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Wednesday 6 August 2008

Journal des débats (Hansard)

Mercredi 6 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 POLICY**

**COMITÉ PERMANENT DE
LA POLITIQUE SOCIALE**

Wednesday 6 August 2008

Mercredi 6 août 2008

The committee met at 0904 in the Sheraton Four Points, London.

**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.

The Clerk of the Committee (Mr. Katch Koch): Good morning, honourable members. It is my duty to call upon you to elect an Acting Chair. Are there any nominations?

Mrs. Christine Elliott: I'd like to nominate Mrs. Van Bommel as the Acting Chair.

The Clerk of the Committee (Mr. Katch Koch): Mrs. Van Bommel, do you accept the nomination?

Mrs. Maria Van Bommel: I do.

The Clerk of the Committee (Mr. Katch Koch): Any other nominations? There being none, I declare Mrs. Van Bommel elected as Acting Chair.

The Acting Chair (Mrs. Maria Van Bommel): Good morning, everyone. I'd like to call this hearing to order. This is a hearing into Bill 77, An Act to provide services to persons with developmental disabilities, to repeal the Developmental Services Act and to amend certain other statutes.

The proceedings are being recorded for Hansard, so for anyone who wants to speak, all comments will be on the Hansard record. There is also simultaneous interpretation available for anyone who needs it. One of our interpreters is in the booth there.

0910

FRED BLAKE

The Acting Chair (Mrs. Maria Van Bommel): At this point, I'd like to call our first witness to the table, and that is Fred Blake.

Welcome. I would like you to introduce yourself for the Hansard record. You have 15 minutes to make your presentation. You can use up the entire 15 minutes for that presentation, or if there is time left, we will have an opportunity for the members of the committee to make comments or ask questions. If you would like to start, please do.

Mr. Fred Blake: My name is Fred Blake. I live here in London, Ontario, and I am the proud father of a 28-year-old developmentally challenged adult. The good news, I guess, is that my son Stephen is on the bright end of the spectrum. He's bus-trainable. He's quite independent.

Just so that we're sure that we're not afraid of change, when we lived in Windsor, Ontario, we were involved in one of the first programs at Forest Glade elementary school in Windsor for half-day inclusion in regular class and a half-day separation for life-training skills. When we moved here to London, he was at Saunders Secondary School. He graduated from Saunders Secondary School, obviously, at age 21. Also at that school, he had some employment opportunities in the community.

I would like to focus on the employment opportunities for Stephen, and how I see whether Bill 77 would help that or not. After his graduation, I was proud to aid Community Living London in lobbying MP Joe Fontana and my own MP, Susan Barnes, for transition funding, which was extra funding that allowed Stephen to be placed in Plastic Packaging, which is what we call a sheltered workshop. I guess that's the term for it. It's run by Community Living London. Another workshop that they run where he is currently is Opp Art. He probably would never have got the opportunity, immediately after graduation, to be in those workshops absent that transition funding. In addition to having a place to go which he calls work, he also has had some employment opportunities in the community, at some gas bars and restaurants, mostly seasonal, mostly temporary, mostly part-time. But he has had some opportunities because of the skills he's learned and because of the support he's had through Community Living London.

What does Stephen have today? He has a place to go five days a week where he works at Opp Art. They have a contract there to do some gas meters, which he's quite proud to perform. He also has a part-time job at a dentist's office not far from the workshop doing some groundskeeping. Again, it's seasonal; obviously in the

winter that's going to end, but he does have a part-time employment opportunity.

What I can't emphasize enough is that he really has no concept of that cheque, how much money it is, what it means. It's self-esteem. Even though he's working like that, he knows he's different. We get the questions all the time. "What's going to happen later? Why am I not like my brother?" so on and so on. It's very tough.

Again, he's had some opportunities through Community Living London. Why, you might ask, has it not been a complete success? Why is he not employed totally? Why does he still have to depend on the workshops? I would say specifically to you that there is not enough staff to support him in the employment opportunities. There are not enough employers in this community identified as being willing to employ people like my son. It's amazing how far we can go for physical disabilities and the accommodations we make for them. There don't seem to be the same opportunities for mentally challenged persons. Very high turnover of staff: He seems to be working with different people all the time.

But I have to say I am one of the lucky ones, we really are, because he has had those opportunities. He still has a place to go five days a week to work, he has some self-esteem and he is somewhat occupied. I have to tell you that, without Community Living London, he wouldn't have it; he would not have any of this.

So what happens if I was a person who had to access some direct funding, which, in my understanding, is one of the options in this bill? I have no idea where my wife or I would go to hire somebody, to get somebody, to have a comfort level that this is a very well-trained person, a committed person, a safe environment. I know that when Stephen goes to Opp Art it's a safe environment. I know those people there; they're excellent.

I don't know how I would hire somebody when I know that I couldn't promise them, perhaps, medical coverage, a pension plan. I don't know what I would do. What happens if that person gets sick or whatever? I just don't know what I would do. I don't know how I would go about achieving all those goals through direct funding.

What would be more important to me is that maybe Stephen has no place to go, maybe he doesn't have the self-esteem that he has now. I'm afraid that, if I was lucky enough to get somebody—I think I would be in a constant hiring mode—I just wonder if it would be like a glorified babysitting service. I just don't know if they would have the skills and the ability to access all the things that Community Living London has done for me.

I'm really nervous. I'm not a legislator or whatever, but I know there is a section in the bill, 40(1), which makes me a little nervous as a parent. I'm afraid that if Stephen is reassessed at one of these centres or whatever, I'm not sure—even though you say that he's not going to lose the services he has now, that makes me nervous, that he would be reassessed and perhaps lose those services.

I really don't think that the direct funding is going to solve the problem, because I believe that Stephen needs

the opportunity to get out in the community and to work more. If he has those opportunities, then I think it's a win for everyone, because now that he needs less of a level of support through your ODSP program, his self-esteem is better. I just don't know how we can achieve that unless we have committed and trained people, and people who can identify opportunities in the community. I really believe that agencies such as Community Living London can assist that if they had some more staff and resources to do that. I don't know how I would hire somebody with direct funding who would have those kinds of contacts and that level of expertise.

The extra transition funding that was given has already helped Stephen access what he has today. If there were more opportunities for him in the community and more resources with Community Living London he would have even more opportunities. I don't see direct funding accomplishing that. I believe it needs to be done through our agencies, which do a fantastic job, like Community Living London.

The Vice-Chair (Mr. Vic Dhillon): Thank you, Mr. Blake. Good morning, everybody. I apologize for being a little late this morning. There's about six minutes left, so we'll start with the official opposition.

Mrs. Christine Elliott: Thank you very much, Mr. Blake, for being here this morning. The comments from parents are most helpful and really help us point to the issues that we really need to deal with with respect to this bill. My understanding is that the individualized funding is not meant to replace the existing funding that will be going to community living organizations. I'll certainly ask the government members to clarify that.

0920

With respect to your comments about the individualized funding and not knowing how to put a plan in place for your son, if there was a facilitator who could work with you and your family to put a plan in place, would you feel more comfortable with that?

Mr. Fred Blake: I'm not sure that they would have the training and the expertise that I know some of the staff at the agencies have. I don't want to be disrespectful, because I don't know who that person is, but I just would be very nervous about that. I have a comfort level going to an agency that's in "business" helping people like my son. I don't know if I would be as comfortable with an individual or if I could be assured that they would have the expertise to assist him.

Mrs. Christine Elliott: I think your comment with respect to the lack of vocational supports and so on for people who have a developmental disability is a point well taken. I think that this legislation is the start of changing people's ideas and advancing social inclusion. I think the next step is to go to businesses and say, "You're missing a lot of opportunities here." We need to start changing the response from businesses in that respect.

Mr. Fred Blake: I would be first on the list, right in front of you, behind you or beside you if you've got any employers who are interested.

The Vice-Chair (Mr. Vic Dhillon): The government side.

Mr. Khalil Ramal: Thank you very much for sharing that personal information with us.

I'm not sure what led you to believe that this bill would force you to quit seeking services from Community Living London. This bill gives flexibility to families and gives them the opportunity to seek support from the government, if they wish, to continue to care for their loved ones while they're able, physically, mentally and financially. I believe strongly that you can continue, if you wish, to seek services from Community Living London. I worked for Community Living London for quite some time; I know it's a good organization and a good place to support people with disabilities. Can you explain to us what led you to believe that if this bill passes you will lose your services with Community Living London?

Mr. Fred Blake: As I mentioned, if I'm reading 40(1)(b) correctly, it says he may be reassessed by one of your assessment centres or whatever you're calling those centres. So if he gets a new assessment or they target some new needs for him or whatever, I'm not entirely sure that that doesn't mean he would be asked to do something else rather than be supported through Community Living London. If I'm reading too much into it, I'm comforted by your comments. I just hope that I am, because that's my fear.

Mr. Khalil Ramal: I want to assure you that this bill is all about families and giving them some kind of flexibility and support to be able to choose the service they want, whether with communities or agencies or individuals, because as you know, parents know better about their loved ones and how they're supposed to be serviced. That's what the bill's all about. Hopefully, my comments will clarify your concerns and make you comfortable.

AUTISM ONTARIO

The Vice-Chair (Mr. Vic Dhillon): The next presentation is from Autism Ontario.

You have 15 minutes. Please state your name for the record.

Ms. Patricia Gallin: My name is Patricia Gallin. I'm a member of Autism Ontario, London. I'm also the parent of a 23-year-old son with Asperger's syndrome.

I really welcome the opportunity to make this submission on Bill 77. We really applaud the Ontario government and the Ministry of Community and Social Services for updating the Developmental Services Act.

Just a little bit of information Autism Ontario: We are a volunteer network of 30 chapters throughout the province and we represent thousands of families living with children and adults with autism spectrum disorder. 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 autism spectrum disorder, and these children 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 to succeed, adequate funding has to be forthcoming to fulfill the total obligations under this proposed legislation.

The feedback that I am going to give this morning is drawn from Autism Ontario working group meetings and also from polling our membership. I would like to address our areas of concern.

We're really gratified that using an IQ score is no longer a prime consideration for eligibility under Bill 77. Previously, the benchmark was an IQ of less than 70, and this definitely made higher-functioning individuals with ASD, which includes Asperger's syndrome, ineligible for services in some parts of Ontario. Fortunately, in London I have not run into that with my son.

In Bill 77's definition of developmental disability, mention is made that this disability was to have "originated before the person reached 18 years of age." Many people with autism spectrum disorder will not be correctly diagnosed until adulthood due to a lack of expertise and training of professionals, even though, by DSM-IV diagnostic criteria, they would have met the required criteria for the diagnosis prior to their third birthday. It is our expectation that this systems capacity gap would not make such individuals ineligible under the currently proposed definition of a developmental disability.

Under point 4, professional and specialized services, we would like to see included employment and job-training services, psychological services or any therapeutic services. Where services are mentioned in the bill, we would like it to read "services and supports."

Also, application centres: We feel 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 conflicts of interest. If the application centre is also a service agency, choices facing the individual may be somewhat constrained. The bill also 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.

Under Bill 77, direct 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. What are the stated criteria upon which the 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 a facilitator or 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? This is especially crucial for individuals with ASD, where more specialized and not generic services and supports are really vital.

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

0930

Individuals and families enter into a direct contract with MCSS for funding. For this process to be fair and equitable, the individual/family/advocate should have had the assistance of an independent planner/facilitator in order for them to make decisions in an informed manner.

Independent planning and facilitation should be available for families or individuals once they are eligible for funds, and further capacity to appropriately serve adults with ASD must be developed in rural areas in order for the funding of eligible individuals to be meaningfully utilized.

Application centres and the development of a service profile, section 18 in the bill: Under the bill, the service profile would have to satisfy the provisions under the definition of "developmental disability." Our concern is, what are the qualifications of those working in the application centres? Would they have the training and education in autism spectrum disorders necessary for an appropriate understanding of the unique characteristics of this population?

Another problem is the wait lists and 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 wait lists, then they will never receive adequate funding. I was very surprised to see wait lists written right into the bill. Without adequate funding, the majority of applicants are going to be denied service. The 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.

The legal capacity of an individual should be recognized in the bill, along with providing supported decision-making with a planner and facilitator so that people can enter into an agreement for direct funding without surrendering authority to a substitute decision-maker.

We're very pleased to see that the safety and security of adults with developmental disabilities is being protected by home inspections. Bill 77 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 resi-

dences, including supported group living residences, intensive support residences and people's private homes.

We do have concerns about potential conflicts of interest if those 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.

About the service profile in the act: 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 outcomes be measured to determine if the profile was accurate?

Once eligible funds are made available, we want to ensure flexibility, accessibility and portability. If they want to use them in another accepted manner, we hope that can be done, and if they move to another jurisdiction in Ontario, we hope the funds will move.

An appeals process independent of the application centre should be instituted using an unbiased third party.

Finally, 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 ASD.

I really appreciate the opportunity to provide input on Bill 77. Do you have any questions?

The Vice-Chair (Mr. Vic Dhillon): Thank you so much. About two minutes for each side, starting with the government side. Mr. Levac.

Mr. Dave Levac: Thank you very much for your presentation. I appreciate Autism Ontario's complete vision of what we're trying to do in the bill, and I definitely appreciate the fact that you've recognized we're moving forward. No bill is written perfectly, to be very frank; no one's got a monopoly on how to write a perfect bill. That's unfortunate, but there are some changes being contemplated.

The one you talked about, in terms of waiting lists: Historically, just as an "are you aware," there have been bills written with wait lists in them going way back to 1992, by the NDP. They put in the waiting lists to acknowledge the fact that they've got something to target and move forward on. The example I give you is one everyone is aware of, in terms of hospitals. Hospitals have waiting lists; there's a strategy put out on how to deal with a waiting list. The acknowledgement of this waiting list does not entrench, to be clear, an excuse not to invest. Quite frankly, the opposite happens. In every one of the pieces of legislation that had waiting lists entrenched in the legislation, more money was spent to accommodate getting rid of or improving the waiting lists.

I just wanted to alleviate some of your concerns and fears. It's not an entrenchment of not getting money; it's actually an entrenchment to encourage more investment, and we believe that that's going to happen. We've already invested about \$500 million.

The Vice-Chair (Mr. Vic Dhillon): Quickly, Mr. Levac.

Mr. Dave Levac: I just wanted to give you some clarity on that specific issue, and if anyone says it's not entrenched, there are legislations that have entrenched waiting lists.

Ms. Patricia Gallin: Thanks for that information. Let's hope that it means more funding.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. Opposition side.

Ms. Sylvia Jones: Thank you. Excellent brief, Ms. Gallin. I appreciate it. Just to continue on the waiting list angle, I would like your feedback. Even with the waiting list entrenched, it's my understanding that with ASD and Autism Ontario their concern would be if it is based on level of need, then you would be on the waiting list for a very long time. Can you expand on that?

Ms. Patricia Gallin: I think there has to be an opportunity to help people in crisis, but maybe there need to be two kinds of waiting lists. Maybe there need to be funds to support people in crisis, but also there need to be funds available to help the broader population.

Ms. Sylvia Jones: Chair, do I have time?

The Vice-Chair (Mr. Vic Dhillon): Go ahead, yes.

Ms. Sylvia Jones: My second question is related to application centres. You mentioned that you would like to see their role limited. Do you have some suggestions for the committee on which roles you would like removed, or expand on the application centres and what you want taken out or kept in?

Ms. Patricia Gallin: I have a list in the report that I didn't touch on. Under the "application centre" heading we've got some things listed, so those would be the areas that we'd like to see—

The Vice-Chair (Mr. Vic Dhillon): You have some time if you want to state your answer further. It's up to you—no pressure.

Ms. Patricia Gallin: Rather than repeating them all, they are listed in the presentation.

Ms. Sylvia Jones: Yes, it's perfect. It's on page 3.

Ms. Patricia Gallin: Yes.

Ms. Sylvia Jones: Thank you.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

Ms. Patricia Gallin: Okay. Thanks so much.

CANADIAN UNION OF PUBLIC
EMPLOYEES, LOCAL 3943

The Vice-Chair (Mr. Vic Dhillon): Next we have the Canadian Union of Public Employees, Local 3943.

Welcome to the committee. If you can state your name for the record, you may begin. You have 15 minutes. Any time you don't use will be divided amongst the two parties.

Mr. Jim Beattie: My name is Jim Beattie. I'm the president of CUPE Local 3943. Good morning. I want to commend the committee for holding these hearings and to thank you for the opportunity to present our views on

this extremely important piece of legislation. I am here representing over 500 front-line workers employed by agencies that provide developmental services and supports in and around Hamilton.

Our members provide day supports, respite, residential, employment and SIL supports, as well as other supports to over 1,000 individuals. As a front-line worker myself with over 20 years' experience, I've seen how services for people with a developmental disability have changed over the years. Much of that change has been for the better and, while we still have a way to go, we clearly have made progress towards the goal of ensuring that individuals with a developmental disability become full participants in our communities and our society.

Many groups and individuals have been responsible for the positive changes that have occurred and, while acknowledging that, I want to emphasize the role played in those changes by community-based non-profit agencies, agencies like the one I work for, which has been at the forefront of those changes. This, despite the fact that funding has never kept pace with the needs of the individuals whom the agencies support.

0940

It's not surprising, though, that these agencies have been in the forefront of change. Many board members and staff who work for community agencies have close family connections with individuals who receive support. Given the crucial role that community agencies play in the planning and delivery of services and supports to individuals, it is disturbing that greater emphasis isn't placed on their health and long-term viability in Bill 77.

I want to draw your attention to certain aspects of the legislation that we believe need to be amended, and I'll only comment on three areas. Yesterday, a number of concerns were expressed regarding the creation of application centres which the legislation, if passed, will create. I don't want to reiterate all the valid points that were made yesterday, and this morning as well. Instead, I want to speak about our experience in Hamilton.

During the 1990s under the then-Harris government, Contact Hamilton was established. Contact Hamilton was and is an agency funded by the government that provides intake, assessment and referral services for children and individuals with a developmental disability. It is a separate entity from community-based agencies. When it was established, there already was in existence an organization under the auspices of the community agencies, and that organization provided intake, assessment and referral services for families and individuals seeking support. The organization was similar to the one that currently exists in Toronto that you heard about yesterday. Despite its usefulness, though, Contact Hamilton replaced it. To fund Contact Hamilton, the government then clawed back almost \$1 million from the budgets of the agencies in Hamilton—which brings me to the point: How does the government propose to fund the application centres in the legislation? Will, like Contact Hamilton, the funding be taken from existing agencies to establish these assessment centres, and how much will

that cost on a provincial basis? Why do we need to create another level of bureaucracy when it's clear that agencies can do this task?

I want now to turn to the issue of waiting lists and, again, I won't reiterate all that has been said on this issue. Suffice it to say, though, that it is unconscionable in Ontario in 2008 that we could even contemplate enshrining into legislation waiting lists for supports and services that individuals need to fully participate in society. Access to those services must be a right.

On this issue of waiting lists, I want to give you an example of what can happen when individuals are placed on a waiting list without access to services. In the mid-1990s, Sally—not her actual name—was enrolled in the day program where I worked at that time. Sally was in her mid- to late twenties and had been without services and supports for a number of years. When Sally graduated from school, she was outgoing, happy and with good skill sets but without services and supports for a number of years. By the time she enrolled in our program, all of that was gone. She was withdrawn and lacked confidence, and her skill sets were greatly diminished. This is because she had gone without supports and services for so many years. We need to remove waiting lists from the legislation.

The final issue we'd like to address is one of identified needs in relation to community agencies and the services and supports they provide. Again, I'll use examples from Hamilton and the handout. If you turn to pages 36 and 37 in the handout, you'll see the variety of services and supports requested by families and individuals on waiting lists with Contact Hamilton. You'll note that the greatest number of requests are in day supports—127—and accommodation—81. On page 37, you'll see a chart that predicts future needs. Again, the greatest number of requests are in day supports—186—and accommodation—455. Many of these day supports and residential services have been and will continue to be administered through non-profit community agencies.

On the last four pages of the handout, pages 37 to 40, it addresses the issue of requests for Passport funding. I want to particularly draw your attention to page 40, table 50, "Modes of Funding." What it essentially shows there is that many applicants who have initially requested direct funding to act as their own employers have, after they've received funding, decided to receive agency services. This is also true of the current SSAH program, where there are 336 contracts administered by Community Living Hamilton, as opposed to far fewer contracts where parents act as their own employers.

This data is consistent with other findings, and it is that the majority of individuals and families, given the choice, will access community-based agencies for supports and services, rather than act as their own employers.

In closing, we want to reiterate our conviction that quality supports for a person with a developmental disability can only be sustained through public, not-for-profit, mandated services in an adequately funded com-

munity agency system where workers are compensated fairly and provided appropriate training and skills enhancement and where supports meet the needs of individuals.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We have about four minutes each. We'll begin with the opposition. Mrs. Elliott.

Mrs. Christine Elliott: Thank you very much for your presentation. One of the questions you have raised is with respect to the application centres: how they're going to function and whether they're going to be another level of bureaucracy. That question, as you may know, has been raised by a number of organizations and presenters we've heard from, and I believe that is something that will need to be clarified as we move forward. I would just ask that the government members consider that. There's a lot of confusion about that, and that really needs to be dealt with as we move forward with this piece of legislation.

The other issue you were talking about, the need for day supports for people with developmental special needs: There are a number of programs out there, offered both by private and not-for-profit organizations. Are you saying that none of the private agencies are an option for people?

Mr. Jim Beattie: In Canada, we generally hold the opinion that health care shouldn't be a for-profit industry. We feel the same thing with the provision of services and supports for individuals with a developmental disability.

Mrs. Christine Elliott: But wouldn't you also agree that to have a range of choice is a good option for parents because every individual is different?

Mr. Jim Beattie: We agree that there is a range of choice out there. We also feel strongly that, as I said, the vast majority of people will be seeking supports from community-based agencies and that this bill does not address the long-term health or viability of those agencies. There needs to be something in this bill that addresses the agency system.

The Vice-Chair (Mr. Vic Dhillon): Mr. Ramal.

Mr. Khalil Ramal: Thank you very much for your presentation. First of all, I want to thank you for the job you do on behalf of many workers across the province of Ontario. There's no doubt in my mind that the front-line workers who work with many different agencies and group homes across the province of Ontario do an excellent job in order to serve the vulnerable people among us. That's why our government, in the year 2006, invested substantially in supporting those organizations and workers to continue to work and also narrow the gaps, as your union and many others brought to our attention.

My question to you: You don't believe in some kind of standards across the province of Ontario in order to assess people and give them a chance to be equal from the north to the west and to the east and to the south? As you know, at the present time we don't have that standardization, and people move from spot to spot in order to get assessments for their loved ones.

The second question is: You don't think parents have a right to choose the service they want if they decide to keep their loved one at home but they're looking for extra support?

Can you tell us what you think about those questions?

Mr. Jim Beattie: The first one is around a common assessment tool?

Mr. Khalil Ramal: Yes. Application centres.

Mr. Jim Beattie: Yes, we do believe that there needs to be a common assessment tool to gauge the depth of support that's needed by individuals across the province. I think that one of our presentations yesterday brought that out, but I could be incorrect on that. Nonetheless, we do feel that's necessary.

On the second point, we provide services already in parents' homes, and a number of my colleagues with Community Living Hamilton do go, in various capacities, into individuals' homes.

0950

Mr. Khalil Ramal: But what led you to believe that passage of the bill will cut that service and convince the parents to otherwise not seek your service?

Mr. Jim Beattie: We believe that the bill, because it doesn't address the fiscal issues—or we don't see it in there—of agencies, will endanger the long-term health of community-based agencies, particularly with the individual budgeting, where a cost is assigned or can be assigned by application centres to a specific individual. We don't see other issues that need to be addressed financially in the bill there. We believe that the bulk of the changes in this legislation, as opposed to the current act, are around brokerage, individualized funding and those types of things, but not around the overall health of the agency system, which at this current time most people request supports and services from.

Mr. Khalil Ramal: As I mentioned to you, in budget year 2006 we invested a lot in many different agencies across Ontario to address their needs, especially the wages and services for vulnerable people in the province. So that's why we cannot say we're not addressing this issue. This bill came in order to support families, as I mentioned to you, who came to us at many different times seeking support. They said to us and to the people, "We want to keep our kids or loved ones at home. We want to look after them and we're not able to do it. We need some kind of support." That's what this bill is all about—about families, about support for the people who wish to continue supporting their loved ones.

I want to assure you, it's nothing to do with union or against union; it's focused totally on families. The families, if they decide to go to Community Living London or Participation House, whatever organization across the province of Ontario, it's their wish. They'll be seeking some kind of support and training that we are going to place in the province—three spots—to create awareness about families, if they wish, to take this opportunity and ask for funding.

The Vice-Chair (Mr. Vic Dhillon): Okay, thank you very much.

CANADIAN UNION OF PUBLIC
EMPLOYEES, LOCAL 4370

The Vice-Chair (Mr. Vic Dhillon): Next, we have the Canadian Union of Public Employees, Local 4370.

Good morning, folks. If you can state your names before you present, you have 15 minutes. Any time not used will be divided among both parties. You can start.

Ms. Cheryl Marshall: My name is Cheryl Marshall. I've been a caregiver at Community Living Sarnia for the last 20 years and I'm chief steward of CUPE Local 4370.

Mr. Brian Biggers: My name is Brian Biggers, president of CUPE Local 4370, and I've been a caregiver for 17 years.

Ms. Cheryl Marshall: First and foremost, we'd like to thank the standing committee for giving us this opportunity to speak to you on this important issue. As I already said, my name is Cheryl Marshall. I'm chief steward of CUPE Local 4370, representing workers in Sarnia–Lambton. This is Brian Biggers beside me, who is the CUPE president of 4370. Between the two of us, we've got almost 40 years' experience working in the social services sector. I've also been asked to speak by local leadership representing the workers in Essex, Windsor and south Huron to make comments from our region as a whole.

As we worked together to review the bill, it became clear that our experiences with the current system and our concerns with this bill are very similar. Over the years, we've watched the developmental services sector move leaps and bounds in the direction of providing the services and supports to meet identified needs of individuals with developmental disabilities.

Sorry if I go a little too fast. I've got a lead tongue instead of a lead foot.

This being said, there are still many who do not receive all the supports they truly need. Some are without needed supports and other individuals and families struggle with inconsistent support due to availability of supports and services.

As front-line workers and service providers, we recognize that there are problems with the delivery of services and supports for persons with developmental disabilities. We hear families and workers in our area saying, "We need improved access to supports and services." We need access to a wider range of services and supports so that individuals can have individualized plans developed to meet their needs. We need a strong system that people can rely on and, most importantly, we need a high quality of supports and services.

We do not believe that Bill 77 responds to these challenges. We are concerned that: There's no commitment in the legislation to guarantee a level of supports and services that individuals and families can rely on. Currently, we all too often see individuals finally being able to access residential services only when their family comes into crisis and can no longer care for them. This is not appropriate or fair to individuals or their families. Due to the lack of funding, this transition is not planned

in a respectful and supportive way. There needs to be a level of service provided that is mandated, no matter where you live in Ontario.

The application centres are evolving as a new bureaucracy, rather than an expectation that agencies work as a collaborative model. As they already have the experience and structures to do this work, we do not need the emergence of a new bureaucracy that unnecessarily bleeds away resources from our agencies.

There is no legislative requirement to use common assessment tools to determine the eligibility in order to ensure consistency across the province.

The bill entrenches waiting lists, which has been mentioned before. When talking to colleagues in other services, we understand that waiting lists are not something that the government has included in other legislation. It raises big concerns. Why is it necessary in developmental services legislation? For example, in the county of Windsor-Essex, there are 255 people currently on a waiting list with no service. To me, that is huge. Subsection 19(4) states, "If there are not sufficient funds available in an application centre's geographic area to provide one or more services specified in an applicant's service profile immediately or, where direct funding is requested, to provide the direct funding immediately, the application centre may place the applicant on a waiting list"—which is no good—"for the services or funding, as the case may be."

Why, if my child has been assessed in one part of the province, should I be denied access to the supports based on geographical funding? Do families need to move to follow funding from region to region? Where is the consistency in similar degrees of developmental disabilities?

Direct funding does not always ensure there will be services available to the families when they need it. This bill allows the purchase of services and supports from third parties or brokers. It opens a very real possibility of fly-by-night operators and the expansion of for-profit organizations. This means a focus on finding a profit out of already limited funds going into this sector. We have seen home care and nursing homes shift to for-profit providers and a system of competitive bidding which is not good for quality of service. Rolling back to the cheapest way of service provision is not good for those we support and for those who provide the support. It is lose-lose.

Taking a system that is already struggling and fragmenting inadequate funding to potentially hundreds of new employer relationships through direct funding makes quality of service accountability virtually impossible. The ministry's Spotlight newsletter states that the bill grandparents those adults who have received services and they will not have to reapply or be reassessed for eligibility. But in the language of the bill—clause 40(1)(a)—it says that those receiving supports when the act comes into effect are "deemed to be eligible for services and funding" and in (b) "shall continue to receive, or benefit from, those same services until such time as the application centre for the geographic area in which the person resides conducts a reassessment," which we find very disturbing.

We worry that this is a loophole; that while adults are eligible for funding, they may have levels of funding and/or services reduced when the application centre for the geographic area in which the person resides conducts the reassessment. The word "until" becomes a big concern.

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There are families who are interested in the direct funding models. The parents we have spoken to believe direct funding is better than sitting on a waiting list. When we talk about the monies the families have actually received through special services at home or Passport, they say it has not really addressed the needs of their child. They say it's come to a Catch-22. It's one way or the other: Either they pay more and try to get someone who's going to stick around and then go with less service time, or they pay less and get more service hours, and then they see a revolving door of workers. They have said that finding and keeping people is daunting. In addition, they are concerned about assuming the responsibility and the liabilities of an employer. If agencies are having difficulties finding and keeping staff when they provide some benefits and pensions, how are families going to recruit and keep qualified staff?

When consistency of who is working directly with the people is so vital, there is a big concern with direct funding translating into revolving doors of care providers who are not part of an agency which ensures training and accountability. We believe that rather than addressing the challenges we experience in this sector, elements of Bill 77 will further erode the community-based agency while not really providing more choices to parents. Addressing the needs of individual disabilities takes resources. With a system that continues to be underfunded, no model can really be effective.

The bottom line: Our vision is where individuals and families can be supported based on their individualized plan. Whether they participate in community programs, agency programs, are employed or not, live in residential programs, independent living or with their families, required support needs to be reliable, consistent, flexible and responsive. If the supports include needing staff support, then the worker needs to be trained, supervised and have a working condition that reduces the challenges we have seen across the province when it comes to training, recruitment and retention. We believe the services and supports that require staffing are best delivered through an appropriately funded non-for-profit community living agency structure.

Thank you again for this opportunity to address you today.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

Ms. Cheryl Marshall: Sorry if I rushed through. I apologize.

The Vice-Chair (Mr. Vic Dhillon): That's fine. Three minutes each side.

Mr. Khalil Ramal: Thank you very much for your presentation. You mentioned all the talk about the needs

of access to service in the communities. We talk about choices. We strongly believe that Bill 77 will create more choice for families. This does not mean that the family will have the total ability—some families, of course—to do the services by themselves. I agree with you. They're not able to do it. That's why this bill will create a choice for them, whether to do it themselves or to seek service from agencies and Community Living across the province of Ontario. You don't believe that parents have a right to that choice?

Ms. Cheryl Marshall: No, I believe they have a right to that choice, but at what cost is it going to be to them? I live in a border city. I can go and get an MRI done without a waiting list, but it's going to cost me \$5,000. If I want to get it done in Ontario, I'm put on a waiting list for five to 10 months.

Mr. Khalil Ramal: You have to remember, we're talking about choice.

Ms. Cheryl Marshall: I know, but choice—

Mr. Khalil Ramal: Choice for the families—not yours, not mine—theirs, because they know better how to look after their kid or their loved one. That's what the bill is all about: giving them the choice. If they decide to keep their kid or loved one at home and they need some extra support, they have a right, I think, to seek whatever support they're looking for. This is my concern, because we heard many different people who came before the committee yesterday speak about their choice, their right. Of course, your job as a union representative or representing the workers of Ontario is to speak from your own point of view, which I respect and honour, but in the end, it's about choice for the families.

Mr. Brian Biggers: Absolutely. We agree that families are ultimately the ones that have the choice, and we believe that if agencies are properly funded they will have the choice to have a structured setting where the employees are trained adequately and that they have protection if they get injured on the job.

Mr. Khalil Ramal: We're talking about agencies and organizations. I respect agencies and organizations. I was a part of those agencies for many years, and I worked for them. But—we're talking about families—we cannot expand and broaden the support from agencies, communities and group homes to families, to give them a choice, if they seek this service or other services. That's why we're talking in Bill 77 about the choices.

Also, you mentioned the application centres—just another question, a quick one. You said that people move from area to area to seek support and get assessed. So by establishing the application centres, we'll have standardized assessment across the province, so then the family wouldn't have to move. You don't think this is the best way to do it?

Mr. Brian Biggers: I just think that the people who are working with the individuals are the best ones to do the assessments. Who is going to be doing the assessments? That's our question.

Ms. Sylvia Jones: I have a couple of questions. You mentioned in your brief about waiting lists—specifically

250 on a waiting list for Windsor. Can you expand on that? What are they waiting for exactly? Is that residential, respite, a day program?

Ms. Cheryl Marshall: When I was given this, it was 255 people total on a waiting list; 130 on a wait-list who have no support at all—

Ms. Sylvia Jones: So they're looking for anything?

Ms. Cheryl Marshall: Sorry?

Ms. Sylvia Jones: They're looking for anything.

Mr. Brian Biggers: They're looking for anything, yes.

Ms. Cheryl Marshall: And these are families.

Ms. Sylvia Jones: So they would have had their assessment and now they're—okay. Sorry to interrupt.

Ms. Cheryl Marshall: Okay. So 89 families are asking for 24-hour support; 64 are asking for day support—of the 255—63 are asking for individual, specialized support; and then there are 127 respite, and 70 of those are adults. That's what Bill 77 deals with—adults. That's where that comes from.

On the adult list, some of these people have been on the waiting list for 10 years. When it happens with 10 years, not only does the person age, so does the parent. Now you've got brothers and sisters coming back in and they've got to move maybe across the province or move their brother or sister across the country.

Ms. Sylvia Jones: Real quick: You mentioned the application centres, that you envision a new set of bureaucracies, another hurdle that families would have to go through. Would you, then, say that the existing community living system for assessment is the way to keep it? If you don't want the application centres and see them as bureaucracy, what do you want to see?

Ms. Cheryl Marshall: I think what we want to see is that if there are going to be application centres that they work hand in hand with the people who are providing the service already and the people who are trained. What happens eventually is that when we work with individuals, we actually become a part of that core group, that family group, and when we're working with their son for 30, 40 hours a week, we understand services and some things—

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

Ms. Cheryl Marshall: Thank you very much.

COMMUNITY LIVING TILLSONBURG

The Vice-Chair (Mr. Vic Dhillon): Next we have Community Living Tillsonburg.

Welcome to the committee. You have 15 minutes. Before you begin, could you please state your names for the record?

Mr. Bob Parsons: Thank you, Mr. Chairman and members of the committee. Good morning. My name is Bob Parsons. I'm the president of Community Living Tillsonburg. With me today is Marty Graf, executive director of our agency.

Community Living Tillsonburg is an agency that supports people with a disability in Tillsonburg and surrounding areas. We are also a member of the Ontario Association for Community Living.

We want to thank you today for this opportunity to share our thoughts and beliefs on Bill 77. We trust that you will take our recommendations into consideration when reviewing this bill. Since the current legislation has been in place since 1974 with only minimal change, we believe it is important to take the time and get it right, rather than getting it passed within a short time frame.

As you are aware, the southwest region was the location of six out of seven labour disruptions last summer. Our key message to you today centres on the importance of recognition of the rights of individuals supported by community living organizations while living in their own homes. Some people would call these group homes. The Ministry of Community and Social Services recognizes these arrangements as group living. In our current language, we continually strive to recognize that they are residential homes of the people living there. People were adversely affected by the strikes at their homes during the 2007 labour dispute. The rightful entitlement to enjoy the peace, tranquility and security of their own homes, as deserved by any Ontarian, was taken away. Their relationships with their neighbours were affected significantly. We believe that no other citizens in Ontario are subject to having strikes occur at their home, whether they are owners or tenants. People who are supported by Community Living need to have their rights respected as well.

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We ask the government, through this committee today, to ensure that Bill 77 protects the rights of all Ontarians within the developmental services sector whose health, safety and well-being are shamefully placed at risk during a labour dispute. We believe that Bill 77 is a timely and important opportunity for the government of Ontario to provide assurance for continual quality care by ensuring that all Ontarians within the developmental services sector will never be subjected to such dramatic changes as having to deal with replacement workers to take care of their personal day-to-day survival needs. We ask that Bill 77 contain improved regulations that will remove the right to strike by workers who are responsible for providing a continuum of care.

We ask, too, that you consider the impact of this legislation from a human rights perspective. The right of an inspector to enter a premises without notice and without a warrant, we perceive, is going against the right of any Ontarian. We need to ensure the peace and security of citizens within this sector within their own homes. We support the current responsibility for ministry staff to be involved in compliance reviews, and we must continue to work together in ways that respect the dignity of the people we support by ensuring that due notice is provided. Currently, individuals are notified in advance of compliance reviews. Our experience has proven that this will work and is fair and practical to all stakeholders. If the government believes that they should be making un-

announced inspections, then a warrant should be obtained first.

Ontarians within the developmental services sector have not exclusively had all of their rights protected over the years. We are at the threshold of an opportunity to correct this with some additional amendments to Bill 77. We ask you to consider a made-in-Ontario solution in regard to the concept of supported decision-making. This is an alternative to current legislation under the Substitute Decisions Act. It is our belief and our experience that when people with an intellectual disability are involved in decision-making, their decisions are usually far better decisions than those made when others make decisions for them. It is our understanding that the UN charter on disabilities has recognized the concept of supported decision-making, and Ontario has led the way in this approach, and it should be incorporated into the changes being recommended to this act.

As an agency, we also provide supports to children with intellectual disabilities and their families, as well as adults with intellectual disabilities. While this act focuses on adults primarily, we believe that the development of lengthy application forms and assessments that are based on negative perceptions of individuals may not achieve the success the government would like to see for the developmental sector. We have, throughout Ontario, agencies that have over 50 years of experience in helping people with intellectual disabilities achieve their goals and visions and improve the quality of life through good plans and good support services. We fear that these application centres' related forms and assessment process will only lead to people being added to waiting lists, rather than having them access the supports they require to live as full citizens in our community.

We appreciate the efforts by this government and all governments that have worked towards the closure of institutions that this bill recognizes. We fully support and endorse the move towards more choice in terms of individualized and direct funding. We see these as steps that will continue to improve what is available for people with intellectual disabilities.

We would reinforce that it is important to get this bill right and set the stage for many years, since acts of this type do not change very often, as experience shows.

In closing, we ask that you take a human rights approach to this bill. We ask you to consider their right to enjoy the peace and security of their homes so that picketing does not occur there. We ask you to consider their rights to enjoy the continuity of their services because we do believe that we provide essential services. We ask that you consider their rights so that ministry inspectors would provide notice for inspections and/or require a warrant if circumstances deem necessary. We ask you to consider the concept of supported decision-making.

We thank the committee for your time today and we look forward to the support of the government of Ontario through effective and appropriate legislation to meet the needs of all Ontarians within the developmental services sector.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. About four minutes each side. The government side; Mr. Ramal.

Mr. Khalil Ramal: Thank you very much for your presentation. You mentioned many different elements, and we can just focus on two things within the boundary of Bill 77. You mentioned inspection without notice. I guess you're against it because you want the government, before visiting any place, to have a warrant first; apply for a warrant. How can we ensure transparency and eliminate all this abuse from happening on a regular basis?

Mr. Marty Graf: The current processes do work. We believe that compliance reviews, when they're done on a regular basis, are effective in ways to ensure that proper systems are in place. We also have other systems in place where serious occurrences are reported on a regular basis. Those are reviewed by the ministry personnel. We think those combinations of both the compliance reviews and the serious occurrence reporting give the ministry offices and their current staff ways to know whether an agency is doing its job properly or not. We've seen, through those processes, when agencies have not been doing their jobs, that those agencies have been given proper notice and their service contracts have been taken away. Those services were handed over to other agencies when they went out to tender, if you will. So we've seen the experience that the compliance review processes and the monitoring of serious occurrences are two of the main tools that the ministry uses already, and we've seen the effectiveness in that we've seen agencies lose their contracts, based on reviews of serious occurrences and reviews under compliance reviews.

Mr. Khalil Ramal: How can we comfort the parents, who very often report certain agencies and places for abuse and other improper management?

Mr. Marty Graf: Years and years of our history of experience. We've gone through many years of having compliance reviews. We have to, as well, recognize that—again, part of what we were trying to present today was on the rights of individuals. Because people are receiving supports and services, we believe that, on ordinary inspections, people should be notified who live in those homes so that they can be prepared, because for some of them, it is a traumatic experience to have someone they don't know come through their homes and begin asking all kinds of questions.

1020

Mr. Khalil Ramal: But as you know, under Bill 77, private homes are not subject to inspection—

The Vice-Chair (Mr. Vic Dhillon): Thank you. If you can just quickly reply to Mr. Ramal, as we have to move on.

Mr. Bob Parsons: Can you finish the question, sir?

Mr. Khalil Ramal: Yes. I'm saying that private residences are not subject to inspection, as you know, in this bill. Only businesses and whatever head offices.

Mr. Marty Graf: We certainly don't have a problem with inspections coming in unannounced to the head office, for example; no problem at all.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. The opposition; Mrs. Elliott.

Mrs. Christine Elliott: Thank you very much for your very thoughtful presentation. I certainly do agree with you that this a bill with which we should take a human rights approach, because after all, it's not just about an allocation of funds. It's about promoting social inclusion and building meaningful lives for all citizens in our community.

I'm really intrigued by the concept of supported decision-making. We've heard several groups mention that. I'm just wondering if you agree with the comments made by some people that it would be helpful to have a facilitator, someone to help build those circles of support around people, to help them make their own decisions and to help them have meaningful people in their lives after their friends and family, or their parents, particularly, are no longer there. Do you have any idea how you would like to see that work ideally?

Mr. Bob Parsons: We're doing that now.

Mr. Marty Graf: We are aware of many great facilitators in the current system. Some of them are connected with CSCN here locally. There's a lot of great talent out there who have been leading the field in the development of circles of friends and the development of helping people in these supportive decision-making processes. There hasn't been a formal recognition, if you will, from the system on the concept, but the expertise has been doing this for the past 25 years.

Mrs. Christine Elliott: Do you think it would be helpful if that was more formally enshrined in the legislation as something that goes hand in hand with the funding you need to have that planning aspect and the recognition of the rights of the person to participate?

Mr. Marty Graf: We think that would be a very good essential component of the act. We have great planners out there. We have great facilitators for people to access that type of skill set and those types of individuals who are very committed to seeing that desires, dreams, goals and visions of the individuals are brought forward. What we've seen is some great work by those kind of players in our field.

Mrs. Christine Elliott: Thank you very much.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

Mr. Bob Parsons: Thank you, Mr. Chairman, members of the committee.

COMMUNITY LIVING CHATHAM-KENT

The Vice-Chair (Mr. Vic Dhillon): Next, we have Community Living Chatham-Kent.

Good morning and welcome to the committee. If you could state your name for the record; you have 15 minutes.

Ms. Lu-Ann Cowell: Certainly. Good morning. My name is Lu-Ann Cowell. I'm the executive director of Community Living Chatham-Kent and I chair the provincial executive directors' coordinating committee. I

have 33 years' experience working with the community living agency in Chatham and have seen the changes over the years in terms of supporting people with intellectual disabilities to become contributing citizens of their communities.

I thank you for the opportunity to speak to Bill 77, the proposed legislation for developmental services.

It's well recognized within the developmental services sector that there's a need to change the current legislation to reflect the government's wonderful decision to close institutions and to modernize the legislation. The creation of this new legislation should be viewed as an opportunity to support people with intellectual disabilities to exercise their rights to become contributing citizens of this province. However, to accomplish this, I do believe that there are significant changes that need to be made to the bill to ensure inclusive communities.

Community Living Chatham-Kent provides many services and supports for people. Our vision is "Discovering Dreams ... Connecting Lives." In order to discover someone's dreams and what they want to do with their life, you need to plan with the person and you need to plan with those people who are significant in their life.

The legislation, as it is written, provides no opportunity for planning. It speaks to an application centre that will conduct an assessment, determine eligibility, assign a dollar amount and put people on a waiting list.

What if all they needed was help to get set up in an apartment? Our current local mechanisms in Chatham-Kent would address that immediately. The person would not have to go to an application centre, perhaps located in another town, for that support, and by being flexible with our resources for a short period of time, agencies would address the situation. Further, when people and families find themselves in crisis situations, they require support in a timely fashion, not waiting for an appointment with an application centre.

So I address two issues here: the lack of a planning process, and the need to consider a standardized application process at a local level, rather than another layer of bureaucracy called application centres.

The issues people face in our community are not in application difficulties, but in a lack of resources.

Currently, our agency starts working with young adults at age 16. We provide summer employment and assist with co-op placements while they are in school. These activities are not funded by the Ministry of Community and Social Services. We do this because it's important for 16-year-olds to be able to transition into their adult life. When these young adults graduate from high school, they're already involved with an agency for support.

However, as the new legislation reads, these young adults will have to cease being involved with the agency at age 18 and apply to an application centre to see if they are eligible. All this, when the educational facilities have already assessed these young adults, deemed them eligible for support and started a transition plan with the agency. While the person waits for application and

another assessment completion, not only will the momentum of the transition plan be interrupted to the detriment of the person and their family, but it's also double-assessing by two ministries.

The same holds true for transitioning for respite services. These are services that families desperately need and utilize in order to continue to have their sons and daughters reside at home with them. Right now, it is a seamless transition. Our agency provides child and adult respite services, and at age 18 the young adult just transfers into the adult system. Now they'll have to go to an application centre and reapply for a service they've had since they were one year of age. I think we have to look at this: Do families and these individuals cease to need that service just because they've turned 18?

Again, this brings us back to acknowledging and working with local access processes that have this planning process in place.

Our community is also very concerned that a waiting list provision is being legislated. That presumes that there will always be long waiting lists and that people will still not get the services or supports they require.

The legislation should reflect the government's willingness to work together with individuals, families, communities and service providers to provide supports to promote citizenship.

The other issues that we see include the need for a preamble to outline the purpose of this legislation and the expected social policy outcomes. There is no appeal procedure for decisions about termination of support, and there are different accountability measures for agencies versus direct funding models, and I believe very strongly that there should be accountability for every service that's provided to people, including those direct funding models.

Finally, this legislation does not afford dignity and respect for vulnerable citizens of our province. There is no presumption of capacity to make decisions on their own, there is no recognition that community development funding is required to connect people in a meaningful way with their communities, and there is no mechanism where the voice of people can be heard to either appeal decisions or decide what their lives will look like.

1030

Perhaps the most demeaning piece of this legislation is that an inspector may walk into their homes without their permission. Group living should not be identified as beds and spaces; it should be recognized as people's homes, and people who reside there should have the right to reside with the same right to privacy as any other citizen of this province. Anything less reverts to institutional living.

Finally, the lives of hundreds of people were disrupted in 2007 with strikes. They had picketers and disturbances on the front lawns of their homes. As innocent parties, they were forced to endure a lack of privacy and of the right to lead peaceful lives. New legislation provides this province with a golden opportunity to identify the de-

velopmental services sector as a no-right-to-strike sector so this never occurs with those people again.

To be true citizens of Ontario, people who have disabilities require individualized lifelong supports that are flexible and respond to life changes. Legislation that is passed in Ontario regarding those supports and services should reflect that.

I thank you for this opportunity to speak with you. I have also been advised to offer the expertise of the provincial executive directors in designing the regulations that will accompany this legislation. I will leave a copy of this document with you as well as the executive summary of Bill 77 prepared by Community Living Ontario. Thank you very much.

The Vice-Chair (Mr. Vic Dhillon): Thank you. You have about three minutes each. We'll start with the official opposition.

Ms. Sylvia Jones: Thank you.

Ms. Lu-Ann Cowell: You're welcome.

Ms. Sylvia Jones: Excellent presentation. You covered off many of the issues that we've already been hearing in the last couple of days. The no-strike provision, making it a no-strike sector: Is there a way to meet that halfway in terms of no striking at the homes?

Ms. Lu-Ann Cowell: Absolutely. Our goal is never to see people go through that again. It was very disruptive to their lives. They were frightened by the people on their lawns. They were frightened by the disturbances. They felt like they were living in almost a jail-like setting because they couldn't go out, all those kinds of things. If there's any way we can prevent their homes being picketed, we would welcome that.

Ms. Sylvia Jones: Thank you.

The Vice-Chair (Mr. Vic Dhillon): Thank you. Mr. Ramal?

Mr. Khalil Ramal: Thank you very much for your presentation. You mentioned many different elements. I want to focus on three things you talked about: the application centres, inspection and the preamble. On the application centres, first I want to congratulate you in terms of being able to accommodate all the people with disabilities quickly to receive service. But what about other locations that do not have this ability? How can we create some kind of standard?

Ms. Lu-Ann Cowell: I think that's what I spoke to. If we had a standardized application process that was coordinated in each community that families could access, that would eliminate the need for an application centre.

Mr. Khalil Ramal: This is what you mentioned. There's another name for the application centre; we can call it a coordination centre or whatever you want to call it—

Ms. Lu-Ann Cowell: But there's a major difference here. We do this as part of our job. This is not another bureaucracy. The agencies in our community come together voluntarily and assist people with getting them the services and supports they require. Certainly there's a waiting list for some services, like 24-hour residential. The issue isn't in the application; the issue is in the lack of resources.

Mr. Khalil Ramal: Another question is about the preamble. You don't think defining developmental disability and eligibility, being able to receive service, creating the application centre and providing funding directly will be part of citizenship and inclusion?

Ms. Lu-Ann Cowell: No. No, I think we need to be very clear in this, that we identify that people who have intellectual disabilities have the same rights and ability to access their communities as any other person. I bring to your attention the fact that—

Mr. Khalil Ramal: This is embodied in the bill. When you go through the bill, you can see it. Obviously, when we mention all these elements—

Ms. Lu-Ann Cowell: No, there's no mention of community development in the bill. It's a very important function of people to become contributing members of society. In our organization, our community development person made contact with the local Kiwanis Club. We now have a group of people with intellectual disabilities who are chartered Kiwanis members. They have their own club. They volunteer in the community, they give back, they raise money and donate it to charity and they are being mentored by the elite of Chatham-Kent society. That is inclusion, and that's being a citizen of your community.

Mr. Khalil Ramal: So when I give you the right to live on your own and get support and get service—

Ms. Lu-Ann Cowell: Absolutely.

Mr. Khalil Ramal: And that's what the bill's all about: to give families the choice and give people with a disability the choice to seek service and—

Ms. Lu-Ann Cowell: I don't see a problem with people having choice; I see a problem with people not being able to get the resources they require and thinking that an application centre is going to get that for them.

Applause.

The Vice-Chair (Mr. Vic Dhillon): Just to interrupt, I'd ask people in the audience to refrain from any applause or any comments, please; it's a big distraction.

Mr. Ramal, you have two more minutes.

Mr. Khalil Ramal: And how can we ensure safety and transparency without an inspection? As we know, head offices—people are subject to inspections in order to make sure the residents or the people who are seeking support and service are being protected and not being abused.

Ms. Lu-Ann Cowell: I think there are several things that you do here. I can only speak for my agency, but we do have a multitude of policies and procedures; we have zero tolerance for abuse. Does that protect people 100%—

Mr. Khalil Ramal: That's you, though. What about the others? How can we make sure as a government, as parents—

Ms. Lu-Ann Cowell: But the government already does that. We have to have certain policies and procedures in place in order to operate, and that—

Mr. Khalil Ramal: But you mentioned a few minutes ago that policies do not protect people. You have to have some inspections, to come without any notice—

Ms. Lu-Ann Cowell: And that's the same thing with children who are abused or the elderly who are abused—and that would be the legal system. If you are that concerned that someone is being hurt in a residential location, then you would absolutely get a warrant to come in and check that out, and you would do that in anybody's house or in a nursing home.

Mr. Khalil Ramal: What's the difference between anybody's house and an organization like Community Living—

Ms. Lu-Ann Cowell: I think what we've lost perspective on is that group living is not a group home; it's that person's home, and they have certain rights—

Mr. Khalil Ramal: But they're administrated by a business—that's the label. Therefore—

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. Thank you for your presentation.

PEOPLE FIRST TILLSONBURG

The Vice-Chair (Mr. Vic Dhillon): Next, we have People First Tillsonburg.

Welcome to the committee. Please state your names for the record. You have 15 minutes for your presentation.

Mr. Michael Kadey: Hello. My name is Michael Kadey. I'm speaking on behalf of People First Tillsonburg.

I have to discuss the rights that were lost to us last year due to the strike: the right to work and two weeks' pay, the right to go to friends and have meetings, the right to enjoy our homes and independence, and the right to have a voice to be heard.

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Staff behaviour to us was not right. They should act like adults and set an example of their work. It was not right for a health service vehicle to be used to keep people awake with lights flashing and sirens going. People in our homes did not know what was going on. They did not understand why their staff was in front of their homes carrying signs, yelling and blowing horns. We shouldn't feel threatened in our homes.

Relief workers were good, but it took two hours for them to get into the homes. They should be able to get into the homes sooner. What would the staff do if roles were reversed?

People First Tillsonburg feels that the whole impact of a strike should be changed. Only strike at offices, not at homes, or don't strike at all. Get funding ahead of time, rather than strike. We can't strike. Why should staff strike?

People First Tillsonburg feels that the transfer from school to adult should be smooth. A person should not have to reapply for services, and the ministry should update our information regularly as our disabilities do not leave us.

Every prescription that a doctor writes for us should be paid through ODSP.

We need more jobs for people with disabilities so they can live with dignity, cost of living, and have a place of their own. The school should have a program that will train people to work. The government should allow people to learn more skills.

We feel there should be an application centre so people will know where they can get supports and services so they can live a better life. Funding for one person is a good thing, but we have some questions. How does someone living in a rural area get there? Can an application centre be placed in rural areas also? The application centre should be accessible to those who can't drive. Could there be an online version? We agree that inspectors should go into homes in case something is wrong. Some people could be mistreated.

Thank you for allowing People First Tillsonburg to speak.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We'll begin with the government side, about five minutes each.

Mr. Khalil Ramal: Thank you very much for your presentation. I want to congratulate you on your presentation. You outlined and explained the details of the bill very well. That's why we want to have a notice of inspections, in order to protect the residents. You probably heard many different organizations that came before you and spoke against it. What do you have to say to them, as residents, the people who live in homes managed by certain organizations?

Ms. Della Derrough: We feel that there should be an inspector into the home—

The Vice-Chair (Mr. Vic Dhillon): If I could just interrupt, can I get your name for Hansard?

Ms. Della Derrough: I'm Della Derrough of Tillsonburg. I feel that we should have inspectors to go in the homes because there has been a lot of abuse in the years, and I feel that the inspectors should be allowed to go into the homes to make sure they're doing their job and to make sure they're not abusing the people who live there in their homes.

Mr. Khalil Ramal: Do you feel comfortable if you believe that people are going to come any time without any notice to protect you?

Ms. Della Derrough: Yes.

Mr. Khalil Ramal: So you think these are good things to be in place.

Ms. Della Derrough: Yes, I think it's good for people who live in the home to feel that they should be protected, be safe.

Mr. Khalil Ramal: So you don't feel that violates your privacy—

Ms. Della Derrough: Pardon?

Mr. Khalil Ramal: —doing things like an inspection violates your privacy or protections?

Ms. Della Derrough: I live on my own, but I feel that people who are living in the home now should be protected because something could happen or they could get sued, too.

Mr. Khalil Ramal: And you think the application centre will help many others to be assessed quickly?

Ms. Della Derrough: Yes, I think it would be good for the application centre because a lot of people don't drive, and we think it's good for the people who are coming out of the school system so they don't have to fill out an application—just do one application so that they can get the services.

Mr. Khalil Ramal: Thank you.

Mrs. Maria Van Bommel: Thank you for coming in. I really like your idea of the online application, especially in rural areas, and my riding is certainly very rural. Access through the Internet and through a computer is very good.

Ms. Della Derrough: It would be good if we got on the Internet.

Mrs. Maria Van Bommel: But sometimes, I know myself when I do applications, I have questions. How would you suggest—one of the things about going to an application centre is there is someone there to help you. If we do it online, how can we help if you have questions about the application?

Ms. Della Derrough: Do you mean if somebody can't talk—

Mrs. Maria Van Bommel: Yes, or if they don't understand the question on the application. Do you think they need to provide some help?

Ms. Della Derrough: They should have somebody there to provide service, then, so they can know what they're signing.

Mrs. Maria Van Bommel: Thank you.

Ms. Della Derrough: You're welcome.

Mrs. Christine Elliott: Thank you very much for coming this morning. You have excellent topics. I, too, like the idea of the online application. I think it's great for rural, remote areas and for people who may have some mobility problems as well. I think that's an excellent suggestion that we haven't heard yet, so I really like that.

I think with the other aspect that you mentioned, with respect to the difficulties in transitioning from teenagers into adulthood and avoiding double assessments, we really need to take another look at it to streamline that process to make sure it's seamless for people as they become adults.

The other issue, with respect to the no-strike zone, picketing and so on: We take that really seriously. We recognize that it's people's homes that are involved and people need to feel safe and comfortable in their homes. As a committee, we should really take a look at that and see how that can be worked out so that people aren't disrupted and don't feel uncertain about where they're living; so that they have full rights, as everybody does, to privacy in their own homes.

Some of the other items that you've mentioned I think are also excellent ideas, although it's not going to be dealt with directly in this legislation. Your concern around ODSP and earning a living wage and being able to work and supplementing is something that I would

urge the government to take another look at. We would certainly support that, because I think that's probably the next step in terms of achieving inclusion. This is a good starting point, but there's certainly lots more to be done, and I just want you to know that we recognize that and will have that in our minds as we go forward as well.

Ms. Della Derrough: Thank you very much.

Mr. Dave Levac: Mr. Chairman, we're hearing some feedback. So for the committee, when the microphones are on and your BlackBerries or any other electronic equipment are by the microphones, even though they're not active, if they're receiving e-mail, they buzz, the way we've been hearing it. So that's just a point of order for us with our BlackBerries.

The Vice-Chair (Mr. Vic Dhillon): Good point of order, and it was my BlackBerry.

Mr. Dave Levac: Was it yours? Mr. Chairman, I apologize for admonishing you. Forget I said that. Take it out of Hansard.

The Vice-Chair (Mr. Vic Dhillon): Thank you.
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COMMUNITY LIVING ST. MARYS AND AREA

The Vice-Chair (Mr. Vic Dhillon): Next, we have Community Living St. Marys and Area.

Good morning, and welcome to the committee.

Ms. Brenda Mitchell: Thank you.

The Vice-Chair (Mr. Vic Dhillon): If I could have the presenters state their names for Hansard, that would be very nice. You have 15 minutes, and you can start right now.

Ms. Brenda Mitchell: Thank you. Good morning. My name is Brenda Mitchell, and with me are Joseph Lambert and Marg McLean. Joe and I are board members of Community Living St. Marys and Area, and Marg is the executive director. Joe is also vice-president of People First St. Marys/Stratford and a former People First of Ontario board member.

It is an honour to be before you today to tell you about our community, the association we represent and our thoughts on citizenship, supports for people labelled with an intellectual disability in Ontario, and the proposed legislation Bill 77.

St. Marys is a small town of 6,300 in southwestern Ontario and is located between Stratford and London. St. Marys is fondly referred to as the "Stonetown" because of its limestone buildings, huge swimming quarry, and St. Marys Cement. The culture of our community is one of welcoming and including residents and visitors alike. We take our motto, "The Town Worth Living In," very seriously.

Community Living St. Marys and Area, like most associations, was started by families in the 1950s wanting to secure a better life for their sons and daughters. Incorporated in 1962, our association has grown and changed to better serve our community. Approximately 50 people labelled with an intellectual disability and their families

who live in St. Marys and several neighbouring communities use our services. From 1986, our association moved from congregated, segregated services to individualized supports. Since 1990, the association's two main service areas are planning and facilitation service and support service.

Citizenship, human rights and the work of our association have been tied closely through the years. Our history is rich with stories of people moving home from institutions and participating in and contributing to our community. We learned a lot about listening to people, building trust over time, introducing life in community to people who have been excluded, and that relationships are at the heart of what makes good lives. We understand that the work we do locally is part of a larger human rights movement. Our association has supported People First locally and provincially for more than 25 years.

Community development and networking has been a priority for Community Living St. Marys for many years. It is reflected in our agency mission and also in our principles. Over the years, this has translated into participating in and initiating community groups aimed at making life better for all citizens of our community. Some examples of this are developing co-op housing, starting a mobility service, creating literacy services and starting a generic agency to assist people with employment barriers. These initiatives were innovative, only successful through partnership created in response to individual situations, and involved different levels of organizational risk-taking.

If we understand that quality is about having a good place to live, enough money, doing work that is important, having friends and family who care, having opportunities to learn and being valued and respected in the community, then we must understand that this type of investment in our community is really an investment in ourselves and our quality of life. These community initiatives could be seen as safeguards.

I'd like to tell you a little more about person-directed planning and facilitation. Planning and facilitation is an ongoing process that supports people to think about the future and facilitates real change to occur. It is particularly useful in supporting vulnerable people to speak up for themselves, make choices and discover their own unique gifts and dreams. The process supports the person and their family by providing information and creative ideas and connecting to community resources and networks. In our association, everything starts with the person. Planning and facilitation helps determine what support services the person wants and needs.

Nathan's story is a good one to share. He is a young man who ended up in a small rural hospital for three months while service providers in our county struggled to find ways to meet his needs. He had been removed from the group home he had been living in due to his "challenging and destructive behaviours." An intensive behaviour management home was recommended for Nathan.

Fortunately, a planning facilitator began working with him. Within a few weeks, an alternative plan was de-

veloped. A family with a granny flat attached to their home welcomed Nathan to move in. With support from his neighbours and some support workers, Nathan successfully lived in his home for several years. He now lives in a separate apartment on the farm of one of his original workers. He is very involved with his community and has spent many hours volunteering with the local library, his church and the minor baseball association. He has many friends and his once-distant family relationships are stronger than ever. Nathan lives a good life, one that is built in community. Effective planning and facilitation opened possibilities for Nathan that others could not see.

We are sharing some of our association's story and the stories of people who use our service because we believe it is very relevant to the discussion of Bill 77. While we believe that there are some very important components of the proposed legislation, we also believe that Bill 77 misses many opportunities to do more to enhance and support citizenship of people who have been marginalized for years.

In your handout, we have listed some discussion points and recommendations. I'm not going to read through them all. I will read the recommendations and the discussion points which we consider need reading.

Recommendation 1: Change the legislation name to reflect the anticipated outcome: a life in community.

Recommendation 2: Write a preamble with stated vision, values and principles.

Person-directed planning and facilitation is missing from the proposed legislation. We believe that this is a critical component of an effective, transformed developmental service system for Ontario. Based on our 25-year history of planning with people, we know that effective person-directed planning and facilitation, grounded in the values of citizenship, make a tremendous difference in the lives people lead. In the absence of effective, person-directed planning, it is easy to simply slot people into service or have them sit for years on waiting lists.

Planning and facilitation looks at community resources and solutions as the first place to start and is therefore not dependent on system services or funding. The quality of people's lives can become better right away by having someone to help set directions, think about possibilities and reach out to others. It works directly with people and their families on an individualized path and is committed to implementing goals. It works to empower people, build skills and share creative information so that people are less reliant on services in the future. Another way it strengthens people is by assisting to build social networks with family, friends and neighbours.

There is an upfront cost to planning and facilitation, but the savings in actual service costs far exceed the initial investment. We believe that person-directed planning must be available to all people deemed eligible.

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Independent planning and facilitation is when the service is provided outside of the existing service system. Growing research shows that having this option increases

the likelihood that people and families will develop situations to live and work in and relationships with others that are part of their community, as opposed to a placement in a service or program.

Therefore, recommendation 3: that all eligible persons will be entitled to person-directed planning and facilitation.

Bill 77 does not provide for community development. Based on our long history of community involvement, we know that it takes intentional action to create a community that values the contributions of all citizens. Fostering relationships and community partnerships, supporting People First, and creating new and innovative responses to shared issues is dependent on people, time and energy. Investing in communities and their citizens recognizes the significant contributions they make and leads the way for a truly transformed developmental service system in Ontario.

Recommendation 4: Fund innovative community development initiatives that will enhance the citizenship of people labelled with an intellectual disability. Provide ongoing funding for People First of Ontario.

Recommendation 5: Recognize the legal capacity of people who have been labelled with an intellectual disability and provide for supported decision-making.

Bill 77 suggests that waiting lists are not only acceptable but inevitable. Waiting lists for service are not acceptable. Waiting for personal crisis and then to be made a "priority" for the system is very disturbing and can lead to feelings of hopelessness. People do not want to hear from some bureaucrat that their situation isn't bad enough. Often, planning and facilitation support is particularly helpful when people are experiencing a crossroads in their life. The quality of people's lives can become better right away by having someone to help set directions, think about possibilities and reach out to others. If person-directed planning and facilitation is an entitlement, then waiting lists will not be such an issue.

Recommendation 6: Remove the concept of waiting lists from Bill 77. Provide person-directed planning and facilitation to all eligible people.

Recommendation 7: Ensure easy access for all people applying for support by having local offices.

Recommendation 8: Monitoring and evaluation of the application centre needs to be completed by an outside third party on a regular basis.

Recommendation 9: The application process needs to build on assets, not deficits, of applicants.

Recommendation 10: Develop clear values and standards grounded in the principles of citizenship and hold people and agencies accountable to these.

Recommendation 11: Clarify the position on the home inspections and how personal information will be used.

In closing, we congratulate the government on their reconfirmed commitment to the closure of institutions. We would like to thank you for providing the opportunity to speak on behalf of Community Living St. Marys and Area. We will be meeting with our local MPP, John

Wilkinson, later this summer. We are happy to answer any questions you might have.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. You've taken up your whole 15 minutes, so there will be no questions.

Ms. Brenda Mitchell: Read your handout.

Ms. Sylvia Jones: It was excellent.

ENSEMBLE

The Vice-Chair (Mr. Vic Dhillon): The next presentation is from Ensemble.

Welcome to the committee. If you could state your names for Hansard, those who are presenting, and you have 15 minutes.

Ms. Lisa Raffoul: Thank you. I'm Lisa Raffoul. I am a parent. On my right, to your left, are Jackie Barraco and Jane Welsh. Ensemble is a parent-directed resource organization in Windsor-Essex county.

We want to start by first of all thanking you for taking the time to do these consultations and for inviting us to speak and share our thoughts. We will share our thoughts regarding Bill 77 from a parent's and a family's perspective. Being a resource for families in our community, we certainly have the opportunity to listen to, speak to and learn from a wide variety of families in Windsor-Essex county. To start, Jackie is going to share a few of her thoughts with you.

Ms. Jackie Barraco: Good morning. With new legislation, the perception is that families may possibly feel like their input is not wanted, that we would be placed on the outside instead of having a close working relationship with supporting/service provider organizations.

With regard to the random and unannounced inspections, I feel that the dignity of our sons and daughters would be intruded upon. For a stranger to show up at any time, unannounced, to inspect a residence where our sons and daughters are living is insulting and degrading. Although such a home may be operated and staffed by a service agency, these homes must be considered as the individuals' homes, and thus, with random inspections as described in the proposed legislation, these inspections do not respect the privacy of an individual's home. As a parent, I feel it is much more considerate and respectful for an organization and its staff to develop a relationship with the individual and/or their families so that trust is developed. After all, it is support staff who get to know our children—our adult sons and daughters—and it is important for them to feel trusted too. Effective conflict resolution is part of the growth process in relationships, and I feel that it is far more effective to work through concerns with the individual, the families and the support staff together.

A brief question would be, where would the money come from to support these inspections, or the inspectors? Will our families have to give up money yet again for another cause that may not be worthy?

Ms. Jane Welsh: As Lisa said, my name is Jane Welsh. My husband and I have three children, two of

whom have multiple disabilities. For ourselves, upon reading Bill 77—I see the benefits, and we hear from other families the benefits of having options. Every family is individual and needs the ability to make choices.

For our family, I have come to realize in a very short period of time that I need help, so I seek help through supporting agencies. I find I am tired already from raising my children and trying to maintain the family atmosphere. If I can dole out and get help from service agencies, I find that to be a great advantage.

I've created support circles for our children to help with the raising of the children and to help facilitate their needs. The agency can offer information that I need to make choices. They offer community supports. They offer actual social involvement for my children and less isolation.

I need well-trained support staff. The idea of having to go through all the work of hiring, questioning and checking out backgrounds is that much more added to my plate, which is already full. I don't have to worry about providing transportation to have social situations for my children; that's supplied.

I still have input into their daily lives. I think it's very important that the support structures for my children are created but that I'm still involved in their lives and my suggestions and needs are also met and very welcomed. We've created a true partnership that I believe is essential.

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I'm not convinced that the proposed act addresses the fact that funding for these services is not being met. The act states that there will still be wait-lists. This terrifies me. While people are on wait-lists, many things can happen to the structure: stress to all family members, including their disabled children; financial impact, present and future; emotional impact; marriage breakdowns; family separations; and fear for the future.

For me, and my belief for all families, is that the services that are provided are essential services; there shouldn't be a wait-list. I feel that if families have to get into the crisis mode, then there has already been that breakdown. I feel the bill should state that these services are essential for families and that there will not be a wait-list.

The bill also recommends getting creative with the dollars that we can get. Some of the suggestions are to pool our resources as families, but families already have enough to handle. In order to get a bit of relief, you're asking us to share responsibilities with other families. I have all I can handle, and for me to take on another individual for a weekend or for the week in order to give another family a break that they deserve—I have all I can handle. I can't take on any more responsibility. I think there needs to be enough money in the sector for each individual, and families can choose how they go about utilizing that. Our children have value to us, and we value the people and the lives that help support our children.

Whether the funding comes from an agency or direct funding, the money needs to be there to show respect to those people who do that supporting. Wage competition shouldn't be the issue when it comes to getting good, qualified support. The new bill should set a standard for adequate funding so that wages for our support people are equal regardless of whether families choose an agency for support or direct funding. For me, there shouldn't be that competition. If a family chooses direct funding, then there should be enough money to pay them equally as an agency can.

I have more concerns, but I want to leave time for Lisa. I'd like to take the opportunity to say thank you for listening and for welcoming the input of families.

Ms. Lisa Raffoul: Thanks, Jane.

As well as Jane and Jackie's comments, I'm sure you'll hear from a wide variety of individuals and families over the next few days.

One of the points is that we are all individuals. Everybody in a typical family lives their life according to the way they want to do it. Having sons and daughters with disabilities should be no different. We are pleased to see, families are happy to see, that there is choice in the proposed legislation, because with choice comes flexibility and opportunity.

However, I looked at a little bit of the introduction. It says, "The new act provides a new framework for the provision and the funding of services to, or for the benefit of, persons with developmental disabilities." We would much rather see that the new act will be responsive to individuals who have developmental disabilities because "responsive" means, and this kind of mirrors what the group before us said, that it responds to each individual. It is about planning for each individual according to the way they want to live their lives. By stating that it's for the benefit of people or for service for people, again, we can have people slotted into situations where it may not necessarily be their choice. So a service and support system that is responsive is much preferred.

Again, it's up to each individual choice. There are people who prefer the assistance of a supporting agency, and there's a handful of people who prefer direct funding. One of the things that families have told us is that they don't want to be left alone. Even if funding comes directly to them, the majority of funding is for supporting the lives of their sons and daughters. And for a family to become the HR person, the manager of supports, the administrative person, the accounting person—there's a lot of responsibility for families, and we certainly want to know that there are organizations out there to assist us and that we can turn to.

My son is 14 years old. Every couple of years, I have to go through—I self-administer his contracts now. I'm getting tired of being the be-all and end-all. So, as much as I appreciate that there is flexibility in our lives—but what we've learned by working in close partnership with organizations is that this is a constant evolution. Fifty years ago, we began in one direction, and as we learn and grow together, that's how things respond, that's how we

respond to one another. We know that a balance is needed, so we're pleased to see that there is choice, and we hope that there will always be that choice for families.

At the same time, in regard to community development, there's other legislation, the Accessibility for Ontarians with Disabilities Act, and if that's where the community development opportunities arise, I think it needs to work in conjunction. An individual can be given all kinds of funding, but if there is a community that is not responsive and supportive to them, I'm not so sure that their quality of life will be there.

Everybody is an individual, and I just want to be sure that as we develop the bill, we keep that in mind and that people are not left alone.

The Acting Chair (Mr. Yasir Naqvi): Thank you very much for your presentation. We have approximately a minute and 30 seconds for each side. Official opposition.

Mrs. Christine Elliott: Thank you very much for coming again to bring your valuable perspective as parents. You tell us what we really need to hear with respect to this bill. What I think I've heard, and I think the other committee members have as well, from parents, is that you appreciate the fact that there's choice, but it has to be real choice. If you're doing individual contracts, you want to make sure that those people who are working with you can be compensated to the same degree as people who are working in agencies. You want to make sure that it's a level playing field. And you need some help, both in terms of administering the plans yourselves and in terms of respite.

I certainly appreciate the stress that families are under. I wouldn't expect that there would be anything taken away or there would be any expectation that families who are already providing service to their own child would also be asked to do respite for other people's children, because we know that that's simply physically not possible. I would ask the government members to clarify that, but I wouldn't expect there would be an expectation of that.

Finally, I think we want to make sure that you know that we appreciate what you're saying, that we're hearing that, and we want to make sure that there is choice for everyone and that family members are assisted—

The Acting Chair (Mr. Yasir Naqvi): Thank you, Mrs. Elliott.

Mrs. Christine Elliott: Could I just ask one question? Some of the groups have commented about the necessity for planning groups to be involved with them. Would you find it helpful to have somebody to help you facilitate those contacts for your son's individual planning?

Ms. Lisa Raffoul: To have a person assist with planning?

Mrs. Christine Elliott: Yes.

Ms. Lisa Raffoul: Yes, as long as there's follow-up. In our community, there is planning, but families have said there's not necessarily follow-up—because every three months our lives change. So it's about relationships, and that's where the supporting organizations

come in, who are doing the ongoing. Again, it's questionable: Should it be independent planning or not? I think that responding to each individual, no matter who's doing that planning, is what's important—and follow-up.

The Acting Chair (Mr. Yasir Naqvi): Mr. Ramal.

Mr. Khalil Ramal: Thank you very much for bringing a different perspective, as a family.

I want to ask you a question. This bill proposes the establishment of application centres. Do you think that application centres are a good idea to help you to assess your kids or other kids, or do you have no idea about this?

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Ms. Lisa Raffoul: Our thoughts on the application centre have been, where are the additional dollars coming from to fund these application centres? Not necessarily because an application goes in and you fill it out. There could be a panel or a body looking at the applications, and not necessarily is it an application centre that's necessary; there could be an application body, a decision-making committee. But to create a new structure, we've questioned where the funding comes from for that.

Mr. Khalil Ramal: A quick question: You raised the issue about inspections, especially without notice. We heard from People First in Toronto and here—as you know, People First are the people who live independently; they have some kind of disability. They showed some kind of comfort for the inspection without notice. So how would you respond to that?

Ms. Jackie Barraco: If an individual is living within a home, through an agency, they are accountable to the staff, to the families, to the organizations. But what about the private homes? Who are they accountable to?

Mr. Khalil Ramal: No. Private homes are not subject to—

Ms. Jackie Barraco: So then the inspectors, when they're coming into your home—that's a private home.

Mr. Khalil Ramal: No, no. I said that the bill does not propose to inspect private houses, only the group homes that belong to agencies and organizations, because they are considered a business. That's what happened.

Ms. Lisa Raffoul: I think why we don't necessarily find comfort in that is because, again, our lives are ongoing and we would much rather see the supporting staff, the supporting organizations, learn from families and individuals and be required to provide a quality of support. Jackie mentioned trust. Trust is key. I guess what Jackie was alluding to is that if there's direct funding, you could have anybody running the organization.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. Thank you for your presentation. The time is up.

Ms. Lisa Raffoul: Thank you.

LIFELONG CARE GIVERS

SUPPORT GROUP OF SARNIA-LAMBTON

The Vice-Chair (Mr. Vic Dhillon): Next, we have Lifelong Care Givers Support Group of Sarnia-Lambton.

Mr. Dave Levac: Point of order, Mr. Chairman: It's obvious that there's a lot of work that has gone into the presentation of the visuals. I'm wondering if we can ask the organization if we can get them packaged into 8.5 by 11s and given to us so that we can preview them. Obviously there's a lot of writing in it that we won't be able to read while we're looking at them. So I would deeply appreciate it if we could get that turned into a package for us.

The Vice-Chair (Mr. Vic Dhillon): Would that be something that you guys could do for us?

Ms. Wilma Arthurs: Yes, we can.

Mr. Dave Levac: Thank you so much.

Ms. Wilma Arthurs: May I just say: These are the people we're talking about. These are our families, our children and their stories.

Mr. Dave Levac: That's precisely what the intent is. We're very supportive of it; thank you.

The Vice-Chair (Mr. Vic Dhillon): Thank you so much. Welcome to the committee. You have 15 minutes, and whoever is presenting, if they can state their name for the record. You may begin.

Mr. Tom Saul: Thank you, and good morning. My name is Tom Saul and I thank you for the opportunity to speak to the proposed legislation referred to as Bill 77. I am speaking on behalf of the Lifelong Care Givers Support Group of Sarnia-Lambton. This is a newly designed parent group that comes together to discuss issues of mutual concern. I am a parent, a volunteer member of Lambton County Developmental Services and a parent-advocate sitting on the developmental services planning committee of Sarnia-Lambton.

It has been said that a measure of a society can be taken in how its most vulnerable citizens are treated. This tenet holds true for people with intellectual disabilities. Many of our families will be profoundly affected by Bill 77. Therefore, we are pleased to have this opportunity to offer our comments.

My presentation contains a number of questions, which I do not expect you to answer today; however, I respectfully hope that you will honestly reflect on them in your deliberations.

We are encouraged by legislation that intends to make the system easier to navigate, brings needed services and supports closer to the people who need them and provides real choice and flexibility in the supports and services needed. While these are admirable goals, I would respectfully suggest to you that Bill 77, as it is written, will not attain these worthy objectives for the people of Lambton county. In many ways, in our opinion this is actually regressive legislation.

Our opinions are coming from a specific perspective. Let me reflect on involvement and commitment for a second. Take, for example, ham and eggs. The chicken is involved, but the pig is committed. The Legislature is involved in this bill, but parents are committed. At the end of the day, the politicians and the bureaucrats can go home and have their choice in the responsibilities that they will accept on their free time. As parents, we are

committed 24 hours a day, seven days a week and are profoundly affected by decisions that are made by people who are only involved. It is from this committed perspective that that I am addressing you today.

The institution of eight regional application centres is cause for great concern. As we understand it, the regional office will assume the responsibility for completing the application, doing the assessment, scoring the applications and allocating funds. This is a very closed process with no input outside the regional application centre. Where are the checks and balances in this system? Is there room for community input and collaboration?

In Sarnia-Lambton, we have a local access mechanism called Connecting Point, established in 2000. This local office assists parents in making applications for services they require and assists them with completing and gathering of information and assessments that are required. The information is then passed on to the coordinated access. The coordinated access is a team composed of representatives from all the local service providers who meet on a monthly basis. The group works together to review the applications and the available resources and creatively attempts to meet as many needs as possible. A brochure for that organization is attached to the handout.

The system is not perfect, as the demand for resources is greater than the supply of funds. However, it is a very effective process, largely due to the high level of co-operation and creativity that exists between the agencies.

To move the application centre from the county would be a regressive step. This would create additional hardships for parents, forcing them to travel and adding local applications to a much larger catchment area. If we think for a moment of the county as a pond, the applications are now becoming part of a lake as they are added to the regional office, presumably covering a much larger area. Funds are now allocated on a county basis. Will this now change to a regional basis? In the case of an application that is nearing the top of the priority list in the Lambton pond, how will the status change as a result of now being added to the lake created by the newly established regional office?

A common application form is a good idea if it is designed to be user-friendly. The application proposed is of considerable length, 24 pages to be exact, with an estimated completion time of seven to eight hours. This is not making it easier for parents, who are already stretched to the limit in many cases. Will parents be required to complete this application when many hours have already been invested in completing the application currently on file? Will staff be available to assist with this application process? Who will pay for and supervise this staff? Is this the most efficient use of limited resources?

The constructive alternative is to leave the Lambton system intact and use any new funds to create more service options rather than creating another layer of bureaucracy. As one parent commented to me, "If it's not broken, don't fix it." In fact, MCSS program supervisors have suggested that the Lambton model is an excellent

example of best practices and have suggested it to other communities. The local model allows parents to update their application frequently, in some cases monthly.

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As parents age and continue to care for adult children at home, the need and the pressure continue to grow. Committed parents who went against the philosophy of the day 30 and 40 years ago kept their children at home, rather than institutionalizing them. These parents are now being subjected to additional hardships, as community resources are not available to them. By being responsible parents and providing a home in the community, they have saved the province millions of dollars.

What do aging parents do in a time of crisis? Who will advocate for those who cannot speak for themselves when their parents are gone? Direct funding to parents by bypassing agencies is an option for some parents, particularly when they are young and healthy, but this option is not for everyone. Not all parents are created equal and have the skills to train, hire and supervise the staff they require. I have seen numerous examples where parents have been forced to hire anyone they can find, just to get some respite time. The issue of liability will continue to grow as developmentally challenged people are supervised by individuals without proper training and supervision themselves.

Direct funding for individuals does nothing to sustain agencies and is not enough to cover the true costs of providing quality care. Agencies provide an administrative structure, training for workers, buildings, insurance and utilities, not to mention accountability to MCSS. After the recent Auditor General's report, we know that accountability is an issue. We need to support a system built on co-operation and collaboration, with the best interest of our sons and daughters in mind, not a system built on competition. The cheapest product is not always the best option in the end.

The constructive option is to strengthen the agencies providing supports to people in need. Many agencies were created by parents who band together to create a viable system of programs for their sons and daughters. Agencies have the structure to hire, train and supervise staff while developing creative programs to meet individual needs.

We are seeing increasing creativity as agencies work together to provide options and creative program alternatives. One example is Community Living Sarnia-Lambton providing space for a residential program and staff being supplied by St. Francis Advocates, another agency. In fact, Sarnia-Lambton service providers have a long history of working creatively and collaboratively. It is feared that with the implementation of regional application centres, this will be lost.

The commitment and supervision of a local volunteer board of directors helps to ensure accountability and relevance of local agencies. A strong agency system is necessary to ensure long-term continuity of services.

As a volunteer board member for 24 years, I can attest to the growing pressure on the existing system. It is

increasingly difficult to attract and maintain qualified staff to this sector while wages continue to fall behind other groups.

Please remember that families created most of these agencies and the agencies continue to be supported by family members. Private, for-profit companies will never be able to provide the committed supports that volunteer agencies continue to provide. Private companies are involved but not committed the way parents are.

In conclusion, I respectfully offer the following ideas for your consideration and action. You have the power to provide the input that is needed to make this legislation positive and meaningful.

(1) Maintain our single point of access for Lambton county, so parents have local contact for service without having to travel.

(2) Recognize our local prioritized waiting lists.

(3) Create a strong and viable agency system to ensure long-term continuity of quality service options, thus providing parents with program choices.

(4) Allow a direct funding component for those who desire one, but one that does not erode the agency system.

You are involved in this process. We, as parents, are committed to our children and will have to live with the decisions that you make. I respectfully implore you to place yourselves in our positions, figuratively, as you deliberate on the future of our children and our families.

Thank you for your consideration and attention.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

Applause.

The Vice-Chair (Mr. Vic Dhillon): Again, applause—I know these are emotional issues, but I would request that we refrain from applause or any other form of distraction. Thank you very much.

We'll begin with Mrs. Van Bommel. There's a little bit over a minute each.

Mrs. Maria Van Bommel: Thank you very much for the presentation. I want to thank my colleague for suggesting that we try to condense these somehow and get them to all the members of the committee.

Ms. Arthurs, would you explain to everyone about your "real people" campaign and what this is, because people in the audience can't see what we have access to here in front of us.

Ms. Wilma Arthurs: Quickly, for the "real people" campaign, we are taking pictures of families that have children with disabilities who are on the wait lists. This is a cross-section of people who are on wait lists for different services. We just want to show the government who we really are so that you don't just see it on paper. We want you to see our faces, who we are. The stories are included. We are continuing to take photographs right through into the middle of September and we hope to present all of those to the government in the fall.

Mrs. Maria Van Bommel: Thank you very much. It's beautiful; the photos are just beautiful.

Mr. Saul, you have recommendation (2), and that is to “Recognize our local prioritized waiting lists.” Could you expand on that particular comment? When I met with your group, you talked about that, and I’d like the committee to hear further about that issue.

The Vice-Chair (Mr. Vic Dhillon): Very quickly, Mr. Saul.

Mr. Tom Saul: People in Lambton county have been placed on a prioritized waiting list, and over the course of time, as the waiting list progresses, people are getting closer and closer to services, because we’re talking about a small countywide list. If that is expanded to a regional list, we’re going to be adding other names, and it’s going to become a larger pond—a lake was the analogy I used. Those applications will no longer be near the top; possibly, they could be set back years.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. The opposition.

Ms. Sylvia Jones: Thank you. Your concerns about the application centres and what that’s going to do for local existing processes is something that we’re aware of as well, and we’ll be watching it.

Mr. Tom Saul: Thank you.

Ms. Sylvia Jones: I commend you for the work you’ve done so far, and we also fully support what is happening at the community level, and we’ll be making sure that Bill 77—whatever changes come forward are not going to erode those services in any way.

Mr. Tom Saul: Thank you. That’s reassuring.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much for your presentation.

WOODVIEW MANOR

The Vice-Chair (Mr. Vic Dhillon): Next, we have Woodview Manor.

Mr. Paul Cano: Shall I distribute my presentation? Thank you very much for inviting us to present—

The Vice-Chair (Mr. Vic Dhillon): If I can just have your name for the record, and you may continue.

Mr. Paul Cano: Sure, yes. My name is Paul Cano. I’m a member of the parent council of Woodview Manor, a support agency for adults with autism spectrum disorder located in Hamilton.

Thank you for the opportunity to comment on the proposed legislation for services to persons with developmental disabilities. We strongly support the proposed functional definition of “developmental disability” contained in the draft legislation. Backed by the appropriate policy directives and funding, this will provide more equitable services for all individuals with development disabilities. We also support the direct funding of individuals to allow them to choose the most appropriate services for their needs.

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We are a group of parents of adult children with a diagnosis of autism spectrum disorder, or ASD. Our children range in age from 18 to 55. Most of them do not have intellectual impairment, but their adaptive functioning is significantly impaired.

ASD is a developmental disorder of the brain where the ability to communicate effectively and form appropriate social connections is impaired. Many individuals also have debilitating repetitive thoughts and actions. These deficits make the activities of daily living difficult and work almost impossible without specialized supports. It is a lifelong disability.

Our experience has been that during our children’s school years, ASD was often not recognized by the school system as a disorder. We encountered some extraordinary teachers who did remarkable work despite the system in those days. Today, the needs of our children with autism spectrum disorder are becoming better understood. There are now services for preschool and school-aged children. Special programs for children with ASD are provided by most boards of education now. However, as our children move into adulthood, we are finding the same lack of understanding we struggled with when our children were young and the same lack of services and funding. There are very few services for adults with ASD, and those that do exist are inadequately funded.

Individuals with ASD can learn skills and coping strategies. We have seen remarkable progress and growth in individuals in our program who have been provided the right level of services. In a properly supportive environment, they can become much more independent with the activities of daily living, form strong social bonds with their peers and retain gainful employment. They do, however, require regular support to maintain this level of functioning throughout their lives. Individuals with ASD have difficulty in transferring learning from one context to another and coping with change.

We have found that continuing to live with aging parents without other supports is often not the right environment for that progress and growth. All too often, the outcome is social isolation and regression into repetitive thoughts and actions. These individuals who do not develop those vital skills of independence will, in the long term, require much higher levels of support from the community when their parents are no longer able to provide for them.

I’m here today representing a group of parents who have been fortunate that our adult children have found some level of support from Woodview Manor in Hamilton. Woodview Manor is a unique agency in Ontario that provides programs to enhance social and life skills and provides vocational and recreational support to individuals with ASD. The funding for the manor is focused on its program for young adults to prepare them for independent living. It does this very well. However, it receives no funding for the lifelong support that these individuals require to live a meaningful life. Today, the manor is stretched to its capacity and even beyond, while the demands on its services are increasing. The manor staff has the experience and the skill to provide the services that are required but are severely constrained by the current lack of funding. Other communities do not receive even this level of support that is provided in Hamilton.

Our hope for the proposed legislation is to overcome a current barrier to greater recognition and services for adults with ASD. The current legislation defines “developmental disability” in terms of intellectual impairment, but we note that the proposed legislation has a definition of “developmental delay” that is based on functional ability. We strongly support this more modern and useful definition. This is particularly important as the manor tries to support these adults long-term—they are denied funding because they have normal or above-average IQs. We have seen that the definition of “disability” currently requires limitations in cognitive functioning. “Cognitive functioning,” in the legislation, is defined as the ability to “reason, organize, plan, make judgments and identify consequences.” We would like confirmation of our understanding that an individual with ASD who has these cognitive impairments but has a normal or above-average IQ would still be considered to have a developmental disability.

With respect to the policy directives, we hope that as the policy directives are developed they build on these definitions and set out criteria and priorities that do not discriminate against individuals with ASD with a normal or above-average IQ. We hope to have the ability to provide input to the development of these policy directives, as we have graciously been given the input to speak today.

We note with interest that the direct funding of individuals is permitted by the act. We strongly endorse this approach. Allowing individuals to select the services and service providers of their choice can lead to more efficient delivery of services. Individuals and their caregivers know best what services they need to support their activities of daily living and social development. For some that would be a recreational program, while for others it may be a job coach to allow them to retain meaningful employment.

For our adult children, we are not asking for a service that costs a king’s ransom. We are looking for a Goldilocks solution: not too hot, not too cold—just right; not too much support, not too little—just right. Too much support for our adult children and they will not develop the self-reliance to live independently. Too little support and they will regress, lead unfulfilled lives and in the long term require expensive care. With the right level and type of support, they can live independent lives, work and contribute to our community.

In summary, we strongly support the new legislation and encourage you to pass it into law as quickly as possible. We look forward to policy directives and infrastructure being developed that will allow the promise of the legislation to be implemented on the ground. We trust in the government to adequately fund the programs so that adults with ASD can lead independent, productive lives and make their own contribution to their communities.

Briefly, to give you the personal note, I volunteer on the Woodview Manor parent council, as I have a 21-year-old son with ASD who has been well served by the manor. Chris lived there for two and a half years after

high school and learned valuable independent skills to the point where he now lives on his own in an apartment with another Woodview Manor client, and he attends university part-time.

However, this is not yet a happily-ever-after story. He is still quite deficient in job skills. He has never successfully found and kept a job. It is our hope, as parents, that in the coming years this will happen and he will not need to rely on ODSF. However, it won’t be without the support of an agency familiar with his needs that he will be able to attain this goal of finding meaningful work. Beyond that, given that he, as an ASD individual, will have continuing difficulties comprehending social behaviours, communicating and understanding the motives of others, he will get and lose these jobs because of these problems. As well, he will be at higher risk than the general population of mental health problems. His parents, as we increasingly age, will require the help of an agency, such as Woodview Manor, funded through Bill 77 to support us as we support our son. Thank you very much.

The Vice-Chair (Mr. Vic Dhillon): Thank you. We’ll begin with the official opposition—about two and a half minutes each. Ms. Elliott.

Mrs. Christine Elliott: Thank you very much, Mr. Cano, for bringing the perspective of adults with autism spectrum disorder into this whole discussion. I think that’s an important perspective. The fact that you’re talking about functional ability rather than an IQ assessment—I think that’s very relevant and very important. I agree with you completely on that.

Your other comments with respect to the need for vocational supports and opportunities: I think that’s the next piece that we need to take a look at. It’s part of this, not the central purpose of it, but I agree with you that there’s a great need for that.

You mentioned in your brief with respect to what other services Woodview Manor could provide if they had additional funding. Could you expand a little on that for us, please?

Mr. Paul Cano: Woodview Manor currently is supported as a transition organization; that is, to take young adults with ASD, give them the independence skills, and then in a perfect world they would go into the community to find jobs, live on their own and live happily ever after. It’s those individuals who go out and then things fall apart and end up re-entering the transition organization. So it’s supporting them in jobs, like job coaches, to allow them to continue to keep those jobs, and when they encounter difficulty, they have a resource to turn to so they don’t just get fired for their inappropriate social behaviour. It’s to have them navigate and help with crises such as the mental health problems they are subject to. So it’s those adults in their 30s and 40s who end up coming back, looking for help and support because things have fallen apart, and who end up needing the residential side again. I appreciate that, if I’ve got it right, this is addressing a lot of the residential needs of our disabled individuals. That’s not what the bill is all about, but it’s a large part, correct?

Mrs. Christine Elliott: Partly, but it's really the whole person. I think that's what we're trying to get at, the needs of the person over time, and I think what you're talking about is an ongoing relationship that people can continue to have contact with.

Mr. Paul Cano: Yes.

Mrs. Christine Elliott: Thank you.

The Vice-Chair (Mr. Vic Dhillon): Mr. Ramal.

Mr. Khalil Ramal: Thank you very much for your presentation, especially when you have tremendous experience, being a father and also a volunteer with an organization that supports people with disabilities. How do you see yourself being supported if this proposed bill passes, especially in terms of direct funding?

Mr. Paul Cano: Agencies, I think, could either do it as an agency directly funded by the ministry or as providing a fee-for-service thing for job coaching, for recreational services, for these kinds of independent services. I think our organization could function in either fashion, and I think it probably needs to have both. We've heard very eloquently the difficulties of just doing direct funding, because you need that infrastructure for training of support staff and the like. I think we've seen that in the home care sector, with CCACs bidding for services. Sorry; I'm getting into health care because that's my work life. The nursing agencies, now, that aren't directly funded but have to bid: We're finding nursing agencies that aren't as supportive of professional development and that kind of stuff if they're all just bidding on a fee-for-service thing for one particular service. I hope I'm explaining that properly.

Mr. Khalil Ramal: And you know that we propose in this bill to establish application centres, to have the one standard across the province of Ontario. From your own experience, do you think it's a good idea or, as somebody mentioned, it's not a good idea?

Mr. Paul Cano: In our areas, I think that would be the Contact agencies; have I got that correct? Hamilton, Niagara and Brantford have something called Contact. That's how we're envisaging that it will probably happen. We figure that's reasonable. We're concerned about the development of the policy directives that they file, that they are managing the waiting lists and that there are clear policy directives in which the consumers have great input to deal with how they are going to administer this.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

The next presenter is Mr. John Joyce. Is Mr. Joyce here? It doesn't look like Mr. Joyce is present, so we'll recess a few minutes early and we'll convene back in this room at 1 p.m.

The committee recessed from 1149 to 1301.

SHARON AND STEVE SHARP

The Vice-Chair (Mr. Vic Dhillon): The committee is back in session. Our first presenter this afternoon is Ms. Sharon Sharp.

Good afternoon.

Ms. Sharon Sharp: Hello.

The Vice-Chair (Mr. Vic Dhillon): If I can have your names for the record, you may begin. You have 15 minutes.

Ms. Sharon Sharp: I'm Sharon Sharp, and my husband—

Mr. Steve Sharp: I'm Steve Sharp.

Ms. Sharon Sharp: We're going to take turns reading because both of us are nervous.

The Vice-Chair (Mr. Vic Dhillon): Take your time.

Ms. Sharon Sharp: We would like to acknowledge the Liberal government and the Minister and Ministry of Community and Social Services for pursuing public input in regard to Bill 77. As taxpayers, it's always a positive step when our government decides to listen directly to people involved. As parents, to share in this dialogue it also allows us to show you that we are committed in our role as parents of a family member with a developmental disability.

Our family members must live with this legislative act, follow the rules and regulations, and yet strive for the opportunity to enjoy a fully inclusive life as active citizens in our communities.

Perhaps you would like to take a moment to think of a person you know of good character. Reflect on the things that the person says and does, the personal characteristics that make him or her a role model. Chances are that high on the list of role-model qualities is the word "commitment," the unwavering dedication to being a good family member, a loyal friend, to doing his or her job at work and away from the employment site, to doing what's right, what's noble and decent. People with true commitment, like your role model, just seem to have their heads and hearts in the right place. They keep priorities straight, they focus on what's important, and they know inherently that what they believe must drive how they behave, and how they behave ultimately determines the character they possess, the reputation they enjoy, along with the legacy that they leave behind.

Abraham Lincoln had this to say about commitment: It's "what transforms a promise into reality. It is the words that speak boldly of your intentions and the actions which speak louder than the words." We come here today to share our commitment to offer a review and changes to Bill 77 for the benefit of children who live with different abilities; to share with you what is right, noble and decent; to do and keep our priorities straight; and to focus on what's important; and so that Bill 77 will be able to leave a legacy. We trust the committee members and our government will listen to our commitment as parents and families, understand our values of commitment and share in the legacy of this commitment for the future of all persons with a developmental disability by reviewing, amending and conciliating Bill 77.

There are several areas of our family life that we could share with you too numerous to mention. However, we will share that our son has chosen to be a teacher, a brother, an employer, an author, a social director and most of all just the amazing person that he has become.

Bill 77 will have an important impact on him, our family life and our future plans for a good life for our son when we are no longer here. As advocates, we have several concerns regarding Bill 77 and how it will affect our family member.

People with developmental disabilities need to be included in everything; it's their life. Services and programs do not make a life. Friends and family whom the person trusts need to assist the person to be heard. People with developmental disabilities and the people they do trust should decide where the supports should come from, who gives assistance and how the planning will take place. Supports, both paid and unpaid, help people reach their goals, explore their dreams and take risks of everyday living.

Our son has done this personal planning, and nothing was planned without his input. He followed the PATH planning process. We listened to him set out his goals and some far-reaching dreams that he has. We supported his successes in making a life plan following his choices. He has expanded a circle of friends and family to share his daily life with, and they will continue to help him grow. Now he needs some basic constant supports to maintain, enhance and continue his contributions to being included in his own community. Direct funding would do this, funding that would allow for consistent, independent planning and facilitation to allow him access to resources in our community. Families have asked for and find it most helpful to use direct funding options if there is sufficient planning, education and information to assist them. Bill 77 needs to have the structure in place to include person-directed planning, independent facilitation to community resources and funding dollars to back it up to show that this government is committed to standing behind people with different abilities and their families. This is essential for direct funding to be used effectively. This model does not necessarily need all the funding to go through agencies. Therefore, a more equitable balance of dollars would allow these same options to be supportive of families who have chosen direct funding.

Planning should be a responsibility of the individual with family and trusted people in their lives. This planning aspect should be independent facilitation of resources and planning supports provided by legislation of Bill 77. Each person and family is unique, and therefore each plan and funding outcome should also be unique, investing in people and families, not always only agencies and programs.

Agency services have been very helpful in the past—the true foundation of some supports for individuals and families for several years. However, now is the opportunity for them as well to change their way of thinking, become more community-creative and supportive of families' choices and think outside of the box for options. It's time to shift the movement for all developmental services up to the next level. Bill 77 could do this and lead the way to encompass all aspects of human rights and citizenship for people with developmental disabilities.

This legislation should recognize that a person born with a developmental disability is likely to have it their whole life. There's no cure. We know it and you know it, so the bill should not have to keep doing assessments for eligibility or a definition of what a disability is.

1310

Mr. Steve Sharp: Other definitions that concern us are the residential support services, caregiver respite services and host families. These do not seem to be happening in a reasonable pattern across the province. These definitions are very restrictive and do not allow the creative outcomes that individuals and families are striving to attain.

Likewise, supported independent living options need incentives and regulations for community choices and families to be creative with support by using direct funding. Lack of funding for this is also evident.

Eligibility and access: Eligibility is determined at age 18 for ODSP, which is your government process and therefore should be recognized and not in question again. This whole process happens over and over, and families are tired of having to prove their child has a disability. We have used our highly technological expertise to record our son's life progress; we do not wish to do it over and over again. We do not wish to share our entire family life with strangers, either.

Bill 77 does not provide for independent planning supports or facilitation of local community supports. There is no funding for implementing planning, support for individual self-determination or any framework wherein the family can be assisted. Again, legislation and funding to address this issue are missing.

Bill 77 provides that people must be assessed again, evaluated in every part of their life, and then you get to decide what they need and the funding they get. We like to look at our son as a whole person, not bits and pieces. We live an active and involved lifestyle that he participates in as well. We cannot stop each activity to decide what amount of dollars goes to make this happen or that happen. Our family life is ongoing, and we should not have to stop to analyze each piece of it or our son's. We need a simpler process that allows us to be treated fairly and that respects our family lifestyle. We don't particularly want to always deal with the regional office, because it expands the cost of everything we are required to do.

We do not need another profile of our son, to be serviced, slotted into a disability category, labelled and lumped with everyone else. We would like the application and your assessment method to look at what our son can do, what he can learn and things he has focused on for his goals. His positive abilities need to be encouraged by using supports that allow him to be an active citizen in his community. As such, we have always encouraged our children to be active citizens by discussing topics of interest that will impact our family life. Our family believes strongly in the opportunity to vote in elections and to discuss at length the political and governmental rulings in our province and country and how they affect us. Our family has tried to be responsible,

conscientious and creative by supporting him, his plan and his community involvement. With his opportunity to volunteer within his church and non-profit organizations, he has become a teacher, to teach others to show compassion, to learn patience and to develop social relationships by bringing other people together. Natural things happen when natural things are done.

We all know how important service clubs are to support our community resources. Our son was invited to join an Optimist Club and has been an active member for three years. He has participated in numerous fundraising events, has been sponsored to raise pledges for up to two or three walkathons each year and has been fortunate to meet several dignitaries at meetings and conferences. His presence and social skills have brought others to a new awareness of persons with different abilities. He is a valued member of the Optimist Club and offers reciprocal benefits to society and people who know him now.

Application centres will attempt to decide where people with developmental disabilities would go to find services and supports. How or why they could do this is beyond belief. People with developmental disabilities do not want someone who does not know them trying to decide what is best for them or telling them where to go. Therefore, self-directed planning, natural circles of support and separate, independent facilitators to get their own community supports are critical for success. This should be a number one priority after eligibility is decided.

There seems to be a heavy load for application centres to carry to determine who is eligible, to do an assessment, prioritize the list, to develop a service profile, show the way to find resources and service supports, advise the individual of availability of resources, keep track of all expenses and monitor the quality of this process. Boy, am I exhausted. We don't know how they do it.

This seems very much like a problem already, as well as a conflict of interest, to be unbiased in all these decisions. The role of application centres is gigantic and problematic at best. We have asked previously to contain our privacy and confidentiality in this funding process. Families requested a streamlined system for services. However, the key responsibility must be separated so individuals and families can see the transparency of roles. Families need to see a fair process in place.

Ms. Sharon Sharp: Bill 77 has been forged quickly, passed two readings and is being pushed through so fast that even with these summer hearings it is not adequate to reach the outpouring of families and their stories and input at this time of year. In the midst of our family's summer break, as well as each of you losing time at vacation, we must spend our valuable hours trying to play catch-up with this whole Bill 77.

Our son has lost time with us, our family has lost time together, while we researched and debated—

The Vice-Chair (Mr. Vic Dhillon): One minute left.

Ms. Sharon Sharp:—this bill and we have travelled at the expense of our time again today to be here. We do not resent the time spent while talking to you or learning

about our government, but we realized we had to hurry up and do it because it's important. However, the reality is that our son will spend more time sitting on another waiting list.

Bill 77 needs to establish local infrastructure supports and direct funding, including independent planning and community facilitation. A person-directed approach will benefit those individuals, be creative, community-based and cost-effective. Bill 77 should ensure that all supports are available to move with the person. If citizens wish to change their lives, they should be able to move with a fair and respectful process in place. Supports and funding should be flexible, to use as a choice with other supports, and be portable, to move to other communities when necessary.

The Chair (Mr. Vic Dhillon): Thank you for your presentation.

FAMILY ALLIANCE ONTARIO

The Chair (Mr. Vic Dhillon): The next group is Family Alliance Ontario.

Good afternoon.

Ms. Cathy Calligan: Good afternoon.

Ms. Janice Strickland: Good afternoon. My name is Janice Strickland.

Ms. Cathy Calligan: I'm Cathy Calligan.

Ms. Carolyn Calligan: I'm Carolyn Calligan.

Ms. Janice Strickland: Cathy and I are both board members with Family Alliance Ontario. I'm from London, involved with London Family Network, and Cathy with Sarnia-Lambton Family Network.

Family Alliance Ontario has been fortunate to have members involved with the whole transformation process from the very beginning and has had board members on all the committees that have looked at all the different aspects of transformation. So we thank the government and the Ministry of Community and Social Services for giving us that opportunity to also have our input, a lot of which we've seen reflected in Bill 77. We would like to say that's been a positive part of our input.

I am a parent. I have two sons. My youngest son is 22. His name is Jordan and he would have the label of developmental disability. I think a lot of the things we want to say have been said already, but one thing I wanted to say is that the conversation has reminded me of his career through the school system. I had been very involved provincially with advocating for inclusion in the school system. I always hear a similar argument that you can have some inclusion, or the only other option is segregation. The infrastructure was never there to support inclusive education either.

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It sounds like some of the conversation today has been around a traditional service system, or you're on your own with direct funding. I know of families and schools that will say that inclusion doesn't work in schools. But that was also because there wasn't the infrastructure there, there weren't facilitators, there wasn't planning,

there wasn't training for teachers, there wasn't support for families. The same argument seems to be coming up today too. Direct funding is not going to work without the infrastructure of all the things people have talked about. Without the planning, without the facilitation, as well, it will fail.

The other presentations this morning also talked about the vast majority of families choosing agencies and traditional stuff. Clearly that's for the very same reasons: There's no infrastructure there for them to help them have a successful plan for their sons or daughters in the community. It will fail without that infrastructure and then we'll say, "Direct funding didn't work." It's really unfair to not give it the support that it needs to be a good option for families.

Family Alliance Ontario represents families around the province of Ontario. There are family networks in many communities. Our passion and our commitment is to building a world where people with developmental disabilities are recognized, welcomed and included as full citizens and vital members of their communities. We represent Ontarians who are our children, siblings, parents, friends, coworkers and neighbours. Their disability labels have been reason enough for them to be segregated, marginalized, isolated, ignored and largely excluded at times from everyday community life.

My own son has been fortunate to have some individualized funding, but mainly it was because he left the school system early because it was a real failure for him. He didn't get the opportunities for inclusion that we had advocated for. However, since he left school and he's had some of his own funding, his life and our family's life have improved. I don't know if it can improve more than 100%, but it probably has, because he's been able to choose lots of things that he wants to do in the community. He needs full support to do things, but he's volunteering and working right now. He's up at Camp Queen Elizabeth, which is through the Y, a regular camp, and he's on staff. He's been going up there for several years. But all of that has been because he's now had some direct funding.

Ms. Cathy Calligan: My daughter Carolyn, who is with us today, is now 30 years old. She has been out of school for nearly 10 years now. The only support that she receives is through special services at home. With that funding, we have been able to find her some volunteer positions in our community. She also participates at the Y in a water aerobics program three times a week. All this has been done with just a very small amount of money. The amount of money that she receives is very small. With even just a slight bit more funding, she would be able to do so much more. The possibilities are just endless.

I'm going to start making some comments on the bill. We don't intend to make a lot of recommendations, but we do intend to raise our concerns. Some of these you have already heard and some of them you may not have.

One of the first things that we noticed about this bill was the absence of a preamble. We feel that this would

be very important to include in this bill to provide direction. It would serve as a compass to show what your direction is, what you intend to do with this bill. We would like to see things included that would state the value and the dignity of the individual. We would like to see it reflect some of the values and principles that you have stated in the ministry document Opportunities and Action. We would like to see inclusion; we would like to recognize the ability of the individual to contribute to society. We would like to see all of this because it will help shift from traditional services that we are all familiar with and help open up new horizons for people. The services that we have in the province have worked well, and they will always work well for some people, but we need to start expanding on this. We need to give people more creative options to empower them, to become more useful members of society.

The language of the bill has been problematic. We have heard that Community Living Ontario suggests a change of title of the bill to "An Act to enhance the social inclusion of persons who have an intellectual disability." We endorse this; we think that this would be a great improvement.

The language used throughout Bill 77 lacks clarity; it leaves it wide open to interpretation. This, along with the absence of a preamble, just makes it very little more than a document to rewrite administrative functions. We would like to see words such as "services" and "programs" expanded to include the words "supports," "to support an individual in community."

We see that traditional services are well spelled out in this document; we would like to see language included to support new and creative options. Residential service is spelled out—group homes, in-home support—but it fails to include any options that families might come up with. For example, some families would like the opportunity to create a home where their sons or daughters live in a separate apartment, sort of a duplex arrangement or a granny suite, something like this, but there's no mention of anything like that in this bill. So we found this language to be very restrictive. It does not allow for new and creative options.

We very much like the idea of direct funding, but we found that the definition used in the bill is a bit restrictive. We would like to see it expanded to include two unique funding choices: the first choice, to purchase service and programs provided by agencies; and the second choice, to purchase supports outside an agency, to enable an individual to take part in community activities such as work, volunteerism, recreation and living in one's own home. Family Alliance Ontario has referred to this second option as "individualized funding."

Once this distinction is made, the appropriate language must be used to support this second option. This language needs to talk about supports rather than services, community rather than programs, and citizenship rather than day programs and residential services. The legislation needs to move away from creating silos in a person's life to think about the person as a whole being.

We don't silo our own lives into day activities, work, residential; why should we for our sons and daughters? They're a whole person.

Supports need to be more flexible and open-ended to encourage the seeking out of new and innovative ways of supporting individuals in a community. We would like to see the support recognized as portable so that it moves with the person if they should move to a different locality or if they should decide to change where they purchase service from.

We would like to see this funding annualized so that people can depend on this funding from one year to the next and not have to worry about services being cut.

We're afraid that without the appropriate language in this bill, it won't move our sons and daughters ahead to full citizenship and inclusion in the community. We think some work needs to be done there. And of course the rhetoric about policy change must be matched by funding support too.

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Ms. Janice Strickland: We'd like to address, as I already mentioned briefly, the infrastructure needed to make sure direct funding or individualized funding is successful. A lot of that has been talked about in some of the presentations this morning, though, so I don't think I need to say the same things that all of them have been saying.

Families and Family Alliance Ontario have been leaders in demonstrating the success of some of these processes for many, many years. They have been, I think, ahead of their time in seeking out different ways to plan and look for their family members to be out in the community showing that people with disabilities don't have to be spending their time isolated and doing things that they don't choose to do. Things like support circles that families and Family Alliance Ontario have been setting up for their families since they've been infants, and independent facilitation as well—we very strongly have been talking about the importance of that being separate from the traditional structure so that whether or not families want to choose something that's offered by an agency, they can still choose things that are available in the community. I don't know if this area has been addressed, or maybe it was by another presentation: There needs to be some kind of a process, whether it's through the application or the funding decision, where the parents have a place where they can have that decision reviewed. There's somewhat of a process for that with special services at home, but with the Passport funding, there was no process to review that. It's very frustrating to see that that's the final answer.

Ms. Cathy Calligan: I see we're running short of time.

I'm just going to sum up some of what we feel are our important issues. We would like to see you refer back to the document Opportunities and Action and refer back to the underlying principles that you outlined in that document: citizenship, fairness and equity, accessibility and portability, safety and security, accountability and sustainability.

Just a couple of points on sustainability: We know that government is always quick to argue that resources are limited. However, entrenching waiting lists is not an acceptable solution. The population is growing; medical technology has been wonderful in extending the lives of our sons and daughters, and now they are reaching adulthood in increasing numbers. The demand is there, the pressure is there, and the funding is not keeping pace.

Two things must happen to make the system sustainable. First of all, we have to encourage people to move into community. The current support systems, programs and services are expensive; they're costly. People tend to go to this type of support because they don't know that any other options exist. With proper planning, people can look into community, find community placements, find natural supports in the community, and that's going to relieve some pressure on the system.

The other thing that has to happen is that there has to be more funding.

The Vice-Chair (Mr. Vic Dhillon): One minute.

Ms. Cathy Calligan: Funding is important. Our sons and daughters are important. If something is important, you find money for it.

When this bill is ultimately passed, you people will move on to something else. Within a few months, you'll forget all about us. The bureaucrats in Toronto will create a system that's easy for them to follow, easy to work with, and they'll forget about us too. Agency people will work with the rules that you create, and they'll go home at night and put us out of mind for the rest of the day. We're the ones who have to live with it. We live with it every minute of every day—24/7. We really, really implore you to take a look at our presentation and take our recommendations and concerns into account. You can create the most wonderful piece of legislation in the world, but without the proper supports and funding, it's going to be pointless.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much for your presentation.

COMMUNITY LIVING ESSEX COUNTY

The Vice-Chair (Mr. Vic Dhillon): The next group is Community Living Essex County.

Go ahead. If you could state your name; you have 15 minutes. Thank you very much.

Ms. Nancy Wallace-Gero: Thank you. Good afternoon. I'm Nancy Wallace-Gero. I'm executive director at Community Living Essex County. I was to be joined by Debbie Rollier, who is our president of the board of directors; however, due to a family commitment, Debbie was unable to be here and sends her regrets. But I am representing both of us and in fact our entire organization in my presentation today.

I did want to share with you that Debbie is a lawyer. She's a parent. She is a member of the Community Living Ontario board of directors and is currently the president of Community Living Essex County.

I am the executive director at Community Living Essex County. I have worked in this field for almost 40 years. I have two family members who have a disability, so this is my life. This is a great passion and something that is very important to me.

I want to begin by thanking you for the opportunity to comment on Bill 77. It's a timely change for the developmental services sector. After years of outdated legislation focusing on institutional living, the intent of this legislation is a very welcome change.

I do want to tell you a little bit about Community Living Essex County. This is the southernmost community in Ontario, and in Canada, in fact, for those who aren't familiar with the geography.

We were incorporated in 1961 and currently support approximately 600 people of all ages, children and adults, who have an intellectual disability. We also support their families. We have a full range of supported living options: day supports, employment supports, supported living, independent living, family supports, and we assist families with special services at home. We employ approximately 600 staff—200 full-time, 400 part-time—to provide services and supports across the county. We believe our employees are among some of the very best and most dedicated in the province of Ontario and that the work they do is critical to the well-being of the people we support and to their families. We are active members of Community Living Ontario and Ontario Agencies Supporting Individuals with Special Needs, or OASIS.

Our presentation today includes recommendations that are shared with our provincial organizations. Also, we have had to tailor our comments to respect your time, so I'm just going to emphasize five specific recommendations that we would like to make with respect to Bill 77. I'm not going to comment on the positive aspects—there are many—but I am going to share with you the things that we think need to be changed in order for it to be an effective piece of legislation that will do the job that I believe the province of Ontario wants to do.

One of the most significant changes in Bill 77 is the introduction of application centres. We are very concerned about the lack of detail that is provided about the role of the application centres. We are concerned that a lot of this will be in policy directives and regulations. We also see this as one blanket statement about the way things ought to be across the province. We in Windsor and Essex county have a long and demonstrated history of working collaboratively with other agencies and services and families in coordinating available resources for the benefit of people we support. We have an approach that has been in place for a number of years. We believe it's effective and it's cost-efficient, and we would like to see it continued. We believe this can be done respecting some of the qualifications that the ministry, the government, is trying to achieve with application centres.

We would like to see that linkages that exist currently are built upon rather than new structures set up. Mechanisms for providing direct funding to individuals and

improving fairness and accountability will require some new elements, but we believe we can work together with our community partners to put that in place.

We would like to see the description not as "application centres," but rather "application process" and it having some determined requirements that we feel we can fulfill, either by our existing network or by adding to it.

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We are also concerned about the powers of the application centres. We're concerned that they seem unending and, in fact, will take away from the planning and allocation of resources that exist currently. Right now it is the government's responsibility, through its ministry regional offices, to allocate resources. We believe that that should remain with government and that the role of an application process or an application centre should be around the identification and prioritization of needs in the community to ensure fair and equitable access to supports.

The next area I want to comment on is inspections and operations. We find that Bill 77 really is very intrusive towards the direct operation of supports within communities. We feel that it is extremely important that the rights of people be considered in any sort of requirement that the ministry expects to impose. One of the requirements in the bill is that the ministry will have the right to inspect or send an inspector into the property at any point in time. We believe that this does affect the rights of the people who live in these homes. We would recommend that that be changed to require that anybody who would enter the home would have a warrant and have reasonable grounds to do so. It just seems completely unfair that there would be any kind of unqualified right of a ministry official to enter the home of a citizen of Ontario. It doesn't exist in other jurisdictions and it shouldn't exist for adults who have an intellectual disability.

We also, in that same section, are very concerned about the ministry's ability to assign a manager or re-assign responsibilities with respect to the organization to really take over the affairs and manage the affairs of the agency. Rather, we recommend that this be narrowed to those services that are on contract between the ministry and the agency, that those are the only affairs where the ministry really can be so intrusive. Of course, they have the right to set rules when they provide the funding, but they don't have the right to take over an entire organization that does much more than just deliver services to government and to the people based on contracts with government.

I'm going to skip over a little bit, because I do want to get to a very important issue, one that is not in any way addressed within Bill 77. There are many recent and past injustices in the lives of adults who have an intellectual disability, many of which have created disruptions, significant risks and sometimes serious harm to an alarmingly large number of people. While we know that typically people are protected by an inclusive life within their community, surrounded by people who know and

care about them, far too many people are victims of various forms of abuse and neglect. We would like to see some protections built into this act.

Many people we have supported over many years have told us that the single most important issue for them in their lives is to feel at peace in their own home, to feel protected from harm and to have a sense of safety and security that is within their personal control. At Community Living Essex County, we've developed significant policies, training programs and other vehicles in an effort to ensure that people supported have peace, protection and security, but sometimes there are still concerns that emerge, and extremely vulnerable people require protections. We are the one province in Canada that has no such protection for vulnerable people. We believe there needs to be something included in this act that speaks to that.

We recommend that Bill 77 address issues of protection by naming either an ombudsman or an adult advocate who would be available to adults who have no one to speak on their behalf and to ensure that a mechanism is put in place to report abuse and ensure that, where necessary, protections are put in place. This is an area that does require a lot of additional discussion and consultation. It was raised during the consultations around the transformation of the Developmental Services Act, and for some reason it was completely left out of this legislation.

One other area that concerns us is the development of regulations. There's a lot of room left for regulations to be developed that can in fact restrict the rights of people and the sorts of supports and services that we are moving towards in our communities. It's also our recommendation that the standing committee make clear its expectation that the public will be fully consulted on concepts and ideas related to the regulatory framework for the legislation before the government undertakes the process of drafting and adopting regulations.

Maybe I won't use up all of my time, but I do thank you very much for your attention. I've given you more detail in the paper that I've provided to you, but I really hope you do take our recommendations very seriously. Our board of directors is most concerned that changes be made before this new bill is announced. Thank you very much.

The Vice-Chair (Mr. Vic Dhillon): Thank you. About a minute each. Ms. Elliott.

Mrs. Christine Elliott: Thank you very much for your presentation. The one item you mentioned that we really haven't heard about before is the issue of neglect and abuse, and your suggestion that someone perhaps like an advocate, an ombudsman, or something of that nature might be able to fill in. Would someone like the official guardian, who's already there to protect vulnerable people, be an appropriate person? Would you like to see something like that entrenched in this legislation, to say specifically that someone like that could become involved where there might not be family members there to protect someone?

Ms. Nancy Wallace-Gero: I'm not sure I'm an authority to speak on the role of the official guardian, but it

is my understanding that the role is primarily around health care and financial matters. Sometimes it is really more important that there be an objective, outside person who can sort of be the one that if there is an allegation or a suspicion of abuse going on—I'm thinking of circumstances like Tiffany Pinckney in Mississauga, a 23-year-old woman with autism who was living with her family; this was 2005. She died of neglect—

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

Ms. Nancy Wallace-Gero: Sorry. Thank you.

The Vice-Chair (Mr. Vic Dhillon): To the government side. Mr. Ramal.

Mr. Khalil Ramal: Thank you. I get a chance to ask a question too.

Thank you very much for your presentation. I will be quick. My question is around neglect and abuse. That's why we have the inspection without notice, in order to ensure the safety of the residents. Of course, the aim of the inspections is not the residents but the agencies who must demonstrate that those homes are looking after those residents. So I don't see why you are opposing that.

Ms. Nancy Wallace-Gero: I'm not opposed to the ministry coming into homes. I think they should come in with notice, that's all, and they should come in with a warrant that gives some—

Mr. Khalil Ramal: But that would defeat the purpose of the inspections.

Ms. Nancy Wallace-Gero: Well, a warrant doesn't require notice. They could arrive with a warrant. It's just that we believe it's very important that these be considered people's homes first, and it's the rights of the residents who live there. We feel very strongly that they need to be able to be a part of understanding why somebody would come into their home in a very intrusive way. To just randomly allow government—I worked for government for a number of years, so I'm hoping there's no one who works for government like this, but I would hope that they would always come in only when there's some substantial reason to do so. I'm not convinced that would happen.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much for your presentation.

Ms. Nancy Wallace-Gero: Thank you.

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MIDDLESEX COMMUNITY LIVING

The Vice-Chair (Mr. Vic Dhillon): The next presentation is by Middlesex Community Living.

Good afternoon and welcome to the committee. If you can please state your name for Hansard, and you may begin.

Ms. Sherri Kroll: Thank you. Good afternoon. My name is Sherri Kroll and I'm the director of organizational development with Middlesex Community Living in Strathroy. I'm also the parent of a six-year-old boy who has been diagnosed with an intellectual disability.

Thank you for the opportunity to speak to Bill 77, the proposed legislation for developmental services.

I would 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 and have implications on me as a parent and on my son as a service recipient. The proposed legislation looks to address a number of important issues of significance to the developmental services sector. Middlesex Community Living believes, however, that important changes should be made to the bill that will enhance our ability to create a truly inclusive society. I will focus my comments and proposed changes on those things MCL feels will help ensure that people who have an intellectual disability have full control over the decisions and activities that shape their lives.

While there are many issues that deserve attention, I wish to focus on the following two matters: person-directed planning, and living in peace and security.

With respect to the first issue, person-directed planning, Middlesex Community Living recommends that person-directed planning be added as a funded element that is available to all those deemed eligible for supports and services. Such planning should be made available after a determination of eligibility but before a person applies for services or funding and before his or her needs are assessed. Person-directed planning should be made available to the individual on an ongoing basis whether or not the individual proceeds to apply for support or funding beyond planning. Person-directed planning should not be carried out by the application centre but by individuals or agencies that are recognized as qualified planners according to standards that should be set through a regulation or policy directive.

The entire system envisioned by Bill 77 can only have integrity if persons seeking support services under the new legislation are clear about what it is they wish to apply for. Without that, they will face the same situation that has prevailed down through the years; namely, they will be offered services from a list that has been identified by someone else as appropriate in general terms for an entire population. People need supports that are uniquely appropriate to their personal needs at a particular stage in their lives. True person-directed planning looks not only at supports that may be accessed under the provisions of this legislation, but also at supports that are available in the context of the individual's family, community and natural supports, which can often be accessed without government funding or other intervention.

The concept of mandated planning for persons with disabilities is embodied in regulation 98/181 under the Education Act. It is required that an individual education plan be developed for every pupil who is identified as exceptional within the terms of that regulation. In British Columbia, a plan is required to accompany a request for

funding or funded supports. Facilitators assist with the development of that plan. But this model has been criticized because facilitation is not fully independent from the funding allocation. MCL has included in your package a list of research documents that show the benefits of good planning for life in the community.

Person-directed planning can be addressed in the legislation by considering the following change: Subsection 4(1) of the bill should be amended by making the first numbered service to which the act applies read "Person-directed planning," and renumbering the successive items in that subsection accordingly. A definition of "person-directed planning" would have to be added to subsection 4(2), and that could read, "'person-directed planning' means services that assist an individual and his or her personal network to plan for a life in the community."

The bill should also make it clear that such planning would be made available at the expense of the ministry, but not as a function of the application centres, to all persons who demonstrate their eligibility for services under the act, before consideration is given to which additional services may be appropriate to their needs.

A section should be added to Bill 77, appearing after section 16, "Review of determination," that would read:

"Planning supports

"(1) Upon determination of eligibility, the application centre shall instruct the applicant as to supports and services that are available for planning.

"(2) An allocation will be made for the purposes of funding the service indicated in subsection (1)."

These amendments must include provisions for continuing review of plans to assess the effectiveness of supports that may have been accessed under the act, and to identify new and different supports that are appropriate to the person's changing circumstances and aspirations.

With respect to our second matter, living in peace and security, Middlesex Community Living believes strongly that we can no longer allow others to have the legal authority to disrupt and intimidate people in their own homes, as occurred during the labour strikes in the summer of 2007. Middlesex Community Living highly recommends that developmental services be identified as a no-strike sector and that provision be established within the legislation to create an arbitrated settlement mechanism to address future labour disagreements. Provisions such as those found in the Hospital Labour Disputes Arbitration Act, or HLDAA, should be included within Bill 77 with the aim of ensuring that the disruptions to people's homes and lives that occurred last summer never occur again.

During the summer of 2007, many people supported by seven Community Living agencies, of which MCL was one, endured difficult strikes and picketing, which targeted their homes. During the strikes, many people were confined to their homes or forced to move away from their homes. Neighbourhoods were disrupted by picket lines, porta-potties, shouting, megaphones and whistles. In some locations, this occurred at all hours of the day and night.

I wish to share with you some personal quotes taken last summer from self-advocates who were directly impacted by the strike. Their comments included: "The curtains had to be closed all the time." "The workers shouted at me." "A lot of swearing and bad words." "They shouldn't be on my property. There was garbage, cigarette butts and a porta-potty in my front yard." "I couldn't go anywhere." "I was trapped in my own home." "I was moved to a hotel. I was very bored, staying in a room for a long time. I had no other choice." "Picketing centred us out. Everyone now knows where we live. We are supposed to be fitting in." "No one knew that I had a worker. That was a private matter." "It's hard to discuss my feelings of what it feels like to cancel your life." "My reputation as a member of this community has been ruined."

Following the strike, the following powerful comments were made: "I feel like everything is different now. It's hard to explain, but I don't think things will ever be the same." "No one said, 'Sorry.'" "Someone owes me an apology."

The concept of essential services is well established in the context of labour relations where workers provide services that cannot reasonably be withdrawn because of the extreme risk of harm such job action would impose upon citizens. Prohibiting strikes in police and fire services are the most common instances where strikes are simply prohibited. In Ontario, the Crown Employees Collective Bargaining Act provides for a similar approach based on the mutual identification by labour and management of those elements of any particular collective agreement that constitute essential services that by agreement would be maintained during any work stoppage by other employees in the bargaining unit. Services provided by Community Living in Manitoba are subject to the provincial Essential Services Act.

Declaring the developmental services sector a no-right-to-strike sector would ensure that such a violation of the rights of people who lived in these homes wouldn't happen again and, furthermore, would introduce arbitrated settlements which could encourage wage parity between people working in this sector and others doing similar work.

Strikes involving support workers in the developmental services sector, and particularly picketing of people's homes, are not simply an annoyance to an innocent third party. The harm done has been demonstrated to be both intolerable and lasting and certainly not compensable in any material way.

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This matter can be addressed in the legislation by considering the following change. The bill should be amended to incorporate the provisions of the Hospital Labour Disputes Arbitration Act, or HLDAA, with respect to arbitrated settlements. Alternatively, a developmental services arbitration act could be considered, with provisions that approximate those under HLDAA.

On behalf of Middlesex Community Living, I strongly urge the committee to address the issues of person-directed planning and living in peace and security in

order to ensure that the legislation is effective in addressing the needs of people in Ontario who have a disability. Thank you for your time.

The Vice-Chair (Mr. Vic Dhillon): Thank you. We have a couple of minutes each. We'll start with the government side. Mr. Ramal.

Mr. Khalil Ramal: Thank you very much for your presentation. You talked about many different things. In general, I want to ask you questions about how, if this bill passes, it's going to affect your organizations for the positive or negative.

Ms. Sherri Kroll: I see great effect on the organization in general. I think it's going to limit our ability to truly provide quality supports to individuals and perhaps reduce our freedom to really know the person and provide services at a very individual level to each individual based on their uniqueness. I'm afraid that vacancies in service would simply become spots, and agencies could be forced to accept people into service where there may not be a great fit with an individual who's already in service, and we might lose our ability to help control and manage those situations appropriately.

Mr. Khalil Ramal: But, as you know, the bill does not mean every family is going to seek individualized funding. Some individuals are going to ask for it. In general, in this bill we're expanding and broadening the support in order to include families who wish to seek individualized funding for their kids or for their loved ones. What's your comment on that?

Ms. Sherri Kroll: I appreciate what you're saying, but I'm concerned that when there are opportunities available within a service organization to provide supports to a person, there's going to be limited ability for the organization to make the decision about who accepts or who is able to move into that vacancy, and I think, ultimately, the people who are in service are going to be impacted by that and their choices may not always be recognized.

I also very much share the concerns of the former presenter about the ability of government to come into people's homes without having appropriate notice periods given, and I think that truly is a rights issue that needs consideration for people with disabilities.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. The official opposition.

Ms. Sylvia Jones: I don't really have any questions, Ms. Kroll. It was an excellent presentation. I did not realize the one comment you made about Manitoba and the no-strike zone, so I'm going to do some more research on that one. Thank you.

Ms. Sherri Kroll: Thank you for your consideration.

Ms. Sylvia Jones: Yes, it's a good one.

You didn't really get an opportunity to talk too much about the application centres. I wonder if you could share with the committee a little bit of the issues, if you see any, with the application centres.

Ms. Sherri Kroll: I am concerned about the proposed function of the application centres developing service plans for individuals. I think that the concept of planning

should really be an independent function, not a function that's covered under the application centres' role. Even internally at our service organization, we've seen a huge difference when we've had planners who don't work directly for the person do planning for them. You get a much broader vision of a plan. You truly get a plan that identifies the person, who they are, what their dreams and aspirations are. When people who are in the service and know about the opportunities in service do planning, we tend to put blinders on and only focus on the opportunity and try to fit the person into a vacancy, as opposed to truly understanding what a person wants and then developing services around them. So I really hope that that would be considered in thinking about what the role of those application centres would be.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

KATHY SZUBA

The Vice-Chair (Mr. Vic Dhillon): Next, we have Ms. Kathy Szuba.

Ms. Kathy Szuba: My name is Kathy Szuba. I'm a wife, a mother and, most importantly, a caregiver. I'd like to thank you for listening to me today.

For years now—decades, actually—I've been thinking that there's something wrong with the way our system works. I know this because no matter how hard we struggle, nothing ever gets easier for us and no one seems to notice.

I listened carefully recently to Mr. Prue as he was speaking in the House about Bill 77 and became a bit more optimistic that finally some things I've been concerned about might be addressed. We've constantly fallen through the cracks, and no one even knows that we exist. So I'd like to tell you a little bit about our lives and see if anything in this bill might apply to us and others like us.

My husband and I care for our severely disabled daughter at home. Michele is 41 now. We've cared for her since birth. We want to care for her, and no one else would be able to do this. She needs total care and has many seizures. Our goal every day is to keep her healthy and comfortable and provide her with the best quality of life possible. We succeed in doing this, but it requires continuous, one-on-one care. When she was a few months old, the doctors told us we would never be able to take care of her at home. Needless to say, they were wrong.

My husband and I chose to farm so we could work at home. Early on, we had our parents, who assisted us in providing Michele with the daily care she required. My mother was a godsend, and Michele was a very big part of her life. However, for the past 20 years, we have been down to just my husband and me to provide the constant care our daughter requires. One of us stays with Michele while the other does the work of two people outside. We cross paths in the doorway, one of us hurrying in, the other hurrying out. Nothing is ever done leisurely. I have

had to become a real superwoman. Sometimes it's impossible to do everything that is expected of me, but Michele is never neglected and her needs always come first. I've sat by her bed night after night when she was sick, since she wouldn't be able to call me. I faithfully reposition her every two hours each and every night, and she's never had a pressure sore or pneumonia.

My husband has developed severe rheumatoid arthritis, and it is now most difficult for him to help me move or lift our daughter; this at the same time when his physical situation has limited the work he can do on our own farm.

Farming is providing very little income for our family these days. It is impossible to save for retirement when it is hard just to get by now. We haven't been able to renovate our house to be disability-friendly; the wheelchair doesn't fit into the bathroom, as the doorways are too narrow, and Michele's room is very small. Nothing is handy; we do everything the hard way. Renovations are not affordable, as are a lot of other things people take for granted.

Anything that is not necessary for Michele's care would be considered to be a luxury by us. Our vehicles are old. Recently, we purchased a newer van to accommodate Michele's wheelchair in case of an emergency. However, we noticed that the PST rebate is taken away, even on a handicapped-use van. Meal replacements were covered by ODSP for a couple of months, but they've been discontinued because they said too many people were cheating. When Michele has seizures, she's too tired to eat and the canned meals were easier for her. We never cheated, but it didn't seem to matter. More and more things are taken away. Nothing new is added; it's a constant fight to try to get anything. We recently purchased a hospital bed for Michele. We thought for sure there would be some assistive-devices funding to help with this purchase, but nothing again.

In November, it will be three years since I asked the doctor to make a house call. Michele had asthma-like symptoms and was having some shortness of breath. Finally, a pharmacist and I solved Michele's problem ourselves, and I'm still waiting for the doctor. I guess I've become somewhat of a doctor myself, because so often we feel like we are on our own. Michele cannot communicate, but I can read her every movement and expression.

In spite of the many difficulties, we would never think of not caring for Michele. We live for her. She is much too disabled, and we are sure she wouldn't last long without us. We've given everything in us and more, all of our time, our energy and our money, for 41 years. This has been our choice. Ours is truly a long-term-care home.

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Recently, while reading through the bulletin Spotlight on Transformation, it has come to my attention that the annual cost to provide support for some people is upwards of \$100,000. The fact that we have never received even one penny for our efforts makes us feel that our services for Michele are considered to be totally worth-

less. I mentioned this once to a caseworker, and she told me that there are some lovely homes where our daughter could go if we couldn't afford to look after her. What kind of thinking would take a totally helpless person from a loving, caring and capable family, put them in a home and pay a stranger to look after them? Why are the services of a public service provider funded, while a struggling family providing quality care every hour of every day, year after year, receives no reasonable assistance, not even a small portion of that \$100,000-plus?

My husband and I have never had a vacation. In fact, we have never spent a night away from our home. There are no sick days for me, even though there have been times when I have felt so sick I could barely lift my head off the pillow. Michele always comes first. I cannot go on strike. I have no benefits. My husband's drug costs are enormous. It appears to me that caregivers at home are out of sight and out of mind. Through the entire time period we have been providing for Michele—41 years—never has anyone asked us, "How are you managing? Do you need anything? Could we help in any way?"

I was so insulted when an ODSP person came to our house to see Michele for herself, took down a great deal of information, then demanded to see her bank statement. They said they had to be very careful to see that we weren't profiting. Right then, I knew that this person knew nothing about situations like ours.

We have the same obligations that normal families have but with such disadvantages. Every day is a struggle and, more importantly, a financial hardship.

Some people tell us that caring for Michele must be such a burden, but to my husband and me, the real burden would be not to be able to care for her. All any family in our situation is looking for is respect and the opportunity to make reasonable choices in the care of our children, the opportunity for choice that comes without the disadvantage of undue financial hardship. Although we have never asked for anything, I think it is time that some assistance is made available for those who look after their family members at home. We have more than pulled our weight and never complained. Michele's cost to society has been very minimal for 41 years.

Just because we are parents doesn't make us any less important than other service providers, nor should we be treated differently. My services to Michele come from my heart and have proven effective for over 40 years. No amount of money could ever come close to paying me for that. To be truly fair to everyone, however, and for us to have a small amount of dignity, some financial support would be greatly appreciated.

We don't have high expectations. Our family values are simple. If I wake up sane, Michele feels well, and my husband is not in too much pain, I say to myself, "It's going to be a good day."

I thank you for listening to me today and hope you review my comments and see if there's anything in there for us.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We have three minutes each. The government side.

Mr. Khalil Ramal: Thank you very much for your presentation. This is why the government designed Bill 77: in order to support families like yours who decide to continue to care for their loved ones on their own. I hope that if this bill passes, it will benefit you a great deal, give you some kind of support and some assistance if you decide one day to go on vacation or seek some kind of support from specialized people who come to your house. I wish you all the luck and thank you very much for what you do on a daily basis.

Ms. Kathy Szuba: You talk about providing services; that isn't the main thing that we need. We have special services at home. We have a person who comes in—we're allowed seven hours a week—but that doesn't do anything. That worker gets the money. We go away, we come home, and we haven't gained anything. We would actually like to have financial assistance. I'd like to have my services paid for, because I'm providing a service, the same as any service provider anywhere. Why couldn't I, just like any other home care worker, be paid a little for my services? We are the ones who need to care for her, with hardly any income. Any services that a worker will give will not do anything for us, because we won't gain one dollar by that.

Mr. Khalil Ramal: But you see, the bill is designed not to give the parents some kind of, what do you call it?—to gain financial support. This bill is designed to give the parents the kind of support they need in order to service their kids. That's the way it goes, because naturally it's our obligation as parents to look after our loved ones.

Ms. Kathy Szuba: But not when they're 41 years old. We want to look after our loved one. If we didn't, we wouldn't have done this for 41 years. I am also a service provider. No one has provided as many services as I have for 41 years.

Mr. Khalil Ramal: Sadly, this is not designed to give the money for the parents in order to get paid for what they do for their loved ones. The system is designed to give the parents the ability to seek some kind of service outside their house. And also, if they cannot care for their loved one, there are a lot of organizations across the province that are designed to do this job.

The Vice-Chair (Mr. Vic Dhillon): Thank you, Mr. Ramal. Mrs. Elliott?

Mrs. Christine Elliott: Thank you, Ms. Szuba, for your comments. I think that you've really touched at the heart of what this is all about. You and your husband—and many other families—have quietly gone about taking care of your child in your home without asking for anything and being largely unnoticed and not appreciated for your efforts. You have saved the government millions and millions of dollars over the years.

I think, from the comments that you've made today and many other people have made, that the time has come for a change. That's what we need to grapple with as we look at how this bill is being designed, how it's going to help individual families and provide the individual supports that you need to continue and, in your

case, to care for your daughter as long as you and your husband are able, and also to know that when you're not able there are going to be the caring supports—not just the financial supports—that we all hope for for our children. I really appreciate the comments you've made, and please know that we will take them to heart when we continue our discussions.

Ms. Kathy Szuba: Thank you very much.

The Vice-Chair (Mr. Vic Dhillon): Thank you for your presentation.

ONTARIO AGENCIES SUPPORTING
INDIVIDUALS WITH SPECIAL NEEDS
WOODSTOCK AND DISTRICT
DEVELOPMENTAL SERVICES

The Vice-Chair (Mr. Vic Dhillon): The next presentation is from the Ontario Agencies Supporting Individuals with Special Needs and Woodstock and District Developmental Services.

Welcome to the committee, gentlemen, and good afternoon. If we can get your names for Hansard, you may begin. You have 15 minutes.

Mr. John Bedell: Good afternoon. My name is John Bedell. I'm the executive director of Woodstock and District Developmental Services. Mal Coubrough sits to my left. He's the president of the board of Woodstock and District Developmental Services.

Thank you for the opportunity to be here. Thank you for your attention. It's been a day and a bit and you have two and a half still to go and you're still with it, so I commend you all for still being with it.

Woodstock and District Developmental Services has been providing supports and services to people with developmental disabilities for about 50 years. We are the average kind of organization, having 190 staff, an over-\$6-million budget, supporting 200 people, funded by the Ministry of Community and Social Services.

We were one of the six founding member agencies of OASIS, Ontario Agencies Supporting Individuals with Special Needs, some 10 years ago. That organization now has a membership of 140, some 25,000 staff, 27,000 people and about two thirds of the budget given to transfer payment organizations.

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OASIS is a founding member of the Provincial Network on Developmental Services. The OASIS response and the provincial network response to this legislation will be forthcoming to you. OASIS met and approximately 70 organizations met to review the legislation, and they came up with a list of matters to be raised. We're just going to focus on five, some of which you've heard, a couple of which you may not have, today, just for the sake of variety, even though I wrote it yesterday.

First is the future role of service provider agencies. During the transformation process, we heard repeatedly from politicians and bureaucrats that the transfer payment agency system was the backbone of developmental ser-

vices. We were, to quote the minister when she spoke at the OASIS conference in Niagara Falls, the "jewel" in her crown. Yet the words that have been spoken and the words that have been written in Bill 77 do not necessarily match.

There is the establishment of another arm of bureaucracy. There's the potential for fines for boards of directors who fail to comply with as-yet-unidentified quality assurance standards.

The bill doesn't provide for a framework of communication and collaboration that's necessary to co-ordinate service delivery. Co-ordination in funding is required between the service provider agency, the application centre that's proposed and the ministry. It's unclear how application centres will commission services from a service provider agency, especially if it does not have the resources so to do.

Such ambiguities make it difficult to determine the ministry's future intentions for service provider agencies. If we're not directly connected to application centres through a contract for service, and if application centres can contract with third parties, including for-profit organizations, through direct funding agreements, it raises the question of whether the ministry contemplates a role for service provider agencies in the future, and, if it does, what that role might be.

While we welcome the concept of direct or individualized funding, and those two are different, for those who might wish it—in fact, we have some people supported in our organization currently receiving individual funding—we would like to see the importance of a strong, viable, accountable transfer payment agency system included in some form of preamble to the legislation.

We believe the legislation should have a preamble that will speak to the spirit and the moral guidance of the act and include foundational value statements, statements as to the scope and purpose of the legislation, and a base definition of minimum standards of support—we would suggest that a review be made of the UN Convention on the Rights of Persons with Disabilities in this regard—and in addition, a statement of the importance of the transfer payment agencies within the system. Not only, we believe, would such a preamble assist in guiding in the development of policy directives and regulations; it would clearly communicate the very purpose of the act and the vision for the social change that's taking place in this sector.

Third is funding: There are a number of funding concerns which this proposed legislation raises. We're very supportive of the expanded definition of eligibility to include individuals who have previously been excluded. While that's good on the left side, on the right side there have to be some funds found in order to meet that expanded group of people.

We're heard a lot today about application centres. It's hard to envision exactly what the system will look like and exactly what the costs will be, but history shows that when we had Making Services Work for People, more affectionately known as "making people work for

services,” we had central points of access, and those central points of access were funded by levies on existing organizations, which meant a cut in direct service, which meant increased waiting lists.

It’s further not clear what the provisions will be for people currently receiving service. We know that their eligibility will be grandparented, but not necessarily their access, their priority or their level of funding. That’s a concern for individuals, for their families and for organizations, including staff, especially if there are to be significant reductions. We would request a statement pertaining to the transition to allay the fears of all concerned in this regard.

Mr. Mal Coubrough: Fourthly, we would speak to the governance and liability of agencies. A system where options and choices exist for individuals and their families is dependent upon services being available. The not-for-profit system relies on community support and on volunteers willing to take on the responsibilities and accountabilities of overseeing these organizations through a board of directors. Community agencies have developed and grown over the years in response to local need. The tremendous diversity of Ontario is reflected in the individual bylaws and board composition of such local community agencies.

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 the application centres or third party providers within the legislation. Clarification is required as to why service agencies are the target of this particular section.

Further, of particular concern to me as the president of a board is the liability imposed by 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 the board of directors could be held individually responsible for this transgression. OASIS has obtained a legal opinion that expresses concern that directors’ liability insurance may not cover this particular situation. Given the current difficulties that some local community agencies have in recruiting and retaining competent board members, this punitive aspect of the legislation should be removed. When you have that kind of liability, it’s a barrier to board recruitment. When you are recruiting a new board member and you say, “Oh, by the way, you’re on the hook for the first five grand,” it really doesn’t kick up their enthusiasm.

Reviews and appeals: The legislation includes 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 directly to the judicial route, which can be a lengthy, costly and quite inaccessible process. Using dollars intended for social services subsumed in the judicial process leads to a decrease in social services

unless the ministry is funding the process. Delay in resolution inherent in the judicial process hurts our folks with special needs and their caregivers.

More equitable, transparent and fair would be a third party dispute resolution 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 might include disputes between service provider agencies, application centres, ministry, families, people receiving direct funding and/or people receiving services or not, as the case may be.

Indeed, perhaps this is a missed opportunity in this particular area of dispute resolution. Perhaps a local mediation or meta-arbitration process could be set up to resolve these issues. It is my understanding that the Ministry of the Attorney General has for some time experimented with several pilot applications. They may be an excellent source of suggestions and/or wording in any revisions to your dispute resolution processes. Ultimately, of course, the fallback position is and must remain the judicial system available to everyone.

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We thank you for your favourable consideration of these and the many other issues raised by OASIS and the provincial network, and we do look forward to the fruits of your labour. Thank you for your time.

The Vice-Chair (Mr. Vic Dhillon): Thank you for your presentation. A couple of minutes each. We’ll begin with the official opposition.

Ms. Sylvia Jones: I just wanted to thank you for the presentation. You’ve touched on the reviews and appeals a little more than some of the other presentations. The idea of using the judicial system just frightens me—to talk about delays and wait-lists again. It would be a beautiful way to delay service once again, not to mention, as you’ve said, the cost involved, so we’re going to have to look at some alternatives.

Have you seen any mediation or appeal processes that are currently in place that could be used under Bill 77?

Mr. Mal Coubrough: The base principle of mediation is a neutral facilitating third party who tries to get folks to solve their own—I do know that the AG was trying something, I believe in Ottawa in the family court system, but I’m a little out of date on that.

Ms. Sylvia Jones: Yes, I’ve heard about it with the family court system, but I’ve never heard it with—

Mr. Mal Coubrough: It’s the same principle. It’s a dispute. We call it an appeal. It’s a dispute—“I say, he says, I think. Let’s sit down and work it out.” The principles are universal. The technique—heaven forbid—could apply to the Ontario Municipal Board to speed up dispute resolution processes.

Ms. Sylvia Jones: Thank you.

The Vice-Chair (Mr. Vic Dhillon): Mrs. Van Bommel.

Mrs. Maria Van Bommel: Thank you for your presentation. You were right; he did bring up some things that we hadn’t heard before. I’m particularly interested in

your comments about liability for board members. I'm assuming that board members in your board are similar to hospital board members, where it's basically a volunteer position?

Mr. Mal Coubrough: Yes.

Mrs. Maria Van Bommel: Okay. So any liabilities and that are covered by the board itself, the cost of insurance—

Mr. Mal Coubrough: We have an insurance policy, yes.

Mrs. Maria Van Bommel: And your legal advisers have told you that there's a possibility that that insurance would not cover?

Mr. Mal Coubrough: Would not cover this particular type of infraction or perceived infraction.

Mr. John Bedell: That's correct.

Mrs. Maria Van Bommel: Okay. I'm a little surprised, because I would assume it to be the same process as would happen if you were on a hospital board or that sort of thing. Thank you very much for that answer.

The Vice-Chair (Mr. Vic Dhillon): Thank you, gentlemen.

WINDSOR-ESSEX FAMILY NETWORK

The Vice-Chair (Mr. Vic Dhillon): Next we have the Windsor-Essex Family Network.

Ms. Michelle Friesen: Good afternoon. My name is Michelle Friesen. I'm from Essex county. I live in a small town called Woodslee. I am involved on a few fronts, and have been with transformation from the beginning.

Firstly, I am here as a parent and a mother of an adult daughter who is 27 years old and has a developmental disability, physical disabilities and some multiple, complex medical needs. But before playing that role in this report, I wanted to mention as well that I'm the co-chair of the Individualized Funding Coalition for Ontario. We've chosen not to make a formal presentation at the standing committee. We'll be submitting something, as so many of our individual members and organizational members are making presentations. We're also in support of the ad hoc provincial group that met, and I think you've received that brief from Judith McGill.

In addition, I manage and coordinate the work of the Windsor-Essex Family Network, which is primarily a volunteer organization. We receive no Ministry of Community and Social Services funding. We rely on foundations, donations, membership fees and that kind of thing. Today, that's the role that I play.

Windsor-Essex Family Network met with a focus group of families in July, 14 different families that included a good cross-section of people who are involved in utilizing the model of support that came out of Making Services Work for People in Windsor and Essex county. I'm going to just do a comparison of the kinds of features the families said they held near and dear to what they think might happen as a result of Bill 77. These families

looked at both the original legislation and the plain-language version. I will mention that the families included senior citizens, three of whom were over 75 years old; there were six parents between the ages of 45 and 60; there was an individual; a brother, a sister and a brother-in-law. So we had a good mix of people from all around the area.

This is a comparison of the features in Windsor and Essex county to what the province of Ontario may be developing. For 10 years in Windsor and Essex county we have experienced a model of support that does not exist systemically anywhere else in the province. In addition, families in our community have 25 years of experience and practice with special services at home. Families have worked hard to ensure accountability, made good use of dollars, and provided quality lives for their family members with a disability.

One of the important features that we have found in Windsor and Essex county that has been entrenched in service contracts with agencies since 1997 is portability. Portable funding has been entrenched, and many families want to keep it that way. Without portability, they say, their sons and daughters, sisters and brothers cannot live as true citizens and their human rights would be compromised. They want to choose where they live and what kind of support they need—critical to all citizens of Ontario. All of us in this room want to have those choices. Even though we know from research and experience in our area that only a small number of people actually utilize portability, it must remain as a choice. We cannot go backwards.

We took the liberty to speak to the executive director of the community living organization in Windsor to ask about portability and how it had affected that organization, because there are a lot of fears around the province about what that will do to the transfer payment system. He was very clear to say that it can be worked out respectfully, working and mediating a contract through; nobody rushes out. It would be our intention that that not hurt a person, an agency or anybody, that systems could be in place. There is no mention of portability in Bill 77.

The next important feature to people and families in Windsor and Essex county is independent planning and facilitation. There's been lots of talk about planning—person-directed planning, independent planning. We clearly believe that through the Windsor Essex Brokerage for Personal Supports, also called Brokerage, which has been providing unencumbered independent planning and facilitation to people and families in Windsor since 1998, when it began as a pilot project supported by this ministry, people have become empowered; people have had more choices. It has been very helpful with people and their families who needed support to understand their different views, sometimes from the person to the parents. It has been very helpful for people who don't communicate typically the way the rest of us do, as they listen deeply and get to know people. It has been very important for those who have wanted to take different

risks and try different things and create their own supports. It has been very important for people who have chosen the traditional system and who need help mediating their supports from within.

There is no mention of independent planning and facilitation in Bill 77. Instead, the bill speaks of the application centre working with you to decide what supports you need.

Creating a profile: People are also expected to identify when they want direct funding or base-funded support without the benefit of independent planning and that information first. When people apply for funding, they should not have to choose upfront which support they want to use. They would need the education and the information opportunities. Life changes, and people should be able to make those changes as things change.

Individualized funding with choices for flowing funds and supports has been a critical support in Windsor and Essex county for the last 10 years. People have chosen their services and supports and they've changed them as needed. They have created things from the ground up and they have chosen which transfer payment agency they wanted to hold their funds, track finances and assist them with monitoring and accessibility. They have spent their funds according to a budget and a personal support agreement. The people themselves, with the help of family or a support network, have decided what kinds of supports they need. Many families have gained a wealth of experience and they have found that the blending, sometimes, of traditional support through the TPAs and individual supports have worked for them, and they have found choosing what level of assistance they need helpful.

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There are limited to no options in Bill 77 with regard to the way direct funding is described. It appears to be an all-or-nothing option for managing the funds. The infrastructures needed to support people and families are not mentioned in Bill 77. According to the bill, the application centre would determine what services a person could receive, allocate finances, serve as the bank, and would do the accountability and monitoring. This would be a huge conflict of interest, resting in one organization.

The other thing that is critical to our community is that for almost 10 years, we have developed and successfully utilized a respectful prioritization process. It did not cost extra funds and there were no levies taken from agencies to create this. This respectful process utilizes a process coordinator, with volunteers who sit on a priority panel. The panel is made up of our peers and community members. It is anonymous to us. In turn, requests from families with applications and their plans go forward anonymously. So there is no decision-making, in terms of everyone's in a golden fishbowl and agencies know exactly your business. That is something our families in Windsor and Essex county absolutely fear. Families have trusted this process and are hopeful that there would be some way to make room in Bill 77 for something like this to continue. The application centre model has the potential for derailing the process coordinator, our respect-

ful prioritization process, the choice of banks or transfer payment agencies, and the flexibility and monitoring and accountability.

Equal partnerships and monitoring: The person, family and agency have responsibilities in this system we've created and are treated as equals. Monitoring and accountability include family, friends and/or a network of support to ensure the person's quality of life. In this work, families who use brokerage have been more than willing to give back their funds toward the end of the fiscal year so that other families could be helped. This provides an opportunity for others to use the funds and has resulted in a caring, community-minded approach where people are responsible to each other. This is empowering.

The application centres described in Bill 77 have an enormous amount of control; they appear almost godlike. They make a lot of decisions for the person and family, which could potentially take away from the creativity and the responsibility that people have embraced in Windsor and Essex county.

We have embraced what we call an "empowerment model." This means that all the control for important functions in the system exists in different places and organizations; they are not under one roof. To have all the functions under one roof or in one aspect of the system mimics the old institutional model. In the empowerment model, advocacy, planning and facilitation, direct services, and supports and allocation would all exist in different places. There needs to be the opportunity for those functions to be available in different organizations.

Bill 77 derails the empowerment model. It describes a case management, service coordination, managed care model. This is not empowering. Many families do not want something that mimics the CCAC medical model, nor do families want all the features and functions they require to only be available through direct service providers and/or application centres. There needs to be some infrastructure for independent planning and facilitation outside of the service system and some way to strengthen independent and autonomous people and family groups.

Healthy tensions created in an environment lead to creativity and responsibility. Over the 10 years that this has existed in Windsor, in fact, the traditional support system has grown, and we know that two thirds of people and families will choose that, and this transfer payment agency system will continue to be needed. At the same time, what we're looking for are options for that one third of people who may want to do things differently and create things from the ground up themselves.

Supports, as we know and understand them: To many of us in Windsor and Essex county, the word "supports" means being able to purchase what is needed to live an everyday life. It is not about being in service or having a life provided by one service program. In Bill 77, agency services are described as being "prescribed services," "being serviced," and "service" words are all over the bill. Our own lives and those of our family and friends

are not built around services or even “service” words, but around a home that is developed with help of family and friends and people who are hired or contracted to support the person. The word “supports”—a more natural way to look at life—is not found in the original Bill 77, although we do see it in the plain-language version. We would like our everyday lives described in a manner that doesn’t mean that we’re being serviced or that our sons and daughters or brothers and sisters are being serviced.

In summary, the families who came together on July 15 as a representative group in our area give credit to the ministry for the new definition of “developmental disability” and for determining that new legislation is needed. In addition, the move to direct funding is a positive one, but grounding the document in values and clarifying what infrastructures would be available to empower people who choose direct funding and want to live everyday lives would be critical to enhancing this legislation.

The following questions have arisen: What will happen to our sons, daughters, sisters and brothers if their lives are reduced to economics and standardized templates, as opposed to a life of quality, as determined by them? Amending Bill 77 could avoid this scenario. Will the empowerment of families that families have experienced by the good characteristics of the Windsor-Essex model be eroded? What will happen to special services at home? Will SSAH have to go through the application centres? Families are concerned about any changes and erosion to the immensely successful SSAH program that may occur.

Families have watched the closure of the institutions and the resources available to the individuals who have moved there. Some have found this heartbreaking when they sit on a wait-list and have supported their family member in the community for years and years. This is especially true when we watch parents between 80 and 90 years of age who are still caring for a son or daughter with a developmental disability at home, with little or no support. It is even more heartbreaking to be aware that infants and preschoolers do not have special services at home support at an important and critical time in their growth. Parents, sisters, brothers and others, as main caregivers, need support from the government of Ontario. The entrenching of wait-lists has made more fears arise around that. Families, in general, are living with a great deal of stress and anxiety. Add to that the reality of caregiving, a lack of resources, their own aging, fears about Bill 77 and what that could do to undermine the local model of support we’ve had in Windsor and Essex counties—something tried and true—and the anxiety increases. There are some very concerned parents reflecting on how people will live as full citizens and actively pursue their basic human rights, with Bill 77 in its current form.

We respectfully ask this government to consider making some amendments to Bill 77 that would consider the success of the model that we’ve used in the last 10 years and make room for that. People and families have been responsible and active partners. We ask that you

refer to the document prepared by Judith McGill from the provincial ad hoc group, as well, and consider those thoughts. We ask that you consider working with the Individualized Funding Coalition around definitions and possibilities for person-directed planning and the idea of independent planning and facilitation.

Lastly, we would like to sincerely thank you for taking the time to consider our thoughts and our concerns.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. That was perfect timing, so there will be no questions or comments.

WINDSOR-ESSEX BROKERAGE FOR PERSONAL SUPPORTS

The Vice-Chair (Mr. Vic Dhillon): Next, we have Windsor-Essex Brokerage for Personal Supports.

Good afternoon, and welcome to the committee. You have 15 minutes. Please state your names for the record; then you may begin.

Mr. Rolly Marentette: Rolly Marentette.

Mr. Al Hendry: Al Hendry.

Ms. Marleen Crawford: My name is Marleen Crawford. I’m the president of the board of directors of Windsor-Essex Brokerage for Personal Supports. I’m also the parent of a 33-year-old daughter who lives with developmental and physical disabilities every day.

You will hear me refer to “Brokerage” as I speak. I want to begin by thanking the Liberal government for bringing about legislative change that includes direct funding. We know the work that is involved in transforming a system, and we commend the Liberal government for its transformational document Opportunities and Action—Transforming Supports in Ontario for People Who Have a Developmental Disability. Based on that document, we would encourage this committee to ensure in writing that this is an act that enhances social inclusion for persons who have a developmental disability.

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Our community began by recognizing that, along with individualized funding, there was a need for infrastructure support that would enable people to build meaningful lives in their neighbourhoods and community. For those people who do not want what is available within an existing agency or who no longer need to fit into the existing services being offered through ministry-funded agencies, we believe innovation is the answer.

Brokerage began as a project in 1997 and received ongoing funding from the ministry in 1999. Brokerage was established to provide information from a broad range of options and to provide independent planning and facilitation support, assisting people and their families and others whom they trust to define their lifestyle. This takes into consideration all aspects of their life: housing, recreation, work, education, volunteering, getting together with friends and everything else that we take for granted. A protocol was signed with service-providing agencies in 1996 agreeing that if people and families were not happy with their supports and could not get

resolution to their concerns or were moving to another city or town, they had the right to move the support dollars to the agencies of their choice. That portability clause is written into the service contracts with agencies today in our community. Brokerage assists with mediation, negotiation, shopping around for those services and supports and moving funds if needed. Contractual agreements are also completed.

Now I'll talk to you a little bit about what we have learned in the past 10 years and make a few suggestions.

(1) Bill 77 needs to reference the work that the United Nations has done: the principles of respect for a person's inherent dignity and individuals' autonomy, including the freedom to make one's own choices, as well as having the equality of opportunity. The person's voice is missing in Bill 77.

(2) Our work in Windsor-Essex county was based on recognizing supportive decision-making. The United Nations Convention on the Rights of Persons with Disabilities has included the recognition that a person labelled with a developmental disability has the legal capacity to make sound decisions through supported decision-making.

(3) Bill 77 needs to include independent facilitation and planning support. Not only should this be made available to those who choose to have direct funding, but it should be seen as a basic right to each and every person with a developmental disability once they are deemed eligible for funding and/or services. If there is fairness and equity in the system, then the sector cannot focus all its energies on those deemed the most in need.

(4) Portability should be included in the legislation. People should have the right to move their support dollars whether they have direct funding or need their support dollars to be unbundled from an existing support arrangement within an agency. They should be able to move those resources to another agency or town if needed. The broker function needs to be added to make this work.

(5) There is a serious wage disparity between those who work in an agency and those working in the community under direct-funding arrangements. We want to see support workers receive a valued wage when working for an agency, but we believe the same is true for those supporters who are contracted or hired by a person or family. My daughter Megan has both contracted and hired people who support her.

(6) The legislation refers to internal reviews that may result in the termination of direct funding if misused. Part of an independent planning process is the building of knowledge and capacity to direct one's funds. Through this process, people, along with their families, decide whether or not they have the capacity.

(7) To enable direct funding to be a viable and sustainable option for people and families, Bill 77 needs to clearly state that investing in infrastructure supports is necessary. Those supports are independent planning and facilitation, a brokerage function, human resource sup-

ports, as well as supporting autonomous advocacy and self-advocacy groups.

During the past 10 years, people with disabilities and their families in Windsor and Essex counties have had individualized funding or dollars of support attached to them. During that time, the option of individualized funding for people and their families and the ability to direct it themselves has not resulted in lost jobs for workers. The fine agencies have remained viable and strong in Windsor and Essex counties. This is not a competition; this is a choice.

You have quite a job ahead of you, and I commend you for really looking at this bill. My daughter needs you to ensure that Bill 77 gives her a voice and a choice in how she lives her life, with our support and paid support. She is fully included in her community. My daughter is evidence that independent planning and facilitation, coupled with direct funding, need to be sustainable in Ontario.

Just as a note of interest, we've been planning for two and a half years for my daughter to live an independent life, move into her own home and start living as a part of her own community. We started planning well before we had any individualized funding, but we knew that it was something that we needed to do because my husband and I are getting older and we wanted to see her in a situation that was safe and where she is included as a full citizen of her community. As we speak, this week we are doing the training for her support workers who will be taking care of her in her home, and she'll be moving into her home next Tuesday. This would not have happened without Brokerage and the support that they give us and the independent planning and facilitation that has taken place over the past two and a half years. We value what we have in Windsor, and we sincerely hope that you take a look at us and see what we have.

Thank you so much for listening to me.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We have a little bit over two minutes for each side. We'll begin with the official opposition.

Mrs. Christine Elliott: Thank you very much for your comments. We certainly will be taking a very hard look at what you're doing with your agency. I'm also really interested in your personal comments about the length of time that it took for you to build an individual plan for your daughter. I think it really does speak to the need for those independent, individualized planning supports, because it's not just a simple matter of getting the dollars and using them with one particular support. As I understand it, there are circles of supports that need to be built, not just for financial support but to ensure that your child is going to have the kind of life that you want them to have in the community. So I agree with you. I think it's essential. Thank you for your comments.

Mrs. Maria Van Bommel: Thank you for your presentation. I'm curious about the empowerment model. I see you have a chart of that model in your presentation, and the previous presenter also talked about the functions being separated. How does Brokerage work? Where does Brokerage fit into this model?

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Ms. Marleen Crawford: Well, they are the planning part of that model, the unencumbered planning part of that model. We work with people who request our services. We sit down and the brokers—Al here is a broker; Rolly is a board member. Al works with individuals who ask for their help. He sits down and listens. The previous speaker spoke about deep listening. The brokers are past masters at deep listening and trying to get an idea of what would work best for the individual and then doing the planning to achieve this, the goals.

Mrs. Maria Van Bommel: Where do families enter the system in this model? Where do they start? If you're coming for the first time to find help for your daughter, where would you enter into this model?

Ms. Marleen Crawford: Well, it may start in any one of those. In an advocacy organization, they recommend Brokerage for a family to start thinking about planning. High school: Brokers go out to high schools and talk to the teachers about giving good information to families when children are making the transition from the high school setting into the adult world. That can be like dropping off the edge of a cliff. Whoever can provide information about Brokerage, that's the way people find out about it. There are service delivery organizations who will say to families, "You might be helped by Brokerage." Families will find out about it through networking and partnering.

Mrs. Maria Van Bommel: I'm just trying to—I've had a number of people over the years come through my office and talk about the fact that they're looking for sort of a one-window approach where they can start at one point and they know where that point should be and then go out. That point would then send them in those directions, because most people don't know where to start. They are trying to figure out where they can find the services for their child. I've had people come to my office and say they weren't aware of services until their child was no longer eligible for them. They were kind of angry that they hadn't been aware of these services, because they needed them.

Ms. Marleen Crawford: That happens quite often. Brokerage is the central point of information for adults in the Windsor-Essex area.

Mr. Al Hendry: We walk along with people, so they would contact us as a first information and then we would begin a relationship with them that never ends. It doesn't stop just because they've got some services or something. Once they've maybe achieved some level of support that they want, we continue to evolve with them as their life changes.

Mrs. Maria Van Bommel: Thank you.

The Vice-Chair (Mr. Vic Dhillon): Thank you for your presentation this afternoon.

BILL HILTZ

The Vice-Chair (Mr. Vic Dhillon): The next presenter is Mr. Bill Hiltz. Mr. Hiltz?

Mr. Bill Hiltz (audio recording): My name is Bill Hiltz. I am not disabled; I am differently abled.

The Vice-Chair (Mr. Vic Dhillon): Sir, can I just ask you to state your name?

Mr. Arnold Row: Yes. My name is Arnold Row. I am an intervener with Bill.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

Mr. Arnold Row: Bill has been struggling with the effects of his very sedative seizure medication. We weren't sure that he was going to be able to prepare this presentation. Because it was important to him to appear before you today, Bill, with his support network, decided that it would be important to use a different way to help get his message to you. So please bear with us for a few minutes as we do something a little differently. Could we ask for a little interaction between us and you personally? Is that acceptable?

The Vice-Chair (Mr. Vic Dhillon): Yes, that's fine.

Mr. Dave Levac: Thank you, Mr. Chairman.

Mr. Arnold Row: What we're going to ask is that each of you take on a disability so that you can understand exactly where we're coming from. We're just going to take a couple of minutes and do that. Thanks for indulging us.

Mr. Dave Levac: Just as we're setting up: I find this to be a very appropriate exercise in that all, if not most, MPPs have been asked to participate in this kind of activity in their communities, with community living. Most have been able to successfully navigate this, which is why I'm committing to you that I think this is an appropriate activity for the committee, not to be seen as anything other than a learning experience. So I just wanted to put that on the record.

1510

The Vice-Chair (Mr. Vic Dhillon): Thank you, Mr. Levac.

I'd just like to state that some parts may be difficult to record in Hansard, so just keep that in mind in terms of making sure we get everything on record as much as possible.

Mr. Arnold Row: Thank you. Everybody, just take a minute and realize what it's like to be blind, to be deaf or to have any other differing ability like autism or spina bifida. Just think about that for a minute.

In the next minute, Bill asks that you please consider how you felt. I'll just keep reading, and I suppose that if you've got earplugs in, you probably want to take them out if you want to hear what I have to say, but otherwise, you can keep them in.

He wants to know how you feel having lost your choice and control of your life for the last few minutes. Were you less able to make decisions because of the differing abilities we gave you? Some people would think you were not able to make such decisions, but with the right supports, you would be able to make decisions about your life.

This is why and how Bill thinks that Bill 77 needs to be changed before it becomes law for many more years to come:

“Choice: Choice and control are very important parts of citizenship. I was denied citizenship for eight years of my life. I know how important citizenship is. When I was younger, I lived in a facility. My life was not mine; it was theirs, but now I make choices about my life. I live in a home with a family, one that I chose. I choose the people who help me. They help me to make choices about my life. I don’t bite myself anymore because people listen to my communication.

“Language is important. The language must change to break down barriers. ‘Disability’ is too limiting; it means not being able, but that is wrong. We are all able. We all have differing abilities.

“Services: Change ‘services’ to ‘supports.’ Nobody needs services to be a citizen. They need supports to help them be a real part of their community. I don’t want special services; I want help to use services already there. Only that way will we all learn to accept one another.

“Individualized funding: Thank you for listening and giving us individualized funding. Individualized funding is an important part of building citizenship, but please do it right. ‘Right’ means listening to the people who need the supports. We are the experts.

“Planning: Person-directed planning is so important to build a life and community. You all do it easily. For people with differing abilities, it takes a lot of work.

“Here’s a picture of my life in community. It is possible only with the help of many: a facilitator, my support circle, my interveners, my family home providers, my doctors, my nurse and my friends. They give me the chance to experience life, to include new people all the time. You have that picture there in what we handed out.

“My strengths and abilities and knowing what is important to me have opened many new doors. Joyce and I gathered people around me to help ask questions and plan for my life in community. Without funding, my life in community was not possible. Work was needed to get funding. We did the work; we got funding. But there was a difference of philosophies between us and our service provider, so we had to call on the help of my support circle to help me solve that problem, but we couldn’t quite do it alone. So, by networking, we found Helen, a great facilitator. She was able to solve some of the problems we had. My life is so much better now.

“In 2002, we asked the ministry to let us move my funding to another agency, but they wouldn’t do that. My funding is portable, but only within the program. We asked the ministry to make my funding individualized. They said they couldn’t do that; there is no such thing as individualized funding. We gave examples of people who have individualized funding, but they still said no.

“This whole thing made me very sick, physically. So after trying everything else, we went to Queen’s Park, to the minister’s office, to ask again. Still the answer was no. After that, things were made really hard for me. That’s when we really needed the help of our facilitator.

She made things better for me. My support circle worked hard. We have all the things we need to make individualized funding work, but the ministry is still saying no, so we are hoping that we can soon move my funding.

“The stress level was high. Everyone around me was working so hard. None of this had to happen if funding had been fully portable. We can’t find anything in Bill 77 that says that we would be able to move my funding, but the vision for transformation says money should go with them if they move to another community in Ontario; it should be portable. Each person has their own needs. People should be able to decide for themselves who will provide the supports they need and how those supports will be provided. The money should be flexible. I just want to choose the agency that would make things better still and give me control.

“We talked with the deputy minister a few years ago. He said that with the new system, we would be able to move the funding, so we wait.

“I hope that because I have said these things, things will not get rough for me again, but I think you need to know why this is so important to me. That is why I am here today. Even though things are good for me now, it is still important that things change for others. That is why I am a member of the Individualized Funding Coalition for Ontario, Family Alliance Ontario and London Family Network.

“I was part of the provincial ad hoc working group for Bill 77. This group was made up of people from many organizations. We all shared the same vision for a support system based on citizenship. We came up with recommendations to help make this bill be the best that it can be. I hope that you will think of me, the person who needs supports, when you consider the recommendations. These are important to me and need to be in the bill.

“(1) Provide the right of good choice.

“(2) Hear the voice of the individual in making decisions about their life.

“(3) Change the language to focus on abilities; focus on supports, not services.

“(4) Provide person-directed planning.

“(5) Provide fully portable, individualized funding.

“(6) Provide the supports needed.

“(7) Supported decision-making: Let me decide the help I need.

“(8) Support for networks: It is important to have people around you to help build a life in community. Remember, I am not disabled; I am differently abled and I can do many things. I just need help to do them.

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“I would like to share with you one last thing—my poem.”

The poem is also inside the Walk a Mile in My Shoe flyer that you received; it’s in the centre there. A reminder about the Walk a Mile in My Shoe: It’s on September 13 and it’s interaction for awareness for people who are differently abled. We would love it if anyone could attend.

I’ll just read the poem.

The Chair (Mr. Vic Dhillon): Can you read the date for the Walk a Mile?

Mr. Arnold Row: September 13, 2008.

This is the poem that Bill wrote. I'll do well to get through it without getting choked up:

“Understanding People

“A set of standards by which to judge
to their friends, they give a nudge,

“When they see me come their way
they stop and walk the other way,

“Or even worse, they stop and stare
as if I'm stupid and unaware.

“If only they could know that I care
how people view me; it's just not fair.

“I feel the very same as others do;
they should try and walk in my shoe.

“Life's not easy when the body that you own
was given to you broken down.

“They may be mean, they may be cruel, they may be bad,

but most of all, they just don't understand.

“With some time and special guidance
we can have a great alliance.

“For an hour or for a day,
we all need friends along the way,

“So when you see me come along,
try not to focus on what is wrong.

“I am a person just like you
who needs and deserves a good friend too.

“Just walk beside me straight and tall
and be the friend that I can call
when I am lonely and afraid.

“Just remember what I've said:
All you need is to understand.

“Do not judge; just take my hand.”

Written by Bill Hiltz.

Sign language.

Mr. Arnold Row: Bill would like to thank you. Thank you very much.

The Vice-Chair (Mr. Vic Dhillon): Thank you for your presentation.

We'll wait a moment till Bill is adjusted.

INDIVIDUALIZED FUNDING COALITION FOR ONTARIO

The Vice-Chair (Mr. Vic Dhillon): Just to let you know, the next presenter is Ms. Joyce Balaz.

Ms. Joyce Balaz: Good afternoon. My name is Joyce Balaz. I'm a family home provider for Bill Hiltz, the previous presenter. Bill and I are very actively involved in the Individualized Funding Coalition for Ontario, as well as other like-minded organizations. So I appear here before you wearing a few hats. It was hard for me to decide which hat to wear as I make this presentation to you, but after long deliberation, because individualized funding is so important to Bill, I will present on behalf of the Individualized Funding Coalition for Ontario. But I must do so with Bill's issues in my heart, because it is his

strength that keeps me advocating for a better Ontario and Canada, one of citizenship and full inclusion.

As was mentioned with Bill's presentation, we didn't know if Bill was going to be able to prepare his presentation. I've tried to cover the issues raised at the last Individualized Funding Coalition for Ontario meeting that Bill identified as what he wanted to present, so please forgive the duplication. My presentation was finished before Bill was able to complete his, and please bear in mind that what Bill did prepare took many hours of very focused work.

I am thankful every day for the experiences, the learning, the understanding, the many people, the joy and the love that Bill has brought into my life. It is through these experiences that I have gained the courage to speak with you today and to pass on to you what I have learned over the past 18 years of knowing Bill and over the past seven years of working with the Individualized Funding Coalition for Ontario.

“The Individualized Funding Coalition for Ontario”—I may say “IFCO” to shorten time—“supports the self-determination of persons with disabilities. We believe that all people should have the control over decisions concerning where they live, with whom they live, with whom they associate, and how they spend their lives. In order to achieve this we recognize that Ontario must develop a system of funding 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/her supports.” That comes from the accord the Individualized Funding Coalition members must sign.

One key thing that I have learned is that Bill is not disabled; he is differently abled. He has taught me so much. Therefore, throughout this presentation I have endeavoured to be mindful of my language and wherever possible changed the term “developmental disability” to “diverse developmental ability.”

Because of some very unfortunate circumstances relating to Bill's supports, Bill and I found it necessary to reach out to the larger community, and as such we became involved with the Individualized Funding Coalition for Ontario; Family Alliance Ontario and London Family Support Network. Most recently, as part of our advocacy, we've worked with others from similar-minded organizations such as the provincial ad hoc working group on Bill 77.

That position paper was submitted at the hearings yesterday. We find that the recommendations from each of the groups we are associated with are quite similar, as they are derived from the same sound values and principles of citizenship and full inclusion in society. These values and principles have fuelled our advocacy over the past seven years. We therefore wish to endorse the recommendations made by the groups mentioned above.

We wish to applaud this government for acknowledging that there are many barriers in society that prevent persons with differing abilities from being fully included in society. There is no doubt that legislation is

necessary to help bring down these barriers; however, that will still not ensure full inclusion.

One cannot legislate understanding and acceptance. That can only be accomplished through first-hand experience. In the words of Judith Snow, the first person in Canada to receive individualized funding for personal supports, a past co-chair of the IFCO, an author, speaker and advocate for inclusion whose work is recognized and sought after internationally: "Society will change when I am in it."

In May, the Parliament of Canada unanimously called upon the Canadian government to ratify the UN Convention on the Rights of Persons with Disabilities. However, many of the elements are under provincial jurisdiction. By including key elements in this proposed legislation, which would allow Canada to ratify the convention, the government of Ontario will be seen as a champion for the rights of persons with disabilities.

Bill and his support network have been strongly advocating for individualized funding for Bill since 2002. It's now 2008. That advocacy was assisted by the diligent efforts of the IFCO.

The IFCO has been very actively working with the ministry to ensure that the key elements necessary to make individualized funding a reality in Ontario become part of the transformed system. The coalition has been involved in expert policy forums and small working groups, has made submissions at every stage of the transformation process, and has produced research to support the positive outcomes made possible with individualized funding. They produced a person-directed planning guide which was made available for people applying to the Passport program.

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We commend the ministry for listening to the many individuals in Ontario who have been asking for individualized funding. I believe it's about 20 years they've been working at it. We applaud the government on its efforts to transform the system; to move from a welfare-based service model to one which is citizenship-based.

However, the proposed legislation does not include many facets that are vital for ensuring successful individualized funding and full inclusion in society. Key elements that need to be included in this legislation are:

- the right of choice and self-determination;
- ensuring the voice of the individual is truly heard; so often we make decisions for them because we think it's easier or it's right, but we need to really listen;
- the right to be actively involved in development and decision-making with regard to policies and regulations;
- positive language that speaks to ability, not disability;
- provision of supports necessary for individuals to access already existing services;
- person-directed planning for a whole life;
- the right of supported decision-making;
- adequate funding that is flexible and fully portable;
- provision of supports for autonomous groups and networks to enable community building to help build an inclusive and accessible Ontario;

- ensure equal funding for both direct-funding and service-provision models;

- ensuring that processes are not discriminatory; and
- a guarantee that processes are free from any conflict of interest.

While I cannot speak of our experience to all of these key elements in the time allotted, I will speak to those that are most important for Bill, as he is my first priority. For the legislation to be effective in promoting inclusion, the language of the bill must be more positive. It must speak to abilities rather than disabilities; it must focus on supports rather than services. Supports enable inclusion, while services tend to segregate. The name of the bill must be more reflective of the vision of a citizenship-based system of supports. A recommendation would be, "An Act to enhance the social inclusion of persons who have diverse developmental abilities, to repeal the Developmental Services Act and to amend certain other statutes."

This legislation should include a preamble clearly reflecting the vision and principles of the transformation process guided by citizenship, including access, rights, full participation and being valued as an equal member of society. This would proclaim the social change intended by the legislation.

To promote citizenship and full inclusion, the legislation must ensure that there is access to the supports necessary to participate in the community, such as person-directed planning, which focuses on strengths and abilities, provides for a seamless transition through life's known changes, responds to emergency, life-altering situations, and is proactive, thus preventing crisis situations from arising. It must be ongoing and available to all who are deemed eligible.

This is essential to enable an individual to experience meaningful participation in their chosen community. It is through this planning that an individual will decide how best to access those required supports. As such, it must be whole-life-based and independent of direct service provision.

Person-directed planning will also enable the individual to gather around them the networks of support that they require to help them as they participate in society. The use of a good facilitator/planner will assist with this process, as it takes time and effort to build a supportive network. It would serve the ministry well to include supports for support networks and autonomous groups to enable them to help build an inclusive and accepting Ontario. Building natural relationships with others in community will only be achieved by being a part of that community. This will help build and maintain the support network. This support network can then assist the individual to make the decisions that affect their lives.

In order to provide for full citizenship for people with differing abilities, it is important that the legislation include supported decision-making, which has been a viable alternative to substitute decision-making in Canada for over a decade. Supported decision-making

has been adopted into international law under article 12 of the UN Convention on the Rights of Persons with Disabilities. It is highly recommended that Bill 77 include provisions to recognize the legal capacity of all people and provide for supported decision-making in order to ensure that people can enjoy their legal capacity.

In the blueprint for transformation, Opportunities and Action, the plain-language version talks about flexible and portable funding. It was the third of the six big ideas of the vision of a new system of delivering supports. It talks about portability, and you've heard it time and time again, I'm sure. However, this key element is not in the proposed legislation.

The absence of fully portable, flexible funding from this legislation has us very worried. In Bill's situation, he and his support network have worked diligently to ensure that Bill controls his own life and makes the decisions affecting his life. However, one piece is sadly missing: that of being able to use the agency of his choice, because his funding is tied to a specific program. We have had many conversations with ministry officials and with our MPP, Khalil Ramal, about trying to get those things changed. We have been told that we should be able to take Bill's funding to an agency of his choice under the transformed system, and the timelines given are very close to the present. This would provide the ultimate in choice and control for Bill.

The legislation must ensure that there is adequate funding available to purchase those supports necessary to participate in community life. There must also be a guarantee that both the new direct funding model and the current agency-based system are funded equally. The IFCO has been asking that a portion of any newly allocated funding be directed towards individualized funding models; however, while there was an allocation of funding made to the agency-based service sector, there was none to either the special services at home or Passport programs in 2008. There's a lot of inequity there.

We recommend that the sections relating to waiting lists and prioritization be removed, as they are both discriminatory. Their existence clearly demonstrates that the ministry is well aware of the fact that the sector is seriously underfunded and that people are currently waiting and will continue to wait for service or funding to support them in the community.

We see the entire section on application centres as another major concern. Entrenching all of the functions in legislation will not allow for the new system to evolve. With all of the processes in one spot, it just creates an inherent conflict of interest. You can't allocate and assess and check out how the service provision is going fairly. Many of the policies and regulations relating to the application centres are currently being developed, but without the voice of the individual in that process. We acknowledge that there has been public input on these various aspects; however, as stated before, when we look at Bill 77, it's obvious that it has not been heard loudly and clearly enough.

The assessment process based on a needs scale without first considering what that individual needs to be

able to participate fully in that process leaves the door wide open for the assessment to be done about the individual without their voice being heard. The allocation of funding will take place based on a needs scale, with a certain cap on funding. There has been no consideration of what the individual truly needs to be a full participant in their chosen community. Again, the voice is missing.

In order to determine what supports a person will need to be able to fully participate in community, many determinants must be considered. This cannot take place in a single assessment session. It's taken me years to know what Bill needs. Life in the community is different for each and every individual. Their needs are different, so how can a compartmentalized needs-based assessment scale truly provide the necessary information on which to base an allocation of funding for community participation? It simply can't.

Implementing person-directed planning with facilitation once eligibility has been determined enables people to discover that they may be able to access already-existing resources and supports in the community, thus reducing government dependence and enabling an accepting and inclusive Ontario.

The ministry can go a long way in enabling an inclusive Ontario by looking at how best to provide supports to individuals to access already-existing services. This is more cost-effective, as changes that are made to existing services to accommodate the needs of persons with disabilities would also serve to assist all members of society. I'm thinking of parents with strollers; I'm thinking of delivery people. Many, many people would benefit from having these accessibility issues addressed, like public transit that's fully accessible, family washrooms—think about having to go as a mixed-gender group into a specific washroom; it's not very nice—ramps instead of stairways so that everybody can gain entry, not just people who can walk up stairs. Not only does this serve to build an inclusive society; it negates the stigma of being "special" and requiring special services. Bill would be the first person to say, "I am not special. I am a person just like you."

Understanding will go a long way in helping to build an inclusive Ontario. Let's start to gain that understanding by listening to those who know first-hand what it is they need to be a full, participating member of society.

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Yesterday, today and over the next two days, you as a committee will listen to various presentations. The decisions you make will live on in Ontario for many years. You will hear from service providers, union representatives, advocates, families, and/or support networks, but most importantly, you will hear from the individuals themselves. As you consider what you hear, the voice of the individual must be considered as the most important. The next is that of the family and support network as they continue to provide natural supports for the individual on a daily basis.

I look around; there's nobody with a diverse developmental ability on this committee, nor in the people

who have created the legislation and will develop the subsequent policies. While it is true we have been consulted—

The Vice-Chair (Mr. Vic Dhillon): Thank you very much for your presentation.

Ms. Joyce Balaz: Can I just ask one more thing, please? When you consider what you're hearing, ask, "If I were a person with a diverse developmental ability, how would what this presenter is saying affect my life?" Only in that way can you make the right decisions.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

Mr. Dave Levac: On a point of order, Mr. Chair: I noticed that it was a prepared document. If we could get a copy, I'd appreciate it very much.

The Vice-Chair (Mr. Vic Dhillon): Mr. Koch will get everybody a copy.

NEW VISION ADVOCATES

The Vice-Chair (Mr. Vic Dhillon): Our next presentation is from New Vision Advocates.

Welcome to the committee, sir. Good afternoon. If I could have your name for the record; you have 15 minutes.

Mr. Mark Anderson: Good afternoon to you too. My name is Mark Anderson. I am a director on the New Vision Advocates executive board. New Vision Advocates is a group of people with intellectual disabilities who advocate for ourselves and on behalf of others with intellectual disabilities.

I would like to begin by congratulating the Ontario government on its efforts in transforming developmental services and working to create a more inclusive society for all citizens. The proposed legislation looks to address a number of important issues of significance for services for people with intellectual disabilities. We believe, however, that important changes must be made to the bill that will enhance our ability to create a truly inclusive society.

I will focus our comments and proposed changes on the things we feel will help ensure that people who have an intellectual disability have full control over the decisions and activities that shape our lives and we are given the support needed to live as full citizens. While there are many issues, I would like to focus on the following three: the scope and purpose of the legislation; the inspections and operation; and the protections and appeals.

With respect to our first issue, we believe the legislation would benefit from the inclusion of a preliminary introduction aimed at describing the social change that is intended by the legislation. The preliminary introduction that we have recommended draws on the principles, values, goals and mission of developmental services and statements made in Opportunities and Action.

There are precedents for the inclusion of preliminary introductions in legislation in Ontario. The most recent precedents are the Long-Term Care Homes Act and the

Human Rights Code. Other acts that have included a preliminary introduction are the Ontarians with Disabilities Act and the Family Law Act.

New Vision Advocates members have been working hard for the past three years to educate our community about the importance of equal citizenship for all. We ask the government to support us in our work, and to do this by including the following statements in the preliminary introduction to Bill 77:

People who have an intellectual disability are equal and valued citizens of the province of Ontario and enjoy the full rights of citizenship, such as access to justice, health care, education, transportation, and other benefits of citizenship.

Many people who have an intellectual disability experience barriers in society that prevent them from enjoying their rights of citizenship and hinder their full participation in the social and economic life of the province on an equal basis with others.

Supports that are provided to people who have an intellectual disability are intended to enhance opportunities to enjoy the benefits and fulfill the duties of citizenship and to participate in the social and economic life of the province on an equal basis with others. Paid supports that are provided to people who have an intellectual disability should assist a person to strengthen relationships and should build upon and facilitate the supports that are available through community involvement; they should not replace them.

A person who has an intellectual disability has the right to make decisions about things that affect his or her life.

The second issue we feel strongly about is the right of adults with intellectual disabilities to feel secure in their own homes and to have the same right to privacy as every citizen. As advocates and people who receive support, we have fought hard to have our homes viewed as homes, not as someone's workplace. We feel that regardless of the classification a person's residence falls into, such as supported group living residences or intensive supported residences, it is first and foremost their home and must be treated as such. There should be no provision that allows an official to enter that home without the consent of the person or persons living in that home. If no consent is given, then a warrant must be obtained based on reasonable assumptions of wrongdoing. We feel that allowing someone to enter a home just because it is classified as a group living situation will be treating people's homes as mini-institutions.

We must recognize that this issue has been successfully addressed elsewhere. Ontario's new Long-Term Care Homes Act, subsection 146(2), reads: "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."

We recommend 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 replaced with the following: “except with the consent of the occupier of the residence or under the 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 except with the consent of the occupier of the residence or under the authority of a warrant.”

In subsection 27(4)(d), delete the words “a residence referred to in subsection (3) or of other” and “residents or other.”

The amended subsection would read:

“(d) 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 present in the premises, including persons receiving services from a service agency, about,

“(i) the adequacy of the staff,

“(ii) the range of services provided in the premises, and

“(iii) any other matter considered relevant to the provision of services to persons with developmental disabilities; and.”

The last issue that we would like to address is that a person’s direct funding agreement should never be cancelled for reasons of misuse where direct funding was being managed by someone other than that person, including a family member or guardian, and the person is found not to have played a role in the misuse. A person should not be punished, through the withdrawal of his or her supports, because of mistakes that were made or wrongful actions that were undertaken without his or her consent.

Our recommendation is to add a clause to subsection 11(9) which would state that if a person who was benefiting from supports provided under an agreement which was terminated under section 11(9) was not responsible for the decisions which caused the termination of the agreement, a new arrangement should be sought for the management of the funds and for the continuing provision of services.

We strongly urge the committee to address the issues of scope and purpose of the legislation, inspections and operation, and protections and appeals in order to ensure that the legislation is effective in addressing the needs of people in Ontario who have an intellectual disability.

Thank you for your time.

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The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We’ll begin with the government side; about three and a half minutes each. Mr. Ramal.

Mr. Khalil Ramal: Thank you, Mark, for your presentation. You did an excellent job.

Mr. Mark Anderson: Thank you, Khalil.

Mr. Khalil Ramal: How’s everything? Good?

Mr. Mark Anderson: Yes.

Mr. Khalil Ramal: Okay. I have a question for you. You mentioned the inspection. Bill 77 proposes that an inspection will be done without notice. You like that?

Mr. Mark Anderson: Yes. We’ve just asked that if the person doesn’t consent, a warrant be obtained because it is, first and foremost, their home. Their privacy should be respected as such.

Mr. Khalil Ramal: But you, as residents, live in the house, and somebody is looking after you from a service provider. If that service provider is abusing you for some reason or not looking after you very well for many reasons you mentioned, do you think it should be an inspection without notice to protect you and make sure everything is—

Mr. Mark Anderson: Yes. It should be to protect the person because it is, like we have said, first and foremost their home. It doesn’t matter what the classification is; it is their home.

Mr. Khalil Ramal: And I agree with you: You shouldn’t lose your funding if somebody made a decision on behalf of you or made a mistake. You shouldn’t be affected. It’s a good point and I support that. I wish you all the luck and thank you very much for coming before us. You did an excellent job.

Mr. Mark Anderson: Thank you.

Mr. Khalil Ramal: I’m still waiting for your invitation to your house.

Mr. Mark Anderson: Yes, I’ll have to e-mail that one to you.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. The official opposition.

Mrs. Christine Elliott: I’d also like to thank you very much for your presentation, Mark. I would just like to make a comment that seems to be in common with your presentation as well as Bill’s and Joyce’s before, and that’s with respect to the need to recognize the social inclusion that’s meant to come from this legislation as well as the supports and the financial part of it. I think that if we’re to achieve the full transformation, the comments that I’ve been hearing from many people indicate that it’s not just a transformation with respect to the system that’s presently in operation, but it’s a transformation of the way our entire society sees people who have different abilities. I think that that’s something we really need to concentrate on and look through that prism, as we look at what we want to achieve with this legislation, because until we can change or shift people’s way of thinking to think about the abilities everybody has, we’re not going to get it. We need to look at that and figure out how we can get people generally to understand what needs are so everybody can participate. Then we’re going to have it.

Thank you very much for making a big contribution to that.

Mr. Mark Anderson: You’re welcome.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much, sir, for your presentation.

COMMUNITY LIVING LONDON

The Vice-Chair (Mr. Vic Dhillon): The last presentation is from Community Living London: Mr. Hewett.

Good afternoon and welcome to the committee. You have 15 minutes, if you can just identify yourself for the record.

Mr. Jim Hewett: Good afternoon. My name is Jim Hewett. I've been a volunteer member of the board of directors of Community Living London for the past eight years. I am also a parent of a young man who has an intellectual disability.

I am aware that you have already heard from several community living agencies today, and I am confident that you are familiar with the many roles we play in our respective communities. Here in London, community living touches the lives of 900 people with intellectual disabilities and their families every year.

I want to thank you for the opportunity to speak to Bill 77, the proposed legislation for developmental services. I would 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.

We believe, however, that important changes should be made to the bill that will enhance our ability to create a truly inclusive community. Community Living Ontario has already submitted a list of 19 recommendations to the committee, and Community Living London endorses those recommendations.

Today, we will focus on comments and proposed changes regarding three of the recommendations which have particular significance to Community Living London and its constituents: the proposed application centres, which is in section 8; the issue of immediate takeovers in sections 30 and 31; and the right of people with intellectual disabilities to live in peace and security, which was not addressed in Bill 77.

With respect to the establishment of application centres, we believe that in order to address potential conflicts within the application process 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 or eliminating any potential for conflicts. To this end, the legislation should refer to an "application process," rather than "application centres." Allocations of funding should remain the direct responsibility of government.

Here in London, various service agencies work cooperatively throughout the CSCN, the Community Services Coordination Network. We do not want to see collaborative processes developed with CSCN discarded and replaced by a new application centre. Further, a person with an intellectual disability should not have to make application for services, have their needs assessed, receive an allocated amount of service, and have those

services evaluated by one entity. While these elements need to be coordinated, there is too much room for conflict having all of these elements provided by one entity.

This matter can be addressed in the legislation by considering the following additional changes.

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

Subsection 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 described 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.

With respect to our second matter, immediate takeovers, we recommend that the powers of the ministry extend only to the capacity to assign a manager and reassign responsibilities related to services described in ministry contracts. These powers should not allow the ministry to interfere in the governance of community corporations, and as such, should not extend to the management of the affairs of a service agency, as described in subsection 30(1).

The contracts that are held between the ministry and local associations to provide services are subject to the conditions of Bill 77 and the conditions of the contract. However, local associations hold contracts with a wide variety of stakeholders other than the ministry. At Community Living London, we have contracts with and receive funding from the government of Canada, the Ministry of the Attorney General, the Trillium Foundation, the Ministry of Health, United Way and the Ministry of Children and Youth Services, and we have hundreds of dollars in sponsors.

While the government holds contracts with local associations, they enjoy certain benefits that come from the fact that the local associations are made up of volunteers and persons who share a common concern. Much more than running a business, a local association shares the aim of building inclusive communities. Powers of government over associations and actions may be addressed to two main concerns for harm: funds, and health and safety. Actions which are taken based on these powers should be addressed only to the cessation of that harm and correction of it.

This matter can be addressed in the legislation by considering, in subsection 30(1), deleting the words "affairs of the service agency or application centre" and replacing them with "contracts that are held between the service agency or application centre and government." The amended section would read, "Upon notice to a service agency or an application centre, the minister may, based on grounds set out in subsection (2), appoint a person to take over and manage the contracts that are held between the service agency or application centre and government."

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In section 31(1), delete the words “affairs of a service agency or application centre” and replace them with “contracts held between a service agency or application centre and government,” and add the words “over that contract,” at the end of the clause. The amended section would read, “If a manager is appointed under section 30 to take over and manage the contracts held between a service agency or application centre and government, the manager has all the powers of the board of directors of the agency or centre, as the case may be, over that contract.”

The third recommendation I wish to make is that Bill 77 needs to address the rights of persons with intellectual disabilities to live in peace, harmony and security. We can no longer allow others to have the legal authority to disrupt and intimidate people in their own homes, as occurred during the labour strikes in the summer of 2007. Community Living London experienced a strike which lasted almost nine weeks. During this time, we were forced to shut down many of our services and focus our resources on providing essential supports to individuals in supported living environments. The individuals who lived in these supported living environments were forced to endure the continuous presence of picketers in front of their homes. The picketers were often loud, threatening, and extremely intimidating. To quote a person with a disability who experienced this first-hand, “The staff were yelling and swearing. They were right in front of my home. It was so loud that no one could sleep. The neighbours couldn’t sleep either.” We need to do more to protect vulnerable citizens from this type of action.

We are therefore recommending that developmental services be identified as a no-strike sector and that provision be established within the legislation to create an arbitrated settlement mechanism to address future labour disagreements. Provisions such as those found in the Hospital Labour Disputes Arbitration Act should be included within Bill 77 with the aim of ensuring that the disruptions to people’s homes and lives that occurred in 2007 never occur again.

The concept of essential services is well established in the context of labour relations where the workers provide services that cannot reasonably be withdrawn because of the extreme risk of harm such job action would impose upon citizens. Prohibiting strikes in police and fire services is the most common instance where strikes are simply prohibited. In Ontario, the Crown Employees Collective Bargaining Act provides for a similar approach based on the mutual identification by labour and management of those elements of any particular collective agreement that constitute essential services that by agreement would be maintained during any work stoppage by other employees in the bargaining unit. In another precedent, services provided by Community Living in Manitoba are subject to the provincial Essential Services Act.

Declaring the developmental services sector a no-right-to-strike sector would ensure that such a violation

of the rights of the people who live in these homes wouldn’t happen again. This matter can be addressed in the legislation by considering the following addition or change: The bill should be amended to incorporate the provisions of the Hospital Labour Disputes Arbitration Act, HLDAA, with respect to arbitrated settlements into Bill 77. Alternately, a Developmental Services Arbitration Act could be considered, with provisions that approximate those under HLDAA.

I strongly urge the committee to address the issues of application centres, agency governance, and the right of people with intellectual disabilities to live in peace and security in order to ensure that the legislation is effective in addressing the needs of people who have an intellectual disability in Ontario.

Thank you for your time. We would be happy to answer any of your questions. I also have copies of my presentation, as well as the 19 points from Community Living Ontario.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. A little bit over two minutes each. Ms. Jones from the opposition.

Ms. Sylvia Jones: Thank you, Mr. Hewett. You’ve raised many of the points that other presenters have come forward with in the last couple of days. I think it’s telling that, whether you’re talking from a community living organization, as a planner, a family member or an individual, there are some consistent messages that are definitely coming through. I hope our committee gets the message.

Mr. Jim Hewett: I hope they do too.

The Vice-Chair (Mr. Vic Dhillon): Thank you, Ms. Jones. Mr. Ramal.

Mr. Khalil Ramal: Thank you very much for your presentation. As my colleague mentioned, the same points were mentioned at different times yesterday and today, but the most important things people mentioned were an application centre and a processing centre. Can you give me your perspective on those, the difference between an application centre—

Mr. Jim Hewett: An application centre as opposed to a processing centre? There are too many variables in here. There are too many agencies involved with the supports for the individual to have one particular centre decide on what supports are going to be required and what they’re going to get. It just doesn’t make sense. In the city of London alone, we have so many different agencies providing supports. We all work together in providing those supports to individuals. We cross-provide supports, so to have a particular centre just determining what that individual is going to receive doesn’t make sense, and we don’t like that idea at all.

Mr. Khalil Ramal: So how can we, as a government, make sure there will be one standard applied across Ontario if we have a really different model and different applications? How, in your view, can we manage the applications—

Mr. Jim Hewett: We have the CSCN right now, which provides a sort of starting—a coordinating network. But to say that they’re going to then make the deci-

sions for all the agencies or to say that only this agency could provide a service is not the way that it's going to meet the needs of a person with an intellectual disability. There are too many variables involved.

The Vice-Chair (Mr. Vic Dhillon): Go ahead, Khalil. You have over a minute.

Mr. Khalil Ramal: As you know, at the present time, one individual or one family applies four times. That's why the waiting list is so huge. So to make sure we have one centre coordinating between all of them—that's why the bill proposes an application centre, to make sure all the people go to one centre and coordination is in place, in order to see how we can service the people across the province.

Mr. Jim Hewett: I certainly want to have a strong hand in however this process is going to come about to ensure that the needs of a person with an intellectual disability are going to be met within the community. I'm sure you've heard that funding is a major issue. That's just one part of it, to make sure that—we have waiting lists because we have inadequate funding within the sector. We can reduce waiting lists when funding increases. But just to put an application centre: in and say, "There are only so many dollars to go around, so unfortunately you're down at number 250 on the list, because we don't have enough money"—that doesn't address the needs of individuals with an intellectual disability. The needs are now; the needs are in the community. We need a lot of things, not just a process; we need additional funding as well.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. Mr. Levac.

Mr. Dave Levac: On a point of order, Mr. Chairman: Today, from this deputation, and from others yesterday, we've heard about the strike-free zone, no-right-to-strike sectors and other pieces of legislation. I'm wondering if we could have the legislative research do a small project for us, and I'm sure that the members opposite would agree to this, on where such legislation exists in the different sectors in Ontario; where in the rest of the provinces in Canada this type of legislation takes place and what it's used for; the declaration of essential services; and the containing of or changing of strike

provisions in sectors that are dealing with third party individuals. So I'm looking for support from the committee and the members if that piece of research would be appropriate for us to have before clause-by-clause.

Mrs. Christine Elliott: That would be most helpful. We were going to ask the same request, so thank you.

The Vice-Chair (Mr. Vic Dhillon): Research, do we have that?

Ms. Elaine Campbell: Yes.

Mrs. Christine Elliott: Excuse me, Chair?

Mr. Dave Levac: Did I start the ball rolling here?

The Vice-Chair (Mr. Vic Dhillon): Ms. Elliott.

Mrs. Christine Elliott: I do have one further request of Ms. Campbell, if I may, Mr. Chair.

The Vice-Chair (Mr. Vic Dhillon): Absolutely.

Mrs. Christine Elliott: One of the groups spoke about the need for a person or an organization to look into issues with respect to abuse and neglect. There was some discussion about the role of the official guardian. I was hoping that Ms. Campbell could help us with determining exactly what the mandate is of the official guardian, if they would be appropriate to be of assistance in this circumstance or not; I am just not sure. If we could get that assistance, that would be helpful as well.

The Vice-Chair (Mr. Vic Dhillon): We'll get that to everybody.

Mr. Khalil Ramal: On a point of order, Mr. Vice-Chair: On behalf of all the presenters who came before us today, I want to thank the committee for coming to London and listening to all of the wonderful organizations.

The Vice-Chair (Mr. Vic Dhillon): And what are you doing for us, since we came to London?

Mr. Khalil Ramal: Well, Community Living London is going to invite you for supper tonight if you stay in London.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much, most of all, to the presenters for your presentations. Thank you, committee and staff, as well.

This committee stands adjourned till tomorrow morning at 9 a.m. in Timmins, Ontario.

The committee adjourned at 1610.

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