinct separation between service provision and application centres—and I do think that is contemplated in paragraph 37(e) of Bill 77, in which it states that there may be a decision to prevent application centres from also being service agencies. I would prefer that that be clarified under law so that there is no disincentive, that there is no conflict of interest for service providers and for families.

I want to move now to access to and adequacy of funding. It's clear to me that Bill 77 is created to improve the quality of lives of individuals with disabilities and their families, and that really can only happen if access is sufficiently simple that all individuals, regardless of their abilities, are able to access these services. I have been told by family members who have attempted to get Passport funding that it's a complex procedure. The

applications are complex, there is non-transparency with respect to eligibility criteria, and there is uncertainty as to whether you will receive services, and if so, when. There's also unsecured funding from year to year, so that even if families do have a plan in place for their loved ones, they can't guarantee that that will continue because there's no funding. So agencies who provide service for those individuals are concerned about whether to take on those care programs because they don't know whether they'll be hired from year to year.

Families of children with autism and of those with disabilities may be of assistance to you, and certainly the individuals themselves may be of assistance to you. We have a lot of experience with running the autism intervention program and other social service programs, and we can help you with respect to determining what works well and where the challenges lie.

I want to talk about distribution of funding now, and I want to say that it's entirely appropriate that the funding be tied directly to the individual with a disability.

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We know there are some agencies that are concerned that they may be vulnerable to variable case loads if the funding is high to the individual with a disability. Let me tell you that parents of individuals with disabilities, their families, and the individuals are clear that the needs of the individuals with disabilities must never be superseded by the needs of the agencies who serve them.

Families must have the option to vote with their feet, and in so doing will encourage and motivate service agencies to provide high-quality, cost-effective programming. We have seen some often absurd outcomes that result when funding is not tied to the individual, as, for example, occurs in education when special-needs assistants are not tied to children. What can happen there is that when a child moves from one school to another in the middle of the year, the child moves to a new school where there is no support for them, and the education assistant is not required to move and so they stay behind at the old school where there's no child to support.

Families will be able to purchase high-quality services if given direct funding. History has demonstrated that even in the context of perceived lack of infrastructure, families have recruited and retained trained experts and qualified ABA therapists. By contrast, direct service providers were at the same time complaining that despite increased funding, they weren't able to expand the number of children they served because of inadequate infrastructure. Agencies provide one-size-fits-all approaches; families individualize to their family members.

This isn't to say that service agencies aren't the answer for some families, but giving the option really does respect the dignity of individuals with disabilities who often can speak for themselves and can very clearly articulate what their needs are and what their wants are for their care planning processes.

So I would like to propose that direct funding be a clear and viable priority under Bill 77, and that the needs of individuals with disabilities be prioritized over those

of the agencies, that the funding be tied directly to the individuals, and that funding that's allocated actually be sufficient to result in important and meaningful outcomes for the individuals and their families, and that families of individuals and the individuals with disabilities themselves be consulted about how to actually roll out the nuts and bolts of this bill when it becomes law.

Finally, I want to talk about meaningful service delivery, and there are two points here. One is that we know, for example, that there are concerns about the income arising from RDSP being considered in terms of other income-tested programs and the fact that that may put families in a position in which they have to decide between the RDSP and social programs, and that's a very difficult position to put families in. Please don't do that for this program. Ensure that funding under this program is not considered income for the purpose of other income-tested programs. Finally, I would encourage the government to please collect data so that you know what this funding is being used for, what the programs are, the relative efficiency of the different funding mechanisms, and most importantly, what the relevant client outcomes are.

I want to thank the government for this important initiative; I want to thank you, the committee, for your time; and I want to thank Friends of Children with Autism, who have provided very important contributions to my presentation today.

The Chair (Mr. Shafiq Qaadri): Thank you, Dr. Laredo. We have under 90 seconds per side. To the government and Dr. Ramal.

Mr. Khalil Ramal: Thank you very much for your presentation. You explained exactly why we're introducing Bill 77. You outlined the details of the aim and goal of Bill 77. That's why we have the individualized funding: so that it goes to the family. We believe strongly that the families deserve to choose the program that fits their kids and benefits their kids and also utilize benefits from the programs and services in the community instead of going miles and miles to seek service. I want to tell you of our commitment to emphasize all the elements you mentioned.

The Chair (Mr. Shafiq Qaadri): Thank you to the government side. To Ms. Jones.

Ms. Sylvia Jones: You've raised some excellent points. I appreciate you taking the time this morning.

I wanted to just quickly touch on the RDSP, because I have put forward a private member's bill, and now you've explained in a very eloquent way why I would like the government to either take up that bill or support it. Thank you. Hopefully, when Bill 94 comes for debate, I can keep you going on that support.

You mentioned, in terms of funding, that it should be equitable, it should tie to the individual, which I have heard in other conversations. Do you find that the funding currently in place—and specifically with Bill 77, because there has been no additional announcement of funding. Do you think that the goals of Bill 77 are going to be achieved with the funding that is in place?

Dr. Sheila Laredo: It's unclear to me at this point what funding is actually in place for Bill 77. Certainly, that is one of my concerns, that there be enough money so that the individual programs, on an individual-by-individual basis, are sufficient to have meaningful outcomes for those individuals, and also that there is enough money for all individuals to benefit. If everybody benefits just a little bit, that may actually be no benefit at all. There has to be enough for everybody and enough for each individual to have meaningful benefit in their community.

The Chair (Mr. Shafiq Qaadri): Thank you, Ms. Jones. Mr. Prue?

Mr. Michael Prue: I just want to go back to the equality of funding and the statement you made. You said there are 1,500 children with autism who are being serviced and another 1,100 on the waiting list?

Dr. Sheila Laredo: Approximately.

Mr. Michael Prue: For there to be equality of funding, and for this bill to succeed, would I be correct, then, that you're looking at probably a doubling of the amount of money so that all children could be looked after?

Dr. Sheila Laredo: There wouldn't necessarily need to be a doubling of money if the money was used more effectively; I've shown you that. We have rough estimates in 2008 that show that the direct funding option costs about a third to a quarter that of the direct service option. So it seems to us that if the money is used more effectively, a complete doubling of money might not be necessary to eliminate those wait lists, and eliminating the wait lists will have perhaps a significant impact on the number of people who need to be served under Bill 77 down the road.

Mr. Michael Prue: The bill itself, though, contemplates wait lists. I've never seen that in a bill before. Can you comment on that?

Dr. Sheila Laredo: I absolutely have concerns about wait lists. We've seen the devastating impact of wait lists on children with autism having to wait 18 months or more for service when it's clear that starting service early has an important impact. We know that families often don't get funding or are delayed in the funding that they want under Passport, although I personally don't have that kind of experience. I would like to see that there's going to be some thought as to how to make this as cost-effective as possible so that there are no wait lists.

Mr. Michael Prue: Thank you.

The Chair (Mr. Shafiq Qaadri): Thank you, Dr. Laredo, for your presence, as well as your written deputation, which has been distributed.

DURHAM FAMILY NETWORK

The Chair (Mr. Shafiq Qaadri): I'd now like to invite, if she is present, Cindy Mitchell of the Durham Family Network. Ms. Mitchell, are you there? Great. Please do come forward. As you've seen, you have 15

minutes in which to make your deputation. I invite you to begin now.

Ms. Cindy Mitchell: Thank you so much. I come here as a parent of a young woman with a developmental disability and as a member of Durham Family Network. Durham Family Network brings families together, not as recipients of service, but as active participants in moving forward with our sons and daughters to a good life for them, now and in the future. The network offers an opportunity to bring families together for mutual support, learning and shared purpose.

In May of this year, several Durham families came together and expressed deep concern about the inequity and inadequacy of individualized funding. Durham families sent out an invitation to other families across Ontario to respond and participate in a day of action by collecting petition signatures and going en masse to Queen's Park.

Family to family, the word spread across this province, and well over 100 families went to Queen's Park on May 26 this year. On that day, families from across Ontario raised serious questions for the Ontario government on why we have not received the individualized funding and direct support that thousands of families have applied for, qualified for, and need in order to support our disabled adult sons and daughters to be full, inclusive participants in their local communities.

After question period on May 26, many families stayed for the second reading of Bill 77, and we are hopeful that this new act will end the injustice for our sons and daughters with disabilities by ensuring they are equitably and adequately supported to be full, participating citizens.

The Minister of Community and Social Services should be commended for updating the very old Developmental Services Act. The rights and citizenship of persons with developmental disabilities are dependent on this legislation. Families want to have ongoing input into the legislation, including its regulations, to assist the government in getting it right so that our sons and daughters can share a good life with all other citizens of this province.

This legislation has the potential to significantly enhance the social inclusion of persons with developmental disabilities, and families would encourage the government to further promote this outcome by spelling this out in a preamble describing the social change this new legislation aims to achieve.

On May 26, families asked the government some key questions: When can families expect appropriate budget allocations for individualized funding as per the transformation agenda goal? Direct funding programs, such as special services at home, the Passport program and innovative residential program are grossly underfunded. When can families expect fairness, fairness in funding levels and wages? For years, Ontario has denied wage increases to staff hired by families, whereas it has granted increases to service agencies. Families have been waiting for decades for funding equity and adequacy, and their

sons and daughters are also waiting, often at home alone on the couch, waiting for the support they need to participate more fully in our society.

Families were astonished to find that wait lists are enshrined in this new legislation. A whole generation of families have raised their sons and daughters at home and have been waiting for adequate funding for support when their children reach adulthood, waiting for funding and support to ensure their children can continue to participate when high school ends. When will these young people, who have so much to offer our society, stop waiting? The provision for waiting lists in this new act must be struck from the legislation.

Another very viable option, rather than enshrining wait lists and leaving people waiting with absolutely nothing, would be for the legislation to provide for access to resources for independent planning and facilitation. This is a viable option because, with access to independent planning and facilitation, often other more meaningful and cost-effective support options are identified for people. Planning and facilitation must be person-directed, because by having the facilitator work for the person, conflict of interest would be avoided. Person-directed planning and facilitation independent of the service system enables an individual and their family to make informed choices without pressure to select one agency, service or program over and above another. Person-directed planning and facilitation must be an entitlement.

Most of us have heard the term "life happens." Well, life also happens for family and people with disabilities. Parents age, become ill, families move, or their sons and daughters move on and move out. The new legislation doesn't even mention portability and accessibility of direct funding when it is allocated. Families and individuals must be assured of the right to have those allocations available to them if they choose to use them in another way, or with another organization, or move to another community in this wonderful province of Ontario.

Durham Family Network members have been active participants on the provincial ad hoc working group analyzing Bill 77. The group raised numerous concerns about the setting out of specific functions of application centres in the legislation. We share a strong concern for the serious conflicts inherent in the legislation. When one centre is doing the assessing, prioritizing, and determining of funding and programs, there is a very strong sense of conflict of interest, especially in light of no apparent appeal process.

People need to see that they are being treated fairly and within a transparent process. The Durham Family Network agrees with the provincial ad hoc Bill 77 working group that the government should be cautioned against setting out specific functions of application centres in this new legislation, and that it would be far more appropriate to lay these out in the regulations so that changes can be made as the model develops, safeguards can be implemented and practice can be monitored and evaluated over time.

Finally, to summarize, the following are some of the priority recommendations that I would make to the standing committee: Develop a preamble that describes the social change in this legislation and what it aims to achieve, i.e., an act to enhance the social inclusion of persons with developmental disabilities; the provision for wait lists in this new act should be struck from the legislation; person-directed planning and facilitation must be an entitlement once eligibility has been determined; the inclusion of a statement about accessibility and portability of funding allocations as a key principle of direct funding; the description and statements of functions of application centres should be limited until such time as regulatory safeguards are created.

In closing, I come before this committee as a single mom of a young woman who has so much to offer her community and society as a whole. This human potential has been wasting away for three years since this young woman left high school. Her life changed at that time from a life full of possibility and activity in an inclusive school environment to one of long days at home often alone on the couch because eventually I had to go back to work after recovery from a serious illness. Through good planning, we have managed to create some opportunities for my daughter; however, her full inclusion and participation in society would be very significantly enhanced by the potential of this new bill and I'm very excited about it. Thank you.

The Chair (Mr. Shafiq Qaadri): Thank you very much. A firm two minutes per side, beginning with Mrs. Elliott.

Mrs. Christine Elliott: Ms. Mitchell, you've raised some really wonderful points. I'd like to just expand on a couple of them. We've heard from several this morning with respect to the lack of knowledge with respect to funding and how the new program will work without additional funds being added to it. I would hope that the minister would consider that prior to final determinations on this issue so that everyone knows what is actually going to be available to make a final determination with respect to the bill.

Secondly, you indicated that the planning needs to be flexible, to be portable and so on, and you also mentioned the fact that an independent planning agency or an agency that's separate and apart from the service provider would be helpful. Could you speak a little about that to give the committee a little bit more understanding of what you have in mind with respect to that?

Ms. Cindy Mitchell: Absolutely. Access to independent planning and facilitation right after someone is deemed appropriate for this program could mean a really viable option in terms of offering families and individuals different choices because sometimes families and people are not fully aware of what the choices might be. Traditionally, families have just seen the service option. There are families out there that are very capable, knowledgeable and organized and can offer other options within the community that are more appropriate and more meaningful for individuals—participation in com-

munity activities that are inclusive, that offer support to families—that don't cost a thing.

The Chair (Mr. Shafiq Qaadri): Thank you, Mrs. Elliott, with apologies. We'll now move to Mr. Prue.

Mr. Michael Prue: You raised the issue of a preamble. I remember on the day of the debate, I raised that issue in the House. Why do you think it's important to have a preamble to the bill?

Ms. Cindy Mitchell: Because I think you need to clarify the government's intentions for this bill. If it is to enhance the social inclusion of persons with developmental disabilities, that needs to be clearly spelled out so that we can achieve that. A preamble describes what we want to do.

Mr. Michael Prue: A preamble in most legislation or, say, in the Constitution—everything that's in the bill has to be read back to make sure that it's consistent with the goal. Is that why you want it?

Ms. Cindy Mitchell: Absolutely. If the goal is the social inclusion of persons with developmental disabilities, let's be clear on that.

Mr. Michael Prue: If the preamble was there—and I agree with you—how would we juxtapose that with waiting lists? If the preamble says, "We want to make everybody inclusive," and then the bill has a waiting list inside—maybe that's why they don't want to put a preamble in.

Ms. Cindy Mitchell: A very viable option to a waiting list is to support the planning and facilitation, allowing families to look for alternatives. Planning and facilitation can offer that to families. In my daughter's case, she joined a church. She made the decision on her own, and that has offered all sorts of support to her. She volunteered in a community school.

Mr. Michael Prue: Thank you.

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The Chair (Mr. Shafiq Qaadri): Thank you, Mr. Prue. To the government side. Mr. Levac.

Mr. Dave Levac: Thank you very much for your deputation. Obviously, your personal experiences allow you to make some extremely personal and legitimate comments about how people with disabilities should be cared for. My experience is that in my past life I had an opportunity to help do the planning process, which is one of the most difficult things for family members to do, because that's their intent. Actually, for most of the people I've spoken to, it's not really about the money; it's about "making sure that my child's taken care of when I'm not here." So I respect that deeply. But money, when you bring it up, seldom attaches itself to a bill. That's a reality that the opposition knows and anyone who has been in government realizes, that money is not attached to a bill, it's the programs that come as a result of that. So there will be some debate going on, particularly from the opposition, to try to see if there are ways we can attach the money to that. But you're aware that money isn't attached to a bill in a regular writing.

There are three demonstration sites that are going to be set up for about a 12-month period to talk directly

about the decision-making process that you're talking about. So that's an "are you aware" question: Are you aware that there are three demonstration sites—

Ms. Cindy Mitchell: No, I am not aware of that.

Mr. Dave Levac: —to come up with exactly what you're talking about in terms of the planning decisions and the evolution of what we're looking for? So the government is onside with what your thinking is in terms of the planning.

Ms. Cindy Mitchell: But, as a parent active in community, that I'm not aware of that concerns me.

Mr. Dave Levac: Absolutely. It's a good point about communication.

Ms. Cindy Mitchell: Thank you.

Mr. Dave Levac: And we appreciate your efforts so far.

The Chair (Mr. Shafiq Qadri): Thanks to you, Ms. Mitchell, for coming forward and sharing your personal story as well as on behalf of the Durham Family Network.

MELANIE KITCHEN

The Chair (Mr. Shafiq Qadri): I'd now invite, if she's present, Melanie Kitchen to please come forward. You've seen the protocol: You have 15 minutes in which to make your presentation. Please begin now.

Ms. Melanie Kitchen: I am Melanie Kitchen, parent of an individual affected by this bill.

Thank you for Bill 77. You've done the hard part by crafting a bill that recognizes that supports for people with a developmental disability have changed dramatically over the years. It is with enthusiasm that I have joined in the process of transformation whenever invited by the government. Thank you for allowing me to speak and to be a participant once again as you deliberate on the additions and changes to Bill 77 that will make it truly transformative.

My daughter lives with a developmental disability. Melissa requires assistance with all aspects of personal care, including eating and drinking, as well as decision-making. She needs to have somebody available to her at all times. Her support needs are such that we have always needed to be deliberate and determined to ensure she has as many of the experiences and opportunities that others her age have.

Bill 77 brings to a close the era of large institutions for people with a developmental disability. Ours are the children who were born when the Developmental Services Act in 1974 transferred the responsibility for services for people with a developmental disability from the Ministry of Health to the Ministry of Community and Social Services. Our children were born when the concept of helping people who have a developmental disability to integrate into the general community was gaining worldwide acceptance. It is small wonder that 80% of families who have an adult with a developmental disability support them with little or no public funding.

Bill 77 is giving families who choose to continue to directly support, financially and in other ways, their adult sons and daughters the opportunity for a little financial equality with families who have chosen agency services or group homes. Individuals and families will no longer have to choose between living in a group home and using agency services and receiving no financial support from government. As aging parents, it is good to know there will be the possibility of assistance to help our adult children continue to live their lives with the involvement of family and friends.

I have not developed my ideas on how to raise and support my daughter in a vacuum, but through dialogue with and support from other families and agencies. My own values and dreams for my other children, who are on a different point on the continuum of human abilities, have also helped shape how I believe a person with a developmental disability and their family should be supported in our society.

The Ministry of Community and Social Services states on its website, "The ministry wants to honour the choices people and their families make about living in the community to best suit their specific needs. Our mission is to support the realization of the goal of being fully included in society, and for people who have a developmental disability to have the same opportunities as other Ontarians to participate in the life of the community."

Bill 77 goes a long way to doing that. There is remarkable agreement on the issues that need to be included or strengthened or clarified in the bill among the many stakeholders, including agencies, family groups and families, self-advocates and those who do and those who do not receive government funding. You will hear from many of them during these hearings.

There are many issues I would like to speak to, but given our limited time, I will focus on three which seem particularly important to the parent of a woman who has grown up at home and in her community:

- (1) the importance of including supported decision-making in the legislation;
- (2) the importance of including person-directed planning with independent facilitation in the legislation;
- (3) the importance of accessibility and portability of direct funding in the legislation.

Let me expand on these points.

I was surprised to learn that there is no provision for supported decision-making in Ontario legislation for adults with developmental disabilities. By "supported decision-making," I mean that an individual can be supported in making substantial decisions by those they trust. The individual and her support group are extended legal recognition for the purposes of entering into legal contracts. This is particularly important for individuals who are vulnerable to being influenced by those in society who do not have their best interests at heart and who may never truly develop the ability to understand the consequences of some of their decisions.

Supported decision-making is considered a viable alternative to substitute decision-making in other jurisdictions in Canada. It has recently been adopted into

international law under article 12 of the UN Convention on the Rights of Persons with Disabilities.

This government needs to take the significant step towards giving people with developmental disabilities fuller autonomy and citizenship by including the recognition of their legal capacity in this bill and supporting amendments that enshrine supported decision-making. Such recognition provides a mechanism for individuals to enter into an agreement for direct funding without having to surrender authority to a substitute decision-maker or guardian who may be struggling with truly putting the interests of the individual ahead of their own.

My second point is one I have particular experience with and which I believe is very important to families choosing direct funding. There is no mention of independent facilitation and planning supports in Bill 77 for individuals, their families or caregivers. I recognize that some of the details related to facilitation and planning may be included in subsequent regulations and policy, but for direct funding to be a successful choice for families and government, it needs to be incorporated into the legislation, allowing for the full effect of the law.

My family, among many others, greatly benefits from independent facilitation and planning support. Through independent facilitation and planning guidance provided by an organization such as Families for a Secure Future, our daughter participates, with the assistance of her family and a circle of support we call "Melissa's tribe," in directing her own life and making key decisions. The focus is on her strengths and interests, but it also identifies her vulnerabilities and establishes goals for her future.

Focused, goal-directed planning supports need to be provided at the point that individuals are determined eligible for direct funding or services, and it needs to be provided on an ongoing basis. Life goes on even while waiting for funding and services to become available. Providing planning supports at the point of eligibility makes it possible for individuals, their families and caregivers to make truly informed decisions between direct funding and traditional services.

After direct funding is awarded, the professional assistance provided by facilitators helps individuals and families to be more accountable. Facilitators help develop systems for tracking where money is spent. They help individuals and their families think about how their lives might unfold so they can make plans to move forward. They help individuals and families to be accountable for their stated goals.

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The wage disparity that exists between workers hired by families and workers hired by union-supported agencies is large. Families need to be creative in supporting workers in their work, which can be isolating. Independent facilitators, such as Families for a Secure Future, help with this by conducting workshops that allow workers to meet others doing similar work and by assisting families to create a positive and safe work environment.

Planning and facilitation can assist a person to build their personal network, strengthen family and other sig-

nificant relationships, and find meaningful ways to assist the individual to contribute to their communities. This is consistent with Bill 77's aim of enhancing citizenship by working to shift reliance for support away from government funding and towards natural supports. Other kinds of supports and services are provided for in the legislation. Please add independent facilitation and planning.

When supports are more individualized, we have seen time and time again the growth of the individual in ways previously unimagined. Since her days attending Brownies and taking swimming lessons with her peers, my daughter has grown up to live in her own home. Remember, this is a woman who has physical and developmental disabilities that require somebody to be available to her at all times. She is well known at her local haunts, she sits on the local accessibility advisory committee and volunteers in the community.

The experience of people moving out of large institutions also presents us with ample proof that people grow in their independence when they are connected to their communities. All of this has been my family's experience and that of the many other families in this province who have independent facilitation planning.

Is choosing the direct funding option the easier option for families? Probably not. I would believe many families would agree. But life isn't always easy, and people don't shy away from difficulties. Intermittent reinforcement is a strong motivator. Seeing people with developmental disabilities live in our communities improves our society. Supporting the direct funding option through independent facilitation and planning through legislation makes ethical and financial sense.

My third point is short, but no less important. Direct funding should be provided to a person in a manner so that if they choose to move to a different community or change who they accept their services from, they can do so without penalty. Direct funding must be portable and accessible. All citizens get to choose where to live and the services they wish to accept; why not people with developmental disabilities? The ministry should do as it promises, and "honour the choices people and their families make about living in the community to best suit their needs."

Bill 77 would be greatly enhanced with the addition of these provisions for legal capacity, assistance with person-directed planning through independent facilitation and portability of direct funding. Doing so addresses, among other things, some of the concerns with wait lists, protection of the individual, accountability for funding received and adherence to stated goals. I would urge the committee to consider revising the draft bill to bolster its already strong steps towards transforming supports and services to people with developmental disabilities in Ontario. Thank you for your attention.

I do have a written submission, but haven't had a chance to get copies made to distribute to you.

The Chair (Mr. Shafiq Qaadri): Thank you, Ms. Kitchen. We have about a minute or so per side, with Mr. Prue to begin.

Mr. Michael Prue: Just on the last issue of portability, did you personally have any problems with portability in the past?

Ms. Melanie Kitchen: I haven't needed to exercise that option, because our family is very rooted in our community, so we don't see ourselves moving. But I know it has been an issue for other individuals.

Mr. Michael Prue: What would you like to see in the legislation that speaks to the problem of portability?

Ms. Melanie Kitchen: I think the important part is that when it's in the legislation, rather than as part of policy or regulation, then it has the full force of the law behind it. That, I think, is really important.

Mr. Michael Prue: So you would like to see that in the legislation itself?

Ms. Melanie Kitchen: I think it would enhance the legislation, yes.

Mr. Michael Prue: Okay, thank you.

The Chair (Mr. Shafiq Qadri): Thank you, Mr. Prue. Mr. Ramal?

Mr. Khalil Ramal: Thank you very much for your presentation. I think you know the intent of the bill. As you know, its aim is to enhance services for people with disabilities and to support families who are getting old and need some kind of support. Plus, we want to put in place individual funding in order to give families the portability you mentioned to choose a service they think is good for their loved one. Do you think this whole bill in general, if we had some kind of adjustment to it, will serve your needs and other families' needs?

Ms. Melanie Kitchen: I think so. I think it is really exciting to have this bill, and particularly to have so much input over the last several years from the community.

Mr. Khalil Ramal: Thank you.

The Chair (Mr. Shafiq Qadri): Ms. Jones.

Ms. Sylvia Jones: Thank you, Ms. Kitchen. I wanted you to expand a bit on the independent facilitator and planning support, and specifically how you see that and something that you have been able to successfully incorporate into—what is it, Melissa's tribe?—the application centres. How would the two work together so that, in your case, your daughter is best served?

Ms. Melanie Kitchen: I think it needs to be independent, apart from the application centre and apart from agencies providing services and bricks and mortar, because it's too difficult, I think, to be really creative and to see what the other community options are when that kind of planning is associated with a specific agency. It's only natural that those agencies are then going to think first and foremost of how their particular agency can support an individual to meet their goals. That's not always the best way. I think having it completely separate allows for greater creativity and I think—

The Chair (Mr. Shafiq Qadri): Thank you, Ms. Kitchen, for your deputation on behalf of the number of individuals you've spoken about today.

I'll just canvass for a moment: Is Sid Ryan, president of the Ontario division of CUPE, present either in this

room or watching next door? If you materialize, you'll be accommodated, but I think we have now our next presenter, Ms. Patricia MacFarlane. Do we have Mr. Peter Marrese or Chris Bedwell? Is Dr. Glenn Rampton of Kerry's Place Autism Services present?

So one more time: Sid Ryan, Patricia MacFarlane, Peter Marrese, Chris Bedwell or Dr. Glenn Rampton.

KERRY'S PLACE AUTISM SERVICES

The Chair (Mr. Shafiq Qadri): Are you Dr. Glenn Rampton?

Dr. Glenn Rampton: Yes.

The Chair (Mr. Shafiq Qadri): Welcome. Dr. Glenn Rampton is the chief executive officer of Kerry's Place Autism Services. I would invite you to begin your deputation. As you may or may not have seen, you have 15 minutes in which to make your presentation. I understand you have a colleague who is coming—present, not present?

Dr. Glenn Rampton: I have two colleagues. We're a bit early.

The Chair (Mr. Shafiq Qadri): You are.

Dr. Glenn Rampton: I think we were on for 11:45, so they haven't arrived yet.

The Chair (Mr. Shafiq Qadri): I invite you to begin now; 15 minutes.

Dr. Glenn Rampton: Thank you. Kerry's Place Autism Services was founded by a group of parents in 1974 who did not feel that the supports and services at the time adequately met the needs of their sons and daughters with autism spectrum disorder.

We've grown and evolved so that we're currently the largest agency in Ontario providing specialized supports and services to more than 3,500 individuals and their families of all ages across the autism spectrum. We now support more than 3,000 individuals and their families through a broad variety of community supports, more than 150 individuals through a continuum of residential options, and more than 20 individuals in four treatment centres situated in each of the four regions with which we have services contracts with MCSS and MCYS.

In recent years, generic developmental services agencies have had to assume responsibility for a large proportion of individuals with autism spectrum disorder, and Kerry's Place has increasingly focused on the two ends of the spectrum: the crisis prevention and intervention and the harder to serve. We do share our expertise with other agencies through consultation, training and education.

1030

We feel that there are many good aspects to the bill, including the empowerment of individuals and families through the option of direct funding; the portability of funding; and expanding functional definitions of "developmental disability," which, among other features, will allow more people with Asperger's syndrome to access supports and services. Some have been excluded in the past.

We believe that the development and implementation of the networks of specialized care across the province for individuals with more complicated support needs will be a major step ahead, as will development of greater expertise and community capacity to support individuals in the developmental service sector, including those with autism spectrum disorder, through greater access to professionals, video conferencing and other aspects of the networks of specialized care.

Though we're encouraged by Bill 77 and the government's current program to transform supports and services, we do have some cautions and some concerns. Among those are that in 2003 the separation of developmental services and children's services created potential discontinuities of supports and services for children with a developmental disability and their families as individuals reach adulthood. To compensate for this, it will be important that Bill 77 can form one component of an integrated legislative framework to enable lifelong planning and access to supports across sectors, including mental health, education and justice, as well as community and social services and children's services.

More stringent standards and accountability mechanisms must be fairly and consistently applied to any entities providing supports under the bill, not just transfer payment agencies. We don't really see this in the bill; we see more stringent guidelines being applied to transfer payment agencies, but not necessarily to for-profits and people who are going to be providing services through other means. We think that will be a problem.

Application centres: We're concerned that employees of the application centres may not have specific skills and knowledge to assess the highly complicated and specific and individualized needs of individuals with autism spectrum disorder. While they may introduce greater consistency and accountability to individuals and families, they should also continue to reflect the unique character, culture and priorities of the local communities that have informed the development of current access mechanisms. Realistic assessment must be undertaken of the funding required to enable application centres to perform their intended functions. It's hoped that this will not be a bureaucratic exercise, adding a lot more funding to the administrative side of the house and detracting from supports and services.

Without appropriate standards, families receiving direct funding may be vulnerable to providers who do not have the appropriate capacity to support individuals with complex needs. Specialized providers such as Kerry's Place Autism Services must be able to continue working with families and individuals to determine their needs and develop effective, evidence-based, individualized strategies to support these needs.

As noted previously, Bill 77 introduces additional accountability and reporting requirements for the transfer payment sector. We don't object to these; however, these are coupled with stronger ministry powers to direct the work of transfer payment agencies. While Kerry's Place Autism Services acknowledges the need for improved

accountability and quality assurance mechanisms, our concern is that Bill 77 may create onerous expectations for transfer payment agencies and negatively impact the dynamic between the ministry and the governance boards of agencies, not to mention the relationship between boards and individuals.

For example, Bill 77 not only references pre-existing reporting requirements but also obligates transfer payment agencies to provide whatever mechanisms the ministry wants, whenever it wants, in whatever form it wants. The benefits of additional reporting of this type may be outweighed by the burden placed on transfer payment agencies which struggle to meet current reporting requirements within existing administrative resources. Rather than adding a host of additional reporting requirements, the ministry should consider precisely what sort of reports and information it requires and consolidate these into one set of common monitoring tools. Bill 77 also grants expanded powers to ministry inspectors. These may impact upon the privacy and rights of individuals and do not adequately acknowledge that group homes and other residential options are in fact people's homes.

Broader governance issues: Bill 77 grants sweeping powers to MCSS and establishes stringent potential consequences for perceived failure to meet the requirements of the act, regulations or policy directives. These include revoking of funding arrangements and the possibility of direct ministry takeover of a transfer payment agency's operations and resources.

Kerry's Place Autism Services regards these elements of Bill 77 as a continuation of the growing trend towards more direct control and intervention on the part of MCSS over transfer payment agencies. This has the potential to negatively affect the capacity and governance role of the boards of directors with whom the ministry maintains service contracts.

Overall, we encourage the government to consider carefully and critically as to whether there are aspects of Bill 77 that may in fact undermine the transfer payment system and threaten the independence and sustainability of sovereign corporations.

The Chair (Mr. Shafiq Qadri): Thank you. We have considerable time, probably about two and a half minutes or so per side, beginning with the government. Dr. Ramal.

Mr. Khalil Ramal: Thank you for your presentation. I was listening to you carefully when you mentioned the expertise in the application centres. As you know, the application centres would be established in order to make it easier for families from across the province of Ontario to assess their kids and give them the ability to benefit from the services which exist already or that would be designed for their children.

The most important thing, I guess, in an application centre—I'm not sure if you agree with me or not—is they base their decisions on documentation and reports from medical experts. You don't think there's enough in place in order to create some kind of fairness when they make the decisions?

Dr. Glenn Rampton: I think that many people with children with autism spectrum disorders would say that the system doesn't understand and hasn't really understood their children. Sometimes that's professionals, but very often it's people in the generic developmental services system. The application centres have good features. We're just arguing that there needs to be expertise which understands the specific requirements of autism within them, and we haven't seen any provisions for that yet. In fact, the autism sector wasn't even included in the primary consultations which led to the act and led to the work thus far, so we're skeptical.

Mr. Khalil Ramal: What do you think about the bill in general? Will it serve the needs of people with a disability?

Dr. Glenn Rampton: We have really been advocates of individualized approaches, individualized funding and person-centred planning approaches and so on, and we've pioneered a lot of those sorts of things, so we're very much in favour of the tenor. We're just arguing that there needs to be thought given to make sure that the needs of people with autism are fully reflected. Quite frankly, in the sector up till now, they generally haven't been.

The Chair (Mr. Shafiq Qadri): To Mrs. Elliott.

Mrs. Christine Elliott: I'm also particularly interested in your comments with respect to the application centres. I think there is some thought that once the diagnosis has been made or indicates that somebody medically qualifies, the centres will become bureaucratic money-handing-out organizations, but of course they're a lot more than that. In order to build a plan for someone to be able to successfully go from childhood into adulthood and be flexible enough as they grow older and their needs and interests change—and of course, there are legal and estate planning considerations. There are a lot of things, as I understand it, that need to be considered in order to build a life plan for someone. Could you expand on that a bit for the committee, please?

Dr. Glenn Rampton: I think they could be more than bureaucratic exercises, but it really depends on how they're implemented. They could be a place where money is handed out. I think it depends on the sensitivity and the way they're set up and the way they are commissioned, what they're meant to do. If they are just meant to be gatekeepers, that's what they'll become. We would argue that there needs to be a lot of thought put in, with the right people and the right expertise.

Mrs. Christine Elliott: Do you find that most families need that additional assistance, that it's not enough to just have the money, that they need the assistance to know what to do with it to get the best value and to do the best for their child with it?

Dr. Glenn Rampton: Our family has an adult daughter with autism, and it's been a struggle for the system to understand our needs. I think things like portability will be great. I think that having common standards across the province will be really good. But for all of

these provisions, the proof will be in their implementation, how they're exercised.

The Chair (Mr. Shafiq Qadri): Mr. Prue.

Mr. Michael Prue: There have been some concerns that the application centres may run into the same difficulties as CCACs: They're good in principle, but without the funds and without the expertise, they actually don't do what they're supposed to do. Is that your fear?

Dr. Glenn Rampton: That would be my fear, but it doesn't have to be that way; they could be implemented well. But that would be my fear, that they will become bureaucratic exercises and they will become gatekeepers. If there's not enough money, they'll be trying to dole out the same amount of money or a little bit more money across more people, and especially for some subpopulations and the more difficult-to-support populations, that would be very much a problem.

Mr. Michael Prue: I'd like you to expand. You said that you were not consulted or the autism community was not consulted at all at the preliminary stages of the bill. Did you seek to be heard?

Dr. Glenn Rampton: Yes, we did. Our board chair—who wanted to be here today; he probably will arrive a bit later—actually wrote a letter in that regard and we were told in the process of the consultations that later on we'd have a chance for input, but that's not the same as being there at the ground floor and having input into the foundation of the policy framework and the bill itself.

Mr. Michael Prue: Do you know of any other groups dealing with autism that were invited to the table?

Dr. Glenn Rampton: There were none. We made the same argument with Autism Ontario and so on and so forth, and now there is more of a tendency to consult, but at that time there wasn't. I don't think the special needs of folks with autism were recognized.

The Chair (Mr. Shafiq Qadri): Thank you to you, Dr. Rampton, for your presence, deputation and of course for going early.

I would now invite, once again, Sid Ryan, if he's present either in this room or next door. Patricia MacFarlane? Peter Marrese and Chris Bedwell?

Mr. Dave Levac: Just for the sake of the committee, we might want to consider doing a short recess in order to provide for the clerk to make some phone calls and see if he can locate anybody else who's coming, because if they do not present now, we've used up our noon hour.

The Chair (Mr. Shafiq Qadri): Fine. We will recess until 11 a.m.

The committee recessed from 1042 to 1103.

CANADIAN UNION OF PUBLIC
EMPLOYEES, ONTARIO DIVISION

The Chair (Mr. Shafiq Qadri): Ladies and gentlemen and colleagues, I would respectfully ask you to please assume your seats so that we may begin with the further deputations.

I would now, on behalf of the committee, like to call forward Mr. Sid Ryan, president of the Ontario division

of the Canadian Union of Public Employees, CUPE. Mr. Ryan, no doubt you have seen the protocol many times before. You'll have 15 minutes in which to make your presentation. Any time remaining will be evenly and firmly distributed among the parties afterward. I would invite you to introduce yourself and your colleagues and to please begin your deputation now.

Mr. Sid Ryan: Okay, thank you very much, Chair. My name is Sid Ryan. I'm the president of CUPE in Ontario. To my left is Kathy Johnson, a researcher in development and policy in the social services sector of CUPE, and Jim Beattie, who is a front-line worker and also chair of the social services committee dealing with developmental services.

We are here on behalf of 8,000 front-line workers providing services and supports to Ontarians who have a developmental disability and their families. Our members care deeply about their work and the individuals with whom they work. We've spent many years raising an awareness among the public and you, here at Queen's Park, about the problems that exist in the developmental services sector. These problems include inconsistency of supports that are available across the province. A family that lives in one community may have access to several options, while a family in another part of Ontario could wait for years before getting any help.

The sector has been seriously underfunded and faces serious problems with recruitment and retention of staff. That in turn affects the consistency of supports for individuals who need consistency from qualified workers who understand their individual complexities.

We participated in the consultations held by the Ministry of Community and Social Services on their plans for the transformation of developmental services. We hoped to see legislation that would resolve some of the existing problems and move forward with improved supports and services. We have been seriously disappointed. Not only does Bill 77 not address these problems, it proposes a model that we think would set back developmental services, putting these crucial supports for Ontario families on the same disastrous road as home care has taken in this province.

It has all the signs of following the home care path: the creation of a new level of bureaucracy in application centres, the potential for application centres to require service agencies to participate in competitive bidding, and allowing third parties to participate in direct funding arrangements. This latter point is just another way of introducing privatization to the sector by stealth.

The bill proposes the establishment of application centres that would assess individuals and decide whether they are eligible for services and supports, either through direct funding or through an agency. The move to a single point of access in Ontario's home care sector through the CCACs has resulted in service reductions for many recipients. Costs have increased as for-profit providers have usurped non-profit community-based providers under a competitive bidding system in which agencies are forced to compete for scarce funding dollars.

Less care, poor quality, low wages, casualization of the workforce, high rates of staff turnover and service reductions are the hallmark of the home care system today. We do not want to see that happen to individuals we support and their families. The developmental services sector is already struggling with some of these problems: low wages, casualization of the workforce, with about two thirds working part-time or relief, and high rates of staff turnover.

Bill 77 almost predicts service reductions. One of the most egregious sections in Bill 77 is part V, which actually entrenches lists in legislation. It's unbelievable that in Ontario, in 2008, our Legislature is prepared to tell persons with a disability that once they turn 18 years old they will have to wait for the supports that help them to be full members of our communities, because we are not prepared to spend the necessary dollars.

There are more than 13,000 Ontarians on waiting lists for residential services, day supports and other supports and services. Many families are waiting for five or more years for 24-hour residential service. Instead of fixing that problem, Bill 77 is trying to shift even more onto families through direct funding. Right now a minority of families avail themselves of individualized funding arrangements, and many of those have found the stress of managing these arrangements, along with taking on all the responsibilities that go with the role of employer, simply too much.

Our members who work on the front lines believe there must be individualized planning, but not individualized budgeting. Direct funding will contribute to destabilizing the existing decades-old, community-based agency infrastructure.

Service agencies provide oversight, they supervise their staff and ensure consistency in the quality of supports, and under Bill 77 they would be subject to strict accountability measures.

Neither individuals, families nor third party brokers would be subject to those same accountability measures. The bill would require them to account for how the money is spent, but there is no accountability regarding the qualifications of workers they may hire, or the quality of supports provided.

CUPE Ontario has submitted a written brief with recommendations for changing Bill 77. One of those recommendations is that those accountability measures apply to families and third parties as well as service agencies. I will not go through every recommendation here, but will highlight some of the specifics. At the back of the brief that we presented, you'll find all of the recommendations.

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It is time for Ontario to make a commitment to its residents who have a developmental disability. Bill 77 should be amended to mandate services so that those persons have every opportunity to fully participate in their communities. It is unacceptable to leave people languishing on waiting lists, especially when they've been receiving support as children under the Education Act or

the Child and Family Services Act. If an individual is assessed, found to be eligible and necessary supports and services identified, then those supports and services should be provided without delay. Section 19(3), which allows for the entrenchment of waiting lists, should be deleted.

We'd also like to see the removal of application centres as new entities separate from existing service agencies. Instead, agencies in a geographic area should work together on coordinated strategies to meet the goals of the bill. In some areas, such as Toronto, they are already collaborating to coordinate intake and assessments.

You will not be surprised to hear that CUPE members would like the bill to clearly ensure that public monies go only to not-for-profit service providers. We are concerned that the emphasis on direct funding will lead to a proliferation of private brokers and a repeat of the home care disaster.

Finally, we are seeking a commitment from the ministry that there will be open, transparent and comprehensive consultation on the regulations to be developed to support this legislation. The regulations must ensure that there is a common assessment tool across the province and consistent availability of support and services.

You have another crucial task as members of the Ontario Legislature. The general thrust of Bill 77 is to provide more supports and services to persons with a developmental disability and their families without investing additional funding into the system. You must press the government to continue improving on the investment that began with the 2007-08 budget. Without that investment, positive change will not occur.

In closing, CUPE's vision for a transformed and healthy developmental services sector includes a number of key elements. Quality supports for persons with a developmental disability can only be sustained through public, not-for-profit mandated services in an adequately funded community agency system, where workers are compensated fairly and provided training and skills enhancement opportunities. Supports must be tailored to meet the needs of individuals; that is, individualized planning, not direct funding.

The Chair (Mr. Shafiq Qadri): Thank you, Mr. Ryan and your colleagues. We begin with the Conservative side. Ms. Jones.

Ms. Sylvia Jones: You mentioned that you are looking for individualized planning, but not individualized funding. Can you expand on how you see that working, either within the application centres—or maybe you have a different goal?

Ms. Kathy Johnson: Currently, in all the agencies that we have members working in, individualized planning has already been implemented and in fact is the focus of many of the organizations that deliver services. We believe that's the way to go and that that's very important. Our understanding is that the application centres are an opportunity to do an initial assessment, which the agencies have the capacity to do and in fact are

currently doing. Under the Toronto model, they have a consistent way that people access through the services to ensure that that happens.

Ms. Sylvia Jones: So would the individualized planning be staffers who work within the application centres?

Ms. Kathy Johnson: No. I think that what we're—

Ms. Sylvia Jones: In your ideal.

Ms. Kathy Johnson: In our ideal, it would be the people who provide the services who are trained to ensure that assessments and individualized programs can be developed. That would happen in a coordinated way. In our ideal, the tool to do that would be a consistent tool that would be used in every single assessment process in the province. What would happen then is that as they access those resources that are identified, in the event that there's going to be a reassessment, that reassessment would be done with the families and with the individual, with the workers who support them and are trained to help put those plans together.

The Chair (Mr. Shafiq Qadri): Thank you, Ms. Jones. Mr. Prue.

Mr. Michael Prue: How much time? You didn't state—

The Chair (Mr. Shafiq Qadri): About two minutes or so.

Mr. Michael Prue: Okay. Your recommendation number 3 is to replace the proposed application centres with community-based agencies. Why do you think community-based agencies would do a better job?

Ms. Kathy Johnson: Because they're doing it now. In Toronto, the existing service providers have worked out a process where they have coordinated the resources around assessment, access and referral. Our concern is if you set up a parallel system, that drains already scarce resources into setting up a parallel system. Down in the Windsor area, for example, they've piloted another system, and what the workers have reported to us—in fact, the application centre employees come back to the workers in the agency, and they do the initial drafting because they know the individuals and the families. Then their individual draft ends up going back out to the outside application centre per se, which is really, again, a bleed away from resources from the people who can already do the work.

Mr. Michael Prue: You also are suggesting the deletion of subsection 19(3), waiting lists. This is a very contentious issue, waiting lists. You are suggesting that additional funds be given, similar to children's aid societies. How do the children's aid societies—can you explain to the committee how that works?

Ms. Kathy Johnson: Under children's aid societies, there's a funding formula that's based on service volumes. If agencies require more money than what they are allocated under section 14, they're able to actually come and ask for a review of those funds so that they ensure that the mandated services—and that's the key part that this legislation is missing. There is a certain level of service that's guaranteed to every child and every

family in the province under the children's aid/child welfare legislation. That's missing here.

The Chair (Mr. Shafiq Qaadri): I'll have to intervene here. Thank you, Mr. Prue. To the government side, Dr. Ramal.

Mr. Khalil Ramal: Thank you, Mr. Ryan, for your presentation. I have two things I want to talk to you about. First, the application centres that you mention: I want to tell you that the aim and the goal of the application centres is to create a unifying system across the province of Ontario to eliminate the bureaucracy which already exists because there are so many different duplications and we didn't have a method up to the present time. That's why the application centres will be created, to create that unifying method across the province of Ontario.

The second thing: As you may know or not, I worked with both systems. I worked with Community Living London as a staffer and also with the Ministry of Community and Social Services with a big facility back then when we had the facility in Woodstock. I remember from that day until now, so many people—and today especially, so many families came to us and supported us, the government and Bill 77, because the bill gives families the flexibility to choose the service. It doesn't mean they're going to go against the union or a unionized person, because as you know, we are dealing with a human touch, with human beings. The father or the mother—some of them—want to continue to care for their kids, for their loved ones, but they need some kind of financial support. That's why Bill 77, if passed, would give those families that support they're looking for and give them the chance to choose and decide which service would be good for their loved one.

Mr. Sid Ryan: With all due respect, that's Orwellian double-speak—

The Chair (Mr. Shafiq Qaadri): Very briefly, please.

Mr. Sid Ryan: —because when you talk about the CCAC model, it creates a level of bureaucracy. I know you're saying that the intent here is not to create bureaucracy, but in actual fact, if you bring in an application centre, you're adding a layer of bureaucracy which is going to suck money out of the system. Already, as you've just heard from our researcher, the agencies today are able to do the assessment themselves and all you need to do is find a tool, like you did in Toronto, to be able to coordinate—

The Chair (Mr. Shafiq Qaadri): With respect, I will have to intervene there. Thank you, Dr. Ramal. Thank you to you, Mr. Ryan and your colleagues.

Mr. Sid Ryan: Excuse me a second; I've got 30 seconds to answer. He took two minutes to ask the question. I get 30 seconds to answer it?

The Chair (Mr. Shafiq Qaadri): Thank you, Mr. Ryan—

Mr. Sid Ryan: You could at least give me a chance—

The Chair (Mr. Shafiq Qaadri): —on behalf of the committee, and for your testimony on behalf of the

Canadian Union of Public Employees. I now invite our next presenter, Ms. Patricia MacFarlane, to please come forward.

Mr. Sid Ryan: It's good to hear you've got an open-door policy here; you listen to your presentations.

The Chair (Mr. Shafiq Qaadri): We invite you to review it on your video, Mr. Ryan.

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PATRICIA MacFARLANE

The Chair (Mr. Shafiq Qaadri): Thank you, Ms. MacFarlane, for coming forward, as well as for your written deputation, which has been distributed to the committee. As you've seen, you have 15 minutes in which to make your presentation—a firm 15 minutes—irrespective of entourage or photographic support. I will invite you to now begin.

Ms. Patricia MacFarlane: Honourable Chairman, ladies and gentlemen, my name is Patricia MacFarlane and I am here to speak for my daughter, Paula Campbell. Paula is 53 years of age and she is physically as well as mentally challenged. She is in a wheelchair and does not speak.

I am very grateful to the Ontario government for this opportunity to express what I feel about Bill 77. I will read further and give my honest opinion what could happen if this Bill 77 goes through without major changes to amend the bill. I think it will be a horrendous time, both for the clients in Ontario as well as for their families. You really have no idea what could take place. Our sons and daughters are very special. Even though some of them are not able to speak for themselves, they are very aware that something not good will be going on for them.

Paula lives in a group home on Union Avenue in Prince Albert near Port Perry. The staff there are very caring and even know who likes to have a bath or prefers a shower. They know what each of them likes to eat and even know what each one enjoys in music. Isn't that marvellous?

They have had some wonderful trips in their lives, like going to Florida and seeing Disneyland three times. New Orleans was great fun for them before the huge storm. They absolutely loved Niagara Falls. Elvis Presley's place was beautiful, with a delightful surrounding area. They went to Wonderland this summer and will spend time at a cottage in Wasaga Beach. How well we know what it is like to have some joy and fun in our own lives, and they are no different.

The staff at Union are like angels and really care for our family members. I can only say good things about them. They now bring Paula to Toronto once a month as I am no longer able to drive due to health reasons.

When you start to assess each client, will you be able to know all that I have told you? Will you be there to see what happens if you bring in the agencies that you think will be better? You had better think again. My friends in the government, you do not have a clue how these agen-

cies like CCACs operate. I have heard many complaints about them and the lack of work accomplished.

This past year, I had a severe fall and had to have such an agency too. I finally had to let them go for what they were not doing. Do you realize the amount of caring and work that is done each day at Union by the staff? No, I do not think you do. If you did, this nonsensical bill would not even be on the docket. Have you given any consideration to all the staff that would be needed? Even now, as we speak, there are flyers going to Union Avenue group home asking staff for help in regard to the care for their family members. There is not enough good and decent help available for these people.

If you bring in agencies like we have in Toronto, God help our family members. These people are not trained and not caring. In Toronto, some of the agencies are paying \$10 per hour, therefore attracting the people we do not wish to look after the clients at Union or anywhere else.

Have you looked at the parents who are now aging rapidly? How do you think they are going to search for help when there are so few trained staff available? Will they have the energy to take this over? I think not. You will spend a fortune on something which will probably never work and will waste money.

I now ask you to search your hearts and use all the intelligence you have to rethink this very serious situation that you are planning. I am not qualified to tell you what would be a better solution to all these problems, but I do suggest that they need agencies like Central Seven with well-trained and well-educated staff. Clients would be much better treated than what you are suggesting for them. Fund more money for these agencies. Central Seven is an agency that oversees some group homes in the Durham area. They are well organized and make sure our family members are well taken care of. They are located in Port Perry. The clients receive physicals, dental visits and eye examinations throughout the year. We have an assessment for Paula every year showing the improvement she has made and what plans they have for Paula in the coming year. The home is well decorated and very clean, making it a very special place for each of them. All repairs are kept up. So you see, if something is working well, why change it?

In closing, I ask you to read the information from Yahoo! Mail called Parents' Concerns. Also read CUPE's recommendations on Bill 77, which will contribute to the improvement of developmental services in Ontario. To my mind, these are excellent recommendations.

Thank you all for listening.

The Chair (Mr. Shafiq Qadri): Thank you. We'll have a generous amount of time, about three minutes per side, beginning with Mr. Prue.

Mr. Michael Prue: How long has your daughter been in this home?

Ms. Patricia MacFarlane: Since 1989.

Mr. Michael Prue: Have you ever had any difficulties or problems with them?

Ms. Patricia MacFarlane: Never.

Mr. Michael Prue: Do you foresee difficulties or problems developing if you are required to go to an assessment centre or have your daughter assessed?

Ms. Patricia MacFarlane: Yes.

Mr. Michael Prue: Do you think she needs to be assessed again, or are you happy with the assessment that has taken place up to this point?

Ms. Patricia MacFarlane: I have an assessment on her every year. I see her once a month, and I'm very happy with her health. She has lovely pink cheeks, she's kept very nicely dressed, and I'm just so happy with her care.

Mr. Michael Prue: This bill doesn't have a financial aspect to it; the government members say they'll get on to that in a year or so, after they've done some studies. Do you think that more money needs to be spent in this sector?

Ms. Patricia MacFarlane: Definitely. They probably should get a raise this year. These people work harder than RNs do in a general hospital. They have to lift these children and they're very heavy. They have to feed many of them. Yes, I think there would be a problem unless they do some funding. I think it's a good idea.

Mr. Michael Prue: You made a comment about \$10 an hour. Do you know how much the staff at Union are paid?

Ms. Patricia MacFarlane: Not totally. I don't ask questions. If they want to tell me, that's fine. But I know it's not a whole lot. An RN makes much, much more. They have young people going in to help who are trying to get their education on the side, but then they leave because we're not paying them enough. It's hard to see them go, and it's hard for them to leave. They love their work.

The Chair (Mr. Shafiq Qadri): Mr. Levac.

Mr. Dave Levac: Thank you for your presentation and expressing your concerns. I heard very clearly that this is your honest opinion about what the bill's outcome would be. Can you point out some specifics that have offended you about this? You believe that the bill, if passed unamended, will adversely change your situation today?

Ms. Patricia MacFarlane: Yes. In this bill, you do not express very clearly what could happen to the people who are already in service and doing quite well.

Mr. Dave Levac: So you're assuming that it will be negative.

Ms. Patricia MacFarlane: I don't know.

Mr. Dave Levac: You also indicate in your presentation a few times that none of us have any idea of what's going on.

Ms. Patricia MacFarlane: I don't see how you would; you're not there.

Mr. Dave Levac: I wouldn't want to make assumptions about your family, but in terms of our experiences—and I would include members of the opposition—we would not make a generalization about what you're telling us. What I am concerned about is that you're

expressing a generalization that none of us have had any experience whatsoever in this field, and I would tell you very clearly and candidly that that's not a fact.

Ms. Patricia MacFarlane: That's okay, you have your opinion.

Mr. Dave Levac: It's not opinion, it's fact. It's fact that people have these experiences and that the staff and the individuals from the ministry are experts and they've had experiences as well. So I just would hope that you would not make those assumptions based on the fact that your emotions are telling you that no one knows what's going on.

Ms. Patricia MacFarlane: I can respect what you're saying.

Mr. Dave Levac: Thank you. I appreciate that.

What I think you're saying is you believe the situation that your daughter is presently in would be changed for the negative.

Ms. Patricia MacFarlane: I don't know. I'm hoping not.

Mr. Dave Levac: Okay. Your deputation is very challenging, and I'm sure that the staff have heard it very clearly. We'll make sure that we take a look at the circumstances behind the organizations you're speaking of. I agree with you that there needs to be a very strong component of the staffing issue. There have been raises recently, not as major as we would like them to be, but there have been some improvements. We've spent half a billion dollars improving the sector, with the hopes of continuing to do so.

1130

Ms. Patricia MacFarlane: Good. I respect that.

Mr. Dave Levac: Thank you very much.

Mrs. Christine Elliott: Thank you, Ms. MacFarlane, for your comments. I'm a member from Durham region, so I'm very familiar with the work that Central Seven does. They certainly enjoy a wonderful reputation in our community and they do excellent work.

I was very interested in the comments that you make in your paper, because it's very much a heartfelt view of a parent. What you really want—as all parents want for their children, whether they have special needs or not—is that they be seen as people with real needs and individual personalities. I think that, for all of us, is going to be important as we move forward with consideration of this legislation, to recognize that each child has their own special needs, wants and desires. We have to remember to take care of that and focus on that as we go through our deliberations, so that each child's needs are recognized through careful planning. Does that fairly encapsulate what you're saying?

Ms. Patricia MacFarlane: Thank you for that, and for acknowledging what I've said.

Mrs. Christine Elliott: Thank you.

The Chair (Mr. Shafiq Qadri): Thank you, Ms. MacFarlane, on behalf of the committee, for your presence, for sharing your personal story, as well as your written deputation.

PETER MARRESE

CHRIS BEDWELL

The Chair (Mr. Shafiq Qadri): I'd now invite our next presenters. They are Peter Marrese and Chris Bedwell. If they are present, would they please come forward and be seated. Gentlemen, you've seen the protocol. You have 15 minutes in which to make your presentation. Should you have any videographers or photographers for immortalization, as has been done, please feel free. Please begin.

Mr. Peter Marrese: Good morning, everyone. My name is Peter Marrese. I want to thank you for inviting me to share some of our views on Bill 77. My friend, Chris Bedwell, is here with me. He's going to give you some feedback as well. We are honoured to be here today on behalf of our colleagues, who will be the ones most affected by this bill.

I was diagnosed with a developmental disability when I was 12 years old. Back in 1970, my parents and those who tried to help me did not know much about places like Community Living Toronto. Finally, when I was 18, I was introduced to the association. It was the intake workers who helped me find a support worker. My support worker has helped me to live more independently, like learning to cook, banking, finding a job that I like and am good at, and helped me to become an advocate for my colleagues.

This is why I think receiving direct support from an agency is important. The bill talks about application centres that would be responsible for assisting a person and helping them find supports and services best for them. Having been part of Community Living Toronto since the 1970s, I have formed many great relationships with the staff who help support me.

I feel that the intake staff, who work directly with agencies, can assist individuals better since they know the agency very well. They also get to know the support staff workers who help us do things such as banking, cooking, finding jobs, as well as helping us to reach our goals based on our interests.

The application centres could take away from personal relationships that intake workers have with our support staff and agencies. The support workers who help me care a lot about my choices. They believe that people with intellectual disabilities should, just like everyone else, have the right to choose where they get to live, what they get to do during the day and interests and hobbies that they like best. I believe that I should also be able to choose the agency that I want to be a part of and the support staff who will help me achieve my goals.

Through our agencies, my friends and I not only get a chance to do things like attend workshops and clubs run by our agencies, but also programs in our neighbourhoods that are not funded by the government. Because our agencies work closely with the neighbourhoods we live in, they can help us find activities we'd like to participate in, like painting, drama or sports clubs. If the application centre would handle these things, I'm not

sure that they could know of all the activities available to our community. This would make a lot of people sad and would leave some of us separated from the people in our neighbourhoods. It could also mean some people might not have access to programs and services while they are still on the waiting list for funding.

Being apart like that from our communities could only make it harder for us to live a normal life. It is why I think that application centres could not really know the agencies that help us. It also could take away from the control and choices that people with an intellectual disability have.

Another big problem with this for my colleagues is quality of life. People who don't have disabilities can earn money without it being taken away. For the majority of us, who need extra help from the government to pay our rent, our bills, when we have a job, we are given much less than we deserve.

For a lot of my colleagues, things like groceries and coffee or even public transit are very hard to afford. It would be nice to see Bill 77 help us to live a better quality life. Right now, when people get their ODSP cheque, they barely have enough to live. If they have a job, half of that money they make is taken back by the government. None of my friends have extra money in the bank, even if they are working. I know that once in a while, some of my friends would love to do something fun, like watch a movie, without worrying about having enough money to buy things like groceries.

I would like to thank you for letting me speak to you about this bill. I hope that I helped you to understand the concerns some of my colleagues have about the bill, and I think it is great that you want to make a positive change in my life as well as everyone else who has a disability.

My friend Chris is also here today to speak to you. He'll talk about his experience living with a disability and his thoughts on Bill 77. Thank you.

Mr. Chris Bedwell: Thank you, Peter. Good morning, everybody. My name is Chris Bedwell and I would like to start by thanking you for this opportunity to speak on Bill 77.

I have looked over the bill and I am happy to see that the government is trying to improve services and supports for people who have developmental disabilities and their families. But at the same time, I have some concerns about Bill 77 and how it will affect my life and the lives of my friends and colleagues.

One of my main concerns about Bill 77 is the definition of developmental disability. According to the bill, a person with a developmental disability learns, understands and remembers at a slower pace than others, and this affects their ability to live without supports. Following this definition, I am a person with a developmental disability. However, the bill also says that a person must have these limits before they turn 18. I was not diagnosed until 2001, when I was 39. So I am wondering, does this mean I will not be able to receive funding or services under Bill 77, whether it be ratified or not?

There are many people like me who grew up in a time where we did not know as much about developmental disabilities as we do today. When I was young and going through school, I failed fourth grade twice. That seemed like just another school thing, but no one said I might have a disability. Back then, we also did not know much about services and supports that were available to people with developmental disabilities. I was lost between the cracks because I did not know about Community Living Toronto or how to access their services. There are many people like me who learn how to get help late in life, and I'm concerned that we might not receive support under Bill 77.

I would also ask, what will happen to people who come to Canada from different countries? In many countries there is not as much awareness even today about developmental disabilities. If someone 18 or older comes from another country where they have not been diagnosed with a developmental disability, does that mean they won't be able to receive funding or service in Canada?

Finally, what about people who develop a disability after the age of 18 like myself? Will these people be unable to get support because of Bill 77? I would like to see Bill 77's definition of people with a developmental disability changed or removed—that would be the age limit in this case—because it excludes many people who require support.

My second major concern about Bill 77 is that it limits the role of agencies that people like me have grown to trust. I can appreciate how important agencies are because when I was first brought in to Community Living Toronto, I had been living on the streets for five months. It was a constant struggle living on the streets, and if it had not been for Community Living and the good Samaritan who first picked me up, I would not be here today.

Because of the help I have received from agencies, I have a place to live, an opportunity to be involved in the community and a number of friends that I have met through agency programs.

I understand that under Bill 77 the government could put directors into place who would tell agencies and application centres how to work, who to support and how to give out funding. It is very important to me that the government work with these agencies in developing these policies. I have developed trust in the experience and knowledge of staff members at Community Living Toronto and similar agencies. I would be more comfortable if the government consulted the people who are already overseeing the agencies before making decisions about services and funding, and who will get them and how.

I would not be here today without support from the agencies. It's important for me to know that major changes to agencies and how they operate won't be made without first consulting the agencies, and that their experience and knowledge will be used wherever possible.

Those are my concerns about Bill 77. I would like to thank the government once again for trying to improve

support for people with a developmental disability and their families. I would like to thank everyone for giving me the opportunity to speak today about my concerns. Thank you.

The Chair (Mr. Shafiq Qaadri): Thank you, Mr. Bewdell. We'll have about a minute or so per side, with Dr. Ramal.

Mr. Chris Bedwell: Excuse me? It's Bedwell. Sorry, thank you.

The Chair (Mr. Shafiq Qaadri): Bedwell. Thank you.

Mr. Chris Bedwell: You're welcome.

Mr. Khalil Ramal: Thank you, Peter and Chris, for your presentation. Thank you very much for coming forward and sharing with us your experience. I want to assure you that the aim of Bill 77 is not to complicate the system but to make it easier, more accessible and more flexible for many people who want to choose different services. I want to assure you also, if you are receiving your services, it's not going to change; they will continue. The aim of Bill 77 is to give the chance to families and parents who want to look after their kids or members of their families and need support from the government. Thank you again, and be assured you'll be looked after.

Mr. Peter Marrese: You're welcome.

Ms. Sylvia Jones: Thank you, gentlemen. That was an excellent presentation. You're the first presentation that's talked about the definitions and the 18. You made a very reasoned argument as to why that should be amended, so we'll be watching that one to see if it can be changed.

The Chair (Mr. Shafiq Qaadri): To Mr. Prue.

Mr. Michael Prue: Yes, you were also the first person to raise the thorny issue of people who come from other countries, who immigrate to Canada, and the services that may or may not be available to adults and whether or not they had been diagnosed in their previous lands. Have you run into people like this? Do you have colleagues like this who are having difficulty getting assessed or getting the necessary services, people who did not grow up or live here until they were adults?

Mr. Chris Bedwell: Yes.

Mr. Peter Marrese: I'll give you that thing. In our agencies, we have parents who do not understand quality of life for their daughters and sons and there are terrible problems with them. We keep bringing in the multi-cultural-speaking staff and take staff supporting—that is a big issue.

Mr. Michael Prue: Thank you.

Mr. Peter Marrese: You're welcome.

The Chair (Mr. Shafiq Qaadri): Mr. Bedwell and Mr. Marrese, I'd like to thank you on behalf of the committee for your very powerful and important presentation and for coming forward and for any other deputation that you may be offering us in the future.

If there's no further business, this committee stands recessed until 1 p.m.

The committee recessed from 1144 to 1302.

CANADIAN ASSOCIATION FOR COMMUNITY LIVING

The Chair (Mr. Shafiq Qaadri): Ladies and gentlemen, colleagues, I'd invite you to please be seated so we can reconvene. As you know, we are the Standing Committee on Social Policy, meeting for consideration of Bill 77 to do with the disabilities act.

I'd now like to invite Michael Bach, if he is present. That's great. Mr. Bach, please come forward, and thank you for coming on behalf of the Canadian Association for Community Living. As you've perhaps seen the protocol, you have 15 minutes, firmly enforced, in which to make your presentation. Any time remaining will be distributed evenly amongst the parties for questions and comments. I'd invite you to please begin now.

Mr. Michael Bach: Thank you, honourable Chair and members of the standing committee. Thank you for the opportunity to present before you today.

The Canadian Association for Community Living is the national association that advocates for people with intellectual disabilities. We're a federation with local and provincial or territorial associations across the country. Community Living Ontario is our provincial member in Ontario. Community Living Ontario has submitted a brief and is presenting later this afternoon. By way of introduction, I just want to say we fully endorse and support and urge that the recommendations of Community Living Ontario be incorporated into the amendments.

We wanted an opportunity, also, as a national association, to present before this committee because this act speaks directly to the issue of disability supports, how people with intellectual disabilities are going to access those supports and how they're going to be delivered. We see this as fundamentally an issue of the citizenship and inclusion of people with intellectual disabilities. We believe that at this watershed moment, as large institutions are closing, Ontario is in an ideal position to take leadership in this country on establishing a disability support system that will truly advance the inclusion of Canadians with intellectual disabilities. That's how we have built, or attempted to build, a fair and equitable social justice framework in this country—by provincial jurisdictions learning from one another. We felt we wanted to take the opportunity to speak to the committee.

There are four issues that I'd like to emphasize in my presentation, and I would like to leave a few minutes for questions and answers:

- the explicit purpose of this legislation and the link between citizenship and disability supports and its reflection in the legislation;

- the elements of a direct funding system that need to be in place for direct funding to work; we've learned about those elements over 20 years of experience and research in this country, and I wanted to share a few comments on that;

- the importance of more explicit recognition of the issue of legal capacity so that people with intellectual dis-

abilities can, in fact, enter the agreements that are provided for under this legislation;

—the language of waiting lists in a piece of legislation like this that is to be visionary and to serve Ontario for generations to come.

The link between disability supports, inclusion and citizenship: We define disability supports as any good or service that a person with a disability requires to carry out the activities of daily life and to participate in the social, economic, cultural and political life of their communities. For someone with a mobility impairment or disability, that disability support could be a wheelchair. For someone who has certain degenerative neurological conditions, the disability support could simply be an air conditioner. For many people with intellectual disabilities, the provision of disability support is personal assistance for access to education or participation in the community and in the workplace.

There's a fundamental link between access to disability supports and citizenship, yet the legislation makes no reference to that link. Our concern is that, as it seeks to establish a kind of watershed moment in the history of this province and really address and confront the legacies of institutions that people still live with and the legacies of law and policy in this province that have left so many people with intellectual disabilities isolated and alone in their communities, this legislation needs to be about more than the machinery of services. Provision of services is in the service of something. It's in the service, we believe, of full citizenship and inclusion, and we would urge that a legislative purpose be incorporated into the act. We think the language that the government used in launching its transformation exercise, of which Bill 77 is really the legislative culmination, would serve well as the starting point for that language.

Principle number one that the government articulated for the transformation exercise was: "Citizenship—supports for people who have a developmental disability promote self-determination and participation in all aspects of community life."

Simply and clearly stated, we believe that kind of statement should be incorporated into the legislation and would serve as a benchmark for accountability and for assessing the extent to which the provisions this act puts into place and the services it funds are in fact achieving that goal. We need to know the goal for which services are being funded because services have been extensively funded in this province in the past, but they've led to outcomes that we now fundamentally reject as a society. I think that experience, the institutional legacy of previous law and policy in this province, would advise us to incorporate a more explicit objective for the legislation.

If I could turn to the elements for direct funding to be effective, we know from experience, from demonstration projects in this province, across the country and indeed internationally, that to make direct funding realize its potential benefit—and research has demonstrated benefits: increased health, increased health status, increased

life expectations, increased capacity, participation, economic benefits etc.—you need more than a funding allocation mechanism. All that this legislation puts in place is a funding allocation mechanism through the application centres. We would urge that the legislation speak to the other pieces that we know and the research tells us are essential.

One is independent planning support. People don't plan for services; they plan for a life. Ministry-funded services may or may not play a role in a good life for a person with an intellectual disability. People need access to someone who can assist them in developing a life plan for themselves that identifies the range of supports in the generic community, the natural supports that they're going to require and the place, if any, of developmental services funded by this ministry.

1310

Currently, there's no provision in this framework to give people access to that planning support. We think that could be one of the prescribed sets of services that the ministry provides. As the research suggests, we think it also should be independent planning support, so that you've got someone outside of the funder, outside of the service agencies—which are doing good work—where you can go to help you develop a plan, so that that planner has no conflict of interest in developing a community-based plan for inclusion and support for that individual.

We think other services that should be added to the list of prescribed services are assistance in developing personal networks and relationships, which are a bridge to the community, assist people in making decisions and can assist people in exercising their legal capacity to enter those agreements. To a large extent, people with intellectual disabilities are excluded from their communities, isolated and alone in many instances. Given the institutional legacy, I think there's a positive duty on the state to invest in the capacity of personal networks to assist someone in creating a bridge to the community.

The whole issue of legal capacity is picked up to a large degree in Community Living Ontario's brief, and it will be in the brief that we submit later this week. People's right to supporting legal capacity has recently been recognized in the UN Convention on the Rights of Persons with Disabilities. That's a landmark convention in recognition of a right to supports. We think there needs to be some recognition in this legislation that people may need support to make decisions and to enter an agreement. Otherwise, there will be pressure to have people declared incapable of entering those agreements and to have a substitute appointed for that purpose. So we believe there should be recognition of the right to support. Again, that could be a prescribed service in the list of services.

We think for direct funding to work—and we think that's such an important element, and we congratulate the government on introducing that in this legislation—there needs to be some investment in community capacity so that we can develop the capacities of self-advocates, of

family networks, of generic services in the community and of service providers to develop this reform that this legislation envisages. Again, investment in community capacity could simply be another prescribed service.

Finally, we think the legislation should empower the minister to establish the mechanisms as needed for an application and approval process that will enable the provision of supports to meet that objective that I stated at the outset; that is, supports that will enable the self-determination and inclusion of people with intellectual disabilities.

Let's not fix the one and only mechanism in application centres; let's leave it open and empower the minister to establish mechanisms as needed, so that we can learn and innovate as we go.

With those comments, if there's any time left for questions, I'll close it off.

The Chair (Mr. Shafiq Qaadri): Thank you. We've got 90 seconds per side, beginning with the Conservatives. Ms. Jones.

Ms. Sylvia Jones: Because you are the first one representing all of Canada, can you enlighten the committee: Are there other examples where independent planning services and/or the application centres as set out in Bill 77 are in existence?

Mr. Michael Bach: Alberta has the most extensive development of direct funding for people with developmental disabilities. They also focused primarily on the funding allocation system. They do make funding available to purchase independent planners, but that system wasn't highly developed, and we're seeing that basically what's happening is direct funding contracts get rolled up into a service provider contract. The benefit of direct funding isn't being realized to the extent that it could be, and the evaluations are showing that. It's too early in other jurisdictions. BC is going down this route, as is New Brunswick, but it's still too early to see. I think that there are some demonstrations in Ontario—in Windsor, in Toronto, in Thunder Bay—that have demonstrated in the evaluations the importance of independent planning.

The Chair (Mr. Shafiq Qaadri): Mr. Prue.

Mr. Michael Prue: Just on that same point, in Windsor, in London, and in other places, they're doing it without a new mechanism that's being proposed by this bill. Is it successful?

Mr. Michael Bach: I've been involved in the evaluations prior to my current position, and others have conducted evaluations, and the provision of both independent planning and direct funding has shown huge benefits in this province both for people with intellectual disabilities and for their families.

There were also a number of lessons that are being learned about how you manage the allocation of funding fairly, how you ensure that people have access to the planning support that they need, but in principle those demonstrations have proven that these kinds of mechanisms work and have the intended benefits.

Mr. Michael Prue: But this is being done without the new application centres, as envisioned?

Mr. Michael Bach: Yes, but they've been demonstration centres. So there have been provisions that have been set up, either under an area office of the ministry or through a demonstration project like the project with Family Service Association of Toronto, to manage this exercise. You do need some mechanism. They remain demonstration initiatives that can't really grow into something more systemic without a legislative framework. That has certainly been the direction that was taken in Alberta and British Columbia, and anticipated now in New Brunswick. So you need some mechanism, I think, some legislative framework to put this into place.

The Chair (Mr. Shafiq Qaadri): Thank you, Mr. Prue. Dr. Ramal.

Mr. Khalil Ramal: Thank you, Mr. Bach, for your presentation. I think it's important that a person like yourself has the ability to work with all the associations across the country and then give some kind of comparative ideas and opinions. So you think, then, that the application centre is very important to unify the eligibility?

Mr. Michael Bach: There needs to be some process for determining eligibility and allocating funding. I believe that that should firmly rest with the government. The status of these application centres isn't entirely clear to me in the legislation. I think it would be a mistake for the government to give that power away. Government's responsibility is to allocate resources and to make tough decisions. I don't think that job should be given away to the community. It remains, fundamentally, a political act and decision. In terms of accountability for the funds allocated and how they're allocated, it should remain with the government. That's certainly my view.

Mr. Khalil Ramal: So you talk about citizenship.

Mr. Michael Bach: Citizenship? Yes.

Mr. Khalil Ramal: If, hopefully, this bill passes as it is, I think it will strengthen the citizenship idea and philosophy behind the whole concept of this bill. You don't think this bill is good enough to strengthen the citizenship idea?

Mr. Michael Bach: I think that it has the potential, but needs to state clearly that the purpose of funding services is to advance the full participation—

The Chair (Mr. Shafiq Qaadri): I have to intervene there. Thank you, Dr. Ramal. Thank you, as well, Mr. Bach, for coming by and testifying on behalf of the Canadian Association for Community Living.

CANADIAN UNION OF PUBLIC EMPLOYEES, LOCAL 2191

The Chair (Mr. Shafiq Qaadri): I now would like to invite on behalf of the committee Mr. Edgar Godoy and Teresa Colangelo, if they're present, to please come forward and offer their testimony on behalf of CUPE, Canadian Union of Public Employees, Local 2191, Toronto. Mr. Godoy, as you've seen, you have 15 minutes in which to make your presentation. Of course, if

your colleague materializes, she is welcome. I would invite you to begin now.

Mr. Edgar Godoy: Thanks. I have been working as a front-line worker in this sector for at least the last 20 years. I started an Iranian foundation in the late 1980s. Then, since 1992, I have been working for Community Living Toronto.

CUPE Local 2191 represents 1,200 front-line employees working for Community Living Toronto in the greater Toronto area. Our local is also the largest one in the developing services sector in Ontario. Our members deliver a large variety of services, including early childhood education, vocational counselling, employment support training and skills development, residential and vocational supports, as well as semi-independent living, maintenance of our facilities, individualized supports and respite services.

Those are generic terms to describe many of the multiple supports and services that we provide, including preparation of meals, taking care of their basic needs such as hygiene, training in finding jobs, and support in those jobs, as well as other basic needs. Our members are committed to delivering these services within a holistic and integrated approach, which includes individual personal planning, advocacy, empowerment and community participation. Working closely with individual family members whenever possible is an important part of our job, developing those relationships. However, individuals with intellectual disabilities must be provided with universal access to needed services to ensure full citizenship. These support services are best provided within a fully accountable public sector framework.

1320

Despite the challenges faced by our sector, including chronic underfunding, Community Living Toronto has come a long way since the days when parents and advocates were meeting in church basements and funding the supports needed for their loved ones with their own resources and/or charity. Services and supports have been put in place, but there are still systemic barriers such as lack of universal access, chronic underfunding, long waiting lists, inadequate training and high staff turnover.

Some of the concerns that my CUPE local, 2191, has regarding Bill 77 are as follows.

The Services for Persons with Disabilities Act, as it is being proposed, will not address those central issues which are negatively affecting people with support in the developmental services sector. Access, consistency in the staffing and accountability, which is so important to the individuals and families we support, are not addressed. In fact, there will be compounded problems, such as inconsistency in access and waiting lists.

In addition, staffing issues such as the casualization of our jobs, chronic underfunding, low wages, recruitment and retention of staff, WSIB protection, lack of pension and benefits, and health and safety issues in the workplace will become more prominent. For example, over the last decade, as a direct result of cuts to our sector, our local has seen a shift in our membership from full-time

workers, comprising more than half of our membership to full-time staff now numbering fewer than half of the members. These casual workers have no benefits, no pension or other protections that are afforded to full-time workers but face the same challenges, including health and safety concerns and employment instability, which have a negative impact on the quality of service that we deliver. This hurts workers, the services we provide and, most importantly, the individuals and families we support.

The conditions under which we provide services will be compromised with the new service model entrenched within the act. Many association for community living, ACL, workers do not have pensions, as I already underlined. In our local, all part-time and relief casual workers, who are the majority of the membership, have no benefits, no pension. As a result of their low wages, they are unable to afford private pensions or retirement plans—for workers who are supporting the most vulnerable citizens of this province.

Our members as well as ACL workers across the province make significantly lower wages compared to the social service sector workers who do similar work. It is estimated, based on the survey by KPMG in January 2000, that workers in the developmental services field earn 25% less than other social workers who are doing essentially the same type of work. Despite—and I want to emphasize this—the government's recent allocation of additional funding for wage enhancements, salaries remain low. Chronic underfunding of this sector has forced employees to do more for less, which has had a negative impact on staff retention and recruitment as well as on the quality of services that we provide. Services and supports for persons with intellectual disabilities have always been lacking, and that's no secret to any of you, I hope.

Bill 77 does not safeguard against for-profit service providers setting up shop and financially benefiting from the scarce, minimal funding dollars that persons with developmental disabilities receive. This will impact on the quality and quantity of services delivered. There's little or no accountability in the proposed legislation for these third party brokers. There must be amendments to Bill 77 to safeguard against service providers profiting from people with intellectual disabilities.

Long-term, stable and consistent funding for the sector is the only way to deal with these issues that are affecting us on the delivery of services. Waiting lists have continued to grow despite the introduction of individualized funding some years ago. This approach to funding service delivery has not improved the lives of persons with developmental disabilities, as the funding often falls short of the individual's needs.

Individualized funding has created a number of additional challenges for parents and families who wish to manage their own funding. It has forced them to become employers, in such things as equipping, hiring, firing, disciplining, paying and making the appropriate tax deductions for staff who support their loved ones.

This individualized approach to funding has opened up liability to the individuals themselves or their families to be legally responsible for their staff. We support the need for families to have support in their homes. Making them employers will not make this happen.

Families should be able to rely on levels of support from the province, regardless of where they live. Access to service should not depend on how many resources are being used in any given area. If there is any specific identified need for support, then parents should not be left dangling on waiting lists for many years.

Our members are heartbroken. I personally have lived those experiences when we witnessed that the only way some individuals get off the waiting list is for their parents or caregivers to die. Then, not only are they dealing with the grief and loss of the people they have loved and who have always provided care for them, they also have to move into a living arrangement environment without the support of family, as they have died. We believe that's not right; that's not a way to provide services.

We're also very concerned that the bill does not explicitly state that no one who is currently receiving services will have those services decreased in any way. If the intent is that no existing support to individuals and families be lost, then section 40 must be rewritten.

We believe that not-for-profit agencies should receive the necessary funding to sustain and expand the supports and services that they provide. There needs to be an increase in the number of supports and services available to persons with intellectual disabilities to address serious shortfalls and the ever-growing waiting list. Staff must be paid decent wages with benefits, including pension plans and WSIB protection. The quality of supports and services must be maintained.

To conclude, Bill 77 will dramatically impact the way services and supports for people with intellectual disabilities have been provided in Ontario; particularly, forcing not-for-profit agencies to compete for scarce funding dollars, failing to legislate universal access in a mandated level of services for all persons with disabilities in our province, as well as failing to legislate a consistent assessment tool to address their needs.

In addition to what I have outlined on behalf of our 1,200 members, we also fully support the recommendations outlined in the CUPE Ontario brief submitted earlier today for your consideration.

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The Chair (Mr. Shafiq Qaadri): Thank you, Mr. Godoy. We have about a minute per side, beginning with Mr. Prue.

Mr. Michael Prue: I listened intently. The gist of your argument is that you do not believe that this bill is going to do anything but end up in privatizing services. Would I be correct in saying that?

Mr. Edgar Godoy: That's my understanding.

Mr. Michael Prue: Okay. From where do you get this? Is it because of the privatized services in home care

or the privatized services in the homes for the elderly? I mean, we've gone down this road before, so—

Mr. Edgar Godoy: We have had previous precedents, particularly in projects similar to the access centres being proposed today—the CCACs within the home care. Also, when the legislation doesn't establish that, for people who are already receiving those services, they will not be decreased and the creation of third parties that I would assume are for-profit, will change—

The Chair (Mr. Shafiq Qaadri): With respect, I will have to intervene there. To the government side. Dr. Ramal.

Mr. Edgar Godoy: It's in the 15 minutes allocated to me here or to you? Because you will have time to debate the legislation.

The Chair (Mr. Shafiq Qaadri): Dr. Ramal, you have the floor.

Mr. Khalil Ramal: Thank you very much for your presentation. I listened to you carefully. You talked a lot about the relationship between the government and the union and the parents with the unions, but this bill is not about membership of the union or about how the union is going to be supported. It's not going to talk about this at all. We're talking about families, about human beings. So we're talking about parents. They have kids in their home. They want to continue to care for them, right? And they're looking to the government for support. How can you see this as a bad initiative and you or your local thinks that parents won't be able to do it? Can you tell me, explain to the people why—

Mr. Edgar Godoy: We're fully supporting parents here. That's why we're saying that we fundamentally believe that a publicly funded service—and extending the services of the agencies—

Mr. Khalil Ramal: But many families came this morning and focused on—

Mr. Edgar Godoy: —because of the waiting list issue. Agencies have not been able to address those issues. That's what parents continue—if you establish universal access, families will be able to have services and provide the funding to the existing agencies. We're not arguing with—

The Chair (Mr. Shafiq Qaadri): Thank you, Mr. Godoy and Dr. Ramal. I now offer it to the Conservative side. Ms. Elliott.

Mrs. Christine Elliott: Thank you. I also have a question just with respect to the provision of services because you did speak a lot about individualized services and needs. Many parents and families have spoken to us very strongly about that, that perhaps they might choose different living arrangements for their children, that they might want their children to live more independently with other supports and services to really tailor-make a program for their children. Surely you wouldn't see that as being a bad thing. Would you take exception to that in any way?

Mr. Edgar Godoy: I think families deserve the choice, but should not be put in a difficult position where they have to compete for those resources. The issue here

is providing the resources for families that have been waiting for many years because successive governments have not addressed the issue of waiting lists and the needs of their children. Universal access will address it if it goes hand in hand with the proper funding from the government.

The Chair (Mr. Shafiq Qaadri): Thank you, Ms. Elliott, and thank you as well, Mr. Godoy, on your presentation on behalf of the Canadian Union of Public Employees.

AUTISM ONTARIO

The Chair (Mr. Shafiq Qaadri): I will now call our next presenter, Margaret Spoelstra, the executive director of Autism Ontario's provincial office.

Just before you begin, perhaps in answer to your tail-end comment there, Mr. Godoy, yes, I thank you for re-informing this chamber that we have 15 minutes per presenter, strictly enforced, irrespective of what they personally believe they should be allocated for any other ulterior purpose across this province. This is what the subcommittee decided. This committee is travelling to four cities; we are hearing from probably upwards of dozens and dozens of different individuals. As I say, a statement was given to the CBC to this effect earlier today. I repeat: 15 minutes, strictly enforced.

Ms. Spoelstra, I invite you to begin now.

Ms. Margaret Spoelstra: Thank you. I'll stick to my 15 minutes.

The Chair (Mr. Shafiq Qaadri): You will.

Ms. Margaret Spoelstra: Thank you very much, committee, for hearing from Autism Ontario today.

For the past 35 years, Autism Ontario has been a leading source of information and referral on autism and one of the largest collective voices representing the autism community. Members are connected through a volunteer network of 30 chapters throughout Ontario. We represent thousands of families who have children and adults with autism spectrum disorder.

We are committed to increasing public awareness and addressing day-to-day issues faced by families who live with children with autism and the professionals with whom they interact. Our vision is acceptance and opportunities for all individuals on the autism spectrum.

We're very grateful for the opportunity to speak to this bill and that it's been opened again. Many years ago, when rates of autism were one in 1,000, Ontario was unable to meet the needs of this vulnerable population. Currently, one in 150 children are diagnosed with an ASD. Children with ASD grow up to be adults with ASD. Applied to Ontario's population, many of its 50,000 adult citizens will require the supports identified in the proposed legislation, in addition to many other health, education and community supports.

Ontarians with developmental disabilities need legislation that helps each individual to reach their goals and dreams, and allows them more choice and flexibility in the services and supports each receives. They and their

families need a bill that fosters inclusion within the wider community and, equally important, encourages independence. It is admirable that this new legislation promotes citizenship, fairness, accessibility, accountability and sustainability. For these principles espoused by the Honourable Madeleine Meilleur to succeed, adequate funding must be forthcoming to fulfill the total obligations under this proposed legislation.

I want to make a note that we also support the paper that was produced by the provincial ad hoc working group on Bill 77, with the lead author Judith McGill. I just want to make that statement for the record as well.

The areas of concern that we have we'll speak to on individual items.

The first is on developmental disability and the term. We're grateful to see that the IQ score is no longer a prime consideration for eligibility. Previously, the benchmark was below 70. This definitely made higher-functioning individuals with ASD and Asperger's ineligible for services.

In the definition of developmental disabilities, mention is made that the disability was to have originated before the person reached 18 years of age. The many challenges faced by teens and adults and their families when facing an undereducated health care system will continue to mean that many people with ASD will not have been correctly diagnosed until adulthood, even though, by DSM IV diagnostic criteria, they would have met the required criteria for a diagnosis prior to their third birthday. It's our expectation that this systems capacity gap would not make such individuals ineligible under the current proposed definition of a developmental disability.

Regarding the professional and specialized services, employment and job training services, psychological services or any therapeutic services should be included as specialized services. There should be an appeal process to a third party outside the application centre if an individual does not believe the proposed services are an appropriate match for their needs. The term "services," which is mentioned frequently throughout the bill, should read "services and supports."

Regarding application centres, there is a potential conflict of interest when application centre staff manage available services, supports and funding at the same time as they determine services and allocation of funds. Staff may choose to fill current service vacancies, instead of looking for tailor-made services and supports to match individual needs. This is especially crucial for individuals with ASD and Asperger's, where more specialized and non-generic services and supports are vital.

When staff complete applications that conflict with assessment and allocation of funds and prioritization and when staff monitor satisfaction surveys related to services provided, then where is the accountability, or when they deal with appeals concerning services they provide? This should always be done by an outside third party.

In our view, it is unwise to have all of the listed roles set out in the bill undertaken by a single type of entity.

The government should limit the roles of the application centres, as well as institute a system of regulatory safeguards to deal with these conflicts of interest. If the application centre is also a service agency, choices facing the individual may be somewhat constrained.

The bill further confuses things by introducing the concept of a service coordinator without explanation. This role needs to be clarified, especially if that person may be given funds to purchase services.

It was brought to our attention that the application centres were meant to be cost-neutral. We're not sure entirely what that means. Does it mean that there will be a transfer of funds from those agencies no longer providing services that will be carried out by the application centres? Autism Ontario believes that the government must commit adequate resources so that the application centres will be in a position to maximize the services and supports necessary to meet the individual's specialized needs.

Regarding direct funding: Under Bill 77, direct funding means that funding for the benefit of a person with a developmental disability that is provided by the ministry through an application centre in accordance with a direct funding agreement, as described in section 11. This funding may be given directly to an individual with the assistance of a facilitator by the application centre or may be administered by the application centre for the benefit of the individual.

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What are the stated criteria upon which the stated direct funds are allocated? Will the funds be based on existing services and supports currently available, or will the application centre, with the assistance of the facilitator/individual planner, seek out specialized services and supports more suited to the individual's needs? Might there not be a conflict between the services and supports offered by the application centre/agency and the demands of the individual?

To ensure that well-qualified, trained staff can be hired by the individual, they have to be paid a liveable wage compared to staff in service agencies. Will the bill ensure this?

Individuals/families enter into a direct contract with MCSS for funding. For this process to be fair and equitable, the individual, family or advocate should have the assistance of an independent planner/facilitator in order for them to exercise their legal capacity, so that decisions are made in an informed manner.

Independent planning/facilitation should be available for families/individuals once they are eligible for funds to continue the process and to ensure optimum choice and control.

Further capacity to appropriately serve adults with ASD must be developed in rural and northern Ontario regions in order for the funding of eligible individuals to be meaningfully utilized. If you don't have access to services, with people who are knowledgeable, in a region, it just puts you between a rock and a hard place.

Application centre and development of service profile: Under the bill, the service profile would have to satisfy

the provisions under the definition of "developmental disability." What are the qualifications of those working in application centres? Would they have had the training and education in ASD and Asperger's necessary for an appropriate understanding of the unique characteristics of this population? There should also be a process, using an independent third party, to appeal the ineligibility of an individual.

Regarding wait lists/prioritization, people's essential needs should not be addressed through wait lists and prioritization regarding "most needs" criteria. If application centres are premised on the inevitability of waiting lists, then they will never receive adequate funding. For equity and fairness, the focus should not be just on the neediest.

Without adequate funding, the majority of applicants will be denied service. Until legislation indicates that adults with developmental disabilities are entitled to treatments and supports that allow them to live with dignity in their communities, the challenges inherent in any wait list system will continue to create inequities, service decisions based on resources, and to ultimately rely on aging parents to be the backup and unfunded system of support for these vulnerable individuals.

Recognition of legal capacity/supported decision-making: The legal capacity of an individual should be recognized in the bill, along with providing supported decision-making with a planner or facilitator to ensure that people can enter into an agreement for direct funding without surrendering authority to a substitute decision-maker. Once the person with a disability is eligible and making the application, they should have whatever support is necessary in order for that person or family member to exercise their legal capacity to make decisions in an informed way.

With regard to inspections, we are pleased that the safety and security of adults with developmental disabilities is being protected via home inspections. The bill should ensure that any official entering the home of an adult with a developmental disability must secure a warrant based on reasonable assumptions of wrongdoing or serious neglect in the home. This should apply equally to all types of residences, including supported group home living residences, intensive support and people's private homes. We do have concerns about the potential conflict of interest if the people doing inspections are also employed by those running the home. The recent death of Tiffany Pinckney, a young adult with ASD left in the care of her family without monitoring, reminds us that no mechanism currently exists to keep such a tragic story from happening again in Ontario. There may be a role in this process for the Ombudsman.

Service profile: What will happen if the individual needs a service not available in their geographical area? Will an individual's service profile be updated regularly? Will the outcomes be measured to determine if the profile was accurate?

Regarding flexibility, once eligible funds are made available, they should not be denied if the individual

should want to use them in another accepted manner or if they move to another jurisdiction in Ontario.

Appeals: An appeal process independent of the application centre should be instituted, using an unbiased third party.

Finally, with regard to regulations, there should be an opportunity for public consultation when finalizing the regulations for Bill 77. The people establishing the regulations should have expertise in the full range of developmental disabilities, including autism spectrum disorders.

The Chair (Mr. Shafiq Qaadri): Thank you. We have about a minute and a half or so per side, beginning with the government. Mr. Levac.

Mr. Dave Levac: Thank you very much for your presentation. It was very thoughtful and logical thinking.

I'd like to ask a couple of very quick questions. Your indication of the entitlement to treatments—regarding waiting lists in hospital situations and settings, there's a triage that says that this person can wait longer than the other person because of the severity of the concern. Is there any kind of logic that you can accept in that case, because of the obvious resources—because if we spent millions and millions more dollars, we could lower the waiting list.

Ms. Margaret Spoelstra: Yes, absolutely. If someone is in a health crisis, that makes sense to us. But with autism spectrum disorders, when supports aren't in place, things can rapidly deteriorate and you'll find yourself spending phenomenal amounts of money to support the problem situation that arises.

Mr. Dave Levac: And my last question is on inspections. We give warrantless entry permission in many cases. We're doing that in Bill 50 for the SPCA. With permission of the person in the home, you can get a warrantless entry. Is that not a good thing to do? If you tell people you're getting a warrant, sometimes you can't get them as quickly as you want to, and other times you're alerting the person that there's trouble coming. My perspective, quite frankly, would be for the person who is being abused, that we need to get in there and catch them doing bad things to the client. That would be my interpretation. Could you see a way to accept warrantless entries if it was done in that manner?

Ms. Margaret Spoelstra: It could be, but I would suspect that in the cases for individuals such as Tiffany Pinckney, neglect is more the issue.

Mr. Dave Levac: It's long-lasting?

Ms. Margaret Spoelstra: Yes.

Mr. Dave Levac: Thank you.

The Chair (Mr. Shafiq Qaadri): Thank you, Mr. Levac. To the Conservative side, Ms. Elliott.

Mrs. Christine Elliott: Hello, Margaret. Thank you very much for your excellent presentation. You've really highlighted some of the concerns that have been brought forward with respect to this bill by several groups, particularly the role that's to be played by the application centres and the role of the independent third party facilitator, which of course is not provided for in this legislation. I hope that is something that will be clarified

in the course of these hearings because I would certainly agree with you that it's not just a simple transfer payment agency; it's going to be a matter of building a plan which includes many aspects of a person's life. You're building the life, not the service.

Ms. Margaret Spoelstra: Exactly.

Mrs. Christine Elliott: Thank you.

Mr. Michael Prue: Again, I question the thorny issue—down to wait lists. It's the first time I've ever seen those incorporated in a bill and I'm wondering what possible reason the government could have. Have they discussed with you why they're putting a wait list in a bill?

Ms. Margaret Spoelstra: It's a mystery to us. To even establish one in the language doesn't really make sense to us. There are people who all need these services.

Mr. Michael Prue: The government builds housing. I didn't see any wait list—although there is one for housing, I don't see it in any other bill. Will this have an impact on delivery of services if it is incorporated and becomes institutionalized?

Ms. Margaret Spoelstra: Yes. I think there will be people waiting and people who never receive services. That's currently the case. There are families who don't receive what they need for their adult children.

Mr. Michael Prue: We have heard from another deputant that there are 1,500 children with autism being served and 1,100 on a wait list. Is this tantamount to keeping this kind of thing going?

Ms. Margaret Spoelstra: And the numbers will just increase, particularly as these young people become adults. I can't even imagine—as we realize the higher rates at which the children are being referred in the schools and reflecting the prevalence rates of 1 in 150, we'll have even more people waiting for longer periods of time.

Mr. Michael Prue: What do you think they should do instead of having a wait list? We've had one suggestion that groups could come forward and ask for additional funding, such as happens in children's aid.

The Chair (Mr. Shafiq Qaadri): With respect, Mr. Prue, I'll have to intervene there. I'd like to thank you, Ms. Spoelstra, on behalf of the committee, for coming forward with your deputation from Autism Ontario, the provincial office, and for accepting the timing situation without protest.

Ms. Margaret Spoelstra: I could have protested.

ONTARIO AGENCIES SUPPORTING INDIVIDUALS WITH SPECIAL NEEDS

The Chair (Mr. Shafiq Qaadri): I'd now like to invite Tracy Bedford of OASIS. Ms. Bedford, please come forward. As you've seen, you have 15 minutes in which to make your presentation. I invite you to begin now.

Ms. Ann Kenney: I'm Ann Kenney from Community Living South Muskoka, representing OASIS. Tracy booked the appointment for us.

OASIS is a provincial organization representing 140 agencies that provide supports to individuals and families

in the developmental sector. OASIS agencies support approximately 35,000 individuals and their families, employing 26,000 full-time, part-time and casual staff and utilizing \$800 million in MCSS funding.

OASIS members are pleased to see the ministry moving forward with updating the legislation for the system of support for individuals with developmental disabilities. Particularly encouraging is the removal from the legislation of any reference to institutional care and, as a consequence, the discontinuation of the ministry as a direct service provider.

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The system envisioned is one which is fairer, levels the playing field and addresses the significant inconsistencies and resource inequities which have historical roots. The new system includes methods to more easily fund innovative approaches to the provision of support, and there is an emphasis on accountability for funds expended. There is intended to be greater consistency across the province, and this together with common tools will allow for the development of a better-planned and more easily managed provincial system. While there are some concerns with the concept of a waiting list being entrenched in the legislation, the intent to more systematically manage resources and demand for service is welcomed. There are attempts to make the transition as smooth as possible through grandparenting provisions, and this legislation signals to families that their concerns and viewpoints have been heard by the government.

There are a number of issues we would like to raise which we believe will make the legislation stronger.

The bill would be improved by the introduction of a preamble outlining the intent and values that are driving this legislation. This bill, by the very nature of legislation of this type, must contemplate the most extreme and difficult situations and address how they will be dealt with. This results in the legislation sounding particularly punitive and focused on enforcement and punishment. This could be balanced by the inclusion of a preamble with value statements, moral guidance, spirit of intentions, scope and purpose, etc. Not only would that assist in guiding in the development of regulations, it would clearly communicate the very purpose of the act and the vision for the social change that is taking place in this sector.

Of particular concern to us are issues related to the role and governance of the agency system, particularly as outlined in sections 30 and 31, which allow for takeovers, thereby negating the authority and responsibility of the directors of independently incorporated organizations. A system where options and choices exist for individuals and their families is dependent on services being available.

The not-for-profit system relies on community support and on volunteers willing to take on the responsibilities and accountabilities of managing these organizations through boards of directors. These community agencies have developed in response to local need, and the tremendous diversity of Ontario is reflected in their

individual bylaws, board composition, etc. We are very concerned that under Bill 77, as currently proposed, the province would have the authority to impose things like board composition on service agencies without regard for local differences. It is important to note that similar authority does not extend to application centres or third party providers within the legislation. Again, if the intent is provided, that might clarify why service agencies are the focus of this particular section.

There are a number of liability-related issues in the current draft of the bill. It is not clear where all of the liabilities lie in the case of third party agreements which flow through application centres. In the case of an appointed manager in a takeover situation, they are protected from any liability, but that is not the case for volunteers and staff managing the services on an ongoing basis. Given that the appointed manager is protected, it is unclear who is liable during a takeover situation.

Of particular concern is paragraph (c) of section 35(1), in which a person could be found guilty following a failure to comply with reporting requirements or quality assurance standards, even if the failure is unintentional. This might mean that a member of a board of directors could be held individually responsible for this transgression. We have a legal opinion that expresses concern that directors' liability insurance may not cover this particular situation.

As currently proposed, the legislation would appear to apply different standards for different types of service and employ different mechanisms depending on the method of funding, i.e., direct funding versus service agency. We are very supportive of the existence of clear standards for quality of care and believe that the same set of standards should be applied regardless of funding mechanism or service type. As currently drafted, the level of accountability appears higher for service agencies than any other part of the system. This will become a particularly difficult issue as third party and for-profit services become involved in the system and potentially have a lower level of standards to meet than service agencies.

The legislation is not entirely clear regarding the nature of relationships between various components of the system, especially the service agencies, application centres and third party providers. It would appear that the application centres may be setting priorities in isolation from the agencies providing service and the funding available. It is also not clear who will be providing assistance to families to make applications and who will receive funding to support the costs of managing this system. While much of this will be clarified through the drafting of regulations, the actual framework is somewhat confusing in regard to the role of the application centres. This confusion would be somewhat lessened if the act referred to "application process" rather than "application centre," moving the understanding to a series of activities rather than more narrowly defining it by a specific location.

In this sector, we have worked for years to move society's perception away from agency-operated group

homes where people are placed, toward an understanding that this is a person's home in which they live with supports, they make as many of their own decisions as possible and are assisted to do that, and they have the right to be fully engaged in community life. Therefore, we are extremely uncomfortable with subsection 27(2) of the act, which allows entry to an individual's home without warning. This indicates that people requiring significant support with daily living do not have the same rights to privacy afforded to all other members of society.

During 2007, the sector endured serious labour disputes which had significant implications for the very people being supported. Individuals had their homes picketed, relationships were damaged and trusts were broken. Given the nature of this sector and the vulnerability of many of the people supported, we believe the introduction of this bill provides a good opportunity to identify this as a no-strike sector, with provisions within the act to use alternative methods to deal with labour disputes.

We have been very supportive of the inclusive consultation which has occurred around the development of the transformation paper and the legislation. We are fully committed to continuing our work as partners with the ministry in developing the next phases of this process, including the regulations, policy directives and policy guidelines. We urge the ministry to lay out a clear process to ensure involvement of all stakeholders at the development phase of these important implementation pieces and to commit to broad-based consultation throughout the process. One quite successful approach is the one used by the Ministry of the Environment when they post information for feedback for a specified time period on the Internet. We strongly believe that the best results for the system will be achieved when stakeholders are involved right from the beginning in the development of these documents, rather than after they have been fully developed.

Bill 77 is quite silent on partnerships with other ministries and agencies such as LHINs, boards of education etc. While we understand that Bill 77 is only dealing with services funded by the Ministry of Community and Social Services for those individuals with developmental disabilities who are over 18, we remain concerned with the barriers this creates for families and communities attempting to do longer-term and more holistic planning. One clear example is that the government has divided responsibility between two ministries based on an age of 18, and each ministry is only responsible for its own segment of the population. What gets lost is the proactive transitional planning that can and should happen to ensure that the children and youth with developmental disabilities have a smooth transition into adulthood without having to start over with all new assessments, new plans etc.

There are a number of funding concerns which this proposed legislation raises. We are very supportive of the expanded definition of "eligibility" proposed in the bill to include individuals who need service but have been

excluded in the past. We do have concerns about the availability of additional funding to support these additional demands on the system.

Without knowing the implementation details related to application centres, it's hard to envision exactly what the system will look like and, consequently, what the costs will be. However, it is a concern that funding may be diverted from direct service to cover the administrative costs of processing applications, managing waiting lists etc.

It's not clear what the provisions will be for people currently receiving service. The legislation clearly indicates that their eligibility will be grandparented, but not necessarily their access, priority or level of service.

The act does include some internal appeals, which really involve a self-judgment process, whereby the organization making the original decision is also hearing the appeal. In other cases, appeals have to go the judicial route, which can be a lengthy, costly and quite inaccessible process. More equitable, transparent and fair would be a third party appeal mechanism for the various stages of decision-making that occur within the system. This would ensure that decisions are reviewed by an independent body and appeals are heard by a non-biased party. This body could also act as a processor of complaints and provide support for self-advocacy.

One concept that the bill is completely silent on is that of legal capacity. With the introduction of direct funding, there is an assumption that an individual has the capacity to enter into a contract. For some individuals, family members will be willing and able to take on this role, and for others, there will be no one available and that will mean that there is no access to this funding stream and the types of services which might be purchased with it.

OASIS looks forward to being an active participant in the modernizing of the developmental sector, being accountable to the individual and responding to their desire for a fair, equitable system providing for full citizenship within our communities.

The Chair (Mr. Shafiq Qaadri): Thank you. We have about a minute and a half per side, beginning with the Conservatives. Ms. Jones.

Ms. Sylvia Jones: You mentioned the need for a preamble in Bill 77, and you're not the first organization that has raised that. I know one group had talked about the UN convention on the rights. Can you tell me what you have in mind for OASIS?

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Ms. Ann Kenney: We didn't come up with any specific words, but we did feel that the ministry's intent around fairness, equitability, accessibility and accountability are words that should be there. But we also felt that it really gives value to the legislation and not just the punitive nature.

The Chair (Mr. Shafiq Qaadri): Thank you, Ms. Jones. Mr. Prue.

Mr. Michael Prue: If the government put in a preamble, how would it, then, be able to explain a wait list?

Ms. Ann Kenney: I think wait lists may be inevitable for anything. I don't think that we have enough funding to do everything for everyone in this province. I think in any sector you're in, there is a wait list.

Mr. Michael Prue: Okay, but if you put in a preamble setting a lot of lofty goals, you couldn't allow a piece of legislation to then have a wait list in it, or could you?

Ms. Ann Kenney: I think that the current legislation talks to eligibility, not entitlement.

Mr. Michael Prue: Okay. In terms of the issue of the application centres, other speakers have said it may be another level of bureaucracy, and they're not very comfortable with it. Do you see it that way?

Ms. Ann Kenney: It may be. It depends on how it rolls out. In some areas, it's currently working very well. One of the big concerns is how that would work in the north when places are so geographically diverse and there may only be one service provider existing. Would that then become duplication? That's also why we talk about an "application process." We believe the components that are identified as part of the application centre are very valuable.

Mr. Michael Prue: Thank you.

The Chair (Mr. Shafiq Qadri): Thank you, Mr. Prue. We'll move to the government side. Dr. Ramal.

Mr. Khalil Ramal: Even though the bill doesn't have a preamble, by defining developmental disabilities and eligibility, creating a single application assessment centre and providing funding directly to people, we believe as a government that that would define the aim and goal for this bill. You don't think it's enough for you and your organization?

Ms. Ann Kenney: I think we just found that the way it's written it becomes more punitive rather than embracing those goals. We do think that what the application centre is trying to do is a very lofty goal. The fact is that it will provide us with a way to actually identify the people who are waiting and assist them with what their needs are, and may give an ability to argue for more funding for the sector.

Mr. Khalil Ramal: Yes, but as we're doing it right now, we have so many different duplications across Ontario in terms of assessment. So you'd be assessed in this area and you'd be eligible, and maybe in a different area you're not eligible. By creating an application centre for assessment across Ontario, it would unify the standards and the way that people would be assessed. You don't think it's fair for the families and people with disabilities?

Ms. Ann Kenney: I think the new system is fair.

Mr. Khalil Ramal: Thank you.

The Chair (Mr. Shafiq Qadri): Thank you, Dr. Ramal.

Just before you depart, Ms. Kenney, the powers that be need to know if OASIS stands for something?

Ms. Ann Kenney: It stands for Ontario Agencies Supporting Individuals with Special Needs.

The Chair (Mr. Shafiq Qadri): We thank you deeply.

Ms. Ann Kenney: Thank you very much.

The Chair (Mr. Shafiq Qadri): Thank you for coming forward on behalf of OASIS.

COMMUNITY LIVING TORONTO

The Chair (Mr. Shafiq Qadri): I would now invite our next presenters to please come forward, Mr. Rick Strutt, president, and Mr. Bruce Rivers, CEO, of Community Living Ontario. Gentlemen, you've seen the protocol: You'll have 15 minutes in which to make your presentation. If you might just introduce yourselves for the purposes of Hansard recording. I'd invite you to begin now.

Mr. Rick Strutt: My name is Rick Strutt. I am the president of Community Living Toronto. I think you had mentioned it was Community Living Ontario. We're actually Community Living Toronto. Also presenting with me is our chief executive officer, Bruce Rivers.

For 60 years, Community Living Toronto has been a source of support for thousands of individuals who have a developmental disability and their families. Our association was formed in 1948, when a group of parents came together to find alternatives to placing their children in an institution. They formed the Parents Council for Retarded Children, and created the first community-based programs for children with a developmental disability.

Still true to that grassroots vision, we have grown into one of the largest organizations of its kind in North America, supporting almost 6,000 individuals and families in Toronto each year. Community Living Toronto has not only been a leader in developing innovative services that promote the full inclusion of adults and children in their communities, but also in finding ways to expand our capacity for service and collaborating with our community partners to create opportunities and resources for people in Toronto and across Ontario.

The introduction of Bill 77 marks a commendable step towards providing greater inclusion and choice for people with a developmental disability. We are pleased to offer feedback and input as the bill moves forward and a new foundation for the future is laid where individuals and families are more independent and involved in identifying the supports and services that they need to live fully within the community.

To capture this vision that will take us into the future, the bill should include a preamble that confirms the government's commitment to outline the entitlements and full inclusion of people with an intellectual disability. This preamble should describe the intent of the legislation and articulate that people with a developmental disability be recognized as valued citizens who ought to be supported financially and have the same opportunity to participate in all areas of life and community. A minimum standard that ensures a decent quality of life should be embedded in the legislation.

People with a developmental disability should not automatically enter our society's lowest income brackets. However, current guidelines within the ministry and the

Ontario disability support program have made this a reality for 80% of people with a developmental disability who receive income support. Maximum earning levels for people with an intellectual disability are 40% below current recognized poverty levels in Ontario. That is compounded by a 50% clawback of their job earnings. Legislation should protect people with a developmental disability from inevitably entering a cycle of poverty and ensure that they have every opportunity to earn a decent wage, save for retirement and enjoy a quality of life that comes with financial stability.

Community Living Toronto fully supports and advocates personal choice for people with a developmental disability, and direct funding is an important element of true choice and inclusion. People should be able to choose where they live, what they do during the day, who they spend their time with and, most importantly, who supports them in achieving their goals.

However, what works for an individual and their family at one point may not be true months or years down the road. Whether an individual or family chooses direct funding or a voucher system connecting them to a community agency, Bill 77 should clearly define a mechanism for individuals to switch streams without penalty or interruption of service. This will reflect true flexibility and ensure we are not limiting people's choices as their needs and lives change.

The legislation also needs to consider different funding approaches that are reflective of a person's networks and support circle. Those without natural family and connections may require higher levels of service. Further, funding should be portable so that if an individual or family moves to a different location in Ontario, they do not have to re-apply for funding.

For 60 years, Community Living Toronto has been a key presence in the lives of thousands of people with a developmental disability looking for support, direction, access to services and resources in the community. We've also worked to change bylaws, schooling and day-care options, and expand people's development into the arts. Agencies like ours are closely connected to our communities and the services and supports available within them and often provide a full range of services and supports beyond those funded by the government. The legislation needs to recognize the value and resources that agencies bring to the lives of people with a developmental disability and requires great clarification regarding the transfer of funding to the agencies as it becomes available. The bill should also outline a process for stabilizing these agencies during the period of transition that will inevitably follow the implementation of new legislation.

There is little in the legislation that refers to agencies except for various measures regarding compliance and accountability. It is important to remember that agencies are an essential part of a person's independence and skill development and comprise a fundamental part of an individual's support circle.

With three different funding streams outlined in the legislation, regulations are necessary for each, under-

standing that regulations for families may differ in nature from regulations for core services provided by agencies. We suggest that rules governing accountability and compliance around performance standards, program outcomes and quality assurance measures be broadened to include common elements regardless of the funding stream, with sections specific to each funding stream. Ultimately, this will ensure that everyone who receives public funding is held to the same level of accountability.

Bruce is now going to tell you about the collaborative model in Toronto and how this relates to creation of application centres.

1410

Mr. Bruce Rivers: Thanks, Rick.

To begin with, we are hopeful that the creation of application centres will help to streamline the process of identifying and applying for supports and services. There will be one access point for services and supports for people and their families, and it will be easier to track information, gather statistics and compile a centralized database.

For the past several months, Community Living Toronto was a pilot agency for testing the standardized application and assessment tool. Our experience with this pilot showed us that the single assessment tool will do a better job of ensuring access while promoting choice and flexibility for individuals and families across the province. All of these strengths will certainly make for a more transparent and modernized system; however, it will likely not result in increased services for people and their families.

In the city of Toronto, 32 partner agencies delivering developmental services have been working together to develop a collaborative approach to access and service delivery. This system has been in place now for over 10 years. It has connected individuals and families to services and supports while reducing duplication, streamlining access and ensuring that the supports and services meet those individuals' needs and goals.

I'd like to tell you about Sally. Sally is in her 40s and was living with her elderly parents in Peterborough. Her mother developed Alzheimer's and had to be moved to a nursing home. To ease the burden on her father, Sally and her father moved to Toronto to live in a self-contained apartment in her brother's house. However, shortly after the move, her father fell ill and joined his wife in the nursing home back in Peterborough.

Sally's brother, unable to support her both financially and physically, did not know where to turn. Unfamiliar with the sector, he was eventually connected to the integrated response system, the coordinated access to developmental services in Toronto that is known as the Toronto collaborative. When he applied for services, an interim support worker was assigned for up to 10 hours immediately. That person helped him connect to respite services, and also helped them apply for special services at home funding, which they then received.

After talking with Sally and realizing she wanted to live as independently as possible, she was placed on a

priority list for supported independent living. After close to a year, I'm happy to tell you that she is currently in the process of moving into a shared apartment with a roommate she has met and gets along with that is situated close to her brother.

The Toronto collaborative model has helped to reduce duplication. All information is entered into a single database that is shared between Toronto's 32 agencies. That increases service quality as staff have access to the same information. But it's more than keeping records and stats. Every person or family gets a visit from an interim coordinator or support worker who works at one of the 32 agencies to explain to them how the system works and to help them access funding as well as natural, community-based resources and respite. They're connected through this coordinator or support worker before they actually begin to receive what I would call formal services.

We believe that the success of the transformation in this legislation is contingent upon a framework that builds on the successes and strengths of the current system in Toronto as well as the rest of the collaborative efforts across Ontario, while emphasizing accountability to individuals and their families. We strongly recommend that Bill 77 recognize the value of collaborative approaches in moving towards transformation.

A proposed function of the application centres that would be best monitored by community agencies through their collaborative system is the management of wait lists. In Toronto, there are more than 2,700 people who are currently without day or residential supports.

I recently had the opportunity to meet two families who were on the wait list. Both were in crisis. One family from Mexico had recently come to Canada as refugees. While both families are on the wait list, they're not without service. The advantage of the collaborative model and the integrated response system in Toronto is that these families have been able to participate in family workshops and have received referrals to supported services at home as well as occupational and speech therapy. They're also receiving guidance and supports, sometimes from other families, as part of the parent network.

At Community Living Toronto and other agencies across Ontario, waiting on a list doesn't have to mean that an individual or family cannot receive some level of support. Agencies have extensive knowledge of resources available in the community and the individual can be supported to access those supports.

Community agencies also offer unique and innovative services to individuals and families that should be considered core services. Internet-based resources, like Community Living Toronto's connectability.ca website, offer online support, skill development, access to resources, tip sheets and professionals for families and individuals of all ages 24/7. Available for free to anyone with Internet access, it is a virtual community that expands capacity and connects people while they are waiting for funded services. When developing regulations on services and

supports funded by government, opportunities like connectability.ca ought to be considered.

When it comes to legislation and application centres, we suggest you keep it simple, focusing less on the structure and more on key functions and client outcomes. In these tough economic times, it is critical that we build on existing capacity like I've just described in Toronto. Assigning more functions to an application centre will require more staff and resources at a time when those are incredibly short.

Most of the functions of the application centres are already being provided through the current collaborative models. We recommend that application centres should be focused on determining eligibility, tracking data and waiting list statistics, while the actual management and co-ordination of wait lists and the provision of in-depth assessments be left to the community collaboration.

Finally, clear processes for designating application centres should be built into the legislation, along with a clear expectation that they not provide direct service.

Back to you, Rick.

Mr. Rick Strutt: There's nothing more frustrating than going through a detailed assessment process, only to sit for an indeterminate amount of time on a waiting list. There's also the likelihood that given the lengthy wait times, once the funding is available, the original assessment will no longer meet a person's needs.

In order to reduce stress on application centres, shorten wait lists, ease the frustration of people applying for support and expedite the application process, we recommend that there be a distinction between determining eligibility and providing assessments for individuals who are new to service. A shortened application process, followed by a full assessment only when funding is available, would reduce the strain on application centres. It would also result in more accurate assessments as people's needs and situations change.

For individuals who are already benefiting from services, it is expected they will continue to receive the same level of support. At the very least, the assessment process for these individuals should be shortened, as it is unlikely the application centres, especially in large metropolitan cities, will have the capacity to reassess the many individuals already receiving services.

The legislation should also include clear criteria for reassessment. Reassessment should occur only when a person's situation changes, and not be triggered by a shortage of resources. Community Living Toronto continually strives to ensure and extend the citizenship rights, entitlements and lifelong supports of individuals with an intellectual disability.

Central to all these rights is the notion that every individual should have the choice to make decisions pertaining to his or her life and to have personal control over how his or her life is conducted. We question whether the results of the assessment tool will be relevant to the person's life plan or whether the need for reassessment will be governed by the availability of resources.

Consideration must also be given to the changing needs of seniors with a developmental disability. Some individuals, such as those with Down syndrome, tend to age more quickly than the general population and have a much higher risk of diseases related to aging, such as Alzheimer's. Consideration for this group, who may very quickly realize a change in their situation and require an immediate reassessment, needs to be built into the legislation.

Person-directed planning is widely recognized as supporting a person in determining their goals: where they live, what they do during the day, who they spend their time with. People with a developmental disability are increasingly taking control over their lives. They are determining their life plan and drawing on a support circle of family, friends, community partners, volunteers and staff to support them in achieving their dreams.

Planning leads to a better quality of life, increased self-esteem and participation in the community. It is important that planning be built into the assessment process early on, before paid supports are identified and funding is allocated. Planning between the eligibility and assessment stage will result in more accurate funding and increased customer satisfaction.

The legislation—

The Chair (Mr. Shafiq Qadri): Thank you, gentlemen. Thank you, Mr. Strutt and Mr. Rivers, for your deputation and for coming forward on behalf of Community Living Toronto.

Mr. Bruce Rivers: We have a submission that we could bring forward.

The Chair (Mr. Shafiq Qadri): Please bring it forward and we'll have it copied and distributed to members of the committee.

OPPORTUNITIES MISSISSAUGA FOR 21 PLUS

The Chair (Mr. Shafiq Qadri): I'd now invite our next presenters to please come forward. They are Ronald Pruessen, chair, Sheila Swinton and Barbara Ashcroft, of Opportunities Mississauga for 21 Plus, OM21. Welcome to the members of OM21. As you've perhaps seen, you'll have 15 minutes in which to make your presentation, and I would invite you to please introduce yourselves individually for the purposes of Hansard recording. I would invite you to begin now. Incidentally, any written submissions, which you've already provided, thank you very much. Please begin.

1420

Mr. Ronald Pruessen: Thank you. I'm going to be joined by a couple of my colleagues in our organization to speak. Although there will be three of us speaking, I'm going to assure you that we're not planning to triple our 15 minutes, not that we'd get away with it, but that is not the intention at this point. I would also be anxious to refer to the fact that quite a number of our other members are in the overflow room next door, and it's good to have at least their virtual support behind us at this moment.

On behalf of Opportunities Mississauga for 21 Plus, we appreciate this chance to speak to your committee.

Our grassroots organization is eight years old and represents an ever-increasing number of Mississauga families—150 families by this point, in fact. We are the mothers, fathers, siblings and grandparents of young and middle-aged adults with developmental disabilities. In my own case, I am the father of a 31-year-old daughter, Caroline, who is both physically handicapped and intellectually disabled.

Our identity as family members is important, a contrast at least to the testimony I've been hearing over the last hour or so. Because of who we are, we have profound experience with developmental disabilities. Between us, our 150 families have more than 6,000 years of experience dealing with people with developmental disabilities—6,000 years of 24/7 experience. This gives us a special vantage point from which to consider Bill 77, and we have given the bill our close attention.

Our interest is an extension of our serious engagement with the entire transformation-of-services effort. The Honourable Sandra Pupatello, then Minister of Community and Social Services, announced the study and review process that helped to generate Bill 77 at our annual general meeting in 2004. We then participated in the public forums that led to the publication of the ministry's Opportunities and Action document. Indeed, we met several times with previous parliamentary assistant Ernie Parsons as that study was being prepared and met as well with the Honourable Madeleine Meilleur.

What does our personal experience and our organizational engagement lead us to see? We want to emphasize two components of our thinking: on one hand, praise and appreciation; on the other hand, the way in which our positive feelings are being restrained by some concerns and doubts.

Positive feelings deserve initial emphasis. Our families were struggling with the severe shortcomings of Ontario's programs for adults with developmental disabilities before the present government was elected. We know—we really know—how bad the problems were in the 1980s and 1990s. We remember all too well how carefully gathered evidence and clearly reasoned pleas for attention to long-neglected needs were met with callous indifference or empty words. To its great credit, this government has admirably replaced closed doors with open ones and has been gradually convincing many of our members that its heart is genuinely in the right place. Bill 77 suggests the possibility that more recently minted words do not have to simply float away on the wind. We extend our heartfelt thanks for this and say, "Well done—so far."

The "so far" is important. The "so far" in this praise brings us to the concerns and doubts that complicate our appreciation. As we look at Bill 77, our members are quite worried about what we see as elements of vagueness and incompleteness.

We would highlight two examples that are particularly important to us. Barb?

Ms. Barbara Ashcroft: First, we strongly believe, as we've heard presented today, that a milestone piece of

legislation like this should include a preamble that clearly identifies the rights of Ontario citizens with developmental disabilities.

I'm Barb Ashcroft, and I'm a member of the Retired Teachers of Ontario district 39 political action committee. We are supporting OM21. Our organization is advocating on behalf of seniors and aging parents who find themselves in great stress without sufficient support for residential and respite services for their adult children with developmental disabilities. The adult children of these parents are citizens for sure, and no one in this government would deny that. A bill that seeks to initiate more serious action in addressing the problems of this especially vulnerable group of citizens should clearly declare that they are entitled to minimum standards of care and support in key areas.

Through the Education Act, these people have always been entitled to programs and services without prioritization and waiting lists. School boards were expected to provide programs and services, and still are. We wonder why this kind of entitlement no longer exists after 21, when the individual's disability continues. Given the needs and vulnerabilities of this group of Ontario citizens, their right to appropriate housing and continued education supports should be declared.

Without an explicit recognition of rights, Bill 77 would lack an appropriate grounding as well as the standards against which progress can be measured.

Mr. Ronald Pruessen: Our organization's second concern with Bill 77 is the absence of budget information—the absence even of words about more abstract budget targets or a projected trajectory for improvements. Problems that have been profoundly neglected for decades cannot be solved without the provision of significant resources—new resources. Our 150 families know that, as do thousands of other families across the province.

We frankly would have preferred to have Bill 77 accompanied by budget information. If the budget details are going to come later, as seems to be the case, we have no choice but to be patient, as we have been patient for decades. But you need to be aware of the fact that we will be watching carefully to see what substantive life will be breathed into this bill. You have brought us to a moment where we now expect meaningful, real progress on the road you have encouraged us to chart with you—meaningful, real progress in particular on matters like respite and residential supports for the thousands of families who did not institutionalize children 20, 30, and 40 years ago, the thousands of aging families struggling with the strains and health problems produced by decades of exceptional responsibilities.

Ms. Sheila Swinton: I'd like to help you understand why respite and residential supports and funding are important to the caregivers. I am a caregiver. I have a 23-year-old daughter who is mentally challenged, does not speak, is not toilet-trained and needs constant supervision.

In many of our cases, our loved ones are stronger and more energetic than ourselves. Due to the nature of

behavioural variances that can and do result in crisis situations, we are often left physically and mentally drained. Also, due to the aging process of ourselves, we have less physical energy to deal with the physical demands required to care for our family members. Often, there is a very despairing and emotional strain as well from being constantly trapped because we cannot leave them unattended. Our every move has to be carefully planned and calculated in advance; for example, to do something as simple as go out to the store briefly, and then we have to pay someone just to do that. Also, due to our aging, there is a concern of who will take care of all these responsibilities when we can no longer do it, and we worry about when we are no longer here at all.

We desperately need the services related to respite and residential support. We already have in place an assessment process regarding this, and direct funding or service funding models are already in place, so we don't need to start over again regarding these areas, but we do need to expand funding so that new respite and residential facilities can be created. These are our main concerns.

Mr. Ronald Pruessen: It is a wonderful thing that you have worked with families and agencies to chart a road forward, but it is an achievement that now carries serious responsibilities with it. Do not imagine that the admiration that has been generated by the transformation effort to date will either linger or quietly fade away if words do not translate into deeds. There will almost surely be a whirlwind of disappointment and anger if the government sees the essentially preparatory provisions of Bill 77 as sufficient or if the government believes that the template or shell conceptualized in this bill will allow the transformation effort to quietly come to rest on a back burner.

Do not imagine, either, that tiny funding increases will allow achievement of a necessarily ambitious vision, especially if minimalist new funding is dedicated primarily to administrative procedures, application centres and the like. If this happens, then the template or the shell that Bill 77 is designed to create will be seen as the set-up for a shell game, and "shell game" will be a fair and loudly proclaimed label.

To conclude, we urge the government to continue as it has begun—to continue boldly as it has admirably begun. Take the splendid impulse to transform the services provided to Ontario citizens whose needs and vulnerabilities have been neglected for decades and match fine words with powerful actions.

For our part, we will continue to work and to offer praise, if you also continue. Families like ours are as ready as we have always been to help devise quality programs that are efficient and cost-effective. We are anxious, in fact, to pair community energies and resources with government resources to create services and opportunities that neither of us could create on our own.

Opportunities Mississauga, for example, has designed a transitional respite and residential program that would allow a group of 12 adults with developmental disabilities to receive significantly improved services with

the same dollars that would ordinarily support four. We do not, in other words, expect you to do this alone. Indeed, we do not want you to do this alone. But you must be prepared to go beyond words and administrative changes if partnerships are to succeed in solving very serious problems. What a wonderful achievement it would be to solve those problems. What a terrible failure it will be if you do not now move across the threshold on which you are poised. Thank you.

The Chair (Mr. Shafiq Qaadri): Thank you. About 30 seconds per side. Mr. Prue?

Mr. Michael Prue: That was quite brilliant. You didn't say anything, though, about how some jurisdictions in Europe actually give an allowance to families who keep their loved ones at home. There's nothing in this bill about that either. Has your group given any thought to that as a partial solution, or would it work?

Mr. Ronald Pruessen: I don't think we've given it extended thought. Our primary emphasis has been on developing a range of options, under the respite and residential headings in particular, although we began our work in the devising of day activity programs. A range of options that would take us far beyond what has been, to date, an awful lot of emphasis on supported independent living arrangements, which are admirable for those they are appropriate for, but huge numbers of families—

The Chair (Mr. Shafiq Qaadri): Thank you, Mr. Prue. To the government side. Mr. Delaney?

Mr. Bob Delaney: Thank you very much. Certainly, as a Mississauga member, I especially welcome you. I looked at your address; you're down in the Clarkson area, I think. Representing Meadowvale, Streetsville and Lisgar, I guess that explains why I haven't visited you.

Mr. Ronald Pruessen: Well, it would be a post office box you'd be visiting, anyways. But you're welcome to do so.

Mr. Bob Delaney: I guess you're aware that much of the funding decisions are made each year in the budget and that the government's 2007 budget committed an additional \$200 million over four years to the developmental services system. What's the relationship that you have with the staff in our area and—

The Chair (Mr. Shafiq Qaadri): Mr. Delaney, I'm sorry, the question will have to remain rhetorical for now. I'll change to Mrs. Elliott.

Mrs. Christine Elliott: I would like to thank you for your tremendous presentation, because the value of the family and caregivers' viewpoint is critical here. I certainly agree with you that what we have here is a piece of legislation with tremendous possibilities, but right now, there are large parts of it that are yet to be completed. That's part of our responsibility over on this side of the committee room, and I want you to know that we do take that very seriously. We do understand that the need is not only to make a life for your adult children, but also to know that you, as caregivers, are going to have your needs met; that after all of the years you've put in, you know your loved ones are going to be cared for. Maybe no one will ever care for them to the same degree

you do, as parents, but we recognize the responsibility to ensure that your children are cared for and given their appropriate place in our society, which is the same as everybody else.

The Chair (Mr. Shafiq Qaadri): Thanks, Opportunities Mississauga for 21 Plus, for your very well-received presentation.

FAMILIES FOR A SECURE FUTURE

The Chair (Mr. Shafiq Qaadri): I'd now invite, on behalf of the committee, our next presenter, Judith McGill, who's the executive director of Families for a Secure Future. Welcome, Ms. McGill. As you've seen, you have 15 minutes, start to finish. We invite you to begin now.

Ms. Judith McGill: I'd like to begin by thanking the Liberal government for all their work on developing the bill so far and all of you for your commitment to people with developmental disabilities in this province and your willingness to make this bill the best it can be, through extensive consultation.

My name is Judith McGill. I'm the executive director of Families for a Secure Future, which is a family-governed provincial organization that offers facilitation support to individuals with a developmental disability and their families. We're dedicated to ensuring that individuals have the support they need to take the next step in their lives, whatever that may mean.

We assist individuals and their families to re-imagine what's possible and how they might become full contributing citizens in their local communities. We take our direction, as facilitators, as much as possible from the individuals we support. We assist them in building their support network so they can make decisions in a supportive context. We support families to come together to learn and grow in family groups.

As a facilitator for over 15 years, I've personally supported many individuals and their families to manage their direct funding as well as helped individuals navigate the service system in order to get their needs met. Families are quite capable of doing the work of direct funding and have been for over 25 years.

I'm also speaking here today as a member of the coordinating team of the Individualized Funding Coalition for Ontario. The coalition represents several groups from across the sector. We're committed to self-determination of persons with disabilities. We believe all people should live with dignity and have control over their decisions concerning where they live, with whom they live, with whom they associate, and how they spend their lives. To this end, we believe it's imperative to build a funding system in Ontario whereby the person requiring assistance, supported as appropriate by family and/or significant others, has access to and control over the funds allocated for his or her supports.

This is, as you know, one of the key features of Bill 77, referred to as "direct funding." The Liberal government must be highly praised for finally establishing

direct funding as a bona fide choice for individuals with developmental disabilities and their families.

As a coalition, we have, over the past 10 years, played a pivotal role in informing the dialogue and providing research in this area, and we expect to do so in the future as it rolls out.

Finally, today I will speak primarily on behalf of the provincial ad hoc working group on Bill 77 that was pulled together in June and July to consider the impact this bill will have on individuals and their families. You each should have a copy—I guess it's being handed out now—with a full analysis of our recommendations and a summary of them.

As you've heard already today, there's a great deal of convergence between speakers, and I will deal with only a few of the recommendations in the report. Let me begin.

Once this bill is passed, we believe it's imperative that the government have an open and transparent consultation in regard to what will be the most significant aspect, and that is the regulations. We hope and suggest that that should involve families as much as possible. Families are ready and willing to consult.

Transformation is about much more than services; it's about supports for building a meaningful life where people can contribute and have relationships and have the support to build their personal networks.

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We believe it's critical for Bill 77 to consider a preamble that establishes the philosophical rationales for making the momentous changes that are being proposed and that clarifies the inherent legal rights of people with disabilities. A clearly stated articulation of the intent of Bill 77 will assist policy-makers into the future and will be the basis of giving clarity for all legal interpretations as we go forward.

Faced now with a wonderful opportunity to align ourselves with the UN declaration on the rights of persons with disabilities, we implore the government to consider finding ways to align this legislation with that international law. To that end, in our brief we have a number of ways to align it with the UN declaration as well as their stated transformation principles.

For direct funding—which we see as a pivotal piece and probably the most transformative part of the bill—to be a bona fide option, we suggest there are three main things that need to be addressed and addressed well: one, there must be a recognition of legal capacity; secondly, there must be accessibility and portability across the board; and thirdly, there must be a recognition of and provision for independent facilitation supports to be provided. I'll go through those three things that make this a bona fide option.

Firstly—and this will be dealt with more thoroughly by my colleague Orville Endicott of Community Living Ontario, who's next—it's an important aspect of any direct funding model that individuals be recognized as being able to direct their lives and the decisions that have great import in their lives. The UN declaration recognizes

the right of individuals to make decisions. We would like you to consider that in many jurisdictions in Canada and internationally, decisions are being made with high efficacy. The individuals are making decisions in supported decision-making contexts. You heard reference earlier to those contexts being personal support networks. Families for a Secure Future works in that way, as do many other family-governed organizations' facilitation models, where people make important decisions alongside of loved ones and those who have a continuity picture of their lives.

Accessibility and portability: It's been mentioned before, but the legislation doesn't actually embed that as a right. We believe it's fundamental to clearly state that anybody receiving a direct funding allocation has a right to have these dollars available to them if they choose to use it in any other way and with any other organization, or, in fact, if they move to another organization.

Thirdly, independent facilitation support: As you've heard this morning, there is no mention yet in Bill 77 of the need to offer independent facilitation and planning support to both individuals and their families. This kind of support is of benefit to both individuals and their families as they move forward, as they plan. And mostly, in this legislation, for direct funding to be a bona fide option, it will help if it's provided as an option. Once somebody is deemed eligible, it will actually be a prudent course, in that it will allow people to make a decision between the funding options and service options available.

Intentional provision of these supports enhances accountability, but it's critical for people not to be put on hold. People have mentioned the waiting lists. Providing independent facilitation support as a way of people beginning to build and unfold what it is they're meant to do and need to do in terms of what they experience and what their impairment dictates—all of those supports can be provided through a relationship with facilitators that can help map out the next step, with the family and the individual directing that process.

Facilitation services must be included in the bill, under professional services. We agree with CUPE, who spoke this morning, that there needs to be a guaranteed level of both support and services, and we perceive that to be a minimal support, being that of providing facilitation for guiding and mapping out the next step.

The provincial ad hoc working group on Bill 77 takes the position that provincial legislators must reconsider the prioritization mechanisms provided for in this bill. People's essential needs must simply not be addressed through waiting lists that are prioritized in terms of most-in-need criteria. Application centres are premised on the need for waiting lists, and Bill 77 sets out to legitimize waiting lists. It assumes that there will never be adequate funding to support individuals with developmental disabilities in this province and that some will not ever get the basic support that they need. This basic presumption must be challenged. If there is to be true equity and fairness in the sector, there must not be a focus solely on

those defined as most in need. Giving priority ranking to those considered most in need without adequately responding to a majority of others' needs is an issue of fundamental rights. As well, the use of waiting lists to deal with people's most essential needs has a discriminatory effect across the board.

We ask that ongoing independent facilitation and planning support be offered as a basic right to each and every individual with a developmental disability once they're deemed eligible. By offering this as a minimal provision of support once they're deemed eligible, the ministry will ensure that individuals are not severely disadvantaged as they wait for access to direct funding or supports.

We'd like to say something about application centres. Fundamentally, they must not be involved in direct service provision of any kind. The provincial ad hoc working group strongly cautions the ministry against setting out the specific functions of the application centres in legislation. It's far more appropriate to lay these out in regulations so that the changes can be made as the model develops over time and safeguards are implemented.

Allocations, as Michael Bach from CACL said, must remain with the government. We've laid out in our report that you'll be able to read a number of serious conflicts of interest that we perceive hold up the initial conceptualization, as it's stated in the bill, as far as application centres go.

We understand that the government undertook the application centres as a form of one-stop shopping to respond to families that asked for a simplification of this complex web of supports and services. We understand that, and yet, with the conflicts inherent in a service that has no separation of functions, we believe that there needs to be careful consideration of where the conflicts exist and working through those as the model evolves.

Finally, application centres: There's nothing in the bill that tells us how they'll be governed, how families and self-advocates might have impacts or guide the development of them in each of the regions.

We would also like to say, finally, two things about resource commitment; that is, how will any of this happen in a way that's adequate at all if there's no commitment in terms of budgetary moving forward, a sense that the unequal access direct funding in the past compared to agency doesn't just continue to evolve and continue? For direct funding to be a bona fide option, we have to address the severe wage disparity in this sector, where community contractors working with individuals are paid much less than agency sector staff, and we are in jeopardy of creating an under class of community workers who are paid 30% to 40% less than their agency peers. That needs to be addressed and it can only be addressed by putting money into the direct funding options.

The Chair (Mr. Shafiq Qaadri): Thank you, Ms. McGill. We have about 30 seconds per side. For the government, Dr. Ramal.

Mr. Khalil Ramal: Thank you very much for your presentation. It was a well-thought-out presentation. I

assure you we're going to take it under consideration and hopefully, after we've finished with the consultation across Ontario, you're going to find a good bill to serve the needs of the people of Ontario. Thank you.

1450

The Chair (Mr. Shafiq Qaadri): Thank you, Dr. Ramal. To Ms. Jones.

Ms. Sylvia Jones: Thank you, Ms. McGill. I wanted to touch on the planning and facilitation support because it's come up in a number of the previous presentations already. How long has that model been in existence in Ontario?

Ms. Judith McGill: I've been an independent facilitator now for 15 years and the Windsor model has been around now for just over 10. The significance is unencumbered, where we're not part of service models that may direct you in any way that matches with their priorities.

The Chair (Mr. Shafiq Qaadri): Mr. Prue.

Mr. Michael Prue: In your deputation, you seem to want to circumscribe the powers or authorities of the application centres. Other deputants have talked in terms of having them keep statistics and other minor things. Is that the role you see for them?

Ms. Judith McGill: Data management is one of the functions and we don't have any problem with that. We agree with the dual diagnosis presentation this morning in that we need to ensure privacy of information and abide by that act. I think what I tried to say is that the application centres shouldn't be too prescribed in the legislation, that that should be worked out in the—

The Chair (Mr. Shafiq Qaadri): With respect, I will have to intervene there. I thank you, Ms. McGill, for your contribution on behalf of Families for a Secure Future.

COMMUNITY LIVING ONTARIO

The Chair (Mr. Shafiq Qaadri): I would now like to invite, on behalf of Community Living Ontario, Dianne Garrels-Munro, president; Keith Powell, executive director; and Orville Endicott, legal counsel. As you've seen the protocol, you have 15 minutes in which to make your presentation, and please begin now.

Ms. Dianne Garrels-Munro: Thank you. Good afternoon. My name is Dianne Garrels-Munro and I am president of Community Living Ontario. With me today are Keith Powell, executive director of our association, and Orville Endicott, our legal counsel.

Community Living Ontario, with more than 12,000 members in 117 local associations across the province, is part of a national and international movement advocating for the citizenship rights of people who have an intellectual disability. Thank you for this opportunity to provide our thoughts on this important legislation that will replace the decades-old Developmental Services Act.

One of Bill 77's most important features is that it removes the legislative authority of the government to operate institutions. This provides the opportunity we have long been waiting for: for Ontario to take the next

step in creating truly inclusive societies. We applaud the government for adding provisions in the bill to allow for direct funding to those individuals and families who choose it. These significant changes signal a new era with respect to how our society perceives and supports people who have an intellectual disability. It will be an era in which persons who have intellectual disabilities are recognized as fellow citizens deserving of every opportunity for self-determination, inclusion and participation in Ontario society.

Community Living Ontario has developed 19 recommendations related to the proposed legislation. Our recommendations are provided in detail in our written brief and appendix, which we thank your clerk's office for making available to you today. Our limited time with you means that we can only provide a brief overview of the recommendations that we regard as being of particular importance.

We would first like to consider the title of the legislation, which speaks only to services, thereby setting a tone that is too reflective of our history rather than our future. Services do now and will continue to play a critical, important and positive role in providing support to many people who have an intellectual disability. However, the key aim of the transformation of Ontario's system of supports must be to continue the shift toward connecting people to the community while reducing the reliance on special segregated places and programs created for those with disabilities. Services and funding should be seen as important tools to support inclusion, but the end goal is life in the community. Recognizing that the title of the legislation plays an important role in setting the tone and intent of the legislation, we recommend the title of the act be changed to "An Act to enhance the social inclusion of persons who have an intellectual disability."

Further, the legislation would benefit from the addition of a preamble aimed at describing the social change that is intended by the legislation. Many of Ontario's statutes now include such a preamble. By clarifying that the legislation is meant to provide the supports that will enable people to have access to all areas of community life, we can more clearly understand the role that such supports must play in connecting people to life in the community, not placement in special services.

A central theme that ties together all of our recommendations with respect to Bill 77 is an idea that people who have an intellectual disability are capable of exercising control over their own lives when they are afforded the necessary supports. This is consistent with the principles enshrined in the United Nations Convention on the Rights of Persons with Disabilities, which came into effect May 3, 2008. Up to the end of July, 32 countries had ratified the convention. While it has not yet been ratified by Canada, we see this bill, if appropriately amended, as an important contribution by Ontario toward attaining the necessary national consensus to secure such ratification.

Article 12 of the UN convention says in part that "States Parties shall recognize that persons with dis-

abilities enjoy legal capacity on an equal basis with others in all aspects of life" and receive "the support they may require in exercising their legal capacity."

In accordance with this internationally recognized standard, it is recommended that Bill 77 include provisions to recognize the legal capacity of people who have an intellectual disability and to provide for supported decision-making in order to ensure that people can exercise their freedom of choice.

To ensure that people are afforded all the information they need to have control over decisions that affect their lives, we recommend that person-directed planning be added as a funded service that is available to all deemed eligible for support under this legislation. Such planning should be made available before a person completes or receives an application for services or funding. Such a provision could be truly transformative, as it sets an expectation that people will plan for life in the community, rather than in services, and that they will give due consideration to the support that is available to them from the community and their family before considering what support might be needed through government funding.

Much of Bill 77 pertains to the establishment of application centres through which people can access the supports and services they require. The application centres are intended to carry out a broad range of functions related to determining eligibility, applications, assessment of need, allocation of funding, placement in services, data collection, complaints review and measurement of outcomes. If all of these elements are to be delivered by a single body, a number of serious conflicts would occur.

The most serious of these conflicts would be that the body responsible for determining allocations to address individual needs would be the same body that would determine in the first place what those needs are. Such a structure, in light of the limited funding available in this sector, risks seriously distorting and under-reporting the needs of people seeking support.

In order to address potential conflicts in the application processes and to build on effective processes currently being used, the legislation should make clear the various elements that might be delivered by different bodies within a given region. This approach would build on existing mechanisms that are connected in such a way as to ensure easy access for people applying for the support while eliminating any potential for conflicts. To this end, the legislation should refer to an application process, rather than application centres. The responsibility for allocation of funding should remain a direct responsibility of the government.

The provisions in Bill 77 to legislate waiting lists are quite alarming, especially when considered in conjunction with the provisions for creating application centres that would shift many government responsibilities to an arm's-length third party. Taken together, these provisions appear to suggest that the government expects to systematically underfund the sector. We

recommend that the provisions in this act related to waiting lists be struck from the legislation and instead that the legislation be focused on strategies by which people can have their support needs met through realistic, person-centred planning and funding that is consistent with such plans.

Bill 77 contains little in the way of safeguards for people receiving supports and services, and we will now address a number of safeguards that we feel should be included.

1500

We would first look at the provisions that are needed to protect people against having the peace and security of their homes violated, as occurred during the strikes by social service agency workers that took place in various communities in the summer of 2007. It is simply intolerable that picketing should be permitted to inflict lasting harm on people who are not parties to labour disputes, as was the case during those strikes.

Community Living Ontario recommends that the developmental services be identified as a no-strike sector and that the provisions be established in legislation to create an arbitrated settlement mechanism to address future labour disputes such as those found in the Hospital Labour Disputes Arbitration Act.

Measures must be in place to ensure that individuals and families who choose the direct funding option are able to purchase quality support in the community. Such measures must include provisions that workers available for hire through direct funding will be paid a reasonable wage comparable to that of workers in service agencies. To ensure quality in the support provided by these workers, adequate training must be made available to all workers in the sector.

An individual's direct funding agreement should never be cancelled for reasons of misuse where direct funding was being managed by someone other than the individual, and where the individual is found to have not played a role in the misuse.

Furthermore, the act should clarify that a process be in place through which a person for whom direct funding has been involuntarily terminated can have the funding reinstated after meeting specified requirements.

We also believe that Bill 77 ought to include mechanisms that will help ensure that people with disabilities are not at risk of abuse and neglect by those who are trusted to provide care and support.

Persons who have been receiving support in the past have suffered terribly when these supports have subsequently been declined by caregivers. The tragic fate of Tiffany Pinckney, who was systematically starved to death by her sister after support services were rejected by the same sister, demands the creation of new safeguards. We recommend that Bill 77 be amended to mandate access to an individual when supports are declined, or on behalf of that person, in order to ensure that there is appropriate follow-up and oversight.

You will also see in our written submissions a cluster of recommendations that, if adopted, would authorize the

Ministry of Community and Social Services to make investments in strengthening the support services system in addition to funding supports to individuals. We have characterized these recommended investments under the heading "Community Development Initiatives," and they would include such things as promoting innovation and training, development of direct funding administration models and the encouragement of advocacy groups and networks.

Finally, recognizing that an inordinate number of issues related to Bill 77 are being left to be dealt with through regulations and policy directives, we ask that your committee make clear its expectations that the public will be fully consulted on the development of the regulatory framework for the legislation before the government completes the process of drafting and adopting regulations and policy directives. Such an expectation should be written into the act.

We applaud the government for its work on transformation and providing this opportunity for consideration of a new legislative framework. We offer all the support we can provide in ensuring that the implications of this legislation are fully considered. We encourage you to review our written brief, which outlines the specific actions that we feel must be taken with respect to each of the recommendations.

Thank you for your attention to our suggestions. We would now welcome any questions you may have.

The Chair (Mr. Shafiq Qadri): Thank you. We have about a minute per side. Ms. Jones.

Ms. Sylvia Jones: I am curious because the application centres and the questions surrounding them is a recurring theme. You mention that there are too many roles for the application centres. Would you give your advice to the committee as to which things you would like to see removed from the application centre?

Ms. Dianne Garrels-Munro: I'm not sure that we want anything actually removed; we just don't want it being one body that is covering it. You need two or three—

Ms. Sylvia Jones: So as an example, would the appeal process be one aspect that should not be part of the application centre? Or do you have—

Ms. Dianne Garrels-Munro: I'm going to turn it over to Keith Powell.

Mr. Keith Powell: One of the things that we need to recognize is that currently, and as would be the case if the application centres were created as proposed, the government has a responsibility to be both a steward of the public dollar and a steward of the public good. We've identified that, as proposed, an application centre would be in conflict around those two responsibilities. Therefore, the decisions that relate to planning and identification of needs are better done by the community and the experts. The government should not put itself in a conflict position—

The Chair (Mr. Shafiq Qadri): Thank you, Ms. Jones. Mr. Prue?

Mr. Michael Prue: I think you're answering that quite well. Keep going.

Mr. Keith Powell: So the issue here is to come up with a model that ensures that the 30 or 40 years of wisdom about how to support individuals who have intellectual disabilities—wisdom that's in agencies, in the ministry and in families—can apply itself to the process of attaching public dollars and voluntary support to individuals. Government has to avoid creating a body, or itself being in conflict over how much money is necessary from the public purse, to ensure that in addition to natural supports, there's adequate support for an individual, as identified in their plan.

Mr. Michael Prue: Thank you very much.

Mr. Khalil Ramal: Thank you very much for your presentation, Dianne. You mentioned there shouldn't be an application centre, but there should be an application process. In your mind, what's the difference between a centre and a process?

Ms. Dianne Garrels-Munro: I'm going to turn to my colleague, Orville.

Mr. Orville Endicott: I'm not sure that I'm the best person to deal with this. As quickly as I can, I think, as Keith said, we want to make sure that existing processes are not swept away and replaced by something that inevitably is bureaucratic. If it's given all of the authority that Bill 77 now gives it, it's going to be conflicted.

Mr. Khalil Ramal: We heard, too, many people this morning before this committee mention that it should be an independent application centre, not tied to organizational agencies, to make sure transparency and accountability are in place. What do you think about this?

Mr. Keith Powell: I think it gets back to the point I made a few moments ago. It is critical that the support that's available to a person and the plan for their life that comes into place is one developed by the community and families—

The Chair (Mr. Shafiq Qadri): With respect, I will have to intervene there. I would like to thank, first of all, Dr. Ramal, but also, for your representation on behalf of Community Living Ontario, Ms. Garrels-Munro, Mr. Powell and Mr. Endicott.

PEOPLE FIRST OF ONTARIO

The Chair (Mr. Shafiq Qadri): We will now move to our next presenters, who are Barbara Fowke, president, and Kory Earle, member, of People First of Ontario.

Interjection.

The Chair (Mr. Shafiq Qadri): Sure, we'll have that distributed for you.

Welcome, and please be seated. I'd invite you to begin. As you've seen, you have 15 minutes in which to make your combined presentation. Please begin.

Ms. Barbara Fowke: Hello. My name is Barb Fowke and I am the president of People First of Ontario. I am here with Kory Earle of our board to talk about People First's concerns.

First, I would like to talk about who we are and why you need to hear from us. People First of Ontario is a

province-wide organization made up of, and run by, people who have been labelled with a developmental disability. We want all people to be treated equal. We want others to see us as people first, not disabled people. We want to be included in all areas in the community, not excluded in schools, institutions or in our social activities. We want to have the support that we need to be fully included in the Ontario communities that we live in.

We are pleased that the government of Ontario recognizes that changes have to be made in order to give people who are labelled more choice and control over their lives. Although we realize that the current act, the Developmental Services Act, is 35 years old and outdated, we know that once this new act is in place, it too will be around for a long time. This new act will affect us more than anybody else on a day-to-day basis.

This is why we need to say our concerns at this important point and demand that they be heard. This is also why we were so surprised, disappointed, and some of us were even sad, when we heard that People First of Ontario was not selected to make an in-person presentation. The government people who decided who would participate in the conference call made us feel that we were less important than service agencies, when we know we are the most important group to hear from. It also shows us that you do not understand much about who we are. People labelled with a developmental disability have problems communicating in a conference call. In person is the best way we can meet and talk about our needs.

Now Kory is going to talk about some of our problems with the act.

1510

Mr. Kory Earle: Thank you. Here are the things that we are concerned about.

Concerns around inspections: We are worried that inspectors will be able to go into people's homes without any notice. We understand that if someone is being hurt or abused, this is a good thing, but what the government has to realize is that our homes are private and personal spaces, just like your homes are. If the government inspectors can come into a person's home unannounced and look at paperwork, at belongings, and ask questions, this goes against our human rights. This is no different than when striking workers picketed in front of people's homes last summer in Ontario.

A government officer is not able to just walk into a non-disabled person's home without legal documents, so why can they do this in our homes? We think that an inspector needs to have a legal document, like a warrant, that explains that they have a good reason to come in before entering our homes.

Concerns around definitions: We are concerned about some of the definitions in the proposed new act. For example, what does the act mean by "family"? We have to remember that many people with developmental disabilities do not have families. Our concern is if we do not have a family member to help us set up our funding and supports, who will help us? The act cannot forget people who do not have families.

Also, the new definition of developmental disability is very medical. The new intensity scale is also very medical. It worries us that the amount of supports and funding you might get is based on your level of need—and people who will be getting trained across the province on how to deliver this test. We fear that we may go back into the Ministry of Health as sick people instead of people who need supports to live in their communities.

We want to make better lives for ourselves, just like you. Our dreams are not just based on our level of disability. Our dreams and needs are bigger. We want to work in stores, go to college, be poets and actors, have real friends, volunteer and take dancing lessons. These are the kinds of things we need support for from the whole community. We want to be seen as individuals, with individual needs for supports to make our dreams come true.

There is not enough on supporting people to live in the community. If we are seen as individuals, there will be more community-level planning. There is nothing much in this new act that talks about planning for our lives in the community. For example, do we have to be in a group home to receive services or supports? We want to be supported in the community with people of our own choice and supported to make our own decisions.

The new act spends a lot of time talking about agencies and services. For example, the act talks about waiting lists for services. We would rather it talked about having our support needs met through ideas such as person-directed planning or supported decision-making. The ministry talks about citizenship, but unless this act helps us plan towards life in the community just like everyone else, how can we be true citizens?

Concerns around the application centre process: We have many concerns with the idea of the application centres. The application centres decide who is eligible or whether you have a developmental disability and whether or not you sit on a waiting list, etc. What happens to the people who need the supports but are not seen as a priority by the application centres?

Transportation to one access application centre in large regions is also a big concern. Because a person's eligibility is determined by these application centres, they must be accessible to everybody. In rural and northern communities, this is difficult.

It seems like the application centres have a lot of rules and authority and can therefore put us in a vulnerable situation. We agree with Community Living Ontario: The act should talk about the application process, not centres.

Now I'll pass it back to Barbara.

Ms. Barbara Fowke: Threat to our rights: There is nothing in the act that talks about what people are entitled to or have a right to. Again, we can't talk about citizenship unless we talk about rights. We worry about our rights as citizens, for example, when the act talks about personal information. The ministry has the right to collect information for anyone applying for supports and funding. This means that our personal information is in a computer. Where that information will go and where it can end up is not clear to us.

Threat to people having a voice and being independent: One of the most important things People First does is assist people who are labelled to have a voice and be heard. We need to be supported, however, in order to have a strong voice. We should have an adviser to read through anything before we sign it. An adviser is someone we trust and feel comfortable with. An adviser does not make decisions for us. We need an adviser in order to help us get supports.

Direct funding is something we think is very good, but without support to understand agreements, we can be very vulnerable once again. We are very vulnerable in signing agreements we don't understand and hiring the wrong people.

We had hoped that the government changes would give people who are labelled with a developmental disability a greater voice and more power and control over their lives. But it seems that through this act people have little control, agencies have more control, and the application centre and government will have tons of power, control and authority. We are very worried about this.

The government really needs to remember we are the ones directly affected by the proposed changes to this act. At the end of the day, government people and agency staff go home to a life that they have tried to make good. We go home to what we have been able to get. The more this act and the government of Ontario begin to see us as individuals who want to live in the community with proper supports, the better that home and life will be.

Thank you for letting our voice be heard.

The Chair (Mr. Shafiq Qadri): Thank you very much to you both. We'll start with the NDP—about a minute and a half per side. Mr. Prue.

Mr. Michael Prue: You two are concerned about the application centres. Can you tell us what you want to see instead of those application centres?

Ms. Barbara Fowke: I'm not sure.

Mr. Kory Earle: The only thing we can really do is go back to the board of Ontario, which is coming up, and ask them what suggestions we would like to make—

Ms. Barbara Fowke: That's the only thing.

Mr. Kory Earle: —to the government, because at the end of the day, this will affect People First more than any agencies out there.

Ms. Barbara Fowke: We can certainly talk about that on our board.

Mr. Michael Prue: The two of you are obviously very successful living in the community, I can tell.

You didn't say anything about this, but another group did earlier, and I didn't have a chance to ask them the question. They were very troubled that the government claws back money from people who work in the community and thought that it was forcing people to live in poverty. Does People First have that same opinion, that the government shouldn't be clawing back the extra money that you earn?

Ms. Barbara Fowke: My personal opinion is that people from People First do get worried about something like that. I'm not sure, but I think People First does get worried about that.

The Chair (Mr. Shafiq Qaadri): With respect, I'll now turn it to the government side. Dr. Ramal.

Mr. Khalil Ramal: Thank you very much for your presentation. I want to echo my friend Mr. Prue: You're doing well to address your issues. You raised some concerns about someone entering your house to inspect it without any warrant. I think the bill was clear about it. If you live in your own home and not a business centre, you wouldn't be subject to this section of the bill.

1520

Secondly, you seem worried about the application centre and you referenced Community Living Ontario, which wants to distinguish between an application centre and an application process. Mr. Prue asked that question here, what's the difference between an application centre and the process. But since you are receiving the service, why do you have to worry about those application centres? You're already eligible for the service and support. So can you explain to me why you raised this issue?

Mr. Kory Earle: The reason why the issue is raised is because you have to remember that there are a lot of people involved at People First who may not have the proper supports that they require. You have to remember that they also go through the application process. They still have to go—

The Chair (Mr. Shafiq Qaadri): With apologies again, I'll need to intervene. To the Conservative side, Ms. Jones.

Ms. Sylvia Jones: Thank you. I'm glad we were able to fit you in today. You both mentioned the need for planning and the need for advisers, particularly when you're dealing with direct funding. Do you currently use an adviser?

Ms. Barbara Fowke: In People First, we do. Most people do because people like me or other people don't understand plain language and so they need people to explain things to others in plain language about what's happening, otherwise people like me would get very lost. Plain language is very important.

Ms. Sylvia Jones: So it's worked for you.

Ms. Barbara Fowke: But we do need advisers to help us work things through, like these things, like the papers.

Ms. Sylvia Jones: Thank you.

Mr. Kory Earle: It's very important.

Ms. Barbara Fowke: Yes.

The Chair (Mr. Shafiq Qaadri): Thank you, Ms. Jones, and thank you to you, Ms. Fowke and Mr. Earle on behalf of People First of Ontario. Thank you for your deputation, written materials and for coming forward.

A CIRCLE OF SUPPORT

OAKDALE CHILD AND FAMILY SERVICE

The Chair (Mr. Shafiq Qaadri): I'd now invite our final presenters of today, Andrea Rifkin, member of the Ontario Association for Residences Treating Youth, and representing A Circle of Support; Oakdale Child and Family Services and colleague. I invite you to please be

seated. And as you've seen, you have 15 minutes in which to make your combined presentation. If you might just introduce yourselves individually, please begin.

Ms. Andrea Rifkin: Thank you. I'm Andrea Rifkin from A Circle of Support and beside me is Lisa Bache from Oakdale Child and Family Services. Together, our agencies serve a total of 100 young people with disabilities, all of whom would fit a description of complex care needs. These special folks come into our care as children and generally remain with us as adults, largely because they are so very much a part of our family group and because without an appropriate alternative as they become adults, they remain in our care.

Thank you for this opportunity and privilege to participate and to be here to speak for those who cannot speak for themselves in this debate.

It is my pleasure to comment on Bill 77, the Services for Persons with Developmental Disabilities Act. The introduction of Bill 77 builds on the government's commitment to making Ontario inclusive for people with disabilities and, as such, we support the sensibility of the bill. After all, both Lisa and I have promoted this notion of inclusion with our young people in the community for over two decades.

We are aware of many of the concerns presented so far, and that will be entertained in the process later, and we want today to highlight some of the concerns that we have not seen expressed to date.

Empirically supported, 38% of individuals with a developmental disability have a dual diagnosis. All individuals in the disability services sector are challenging to manage and require compassionate and sophisticated care. People with dual diagnoses have complex care needs that require services across sectors including, but not limited to, developmental, health and mental health services.

Here are some concerns with Bill 77 which we would like to share with you today.

(1) In this bill, application centres are tasked with managing the client's case, assessing the condition, determining funding, as well as providing services to the individual. In effect, it's operating as a multi-service centre. Currently, Prescott-Russell is a pilot project for the amalgamation of child welfare and protection and developmental services under this similar umbrella system of care for children. Similar systems are being implemented in Lennox and Addington and Niagara Falls. Giving one group or organization the ability to be responsible for the assessment, treatment, funding and accountability is not the best model for the person in care. The proposed model replicates exactly what is flawed in the child welfare system, with the relationship of children's aid societies and the private sector caregivers. Our recommendation, therefore, would be that assessment, funding allotment and service provision should be separated. This would allow for the accountability to be judged or determined by an independent third party. The resources would be funded directly through community and social services or a third party agency, like a community network service. An example of the direct

funding model could be that a case management agency would hold the case, a service agency would hold the care of the individual, and a third party agency would monitor the resources, standards, accountability and outcomes of all cases.

(2) Many important details of Bill 77 and how it will operate on the ground are unknown at this time and will have to be specified in regulation and/or policy. One of the enormously significant details concerns the qualifications of the persons who would conduct the assessments and the methods and criteria that they would employ. Assessment methods are of immense concern to our families and to the professionals and paraprofessionals who provide service to individuals with developmental disabilities. Our recommendation is to establish a clear set of criteria and specifications for what the qualifications would be for the professionals who would be providing the assessments. We believe these employment criteria should be set centrally and not vary substantially across the province. We do understand, though, that there would be some cultural considerations that may be reflected in the composition of the staff.

(3) Regarding sections 26 to 28, which allow for inspections of the premises of the service agencies, our comment and concern is that the current practice that we see is not ideal. Our recommendation would be to implement a uniform skill set across the province for inspectors and a uniform code of conduct, to be set centrally.

(4) Accreditation standards were not detailed in Bill 77. However, accreditation is necessary as a quality control mechanism. Our recommendation is that we insist that service providers be accredited and ensure that accreditation is carried out by a distinct third party group—CARF would be an example of one of these groups—rather than a peer review system which leaves the system open to misuse and abuse.

(5) Section 22 notes, “A service agency shall comply with any prescribed requirements with respect to the operation of the agency, including any requirements relating to the composition of its board of directors...” The director may appoint inspectors who are able to set standards for service providers and their boards of directors. The inherent problem here, from my perspective, is that there are a significant number of private sector providers who offer much-needed services, and I will say truly exemplary services, but do not have a board of directors. Therefore, these operators are excluded from participating in the developmental services framework as conceived of in Bill 77. We would like to think that this was not the intent of the bill, to exclude such valuable resources. Therefore, our recommendation would be that consideration is given to service providers of all sizes for the efficacy of the legislation.

I think that’s a nice segue to some further comments from my colleague, Lisa Bache. I’m hopeful that we’ve allowed for some time for questions you may have of us.

1530

Ms. Lisa Bache: My name is Lisa Bache. I wish to take this opportunity to speak as a service provider for

the most vulnerable persons and also speak on behalf of my colleagues.

I am the administrator and founder of Oakdale Child and Family Service—since 1973. We are a private children’s residential service with facilities in Toronto, Stouffville and Barrie. In 1976, we established the first residential service for children with autism in Toronto as an independent operator. Our children and adults are developmentally challenged and/or have autism. They need structure, life skills training and community integration.

When they became adults, there were few adult settings to be transferred to, and therefore we had to develop adult programming within our facilities. Age-appropriate residences were established to separate the adults from the children’s programming. Throughout the years, my colleagues and I have expressed a desire to be part of the adult system. We hope and trust that Bill 77 will provide the private residential services with this opportunity. For over 20 years we have provided guidance, work experience outside of the residences and other important adult programming. Some care providers have created their own day programs geared for special needs.

As the government creates more adult homes and our former children are moving out, it is important to concentrate on those clients where a departure from the residence is devastating—adults who have, throughout the years, formed relationships with caring, professional staff, found security and happiness. They cannot understand why they have to leave. It applies especially to clients who have no family and call their residence their home. The familiarity of the environment, staff attachment as family and acceptance in the neighbourhood throughout the years should not be threatened due to repatriation.

They cannot speak for themselves and depend very much on all of us to make the right decision for their future and well-being. Some clients came to us as very young children and have no families. Now they are over 30 years old and our setting is the only family they know. We were asked to continue to serve the over-18-year-old population due to the mentioned lack of adult facilities. We have responded and created adult housing and programming. Our staff are dedicated, committed and long-time employees with professional backgrounds.

I am, therefore, appealing to the government to make provisions in Bill 77 to allow the residential service providers to continue caring for these adults who would be devastated and heartbroken by a move. Just before I came here, I heard that two of our adults, who came to us as little children and have been with us for 25 years now, are being considered to move out. My heart just aches for them, so I’m here to say please, we have to be compassionate and caring for those people.

Oakdale is a founding member of OARTY, which stands for Ontario Association for Residences Treating Youth. OARTY is well known by the Ministry of Community and Social Services and has a good working relationship with all government agencies.

I trust that my demonstrations will have a positive outcome and thank you for allowing me to speak on behalf of those people who are dependent on us to make the right decision for their well-being. Thank you.

The Chair (Mr. Shafiq Qaadri): Thank you. We have less than a minute per side. To the government. Dr. Ramal.

Mr. Khalil Ramal: Thank you very much for your presentation. Many people spoke about the application centres. It seems to me everyone has a different approach to them. Hopefully, when we collect all these approaches, we'll come up with a fine one to please the majority of the people. Thank you.

The Chair (Mr. Shafiq Qaadri): Thank you. We'll move to the Conservative side. Ms. Elliott.

Mrs. Christine Elliott: I'd like to thank you very much for your presentation. Clearly, you have many years of experience in dealing with special-needs adults, and I think some of the points you've made are very well taken, especially with respect to the separation of the assessment, the service, the allotment of funding and the service provision. We have heard about that, as you may know, from many presenters this afternoon. I think it's a point very well taken. We'll certainly take it into consideration in our deliberations.

The Chair (Mr. Shafiq Qaadri): Thank you, Ms. Elliott. Mr. Prue.

Mr. Michael Prue: I just want to fully understand the statement you made about people being forced out of their residences.

Ms. Lisa Bache: Yes.

Mr. Michael Prue: Can you explain in one minute what that really means? What's happening to them?

Ms. Lisa Bache: Well, as a children's residence, we are not usually permitted to serve adults, but due to the lack of adult facilities, we were asked to continue servicing these adults. Now that the government has made available more funding to create adult homes, they are being moved out, and it's like tearing them away from a family. This is what the situation is right now.

Mr. Michael Prue: So they've turned 18, and they're being forced to move on?

Ms. Lisa Bache: Yes, and the only reason we have so many adults now is because before there was a lack of adult services in the government. Now there has been money made available, and they are to move out. This is very heartbreaking for many of our clients.

Mr. Michael Prue: I can understand. Thank you.

The Chair (Mr. Shafiq Qaadri): Thank you, Mr. Prue, and thanks to you, Ms. Bache and Ms. Rifkin, for your presentation on behalf of A Circle of Support and the Oakdale Child and Family Service.

If there's no further business before the committee, I'd just remind you that your transportation will be leaving from the main entrance of Queen's Park at 4:30 p.m. today.

This committee stands adjourned till the London, Ontario, reconvening.

The committee adjourned at 1537.

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