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Vendredi 8 août 2008

Standing Committee on Social Policy

Comité permanent de la politique sociale

Services for Persons
with Developmental
Disabilities Act, 2008

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

Chair: Shafiq Qaadri
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LEGISLATIVE ASSEMBLY OF ONTARIO

STANDING COMMITTEE ON SOCIAL POLICY

Friday 8 August 2008

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ PERMANENT DE LA POLITIQUE SOCIALE

Vendredi 8 août 2008

The committee met at 0833 in the Ottawa Marriott Hotel.

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 Acting Chair (Mr. Dave Levac): Welcome to Victoria North, Ottawa Marriott, for the Standing Committee on Social Policy regarding Bill 77.

AUTISM ONTARIO, OTTAWA CHAPTER

The Acting Chair (Mr. Dave Levac): I'd like to start our hearing by asking Autism Ontario, the Ottawa chapter, Heather Fawcett, to join us.

Ms. Fawcett, thank you very much for being here. For Hansard's sake, we'd ask you to identify yourself and the group you're representing. You have 15 minutes, and within your 15 minutes if you leave time for questions, we'll do so.

Ms. Heather Fawcett: Heather Fawcett, Autism Ontario, Ottawa chapter. Thank you for the opportunity to speak to Bill 77. To introduce myself, I'm a parent of a 17-year-old with Asperger syndrome. For the last seven years I've facilitated Ottawa's Asperger Parents Support Group—a group of 468 families and individuals sponsored by Autism Ontario. I've also helped develop community programs, namely social skills groups for youths and adults, in response to the service gap in our community for higher-functioning individuals with autism spectrum disorders.

Referring parents of children and adults with Asperger syndrome to services has required a lot of resourcefulness and creativity, partly because the disorder has only been recognized since 1994 so development of services lags far behind assessments. Many adults with higher-functioning autism and Asperger's require social skills training, job support, assistance with daily living and other community supports to live independently. They also require treatment to deal with social and emotional deficits, sensory dysfunction and commonly co-occurring mental issues such as depression and anxiety.

Yet few specialized services exist in Ottawa for those with autism spectrum disorders, and of those that do, individuals with Asperger syndrome and higher-functioning autism are frequently excluded on the basis of cognitive capability. As an example, specialized mental health services such as the Royal Ottawa Hospital's dual diagnosis clinic are off limits to those with IQs above 70. Where service exceptions are made, higher-functioning individuals are often the first to lose service with funding cuts. The result is that many parents cobble together resources from the community at their own expense.

So we are very pleased to see the reference to IQ deleted in this act; however, it does not remove the very real possibility that the terminology "cognitive functioning" will continue to be used to exclude those with higher-functioning autism and Asperger's, especially when funding is tight.

I have experienced this personally. When my family moved from Wellington county to Ottawa in 1998 we tried to transfer our special services at home funds and were told that those with Asperger syndrome didn't receive funding in Ottawa because of their cognitive level. The fact that my eight-year-old daughter could not interpret emotions, could not recognize faces out of context and could not engage in a conversation or play interactively with another child was deemed less important than the fact that she could bring home a B on her report card. The story has a happy ending, as the funds did continue and the local policy was changed shortly after. As such, this bill must recognize that social reasoning deficits are every bit as detrimental to independent living as other learning deficits. One also hopes that the bill will address the current inequities across the province and ensure portability of services from one area to another.

Individuals with higher-functioning autism spectrum disorders follow a trajectory that is different than those with developmental disabilities and autism. Most are not diagnosed until school age and others do not come to the correct diagnosis of autism spectrum until they are teenagers or even adults. Any services they receive are late in the game. It is important that the legislation recognize that a diagnosis may be late in coming even though the disorder was inherent from birth.

The bill concentrates a lot of power in the hands of the application centre. There is the potential for a conflict of interest when the application centre is both in charge of approving and managing funding and is one of the agencies delivering services. It may be best if the application centre is a separate entity. At the very least, a third party should monitor parent and individual satisfaction and handle appeals and other situations where there may be a conflict of interest. There is a need for transparency around funding decisions. Parents, individuals and community members should have access to the policies and procedures used for determining eligibility, prioritizing and allocating resources and funding dollars.

It's important that the personnel at application centres are well trained in autism spectrum disorders so they can make the appropriate service decisions. Services must be planned to meet the person's needs as opposed to slotting individuals into available and inappropriate services. The experience of adults in our community with the limited services available has not been positive. For those who get service, they are often shunted from one inappropriate service to another.

The following experience of Jonathan Davies, one of our community members with Asperger syndrome, who I had hoped would join us today, is not atypical. As a child, Jonathan was diagnosed with childhood schizophrenia and autism before Asperger syndrome became a diagnosis. Despite graduating with a high school diploma in 1980 and some years later with a business information systems college diploma, in his adult life he has been referred to and enrolled in activity programs for individuals with intellectual disabilities, those for severe psychiatric illnesses, worked in a sheltered workshop sanding plastic, volunteered for non-profits and stocked shelves.

In his words, "They didn't give me any of the coaching that I needed in order to learn what behaviour is appropriate in what situation. They just got me to use the social skills that I had already, even though the social skills I had already weren't very much, and they did not do what was needed to make them better. In 1993, I had fairly severe emotional problems, largely because of my lack of success socially."

In 2001, he finally received speech and language and occupational therapy to improve his behaviour and communication in the workplace. Today this individual is working part-time at a non-profit call centre where he finally feels he is working in a job that suits his abilities. It took more than 20 years to receive the social skills help he required to get a job suited to his capabilities, at both a great personal cost and a great cost to the system. Unfortunately, the situation today has not changed much.

This is all to point out that services need to be targeted to the individual and not the other way around. This bill makes a distinction between professional services and specialized services. However, all services, whether they are those delivered by a professional such as a speech and language pathologist, psychiatrist or psychologist, or other services such as work training, need to be specialized to the needs of those with autism spectrum disorders. It is hoped that the application centre will have the expertise to develop the service profile accordingly, and that where there are service gaps they will look beyond the obvious and be creative in finding service alternatives that are the right match. Direct funding should provide parents the opportunity to tap into more specialized community resources that have recently developed in response to the service gap. However, the bill says little about the monitoring of individuals or organizations providing the service through direct funding.

0840

Finally, adequate resources need to be forthcoming from the government to make the bill work. Currently, most adults with autism spectrum disorders go without much-needed services. Inevitably, what we don't invest in now will come back and haunt us in the future.

The Acting Chair (Mr. Dave Levac): Thank you very much, Ms. Fawcett. You've left some time and we will split that time up amongst all the parties. We'll start with the Progressive Conservative Party with a couple of minutes.

Ms. Sylvia Jones: Thank you, Ms. Fawcett. I think you were very kind in your assessment of the application centres when you said there's a potential for conflict of interest. Some of the other presenters have described it as judge, jury and perhaps even Supreme Court all rolled in together, so I appreciate those comments. Thank you for your presentation.

The Acting Chair (Mr. Dave Levac): Thank you very much. Mr. Prue.

Mr. Michael Prue: I found the whole story about Jonathan Davies to be quite sad. Is this typical? Is this happening to other people?

Ms. Heather Fawcett: I guess the only thing that's not typical about it, to be honest, is a lot of parents generally find their adult children aren't eligible for much in any way of services so they don't really even bother to make the effort to try to go through our service coordination here to get any kind of service.

The other thing that might not be quite as typical is Jonathan Davies is a very motivated individual. He has persisted for a long time. He has not given up. That may be part of his condition, whereas other individuals aren't quite as persistent and may not have tried so hard to find services that aren't out there. But in general, really, that is pretty common in the sense that there really aren't those specialized services out there that can take into account the condition and what services are required.

Mr. Michael Prue: Now, in the past, the funding of all the programs has been a great difficulty. Even with this new act, do you see a continued need for more funding?

Ms. Heather Fawcett: Absolutely.

Mr. Michael Prue: Many of the people who have been before us talked about how the act looks all well and good: "Fine, we can accept the new act; show us some money." Of course, there's no money here. That will come later, perhaps, in the budget. In order for this act to work, have you given any thought as to how much extra money will be needed in the system?

Ms. Heather Fawcett: That's not a question I could really answer in terms of extra money that would be required, but certainly I would hate to see all of the administration or bureaucracy, say, around creating an application centre take away from the money in the hands of the parents. That would be one of my concerns, that it needs to be budgeted out in terms of being efficient and not becoming another big money drop in the pot, little of it going to parents. I guess that's the only comment I could make.

The Acting Chair (Mr. Dave Levac): With that, we'll move over to Mr. Naqvi.

Mr. Yasir Naqvi: Good morning. Thank you very much for sharing your experiences with us this morning. You talked about the definition of "developmental disability" and that you support that definition, but you raise some concerns about the interpretation of cognitive functioning. If you had to propose some changes to the definition, do you have any suggestions for us?

Ms. Heather Fawcett: Again, I think I'd have to look at it in more detail, but I just feel that it's very often open to interpretation. These individuals have very uneven skills. That's part of the disorder. For instance, my own daughter is in the 90-something percentile for some of her verbal skills. She's in the second percentile for visual memory. So if you're only going to look at one aspect of it, the verbal side of it, she's heading on to university. That may look like she's going to be able to function. However, she can't currently take the bus anywhere because her visual memory skills are so poor. Socially her skills are very poor. She got and lost her first summer job two weeks ago in a week. So there just needs to be a way—maybe it's in the adaptive functioning—to be clear that an individual has very uneven skills and you need to look at the whole picture, I guess.

Mr. Yasir Naqvi: So the application of the definition is key, in your opinion?

Ms. Heather Fawcett: Yes, absolutely.

Mr. Yasir Naqvi: Great. Thank you.

The Acting Chair (Mr. Dave Levac): Thank you very much, Ms. Fawcett, for your presentation, and our committee thanks you.

COMMUNITY LIVING ASSOCIATION (LANARK COUNTY)

The Acting Chair (Mr. Dave Levac): Next, we'd like to call upon the Community Living Association (Lanark County), Mr. Rick Tutt and Ms. Molly Bruce.

As you approach, as indicated, you have 15 minutes. Please identify yourselves and the organization you represent, if you do. Within the 15 minutes, you may choose to be a little briefer and provide some time for question and answer afterwards, but if not, you can use your entire 15 minutes for your presentation. Thank you very much. You may begin.

Mr. Rick Tutt: Thank you. My name is Rick Tutt. I'm executive director of Community Living Association (Lanark County). We're an organization just west of Ottawa committed to advocate for and support people who live with an intellectual disability. With me today is Molly Bruce, a member of our board of directors and a parent of a gentleman who lives with an intellectual disability.

We would like to take this opportunity to highlight several of the issues covered in our written submission, which we have copies of for the committee and which includes more details and a number of specific recommendations. Mrs. Bruce and I will share the presentation.

We believe that the legislation would greatly benefit from the inclusion of a preamble aimed at describing the social change that we hope it is intended to accomplish. Such a preamble should closely relate to the vision statement of the ministry, which is "to promote greater social inclusion." By creating this legislation to be an enabler of access to all areas of community life through the provision of support by the ministry, we can start to break down barriers that exist between government ministries, and we will better position our province to support the ratification by Canada of the United Nations Convention on the Rights of Persons with Disabilities. In our written submission, we've outlined a number of specific suggestions that might be included in such a preamble.

By holding contracts with local associations and other community-based organizations, government enjoys certain benefits that come from the fact that local associations are made up of volunteers and persons who share a common concern. Much more than running a business, local associations share the aim of building inclusive communities. Powers of government over community agencies may be addressed by two main concerns for harm: One has to do with funds; the second has to do with the health and safety of the people who are supported by those funds. Actions that are taken based on those powers should be addressed only to the cessation and correction of that harm. Ministry power must extend only to areas described in ministry contracts. Powers should not allow the ministry to interfere in the governance of community corporations, and as such, should not be extended to the management of "the affairs of the service agency," as described in the draft legislation. An association such as ours is involved in a number of activities, many of which have nothing to do with the contracts that we enter into with the government.

People and their families must be able to purchase quality support within their community. The bill must ensure provisions through which workers available for hire through direct funding can be paid a reasonable wage, comparable to that of workers in support agencies. Without such equity of payment, there's a danger that direct funding—an unquestionably critical element of support, and I stress that—will decay into a second-class or two-tiered system. This is certainly not what families have wanted, or what they have lobbied for for years, or what government has promised and has indeed started to deliver.

In Ontario, there is currently a variety of models of application, or single-point-of-access processes. Some are extremely expensive and overly bureaucratic, while others are more of a voluntary and collaborative nature. We are concerned that the bill focuses on application centres—and I underline the word "centres." We are concerned that less expensive but just as effective collaborative models must not be automatically dismissed. The concept of application processes should replace the concept of application centres. We are also concerned that the ministry not place a number of functions into one hat that would lead to the potential of a conflict of interest, such as assessment, planning, referral, appeals, etc.

0850

In rural areas, it is imperative that the application process be community-based and not centred in a larger and distant community, kilometres away from the local community, the families, the people and their supports. I know you're going to hear more about this in much greater detail in a presentation from the disability services providers in Lanark County.

Ms. Molly Bruce: It's Molly Bruce, Community Living Lanark. The legislation must include provisions to recognize the legal capacity of people who have an intellectual disability and provide for supportive decision-making in order to ensure that people can enjoy their legal capacity. The concept of supported decision-making was pioneered here in Ontario, and has recently been adopted into international law under the UN Convention on the Rights of Persons with Disabilities.

Acknowledging and supporting the legal capacity of the individual can be, perhaps, the most transformative step that can be taken within this legislation. Providing such recognition will allow the person a mechanism through which they can enter into an agreement for direct funding without having to surrender authority to a substitute decision-maker or guardian.

Persons seeking support must be clear about what they need, or they will most likely be offered supports from a list that has been identified by someone else. People must receive supports appropriate to those needs. Person-directed planning must look at supports that may be accessed under the provisions of this legislation and also at supports available in the context of persons, family, community and natural networks. Person-directed planning must be made available after the determination of eligibility but before a person applies for supports or funding and before his or her needs are assessed. It must be available to the person on an ongoing basis and not be carried out by the application centre, but by individuals or agencies that are recognized as qualified planning facilitators, according to standards that must be set through a regulation or policy directive.

Given the scope of decisions that could be made under this bill regarding determinations of eligibility, terminations of agreements and appointments of managers, an independent appeals mechanism is absolutely critical. A person's direct funding agreement should never be cancelled for reasons of misuse where direct funding was being managed by someone other than the individual, including a family member or guardian, and the individual is found not to have played a role in the misuse. The act should clarify that a process be in place through which a person for whom direct funding has been terminated can have the funding reinstated after meeting specified requirements.

Before 1995, the government provided grants to community advocacy groups to assist them in organizing for purposes of education and bringing a voice to issues that concerned them. The developmental services sector would be served well by ensuring that self-advocacy and advocacy groups are able to organize in a fashion that allows them to play an effective role in the public discourses related to the inclusion in the community of people who have an intellectual disability. Financial support should be available to such groups.

We would like to go on record as offering our unqualified support of the submissions you have received this past Tuesday from People First of Ontario, Community Living Ontario and the Canadian Association for Community Living.

In conclusion, we wish to stress that this legislation will have a profound impact on people with intellectual disabilities and their families for many, many years to come. We hope and trust its impact will be one of a positive and supportive nature. Thank you.

The Acting Chair (Mr. Dave Levac): Thank you very much, Mr. Tutt and Ms. Bruce. I appreciate your input. You've left us with some time to share with the parties, to the tune of about a minute or so. I'll be flexible on that. A minute or so each, starting with the NDP.

Just before we do that, you do have a hard copy reference to a presentation. Did we get a copy of that for the clerk to distribute?

Interjection.

The Acting Chair (Mr. Dave Levac): Thank you very much.

Mr. Prue?

Mr. Michael Prue: I'd just like to focus on the comment that was made about the wages of people in the sector and how the new system must bring up the wages to the service sector level if it is to succeed. As I understand it, people working in the service sector earn between $15 and $18 an hour if they're unionized; people who work privately earn as little as $10.30 an hour, up to about $12. So we're talking about a $5 wage gap. How do you propose that the government solve this $5 wage gap?

Mr. Rick Tutt: First of all, I think the wages paid in the service sector are probably higher than you've just mentioned, and it varies from community to community; the ministry has increased base funding in the past year. We don't propose; it's not our job to propose. It's the ministry's job to make sure that families and people with disabilities are not treated as second-class citizens because they have chosen to go a different type of route for their services. A lot of families in this province want individualized funding, and that's funding that they can control, with people they can hire for the type of supports for their sons and daughters that they choose and their sons and daughters choose.

Mr. Michael Prue: Some of the comments in the past have been that the brokerage system will try to do it at the cheapest possible level and will look for those people who earn $10 to $12 an hour, as opposed to people who earn higher, and that this in turn will cause the system not to work. Do you have any problem with the brokerage system that's being proposed?

Mr. Rick Tutt: I don't have a problem with any system. What we have a problem with is the fact that families are given money that forces them to pay substandard wages to people who are doing an equally important job for their sons and daughters as service providers are.

The Acting Chair (Mr. Dave Levac): Mr. Ramal.

Mr. Khalil Ramal: You talked about the government interfering with the organization of agencies. The government doesn't like to micromanage anything in the province of Ontario, so we allocate the money to organizations and agencies, and we hope they will manage the money in a professional manner and in the right way. But sometimes organizations abuse and mismanage the allocations or the funds being submitted to them. So do you think the government, as a guardian of the taxpayers—we're in charge of that, and then we have to answer to the taxpayers—has a right to interfere and come in and manage?

Mr. Rick Tutt: Absolutely, and I would support that. But in my statement, I said I would only support the government stepping in within the bounds of the contract that we sign between our organization and the government, not to take over our agency or our organization. We do many things that have nothing to do with the contract that we sign with the government to provide supports and services, and there have been examples in the past where the ministry has stepped in and has taken over an organization for potentially appropriate reasons but has overly enforced authority. I said very clearly in my oral submission and in our written submission that as far as the contract is concerned, we feel we should be accountable to the ministry. And believe me, as an executive director, we are accountable to the ministry in more ways than one.

The Acting Chair (Mr. Dave Levac): Thank you very much.

Mr. Khalil Ramal: No more time?

The Acting Chair (Mr. Dave Levac): That's it. Mrs. Elliott.

Mrs. Christine Elliott: Thank you very much for your presentation. We've heard very similar comments, as you probably know, from many, many other groups during the course of our committee hearings, central to which, to my mind, is the supported decision-making and the person-directed planning. I think in order to achieve the transformation that this legislation hopes to achieve, that's a really integral piece—and we have been listening to what people are saying—so that you end up with a situation that builds a whole life for a person, using a blend of traditional supports and non-traditional supports that achieves the social inclusion that one hopes this bill will achieve. So I thank you for those comments, and we are taking them very seriously.

Mr. Rick Tutt: Thank you. That's very good to hear.

0900

The Acting Chair (Mr. Dave Levac): You're welcome to respond if you wish, but that's fine.

Mr. Rick Tutt: My only response is, I think Molly mentioned the individual or person-centred planning is really critical, not only how it's done but also in what context it's done. It must be done independently on behalf of and with the individual and his or her family. Around supported decision-making, I would just red flag—that's a danger signal—in a positive way a presentation that will be made later on today from the Brockville and District Association for Community Involvement. Audrey Cole will be addressing supported decision-making, and she is probably the most preeminent volunteer in terms of knowledge of that. As I mentioned in our presentation and others have, the supported decision-making that came out of Ontario and then out of Canada was instrumental in getting into the UN declaration, so we're all hopeful that the committee will look at that very carefully.

The Acting Chair (Mr. Dave Levac): Yes, we've asked for some research on that through Ms. Elliott, and the committee will be given that research. Thank you very much, Mr. Tutt and Ms. Bruce. I appreciate your time and that you've come to present for us.

GREG BONNAH

The Acting Chair (Mr. Dave Levac): Now I would like to ask for the County of Lanark Developmental Services Providers Committee, Mr. Dave Hagerman and Ms. Donna Davidson.

Did I miss somebody? Yes, I did. I'm awfully sorry. Excuse me; I've made a mistake. Mr. Greg Bonnah.

Interjection.

The Acting Chair (Mr. Dave Levac): No, there's an individual in front of your organization. My apologies; it's my happy feet talking again.

Greg, you have 15 minutes, and if there's any time left over from your presentation and the 15 minutes, that's for question and answer. Identify yourself for Hansard.

Mr. Greg Bonnah: Okay, thank you. I'm Greg Bonnah, parent of a 17-year-old child with developmental disabilities.

Thank you for the opportunity to speak before this committee. To start, I like what I see in this bill. It is a great improvement over the existing act, though I feel it misses the mark in two key areas: (1) It fails to include children with developmental disabilities, and (2) it will only work, in my opinion, if the bureaucracy wants it to work. It is my feeling that here in the eastern region of the Ministry of Community and Social Services the needs of the system outweigh the needs of the client.

Section 5 of the bill states, “This act applies with respect to persons with developmental disabilities who reside in Ontario and are at least 18 years of age.” Does this mean that from the age of six to 18, as is currently the preferred model of the Ottawa-Carleton District School Board, our children will continue to be segregated, thus being denied the right to a basic academic education unless the parent is rich enough to, through the courts, force the school board to do what the Ministry of Education states is a basic right of every child?

I ask this because I am a parent of a child that the OCDSB deemed to be expendable. Their expert witness at my child’s educational tribunal indicated that intellectually he was at the 0.01 to 0.02 percentile, and that educationally his needs were not unique. It took four years to rectify this situation, in which time the OCDSB did not provide my child any educational opportunities, and in which time the OCDSB both economically and by using the police and the children’s aid society attempted to bully me into abandoning my child’s academic needs.

In April 2003, the appeals court of Ontario ordered that the necessary resources for my child to reach his full potential be put into place. For the record, this past May, my child participated in the grade 3 EQAO testing.

By excluding persons under the age of 18 who have developmental disabilities from this act, you are ensuring that the status quo will continue. Could one of you experts please explain to a lowly parent how a child who has been segregated all of their scholastic life is expected to function in a fully inclusive environment once they turn 18?

Next I am going to quote from the explanatory note of Bill 77 that I found on the Legislative Assembly of Ontario website: “Under section 8 of the new act, the minister may designate application centres for geographic areas specified in their designation. The application centres shall act as the point of access to services for persons with developmental disabilities residing in the geographic area. Persons with developmental disabilities, or others acting on their behalf, may apply under part V of the new act to application centres for services or funding under the act. The application centre is responsible for determining whether a person with a developmental disability is eligible for services and funding under the act and allocating the funding and services available in the geographic area among the applicants.

“Under section 9 of the new act, the minister may fund services using two funding methods. As was the case under the old act, the minister continues to be able to enter into funding agreements with service agencies who will provide services to or for the benefit of persons with developmental disabilities. Under the new act, the minister may also provide funding to application centres for purposes of direct funding agreements that the application centres may enter into under section 11.”

My dealings with the eastern region of the MCSS have, in my opinion, demonstrated that the needs of the system outweigh the needs of the client. An example of this: In January 2008, special services at home and I came to an agreement with the assistance of the Ontario Human Rights Commission. After three years of documenting the situation, I demonstrated that MCSS was discriminating against my child because we chose to utilize resources outside of the segregated environment. The agreement that my spouse and I signed in good faith was, at the insistence of special services at home, from January to July of this year. In June, as ordered by the agreement, we met with my child’s special agreement officer and explained how we utilized the funding and what we hoped to accomplish with funding for next year. In July, SSAH informed us that we are expected to stretch out the few dollars we received for six months over the entire year. So for the third time in the past four years, I am in the appeal process.

Therefore, given the homeostasis that I feel is prevalent throughout the eastern region of MCSS, it is my opinion that by maintaining the current funding model, it will be the status quo of segregation for persons with developmental disabilities here in eastern Ontario.

To conclude, unless this bill is expanded to (1) include persons under the age of 18 who have developmental disabilities, (2) ensure that children with developmental disabilities have the proper supports and resources in an inclusive educational environment necessary for them to reach their full potential, and (3) ensure that all segregated schools for children with developmental disabilities are immediately closed, and unless the needs of the client outweigh the needs of the system, I fail to see how this bill has any chance of success here in eastern Ontario.

The Acting Chair (Mr. Dave Levac): Thank you very much. I apologize again for missing your name. We do have some extra time, and we’ll be sharing that amongst all three parties. We’ll be starting with the Liberals. Mr. Ramal.

Mr. Khalil Ramal: Thank you very much for your presentation. You mentioned many different issues, but the most important thing you talked about was that in order for Bill 77 to work, it has to include people under the age of 18. As you know, every ministry has a different jurisdiction. The Ministry of Community and Social Services deals with adults. The definition of “adult” is a person past the age of 18, so below that it will be the responsibility of the Ministry of Children and Youth Services.

The second thing you talked about was the application centres. I hope you’re happy with the application centres, because the aim of the application centres is to unify the assessment process across the province of Ontario in order to be able to assess our service.

Mr. Greg Bonnah: It is my understanding that currently there is a tri-ministry agreement in place for education of special-needs children. I do believe that the majority of funding for the four segregated schools that are run here in eastern Ontario comes through MCSS and that they are run under a group-home status. They're not run under education, even though they are education centres. That's my understanding.

The Acting Chair (Mr. Dave Levac): We can get that clarified.

Mr. Greg Bonnah: Second of all, I'm feeling, with the way things are right now, that the application centres are just going to become another big bureaucracy, where all the money is going to go to feed the bureaucrats and very little of it is going to come out to the client.

The Acting Chair (Mr. Dave Levac): Mrs. Elliott.

0910

Mrs. Christine Elliott: Thank you, Mr. Bonnah. The frustration I can hear in your voice is unfortunately all too common with a lot of parents of children and young adults with developmental disabilities. I can understand that to hear it's another ministry that's responsible for it doesn't really answer your concerns.

There's no question that more work needs to be done in order to work on services for young people, and I think there's probably a need for more communication, frankly, among the Ministries of Education, Children and Youth Services and Community and Social Services. That is something that we can certainly take away and have a discussion about, how to better serve the children and the young people rather than to serve the needs of the bureaucracies. But that is a recurrent theme and I think that, although this bill is specifically dealing with people over the age of 18, there's a lot of work to be done in the transition as they come up through the school system and they get prepared to go into the next stage of their lives. So this is one piece that we're dealing with, but we recognize there's much more that needs to be done to coordinate services to make sure that it's person-centred.

Mr. Greg Bonnah: I would agree with you, but again, currently, for the first 18 years of their lives we're segregating these kids and then you expect them to be in a fully inclusive environment. How do you expect them to survive?

Mrs. Christine Elliott: As I say, I think there's a lot more work that needs to be done, and we're listening to what you're saying.

Mr. Greg Bonnah: If you were doing it the opposite way, then I would agree with you totally. But currently—and I do believe in inclusion, believe me; I believe that we should all be included, but I cannot see how most of these kids can come out of places like Clifford Bowey and stuff like that, where they have been segregated and told, "No, stop, wait. Don't take any initiative at all whatsoever. That's frowned upon and you will be disciplined if you do it," and then all of a sudden they're totally on their own once they turn 18.

Mrs. Christine Elliott: I think there are many more supports that we can put into the school system to serve the needs of children with special needs.

The Acting Chair (Mr. Dave Levac): Mr. Prue.

Mr. Michael Prue: I just want to go back to the school system. I'm not as familiar with the school system in the Ottawa area as I should be, coming from Toronto. We have a school in Toronto in my riding called McCordic. It's run by the Toronto school board, but it is for children with severe developmental disabilities. Is that the kind of school you want to shut down?

Mr. Greg Bonnah: There are six of them left in Ontario. Toronto has one, Thunder Bay has one and eastern Ontario has four. There are three of them here in Ottawa. Considering we only have less than 10% of the population, I do believe we have a high percentage of the schools for those with developmental disabilities.

Mr. Michael Prue: But do you want all six shut down?

Mr. Greg Bonnah: I do believe that there is a need for some but, like I say, my child was at the 0.01 percentile, and he just did the grade 3 EQAO testing, but I had to go to the appeals court of Ontario to get the resources in place to do it.

Mr. Michael Prue: I take it from that that the bureaucracy was singularly unhelpful in your case.

Mr. Greg Bonnah: Well, they spent a million taxpayers' dollars fighting me.

The Acting Chair (Mr. Dave Levac): Thank you very much, Mr. Bonnah. I appreciate your presentation. For the record, the consistency across the province is what the aim of the bill is for the adult population and not the education system; so that you're aware.

Mr. Greg Bonnah: Yes, okay.

COUNTY OF LANARK DEVELOPMENTAL SERVICES PROVIDERS COMMITTEE

The Acting Chair (Mr. Dave Levac): The next group—we'll try again—is the County of Lanark Developmental Services Providers Committee, Dave Hagerman and Donna Davidson.

You have 15 minutes to make your presentation. Please identify yourselves for Hansard. At the end of the 15 minutes, if there's time left over, we'll share that amongst the parties for question and answer. You may use the entire time for your presentation.

Mr. Dave Hagerman: Thank you. Just a correction: My name is Dave Hagerman, I'm the chair of the services providers committee of Lanark county, and joining me is not Donna Davidson, but Cathie Hogan, who is a parent of a child who has been on our P and P waiting list for many years. I will start the presentation in terms of the agencies that sit on the service providers committee and Cathie can give you the real story of what it's like to live these issues on the ground.

The Acting Chair (Mr. Dave Levac): Thank you very much, and welcome, Cathie.

Mr. Dave Hagerman: First of all, we would like to commend all the parties for their support of the process of deinstitutionalization of individuals with intellectual disabilities. All the parties in the Legislature, in some way or another, have played a positive role in the 20 or so years that this process has been going forward. As you know, it's been a long time for the institutions to be closed and the individuals within them to be integrated into the community. All political parties sitting around this table contributed to that process.

We also agree that at the end of the day and at the end of the process, there should be a governing statute that reflects the values of community integration; there's no debate on that. We do have a number of concerns about many of the specifics included in Bill 77, however. We go into more detail in our written presentation about these concerns, which I have provided to the clerk, but I'll try to be brief.

The primary point we would like to make is this: The single most challenging issue facing the sector is the lack of funding, not that the existing collaborative access process is unfair and inequitable. I will focus on the idea included in the bill of establishing an entirely new administration labelled application centres. If there is unfairness in the existing system, it comes from the fact that there are thousands of individuals with intellectual disabilities in this province who have gone through an extensive assessment process, have been determined to need support services to function in our communities, and then are told they must wait on a waiting list for an indefinite period of time. Basically, some of them have been on waiting lists for years.

Any system under these constraints and with these expectations will be unfair and inequitable, particularly for those who must wait for service or don't have access to it. The existing system struggles under these funding constraints, but at least it's community based, uses collaboration and co-operation as its operating value, and is subject to provincial oversight. Again, I must repeat: No system placed under these funding constraints would be free of the characterization of being unfair and inequitable. Even with the new system proposed in the bill, if it's not properly funded, it will only be a matter of time before people will say it's unfair and inequitable.

The second point we would like to make is this: If we use the cost experiences of developing access centres in the Ministry of Health, we simply cannot afford this level of extravagance on administration. Given the waiting lists for service that currently exist in developmental services, all available resources should focus on direct service issues, not new bureaucracies. To believe that these new application centres will not require significant resources is just not believable; to suggest that the development of these application centres can be achieved through existing resources is just not believable. It will cost significant amounts of money, and this type of expenditure just cannot be justified given the tremendous need for service on the current waiting lists.

The funding issues then lead us to our next point and probably the most important one, and this is where Cathie will take over: There must be guarantees of minimum levels of funding identified in the bill. Bill 77 as it's proposed is permissive. What the sector really needs is a commitment to mandatory funding of identified essential support services, as currently exists in such services as special education in the Education Act, in which the ministry must ensure that these services are provided, and/or the mandatory funding of ODSP. What we're saying is that the funding elements in the bill should not be permissive, but should be mandatory.

I'll let Cathie take over from here.

Ms. Cathie Hogan: Good morning. My name is Cathie Hogan. I'm here as a parent of two developmentally disabled young men, aged 18 and 21. My 18-year-old son requires residential services. He is severely autistic, he's non-verbal, he has a lot of behaviours, and he's also been diagnosed obsessive-compulsive.

What's lacking in this bill, as Dave has alluded to, is that funding for services for disabled individuals is not mandatory; it's permissive. If individuals meet the criteria for services, mandatory funding should be in place for these individuals.

My son turned 18 earlier this year. He's on a waiting list for residential services and has been since he was eight years old. When he's 21 and finished school, he'll go on another waiting list for a day program.

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While disabled individuals coming out of institutions and out of the care of the CAS slide right into group home spots and day program spots, my son languishes on a waiting list. Just the fact that these waiting lists exist is criminal. How long will he stay on these waiting lists? Nobody can tell me. Until he's 20? Twenty-five? Thirty? Forty? Who knows? He, and many others like him, may never get the residential services that he's entitled to.

Had I given up my son to the care of the CAS or institutionalized him, he'd be residing in a group home right now. But why do parents have to give up parental rights to get services for their children? I've saved my government hundreds of thousands of dollars by choosing to raise my children in their home, in their community.

The challenges that parents like me face every day are so exhausting. We can't meet those challenges forever. They take a toll on the best-equipped people, and as I said, we can't be expected to meet those challenges forever, indefinitely. The need exists for our government to provide residential and day program services in a timely manner. That means yesterday. My government has relied upon me to raise my children, but when I need to rely on my government for services, I get no assurance and no hope. I get waiting lists.

Until age 18, parents of disabled children receive funding through assistance for children with severe disabilities and special services at home, both of which provide funding for parental relief and respite and things of that nature. When a child turns 18, the assistance for children with severe disabilities is terminated. We're left with special services at home, which is capped at a maximum of $10,000 a year, and most make do with a lot less than that. We all apply for the maximum, but we don't get it. So when you're paying a caregiver in excess of $10 an hour, you're paying hundreds of dollars for a 24-hour respite. Even the maximum of $10,000 doesn't go very far. You can all do the math. The thing is that these kids, when they turn 18, still have the same needs that they did at 17—or at seven, for that matter. They still have those needs, but the funding to meet those needs is reduced.

This bill also needs to address the fact that parents and individuals with developmental disabilities need advocacy. Presently, there's no recourse for parents or disabled individuals when they're denied services. Many parents can't advocate for their children because, in many cases, they have special needs themselves. They're elderly, they're in ill health, many with stress-related illnesses. They can't afford to take time off from their jobs to attend a function such as this, or they're just too exhausted. Our service providers, who are already carrying loads that are way too heavy, have no time to help parents advocate. It's absolutely essential that parents have access to third party advocacy.

When I heard about this bill, I was excited; I was hopeful. But the bill, as I presently read it, doesn't excite me. It doesn't give me any hope that my son and others like him are going to get the services they need any time soon. In short, this bill isn't going to resolve any of the issues that I deal with day to day. I'm sure that you've heard this as you've been travelling throughout the province, and you will hear it again and again. So please, please, don't leave us without any hope. Thank you.

The Acting Chair (Mr. Dave Levac): Thank you very much, Mr. Hagerman and Ms. Hogan. I appreciate your coming before us today. We do have some time. We'll start with the official opposition. Ms. Jones.

Ms. Sylvia Jones: Thank you for appearing today—particularly you, Ms. Hogan. I know that this must be challenging to have to bring your personal situations, but it does bring back for us the value of what we're trying to do and the importance of getting it right.

I am particularly heartened to hear you talk about the concern about the bureaucracy of the application centres as they have been set out. It would be our goal to ensure that that bureaucracy does not, in fact, make the situation even worse than it is right now. Thank you for bringing your personal situation to it.

The Acting Chair (Mr. Dave Levac): Thank you very much. Mr. Prue.

Mr. Michael Prue: To Ms. Hogan: I don't think anyone has said it quite so eloquently as you, the frustration of being the parent of a child with disabilities and the lack of access that has been in the system to date.

I want to ask the question about the application centres that are being set up. I've noticed here, on page 5 of the handout that you gave out—although you didn't refer to it, you're talking about, I guess, what can only be described as the boondoggle of community care access centres, with an annual spending budget of $1.576 billion to administer that system. I think that your logic is quite sound here, as you're talking about what it's likely to cost to set up this new system that the government has in mind, at $137 million. Is it your position—and I think it is your position—that the $137 million ought not to be spent on such a bureaucracy but instead plowed right into the system, even as it currently exists; that would be far better use of government money?

Mr. Dave Hagerman: That's the position we argued in the paper. That's correct. The existing system, although not perfect, does have the potential to be able to provide greater access to service. There are limitations, and we've suggested a number of ways that the existing system could be improved. Cathie mentioned a couple of things that are really important, we think, and that is the right for folks with intellectual disabilities to have third party advocacy and the right for parents to have appeal processes that are clear, transparent and accessible—service plans like they have in the child care sector that are open, public and transparent so that people know what the plans are in terms of government priorities of funding. These are all ideas that can be implemented without developing huge bureaucracies that are going to cost—well, we don't know how much they're going to cost, but I think it's not credible to say that they could be done through existing resources.

The Acting Chair (Mr. Dave Levac): Thank you, Mr. Prue. Mr. Ramal.

Mr. Khalil Ramal: Thank you very much for your presentation. That's why, I guess, Bill 77 proposes a change in the act: in order to service yourself and many others across the province of Ontario and give direct funding, and give families the opportunity to choose the service that they think is good for their sons and daughters.

In terms of the application centres, you mentioned, to give an example, the community care access centres at $1.56 billion, and I hope that you don't think that this money goes only for bureaucracy, including service.

Mr. Dave Hagerman: The numbers here did go—I just put the numbers for administration. This is all bureaucracy for the access centre—it's from the Public Accounts of Ontario.

Mr. Khalil Ramal: It's a different take on it, the way we're dealing with Bill 77. We're talking about the application centres. You mentioned that the current system—the present—does not solve the problem. So we're looking for a solution to unify the system across the province of Ontario, and no doubt about it: Communities, organizations and agencies will play a pivotal role in the whole system. So this was our aim and goal for creating the application centres, whether we call them application centres or process applications—whatever title and names. So what do you think? Is something not needed to make the whole process unified across the province?

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Mr. Dave Hagerman: As I said right at the beginning, the primary difficulty, we think, that the sector is facing is underfunding, and no matter how you arrange the deck chairs on the Titanic, if there is not enough funding, any system will be unfair and inequitable. So that's why we think it's extremely important, and we hope that more groups across the province make this point, that the funding in the bill should not be permissive; it should be mandatory, like funding for ODSP is mandatory. Funding for special education is mandatory. Funding for many health services is mandatory. If you qualify and you're eligible, there is some sort of guarantee that you have a right to that service within a reasonable period of time. The way this is set up now, we can go through an extensive application process through the application centre, through the current system, and we can identify essential services for people to be able to be integrated in the community, but even with the application centres, they'll be put on a waiting list, and they may never get service.

The Acting Chair (Mr. Dave Levac): Thank you for your time. I appreciate it very much.

COMMUNITY LIVING ASSOCIATIONS OF DUNDAS, STORMONT AND GLENGARRY COUNTIES

The Acting Chair (Mr. Dave Levac): With that, it brings us to Community Living of Stormont, Dundas and Glengarry with Ann Hysert.

Ms. Hysert, you have 15 minutes. When you begin your presentation, our clerk will distribute your handout. You should identify yourself and the group that you represent, if you do, and if there's any time left over after your presentation within the 15 minutes, that time will be shared with the committee to ask questions. You may begin.

Ms Ann Hysert: Thank you very much. My name is Ann Hysert and I'm representing the Community Living association of Dundas county, the Community Living association of Stormont county and the Community Living association of Glengarry county. They've come together to make this joint presentation to the standing committee today. The reason they've come together is to share their vision of support for the future; to reaffirm the position of Community Living Ontario; to act as stewards for the people and families they support and the communities they serve; to make you aware of the unique geographic area within which they serve and the issues within that area—considering they cover 7,000 square kilometres, and not 12,000 as I have written in the presentation; my math skills are a little off—to work in collaboration with all the parties; to eliminate the unfulfilled promises of programs and funding and to build legislation that will ensure we support individuals with disabilities in Ontario; and to ensure an ongoing, responsive infrastructure that we can depend on.

Our vision: Our collective knowledge of our communities in rural eastern Ontario, our day-to-day involvement and our relationship with families of the people we support, and in turn the very people we are here to represent, and our affiliation with Community Living Ontario allow us to stand before you with knowledge and sincerity.

We've taken a unique approach to our response. We have structured our presentation in a framework designed with functional undertones. We know that you will gather great information from many of the presenters who have come before you today—you have heard some—and we need to have you turn your attention to ensure that we learn from our past, guard against some of the problems that have beset the current legislation and recent initiatives, and learn from other sectors that have made changes and now find that they are forced to restructure again within a very short period of time. We have also looked to models in other countries and how they have enacted best practices. So, we're here to help.

In the past three years, the ministry has introduced the Passport program. This was a wonderful initiative and yet, as of today, people are being told that there will be no allocation. Agencies are unaware of what is actually happening and families are anxious to secure services for their sons and daughters. We have been advised that there are over 1,000 individuals currently on the waiting list. We think this speaks to why we need a structure that ensures the legislation is enacted in the framework we're about to outline.

Extensive work has been done by the agencies and Nancy Draper, and now we find that work is on hold. This has resulted in valuable resources not being utilized effectively and it creates uncertainty for agencies. Such circumstances lead to scepticism and build resentment and distrust between the parties, parents and agencies as well as the government.

In more recent times—I, too, am going to refer to the health care sector—the community care access centres were created, 43 of them in Ontario, and Mr. Hagerman has just described eloquently what happened there. Currently the structure within which they report has been reorganized and a new infrastructure is being implemented. We must learn from this situation, as the cost of restructuring is significant, but the disruption to service can't be measured in dollars and cents.

Finally, we must guard against being trapped by waiting lists: Passport is a glaring example of what can happen. No, we are not naive; we are very responsible service providers and taxpayers, but it's often the easy way out to make minor changes to the status quo and use funding constraints as the only answer. As stewards of the sector, we can only look to the systems in other sectors, provinces and countries to develop the best systems that support the individuals we all serve.

This framework is not just for people with intellectual disabilities. This legislation will impact everyone in Ontario, from the young men and women who went to school with the people we support, to the sisters and brothers who understood the gifts their family member brings to their family, to the employers and volunteers, to the staff who work tirelessly to achieve the goals, and to the government and infrastructure that guide the process. We cannot fail all of these people. We must do our very best, and it would be our pleasure to work with you to make this happen.

Our framework needs to have a vision of abilities, shared values, ethics, accountability, alignment, attunement and, of course, standards.

Vision of abilities: Many countries have legislation or commissions that structure their laws and services on an abilities model. Thus, the language that is used in the legislation and the regulations is described in a positive, supportive way, pointing to people's abilities versus their disabilities.

Shared values: The ministry, agencies, individuals and communities must become stewards of this vision and the resulting support, paid and unpaid. This would create communities of caring and support. Usually, when organizations and governments work together, one can eliminate some costs and bring greater accountability, resulting in high-quality caring and support. When true stewardship is in place, we can realize this goal. I would refer you to the commission Ed Broadbent chaired on stewardship. He has an excellent paper on that sitting, spelling out many attributes.

Ethics: A strong ethical basis allows all parties to understand the rules and rights. Transparency would be evident, and decisions and agreements could be better understood or challenged on an informed and formal basis. There are many ethicists who could guide and support us during this process.

Standards: What you can't measure, you can't manage. We all need standards which go hand in hand with ethics. Standards must be consistently established and measured across the province, not hit and miss.

Accountability: All-around accountability would strengthen the communities we serve. This is not just accountability for the service providers or the parents; it's a tripartite accountability: politicians and government, service providers, and the individuals we support. With true shared accountability, when you have all the parties involved supporting the same goals, there is the collective will to succeed and a framework to draw on.

Ethics, standards and accountability go hand in hand. When you pair this with alignment and attunement, and of course vision and shared values, this becomes a very powerful tool to propel the legislation to great heights and not fall short.

Alignment of the framework is essential if you wish to use the available resources and talents to deliver high-quality programs and services. Alignment means that there is connectedness, time is not wasted, roles and responsibilities are clear, resources are maximized, and the sector can become one of the high performers in the province. Many, many organizational models can demonstrate how this approach has improved their services, maintained costs and retained talent.

Attunement: This is the gold seal. Many organizations are really good at doing all of the above, but when you bring attunement to the process, you introduce the element that holds it all together for the long term. Attunement takes practice, and it avoids the flavour of the month. It takes time and talent. There are many readings, and I made a couple of references to Zander and Zander and the Art of the Possibility which we can draw on.

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The reason we have taken this approach is that we live in an era of change without structure, programs without adequate funding, and work and projects that go nowhere which, in a time of need, are wasteful. We need to do things differently, but we need to do it right.

We, in the agencies of Community Living Dundas, Stormont and Glengarry, take stewardship roles very seriously. It is extremely important that this bill be crafted to ensure that we have all the elements that require sound legislative practice and an operational structure from which to create necessary services and supports. We all have a lot to learn about charting change in this sector, and the need for structure and flexibility is a balancing act that must be achieved.

We have developed a supplementary response in conjunction with Community Living Ontario's position. Our response recognizes issues that may be unique to our geographic area and issues that impact the system as a whole. We're pleased to present them. There are 19 recommendations, and I will not go over them in the interests of time, but I will touch on a few highlights. Therefore, I'm going to skip some. You'll see we have a lengthy presentation. I really would beg you to read that because we spent a lot of time and thought in how to assist you with a structure that will support us.

We move to scope and purpose. Community Living Ontario notes that we require a preamble; we agree. This would set clear direction for the intent of the legislation, and we would suggest it would embody the following: embrace the tripartite stewardship approach and build in vision of abilities, shared values, ethics, accountability, alignment, attunement, and of course our magic standards. That would be really important.

Recommendation 4 is two pages, and that is person-directed planning. We feel passionately about this and our communities have a unique approach to some of this. I will not try to paraphrase and monkey it up. I will draw your attention to the following facts: We see you setting the vision first by person-directed planning, then you conduct the assessment, and then you assess the supports, formal and informal, to make a whole plan, not for the services; it's a plan for the person. So often we fit round pegs into square holes because we have a vacancy here or there. We need to plan for the person and develop services for the person. Some of the key issues that we need for that are high-quality case management, services available close to the people in the area, and we need not to waste dollars on running around and travel expenses when the services need to be close to the client.

Please correct my page 7 as I overstated the geographic kilometres we serve; it's 7,000 square kilometres, not 12,000. My apologies.

The famous waiting lists: We've already referred to the 1,000 applications already on Passport waiting lists, and that's this year. If waiting lists become a right, we have failed. We must avoid legislation and policy changes that recognize waiting lists as a right. There's a second problem with allowing waiting lists. When funding is inadequate and there is a waiting list, the service becomes watered down. I point to the health care system where three baths a week became one, where light housework became no housework, where nursing services became eight to 15 visits a day. We must learn from the health care sector. They have introduced change in the home care sector creating 43 CCACs all with infrastructure, and we heard Mr. Hagerman's costing on that. It would be a bureaucracy that is not needed and a cost we can ill afford.

We understand that the government needs to plan for all the people we need to serve. However, we don't have a method by which we can account for the people who we should be serving. We're recommending that we have a method of looking at who needs to come into the system, who is on the waiting list, who is currently served and who potentially has fallen through the cracks. It is really important that we get a handle on that because, as I've repeated before, if you don't know what you're managing, how can you plan for it and how can you budget for it?

This legislation must envisage a high-performance sector framework where the funding is maximized and accounted for, where talents are managed, where there are retention success indicators and where waiting lists are not the norm.

Application centres: This is very near and dear—

The Acting Chair (Mr. Dave Levac): You have one minute.

Ms. Ann Hysert: Okay. We currently have a collaborative process in the three counties, and there are many benefits from that. We believe in that, and I'll ask you to read number 6.

We also would like, in number 7, to move to an accreditation versus an inspection framework. That would be very central.

I want to speak very quickly to number 9. We are opposed to Community Living Ontario's position that suggests that the agencies should fall under HLDAA. If agencies are covered by HLDAA, they could face potential arbitration wage settlements that could result in increased costs that would perhaps affect an agency so significantly that they could be bankrupt. We support competitive wage structures for employees and we respect that our employees have the right to strike, but we contend that they only have the right to picket locations that are work locations and not the residences for our people. I'll ask you to look at the issues in the rest of that recommendation.

Very quickly, I'm going to touch on protections and appeals. When we go to a variety of options for people, we need to guard against a discount brokerage service—not to say that we don't support people having choices; we need to guard against substandard wages and substandard working conditions.

I will close with this: The approach we have taken is to use leading-edge frameworks and talents within agencies, families and individuals to chart change. If this process dies today, we will all have missed a great opportunity. Our model envisages an ongoing tripartite approach that will support all we serve. I thank you for allowing me to get that all in. If you legislate it, you must fund it or you're sending us all back through the hopper.

The Acting Chair (Mr. Dave Levac): Thank you very much. You stayed relatively close to the 15 minutes. We appreciate your time and your presentation. We'll carry the leftover time to the NDP in the next round.

I will relinquish my chair to the Chair. Mr. Happy Feet will now leave.

RICK McCABE

The Vice-Chair (Mr. Vic Dhillon): Good morning. The next presentation is from Mr. Rick McCabe.

Mr. Rick McCabe: Thank you. For the record, my name is Rick McCabe. I am here as a parent of a 34-year-old developmentally disabled daughter who is currently receiving services through a transfer payment agency funded by MCSS. For that, we are extremely grateful.

I want to thank you for giving me the opportunity to put forth some of my thoughts on the proposed revisions to the act and regulations to provide services to persons with developmental disabilities.

In all of my efforts, I have two main goals: first, to have services available to a greater number of individuals, and one way of doing that is by more efficiently using the existing resources; and secondly, to have a service which is primarily focused on the needs of the residents. Today, there are too many agendas—some hidden—and the focus is not on the residents.

I would love to be involved in a detailed debate on the act, the regulations to follow and any guidance needed to clarify the intent of certain provisions. If, in fact, such an opportunity should arise, I would quickly volunteer.

I wish to make a point today that this act and regulations require very careful scrutiny. I'm going to use a section of the act, clause 27(4)(d), as an example. This section gives powers to the inspector and quickly places unnecessary and crippling constraints on the inspector's power. The section empowers inspectors to inquire from any person on the premises, including residents or other persons receiving services from an agency. The rest of the subsection is irrelevant to my arguments.

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First, this section limits the range of persons the inspector can question to those on the premises, a limitation which should not be placed on the inspector.

The section presumes that residents can adequately respond to the concerns or poor conditions. It appears to preclude advocates. My own daughter's inability and shyness to express concerns should not be construed as an endorsement of the services provided to her. While I'm alive, that is my responsibility, and the inspector cannot even speak to me.

Thirdly, this section does not empower the inspector to compare services to the written commitments made to support the resident.

These deficiencies need to be discussed and finalized in a thorough review of the act and regulations. Every time the words "as may be prescribed" appear, the decisions have not yet been made and need to be considered in the context of the entire regulatory regime, and queried to the same level as the above section.

I'm doing here what comes naturally to me, but this does not meet my objective today. My time today is very limited, and I feel I can better use it by looking at the broader picture and focusing the rest of the review of the act and regulations on three main areas. I am confident that if the revisions to the system are guided by principles and not self-interest, the result will meet the needs of clients and the Ontario public, the two most important groups needing to be served by this act.

I expect you will be inundated with those conducting detailed analysis of the act and seeking revisions to make it less restrictive, to maintain the status quo, and telling you that the system only needs minor revisions. I categorically disagree with that assessment and am very pleased that the act that is currently drafted more adequately reflects the position of most parents.

The concept of direct funding alone makes a major leap in improving on the three areas I wish to touch on today: accountability, advocacy and transparency. None of these issues is mutually exclusive and you will see this in my limited presentation this morning. I'll attempt to explain the larger perspective on these issues.

I see the lack of accountability of the transfer payment agencies, but also the MCSS, as the greatest current deficiency in the system. Without accountability in the financial area and on reporting the delivery of service to clients, no one will ever be able to provide assurance that the resources allocated to this area are being used effectively and efficiently. Inefficiencies in the system will never be identified and rectified without clear accountability based upon solid performance objectives. We need to make this system efficient to serve the greatest number while maintaining accountability to Ontarians.

I have an example of the lack of accountability which supports my contention. The following example should be of great concern to anyone impacted by the system. In a report entitled The Review of the Process for Adults with Developmental Disability in the Ottawa Region to Access Services—what a long title—dated May 2006 and commissioned by the Ministry of Community and Social Services, the consultant very diplomatically and too kindly reported:

"For example, specific expectations related to reporting of vacancies and participation and service resolution are not addressed, and a broad interpretation therefore exists amongst transfer payment agencies of their obligations in this regard.

"To ensure accountability, MCSS must be clear in its requirements of the transfer payment agencies involved in the process to access services. Without this clarity, it is virtually impossible to hold any transfer payment agency fully accountable for its actions. Transfer payment agencies have been placed in the position of defining their own role and responsibilities as it relates to the process to access services. This interpretation may not be in the same context as that which is intended by their funder."

I'd say she was too kind. What this really means is the agencies have been allowed to maintain vacancies for extended periods of time and did not have to report this to MCSS despite the hundreds of people on the waiting list. That is not accountability.

Verbal evidence provided in support of this statement, while not contained in the report, indicated about 38 vacancies existed for months at a time. Where did the resources go that were designated to these vacancies? That is the first question that pops into my mind, but not the only one. This clearly demonstrates a lack of accountability, a lack of clarity in expectations and the need for revisions proposed by this act. Accountability to parents and residents also needs to be added to this consideration. The financial accountability is generally understood, but there is also a need to demonstrate clear and consistent implementation of the needs of the clients.

The greatest need is for persons with developmental disabilities to have others assist them in making the right decision to protect them and to enhance their lives. This should be accomplished somewhat by procedures specific to the residents' needs and activities. Currently this is inconsistent, ranging from the procedures not even existing to not being followed and being subject to frequent breakdowns.

Failure to provide for the clients' needs is of grave concern to parents. This type of accountability to the residents needs clear inclusion in the legislation, and probably in the regulations. I suggest revisions such as requiring agencies to develop, maintain and implement written procedures to address clients' needs. This very prescriptive approach to regulating will be helpful in other areas as well.

I would be remiss if I did not endorse the need for clear accountability from parents in direct funding arrangements as proposed by this act. Every aspect of the system needs to be accountable. I am confident the limited resources expected in this sector will receive careful attention. But financial responsibility is only one aspect of accountability. There is also the need for performance standards for all service providers. We must be able to quantify performance where the service is amenable to this. I have requested the MCSS to provide me with the performance standards, which I assume form an integral part of the current agreements with the transfer payment agencies, only to be told, "The agencies are accountable," with nothing to substantiate that assertion. This is confirmed also by what was in the consultant's report that I referred to earlier.

Accountability to parents and advocates has to become the standard for the sector. Some agencies have considered themselves to be advocates, yet it is my contention that the needs of the residents are not being met. How can you consider this as an option? We can't.

The transfer payment agencies are reasonable-sized businesses, needing people in charge who understand the strategic planning, accounting, human resource issues etc. to lead these businesses in the right direction, not just to keep them alive. It is time to ensure that the agencies are run by leaders and managers, in the most generic sense of these words. It is my contention that there are substantial resources within the sector to increase both the number served and the quality of service. I can't prove it, because I can't get the quantitative information to demonstrate it.

That leads me to my next point: transparency. Nothing frustrates and demeans parents and advocates more than being told you cannot have information that in no way has confidentiality implications. Gross numbers without identifiers would in no way breach confidentiality. In fact, the confidentiality argument is used over and over to restrict the flow of information to parents. Parents are left to draw their own conclusions based upon the limited information available to them. Trust is eroded and the workload for all parties is increased in an effort to stay on top of the situation.

Transparency in the work of MCSS and the transfer payment agencies, with defined limitations, would quickly reduce the workload, improve trust and add to efficiency. If the information does not exist, it's of concern. If the information does not meet current expectations, it's of greater concern. And if the agency fails to recognize a need for the information, it is of great concern.

The job for us, then, is to define what information the MCSS requires and what information would be available to families, if requested.

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Each and every person in the system needs to have an advocate, whether it's a family member or someone else. I have observed great variability in simple things, like the furnishings provided to people within the system, sometimes to the point of being woefully inadequate for the needs of individuals. If these relatively easy items are not dealt with consistently, what is happening to the more subtle needs? These types of things—furnishings—should be observed by the inspectors under the new regime, but the inspectors will need assistance. Most likely, only an advocate will be able to pick up on the more subtle needs. Advocacy is not the work of the transfer payment agencies, nor can they do it. It is a clear conflict of interest and should never be substituted for a third party advocate.

In conclusion, I saw a television show a little while ago—it was a reality show for me—where an aging father was sitting in a hospital as his daughter was ill and undergoing painful treatment. Earlier in the show, we learned his wife had passed away and he was the sole provider for his daughter, with little hope of finding adequate services for her. Worry and fear were evident as he spoke to the nurses and doctors.

In a moment, as he sat alone, while summarizing all of the difficulties, frustrations and fears of raising a developmentally disabled child, he concluded: "The best you can hope for is to outlive your disabled child." If parents continue to feel this after the current revisions to the act and regulations, we will all have failed.

Now is the time to put forth all of the principles for the revision to the act and regulations, including accountability, advocacy and transparency, and to work diligently toward them. Thank you.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. You were right on. You used up all your time, so there won't be any questions or comments.

COMMUNITY LIVING UPPER OTTAWA VALLEY

The Vice-Chair (Mr. Vic Dhillon): Next we have Community Living Upper Ottawa Valley. Good morning, folks. If you state your name for the record, you may begin.

Ms. Noreene Adam: Good morning. My name is Noreene Adam. I am the first vice-president of the board of Community Living Upper Ottawa Valley.

Mr. Paul Melcher: Good morning. My name is Paul Melcher and I'm the executive director for Community Living Upper Ottawa Valley.

Ms. Noreene Adam: I'm going to start off. I have a number of titles to my name. I've told you, first vice-president, and most of them are under the heading of "volunteer." But this morning I want to talk to you about the one that's most important to me—as mother and parent.

I'm the mother of a 34-year-old man who has an intellectual disability. My son Kirby and my family truly appreciate the assistance we receive from the Ministry of Community and Social Services that enables my son to live in his own home, in his chosen community of Pembroke, and to have access to the supports he needs to be successful from Community Living Upper Ottawa Valley, from friends, from neighbours, and of course from our family.

I find it interesting that the Developmental Services Act, which we now see is being changed to a new act under Bill 77, was passed in 1974, the same year my son was born. We've had a lot of experiences under it and I am in full agreement with its being changed to reflect today's knowledge and ideas about people who have an intellectual disability and who can do so much more than what society used to think.

I'm quite excited that the government has proposed Bill 77, and I eagerly look forward to its implementation. As a parent, I see a number of really good things evolving from that new legislation. I really appreciate the statement in the compendium, which says that "the proposed new act recognizes that people want choice and more control over their lives, and that they can live independently with the right supports." I like to hear that the government is saying this and has even put it into writing. This is exactly what my son tells us: He wants to live in his own home, he wants to have a real job—and by that, he means getting real pay. He wants to enjoy leisure activities that he chooses, and he wants to do all of that in the same way that his brother and sister do.

However, there are a few parts of the proposed legislation that do give me cause for concern. I'm going to speak to only two of them this morning because of time constraints. The first cause for concern is the area of legal capacity and decision-making. From what I have read and understand, Bill 77 does not seem to recognize that a person with an intellectual disability has the right to legal capacity. You, the members of this committee, and the government itself must understand and recognize that gone are the days when people who have an intellectual disability are considered as children or childlike. These adults must have the same rights as everyone else in a just society.

I think that there must be a provision in the new legislation that absolutely recognizes legal capacity. I feel there also need to be provisions for supported decision-making, and this is completely different from substitute decision-making.

As a parent, I do not want to make all of the decisions for my son when I know that, provided we listen well to him, he can make many of these decisions for himself with the appropriate information provided to him in ways he can understand. I strongly feel that there must be provision included in Bill 77 that acknowledges and supports that right for legal capacity and, for some people, the provision of supported decision-making. To me, this is what helps a person to be a real citizen in Ontario.

The second concern I have is about planning. I have noticed that in Bill 77 it does not specifically mention that there will be any funding available for person-directed planning. For me and my son, planning was the first and probably the most important thing that was done when Kirby moved into adult life and services. How can someone know what kind of help they need if they can't identify it and if they can't then make plans to achieve it? Planning is the guide to a future life of one's choice. You and I do planning all the time, but are probably just not conscious of how much we plan our lives. My son and others like him who have an intellectual disability often need help to learn what they want to do in their lives. This help can be provided by someone who assists them with planning. But folks who live on disability benefits just cannot afford to hire someone to help them do planning. They need help to plan for the life they dream about. Actually, it was a surprise to us that when planning was done with Kirby, we found out that there were several things he wanted from his life that could be done without needing to get dollars from the government. If we had not had planning services, then we would not have known this. I thought this was really great, because then we didn't have to ask for extra government funding, as we had originally thought he would need. Families and individuals do not always want to be dependent on government handouts all the time.

Now, these are just two of the concerns I have as a parent regarding the new legislation, but I just want you to know legal capacity and independent planning are, to me, the cornerstones of a really grand life here in Ontario. Thank you.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We'll begin with the NDP. Mr. Prue?

Ms. Noreene Adam: Paul, we're short of time.

Mr. Paul Melcher: I'm sorry; I'll be brief.

The Vice-Chair (Mr. Vic Dhillon): Sorry. That's the second time I did that.

Mr. Paul Melcher: As was stated, my name is Paul Melcher, and for the past 15 years I've worked for Community Living Upper Ottawa Valley. I have over 28 years of experience in developmental services in many different positions. I have come to know and admire many individuals, families and professionals over the years.

I started my career during the proliferation of developmental services in the province. Many sheltered and segregated programs were established under the first major provincial initiatives to emancipate people out of provincial institutions. A key element to these early initiatives was the provision of additional resources to support people already living in the community. In those early years, community service models were largely based on the medical or institutional care model. This translated into people being treated, corrected, protected and provided care.

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In time, services evolved, first in teaching adaptive skills to assist people to gain independence and achieve less reliance within the service system and then, to varying degrees today, to supporting opportunities for self-direction and community inclusion. Developmental services, despite often struggling and sometimes stalling, have made progress. Throughout the years, people and their families, although often frustrated, have continued to advocate for rights and supports in citizenship.

Community Living Upper Ottawa Valley wishes to thank the Standing Committee on Social Policy for the opportunity to speak to Bill 77 and citizenship for people affected by intellectual disabilities. We would like to start by acknowledging the need to update and replace the legislative framework for the provision of developmental services in the province. Experience has demonstrated legislation can lead to monumental shifts in how we as a society assist vulnerable Ontarians and their families. The Developmental Services Act of 1974 ushered in an era of community-based services and ultimately, now, the closure of provincial institutions, a necessary and tremendous accomplishment.

The new act, with revision, has the same potential to provide a foundation for needed change. Consultations across the province support further deinstitutionalization and evolution of community-based services, while also calling for the creation of new and innovative approaches to supporting citizenship.

Community Living Upper Ottawa Valley supports enactment of new legislation to guide the provision and administration of public funding to support people affected by intellectual disabilities through a fair, equitable and responsive system of services and support strategies, which includes individualized funding.

The role of developmental services should centre on bridging gaps and linking people, as they desire, to the social, human, political, economic and natural capital in their community. That capital is our citizenship. Developmental services legislation should impact all branches of government and the broader public sector.

The Ontarians with Disabilities Act provides a framework, which may be beneficial in the context of Bill 77 and engaging others.

Absent from Bill 77 and pivotal to reformation is mandatory person-centred planning to relate and respond to the needs and wishes of people in regards to their community roles, relationships, safety and well-being. Decisions that directly affect each person must be made by that person, with the appropriate level of assistance of families and others they choose.

Service standardization should be minimized to allow the greatest amount of personal autonomy and flexibility in the system. There are many ways to plan, design, coordinate, administer and provide services and support. People need to determine why and how this occurs within a framework of expectations in the act or its resulting policy framework.

Accountability to each individual must involve strategies to enable people most affected to evaluate the outcomes and progress towards their goals and the effectiveness of their services and support. They should also have the opportunity to participate in external review mechanisms. Complaint and dispute resolution should be prescribed in the act through internal agency and ministry processes and, when necessary, external mechanisms.

New compliance powers within the act need to be incremental processes inclusive of remediation, enforcement and appeal mechanisms. A role for stakeholder involvement in these processes is essential.

Those providing service and in receipt of public funding must clearly demonstrate assurances for basic outcomes of health, security and safety as a function of the provision, coordination, administration and governance of their services. External forms of review and accreditation should be required and supported by the province.

Broader stakeholder input and participation in local and regional decision-making is necessary to leverage and develop community resources and other forms of support. Greater involvement of community in developmental services will lead to greater inclusion of people and help reduce wait lists.

Rationalizing fairness and equity in funding through assessing levels of need must also involve evaluating quality-of-life issues, personal preferences and equity of outcomes. Ontario has seen similar changes in education, child protection and long-term-care sectors relating to funding, all of which have been revisited, especially as they relate to outcomes for the safety and well-being of vulnerable people.

Community Living is concerned the new act speaks to creating specialized access agencies. We support one provincial application and assessment process, but believe implementation needs to be determined through community consultation to ensure effective and efficient use of resources in the face of growing waiting lists. Rather, the act should identify the outcomes it expects from one provincial application and assessment process, realizing specific models of delivery may come and go.

In conclusion, revisions to Bill 77 have the potential to empower people, communities, and the broader public sector beyond the limits of the developmental service system.

Legislation will affect decades to come. What must developmental services accomplish during this time?

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We'll begin with Mr. Prue.

Mr. Michael Prue: How much time?

The Vice-Chair (Mr. Vic Dhillon): A little less than a minute. Just very quickly, please.

Mr. Michael Prue: Okay. One question, then. This relates to the application centres. Many people have been critical of them because of the potential bureaucracy and probably enormous cost. Would you and your group prefer that the application centres be deleted from the bill and the money that would be spent there spent on direct service?

Mr. Paul Melcher: Yes. We see that there's room for improvements in access and helping people relate their information within the—

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

Mr. Khalil Ramal: Thank you, Mr. Chair. I'll be quick. You talk about legal capacity. The proposed legislation assumes that individuals with developmental disabilities have the capacity to make decisions about their service and support needs on their own with assistance from family or friends or whoever. This would be in place in the new act if this passed. Thank you.

The Vice-Chair (Mr. Vic Dhillon): Thank you. Ms. Elliott.

Mrs. Christine Elliott: Just a couple of quick comments. Your presentation was really informative for me because you answered some lingering questions that I had, both from the agency's perspective and the parents' perspective. The one that I'd like to centre on is with respect to planning and the importance of planning in answering questions when you might not know what's out there.

Planning is really important to help you gather that information both from the agencies as well as from the community, and that there can be many services and programs that can be accessed that might not cost any money. The money part of it is important, but also the social inclusion part that comes into that is really important as well. As a parent, I'm really happy to hear you say that you're pleased with that part of it. Many people have said that they believe the planning part of it necessarily has to happen before the application, and I gather you would agree with that.

Ms. Noreene Adam: How can you think of where you want to go if you don't plan?

Mrs. Christine Elliott: Exactly. I agree too. Thank you.

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

FAMILIES MATTER CO-OPERATIVE INC.

The Vice-Chair (Mr. Vic Dhillon): The next group is Families Matter Co-operative Inc.

Welcome to the committee. If you can state your names before you begin, that would be very much appreciated.

Mr. Paddy Fuller: Yes. Good morning. My name is Paddy Fuller. I'm the acting president of Families Matter Co-op. First of all, I'd like to thank the committee for the opportunity to appear before you today. We appreciate that very much. Families Matter Co-op is a small not-for profit charity that works to increase the opportunities for employment and housing for persons with developmental disabilities. We also act as a forum for families where the families can share information, gather strength from each other and act as advocates on behalf of the family members.

I'm joined here today by Marge McCabe, who is our executive director. She will be making the submission on behalf of Families Matter Co-operative.

Ms. Marge McCabe: I'm Marge McCabe. Families Matter Co-op is committed to respecting personal support choices made by families, being strong advocates for respect and dignity for all our family members, being a catalyst for increasing community capacity, especially in the area of residential and employment opportunities, and being a family voice for change and improvement in the way supports are provided.

We are very encouraged by the efforts of the Ministry of Community and Social Services to revise the Developmental Services Act, and as stakeholders, we appreciate the opportunity to present and be valued participants in the process. We know that the decisions made in revising this act will have a major impact on the future of our family members. Our hope is that this will provide the framework for full citizenship and participation for all individuals with developmental disabilities in the province of Ontario. To ensure that all of our family members have as much control over their lives as possible, whether families and individuals choose direct funding or agency-based funding, the client should be the focus and his or her family or support network should be involved to the fullest extent in decisions that will affect the client's life.

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We request that the following underlying principles be considered in Bill 77:

—person-centred plans include a long-term view of individual support needs and access to reviews and updates and reassessment as required by individuals and families;

—the focus be on person-centred supports;

—accountability, transparency, and independent and unbiased assessments;

—family/support networks be included in assessment and evaluation of service provision;

—performance indicators be required for service providers;

—respect for families and support networks, as participants in supporting individuals;

—the ministry encourage innovative supports and services, not one-size-fits-all;

—equity in accessing support for all levels of needs. Prevention is less costly than crisis intervention;

—advocacy for all individuals being served. Advocates are an independent voice to speak on behalf of individuals without family support;

—appointment of an independent advocate if individuals do not have immediate families or support networks;

—access to all information, for all stakeholders, about supports and services, funding, opportunities, reviews, reports and evaluations concerning the developmental sector.

Families Matter Co-op has chosen to focus on three areas: application centres, planning, and funding.

Number one, application centres: We believe that application centres should be the first place that families and individuals receive information on all community resources; education on how the system works; training for navigation of the system; connection to support groups at all life stages, at all levels of functionality; and for common and shared interests.

If the responsibilities of application centres, as set out in Bill 77, are to be effective and efficient, they should have a clear mandate; be adequately resourced, with transparency, accountability to clients, families and the ministry; be cost-effective; and have regular monitoring by the ministry and reporting to stakeholders through advisory bodies or other mechanisms. But we believe that objectivity will be compromised if the same body is responsible for all of the procedures as listed in Bill 77, and we see it as a potential conflict of interest.

I just want to add that families fear that too much of the budget will go to these centres. As mentioned by others before me, families want more funds for support, and most of us have already had many assessments without any implementation.

Our recommendations are:

—that application centres be responsible only for the procedures of determining eligibility for services and funding, and determining the method of assessing the needs of a person with a developmental disability for services;

—that independent committees, composed of all stakeholders, be responsible for the function of determining the method of prioritizing persons for whom a profile has been developed;

—that the regional offices of the Ministry of Community and Social Services be responsible for determining the method of allocating and for the allocation of ministry resources among persons with developmental disabilities, providing the guidelines used for the prioritization and funding allocations to all stakeholders, and reviewing decisions on a regular basis and providing summaries to the stakeholders.

Our second point, planning: Person-centred planning is very important for all individuals with developmental disabilities and their families. Families need to be able to trust that the person assisting with the plan for their family member's future is objective and unbiased. Navigating and understanding the system can be very difficult for self-advocates and families. Planning should be unencumbered and funding be available for families who choose to go to independent planners. Independent facilitators and third party planners should be appointed to oversee and review person-centred plans for individuals without families or support networks.

Our recommendations are that person-centred plans should include an option for funding if families choose independent planners, and that they be completed in an unbiased manner, separate from service providers and access centres. The families should be well informed and provided with up-to-date information about available planners and facilitators in their communities.

Our third point, funding: In order to make informed decisions in choosing between agency-based or direct funding, families and support networks need to be educated about the ministry's requirements for accounting, monitoring and reporting, and they need information about what can be expected and acceptable when their family members are receiving supports and about how to address their concerns and complaints regarding support services being provided.

Families' concerns and past experience is that individuals being served by residential support agencies, especially those without family members, become isolated from the community, surrounded by paid workers with minimal or no connection to advocates or circles of support.

Our recommendations are, when agency funding is the choice, that families and support circles be provided with information on: ministry requirements for accounting, monitoring, reporting procedures; guidelines on what can be expected and acceptable when family members are receiving support; a process for addressing concerns and complaints regarding support services; and, a process of switching from agency-based to direct funding, if that's their choice, but vice versa.

We also recommend the establishment of an independent advocacy or facilitator panel, ensuring connection for all residents supported by funded agencies and, further, a process for registering all the individuals with the independent advocacy or facilitator panel upon acceptance with agencies. This process could be simple. It could be yearly reviews of person-centred plans, yearly meetings with residents and support circles and submitting yearly reports to the ministry.

Direct funding: In addition to annualized funding for residential and daytime supports that are being considered in Bill 77—and Passport funding—we believe the ability to access in-and-out support dollars would lead families and individuals to become more empowered and encouraged to create more innovative community supports. Families would be more able to cope with the constant demand of their loved ones. It would increase choices, suit more families' needs, cause less stress and could ultimately prevent family breakdown. Family breakdown is one of the factors that frequently contributes to the inability to support our family members with developmental disabilities. This preventative measure would help in avoiding crisis situations that frequently force families to give up and seek annualized 24-hour funding by the ministry.

Our recommendations are: to increase Passport funding to enable more individuals to transition from high school to adult life and enjoy full participation in their communities, whether they choose vocational, employment, therapeutic, leisure, recreational or other activities; to consider the example of special services at home funding in setting criteria for accountability and proper management of Passport or other direct funding; and, to provide funds for in-and-out services, on an as-needed basis, to support families at different times in their lives, in different stages.

These funds could be used for more subsidized respite in and out of home to sustain families when they want to keep their family members at home; for outreach services from ministry-funded agencies or private providers in family homes or community settings, which would reduce the waiting list for full-time support; and, access to mentoring or job coach services for families that find employment or daytime opportunities for their family members, but have limited access to mentoring or support when there's a problem in the workplace or at a program.

Innovative funding: Our members would like to see more partnerships between families and agencies in the area of housing and social enterprise. The innovative residential funding model is a good example of how families can work with agencies to create great opportunities for more individuals, especially those who need minimal support, to leave home. Families Matter Co-op's partnership with the newly established McLean Co-op and the support agency of Christian Horizons is a good example of how families and agencies can work together in partnership.

Our recommendations are for more widely distributed information by the ministry regarding new ideas and methods of how families can work with agencies that could strengthen families and build stronger communities; education sessions in communities on opportunities such as the innovative residential funding model; and, communication about this opportunity and others, through websites, e-mail, mail and other methods, even the ODSP allowance notices for families that do not have access to the Internet.

I thank you for this opportunity. I don't know if I have any time for questions.

The Vice-Chair (Mr. Vic Dhillon): Just about a minute each. We'll begin with the government side. Mr. Ramal? Just one minute each, very quickly.

Mr. Khalil Ramal: Thank you very much for your presentation. It was a wonderful presentation. I want to ask a question. We've been listening to many different organizations, agencies, communities etc. for the last three days. It's been mentioned that families cannot do the job we do, therefore, there shouldn't be direct funding. You stated in your statement that you're working well and that you're happy with the proposed bill because it gives you a chance to look after your loved one. What do you have to say to those organizations that said what they've said in the last three days?

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Ms. Marge McCabe: Of course, we're very hopeful because we believe families have the right to choice, whatever choice they make. But we also know that there's such limited opportunity if you're on a waiting list, as other people said, for 15 years sometimes. Give families some hope by at least opportunities to build in the community and encouraging them to work together with the system. Right now families are feeling very disempowered. No matter how much you want to try and work with the system, it's like—we feel we're not valued stakeholders. I think everyone's missing a big opportunity to include families and to work together and have some creativity.

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

Ms. Sylvia Jones: Thank you very much. I appreciate your presentation. You raised some issues with the application centres, and I wonder if you could comment on the government position that the setting up and operation of application centres will be revenue-neutral and will not bleed limited resources from within the sector. Can you comment on that?

Ms. Marge McCabe: Setting up will be—

Ms. Sylvia Jones: It's not going to cost any additional dollars.

Ms. Marge McCabe: Well, families don't feel that way.

Ms. Sylvia Jones: It's a little hard to believe.

Ms. Marge McCabe: We have a great concern that—we see the system as it is right now, and now we see it getting bigger and bigger. We believe that there has to be an access process, but we have a concern about building bigger bureaucracies because people need support, and there are many ways to do that.

Ms. Sylvia Jones: Particularly if you're going to use the funds within the existing sector.

Mr. Paddy Fuller: I think the main point is that the system as a whole, no matter how you change it, is underfunded. Changing the system without doing something with the funding, I think, will not address all the problems.

Ms. Sylvia Jones: Good point.

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

Mr. Michael Prue: Some of the groups have said that to properly fund the existing system, never mind change it, would cost about $350 million extra. In your advocacy, do you think that the government should be spending the money first and then changing the bill, or do you think that this is the correct way to have gone? They're building hope without any show-me-the-money attitude.

Ms. Marge McCabe: Of course, we're hoping that they will change the bill and have the money there, but I think that sometimes lots of opportunities are being missed because there are lots of assets in the community that could be used. There are many families who want to be involved, and there are other mechanisms that could be put in place that encourage families to work with the system and maybe a way of leaving assets instead of trying to hide your assets, that kind of attitude, because the only way you can get service is to line up at the access point. I don't know if I missed your point, but—

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

PROVINCIAL AD HOC COALITION ON BILL 77

FAMILY ALLIANCE ONTARIO

The Vice-Chair (Mr. Vic Dhillon): The next group is Provincial Ad Hoc Coalition and Family Alliance Ontario. Welcome to the committee. If you can state your name before you present.

Ms. Kathleen Jordan: My name is Kathleen Jordan, and I am speaking as a member of the Provincial Ad Hoc Coalition on Bill 77 and as a board member of Family Alliance Ontario representing the eastern region. The raison d'être for my personal participation in this sector for 34 years is here beside me, and he is participating and contributing today as my timer. I would like to introduce Christopher Campbell Jordan and his very dear friend Melodie Grealy, one of his associates. Start the clock, there, boy.

The launch of Bill 77 represents a significant step in moving the transformation of the developmental services agenda forward. The government is to be commended for this initiative, especially for including provisions for closing institutions and for introducing direct individualized funding. There are a number of topics that I would like to emphasize today that are among those identified by the provincial Ad Hoc Coalition and Family Alliance Ontario specifically. Because of time constraints I will list and speak briefly on the points that I can cover, focusing on those that we perceive to be vital to the success of this bill. I believe that these suggestions will help to clarify and strengthen the legislation.

Number 1, the title of the bill: The name of the bill needs to reflect more accurately the stated purpose of reform. If the title were changed to "An Act to enhance social inclusion for persons who have developmental disabilities, to repeal the Developmental Services Act and to amend certain other statutes," then the bill would reflect this intention.

A preamble to this legislation is essential to record and authenticate the spirit and intent of the legislation. This tool is intended to direct the advancement of the legislation towards its stated goals. It will define the values, principles and beliefs that will drive the regulations and policy development of this legislation. When the transformation of developmental services began in 2004, the Ministry of Community and Social Services developed a set of values and principles to guide the process. These values and principles are documented in the 2006 paper Opportunities and Action. Unfortunately, these values and principles are not evident in Bill 77 as it currently reads. This legislation should be intended not only to reflect the transformation with the developmental services sector, but to advance a much broader concept of social justice, one which respects the inherent dignity, individual autonomy and the full and effective participation and inclusion of all people, condition notwithstanding. A diagnostic level of developmental disability has served to marginalize and disenfranchise our loved ones. It still does.

The language of the bill: The language used within the document should be easy to understand, consistent and respectful of the autonomy of the individual. The legislation needs to give a voice to the people that it's intended to serve, their families and their social networks. In the compendium to Bill 77, there is consistent and constant use of the phrase "services and supports," and yet in the bill itself the term "services" is used exclusively with hardly any mention of supports. "Services" and "supports" have different meanings. They are not to be used interchangeably. The only reference in the bill to "supports" is in section 4, where the legislation defines "services." The term "supports" in this case is used in reference to the nature of services. This is not adequate to reflect a new vision that includes support as a completely different concept to traditional services and programs.

Not only does the choice of words in the bill need to be revisited, but the manner in which the activities or concepts are expressed. I refer you to part IV, section 9(2), and part IV, section 11(2). The legislation directs that the application centre or the government can enter into a direct service agreement with a person with a developmental disability or other persons on their behalf. It is this phrase "other persons on their behalf." What this section should say is that the application centres can enter into a direct service agreement with a person with a developmental disability or with the individual and his or her chosen support person. These words reflect the autonomy and the legal capacity of the individual to make significant decisions with his or her own chosen support. This is what supported decision-making is all about: to do with rather than for. To deny this opportunity to any group of persons based on a collective label is to perpetuate exclusion and legitimize discrimination.

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Direct individualized funding, person-directed independent planning and facilitation: The Family Alliance Ontario and its colleagues have been working with the government for 20 years to establish direct individualized funding options and we have witnessed these programs stalled or stopped. This topic is a very important part of the DSS transformation agenda. It should not be covertly introduced in Bill 77 under a heading related to services. There is no section on direct and individualized services. It comes right at the end there. Direct individualized funding deserves to be attended to within the bill in its own specific numbered part—part IV or part VI; call it whatever you want. The bill is established in parts, but there should be a specific part for direct individualized funding.

Then, following the present format of the bill, sections with the following headings will appear: person-directed independent planning and facilitations; circles/networks of support; and, wage disparity. Let's clean it up. These are things that really should be in the legislation and we don't see them there at all.

As a parent of a 34-year-old young adult who was one of the first individuals in Ontario to be included into his local community school up the street with his brother and sister and his local friends in the neighbourhood, albeit after a human rights complaint and a lot of blood, sweat and tears—that inclusion was difficult, because the infrastructure intended to support this new legislation had not yet been identified or incorporated into the system. That was Bill 82. We got there too fast.

Also, when the special services at home program was first identified in 1982, I was very involved with the ministry in an advisory role to assist the ministry to observe and facilitate the implementation of what I suggest is the first example of direct individualized funding for families and their loved ones to help support them in the community.

But this was just the beginning of the movement. The initiative for this program was to help families to keep their children at home. Children grow up to be adults and so the program was expanded to include young adults over 18. However, only adults with a developmental disability were eligible to apply. We all learned that it is much more expensive to maintain a young adult with complex physical and developmental disabilities in the community and the communities were not prepared for this. The program has never had enough funding to meet the needs of families. However, in spite of that, institutions have closed and life in the community is becoming a more and more viable option. It will not succeed, however, unless direct funding is a real choice with the necessary infrastructure to make it a success. Independent or person-directed planning and facilitation, not to mention wage parity for independent contractors, must be accepted as part of the package related to direct funding. Without all of this, the entire concept will be nothing more than an idea, talk and a frustration for both the government and the families.

I would like to add here that there seems to be a misconception about why families want control over their lives. It doesn't mean that they will not need the support. Of course they will. They will need support to plan, recruit, hire and train workers in the community, and to provide a safe and secure environment for the family member and for his or her workers. We will want everyone to be safe. We need community building and development so our family members are welcomed in the community to learn, to work, to love, to volunteer. Direct funding needs to be a supported choice in order for any other transformation to occur.

Adults with a developmental disability want to move out and leave the family home, just like their brothers and sisters. They want their autonomy, their interdependence, and their own friends and activities like everyone else. However, this lifestyle will require support and intervention and facilitation at all stages, all of which has a price tag.

Equity: Transformation in the developmental services sector cannot happen without a commitment of resources to make the system maximally responsive. There has been in the past unequal access to direct funding options as compared to agency service options. What is the government of Ontario going to do to ensure that the new financial resources are provided for direct funding and person-directed planning and facilitation to individuals and families as a bona fide option now that it is provided for in the legislation?

I am going to conclude now, and I just want to mention by name those articles I mentioned and the ones I didn't mention so you'll know there's still more to come.

First, the title of the bill: Rephrase it. The preamble: Add one. The language: Wordsmith it. Direct individualized funding, person-directed planning and facilitation: Experience it and entrench it. Equity: Ensure its existence. Accessibility and portability: Institute it. Legal capacity and supported decision-making: Make it an entitlement in this bill. Waiting lists: Remove them. Application centres: Change this concept to an application process. Put it in the regulations, not the legislation. There's a lot of work to do here, and I think it just takes time, power, energy and money. It'll break the bank, this one will.

Divestment: Do not do it. Please do not divest your authority and responsibility to the taxpayers of this province. Appeal process is due process: Establish it—that's what being a citizen is. Interministerial co-operation: Organize it—we need it. Community development: Fund it. Safety and security: Provide it. Thank you.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much, Ms. Jordan. Your presentation was right on the time, so there won't be any questions. We really appreciate you coming out.

Ms. Kathleen Jordan: Thank you.

BROCKVILLE AND DISTRICT ASSOCIATION FOR COMMUNITY INVOLVEMENT

The Vice-Chair (Mr. Vic Dhillon): The next presentation is from the Brockville and District Association for Community Involvement. Welcome to the committee. If you could identify yourself before you begin.

Ms. Nancy McNamara: Nancy McNamara, with the Brockville and District Association for Community Involvement.

Ms. Audrey Cole: Audrey Cole, Brockville and District Association for Community Involvement.

Mr. Harry Pott: Harry Pott, parent.

Ms. Nancy McNamara: Good morning. I'm Nancy McNamara, a parent and the current president of the Brockville and District Association for Community Involvement, of which I've been a member for over 20 years. My co-presenter, Audrey Cole, also a parent, is a former president of our association as well, and a well-known, highly respected and dedicated provincial and national advocate on behalf of people with intellectual disabilities for over 40 years. Harry Pott, too, would be happy to answer any questions at the end if we have time. He's a long-time parent with our association as well.

Our local association, known as BDACI, is an affiliate of Community Living Ontario and a local member of the Canadian Association for Community Living. We in BDACI have a 52-year history of which we are very proud. BDACI does not provide traditional services. Over 25 years ago, we transformed ourselves into providing individualized supports where the individuals with intellectual disabilities and their families direct the care and the support that we provide. Thank you for the opportunity to speak to Bill 77.

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While we welcome transformation in the developmental service sector and recognize that the proposed legislation looks to address a number of significant issues, we believe that important changes to the bill are required to ensure that we create a truly inclusive society. Given the limited time we have, we will highlight the following areas of greatest concern to us.

Lack of guiding principles and statement of vision: A statement of vision and principles that will provide the foundation and rationale for reform is missing from Bill 77. They are important because they set the parameters for the provision of supports and the implementation of policies and programs that then give clear guidance and direction in the day-to-day operation of the support system. BDACI believes that new legislation must also reflect through vision and principle statements the progress that has been made over the past quarter century in the enhancement of the rights of people with intellectual disabilities.

The introduction of standardized assessment via the application centres: The lack of guiding principles that I just mentioned leads to significant problems associated with the establishment under the bill of standardized assessments carried out at application centres. BDACI is deeply concerned that these centres will create a bureaucratic structure that will require significant administrative costs that will take away from direct support dollars. If service agencies that are currently providing services are then designated as application centres, severe conflicts of interest will arise, and accountability would be undermined. We are worried that a single agency might well become responsible for determining eligibility, identifying needs and then allocating funds. Instead, as has been proven effective in many areas over the past 10 years, such as in our very own Leeds and Grenville, the collaborative access process can play a role in taking on many of the proposed functions of the application centres, and they operate with minimal cost.

With regard to the assessment process, if government includes not just independent planning but person-centred planning and facilitation, then there would be no need, for example, to develop service profiles, as is currently contemplated in Bill 77. Person-centred planning, supported by planning and facilitation mechanisms, provides people with real opportunities to make decisions and to develop plans that reflect their goals and dreams.

We recommend that the new legislation be changed to allow for the development of an application process that builds on already-existing mechanisms, incorporates the role of person-centred planning and facilitation in the application process and leaves decision-making authority about funding allocation with the ministry's regional offices.

One of the greatest concerns centres on special services at home, also commonly known as SSAH. Part of the SSAH Provincial Coalition's slogan is "Keep it simple. Keep what works for 27,000 families!" At BDACI, we could not agree more. We are very concerned about the future of this invaluable support program. While it's not perfect, it is cost-effective, flexible and personalized, and has a proven 25-year track record of being the number one program of choice of Ontario families, including in our association over 150 families and individuals as well. Sadly, it has had no new funding for two years, and this situation will not likely be remedied if new bureaucratic structures such as application centres are added. Above all, SSAH is the most enhancing and respectful model for the individual with intellectual disabilities. It has functioned as the primer for direct funding and should be used as the model for this type of funding proposed under the bill.

I'll now turn things over to Audrey Cole, who is recognized as an expert in the field of supported decision-making.

Ms. Audrey Cole: Thank you. It's my role to emphasize the critical need for provision in Bill 77, firstly, for recognition of the legal capacity of people with intellectual disabilities, and, consequently, for the provision of mechanisms within the bill for supported decision-making. Without the inclusion of such provisions, as Community Living Ontario has noted, there is legislative incoherency, in that the bill, on the one hand, attempts to enhance the citizenship and independence of people through the application of direct funding, while on the other hand it fails to provide the vehicle through which the person can take advantage of the mechanism. We share the belief of Community Living Ontario that acknowledging and supporting the legal capacity of the individual is, arguably, the most transformative step that can be taken under this legislation.

Without supported decision-making, the mechanisms in Bill 77 for direct funding could be denied to many people with significant disabilities. Those meeting the demands of sophisticated notions such as legal capacity and consent would be free to make application. Others could be denied access or could lose decision-making rights. In other words, as in the past, such people would be denied the recognition of their inherent legal capacity as citizens. Today, in Ontario, with this bill, we have an opportunity to rectify that discriminatory situation.

What is supported decision-making? Perhaps the best way to answer the question would be to say, "Hands up, those of us in this room who can honestly say that we've never, ever sought the advice or support of family, friends, whomever, in making a decision." Were I to see hands popping up around the table, I'd sense an environment of questionable veracity. Human beings don't make decisions in isolation. We're social beings. We look to each other for support in all the significant areas of our lives, particularly in decision-making.

The concept of supported decision-making as a valid alternative to guardianship was pioneered right here in Ontario. It's already recognized in law in some provinces and territories in Canada. It's now adopted in international law, under article 12 of the United Nations Convention on the Rights of Persons with Disabilities, which Canada has signed but not yet ratified. Ontario could contribute significantly to that eventual ratification by including provision for supported decision-making in Bill 77. Already, we are told, some countries are changing legislation to include supported decision-making. It's the only thing that guarantees a mechanism through which any person and every person, given the appropriate support, can enter into an agreement for direct funding without having to surrender authority to a substitute decision-maker.

It's been proven, in supported decision-making, that honest, suitable and totally unshakable decisions can be made without compromise or conflict and without jeopardizing the person's independent capacity. The validity of supported decision-making rests in the integrity of the decision and the quality of the decision-making support. Those are characteristics that are derived from mutual respect, affection and trust, and they're not diminished by arbitrary constructs of decision-making capacity. The Substitute Decisions Act already provides for alternative mechanisms for decision-making. A companion clause is necessary to validate the process with respect to matters falling under Bill 77.

BDACI recommends that Bill 77 include a provision stating that in circumstances where decisions are not made by the individual alone, the decision-making process by which they are made be deemed an alternative course of action, in keeping with the provisions in subsection 22(3), respecting property, and subsection 55(2), respecting personal care matters, of the Substitute Decisions Act.

Powers of attorney, however benign their appearance, are instruments of guardianship or substitute decision-making. By their very nature, they're prone to abuse and could compromise supported decision-making.

BDACI supports Community Living Ontario again in recommending a further provision that would clarify that, in cases where a person with a disability has granted a power of attorney for property or personal care, or both, the exercise of that power of attorney in relation to any decision pertaining to a service or benefit available under this act must include the provision of support to the individual granter, either by the holder of the power of attorney or by an independent third party, or both, to enable the person with a disability to participate as fully as possible in the decision-making process.

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In conclusion, it's not only my belief, but I'm witness to the fact in many cases that no matter how severe the disability, a person can direct the course of his or her own life solely by means of the depth of commitment of his or her trusted support network to his or her well-being. Not only does supported decision-making work for people with intellectual or any disabilities, it works for everybody, and it's the right thing for a caring society to do.

Ms. Nancy McNamara: We wish to emphasize that the social inclusion, the very well-being of people with intellectual disabilities as citizens of our province, is dependent not only on the support that they receive that falls under the jurisdiction of Bill 77, but also on the support outside the legislation that lies within the broader community. This is where the influence of this type of legislation will come to rest. Bill 77 will contribute to the perception that the non-disabled community has about people with intellectual disabilities. It is fundamentally important that this legislation not re-institutionalize the social context for people whom it is intended to benefit by reducing them to mere needs-assessment categories and dollar figures. Instead, we are looking to Bill 77 to help build inclusive communities and to assist organizations like ours at BDACI to enable and enhance individuals' abilities to attain equal opportunity, full participation, respect and value in society.

You have the summary of our recommendations and our brief and we strongly urge the committee to address our concerns in order to create an effective piece of legislation that will assist in the social inclusion of people with intellectual disabilities. Thank you.

The Vice-Chair (Mr. Vic Dhillon): Thank you. About 30 seconds each side.

Mrs. Christine Elliott: Thank you very much for your great presentation. I'm particularly interested in the supported decision-making aspect of your presentation. You may know that we have requested some additional information regarding that—we're most interested in that—from our research officer, but if you have any information that you would like to share with us, we would be most interested in receiving it and reviewing it in the context of this.

Ms. Audrey Cole: It has been and was very much a part of the process, even here in Ontario, at the time of the repeal of the old Mental Incompetency Act and the adoption of the new Substitute Decisions Act. It has not changed; it's just that we know more about it and more people are able to practise supported decision-making. There is a lot of material available. The international materials now that have been used to make it—the United Nations—

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

Mrs. Christine Elliott: May I just ask one more question?

Mr. Michael Prue: I'd just like you to continue, because you have more to say, so just continue to say it. That's my question.

Ms. Audrey Cole: I'm sorry?

Mr. Michael Prue: You were answering a question. Please continue. You're on a roll. I only get 30 seconds. Please go.

Ms. Audrey Cole: That's enough to break my train of thought. You'd have to remind me where I was. We can provide you materials. Materials that were developed here in Ontario form the basis of the materials that the United Nations used to make their decisions, so I think we owe ourselves and we have an obligation to ourselves in Ontario to make sure that it happens here, and this is one way of starting that process, by deeming decisions under this act alternative mechanisms under the Substitute Decisions Act.

The Vice-Chair (Mr. Vic Dhillon): Thank you. Government side.

Mr. Dave Levac: Yes, thank you very much. Not to make you feel as if I didn't have the same train of thought, let's continue. I was tweaked a little bit, though, by the concern that you expressed about the power of attorney. I know that there's a recommendation in here that we've got to get that piece right, because I understand that's where a lot of challenges have taken place. Can you explain to me a little more in depth how we can avoid that pitfall?

Secondly, when you say, "fully as possible"—in terms of participating as fully as possible—who determines that, and is that part of the judge part when you get into a power of attorney piece?

Ms. Audrey Cole: It's hard to actually answer your question in clear points. The problem with powers of attorney is that people can be persuaded to give a power of attorney when, in fact, they would possibly not meet a capacity assessment, but they can be persuaded to give, in all good faith, a power of attorney. But it is, in effect, giving away one's own authority. I think anyone who does that has to understand that that's what they're doing, and that's the problem.

The Vice-Chair (Mr. Vic Dhillon): That was a long 30 seconds. Thank you very much. I apprediate you coming out.

Ms. Audrey Cole: We're done? Thank you.

PARENTS REACHING OUT, DUNDAS COUNTY AND AREA

The Vice-Chair (Mr. Vic Dhillon): Next we have the Parents Reaching Out for Dundas county and area.

Ms. Terry Boyd: Good morning. My name is Terry Boyd. I am the co-chair for the parent support group called Parents Reaching Out. Our short term for it is PRO. We are in Dundas county and we always have families from all over the district, even Ottawa-Carleton, coming to some of our events.

I'm also a parent of an almost 21-year-old daughter with a severe neurological disorder called Rett syndrome. She has been receiving supports from MCSS for over 18 years of her life. I am not sure where my family or my daughter would be today if it hadn't been for the supports we've received from this government.

I would like to thank you for the opportunity to speak to Bill 77. A little background about our support group and the need for support groups across Ontario: We were established to provide support, encouragement and information to families with children with special needs in Dundas county and area. Meetings, information sessions and workshops have been held to provide families with informative information. Families from all over the region, as I have said, have come to our meetings and to our events.

At meetings or private meetings when families come together, we share our concerns, challenges and successes. Very often, we have families come to our meetings with one point of issue that they're in at the moment in crisis with their children. By just sitting around the table talking, discussing, and sharing some of our own successes that other families have had, we've been able to reach out, support these families, come to conclusions and, in the end, resolve their situation. This is done without one dollar from the government. This is the power of a parent support group. We believe that by reaching out together as parents, we can make a difference in the lives of our children and others.

I would like to remind the standing committee—as I've been sitting in the background watching today, I know almost all of the families and parents who have spoken—that we aren't your average parents, if I can say that, across Ontario. Most of us sit on regional and provincial committees for our children's disabilities. Many of us sit on the system planning forum committee. Even in this region, some of us sit on the provincial committee for the MCSS, we sit on the Passport initiative committee, and so much more. We're not the parent who couldn't come here today.

This type of a forum is very intimidating, even for those of us who sit on like committees. The average parent today is at home caring for their child and could not come because they don't have supports, so they can't even leave the house if they want to. The average parent today could be the single parent who has to work today because they're the only income in the household for their children. The average parent today is the one that's disconnected and doesn't even have any services, doesn't know where to look, where to go, doesn't even know about Bill 77, and doesn't know the impact in the decision that you people will make for their future. These are the average parents in Ontario. I believe that throughout this process and when you people deliberate over Bill 77, this has to be remembered—who we're really representing—and remember those of us who work very hard to assist all of you through our time of volunteering.

Bill 77 is very complex. There are many areas to address. I will address only a bit of the portion of the written paper that I presented to you today, due to time restraints. The issues that I would like to focus on are person-directed planning; application centres; mobile satellite offices; waiting lists; the appeal process; and a mandatory agreement between all three ministries: MCSS, Ministry of Health and Ministry of Education.

Our recommendations for person-centred planning are that person-centred planning be included in Bill 77; MCSS funds person-centred planning for families; person-centred planning is completed before the assessment is done. This has been stated before very clearly.

Planning facilitators must be independent from all agencies and application centres, and be non-affiliated whatsoever. This will allow for true planning to begin without anyone wanting to have services provided in one area more than another. Facilitators must provide continued support afterwards to ensure the success of all the choices and the plan that is put into place.

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Our reason for this is because, for many families and individuals, they have never had the opportunity to even think about developing a person-centred plan for their loved one or to have their loved one involved. Many of them have never been able to dream, to have a vision or to make the best possible choice for the better quality of life within the community for their loved one.

In the past, their child has had to fit into existing services and programs. Any family who dared to challenge the system and request direct funding before Passport even came about was considered radical and unrealistic. Families and individuals must be given the opportunity to go through the process of developing a person-centred plan, and only then can they truly envision the rights that are necessary.

Some families are going to need more guidance, and that may be because of intimidation or a lack of experience, education or literacy skills. A non-affiliated planner is, again, necessary so there is a non-biased opinion. If MCSS really wants to make a change, they have to give those involved the information necessary, allow independent planning to take place and provide the continual support by the independent planners so as to ensure the success of the choices that the family and individual have made.

Our recommendations regarding application centres are that application centres be responsible for the procedures of determining eligibility, the assessment, monitoring and administering direct funding to or for the benefit of persons with developmental disabilities; that the collaborative access process with the composition of all stakeholders, including parents, be responsible for the functions of determining the methods of prioritizing persons for whom a service profile has been developed; that necessary transportation funding is included in the budget; and that mandatory education is necessary for all appointed regional staff of all supports and services.

Our reasoning is that families become fearful and hesitant when the same agency they are filling out the assessment tool with will also be responsible for prioritization and the allocation process. Families will not share all that is needed in order to have a true assessment take place. Families will not view the centre and the staff as trusted partners within their child's team.

All too often in the rural regions, we experience the fact that because the office isn't in our area, when we call, they don't even know where Dundas county is, even though they're serving the area. They don't know what agencies provide support. We are left with unanswered questions.

We need staff to come to us in the rural areas. They need to come into our homes, and often this is an issue because families work, and it can't be from 9 to 4. They may have to come in the evening. They may have to work on Saturdays. This is very important so that you can get to all the families across Ontario.

Our recommendation is for a mobile satellite office, which I would like to say is probably their car, where they will be travelling most of the time. Staff needs to travel, as I said, to families' homes; varied working hours, as stated. Necessary transportation funds are needed in the budget, and there has to be mandatory education of the supports and services within the appointed region for all the staff.

There are many rural families that cannot travel a great distance, even into Ottawa if you live in Dundas county. It could be because you don't have a car. It could be because the only car you have is going to work and you're at home with your child with a disability. It could also be that if you wanted to go in, your job will not allow time off with pay, so therefore you have to make a choice, and an income has to be number one for your family. Therefore, there has to be established flexible hours.

If this is done, it will demonstrate that MCSS is willing to accommodate and meet the needs of all families and their loved ones across Ontario. The allocation of funding for staff transportation may seem something that should be done and has been done—well, it hasn't.

With the Passport initiative program, there was not adequate funding given to this region. Therefore, quick, one-stop shopping had to happen with families, and they had to make quick decisions. This left the families frustrated, upset and wondering if they made the right decision in that 15-minute meeting with the agency providing Passport funding. Therefore, we have already seen that when funding for transportation is not included, then there isn't the liberty even of having to have a second visit with the family to make sure that the right decision was made and the funds were used most appropriately for the person with a developmental disability.

Our recommendation for waiting lists is that waiting lists be removed from the draft form of Bill 77. Our reasoning is that there is a concern that including the identified waiting lists within the legislation acknowledges that there will be continually inadequate funds available to address the needs of individuals with a developmental disability, once there has been planning set forth. The focus should be shifted to address the issue of lack of funding of supports and services, rather than to concede the establishment of waiting lists.

Our recommendation for the appeal process is that the application centres and collaborative access process should have no involvement in the appeal process; it has to be third party. This is so that families can feel that they're getting a fair and equitable appeal process, non-biased and non-complicated. It is a huge decision to decide to appeal, something the government has said, and therefore we need to know that we can do this safely and knowing that it will all be fair.

A part that I would like to discuss very quickly is an agreement between the Ministry of Education, MCSS and the Ministry of Health. It is because when children are in a school system, usually these three ministries are involved in some way in school and at home. When a child is transitioning from the school setting to home once more, there needs to be some sort of transition plan, and at this time it is not happening in any way across this province. Therefore, there has to be some sort of agreement between these three ministries. This would be the first step of person-centred planning: the transition plan from high school out into the adult world. If we had this, it would make an incredible difference in the way the adult sector would be prepared for our children.

In conclusion, Bill 77 is the foundation for the future of supports that will be available to our adult children with a developmental disability. Bill 77 will not only have an impact on our children's lives, but on our lives as parents and our entire family. Having a child with special needs affects the entire family unit. If mom and dad are in crisis caring for a child with special needs, the entire family is in crisis, and believe me, this is true; it has happened to my own family quite a few times.

Today, across Ontario, there are families in crisis. I would like to share one situation that's very close to my heart. This could have been my own story two years ago. We have a mom who has her master's degree. They have a daughter who's 22 with Rett syndrome. Their older children have left home and are on to their own jobs and their own life plans. Mom cannot seek employment because she's at home full-time with her daughter.

Her daughter has graduated high school. Their daughter was fully included in the high school setting, even with her high needs. She was continually challenged in school; she had proper supports in place; she was developing new skills; she felt self-worth; she had self-esteem. Mom, today, is at home 24/7, caring for every need for her daughter. Therapy has to be done every day, or her daughter will regress. They have to keep up all of her skills. She has to take care of all of her personal care needs. She has to take care of all of her medical needs. There is no help coming into this house.

Dad has to work seven days a week because mom can't, so dad cannot be much support to mom. This family is in crisis. They've applied for funding. They've been told they are going to be on a waiting list; they're told it will be over a year. They are informed, very educated, very smart, very put-together parents, and they are in crisis. They feel extremely alone. They feel that this government has abandoned them, that their daughter and their family have no value in this government's eyes, and they feel that they are victims of this system today.

There are many more families across the province and in our own region who are in the same situation. Please remember these families as you move forward after this day. Take a moment, if you can, and try to think of yourself: What would I want for my own child if they had a developmental disability? What would I want for my grandchild? What would you want in place? What processes do you want in place, so that you're able to address issues when they come forward?

In the end, we are going to live with the end results—we, the parents, and our children, and our other children. We know the importance of the legislation, Bill 77, and how it will affect our families—

The Vice-Chair (Mr. Vic Dhillon): Could you just wrap up? You have 10 seconds left.

Ms. Terry Boyd: Thank you very much for the opportunity.

The Vice-Chair (Mr. Vic Dhillon): Thank you. There will be no time for questions.

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ONTARIO AGENCIES SUPPORTING INDIVIDUALS WITH SPECIAL NEEDS

The Vice-Chair (Mr. Vic Dhillon): Next is OASIS Ottawa.

The Acting Chair (Mr. Dave Levac): Thank you very much for being here. For the record, please name yourselves and the organization you represent. You have 15 minutes. Within the 15 minutes, if there's time left over, we'll have questions and answers at the very end. You may begin.

Mr. George Braithwaite: My name is George Braithwaite. I'm a former president of OASIS. OASIS is a provincial organization whose mission is to facilitate the sharing of ideas, resources, systems and information. OASIS will liaise with government on behalf of member organizations with the goal of improving the development of cost-effective, quality supports for individuals with developmental disabilities.

I am joined this morning by Jocelyne Paul, on my right, the executive director of Ottawa-Carleton Lifeskills, and Bonnie Dinning, on my left, a serving member on the OASIS board of directors. Both Bonnie and I are parents of adult sons with an intellectual disability.

We are supportive of the decision to create this legislation and are particularly encouraged by the removal of any reference to the institutional structure.

Our overall reaction to the proposed legislation is positive, and specifically, we note the following attributes:

It contains common eligibility standards that will be applied consistently across the province;

It contains the clear intention to utilize a common assessment tool;

The bill brings fairness and consistency in the assessment of eligibility for service and a predictable rationale for the level of service to be provided. This means that people with similar needs can expect similar levels of service and support. The bill contains language which connects the assessed needs of the individual with a funding mechanism yet to be developed.

It is also important to note that the bill contains language which appears to acknowledge that resources are expected to be limited and are unlikely to meet the forecasted demand.

It's beneficial that the bill will require the establishment of systematic waiting lists across Ontario using common criteria. That will permit the following:

—the compilation of credible data which indicates the unmet demand for service across the province;

—the accurate calculation of the fiscal implications of that unmet demand. It will enable greater transparency in matching available resources with a standardized policy for, if I may say, rationing those resources, or, in other words, setting priorities;

—the Ministry of Community and Social Services to have greatly improved ability to forecast its budgetary requirements from these improvements in data collection and consequent to other provisions in this bill, which should enable the ministry to demonstrate value for money.

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

On the topic of development of regulations and policy directives, we have been very appreciative of the inclusive consultation that has occurred around the development of the transformation paper and that associated activity. We know that all provincial organizations are committed to working as partners with the ministry in developing the next phases of this process, including the regulations, policy directives and policy guidelines. What follows is expected to be an evolutionary experience and one which will give substance to transformation.

We believe the ministry would be well served in considering a greatly expanded use of modern media to advise stakeholders of impending regulatory and policy change. One quite successful approach is the one used by the Ministry of the Environment when they posted information for feedback for a specified time period on the Internet. The Environmental Bill of Rights, or EBR, as it is more popularly known, is one such model. Stakeholders at all levels within this sector should be more fully involved, and at an earlier stage than is possible at present.

Ms. Bonnie Dinning: Good morning. My name is Bonnie Dinning. I wish to speak to you on three topics: partnerships between ministries and with other government organizations, role and governance of agencies, and liabilities.

In regard to partnerships, the divided responsibility between ministries based on age and self-care capacity segments services for children, youth, adults and seniors with developmental disabilities and other complex needs. The current approach requires people to enter a new system, with new assessments and new plans, at every transition point. What is lost in this approach is the great value of proactive transitional planning that can and should happen to ensure that those with a developmental disability experience seamless transitioning throughout their life stages.

In regard to the role and governance of agencies, of particular concern to us are issues related to the role and governance of the agencies, as outlined in sections 22 to 25 and sections 30 and 31. These allow for board composition requirements and service agency takeovers.

The current draft of the legislation does not seem to recognize the significant role and benefit of volunteers to this sector and the broader scope of work undertaken by service agencies outside the parameters of the ministry contract. The history and foundation of the developmental services sector is local community and volunteer support.

Service agencies have developed in response to local need over time, often providing much more than that designated in ministry funding contracts noted in section 23. Contractual arrangements and liaisons with a wide range of community partners, often fostered by volunteers to address unique needs in the community, are the mainstay of their business. Agencies rely on volunteers for many things, including a willingness to take on the responsibility of boards of directors. Out of necessity, the makeup of such boards reflects the unique needs and resources of the community that particular agency serves. Too prescribed a formula for board composition imposed under section 22 could be detrimental to the efforts of local communities in meeting the needs of disabled citizens. A more appropriate focus within the legislation could be the role of a board of directors and guidelines for board composition to undertake such a role.

In sections 30 and 31, the powers to assign a manager to take over the affairs of the service agency are of particular concern because agencies can hold a wide range of contracts with a variety of stakeholders other than the ministry. Beyond the legal implications of such a situation for the ministry, the possible liabilities for volunteer directors outlined in the legislation will do much to lessen the enthusiasm of individuals considering such a role. It is also unclear why the focus of takeovers is service agencies in isolation of the proposed application centres.

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

1130

As a volunteer director of an Ottawa service agency and as a parent of a developmentally disabled son, I am very concerned about the issue of liability. Will I be putting the financial security of my son at risk if I continue in this role? What implications does this have for a sector that, as a whole, depends on volunteer involvement? Regardless of what directly funded plans families put in place, the majority will ultimately require the assistance of agencies when they are no longer able to manage those plans. This legislation needs to ensure strong service agencies are the backbone of a developmental services system.

Ms. Jocelyne Paul: Good morning. My name is Jocelyne Paul and I have four issues I'd like to highlight.

The relationships between various service providers and the need for common standards: The legislation is not entirely clear regarding the relationships between the various components of the systems, such as special services at home or between the service agencies, the application centres or third party brokers. We have heard what others have said regarding the application centres. We agree that it should be a process, a series of activities, rather than a specific centre or location.

The legislation appears to apply different standards and a higher level of accountability for service agencies versus other types of services or service providers. It also appears that there are different mechanisms that would apply. This is of great concern in the Ottawa area where there are a number of service agencies as well as for-profit agencies. We are supportive of the existence of clear standards for quality of care and believe that the same set of standards should be used for everyone who is providing services. This will only benefit the people we support, ensuring their—

The Acting Chair (Mr. Dave Levac): Three minutes.

Ms. Jocelyne Paul: —care, welfare, safety and security.

The second area I would like to speak to is funding. We are supportive of the expanded definition of eligibility, but we have three major concerns. There will be additional demands placed on the system and waiting lists will grow. Ongoing additional funding will be required to provide these services. Another concern is that funding will be diverted from direct services to cover the administrative costs, and the legislation is not clear about the provisions for people who are currently receiving services. Individuals will be grandparented for services, but it does not necessarily speak to their access, priority or level of service. Families within the current facility closures have been guaranteed by the government that their loved ones would continue to be served.

Regardless, at the heart of the matter, this legislation is about the people we support and the quality of services that they're able to access; it is critical. Within this framework or any other framework within the legislation, it is dependent upon government providing enhanced funding on an ongoing basis to provide the support that is required.

Another topic is legal capacity, which I will leave you to read within the brief.

The last topic I would like to speak to is the essential services. In the summer of 2007, there were several labour disputes in southern Ontario. In 1996, this occurred in Ottawa with a number of service agencies. Homes were picketed, relationships were damaged, trusts were broken and neighbourhoods were disrupted. This was a very difficult time for both the people we support as well as the staff involved. Given the nature and vulnerability of many of the people we support, we believe that this would be a great opportunity to state that this is a no-strike sector with provisions noted in the legislation on alternative methods to deal with labour disputes.

Mr. George Braithwaite: My final topic is reviews and appeals. The act includes some internal notification of review processes which really involve—

The Vice-Chair (Mr. Vic Dhillon): If you can just wrap up, sir.

Mr. George Braithwaite: —self-judgment, whereby the organization making the original decision is also hearing the appeal. I know that the regulatory process will iron out some of that impression and perhaps remove it completely, but at the moment, that's the impression one is left with.

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

Mr. George Braithwaite: I have one other point, if I may.

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

Mr. George Braithwaite: In other cases, appeals may have to go the judicial route, which can be very lengthy, costly and virtually inaccessible. The provision of a third party appeal mechanism for the various stages of decision-making that may occur within the system would be more equitable, transparent and fair and, if I may close on the note, remove any perception of bias—perception often having taken on the appearance of truth rather than suggestion.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We've got a full day, so we want to try to stay on track.

LIVEWORKPLAY INC.

The Vice-Chair (Mr. Vic Dhillon): LiveWorkPlay Inc.—welcome to the committee. Please state your name before you begin.

Ms. Jennifer Harris: My name is Jennifer Harris. I am a volunteer and self-advocacy spokesperson, and I would like to introduce the LiveWorkPlay co-founders, Julie Kingstone to my left, and Keenan Wellar to my right. Thank you very much.

I would like to thank the standing committee for this opportunity. My name is Jennifer Harris. I am, among other things, a person with an intellectual disability, living and working here in the Ottawa community. I have also been involved with the LiveWorkPlay charitable organization for the past decade, which is most of my adult life. I continue to receive support from the organization in my daily life, but in recent years I have also been contributing to LiveWorkPlay as a volunteer and self-advocacy spokesperson, and as a voting member of the corporation. If you had told me 10 years ago that I would be making the type of presentation that I am making right now, I would never have believed it. I have with me here the organization's co-founders, Julie Kingstone and Keenan Wellar. They helped me prepare this presentation and, should I require it, they will be assisting me.

I would like to start by explaining that just as I've been evolving as a person, so too has the LiveWorkPlay organization been growing and changing. The first thing to understand about LiveWorkPlay is that, although we are a non-profit and registered charitable organization serving 60 people with intellectual disabilities and their families, we are not a transfer payment agency. We receive no direct funding from the Ministry of Community and Social Services.

Secondly, our supports are provided to individuals as young as 13 years of age. We get to know teens and their families as they make their way through high school, and work with them to have a comfortable and successful transition to adult life.

Third, our mission is self-advocacy and contributing citizenship. We are all about helping people take greater control over their own lives, and we work with both individuals and the community around us to build a more inclusive society.

I think these basic facts about the LiveWorkPlay organization are important because although we've had a lot of challenges—mainly, we've had to do a lot of fundraising—we have also had a lot of freedom to pursue what we know is right for individuals and their families.

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I should also mention that as of May 2008, LiveWorkPlay became an affiliate of Community Living Ontario. We are very new to that federation, but I was very impressed with the background information they provided to us about Bill 77, and that has shaped some of our comments to you today.

Next, I would like to quickly take you back to 1997. I had recently finished my time in high school. High school was a very difficult experience with some particularly painful memories, such as being excluded from learning and activities that were deemed inappropriate for me because of my disability.

After high school, I found myself even more isolated, living in my family home with few social or community connections, and an uncertain future. This is a very familiar experience for people with intellectual disabilities and their families that is sometimes described as the post-21 issue. In essence, it means we are largely abandoned by society, without opportunities for post-secondary education, and with few opportunities to live as contributing citizens.

Through happenstance I ended up at LiveWorkPlay in 1998, when the organization was getting off the ground in a big way. In the past I had been involved with organizations in the developmental services system. They had different sorts of programs that I tried that didn't work for me. This was something different.

The approach from the beginning was to get to know me as a whole person, to help me develop my own hopes and dreams, and to support me to pursue them. Instead of offering me a program, they asked me what I wanted to do out of life and said they would help me achieve it. That is, in essence, what all supports and services for people with intellectual disabilities should do. This was a lot harder than it sounds, because my self-esteem and self-confidence were extremely low, and I was very resistant to making even basic decisions on my own life. To be honest, I really didn't like it very much. The staff and volunteers kept refusing to tell me what to do.

Through LiveWorkPlay and learning about the self-advocacy movement, I came to understand that I had both the right and the responsibility to take greater control of my own life. This meant taking risks, such as participating in pilot projects related to employment and housing, through which I sometimes made progress, only to fall back later. But I kept going.

I also tried some different workplaces that didn't go well for me, and it was painful. I often thought of giving up. But I eventually got to the right place; for now, anyway. Along with several of my peers I am currently appearing as an actor in a public service announcement that is airing regularly on A-Channel television. I hope you get a chance to see it on TV, but if you don't, please visit www.liveworkplay.ca and check it out.

I'm still getting used to my new responsibilities as a self-advocate and contributing citizen, but I keep pushing forward. One of the biggest changes in my life was moving out of my family home. Thanks to my experience in housing projects and other LiveWorkPlay initiatives, my family and I decided that I would live in a real home of my own, not in an institution. I have had to push myself many times to overcome barriers to my new life in my own condo apartment, but everyone goes through this stress of making their way in the world. We should not deny people with intellectual disabilities this experience. It is better for the individual, for the family, for provincial taxpayers and for local communities to support people with intellectual disabilities to take greater control of their own lives and live with greater independence.

I won't pretend to understand all of Bill 77. I do understand that the developmental services system is very complicated. At LiveWorkPlay, we also believe it is possible to establish simple and powerful goals for this legislation.

There are some basic positions that LiveWorkPlay would like to see emphasized in Bill 77. I understand that our largest institutions are closing, but at LiveWorkPlay we believe that the government of Ontario should consider that as a starting point. The closing of major institutions is important, but your work is not done.

Having an intellectual disability is not a criminal offence, so why should many of us be forced into shared living arrangements with strangers and have others decide what and when we'll eat, how we'll express our sexuality, what drugs we'll take, or how we'll spend our day?

Housing choices for people with intellectual disabilities should be the same as they are for most everyone else: to live in an apartment or a house that we rent or buy. If we need support, we will invite that support into our home. We will decide. Yes, we'll need help to organize and pay for the supports we need, but we can be and should be in charge of determining what those supports will be and who will provide them.

The province is currently directing enormous sums of money to institutional forms of housing, with little or no funds of any kind available to support people with intellectual disabilities to live in real homes of their own. Bill 77 should support the development of innovative non-institutional housing solutions, in addition to individualized funding for related support costs.

We must find ways to give all people with intellectual disabilities the daily living supports they need without denying the basic personal freedoms that others in our society take for granted. Bill 77 should clearly establish life in a real home as a goal to be supported for all people with intellectual disabilities.

Now, we are not suggesting that this is going to be easy. I told you my own story of how hard it was to learn to make my own choices and decisions, and the help that I received from LiveWorkPlay, my family and my support network. This brings me to our second issue of concern: decision-making and individualized funding. I love my parents and they are a valued resource, but I am fortunate in that they are not my only means of decision-making support, and that is critical. It is important right now for my own personal growth, and it is also important for the future, so that the passing of my parents will not render me helpless.

Bill 77 must recognize that people with intellectual disabilities are going to need help with the responsibilities inherent in an individualized funding model. This help must not be about deciding for us; it must be about presenting information in a way that works so we can make our own informed decisions. This is really no different from a non-disabled person getting help from a lawyer or financial adviser. But when it comes to people with intellectual disabilities, decisions are far too often made on our behalf. This is one of the main reasons why we are known as a vulnerable population and why we are in fact victimized at rates that dramatically exceed the experience of the average citizen.

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People with intellectual disabilities are trained to be vulnerable by a developmental services system that teaches us to constantly submit to the authority of others. Far too often, we are denied the lead role in scripting our own lives, and that must change.

We strongly encourage the standing committee to recognize the need for this change and take steps to ensure that there is respect for the rights of people with intellectual disabilities as capable decision-makers and adequate planning and resources allocated to supported decision-making. To make this possible, Bill 77 must clearly state the right of self-determination for people with intellectual disabilities.

The Acting Chair (Mr. Vic Dhillon): Jennifer, if you want to just wrap up.

Ms. Jennifer Harris: We recommend that such a statement has a place in the first lines of the preamble of the new legislation.

People with intellectual disabilities have the right and responsibility to live as fully included members of their communities, their province and their country.

Thank you for your time. That concludes our presentation.

The Acting Chair (Mr. Vic Dhillon): Thank you very much. Great job.

PLAINFIELD COMMUNITY HOMES

The Acting Chair (Mr. Vic Dhillon): The last presenter for this morning is Plainfield Community Homes.

Mr. John Klassen: My name is John Klassen. I'm the executive director of Plainfield Community Homes. I'm here on behalf of the board of governors of Plainfield Community Homes. I'm also here as a parent; I wear a parent hat, and that hat doesn't come off any time of any day.

Thank you for receiving this response to Bill 77.

We recognize that the introduction of this proposed new legislation, following a lengthy period of consultation, is long overdue and will replace the Developmental Services Act. We are hopeful that the new legislation, once passed, will provide the legislative framework for improving services and supports for people who have a developmental disability and their families.

As described in the explanatory note introducing the proposed legislation, "The residential facilities operated by the ministry under the old act are not continued under the new act and will be closed after the old act is repealed."

Furthermore, the proposed legislation recognizes that people want more choice and control over their lives. Accordingly, "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."

I note also, and particularly as a parent, that direct funding now becomes an option for people with intellectual disabilities and families, and I think this is a very progressive and very necessary new step.

As well, the portability of that funding: Regardless of where you live in this province, there will be this understanding that funding can go with you as you move or as you need to move to another part of the province.

We applaud the government for these and other elements contained in the proposed legislation that are seen as a positive and progressive paradigm shift, offering people with developmental disabilities a more flexible system.

That said, Plainfield Community Homes does have some concerns about the bill.

The proposed legislation is to replace the dated Developmental Services Act, and as we now have the benefit of a fairly lengthy period of consultation, the legislation needs to reflect our understanding of full citizenship for all. It is our contention that the legislation can establish mechanisms that will manage resources, funding allotments, waiting lists and prioritization, among other matters, centred on a paid system of services. What the legislation cannot do is legislate the vast array of relationships and other quality-of-life elements that are essential when we consider full citizenship within communities. A preamble such as has been proposed by Community Living Ontario will go a long way to pointing to social change that many people are now enjoying and that we are all striving toward.

Application centres: Bill 77 proposes the establishment of application centres. These centres will have responsibility for a wide range of functions, including determining eligibility of a person to receive supports, administering an application process, assessing needs, setting priorities, allocating and distributing funds, making referrals to agencies, monitoring the satisfaction of a person with the outcomes that result from the supports they receive etc.

We question the need to establish these new centres that will have governance and administrative structures and be funded to carry on the work that is currently conducted by existing agencies and processes. A number of communities in Ontario have developed collaborative access mechanisms whereby agencies work cooperatively to process requests for service and fulfill those functions called for under the new application system. The counties of Hastings and Prince Edward, for instance, have developed such a model and subsequently put in place a pressures and priorities committee, as well as a case resolution mechanism that has been operating for a number of years. This low-cost, collaborative model has been very effective in responding to and addressing critical and emerging needs of many individuals and their families.

As this proposed legislation is being reviewed, we urge the government to consider the merits of a collaborative model as the preferred approach for ensuring that individuals and families have equitable and fair access to services and resources in communities. We believe there is now sufficient evidence to support the proposition that a collaborative model is superior to a stand-alone, costly new agency because the collaborative model has been built upon and continues to demonstrate the following features:

It is low-cost, with very few dollars wasted on administrative support. The member agencies willingly give their time and expertise to this collaborative model;

Individuals and families can go to any one of the member agencies and know that the agency will plan with them and present their needs before the pressures and priorities committee. The agency continues to be their contact and will represent them through the process to a satisfactory resolution;

The member agencies know the individuals and families and have a relationship with them that has developed over time. This relationship engenders trust—in some cases it hasn't, we recognize, but it can, and we know that it does in Hastings and Prince Edward—in the agency and a proactive and empathic response from the agency to a satisfactory resolution;

This collaborative access model garners the support, involvement and co-operation of each of the member agencies. The member agencies are more likely to share their resources and work together to a common good, so as to respond to individuals and families known to them. The member agencies are committed to this process, to the families and to each other;

A collaborative access model relies less on bureaucratic single-access portals—faceless portals, if you like—and more on the strengths and capacity of communities and grassroots voluntarism. Local associations and agencies are infused with the rich fabric of contributing and supportive community members and their natural connection to the array of community resources, not to mention their cultural, linguistic and associational diversity.

We believe that the introduction of application centres is retrogressive and short-sighted. It reminds us of a health model, frankly. It is certain to cost more and garner less agency co-operation in meeting the needs of people in our communities. We have a model that works and it will be a shame if we create a bureaucratic layer that will do what is already done very well.

1200

I will refer to another section called "Waiting Lists." As an associate member of Community Living Ontario, we endorse and underscore their position on this, so I won't elaborate on the points that they have made for the sake of time. Suffice to say that if this is enshrined in legislation, waiting lists are legitimized, and people need to stand in line to receive a service they may desperately need.

Assessments to determine applicants' need for services: Section 18(3) states that an application centre shall use "the method of assessment specified in a policy directive, conduct an assessment of the person's needs for services under this act; and ... apply the method of resource allocation specified in a policy directive to determine which services may be provided to the person under this act and the amount of funding available under this act for those services." While the proposed legislation is silent on the type of assessments to be conducted for determining the person's need for services, we understand that policies and regulations will require the administration of a supports intensity scale as the prescribed assessment tool that will determine the person's need for services and funding available for this service.

We have long understood that each person with a developmental disability is very unique, and over a lifetime their strengths and needs are ever-changing. Furthermore, people enjoy many relationships with friends, acquaintances, neighbours, family members and paid staff. I can, by example, refer you to my son, who is known by most of our neighbours. He has become a person who is significant to them, a person who is a neighbour and who is a friend. It is for these reasons that Plainfield Community Homes and many other organizations have adopted a person-centred planning approach. Person-centred or person-directed planning is a process of learning how a person wants to live and then describing what needs to be done to help the person move toward that life. It is our belief that a person-centred planning process, when facilitated by trained planning facilitators, will take into consideration the whole person and all of the other factors that impact on the person's life: the effects of the disability, the views of those who care about and know the person, and the opportunities as well as the limitations presented by the need for funding and for paid services. A standard assessment tool, in our belief, will not enable a deeper discovery of the person and what's important to and for the person.

It is for all of these reasons that we would recommend that the proposed legislation recognize person-centred or person-directed planning as a funded service and that it be a methodology for determining a person's support needs and funding. If government is concerned that there is currently wide variation throughout the province on determining a person's support needs, a standard province-wide approach to person-directed planning and the funding of trained planning facilitators will ensure accountability for the appropriate use of public funds, as well as the assurances that we do not look only at a system of paid supports.

One final section that we want to emphasize in our address is that, in fact, a number of the sections in the proposed legislation are still left to be further defined with the development of policy directives, guidelines and regulations. We urge government to introduce a consultative process with Community Living Ontario, OASIS, the Great Lakes Society and other members of the Provincial Network prior to their adoption.

We do have other concerns with Bill 77, such as part VII, which addresses the rights of an inspector to enter a residence without a warrant. Frankly, I personally take great umbrage with this. I think of my son and somebody having access to his room, his property and his home because an inspector decides that that will be so, and without a warrant. While we understand that the government would see this as an unlikely scenario, only used when a person's care and well-being are under question, we have long recognized that all people have full citizenship rights, and an inspection by an inspector of their private home is a fundamental violation of their citizenship rights. Community Living Ontario, OASIS and other members of the Provincial Network have articulated this point in their submissions, and we wish to underscore their concern.

Thank you for receiving my response.

The Vice-Chair (Mr. Vic Dhillon): Thank you. A minute each side; we'll begin with the government side. Mr. Levac.

Mr. Dave Levac: Thank you very much for your presentation. On that last point, there's another thought that's going through my mind. While I completely and totally agree with the citizenship component of the concerns about warrantless entry, from the perspective of warrantless entry, it already exists in many circumstances—for CAS, animal welfare—when there's a suspicion. But it's not in a personal dwelling, so I appreciate that. So the identification that you're making is specific to the dwelling, the personal dwelling place as opposed to the institutional component, and that warrantless entry is permissible with permission. If permission is granted to assist in keeping the person safe, than that would be approvable by your organization? That's an area in which a warrantless entry would be acceptable, if the person permitted them to come in, wanted them to come in?

Mr. John Klassen: We are referring to adults. That the legislation covers adults only is my understanding, adults who have full citizenship rights. We would consider where they live to be their home, so we don't see any room for a warrantless search on what we would consider a person's private property and their private home. It would be similar to having access to your home.

Mr. Dave Levac: Yes—

Mr. John Klassen: We make the contention that they receive funded support, but nonetheless, this is their home and their private domain.

The Vice-Chair (Mr. Vic Dhillon): Thank you. Ms. Jones.

Ms. Sylvia Jones: Thank you. Excellent brief. I'm really pleased that we're hearing from across the sector the concerns with the application centres and how they are currently being proposed, so I appreciate you highlighting that.

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

Mr. Michael Prue: I want to commend you for the whole thing, but let's get back to the warrant. I only have one minute. A warrant can be issued by a number of people, usually a judge or a justice of the peace, but it can be issued under some legislation by someone of senior command. Would that be sufficient? First of all, I find the whole idea almost repulsive like you do, but I can understand there may be some cause, where there is cause shown that a warrant be issued.

Mr. John Klassen: My thought would be that the intent here is right in that there may be concern about someone who is vulnerable, and there may be a thought that the paid system is not in a position to ensure their well-being. If that is the reason or the intent here for this proposed legislation, I would question very much why, or if, there are not people in that person's life who would have an interest sufficient to ensure their well-being, even in a paid system. I simply can't in my heart, in thinking of my son, justify entry into a person's private domain without a warrant, but that form of warrant may well be sufficient. I'm not sure. I couldn't speak to that.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We'll now break for lunch and convene back in this room at 12:45 p.m.

The committee recessed from 1208 to 1247.

LINDA KINSELLA

The Vice-Chair (Mr. Vic Dhillon): Good afternoon. We're going to resume hearings on Bill 77. Our first presenter is Ms. Linda Kinsella. Good afternoon, Ms. Kinsella.

Ms. Linda Kinsella: Good afternoon.

The Vice-Chair (Mr. Vic Dhillon): You may begin.

Ms. Linda Kinsella: Good afternoon, members. Thank you for the opportunity to speak. I decided to speak because of my experience. Ever since I've been a teenager, I've worked with people with disabilities. For four years, I worked for a non-profit organization in a group home for developmentally disabled adults. I'd like to speak, coming from this experience.

I worked for an organization that had very high standards. The care of the people in its care was very high, yet there were still problems. I think the changes being made in the act are good, but I'm concerned maybe about the regulations. How do I put this? What I'm concerned about is that some group homes in particular don't have the high standards. I'm worried about the oversight.

I work for an organization—and I will name it; it's called Christian Horizons—which most of you, I'm sure, are familiar with. They ensure that their people are well taken care of and that the homes are maintained. But in my work since my early twenties, for the last 15 or 16 years, I've worked as an advocate for people with disabilities and have written policy on issues dealing with disabilities. In this work, I've seen homes that are not properly maintained, clients who are not well-treated, and have heard stories of people being abused and, in fact, dying in group homes.

While in this act there is the authority for inspection and regulation, I really want to say that I hope it's strong, that I hope the money to have the inspectors and have the people actually go into the homes and watch what's going on is there, because while many of the organizations that run these homes do a very good job, there are some unscrupulous organizations out there that are mainly doing it for profit and not really ensuring that their people are being taken care of properly.

These people don't have a voice in the same way. Because of their disability, they have a hard time advocating for themselves often. As you saw earlier, some do, but in most of the cases they don't. This is a concern that I have.

Another concern that I have is that while I really like the idea of host family residences where a family can take somebody in and get remunerated—I think that's a really good idea. But one of my concerns is: What oversight is there to make sure that these people are qualified, that they have the skills and background to take care and that they know what they're getting into? I would like to see something that says there's going to be training or some follow-up to make sure the people in these homes are being properly taken care of. While I think the host family idea is a very good idea—it's important to have people with disabilities in the community and in family settings—I have seen and I can see it happening in the future: people seeing it as a way of making money and not really caring about how the people are being taken care of.

As I'm repeating, my concern is that the level of care is low, that there's oversight to make sure that these people who don't have a voice or have less of a voice in our societies than they should are being taken care of. I lived in a small community called Port Hope and I've also done some work in places like Bancroft and those kinds of areas where there's not the staff—it's not like a city where there's lots of people to make sure that everything's being done. Sometimes these people are living in homes that are in the woods or off the beaten track, and there's not oversight.

This is something that would have to be done through regulation. I worked in the group homes in the late eighties and early nineties where there was a lot of oversight. But, as political and economic changes happened in the province, the money for the inspectors and for oversight was taken away, and there were problems. I'm concerned that while these changes that are being made in the act are good and that there is the provision for the oversight, that there is the follow-through and that assurance that people with disabilities are being protected.

So while I see it's in the act—and having read it—that the minister has all the powers to inspect and review these things, I'd like to make sure that it happens. I don't like watching W5 and seeing the stories of children and adults in group homes dying. Along that vein, myself and friends who have worked for good organizations often hear of the things going on in other organizations or have worked for them, and I would like to see some sort of mechanism for whistle-blowers, that if people have worked in these homes and know that things are going on—means for them to report it. I know of someone who was working in a home where the conditions were not what they should be, and she felt like there was nowhere to report it, and when she did try to report it, she was hushed up and told, "Oh, we don't talk about that." I'm concerned that there be a way for a reporting mechanism.

Around the area of funding and direct funding, I see that in the act there is the idea of direct funding, and that's good, and remuneration for host families. I'm going to say something that may sound like a radical idea, but what about paying the families—why is it just host families? If a person with a developmental disability is being taken care of by a family member—and I know this is something in society that we don't think that families should be paid for taking care of, but it's the same as the idea that a mother, a woman staying home with her children, should get some money. Similarly, if you're taking care of an adult child with a developmental disability in your home, you should be able to get some remuneration. It does cost extra money. And yes, I realize that we do it out of love and that people—I have a cousin who is being taken care of at home by her brother. He does not get any remuneration.

Oftentimes it may be that there are resources, but why don't we give family members the actual remuneration? It's there for host families, there's money for group homes, but there's nothing for the actual parents to get some extra money there, other than the dependant's ODSP. So I would like to see that maybe we add something. Yes, I realize that it's a radical idea, but why not? Why aren't we giving some of that extra money to help families?

Families often give their children up to group homes or other situations because they don't feel they can afford to keep them in the home, or that they have the skills. I'd like to see both money being given to families to help them keep them in the family setting as well as more training.

I'm going to go back to the group home issue. While I worked for a very good organization, I was an 18-year-old who happened to know the director through church, given a job because I'd done a lot of work in the daycare, but I had no training. I did get training by the organization afterwards, but I think it would be good—I hate saying, "Just have education," but some sort of training—that there should be some expectation that the people who are working with these people with developmental disabilities are being given the training and have the skills that they really need, because that's a concern. I've seen some people who are good when they don't have training, but some people aren't able to do the work.

I looked at the definition that is in the act—this is the last issue that I will speak to. The definition is that the person must have this disability prior to age 18. In both working in the group home and through family, I know of cases where, for various reasons, they've developed developmental disabilities after age 18, either through accidents or trauma. My concern with it not being covered under this act is: Where is it being covered? Are these people being forced into long-term-care facilities at age 25, as I have seen happen, because they are not able to get in group homes? I would like to see that definition changed so that it covers not just people who have the developmental disability prior to age 18.

Those are all my comments. Thank you.

1300

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We'll start with the PC side; about a minute each.

Ms. Sylvia Jones: Thank you, Ms. Kinsella. You've raised some interesting points and it's not so radical. There are examples in Europe where families are paid to—

Ms. Linda Kinsella: There are a lot of things that are done in Europe that are considered radical.

Ms. Sylvia Jones: Point taken. I think what I'm hearing from you is that you see the need for consistency from the family, the individuals and the service providers.

Ms. Linda Kinsella: Yes.

Ms. Sylvia Jones: You want to see that consistency across the board. I don't think there's anybody who would argue with the validity of that point. Thank you very much.

Ms. Linda Kinsella: Except that it's not happening now.

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

Mr. Michael Prue: The point that you made about training, I think, is particularly germane. Many of the deputants who have been speaking to us are worried that if we go into a choice system, where you can pay for your own care versus relying on the service sector, the level of care, when you pay for it, may not be as great, that the people may not have the same training. You've given your own experiences. Is that your experience, that people who get into this sector often have little or no training?

Ms. Linda Kinsella: Yes, and I've seen both. Often, people get into it because they've been teachers or they've worked in other similar fields, and they don't know what they're getting into. Some of them are very good, but some are not. I think of somebody I know quite well, who would be considered a host family and was taking care of somebody. She was a teacher and worked with people, but I would probably say that is an exception. Even myself—I was 18 years old—I was overwhelmed. If I even had a week or a couple of weekends where I was more exposed to what was going to be expected of me, it would have been better.

I hesitate to say that you need to have a DSW or you have to have a specific education level, but just some requirement of a certain level of training.

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

Mr. Khalil Ramal: Thank you very much for your presentation. Definitely, you brought a different perspective and, as Ms. Jones and many other people mentioned before, it's about family members receiving some support while they look after their loved ones.

You brought up the very important issue of abuse in many different organizations and homes. I did the same job that you're doing right now. I worked with organizations and institutions, and also group homes, and sometimes, in a group home, you work alone. There is nobody with you and nobody's monitoring you. You can do whatever you want. So we think, as we propose in this bill, inspection without notice or warrant is very important in order to protect the vulnerable people among us.

What do you have to say to the many organizations that came—you probably heard them this morning. They consider inspection without notice an invasion of privacy. What do you think?

Ms. Linda Kinsella: Actually, I hadn't thought of that, but it is a valid point. I'll go back to my own experience. A lot of the time, I worked alone, if I was night staff. I worked 11 a.m. till 7 p.m. To be honest, I understand the issue of invasion of privacy, but it might have been good if someone had knocked on my door and said that I had to—as long as there's some evidence of who they were and that, because especially at nighttime, that's the time when abuse can happen. I'm not expecting that it's likely to happen because most people don't work those hours.

The Vice-Chair (Mr. Vic Dhillon): Thank you, Ms. Kinsella. Time's up.

Ms. Linda Kinsella: Oh, I was answering his question.

The Vice-Chair (Mr. Vic Dhillon): We're on a tight schedule and I must move on.

Ms. Linda Kinsella: Thank you.

The Vice-Chair (Mr. Vic Dhillon): You can make a written submission as well, by August 12 at 5 p.m., if you have anything further to add.

DIANE ROCHON

The Vice-Chair (Mr. Vic Dhillon): Next, Diane Rochon. Good afternoon. You have 15 minutes.

Ms. Diane Rochon: Good afternoon. Thank you for having me here. I'm a person with a disability. I've been on disability for many years, since, I think, after my divorce, because I couldn't work at the time and I ran out of money.

About Bill 77, I'm just wondering if people like me who are self-sufficient—I have an apartment, a doctor and a schedule of things I do for my health, and I don't see myself in that bill at all, and that worries me. I have a blank right now; I'm just nervous, I guess.

I try really hard to get better and it's very hard when the system is not behind you. It's a system right now where you are discouraged to do anything to improve yourself. You're not allowed to do anything. I go to the pool. I'd like to have the gym. My doctor and I will discuss all that, and instead of having to give me more pills it's best for me to do exercise. We separate the brain and the body, but they work together. We cannot separate them. If I am not well mentally, I'm going to go down physically as well. So I do the pool with some subvention from the city, but I cannot have the gym, and good nutrition is as important, because I don't have enough money right now. I'm just struggling because I'm at the point where the pool is not enough for me. There was a time where just doing the pool was really hard, but now I've reached the point where I need to do more physical activity. I started to work in a gallery to make hats; I'm an artist. I just need more money to—I don't care the way it's being done. It doesn't necessarily have to be the money; it could be credit or something that allows me to go to the gym. I have to buy the bathing suit, the shoes and all that stuff that goes with it, and I can't right now. I want to be part of society, and having to struggle through a system that closes the door when you suffer depression is not good. I just get down and down because every time I try something, the door gets closed on me. I could say a lot, but right now I'm too stressed. I'm sorry.

This issue about people like me trying to do it on their own—there are good organizations. I have a good doctor, I had a good psychiatrist, and they were helping me because they put the effort on me. They believed in me and that's what I need from the system. I need a system that believes in people, that believes in me, that says, "Okay, you're going to do it; we're going to help you. We're going to give you this if that's what you need to get better."

I'm not talking about tobacco. I'm not talking about drugs. I don't take those things. I don't want money to go and do a party; I want the money to do the right thing for my health. That's it.

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

Mr. Michael Prue: When you walked in the door I asked you—you said that you had been to see your own MPP, Madeleine Meilleur. Was she able to provide any assistance or help for you?

Ms. Diane Rochon: Actually, she told me about this meeting here and she told me to write a letter, to write down what I said to her on the phone and send a copy of it and she'll see what she can do. She has to go and talk, I guess, in Toronto to see if they can do something, because I need the money now; I'm struggling right now.

1310

Mr. Michael Prue: Okay, and I take it you're on Ontarians with disabilities, ODSP?

Ms. Diane Rochon: Yes, but ODSP doesn't do prevention. The health system does not do prevention, and there is a lot of illness, even mental illness, that could be prevented. I know in my case, I was on so many drugs I couldn't think straight. I couldn't understand what was going on. I had lots of problems in my environment. I remember one time saying to a psychiatrist, "I don't want pills,"—I was so upset—"What I want is a good high mountain with trees, to walk on it." I know it sounds funny, but I come from the Laurentians where there are mountains, and I miss them so much. Sorry.

Mr. Michael Prue: Thank you.

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

Mr. Khalil Ramal: Thank you very much for your presentation. This bill basically focuses on families and mothers and fathers to get support for their loved ones who are labelled as intellectually disabled, so I'm not sure if your circumstances fit this criteria.

Ms. Diane Rochon: My kids are old enough now. They're 26 and 23. My ex-husband, after abusing me, abused me in the divorce. The system abused me because they were not there for me. He got everything—the kids.

Mr. Khalil Ramal: Okay. How are your kids functioning?

Ms. Diane Rochon: They're really well. I'm very happy about the way things turned out. They have problems and difficulties like everybody, but they have strong minds.

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

Mr. Dave Levac: Thank you very much. We'll make sure that Madam Meilleur hears about the situation. We'll take your comments and make sure that her office is aware of them so that we can see if we can find some more assistance under ODSP.

Ms. Diane Rochon: Thank you. There are many women. I go to centres for women, and those women are afraid to talk. There are a lot like me. I'm not the only one.

Mr. Dave Levac: Thank you for having the bravery to come here. We appreciate it.

Ms. Diane Rochon: Thank you very much.

Mr. Dave Levac: There's one more person.

The Vice-Chair (Mr. Vic Dhillon): Ms. Jones.

Ms. Sylvia Jones: Thank you, Ms. Rochon. I appreciate your story. I'm afraid you were right in your very first statement, when you said Bill 77 was not written for you. I don't see you in it. You're absolutely right. There are other issues that we have to grapple with as a government, but your personal story is very valuable and I appreciate you bringing it forward today.

Ms. Diane Rochon: Thank you.

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

KEVIN KINSELLA

The Vice-Chair (Mr. Vic Dhillon): Mr. Kevin Kinsella.

Mr. Kevin Kinsella: Good afternoon, ladies and gentlemen. Thank you very much, Mr. Chair and members of the committee, for the opportunity to present. I'm disappointed that the minister has decided not to join you at these hearings, considering they're in her riding. For a couple of reasons, I'm—

The Vice-Chair (Mr. Vic Dhillon): Mr. Kinsella, just to let you know, it is a parliamentary committee and the minister's representative, the parliamentary assistant, is here.

Mr. Kevin Kinsella: I understand, but as I said, this is her riding. However, I will say this: I'm very pleased by what you're trying to do here overall. I'm just going to point out a few holes that I see that perhaps you'll be able to fix.

For example, there's nothing in this act that governs—you talk about governing, who is ODAMR, who can be placed, but there's nothing saying that you can't place someone into a home who doesn't fit the criteria of this legislation. I know of at least one case here in Ottawa where that has happened because the Ministry of Community and Social Services has the power to just decide that this person is going to be placed here. I know of at least one case where someone with a disability similar to mine—perhaps a little more severe—was placed in a home for community living persons and who has a smarter intellectual capacity, or a larger intellectual capacity, and is ending up acting more as staff than as a client.

One of the loopholes that you should close, when dealing with this legislation, is the ability of the ministry to just go ahead and place people into spots that may not necessarily be appropriate. This was a practice that I'm not going to blame anyone for, because it was going on long before Mr. McGuinty came into power, but it's a serious problem.

Another flaw that I do see is that you talk about families and this legislation being supportive of families, but where in the legislation—it talks about housing in the community, where they place people with host families. It talks specifically, saying that the host family won't get any extra money if it's a relative. Say that you place someone with a parent—that's one thing. But what happens if the parents die and you've got a brother or a sister who has to take over. They've got their own family. They would like to host this person, but they need a little extra help. This legislation treats them in a second-class way.

Third, and this is important to me, personally—well, there are two things. This legislation really opens up the idea of guardians and advocates being just anybody. Where is the strength governing who can be a guardian, number one? I understand it's in the guardian legislation, but who says that the people who become guardians are qualified to be guardians? So when you place someone in the community—good idea—what kind of inspection do you have for them? You obviously have an inspection for group homes—and I'm very pleased to see that—but what sort of qualifications would it take to be a guardian of someone with slightly less intellectual capacity, and how easy is it for a guardian to then, since they're doing all this stuff, take the money that is given for the care of the person and waste it? I hope you understand where I'm going with this.

I'm also somewhat concerned that this legislation does nothing, really, to control the use of unregulated care providers, even in group homes or other situations, because I've already seen problems where unregulated care providers don't have the proper training to do the jobs that they're being asked to do, or perhaps they don't have the will. But I get really worried when I see what could be very good legislation being so broad and opening itself up to a lot of people who are unqualified to care for people with some form of diminished capacity.

I think those are my major concerns with the bill, and I hope that this has been helpful. I will leave it for questions and keep this very short if I can.

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The Acting Chair (Mr. Dave Levac): Thank you. We do have some time after that presentation and we'll share that with all three parties, starting with the Liberals.

Mr. Khalil Ramal: Thank you very much for your presentation.

I believe we listened to your wife or somebody related to you speaking earlier about inspection without notice, and they expanded on that regarding a private home, when the person lives with a brother, sister or a guardian, and how we can do that. It's a good point; hopefully we can take it further and see what we can do about it.

Another thing is, how do you think this bill would benefit you if it passes as it is?

Mr. Kevin Kinsella: For me, personally, of course there is no benefit because I don't have the diminished capacity aspect. But I do see it benefiting the community as a whole if it were to pass because, frankly, institutionalization does not work. It's expensive; in fact, it's a complete waste of money in a lot of cases, and it leads to abuse. Putting people out into the community means they're productive. We have some excellent associations—group homes etc.—that really do want to get people productive and in the community and working, as well as enjoying life. I don't see a down side from that point of view.

Where the down sides come in at all in this legislation is from the point of view of who's qualified to be a guardian, how much help are you going to give those families if they're related, that sort of thing.

I don't really see a major down side to the legislation. I see only positives in terms of getting people involved and in the community and getting the community into realizing that persons with disabilities of all kinds are valuable members of society.

The Acting Chair (Mr. Dave Levac): Ms. Jones.

Ms. Sylvia Jones: I wanted to get your thoughts on the application centres and whether they would improve or worsen the ability to place people in group homes.

Mr. Kevin Kinsella: I'm glad you asked. In a city, they might actually improve the situation. But certainly due to the fact that our LHINs, our local area health networks, are so huge, I would think that, overall, the situation would be much worse for people to have these application centres. I don't believe that would be a positive step, because people are going to be forced to go into a community that may be 50 or 60 miles away, instead of having persons come out to them, in a sense. I'm concerned about that.

Ms. Sylvia Jones: Right. Because as written, there would be fewer application centres than there are LHINs currently, so it's an even larger area that they're expected to cover.

Mr. Kevin Kinsella: I think that is going to make it extremely hard on staff, and I think that's a very negative and retrograde step.

The Acting Chair (Mr. Dave Levac): Mr. Prue.

Mr. Michael Prue: You raised something I hadn't really considered; that is, that we've had a lot of parents coming here today and talking about looking after their children or what happens if the parents die before the children and who's going to look after them. You suggested that what would be a normal possibility is that a person with a developmental disability would go to live with their sibling. I don't see in this legislation that the siblings would be eligible to get an allowance or a stipend any more than the parents were.

Mr. Kevin Kinsella: In fact, the legislation specifically states that a relative of any kind would not be eligible for a stipend of this type to assist.

Mr. Michael Prue: Part of the legislation says that the person has the capacity to make that choice themselves, so if they say, "I want to live with my brother," and the brother says, "I can take him, but I can't afford it," then what the person with the developmental disability wants can't happen.

Mr. Kevin Kinsella: Yes.

Mr. Michael Prue: So I hope the parliamentary assistant heard that and heard it well.

The Acting Chair (Mr. Dave Levac): That may or may not be the fact, but I think we need to get that looked into. My understanding is that's not quite correct. We'll make sure that gets clarified.

Mr. Kevin Kinsella: Actually, there is a section in the legislation—I could dig it out and show you specifically—about relatives and how they don't get support.

The Acting Chair (Mr. Dave Levac): Mr. Kinsella, thank you very much for your presentation and coming before us today.

OTTAWA-CARLETON LIFESKILLS INC.

The Acting Chair (Mr. Dave Levac): It's now the opportunity for Ottawa-Carleton Lifeskills, OCL: Mr. David Cameron, Ms. Jocelyne Paul, Gordon McKechnie and Doug Anderson. For the record, if you could identify yourselves and the organization you represent, if you do. You have 15 minutes. If there's any time left over after the presentation inside of the 15 minutes, we will share that among all party members in an equal manner. You may begin any time you're ready. Thank you.

Mr. David Cameron: Good afternoon. My name is David Cameron. I'm the president of the board of directors of Ottawa-Carleton Lifeskills, which I'll refer to as OCL, just to be brief. Thank you to the committee for taking the time to hear our concerns on the bill.

First of all, our number one goal at OCL is to serve and support developmentally disabled adults. We are one of the largest providers of those services in eastern Ontario, serving approximately 100 individuals.

We very much welcome the government's initiative to modernize the legislation concerning persons with developmental disabilities. As an organization, we have a 20-year history of delivering those services, starting primarily with the impetus to move persons out of their regional facilities and into the community. We continue to support that initiative.

We have a demonstrated record of working with application centres—I won't call them application centres, but with Service Coordination Ottawa. So we're somewhat familiar with the concept, but we certainly feel that there needs to be a little bit more detail in the concept, in terms of how that would actually roll out, how it would work and how we would interact with that organization.

We also recognize that the bill, as presented, really represents more of a legislative framework, and that there's a lot of work to be done yet in terms of regulations and policy directives, which concerns us a little bit in the sense that a lot of it is unknown to us as a service agency in terms of how it's going to work. We certainly encourage the government to release drafts of the regulations and the policy directives as they become available so that hopefully we can help and assist the government to provide regulations and policy directives that will work well for the sector.

I also wanted to mention that we're a member in good standing of OASIS, the Ontario Agencies Supporting Individuals with Special Needs. They presented earlier today and we are in agreement with and support the positions they provided to the committee earlier. So our comments—I'm going to keep them brief—are focused on what we think is material to us as a transfer payment agency or what will be a service agency under the new bill.

With that, I'll move to the comments that we have specific to the bill. At a summary level, we have a concern with the definitions of residential supports. I'll go into each of these points in a little bit more detail, as you'll see in the handout. We feel that additional liabilities are being imposed on volunteer boards of directors of the service agencies. We're concerned that obligations may be added to our service contract without corresponding amendments to the contract and associated funding, and that without uniform standards being applied across the sector, it could cause a migration of funding to low-cost, low-service third party providers.

I'll go into a little bit more detail, specifically on subsection 4(2), regarding definitions of services. As an agency, we're concerned that some of what we consider core services that we deliver, or how we deliver something that we call supported independent living and home share, is different from the definitions provided in the bill. So we would be concerned that service that we consider core, that's identified and codified in the service contract we have with the ministry, would not be in conformance with Bill 77.

Our recommendation would be that the legislation perhaps permit a broader range of definitions of residential supports than is currently being contemplated.

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Regarding section 7 for service agencies, the concern we have is that requirements could be imposed by this section that could inadvertently result in unfunded obligations being put on a service agency such as OCL. What that represents basically, then, is a unilateral amendment of our service contract without necessarily the right of review or appeal. The risk for us as an agency is that we would be unable to plan for our services and unable to deliver those services within a balanced budget, as we're required to do under law. Our recommendations would be that Bill 77 should require that requirements that are imposed either by regulation or more especially through policy directives, because there seems to be a little bit more ability to assign those policy directives by a director of the ministry—we would just like to ensure that there's some form of review of the service contract in accordance with those changes.

We also think that there should be formal written notice, rather than just publication to a website, if changes are contemplated that would in fact change the contract under which we're funded.

Sections 30 through 32, which concern takeovers, the power of the manager and personal liability: The concerns that we have on those are specifically around the ability to attract and retain volunteer boards of directors. The bill is unclear in terms of the liability that the board would continue to have once a manager has taken over. If the manager is acting as the board of directors and commits additional liabilities to the organization, the way I'm interpreting it right now would be that I would continue to be liable. I'm happy to accept the liabilities that I've created as a board, but if the manager comes in and creates additional liabilities, I'd like to see some limits on that.

Also, the bill doesn't make clear in whose interest the manager must act. I'm sure we can all read between the lines the intent that we want there, but it is not clear in the bill. The risk for us as an organization is that our board would have additional liabilities imposed on it. The change that we'd like to see, if possible, is that the directors of the service agency not be liable for acts or omissions of the manager, that limits and obligations be imposed on the manager and direct him or her in terms of whose interests they have to be serving. Certainly we think there is an opportunity here to indemnify volunteers from liability. With the Good Samaritan-type act that's in place, where because you're helping you're not necessarily held liable—we'd certainly like to see that extended to volunteers. It's getting harder and harder to attract and retain volunteers with appropriate skills at the board of director level. Anything you can do that would enable that would be appreciated.

Section 11, on direct funding agreements: We fully support the move towards direct funding. We're just concerned that, if overused, there is the potential to create a "marketplace," which could lead to a decrease in the quality of service, depending on how third party providers play in that marketplace. The risk we see is that service agencies could be held to a higher service delivery standard, higher quality assurance standards and performance reporting standards, which could ultimately result in a migration of funding away from service agencies and towards lower costs—but also potential lower-quality providers. We would simply like to see uniform standards being applied across the sector. I think that's a message that was echoed by several groups earlier this morning. We think that it would be reasonable to impose limits on what third party brokers, for example, could charge for their services, because we see that as another way that funding can be taken out of the sector, not necessarily providing direct service.

In closing, I just wanted to let you know that we do plan to submit our written brief to you in addition to the handout that we've just provided. We'll provide that before August 12. We'd certainly like to thank you very much for the opportunity to present to you on our concerns.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. Ms. Jones? There are a couple of minutes to each side.

Ms. Sylvia Jones: Thank you, Mr. Cameron. You've raised some specific things related to the rules and the parameters of the boards of directors which I appreciate, because I think it's something that we're going to have to look at in terms of having to clarify the legislation. Thanks for those specifics.

The Vice-Chair (Mr. Vic Dhillon): Mr. Prue?

Mr. Michael Prue: My questions relate to section 11, and you've made some good suggestions here. We've had many deputants speak about the uneven service levels, the uneven qualifications levels and the uneven pay levels between the service sector and private sector, and also within the service sector, between the unionized workforce and the non-unionized workforce. We've seen salary ranges between about $10 and $18 an hour. Is that $10 and $18—because I had that challenged earlier—a fair reflection, that some pay as low as $10, in those that are not unionized, and some pay as high as $18, in those that are?

Ms. Jocelyne Paul: I can answer that question.

The Vice-Chair (Mr. Vic Dhillon): Please identify yourself.

Ms. Jocelyne Paul: My name is Jocelyne Paul. I'm the executive director with Ottawa-Carleton Lifeskills. I know that people who provide the services for specialized services at home receive around $10. Exactly how much it is, I'm not sure, but I know that in terms of service agencies, the sector, even within Ottawa there is a fairly large difference between what one agency will pay at the lowest end, which could be $14, $15 an hour—I'm not sure—to the higher end of $23 to $25 an hour. There's a big disparity.

Mr. Michael Prue: All right. But that is considerably more than $10.

Ms. Jocelyne Paul: That is.

Mr. Michael Prue: This is part of why I'm zeroing in on what you said here: that the brokers, or the third-party agents, in order to maximize the amount of work they can get, will choose the $10 people, even though those people may have no experience, no skills and no abilities. Is that what you're worried about too?

Ms. Jocelyne Paul: That is correct, and in situations like that the training levels are lower or could potentially be lower. The quality of life could be affected for the people we serve. That's why we would recommend the same set of service standards for everyone to follow, as well as, if at all possible, additional funding being provided.

Mr. Michael Prue: Should the government be mandating that there be a certain level of pay of, say, $15 an hour, in order to level out the fields, if families want to go one route versus another? I'm not saying to lower the people who are making more; I'm just saying that $10 an hour is going to perhaps be unfair to families who want to contract their own services, not understanding that you sometimes get what you pay for.

Mr. David Cameron: I'll take a crack at that, if you don't mind. I guess my thinking would be that rather than trying to mandate a service level of pay, applying a uniform set of qualifications would be helpful in terms of ensuring the right level of quality of service that's delivered.

Mr. Michael Prue: So you'd have to have some kind of a school diploma or something to get into it, or so many years of experience?

Mr. David Cameron: Sure. On the flip side, though, what we're seeing is that it's getting harder and harder to attract and retain staff in these types of positions because as the salaries in other sectors have been increasing, especially with some of the economic activity out west, for example, it's impossible—

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

Mr. Khalil Ramal: Thank you very much for your presentation. I believe that I had the chance to visit your organization this spring. I was impressed with your organization.

I want to talk about liability. I understand that you should put it on your manager's responsibility—I'm joking. People spoke before us today and in the last three days, talking about accountability. You probably heard some of them. Someone has to be accountable, especially at the administration level, whether it's a volunteer or a paid job—they're getting paid—because those people who are at the administration level are making the decisions, and others are excluded from the decisions. So that's why, I guess, to put in place accountability, in order to protect the people who believe strongly in our responsibility to protect, especially when we're dealing with vulnerable people. So we think it's not the fair way.

Mr. David Cameron: We're fully supportive of an accountable environment. I've limited my discussion on liability to specifically around—as a board, a director and a trustee of the organization, I understand that I am liable, and I step up to that liability. Where the ministry decides that, for whatever reason, as a board we're not managing the agency properly and they come in and take over, when that manager then goes about acting as the board, they could incur additional liabilities for the board. We would just like to see that liability set aside and not imposed back onto the original board of directors.

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Mr. Khalil Ramal: Just to continue the question from Mr. Prue, why haven't you—as I mentioned to your organization, I saw people coming and going and you service a lot of people who get direct funding. So do you think, as proposed in this bill, direct funding would be a good model in order to give choice to families and mothers and fathers?

Mr. David Cameron: We fully support the direct funding model. We're, in a sense, adopting a bit of a wait-and-see attitude. At the moment, that's a very small percentage of the client base that we serve. As it goes, it certainly could have fundamental impacts on our organization in terms of how we deliver services, but that's something that we recognize as a reality in the sector and we organize our business as appropriate.

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

NEW LEAF LINK

The Vice-Chair (Mr. Vic Dhillon): The next group is New Leaf Link.

Dr. Karin Steiner: Good afternoon. My name is Karin Steiner. My colleague Howard Smith is passing out the handouts that we have.

I'm making this statement today wearing two hats. First, I'm the parent of a 21-year-old son with autism, Nicolas, who has transitioned from school to life on the couch. I will use Nicolas as a proxy for others in his situation.

We live near the village of Sydenham in southeastern Ontario, population about 1,000. Residents of Sydenham and its fast-growing township of South Frontenac are in a no-man's land of social services between Kingston to the south and Sharbot Lake to the north.

My second hat is that of founding executive director of a new non-profit organization that is currently under review for charitable status. New Leaf Link is being established to support the community participation of adults with developmental disabilities in rural areas. I refer you to the handout for supporting details of New Leaf Link and of our presentation today. My statement will use about half the allotted time, and I would be happy to field any questions.

We're here to highlight the special needs of those who live at home in rural communities. We have two main questions about the newly proposed application centres: First, how many are envisioned and, second, what are the criteria for distribution of centres throughout Ontario? We also raise three concerns that are paired with recommendations.

Our first concern is that the needs of those who live in rural areas will be short-changed. When my son Nicolas was denied Passport funding in 2007, we were told that only five out of 229 applicants were funded in our area and that one person in Napanee and four in Kingston were awarded the funds. I wondered why rural applicants were denied in this round.

The honourable Shafiq Qaadri stated on May 26:

« Aujourd'hui, nous aidons les personnes atteintes d'une déficience intellectuelle à vivre en société, dans toutes les collectivité de l'Ontario…."

« Ces personnes ont tout autant le droit que les autres citoyens de participer et de contribuer à la vie de leur collectivité."

"They need services and supports closer to their homes."

We couldn't agree more; therefore, we recommend that there be separate rural branches of any proposed regional application centre to ensure that the special needs of those who choose to live in rural communities are not forgotten.

We emphasize that people today do choose to live in rural environments. The Honourable Minister Meilleur described historical perceptions of those who were placed in institutions as ones who "would flourish in a secluded rural environment, away from the stress and commotion of everyday life." I suggest that rural environments are not necessarily secluded and that they can offer rich opportunities for maintaining inclusive practices. Our sons and daughters with disabilities are well known to local citizens because their school-to-community programs took them into grocery stores, businesses and municipal offices. Nicolas and others in his generation have been part of inclusive schools from start to finish. Ironically, it's only in adulthood that they face the possibility of losing these supports.

Our second concern has to do with both transitioning and transitioned students. I know another student from Sydenham High School who applied for Passport funding along with my son. Each has now transitioned from 30 hours of school-based support per week to zero hours of community support. We know that more than 30 persons with developmental disabilities have graduated from Sydenham High School over the past 18 years. How many of those people knew to apply for Passport funding? I'm concerned that rural applicants might be under-represented in applying for funds because they no longer have connections with those who could inform them of the competitions. For my son and others, rural schools seem to be the last stop for support before they embark on a life on the couch.

Therefore, to facilitate school transition planning as a springboard for community participation, we recommend that the new application centres include school-based resources and documents in the development of service profiles and in forecasting the need for services in various geographic areas. We believe that the three extra years of schooling to which students with developmental disabilities in Ontario are entitled provide an opportunity to craft a blueprint for community services. Parents in our area long to see school-to-community connections continue beyond school. For example, in-school supports for work in the village hardware store or in the grocery store could be maintained in adulthood. Individual education plans exist for each of our sons and daughters, yet these resources vanish upon graduation.

Our third concern is that even if people in rural areas are informed about direct funding and even if they apply for it, they will remain on waiting lists longer than their counterparts in urban areas. Because there are few services in rural areas, even if funding is awarded, it may be difficult to make maximum use of the money immediately. For example, I have had special-services-at-home money for Nicolas for approximately four years, yet I've only been able to use two years of funding because of the difficulty of finding local support workers with access to a vehicle. Other parents have complained about the same problem. Transportation costs are not funded by special services at home, and we lose the money that we can't spend in any given year.

Therefore, we recommend that special provisions or flexibility in use of funds should be in place for those in rural areas. One scenario might be that allotted funds can be carried over to subsequent years over a set period of time. This type of structure is in place for non-profit charitable organizations, which are permitted to carry a surplus for five years before having to use or donate any extra funds. In addition, some of these funds could be set aside to cover transportation costs, though I would prefer to spend money on service rather than on transportation to service.

We also recommend that a basic amount of direct funding be awarded to all who are on waiting lists for services. Nicolas qualified for $15,225 per annum in Passport funding. He received nothing. Yet a smaller proportion of that amount, say, $5,000, would have enriched his life over the past year. Anything that can be offered to people who are on waiting lists is better than nothing. Sylvia Jones stated, "Agencies still receive 80% of the dollars in the sector and support only 20% of the individuals in the province who have a developmental disability while families who provide support to 80% of individuals ... receive 20% of the overall budget." A guaranteed basic amount for all those on waiting lists would go some distance toward redressing the inequities that currently exist.

In addition, we recommend that some monies be earmarked for rural grant competitions to support service provision in rural communities. We know that the so-called "additional services" mentioned in part VIII, section 37(c), of Bill 77 are just as central to the well-being of adults with developmental disabilities as residential placement. With this in mind, we also suggest that municipal agreements could be undertaken with organizations that offer additional services, not just with those that provide residential services, as currently suggested by part VIII, section 39(1), of the bill.

In closing, my colleague and I thank the committee for including us in your discussions around Bill 77. We welcome any questions or comments you might have now or in future.

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The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We'll begin with Mr. Prue. Two minutes each.

Mr. Michael Prue: Thank you very much. My first question has to go to the thorny question of application centres. You have requested that there be rural branches of the application centres. We've heard that argument, in the north particularly, where they're talking about six rural branches out of Timmins. We've also heard discussion from several people that we not go that route, but that what we have is a mobile application centre where the workers, the people who approve the funds, go out into the community, into the rural areas, and make the assessment in homes; that that is more cost efficient and takes the service to the people rather than the people to the service. Given the two options, which one do you prefer?

Dr. Karin Steiner: I'm satisfied with an emphasis on the special needs of those in rural communities. I don't have an objection to a centralized application centre. I just think that some mechanism has to be in place for addressing the needs in rural areas.

Mr. Michael Prue: In terms of rural areas, you're also very correct. If you live in a city like Ottawa or Toronto, the services and the service providers tend to be in those locations. Should we be attempting to better fund service providers in more rural, suburban or northern areas? Or should we be pushing the option of making the funds available to the families and having them do the work in finding their own people to assist?

Dr. Karin Steiner: One of the recommendations that we had is to provide some kind of grant incentive so that service providers, whether they're located in urban areas or not, have an incentive for providing services in rural areas. We've got Community Living associations in Kingston and Community Living-North Frontenac in Sharbot Lake. I've talked to executive directors at both those organizations hoping that they could pool resources to come together in our area, but they haven't managed to do that yet. They need an incentive.

Mr. Dave Levac: Thank you very much for your presentation and your good ideas. I appreciate them very much.

By way of information, this will be about two or three, possibly four, ministries reviewing the process during regulations time, and I really will take seriously your concerns and your comments about the potential for having the Ministry of Education involved in the process of transition. It's a great idea and we'll make sure that gets passed on through staff to the minister.

We'd also like to indicate to you that the rural issue has come up a few times and that's being listened to very carefully in figuring out how best to provide those services in an equitable manner. I appreciate very much what your concerns are. We've taken them to heart and will do what we can in order to facilitate those. Thank you very much for your presentation.

Dr. Karin Steiner: Thank you very much.

Ms. Sylvia Jones: Thank you for your presentation, Dr. Steiner. I'm also very pleased that you focused on that transition time because I see a real opportunity, when the individuals are within the school system, to tap into doing some assessing and perhaps bringing in the individualized planning at that stage, before you're left out in the wilderness, as you described it. I'd like your thoughts on whether you see an opportunity for individualized planning that begins while the individual is still in the school system, if that's something that would have assisted.

Dr. Karin Steiner: Yes, and in terms of the IEP, which is the individualized education plan, there's always a section on transition planning. When the student enters high school in grade 9, there is a possibility to begin thinking about transitioning. I would strongly recommend that community services get involved even at that very early stage so that there's more time, especially in rural areas, to try to craft that plan so that people aren't left sitting on the couch.

Ms. Sylvia Jones: Thank you.

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

ARCH DISABILITY LAW CENTRE

The Vice-Chair (Mr. Vic Dhillon): Next we have ARCH Disability Law Centre. Please state your name for the record. You may begin. You have 15 minutes.

Ms. Lana Kerzner: My name is Lana Kerzner and I'm a lawyer at ARCH Disability Law Centre. With me today is Kerri Joffe, who is also a lawyer at ARCH.

We have provided you with a written version of the comments we are making today. I think they're being handed out now. We are going to be providing more detailed written submissions by Tuesday, August 12. Because of the limited time we have today, we will not be covering all of our recommendations relating to Bill 77.

ARCH welcomes the opportunity to participate in this public hearing. We are here to talk to the committee about legal rights for people with developmental disabilities. Our comments and recommendations about Bill 77 stem from the experiences ARCH hears directly from people with developmental disabilities, their families and support people and community groups, many of which have their roots in rights violations.

I will briefly describe our organization. ARCH is an Ontario-based community legal clinic that is dedicated to defending and advancing the equality rights of people with disabilities. ARCH is governed by a volunteer board of directors, a majority of whom are people with disabilities. We provide a telephone summary advice and referral service to Ontarians with disabilities and engage in test case litigation. We also make submissions on matters of policy and law reform.

In this presentation we use the term "developmental disability," as this is the term used in Bill 77. In doing so, we note that there are various views regarding the most appropriate language, and we defer to members of the community and people with disabilities themselves regarding appropriate terminology.

Our fundamental concerns relate to injustices and abuse to which people with developmental disabilities are subject in their receipt of services, especially in group homes. In preparing our submission, we reviewed records of calls made to us for advice over the past five years. The majority of concerns relate to serious rights deprivations in group homes that, in our view, society would never tolerate in the lives of people who do not have disabilities. People complain about all forms of abuse in group homes that create a living hell both for the individual and those who support him or her. We have been told about people being dragged down stairs, being left in the cold without blankets, being prevented from seeing family and friends, experiencing neglect relating to medical needs and having their cherished personal belongings stolen. People have been refused transfer requests despite an existing abusive situation. However, they have also been forced to move from one group home to another without regard to their wishes or the disruption created in their lives. Over and over, we hear of desperate and failed attempts to resolve these situations through the group home and/or the Ministry of Community and Social Services that funds the homes.

The committee has heard many people recommend the addition of a preamble to Bill 77. ARCH agrees with this position. Both the government and the community feel that transformation is needed and that the new developmental services system should have as its primary aim the support of people with developmental disabilities to live as full citizens in their communities. Legislation that aims to set new social policy and transform a sector must clearly say so. We need to know where we're going in order to get there.

Although different, a preamble and a purpose provision are both authoritative sources of information regarding the Legislature's intent when it passed the law. ARCH submits that both are required in this legislation. These components serve the important and practical function of guiding the way in which the law is to be interpreted, applied and implemented. A preamble and purpose section will help to ensure that the ministry, directors, inspectors, application centres, service agencies and others who are charged with implementing Bill 77 carry out their duties in a way that achieves the goal of enhancing the citizenship and social inclusion of people with developmental disabilities. In addition, a preamble and purpose section will help to ensure that courts and administrative tribunals will interpret and apply the law in a way that achieves these goals.

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A preamble and a purpose section also serve important law-making functions. Inserting these components will ensure that the legislative scheme is internally consistent by providing a lens through which to evaluate the rest of the bill. These components will also assist future policymakers and legislators to create regulations and policy directives that are in harmony with the rest of the act.

The preamble should articulate our belief that people with developmental disabilities are equal and valued citizens of our province and that the services provided to people with developmental disabilities must enhance their opportunities to achieve full citizenship. The preamble should affirm that people with developmental disabilities have the right to dignity and self-determination, and it should recognize the need for public accountability and transparency with respect to services.

Our written submission will provide more details about what should be included in the preamble and purpose provisions in order to meet the bill's objectives.

Bill 77 is extensive and detailed but does little to address the concerns we hear. It is ARCH's view that these problems have arisen in part from the flaws and gaps of the current Developmental Services Act and its associated regulations. There is an absence of a clear statutory framework. A vision of full participation and citizenship requires that the dignity and well-being of people who have developmental disabilities be respected. It is our view that substantive rights need to be enshrined in law in order for this to occur. These rights are largely absent from Bill 77. It is our grave fear that without amendments to the bill to remedy this omission, people with developmental disabilities will have no legal tools with which to address their concerns. New laws will exist, but the lives of the people to whom these laws are aimed will remain unchanged.

In this respect, ARCH recommends that Bill 77 include a statutory provision for substantive rights for people who have developmental disabilities. These should be set out in a separate section and referred to as a bill of rights. These should apply with respect to both funding and services. At a minimum, several rights should be specified, such as:

—the right to live free from discrimination, harassment and abuse;

—the right to raise concerns or recommend changes and complain without fear of reprisal; and

—the right to be treated with respect and to promote the autonomy of people with developmental disabilities.

There must be a specific provision in the act that states that the act, regulations and all agreements between the crown, service providers and those receiving services be interpreted so as to advance the objectives set out in the bill of rights.

Similar bills of rights are enshrined elsewhere in Ontario laws, notably in the Long-Term Care Act and the not-yet-in-force Long-Term Care Homes Act, as well as current legislation relating to long-term-care homes. We do not recommend a wholesale adoption of these, as rights must be tailored to the context of people with developmental disabilities. Specific rights relevant to the developmental services regime must be identified and articulated in a bill of rights in Bill 77.

The bill of rights must be in plain language and available in accessible formats, such as pictures. There must be a requirement that people in receipt of funding and services are made aware of it.

The complete omission in Bill 77 of specific provisions for addressing abuse is a mystery to ARCH in view of the documented research, confirmed by ARCH's experience, relating to abuse of people with developmental disabilities. It has been estimated that over the course of their lifetimes, people who have a developmental disability are at least one and a half to two times more likely to experience abuse than people who do not have disabilities. Community Living Ontario, in their written response to Bill 77, also expresses concerns relating to abuse.

Because of the severity and prevalence of abuse, it is imperative that the statutory framework address situations of abuse which occur in the context of services and programs for people who have developmental disabilities. This must be addressed specifically, directly and comprehensively. The scheme should include several components, including duties of both the ministry and service providers to prevent, recognize and address abuse.

Detailed legislative provisions regarding abuse, especially in relation to the populations which are most affected by it, are not new to Ontario legislation. Both the Long-Term Care Act and the not-yet-in-force Long-Term Care Homes Act contain comprehensive provisions relating to abuse.

Ms. Kerri Joffe: Bill 77 provides for a review if an application centre decides that a person is not eligible for direct funding or services. The person or entity who will conduct the review, and the rules and procedures that apply to the review, are not dealt with in the bill. These are left to be defined by regulations, which, in our view, is wholly insufficient.

ARCH submits that a full right of appeal for eligibility decisions must be incorporated into Bill 77. It is essential that such appeals be made to a person or entity that is independent from the application centre. This is the only way to ensure that the appeal is unbiased and fair. We recommend that the appeal be to a director appointed by the minister, with a further appeal available to a designated administrative tribunal or board.

It must be noted that appeals of administrative decisions to independent tribunals exist for many other government-funded services. For example, the Social Benefits Tribunal reviews decisions regarding Ontario disability support program benefits and Ontario Works benefits. It is troubling to us that Bill 77 does not extend the same rights to people with developmental disabilities.

Decisions about eligibility for services or funding have an enormous impact on the lives of people with developmental disabilities and their families. The result of eligibility decisions is that people may be left without the vital services they need, such as group home placement, care at home or respite. People with developmental disabilities should have the same rights to appeal eligibility decisions as are afforded to others.

It is crucial that the appeal process be accessible to people with developmental disabilities. Similarly, the administrative board or tribunal that hears appeals must also be accessible for people with developmental disabilities. It must have procedures that are flexible and enable people with developmental disabilities to easily participate in the process. Tribunal members must have specialized knowledge of developmental services issues and must have training in working with people with developmental disabilities.

It is also deeply troubling to us that Bill 77 does not set out any process to enable people to make complaints about the services they receive. This is especially so in view of our submission that the Ministry of Community and Social Services must ensure that services are being provided that comply with the act and any regulations or policy directives. This is integral to the provision of services in a way that ensures public accountability and transparency.

The bill only says that the Lieutenant Governor in Council may make regulations governing practices and procedures relating to complaints and that the processes will, in fact, be defined by regulations. In our view, this is insufficient.

ARCH recommends that Bill 77 include a full complaint process. It is particularly important that the bill include provisions allowing for complaints and appeals based on a violation of the rights set out in our proposed bill of rights.

The Vice-Chair (Mr. Vic Dhillon): Thirty seconds.

Ms. Kerri Joffe: It is common for complaint processes to be laid out in other Ontario legislation. The not-yet-in-force Long-Term Care Homes Act and the Long-Term Care Act both contain provisions that establish a complaint process. People with developmental disabilities must be afforded the right to make complaints about services they receive, and especially when these services do not meet the requirements set out in the act and any regulations or policy directives.

Because of the power imbalance between people with disabilities and the Ministry of Community and Social Services—

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. The time allotted for you is up. You can hand in the remainder of your submission to us. Thank you. We have a very tight schedule. There are lots of people presenting.

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TAYSIDE COMMUNITY RESIDENTIAL AND SUPPORT OPTIONS

The Vice-Chair (Mr. Vic Dhillon): Next is Tayside Community Residential and Support Options. Good afternoon. If you can state your names, you have 15 minutes. You may begin.

Ms. Wynn Turner: My name is Wynn Turner. I'm the president of Tayside Community Options. Accompanying me is Steve Tennant, who is the vice-president of the board of directors of Tayside Community Options.

Good afternoon to all the members of the standing committee. It is a pleasure to be here and to make some representation on behalf of the people whom we serve. I'd like to, as Steve will, tell you a little bit about my background, which is quite extensive in health and social services. Over a period of 42 years, I've worked in a variety of positions, including the administrator of Rideau Regional Centre at Smiths Falls from 1986 to 1997. I was also an interim executive director of Ottawa Valley Autistic Homes, and I provided expert advice to the Ministry of the Attorney General for the Ontario public service after my retirement.

In other fields, I was also an administrator of a long-term-care home, and I'm familiar with the legislation under which those homes operated and the bill of rights referred to by the previous presenters.

A little bit about Tayside: We are a not-for-profit charitable organization. We operate four group homes. We have an independent living program and a home share program, as well as social housing. Additionally, we have child care and social housing programs under our wing, and we primarily operate all of our programs in the town of Perth, Ontario.

Let me first congratulate all three parties for supporting the move to community living and all those transfer payment agencies and public servants who worked so hard to realize this dream. We can be truly proud in Ontario for the system that we have created. Here we are, celebrating this very year the creation of a completely community-based service system. This system emerged from people across this province advocating for better services for people with developmental disabilities. It resulted in a visionary document called Challenges and Opportunities which was released in 1987. The vision was to close all institutions by 2012. We are four years ahead of that commitment. Congratulations to all those who achieved this dream.

But let me now get to the tough part. I have three points that I wish to speak to where we believe that this act needs significant strengthening: First, we are operating a system that is underfunded; secondly, I will be speaking to third party advocacy, as the previous speakers did; and thirdly, the stability of funding for a charitable not-for-profit system.

First, then, let me speak to the chronic underfunding for this sector and some of the fears we have as a result of this for the act which is being presented.

Having achieved a vision, we are sad to see that this act makes no commitment that all individuals with intellectual disabilities or developmental disabilities will have the right to receive the services and supports that they need, because we are enshrining a waiting list in this legislation.

We believe that the dream for justice for the most vulnerable in our society will not be done until there is fair and transparent accessibility to services currently afforded to the deinstitutionalized and the wards of the province. Those individuals who have a developmental disability should have a right to the same level of service afforded to those who have been deinstitutionalized. Right now, there is a glaring inequity shown by long-term community waiting lists that would make waiting lists in the health services sector look very modest across this province, quite frankly.

These waiting lists have been validated by agency and ministry staff through the Making Services Work for People assessment tools which were produced by the ministry some time ago. Although the community system has received additional dollars, both operating and capital, these dollars have almost exclusively been used for those coming out of the closing institutions—essentially a transfer of dollars within the total system, not new money. Families who have kept their children home do not receive equivalent care when it is needed. They just go on waiting lists with crisis after crisis, accommodated with funding only when there is no alternative—often having to be done somehow within the MCSS. It is this underfunding that promotes the perception of the system as impenetrable because there are no guarantees, and frankly, those individuals with parents who are strong advocates for them are better at getting the system to work for them. But what about the rest?

We have other legislation in this province that sets out a mandate for services in its act. For example, the Education Act addresses the special educational needs and the right to education for all children with special needs. When that legislation was passed a long time ago, and I remember it well because I was a juvenile probation officer at the time, there were many who said it could not be done. But it was—just like the institutional end happened—and in addition to other services, children with developmental disabilities were integrated into the school system. There is no such guarantee offered in this bill for meaningful day programs for adults who, due to their level of intellectual functioning, will likely never be able to perform paid work.

I say to you today, our province can do better for its most vulnerable. We need to make the funding of essential services to individuals with developmental disabilities mandatory in the act as a fundamental condition of citizenship. This would include increases in special services at home funding, day programs, and relevant residential placements for these individuals.

Along with this, clear entitlement provisions should be captured to ensure that the system is fair and transparent, to make clear to citizens what they are entitled to receive. There is no such setting out of what people can expect in this province if they are currently not receiving services.

As I said before, not all people with developmental disabilities have the advantage of the advocacy of their natural communities, families or APS workers. We believe these most vulnerable people should have the right to honest, arm's-length advocacy to ensure their best interests are represented. We note that there are no provisions in the act to protect the safety and security of vulnerable adults with an intellectual impairment through a formal complaint procedure or third party advocacy. Long-term care has one, children's services has one, so why do adults with developmental disabilities not have one?

Thirdly, there is a need for stable funding for agencies to be able to operate their programs successfully. We believe that the current charitable not-for-profit model of service should be continued to ensure quality of care and putting every dollar into service, not profit.

I thank you for the opportunity to speak to you today. I sincerely hope that you will take these ideas back to your deliberations. The critical question is, can we do much better for the most vulnerable in our society?

Mr. Steve Tennant: I'm Steve Tennant. I have been working in the field of developmental services for 34 years in group homes and in workshops, when they existed, and I've been an adult protective service worker in the town of Perth and surrounding area for the past 26 years. I've also sat on the board, as a vice-chair, for Tayside Community Options since its inception 19 years ago.

I am concerned, as is our board, about the following issues: no legislated guarantees for care of this most vulnerable population, underfunding, and a legislated lack of advocacy.

There have been a lot of changes over the years in regard to services for developmental disabilities, as Wynn outlined. Most of these have been positive, where we've learned best practices and our clientele and their families have benefited.

To be honest, though, this bill really scares me. I see the province stepping away from its responsibility. When I see waiting lists being validated in legislation, let's face it, I cringe. Examples are the Education Act, which provides guarantees for special education for people with disabilities, and the health care act, which also has minimum standards.

There must be some way that legislated guarantees of support can be there so families can be assured that ongoing supports for their loved ones will be there when they are no longer able to provide.

Bottom line: People need day program options and appropriate supported accommodation options that would reflect their response to their needs and wants.

One of the positive improvements was the decision to close the institutions. We see that happening with Rideau Regional right now. Unfortunately, what we're also seeing is a double standard of care in our province.

Tayside Community Options, our organization, is looking forward to opening a new group home in Perth for six adults from Rideau Regional Centre. These folks are severely multiply handicapped, requiring total care, so we planned with ministry representatives. This specialized home's capital costs are in the neighbourhood of $900,000 to address their needs.

Meanwhile, Tayside has brought several proposals to the planning table asking for funding for group homes costing a fraction of this to respond to needs of local adults who also have multiple needs and whose parents have saved the government millions of dollars by keeping their children at home, and we're continually told there's no funding.

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The same thing appears with transition-aged youth who have been in the child welfare system who, when they become of age and require ongoing support, have huge price tags automatically annualized for them. Meanwhile, agencies in the community who are trying to support the same type of individuals who may still be living at home and may have the same problems are not getting the dollars that they need.

Unfortunately, supported beds only seem to be available in our area when the death of a resident happens at one of the group homes. Let me tell you how difficult it is to look weary people in the eye—parents and siblings—when they've had to hear that there are no funds for them after they hear what incredible funding is happening for people who are directly connected with government supports.

I trust those who work on this bill will remember the old adage that government will be measured on how it supports its least able. Allowing waiting lists is unacceptable. People with developmental disabilities have rights, too, as I'm sure you've heard over and over at this table today. Legislated guaranteed care for our most vulnerable is imperative and needs to be corrected in this act.

In regard to underfunding, which is the real issue: Though we certainly have inequities in the current system, overall I truly believe we've developed across this province a very good system of agencies who do their best with what little they get to provide for individual needs. Unfortunately, this system is stretched to the point of breaking down for no other reason than underfunding. The strikes last year were prime examples. As our population grows and ages, so do our needs. Waiting lists around the province already exist. These prove there are huge needs that require immediate funding.

There already exists a system for applications, with knowledgeable staff who can assess and develop plans for people's needs. This system may need to be tweaked in some areas, but the last thing we need is another level of bureaucracy.

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

Mr. Steve Tennant: One of the issues that also comes around is in regard to trying to deal between ministries. I have been trying to get support for a 20-year-old client who has Duchenne muscular dystrophy and disabilities and having incredible difficulties trying to get things that would be affordable. His supports would cost $55,000 a year to be able to keep him in his home so that his mother can go out and work. Unfortunately, I'm having trouble getting those funds, and he may end up being hospitalized, which will end up costing $2,000 a day, or $730,000. How responsible is that?

I also want to reiterate the importance of legislated advocacy. Yes, I am an adult protective service worker, and I strongly believe that this population needs third party advocacy. We have some wonderful families out there, but we have a lot of people who have no connections and need third party support to get through the bureaucracy that we are presenting before them.

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

PEOPLE FIRST OF CARLETON PLACE AND DISTRICT

The Vice-Chair (Mr. Vic Dhillon): Next we have People First of Carleton Place. Good afternoon. If you could state your names for the record, you may begin. You have 15 minutes.

Mr. Kory Earle: Good afternoon. My name is Kory Earle, the president of the local chapter. Right beside me is Manon Lépine, who is the vice-president of People First of Carleton Place and District. You heard People First of Ontario speak on Tuesday regarding several issues you'll hear again, but I think it's extremely important that what we say today will really reflect on your decision in making Bill 77.

Who we are and why you need to hear from us: People First of Carleton Place and District is an organization for people with intellectual disabilities. We started our local chapter in 2006. We are a province-wide organization, so therefore we fall under People First of Ontario. We want all people to be treated equally. We want others to see us as people first, not disabled people.

People First of Ontario helps people who have been labelled to speak for themselves. We help people make their own decisions. We teach people that they have rights and many abilities. People First of Ontario wants people who are labelled to have real jobs with real pay. We want people to have safe places to live that they can afford. We want to be included in all areas in the community, not segregated in schools, institutions or our social activities. We want to have the support that we need to be fully included in the Ontario communities that we live in.

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

You need to hear what we have to say, and we ask that you take us seriously.

Concerns around inspections: As I indicated on Tuesday, we really do hope in regard—in Bill 77, it indicates that the ministry can walk in to any resident or group home without a warrant. We disagree. Why should the government have the right to walk into these people's homes? The problem is that people with disabilities are losing their rights. They cannot walk into your home unless they have a warrant. I understand that this is because they want to make sure nothing is going on, although these residents in these homes—if something is going on, what is the government going to do? Shut it down and leave these residents homeless? We think that an inspector needs to have a legal document, like a warrant, that explains that they have a good reason to come in before entering our homes.

Another point related to inspections is that the government has to realize that people are afraid of speaking up. This is because they are afraid of losing their supports and funding. This is why some people can be afraid of service agency staff or government people.

Ms. Manon Lépine: Title of the legislation: While this act would mean that it would still be called the Developmental Services Act, we think the government should look at the act and change the name to include "Intellectual Disabilities Act." I think that "developmental" is labelling someone. The government would not want to be labelled, so why should people with disabilities be labelled? This needs to change.

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

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

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

There's not enough on supporting people to live in the community. If we are seen as individuals, then there will be more community-level planning. There's nothing much in this new act that talks about planning for our lives in our communities. For example, do we have to be in a group home to receive services or supports?

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We want to be supported to live in the community with people of our own choice and supported to make our own decisions. The new act spends a lot of time talking about agencies and services. For example, the act talks about waiting lists for services. We would rather it talked about having our support needs met through ideas such as person-directed planning or supported decision-making.

The ministry talks about citizenship, but unless this act helps us plan towards life in the community, just like everyone else, how can we be true citizens?

Mr. Kory Earle: Concerns around the application centres: In Bill 77, it indicates that the government will be putting up application centres for people to apply for supports. With these application centres, there will transportation issues and much more, and you can't even be guaranteed that you would get the supports that you need. Please keep in mind that it seems like the application centres have a lot of rules and authority and can therefore put us in a vulnerable situation. We agree with Community Living Ontario: The act should talk about the application process, not centres. We also think the government should be clear on where these are going to be placed. All application centres must be accessible.

Fear of losing rights: I really want this one underlined because there's nothing in the act that talks about people's rights. The act talks about a lot of things, but it does not talk about people's rights. Our local chapter has a problem with that. It just seems that the government will be in control of what people with disabilities do. We are asking the government, when making a decision in regards of this act, to really look at the person who will be affected the most. We think the government should put in the act talking about the rights of people with an intellectual disability. I think that one should really be underlined a million times, to be clear in the act about people's rights.

Ms. Manon Lépine: Threat to people having a voice and their independence: One of the most important things People First does is assist people who are labelled to have a voice and be heard. We need to be supported; however, in order to have a strong voice, we should have an adviser to read through anything before we sign it. An adviser is someone who we trust and feel comfortable with. We choose our adviser. The adviser shares and listens and helps us understand. Advisers share what they think with us and reword things in plain language so we understand. An adviser also helps us make decisions. An adviser does not make decisions for us. We need an adviser in order to help us access supports.

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

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

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

Mr. Kory Earle: Conclusion: People First of Carleton Place and District would like to thank the government for allowing us to speak today. We also want to say that in this act it states that all agencies and other people will be accountable for what they do. We agree with the government on accountability and we have dealt with agencies before where they where they not accountable for what they have done. So we really encourage accountability, not necessarily just for agencies but for all. Thank you.

The Vice-Chair (Mr. Vic Dhillon): Thank you. There's about a minute each. We'll begin with the government side. Mr. Levac.

Mr. Dave Levac: Thank you for your wonderful presentation. I appreciate the depth of which you've spent to get an understanding, and providing us with an understanding, of the position that you take at People First. There are several other groups that have spoken, but none as eloquently as you about your own selves. I appreciate it deeply.

We have heard, and we are going to be making sure that this voice is heard. The staff and the government, along with the opposition, I'm sure, will remind us of what your concerns are and we'll try to entrench those concerns in the development of the bill. Well done.

The Vice-Chair (Mr. Vic Dhillon): Ms. Jones?

Ms. Sylvia Jones: Thanks for your presentation. It's nice to see you again. I am particularly interested in the issue you raise about people's rights. If, as you have pointed out, we haven't changed this act in 34 years, then let's make sure we get it right this time around. So we'll make sure, at least on the opposition side, that we try to keep that focus. Thank you.

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

Mr. Michael Prue: Thank you for what you said. Two sentences are particularly poignant to me and I want to commend you for putting them down.

You say, "At the end of the day, government people and agency staff go home to a life that they have tried to make good. We go home to what we have been able to get." I think that says everything in a nutshell about what's happening here.

I just ask one question: You talk about the necessity of a warrant. Who do you see issuing the warrant, or do you care? Sometimes it's judges or justices of the peace and in some laws it's senior people in the department. Or do you just insist that due process is followed?

Mr. Kory Earle: This was brought up Tuesday in regard to inspections and stuff like that, for warrants. A lot of people may disagree with me. However, I'm going to be very bold about it, because the fact is we're not disagreeing with inspections. We don't want that in any text taken away. What we're trying to say is that there are other people inside and that if a situation arises, deal with that outside or deal with that somewhere else.

I believe that you guys, you government people, would not let anybody into your house unless someone has a warrant. I just cannot express how—if you guys aren't putting yourself into the situation of that person who has a disability—

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

ONTARIO PUBLIC SERVICE EMPLOYEES UNION

The Vice-Chair (Mr. Vic Dhillon): Next we have the Ontario Public Service Employees Union. Good afternoon. If I can get you to state your name, sir—

Mr. Smokey Thomas: Smokey Thomas.

The Vice-Chair (Mr. Vic Dhillon): You have 15 minutes. You may begin now.

Mr. Smokey Thomas: Thank you. Good afternoon. My name is Smokey Thomas and I'm president of the Ontario Public Service Employees Union. I'm here today to speak to our concerns about Bill 107.

OPSEU represents 8,000 people who provide supports to people with developmental disabilities all across Ontario. Our members' close relationships with the individuals they support and their families, along with years of experience, provide them with significant insight into what is needed in the sector. I would like to say that we recognize the need for new legislation for this fast-growing sector.

For years, OSPEU has been pushing the government to make services for people with developmental disabilities a priority. We know that too many people with developmental disabilities are going without the supports they need. The government must deal with the long waiting lists that are preventing many families from accessing necessary programs and supports.

We applaud the fact that the government is making people with developmental disabilities a priority. The need for improvements and change has been identified by people with developmental disabilities, their families, government, staff and caregivers, and transfer payment agencies. But we have some concerns about the form that change is taking. Change is necessary, but it has to be the right kind of change.

As it stands now, Bill 77 will lead to a serious erosion in the quality of services currently provided by developmental service agencies. The new bill, as structured, will lead to destabilized funding for agencies and the creation of a parallel, privatized, competitive bidding system similar to the one that has been so disastrous in home care.

That's why I'm here to speak to you today. It is really important we get this right. Too many people's lives and well-being depend upon it.

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Most families who have a child with a developmental disability want quality supports and services they can count on as provided by the community-based developmental service agency system. Most families' lives are extremely demanding and they don't have the capacity to manage the many different types of supports and services their loved ones need. OPSEU is worried about aspects of this legislation that will lead to the erosion of the quality supports agencies are now able to provide. Our biggest concern with this bill is the creation of individualized budgets through the proposed assessment process. What this bill sets out is a needs assessment of each person with a developmental disability and then attaches a dollar value to the service needs of that person.

The creation of regional access centres and the development of a standardized needs assessment to ensure everyone is getting the supports they need has the potential to be very helpful for families. This aspect of the proposed reforms could make it much easier for families to identify what services are available, and standardized assessments could help ensure everyone gets the level of supports they need.

The problem comes with attaching funding dollars to the assessment results. If this bill goes ahead as is, instead of receiving a stable block of program funding as they do now, agencies will begin to receive the funding as it comes with each person for their service needs. This will mean a loss of essential administrative and overhead costs that go along with running an agency. Agencies will be forced to cut corners to cover operating costs.

As a consequence, the quality of supports agencies now provide will deteriorate. And since the funding will be tied to the client, agencies will become vulnerable as clients move on. Agencies will go without these funding dollars while they work to fill the placement.

It is critical that all reforms work to expand and improve the quality of supports developmental service agencies provide. Serving more people cannot come at the expense of the quality of supports everyone is now receiving.

Another of our big concerns with this legislation is the creation of third party private brokers. As you know, there are long waiting lists for services all across the province. If the bill goes ahead as is, this will mean families will have very limited options after receiving an assessment. Technically, they will be able to use their assessment to access agency-provided services, but in most cases it will mean staying on the same waiting lists they're already on or taking the individualized funding option.

Given this limited option, most families will have no choice but to take the individualized funding. Most working families don't have the capacity to find, hire and manage all the different types of supports and programs they need. They'll have no choice but to turn to the newly created privatized brokers. These brokers will take an automatic cut off the top and then find the lowest bidder to provide the services. This provision in the bill opens the entire sector to privatization and lowest common denominator service provision, as we've seen through the competitive bidding process in home care. It doesn't work in home care and it won't work in developmental services.

Lastly, we're very concerned that the assessment process will lead to a loss of services for some people now receiving high levels of support. This bill sets out to provide services to more people within existing funding dollars. It also legislates the assessment of everyone with a developmental disability, including those already receiving services.

The inevitable outcome of this assessment, given the goal of equalizing services for everyone with a developmental disability, is the loss of services for some already in the system, as was also seen in the home care sector. Although many improvements can be made to the current service delivery model, dramatic increases in funding are essential to any plan that professes to meet the needs of this growing and vulnerable population. The reality is that medical advancements have meant that many more babies are surviving at birth with developmental disabilities and they are living much longer. This means that the need for developmental services is on a steady incline, as has been seen for years.

At the same time, the government is in the process of moving 1,000 of the highest-needs people with developmental disabilities out of the three remaining regional centres and into community agencies, putting a further strain on the system. No amount of tweaking is going to fix the overarching problem that there just simply aren't enough services to meet demand.

Over the last year, the government has made some significant steps in increasing funding to this sector, but the reality is that the present level of funding doesn't come close to meeting the real need. At this point, the government has made no clear commitment to transfer all funding now dedicated to running the regional centres into the community-based system.

In conclusion, I would like to again applaud the government for making people with developmental disabilities a priority. We recognize your intention to improve supports for families and individuals, but we have serious concerns that aspects of these proposed reforms will lead to a serious erosion in the quality of supports currently provided through community-based agencies.

We would appreciate the opportunity to work with the government to amend this legislation to ensure we get these reforms right. First, it's critical that the funding model for developmental services agencies not be tied to the proposed individual budgets created through the needs assessment process. Without core, stable funding, agencies won't have the capacity to provide consistent, quality supports. Second, third party, privatized brokers must be eliminated from this bill. The creation of a parallel private for-profit system within developmental services will only lead to real long-term problems. Third, we ask that if the government is going to insist on closing their three remaining regional centres, they publicly commit to transfer all funding now dedicated to running the centres into the new community-based system. This funding must be in addition to all other money already committed.

We would also like the government to take advantage of the large talent pool of highly trained staff who work at the centres. Your efforts to ensure their placement in the community sector would help to build on the quality support now provided. People with developmental disabilities need quality support they can count on, and it's up to all of us to ensure that happens.

Thank you very much.

The Vice-Chair (Mr. Vic Dhillon): Thank you, sir. We have exactly two minutes to each side. We'll begin with the PC side.

Ms. Sylvia Jones: Thank you, Mr. Thomas. I wanted to ask you one question in terms of your concerns with direct funding. While I have spoken to many families and individuals who are very much looking forward to that opportunity, if you disagree with that—which, based on your brief, I'm reading—where do you see the role of the family and the individual in choosing the most appropriate services for them?

Mr. Smokey Thomas: If you're going to have assessment centres, I truly believe that the current agency system in place could be built upon to provide that function, for a couple of reasons: (a) They already have the capacity—they do it now; (b) it's not-for-profit; and (c) you wouldn't have to invest—I don't know how much it would be—to build new infrastructure and a new system. I heard someone say a new level of bureaucracy, but we don't believe it is required. You have the capacity in the system. You already do it now.

Ms. Sylvia Jones: Yes, I have no qualms about not moving forward on the application centres. I was more looking for your thoughts on where the role of the individual and the family is. If they can't access direct funding, what role do they play in choosing the most appropriate level of supports and services?

Mr. Smokey Thomas: They already play a role, but if you were to look to the psychiatric hospital system, the change to the community there would provide some very meaningful direction in this sector in terms of advocacy. I think the advocacy role in all sectors should be expanded upon. We don't have to reinvent the wheel. It already exists within the current system; you just have to look for it and find it. Families are very involved in both systems—the psychiatric hospital system and the mood of the community. The role of the families working with staff and the clients has been increased dramatically, so it's already there. It can be made to work without introducing a profit margin to it.

Mr. Michael Prue: A couple of questions: The first one has to do with those workers who are currently in the three regional centres. You made the statement that you "would ... like the government to take advantage of the large talent pool of highly trained staff who work at the centres. Your efforts to ensure their placement in the community" etc. Is the government not committed to placing those workers within the expanded community service centres that they're advocating?

Mr. Smokey Thomas: It's going that way, but it's slow and arduous. The transfer of dollars to the community system: there's not a large enough influx relative to the payrolls of those sectors and the community system is not built. So what we're saying is if you look at the people who work in those facilities, they could actually help you build and expand the capacity of the community system. As well, people in those facilities do the assessments. They provide a range of services that are needed by everyone whether you live in an institution, a small community or in a group home. We've long advocated what we call the hub model, and that's kind of what the community agencies could provide. We'd like to see the government sit down—and there's some work being done and some headway being made, but there's a large number of people on both sides of the equation, a large number of workers looking for work and a large number of people looking for services. If we could get both parties to sit—well, our side will sit at the table, and if government would sit down and be creative, I think we could really—

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

Mr. Joe Dickson: Thank you, Smokey. Just for future reference: There's a minor technicality in the introduction. It's Bill 77, but listen, as an old typesetter, I've made lots of typesetting mistakes in my life, so don't let it concern you.

I just have a bit of a quandary. As a businessman with a non-union staff, even though I have a couple of pressmen who, at my encouragement, maintain their union membership—I just like to see them do it as a safeguard—and as someone who worked as a youth under the old UAW and even just a couple of months ago supported our hospital workers—and a real problem we had—I always have concern for a fair wage, and generally that means more money.

But in the last few days we've heard some real problems in a recent strike. My question is, because of the sensitivity to people with developmental disabilities and the indiscretions that occurred during that strike, should service providers and agencies be declared an essential service to really ensure a caring, uninterrupted level of service for residents with disabilities? Or alternatively, if they were union members, how could you guarantee that would never happen again?

Mr. Smokey Thomas: It would be up to the government to declare them an essential service and pass legislation, and get into a fight with us, but you might win that fight. I personally believe that some unionized people who work in this system would welcome losing the right to strike, but they wouldn't have an alternative to settle the dispute. You'd have to have a binding arbitration option. You would find some people who, I believe, wouldn't care, and you would find some people who would stand up and say, "It's my democratic right to remove my services through a lawful process if I so deem." So I think you'd have a really mixed opinion. It would be up to the government to take it away.

Is it an essential service? Perhaps the government should look at the provision. In the OPS, there is a provision of essential and emergency service built into legislation, so that's probably a review for another day. But those strikes were as much about the quality of services as they were about getting more money into the system, as well as wages—

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

MARCEL WALSH

The Vice-Chair (Mr. Vic Dhillon): Marcel Walsh? Welcome to the committee, Mr. Walsh. You have 15 minutes.

Mr. Marcel Walsh: My name is Marcel Walsh and I'm here today for my sister. My sister is in her mid 40s and is multiply handicapped. This bill and how it is implemented will directly impact on my sister, my mother and eventually on my life.

My sister has always lived at home and is cared for on a day-to-day basis by my mother. My parents, a long time ago, decided they wanted to keep her at home with them and be cared for by them. My mother now provides all the care, but her health is failing and of course she is aging. I am the only other family member who lives close enough to provide some support for my mother. My mother's whole life has been caring for my sister, and it will continue to be that way until she passes away.

As my other family members are spread out with their own families and they've expressed clearly that they will not be assuming the care of my sister when our mother passes, I will need to make important decisions on behalf of my sister. Whatever plan is put in place, it will mean big changes for her life.

When my mother is no longer able to care for her, it will be important to move her into a setting, possibly her own home, as she ages. As few transitions as possible is important to her well-being. I am certainly not in a position to provide the high-intensity 24-hour care that she needs, nor would she be comfortable with having her younger brother bathe her and take care of her most personal and intimate cares. Also, we will be growing old together. She will need a residential placement where her needs can be met. I personally will always be involved, but she will need the support of a Community Living agency that is healthy and well-resourced. Before moving into a residential home, I anticipate a period where she will need support in order to have her stay as long as possible in her own home with my mother.

I am here because I am looking at my sister's future.

I believe all people, including my sister, are citizens of this country and province and should be entitled to the care and support that they need to be safe, secure and able to participate in community life as much as possible. This requires good, solid supports. It needs legislation that's going to commit this level of supports as a right and that people are not put on waiting lists depending on how much monies are in a particular geographic region. There should be a clear commitment of the government that these services be provided to those who need them.

I personally began to work in the developmental services field when I was 16 years old. Although I went to school to get my master's in psychology and a nursing degree, it was not long before I came back to working in the developmental services sector. It is where my heart is. I have worked in three provinces: Nova Scotia, Alberta and Ontario. Of the three provinces, I believe Ontario, with all of its challenges, provides the best care. I believe, however, this legislation is moving us in the absolutely wrong direction.

I want to tell a story from my Alberta days experience. I was hired by an agency to work 9 to 5, Monday to Friday, in a family's home. The family needed to take out extra insurance to cover their liability, as the son I was working with had high behavioural needs. The parents had a falling out with the agency and fired them, but asked me to continue. They had choice, so they decided to move their pot of money to another agency that had just been established. I was committed to this family, so I stayed. They transferred their contract to the new agency. The new agency, in turn, bounced two of my paycheques, so the family moved to directly funding my position without agency support. They had their own resources to top up my paycheques, but still I had no benefits. I had no supervisory supports and they had no coverage if I was sick.

When their son threw me down a flight of stairs and I broke my tailbone, the family paid me but needed to hire someone to cover for me while I was recovering for six weeks. I realized that if I was hurt again they could not afford to pay me. I realized how vulnerable I was and how isolated I was. I did not even have co-workers or supervisory supports to assist in developing new strategies to deal with the behavioural issues. I had to make the difficult decision to leave. These were great people, but I had no ongoing training, no accountability except with the parents, whose perspective was limited to their own experience, and no protection if I was injured.

I still keep in touch with the family, and they are wonderful people. I worked in their home for more than a year. After that, it was a revolving door for them with big gaps where they had no one to provide support. This story repeats itself many times. It does not work having a pool of workers floating out there; they are providing service with no ties to an agency. It does not provide good supports.

The government says it is about choice. My wanting the best for my sister is not a choice, it's an expectation. She deserves it, and it should be her right. Developing a system that does not have the same accountability for everyone who works in it is not the best for my sister. Having Community Living agencies struggling to keep staff is not good for my sister either.

What is best for my sister is a system that ensures dignity and respect and that the planning and services are delivered in a thoughtful, caring and well-resourced way. Choice for my sister is being able to access service to keep her at home as long as possible and then moving into a residential program when it becomes time. Choice is about having the types of supports that fit her needs as they evolve. It is not about whether I get to manage the money or not.

I strongly urge the government to put language into the act that commits them to providing the services to people supported by services to this sector. Waiting lists for people is not the way to respond to need. I urge you not to go down this road of a floating pool of people providing support without the supports of an agency. I've been in both systems, and the direct funding model, in my mind, has more down sides than up. Thank you for your consideration.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We'll begin with the NDP—about a little over two minutes.

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Mr. Michael Prue: Thank you; that was an excellent presentation. I think you put it probably more succinctly than I've heard from anyone else in terms of the problem with direct funding. The workers, in your experience, were vulnerable. Was that the experience in Nova Scotia as well as Alberta?

Mr. Marcel Walsh: I never worked in a direct funding model in Nova Scotia. When I worked in Nova Scotia, I was nursing at the psychiatric hospital, and I also worked for a privately run agency in Nova Scotia, where the wages were less than for one to be able to function.

Mr. Michael Prue: Also, and I don't know what your experience was in Alberta, but we know here in Ontario that the wages paid for people who do not work for agencies tend to be lower, in the $10 or $11 range. Those who work in agencies tend to be between $11 and about $15, although there is some dispute over that, and then, for those who work in unionized places, we've heard today as high as $23 in the Ottawa area. Can we expect, if we go with the model that's being proposed, that this will actually drive down wages in the sector?

Mr. Marcel Walsh: I believe so. I believe it will drive down wages and I believe that it would drive down the actual quality of care that we provide to persons with disabilities.

Mr. Michael Prue: You hit another good point in terms of benefits. I'm not sure whether people who hire individuals privately are required to pay that if it's the government, or perhaps we can ask that question: whether or not they will be required to pay benefits and hospitalization and all of those things or whether it's intended to be a contract service. In Alberta, was it a contract service?

Mr. Marcel Walsh: I started with the agency and I was hired into that role because it was an individualized funding project. The parents became disgruntled with the actual agency that I worked for and they fired the agency. Then they moved to a new agency that had just opened its doors for individually funded projects. After then bouncing my paycheque twice, the parents asked me if I would continue on with them and they would pay me directly. I had no WSIB coverage. I had to pay my own EI. I had to do all of that, so I was more self-employed. And when I was injured—

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

Mr. Dave Levac: Thank you for sharing your experiences. So your belief—I just want to make sure I strongly understand this—is that self-directed or personally directed funding would cause more harm than good and that it would lead to bad situations versus having parents have more say along with their adult children—an opportunity to have a more specifically designed program. Is that what you're saying?

Mr. Marcel Walsh: I'm saying that it could lead to more problems than good, yes.

Mr. Dave Levac: Okay. Thank you for your opinions. We'll make sure that they're recorded and shared with staff.

Mr. Marcel Walsh: Good. Thank you very much.

The Vice-Chair (Mr. Vic Dhillon): Ms. Jones.

Ms. Sylvia Jones: Just one quick question, Mr. Walsh. I think we'll have to agree to disagree on the direct funding model, but I would be interested if you have any thoughts on the personalized planning, individualized planning—if you have seen that either in your own family situation or perhaps in other roles that you've played.

Mr. Marcel Walsh: I have actually taken part in 24-hour planning in Alberta for the individual I worked with, to sustain him with actual direct funding, so I have been a part of that. Where my own family concerns are, we have not gone down that road as of yet.

Ms. Sylvia Jones: Is that because that has not been available to you or—

Mr. Marcel Walsh: Waiting lists are long, and at this point—

Ms. Sylvia Jones: For individualized planning?

Mr. Marcel Walsh: No, not for individualized planning.

Ms. Sylvia Jones: That was my—

Mr. Marcel Walsh: Okay. No, we have not done that.

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

NADIA WILLARD

The Vice-Chair (Mr. Vic Dhillon): Nadia Willard?

Ms. Nadia Willard: I have 10 copies of my presentation. My printer ran out of ink.

The Vice-Chair (Mr. Vic Dhillon): You have 15 minutes, and—

Ms. Nadia Willard: I have three portions. I was going to time them, five minutes each. That's all right.

First of all, I want to thank you for giving me the opportunity to speak to you about disabilities that people cannot see. My name is Nadia Willard. My husband and I have raised three children. Two of the three children have learning disabilities: the oldest child, a daughter, and the youngest child, a son. I am very nervous, so please bear with me.

I'm going to talk a little bit about the two children who have the disabilities and then the son who does not. Tina was diagnosed in grade 11 with an auditory memory disability. The psychologist who tested her could not determine how Tina learned and how she managed to get to grade 11 with an aptitude of a grade 7 student. Tina's school marks, at the time, all through her school years, ranged from the high 50s to the mid 70s.

Ian's story is just a little bit different. He's the youngest son and was also diagnosed with a learning disability. His disability was diagnosed in his third year of university. His disability is related to processing speed. This means that he needs a longer time to learn subject material and longer time frames to write exams and reports. His scores were significantly below predicted, based on overall ability.

Prior to grade 5, Ian's marks were H—they were marked on H, which is honours, A, B, C, D—so up until grade 5, he had nothing but Hs, except his penmanship, which was a B. After grade 5, Ian's marks hovered around the high 60s to low 70s.

Our middle child, Nathan, who is the talented, or, "ordinary" child, was not only successful in academics; he was also interested in highly competitive sporting activities. Nathan's marks ranged between high 80s to high 90s, and in grade 12 he was determined to have an overall average of 95. At the end of the year, he graduated with a 94 average.

I want to talk a little bit about our family. I can see ourselves in the lower-middle-class range, economically. The parents are both well-educated: a teacher, and I came out of nursing. We believed that to give a good foundation for our children, we needed to expose them to a whole variety of activities. We took them travelling; we gave them music lessons, dance lessons, hockey, football, whatever, to get them well-rounded.

Nathan seized all those activities and pursued them with zest. Ian enjoyed them, in part, competitively, but when he realized he could not compete at a high level, he started to withdraw. Our Tina, through all those experiences, learned that the country of Canada was an incredible place to live in. She was very happy, and always in awe of everything that we showed her.

We were highly supportive. We knew that our daughter had a problem, but it was not diagnosed until grade 11. With her, they told us that if she was detected at about a grade 2 or grade 3 level, they could have taught her how to process in order to get into the high academic level. Her IQ is really quite high, but the processing for her was not there.

Ian, socially, was always a bit behind. He always did not fit into the mould and was always marginalized by peers. Also, from grade 1 to grade 5, he was sort of the star pupil. We asked, "Who's the smartest in your class?" and he said, "Well, I am. I know everything." When we asked Tina the same question, she said, "I'm probably the bottom of the heap." These kids knew where they were, academically. After grade 5, Ian would say, "I just don't know why I know, and I hear, and I understand, but I can't get it out." So, there was a problem.

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We lived in a small community. Not wanting to rock boats, we didn't pursue a whole lot. We'd go to the school psychologist, whatever. They told us everything was fine with these kids, until the crunch came: They became depressed and they withdrew from the world. They were suicidal, the two, the youngest and the oldest. It behooved me that the health care system, the education system, which my husband was part of—we couldn't get to that point for them to make them feel like they were worthwhile. These children, our children, are not the only ones. I want to be very clear. I do not believe that we are the only ones facing this in life. They have abilities and capabilities, but because of the narrow idea of what they are expected to achieve, these kids pull away and cannot find the courage to get there.

They were marginalized in school. I want to tell you the story about how Tina was marginalized. Tina was in a really high-achieving classroom. In our community there was a private school. Tina was the only child in grade 9 not to receive an invitation to attend the private school. That mortified her—not that we would have ever let her go there, but the idea of exclusion was at that point. It was because her marks were not in the 80s and 90s—part of it. She was a really good athlete, so they could take her as being a fairly decent one there. What came out of that was depression. She isolated herself. She lost belief in herself that she could accomplish anything. Her esteem and image were totally damaged. Her social development at the same time was probably about a year and a half to two years under where all the other kids were.

When she was tested, we were told that she could not go to a post-secondary form of education, that she would never complete it, that she did not have the ability. So we talked about it, and what they told us was that if she took one class, which she did—she got a 92. When buckled up with another two or three classes, her marks dropped to 49 and 52. It was just the process that she had.

So she was unable to get a secondary education. What that did for her was pull her down into entry-level employment of minimum wage, not being able to go to school, not being able to work at a high-paying job, to sort of survive. She existed on minimum wage for a whole number of years.

When she finally did land a job that was consistent—she was with an employer for about three years—the employer started to pressure her to take a position in management, and she refused. She refused consistently for about eight months. Finally, she decided that she would tell them why she was not going to take the management position. She went to the boss and told him that she had a learning disability and she thought that she could not produce the way a manager could produce because of the disability. Within two weeks, she was fired.

To put all that together, she had to work very hard all the time just to pass. In grade 11, she was functioning at a grade 7 level, and it still baffles us as to how she's learning, because no one ever really figured that out. The end result is, when you are honest, society does not accept the capabilities of an individual. They shunt them out the door.

Ultimately, we hired a human rights lawyer from Calgary, and our Tina became my hero at that point because the lawyer had given her a whole list of reasons of what she could do in terms of making the employer pay, and all she asked for was severance from the date of firing to the date of closure of the agreement. She asked for a good reference and she asked that the employer never do that to anybody else who comes forward with a learning disability. She got that.

Tina is 38. At 35 is when she started to understand and shake the commonality that she did not have abilities and capabilities, that she could do things, that she was capable. Just this past year, in March, she was promoted within Parks Canada from working in campgrounds to the accounting department, and what she tells me now is that they can't believe that she can learn—take no notes and remember everything that has been said, spot errors and find them.

Tina's story now is a success story, but to watch this all go through and watch and know that there are other children who have faced this—early detection is really, really important to help these kids become as productive as they choose to be in their adult life. That's the story of Tina. She, by the way, has not actually, to this date, realized her full potential, what she is truly capable of doing. She is just in that mode of realizing. So in the long run, it is a success story.

I want to talk about Ian. Ian, from kindergarten to grade 5, was an honour student. He knew everything. He was carefree, kind of. He was stressed at times, but he always worked through it. Grade 5 was when, in the first term, he still had honours and all his marks. The second term, his marks dropped to Ds and one C. We looked at this and we went to the teachers and we asked, "What's going on here?" And the teacher's response was, "It looks like he wasn't trying." We talked to Ian—and I think this may have been an excuse, but in his own little way, it was his way out—and he said, "Everybody bugged me about how smart I was, so I decided not to be smart."

After that second term when everything went down, the third term he brought his marks back up, but they were only Bs and As. But it was, in retrospect, at that point right there where he should have been tested—early detection. We went to the teachers. At the time, the teacher-student ratio in the classroom was like 35 to 1. Ordinary teachers are good teachers, but when you start pulling in children with disabilities, and they have to make—all it takes is four parents to say that there's something wrong with four children. That teacher then has to end up preparing four or five different types of lesson plans to accommodate the curriculum. That is a burden that teachers do not have to give—

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

Ms. Nadia Willard: Okay. If there's anything to say, early detection and support mechanisms, financial and personal, to help children not get into—what you're looking at is Bill 77. There's lots of abuse. You could lower that down. I know it costs a lot of money, and whatever.

All right, let's go to the conclusion. In conclusion, I would suggest that the experiences of my children are not significantly different than most children in our society. Our society's desire to nurture success in very narrow terms means that we have marginalized many talented and productive people who are struggling and producing far below their capacity. I commend you for moving this legislation forward and putting health, social services and justice issues into the same legislation. I did not see any significant reference to education and to early detection of disabilities in learning. Any attempt to address disabilities without using an approach that addresses the complete needs of individuals will not be as successful as you think it is.

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

Mr. Khalil Ramal: Thank you very much for your presentation—

The Vice-Chair (Mr. Vic Dhillon): I'm sorry; I'm sleeping here. She's used up her time.

Ms. Nadia Willard: I can answer questions later, if you want.

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FAMILY VOICE OF LANARK COUNTY

The Vice-Chair (Mr. Vic Dhillon): Family Voice of Lanark County is next. Good afternoon. You have 15 minutes. If you can state your names for the record, you may begin now.

Ms. Joyce Rivington: My name is Joyce Rivington and I have a co-presenter with me from Family Voice, Cora Nolan. We are parents of young men who are in their early 30s. We belong to a group of families that have children with developmental disabilities. Family Voice assists families to network with one another, with provincial family organizations and groups. We provide support, resources and information sessions to raise awareness of what options can be available and what is currently being offered.

We strive to ensure recognition of the value and contributions of individuals with developmental disabilities in our lives and communities. At this time in history, with the transformation of developmental services, it is critical that individuals and their families are recognized as the true stakeholders—those who live a lifetime with the impact of decisions that directly affect their lives.

We are thankful to this committee for giving us the opportunity to speak here today. Both Cora and I have been very involved in the transformation process and we are really pleased that we're going to be able to present the issues today.

To ensure the lives of individuals with developmental disabilities are free of historic prejudices and injustices, we believe the following areas need to be addressed and incorporated into the new act. We respectfully submit the following:

(1) The act must reflect the true spirit and intent of what transformation of developmental services is intended to accomplish. The purpose of change must be clearly identified in a preliminary description. The proposed legislation does not identify the depth of social change or the language of change to create a new vision and reality for individuals and their families.

We recommend a preliminary description that includes the following section taken from the vision paper In Unison: "Persons with disabilities participate as full citizens in all aspects of Canadian society." With commitment from all segments of society, persons who have a developmental disability will "maximize their independence and enhance their well-being through access to required supports and the elimination of barriers that prevent their full participation."

(2) The title of the act needs to encompass the purpose of the intended change and reflect the building of capacity of people versus service provision. "Services" is not an adequate description. Transformation is not just about services; it is about providing support that enables individuals to have the same opportunities afforded to all citizens.

We recommend "An Act to provide support and services to persons with developmental disabilities, to promote and enhance full inclusion in society, to repeal the Developmental Services Act and to amend certain other statutes."

(3) Stakeholders: For equality to be achieved, equal status must be given to individuals, their families and advocates. Exclusion of families from the lives of individuals with developmental disabilities has created the prejudices and injustices that exist and that will continue to exist. Individuals directly affected by decisions that are made need to be equal partners at decision-making tables.

We recommend recognition, status and voice be given to all stakeholders.

(4) Person-centred planning, networks of support and independent facilitation are vital mechanisms to promote choice, independence and quality of life.

We recommend person-centred planning, networks of support and independent facilitation be identified and recognized as legitimate support and service options.

(5) Application centres: Too much power is given to centres to assess an applicant's need and develop a service profile with no evidence of individuality, fairness, democracy or right of appeal. The centre appears to inflict another form of control and rule over individuals who are supposed to be set free from institutional bondage. Transformation should not be a move from institutional centres like Rideau Regional Centre to an application centre.

Many individuals with developmental disabilities have benefited from early integrated preschool programs, inclusive education, person-centred planning, special services at home and other forms of individualized funding. To some families, the proposed legislation is already feeling outdated. Individuals are at different levels and different places in their lives. The concept of an application centre does not identify or appear to recognize self-determination and true citizenship rights. As so well expressed by self-advocate the late Pat Worth, "Deinstitutionalization can equate with citizenship only if it means freedom."

We recommend that careful consideration be given to the role of centres—if not eliminated.

Ms. Cora Nolan: To continue:

(6) Individualized direct funding: The act must recognize the need to increase choices for individuals and their family and caregivers who wish a greater voice and more active role in how support and services are provided—when, where and by whom. Quality of life is achieved when individuals and their families are supported to identify their needs, determine preferred supports and have control over required resources to the extent they desire to enable the pursuit of a chosen lifestyle.

We recommend that individualized direct funding be clearly identified as a viable choice for individuals and their families.

(7) Wage equity measures: Individuals and their families who choose individualized direct funding must be given sufficient funds to allow for wages comparable to workers in the service system. Special services at home and the Passport funding initiative are current examples of individualized funding models that provide choice and flexibility but have no provision for cost-of-living increases. There are currently blatant imbalances and unfair practices. Wage enhancement was given to the social service sector employees but not to families with direct funding. A transformed system must be accountable and transparent to individuals and their families.

We recommend the provision of fair and equitable wage and cost-of-living increases for support workers contracted by individuals and families, comparable to staff of service agencies.

(8) Waiting lists, such as occurred with the Passport initiative, have put an unacceptable and intolerable strain on many individuals and their families in Lanark county and across the entire province. There was no funding for people, but there is money to hire expensive consulting firms. Waiting lists are contrary to the vision of transformation and inhibit individuals with developmental disabilities from participating as full citizens in all aspects of Canadian society, maximizing their independence and enhancing their well-being through access to required supports and the elimination of barriers, such as waiting lists, that prevent their full participation.

We recommend that waiting lists be removed.

(9) Inspection of homes: The infringement on the rights of individuals with developmental disabilities suggests that they do not have the same rights as afforded to the non-disabled population. The suggestion of this type of authority over a fellow citizen is regressive and of an institutional mindset of "different and therefore not having the same right to personal dignity, privacy and respect."

We recommend that safeguards be in place to ensure the rights of individuals with developmental disabilities are not infringed upon by invasion of their homes.

(10) The right to an independent appeal process.

We recommend that the act incorporate a fair, independent and unbiased appeal process.

In summary, as families who have sons and daughters with developmental disabilities, we have tremendous concern regarding the issues identified. Some of the issues are of particular concern because of the potential to have the needs and rights of individuals and their families exploited and/or violated.

We request that before Bill 77 is passed into legislation, careful consideration be given to our concerns to ensure that the voice of people who have a developmental disability and those who care and love them is heard.

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

Mr. Khalil Ramal: Thank you very much for your presentation. We listened, basically, to the same suggestions from many different organizations across Ontario; there's no difference. I especially want to take your input in terms of application centres; it seems like the most important one.

Throughout the province in the north, in London, Toronto and the Ottawa area, people came to us and told us, "We are successfully able to manage our jurisdictions." How can we unify the whole system across Ontario without creating a centre combining all of these collective efforts, in your own opinion?

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Ms. Joyce Rivington: In our county we have a pressures and priority committee and we've been involved in advocacy for our children's—

Mr. Khalil Ramal: No doubt you do an excellent job in your county and other counties, but how do we connect all these people together? We have to have some kind of mechanism, a centre to connect all these organizations, all these efforts together, in order to have a unified standards system across the province of Ontario.

Ms. Joyce Rivington: The regional offices have been working, listening to people over the years. I think that if there's the opportunity for people to have a better connection with people—the centres aren't going to understand the personal needs because our area is rural, and where are these centres going to be? Also, the term "centre" is a concern because it has a "centre" ring to it. We're sort of putting people in boxes again, centres, and then they're all going to be at the door of centres, the unemployment centre, to get what they need. I think it has that—

Mr. Khalil Ramal: We can change the name if that would help you.

The Vice-Chair (Mr. Vic Dhillon): Thank you. Ms. Jones.

Ms. Sylvia Jones: Let me help you: It has a bureaucratic ring to it.

Ms. Cora Nolan: It's another level of government, too.

Ms. Sylvia Jones: Yes, absolutely.

Ms. Cora Nolan: It gets overwhelming after a while.

Ms. Sylvia Jones: I don't have any questions for you because you've done a very good job of encapsulating the issues that families and individuals have been raising about Bill 77. I appreciate you coming forward today.

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

Mr. Michael Prue: Just a question here around your point number seven: wage equity measures. You make the statement, "Special services at home and the Passport funding initiative are current examples of individualized funding models that provide choice and flexibility but have no provision for cost-of-living increases. There are currently blatant imbalances and unfair practices." I don't know whether you were in the room, but about three or four deputations ago, a man gave his example of when he worked in Alberta and had to pay his own bills and the family had to pay it. If the system that is being proposed is to succeed, do you believe that the people who work in the sector have to belong to an organization so they're covered, or do you expect them to be private contractors and subject to what happened to that man?

Ms. Joyce Rivington: I think there could be different types of service. For some people, they might choose a service organization; for others, it may work to hire somebody privately. It just depends where people are. It's just like everybody in this room. We're at different places in our lives. Certainly there are going to be problems with some private contractors or some for-profit agencies because I have heard that: that they are not accountable and they don't have to be accountable to the ministry. But if families are involved—certainly over the years I have had, personally, a lot of success, but then again we have individualized planning and networks of support and we buy into that belief system and philosophy, so it works, because we have everything that goes along with it. Perhaps for the person you're referring to, it sounded like that family was isolated and they were just hiring on their own and they weren't connected.

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

CONNIE HURTUBISE

The Vice-Chair (Mr. Vic Dhillon): Good afternoon. If you can please state your names for Hansard, you have 15 minutes.

Ms. Connie Hurtubise: My name is Connie Hurtubise, and with me is Amy Parker. You are getting to the end of four very long days, and we thank you for this opportunity to appear in front of you as one of the last presentations of this consultation process.

Let me start with saying that the government of Ontario's stated commitment to revitalize social services and to provide effective supports for vulnerable people in the province is so important. The social service field is the third pillar, along with the first two pillars of education and health. So in 2004, when the government announced that the province would be transforming supports for people who have developmental disabilities to create a coordinated system of community-based supports that is accessible, fair and sustainable, there was huge hope that a long-time-neglected group within our province had become a higher priority on the government's agenda.

Amy and I come here today as front-line workers in the developmental services sector, Amy from an agency in the Ottawa area, and I'm from an agency in the Cornwall area. We are not here representing our employers. We thank you for the opportunity to participate in this consultation process.

The government has had lots of feedback from various sources over the last number of years. Although there are clearly some differences, there is a strong theme of problems related to access. The goal articulated by the government is making the system fair, easier to use and more accessible, having the opportunity to access funding no matter where you live, and having flexible funding which would allow for choice so that decisions could be made for the appropriate supports and services for the individuals. It is what we all want for this sector. Amy and I work in this system, and we have had the privilege of meeting, talking and working together with families and workers, so we are not at all surprised by the findings of the past consultations.

Although we applaud that the government is taking the developmental service sector revitalization challenge on, we are discouraged with the direction of Bill 77.

A consistent message that is heard is that it's hard to access the current system. There are not enough supports, not enough workers, insufficient wages to recruit and retain qualified workers, and all too often we find that there are families to this day still having very hard times. The 2006 report by Ernie Parsons also sets out these very challenges.

One of the main principles underlying the transformation of developmental services is that people who have a developmental disability are people first, and it is therefore important that we start there. In May 2006, the government suggested that a successful outcome of the transformation will be the extent to which people who have a developmental disability are recognized and valued as being part of their community. Our shared goal is to enable people to live in their communities as independently as possible and to participate as full citizens in all aspects of community life. We believe strongly that this commitment must underpin the legislation. Our recommendation is to include a preamble to the bill that acknowledges the inclusion of all residents as the foundation of our strong Ontario, including persons with developmental disabilities.

We believe that inclusion moves from being an ideal to becoming a reality when we acknowledge the entitlement of persons with developmental disabilities to support services that are available consistently across the province and are based on person-centred planning. Citizenship should serve as a benchmark for legislation as it will give clear value statements and guides for the development of regulations.

In order to meet our shared goal, we believe that the legislation must also guarantee access to service. A mandating of service is crucial in the support of individuals with developmental disabilities and their families. Families, agencies and workers are pushing hard for a system that is proactive and responsive. The reality is that resources have not been provided to do this in a way that fully responds to individual and family needs. When you look at the length of waiting lists and the difficulty of access to supports and services to support individualized plans, it really comes down to creating an infrastructure to support the commitment of supports and services. The response should not be legislation to manage waiting lists.

I can share an experience that we've had within our agency on the waiting lists. We have a respite bed, and one individual was there for a weekend. Her family was so overwhelmed with her care that they just never came back and picked her up; she stayed with us. We've managed to move other individuals around within our agency in order to support this individual. The family was at their wits' ends. She's still with us after 10 years. She's doing great. Her family is very involved in her life, but they basically had their backs against the wall and they couldn't do anything else.

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Parents should not have to take this type of action to access service. This situation is not as uncommon as you think. Families needing to access residential beds or independent living supports must often be in crisis before they move to the top of the list. This is heartbreaking.

There has been lots of discussion around the concept of choice. Amy and I fully support the right to have choice, but where's the choice if you're sitting on a waiting list? Bill 77 has entrenched waiting lists right in. Where's the choice if a family must reach crisis in order to be bumped to the top of a priority list in order to receive services? Is it more appropriate, caring and respectful to have families' involvement when implementing a change for a family member than to invoke the change after the death or breakdown of a parent or caregiver?

Also, access to support to keep people in the home or access to community programs is challenging. Funding and supports need to be innovative and flexible. Individuals need to know that their access to services will change over time as their needs change. Choice is not about a funding model; it's about individualized person-centred planning. It is having quality mandated supports and services provided by qualified staff who are supervised.

Too often, Amy and I talk to families who have successfully received funding under the current individualized funding program in order to support their family member, only to find that they cannot find qualified workers or people who are willing to do the job. They must concern themselves with hiring, training and managing staff. They must do without services when the worker they've hired is sick or injured. These situations fail to provide consistency for the vulnerable individuals we strive to support. There can be no choice if the supports and service are not in place in the community to take an individual's plan, and that person's and their family's hopes and dreams, and put them into action.

Individualized funding caters to a few. There is concern when focus on this legislation seems to be an expansion of the funding, rather than committing to a level of services and access. By far, the greatest demand for services are services delivered by community-based agency programs. If the legislation ignores strengthening agencies, then it is a disservice to the individuals with a developmental delay and their families.

Community agencies have a structure to ensure staff are trained, supported and held accountable for service delivery. Supports need to be equitable and people should receive quality, mandated supports across the province. There needs to be a set standard of quality service for all.

What good is recognizing necessary supports and services that a particular individual in the family may require if the community or surrounding area does not have that service? Does this legislation have a plan for providing the necessary supports and services, regardless of where you live in the province? How can the goal of recognizing people who face the challenge of a developmental disability every day, as people first, be faced without a plan to ensure supports and services are mandated for all and will be available, regardless of their geographical area, severity of disability, existing services etc.? Does this bill identify these questions?

Systems are put in place for a reason. They are there to ensure consistency and quality. This legislation further fragments this sector. If the focus of this legislation is about choice, then create legislation that commits to mandate service and fund it so that there is choice of appropriate quality accessible supports and services for individuals with developmental disabilities.

One final point is a concern about individuals needing to be diagnosed by the age of 18 in order to be covered by this act. This means that individuals who are incorrectly diagnosed prior to the age of 18 would not be eligible for service and supports under this act. This is likely an oversight and we urge the standing committee to recommend changes to ensure that this doesn't happen.

We thank the committee for hearing some of our concerns.

The Vice-Chair (Mr. Vic Dhillon): There is time for brief comments and questions, about a minute. We'll begin with Ms. Jones.

Ms. Sylvia Jones: Thank you. I couldn't agree more that the diagnosis shouldn't have to occur before 18 in order to have access to services and supports.

You mention that the funding needs to be innovative and flexible, and yet you believe that individualized funding caters to a few. How do you match those two statements?

Ms. Connie Hurtubise: About 80% is community agencies, and the individualized funding is catering to the individuals who aren't part of that.

Ms. Sylvia Jones: But Bill 77 isn't doing a swap. It's legislating that there is the option of direct funding if families so chose, so it is giving, in my opinion, that flexibility.

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

Mr. Michael Prue: I'd like to thank you for your deputation as well, but just to stay in that same vein in terms of individualized funding, has your agency, community living, given any thought to people who choose to go outside the system as it mainly exists now to hire their own people, whether those people will be employers or whether they'll be hiring a contract person? I know this is difficult, but the gentleman who was here earlier, Marcel Walsh, really made a point of his experience in Alberta where he worked under both. Have you and your agency thought in any way whether families would be invited to employ someone, or whether they would sign a contract? I think there's a difference.

Ms. Connie Hurtubise: I'm not sure how our employer is seeing doing this, because we don't really have too many conversations about that. I do know from experience of a staff member who has a child with a developmental disability who was an active member of our agency. She applied for the individualized funding, so she had to withdraw him from our agency and then turn around and purchase these services. But the money that she received is nowhere near the amount of supports that she received from us when her child was attending our program.

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

Mr. Dave Levac: I was interested in hearing your explanation regarding the fragmentation of the delivery of service if the direct funding were to take place. You believe that it will actually diminish what the agencies are providing and actually not deliver the service that the individual parents are negotiating for. Is that a correct assumption, the way I'm hearing that? There's going to be a diminishment of the service right across the board?

Ms. Connie Hurtubise: I don't know if there's going to be a diminishing of services, but the individuals who are accessing the individualized funding will now be put on waiting lists, and they'll be at the bottom of the waiting lists to receive the services that they are basically already receiving now through the community agencies.

Mr. Dave Levac: So the assumption you're making is that the waiting lists are being created so that it can be a delay in the providing of that service.

Ms. Connie Hurtubise: The waiting lists are already there.

Mr. Dave Levac: Correct. So it's an acknowledgement of the fact that the waiting lists will not disappear, so that no one can get left off, as we would do for waiting lists for operations in health care, or waiting lists for any other services. That entrenchment has taken place in other legislation in order that those individuals who are on a waiting list are not just simply pushed off and forgotten completely.

Ms. Connie Hurtubise: I'd have to get back to you on that one.

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

ACCESS NOW

The Vice-Chair (Mr. Vic Dhillon): Access Now? Welcome to the committee.

Mr. Charles Matthews: I hope I'm going to be able to move most of you as I just almost moved your furniture.

The Vice-Chair (Mr. Vic Dhillon): If you can identify yourself, sir, before you begin. You have 15 minutes.

Mr. Charles Matthews: I'm Charles Matthews. I'm president of an organization called Access Now. We also produce a newspaper. Very basically, I'm going to give you a little idea of who we are and what we're doing, and then give you a little feedback on Bill 77.

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Where it all began: Prior to May 10, 2001, 12 of the founding members of our parent organization, Disabled and Proud, had worked on accessibility issues for many years, three of us for over 10 years at that point. I, Charles Matthews, am one of the original co-founders of Disabled and Proud, along with Jean Wyatt. Unfortunately, Jean left us a couple of years ago. I have been working on accessibility and health issues ever since the early 1970s. I have been the president since the inception and continue to stay in this capacity, not only for the group known as Disabled and Proud, but as the publisher and editor of our newspaper, Access Now, as well.

On May 10, 2001, the Para Transpo strike ensured that the disabled community went without service for almost 10 weeks—70 days. A group known as Action Ottawa, which many of us were part of, primarily consisted of concerned disability activists who successfully held a protest march that basically shut down the rush hour commute home here in Ottawa. That's the most militant we've ever been, by the way. Disabled and Proud was actually taking shape on that day, and within a week, we were officially formed. I invite you all, in a future time, to visit our website, accessnow.ca, and you can read more on this. I will be submitting all of this in writing to each and every one of you.

From June 14 to June 18, 2001, there was a summit here in Ottawa called the Ottawa 20/20 summit. This summit was a result of a dynamic process where citizens, in collaboration with city staff, articulated a shared vision for the new city of Ottawa, and they called it Smart Growth, referring to the forms of development that enhances the quality of life in communities, complements functions, ecosystems, and uses tax revenues wisely. This summit examined the concept of a smart growth and how it could be applied to Ottawa. It also explored the many challenges that wait ahead, including everything from transportation to economic growth to affordable housing, arts and culture, as well as our evolving social needs.

It was at this summit that Disabled and Proud started its work at both the municipal and federal levels. We also were one of the few—about 10 in Ottawa—working along with David Lepofsky on getting an ODA committee formed, based on the Liberal/Tory report from the 1990s. There was no information that was reliable in mainstream media for news on accessibility issues, so we at Disabled and Proud decided to start a newspaper called Access Now. This started in 2002. There are copies all over the room, which we're more than glad that you help yourselves to, and you can see a little bit of who we are and what we do at all three levels of government.

Access Now is the name of our newspaper and, as you know, our parent group, Disabled and Proud, which has been leading co-ordination for seniors and disabilities who independently advocate for accessibility for all. We are inclusive and supportive of each other, and not only for our benefit but also for the benefit of all who strive for independent living and the right of accessibility. We communicate with each other in many ways: through face-to-face gatherings, meetings and technologies such as the telephone and Internet. Our goal is to make the best use of all our resources and our strengths. We support each other to be more empowered, better informed and aware of our issues, as well as unique and innovative solutions toward daily survival.

We strive, through sustainability funding, to be viable. In a perfect world, Access Now may not need these funds; however, we're here for as long as the mainstream media does not report on what we need to know about and as long as those with disabilities and seniors alike need each other's friendship and support.

I personally have worked with the minister, Madeleine Meilleur, not only at this time but also back when she was a councillor in the city of Ottawa and chair of the transportation and transit committee. A lot of the transit issues that started going really forward and ahead in this city were developed from that first transportation committee between the years 2000 and 2003. Another member here was also on a lot of those boards, and he did a remarkable job as well.

Madeleine Meilleur was also the founding councillor for the accessibility advisory committee here in the city of Ottawa. This was all done prior to the ODA.

The next part of my presentation, which is going to be forwarded to you, is long-winded, and basically it's all your words from the community website, so you'll have to agree with all the facts and figures in the next four pages—word for word, by the way. So I continue with my presentation. These words are from the communication centre of the ministry, and what we're doing here today. The reason why I'm skipping over this is because I want to allow for all my points to be put forward today.

We at Access Now agree that the current development disabilities act was outdated and Bill 77 is indeed a step forward. Our major concern is that the replacements and new systems will be put in place but will be factual and not just window dressing, as we've seen from previous governments. The last government, Eves-Harris, promised, when they told everyone to go home early from the hospitals, that the government will be putting in place home support services so it may help with the bed shortages in the hospitals. When our clients did go home with these so-called supports at home, they quickly learned that these supports were not a reality at all. Many wished they had stayed in the hospital, and many more had to be re-hospitalized or even returned with acute care needs because of miscommunication in the supports being in place.

We also needed accountability. One of the major concerns we get from our clients—or readers, in this case—is the lack of accountability. One of the major services that a person with developmental disabilities needs is a trustee, as an example. Currently, we have many readers who have contacted us over the last couple of weeks to voice their concerns that they've not even seen an income statement for the last four or five years. So when they have a trustee who is taking money and then paying it on their behalf, shouldn't there be some accountability there? Even when requests for funds are put into the trustees' hands, direct funding may be the way to get the trustee to account for their services.

The only negative we're hearing about this bill is from the current suppliers of the services. In fact, some of them may be losing their jobs. Examples are in the letters you've all seen from OPSEU in regard to the fact that employees are going to be losing benefits, they're losing their jobs, so on and so forth. Well, my answer to all that is very basically, if they're doing the jobs in the right place, then people wouldn't need to go to other services. But with this bill, it basically gives additional services for direct funding and does not take away from those services, so any of the agencies out there that are doing a proper job don't have to worry.

The general feeling is great. Maybe other sectors will get the message that they should be doing the best they can for their clients and not what's best for keeping their clients dependent on a broken service.

The last point that we want to emphasize is that we should not be going from legislation that segregates all to assist them and then come up with another legislation that basically is going to put everybody in a totally integrated environment without the proper supports, so they won't reach their full potential. Last but not least, we want them to look to the organizations that truly help their clients and go that extra step in supplying services so desperately needed.

Now, I do have some comments that I'd like to make at this time, or I'm open for questions. I'd like to make some comments about some of the things I've heard here today that were either not factual, or misleading or something in one way or another. First of all, we're giving you true feedback here because we do not represent an agency that is getting paid from the government to do different services in any way, shape or form. The only funds that we get from any kind of government are from advertising in our newspaper, people who support us, basically. When our readers come to us—we're all volunteers, so none of us is making a single dime, including myself. We've been doing this since the 1990s and we're all volunteers, so any kind of personal gain is not being recognized here.

Our clients come to us because they sometimes have a lot of problems with the systems that are out there. A good example is one of our clients: "I can't get much help from the mental health societies and organizations that are out there. But I want to tell you, Charles, that Y's Owl has been supporting me for two and a half years, and they don't have to, but they're doing a great job." That's a pat on the back to Y's Owl.

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One of the problems that we're having with a lot of the clients who have developmental disabilities is with the system the way that it's set up right now with OCAPDD. One of the problems and the most major problem that they're having here is with regard to the follow-up trustee. Once they wean a person off of a certain part of their service, they don't contact them ever again. Follow-up is very important, especially with developmental disabilities.

One example of this is a person who had a doctor. They have a cognitive disability where they have a lot of problems getting to a doctor. So they used to pick them up at first, take them to the doctor, then wean them onto the bus service and eventually have them take the bus themselves to the doctor. Good enough. About a year later, that person lost that doctor and needed a new doctor. She said, "Can I get some help?", and they said, "Well, we showed you how to get to the doctor." It's a different doctor. This person should have no question, in any way, shape or form that OCAPDD could have helped this person once again.

Another thing is in regard to the legislation. What we find is that a lot of organizations around there have been around for a long time, and at one time, they were very, very good at what they did because they were the only ones out there doing some things. A good example of that is in DPCR, Disabled Persons Community Resources, which basically is being used as a staffing function by the city because they've done a great job for many, many years; they continue to do so. But the people there are dependent on a person being dependent, because that way they keep their jobs. When everybody comes out and starts doing things, like volunteers in our case, where we want things accessible and that's our goal, we get a hard time sometimes.

Some of them, as an example, have also been doing a good job for a long time before, but they've kind of outgrown that and are basically empty shells right now. This is where I want to emphasize that this standing committee—and also the Ontario Disability Support Program Act, as well as the ODA—should start taking a look at organizations that are really out there and actually doing the front-line work, that are actually going out there and helping the people who need the help.

One good example of this is when you're looking to the community for legal advice. One organization that's doing a great job—and you heard from them today—is ARCH. I suggest that the committee and subcommittee, when you're setting up the regulations, look closely and work closely with ARCH, because that's where their interests are. There are other organizations out there that raise millions of dollars, and they are basically empty shells. One good example of that—I don't usually like to badmouth, but in this city and across the province as well, there's an organization that's called Reach, and it's nothing more than an empty shell. Meanwhile, millions of dollars are funnelled into this organization, and the actual work being done on all kinds of legal advice, as far as disability work goes, is by ARCH itself.

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

Mr. Charles Matthews: One minute? Okay. To wrap up: Very basically, listen to the voice of the disabled community. Keep on doing what you're doing with Bill 77—but I do want to emphasize the fact that you have to put in what is going to be available once this act is put into place: what kinds of systems are out there and also what kind of legislation can guarantee the people that they will have an effective act with the supports behind it to actually make it possible, not like in the physically disabled community with home care support, where it was not put in place. The direct funding under the ODSP Act in regard to home care and all of that: We want to make sure that the developmentally disabled basically get that support as a reality rather than something that's retractable.

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

ONTARIO ASSOCIATION OF RESIDENCES TREATING YOUTH

PARTNERS IN PARENTING

The Vice-Chair (Mr. Vic Dhillon): The last deputation is from the Ontario Association of Residences Treating Youth.

Ms. Christine Rondeau: I'm Christine Rondeau, representing the Ontario Association of Residences Treating Youth, which is a provincial organization for private residential care and treatment providers. Many providers also provide support to adults with developmental disabilities. As well, I am a co-owner of two private agencies here in Ottawa, one named Partners in Parenting and the other named ACEworks. In total, our organization serves over 80 adult clients daily who will be directly affected by Bill 77, as well as another 20 children in the child welfare system who will be affected by this bill in the next few years. Therefore, sustainability of this bill is vital.

It is my pleasure to be here today to comment on Bill 77. The introduction of this bill builds on the government's commitment to make Ontario inclusive for people with disabilities, and as such, we support the sensibility of this bill. We are aware of many of the concerns presented so far and we want to highlight those concerns which we have not yet seen expressed.

In this bill, application centres are tasked with managing the client's case: assessing the condition, determining funding, as well as providing the service to the client. In effect, it is operating a multi-service centre. Currently, Prescott-Russell is the pilot project for the amalgamation of child welfare, developmental services and child protection under one umbrella system of care for children and adults.

Similar systems are being implemented in Lennox and Addington and possibly Niagara Falls. Giving one party or one organization the ability to be responsible for assessment, treatment, funding and accountability is absolutely not the best practice or the best model for the persons in care, who are by definition vulnerable, either because they are children with CAS or because they are developmentally challenged as per the DS sector.

In Bill 77, the proposed model replicates exactly what is flawed in the child welfare system. With the relationship of the CAS responsible for the needs of children as their guardian balanced against service, they can provide in-house versus seeking specialized, often more appropriate services.

Our recommendation: Assessment, funding allotment and service provision should be separated. This would allow for the accountability to be judged, determined and monitored by independent parties in each discipline within the service continuum. Third-party scrutiny of each role would be ideal. Resources would be funded directly via MCSS or a third-party agency—for example, a community network service. An example of this model is: The case management agency holds the case, the service agency provider holds the care, and the third-party agency monitors resources, standards, accountabilities and outcomes of all cases.

Another of our policy recommendations to the ministry is third-party accreditation. None of the CAS residences are accredited, and this is a concern. As a sector, we have begun the process and can speak to its exactitude and the demanding and thorough investigations involved in accreditation. Accreditation standards were not detailed in Bill 77, but accreditation is necessary as a quality control mechanism. Our recommendation is to insist that all service providers and access centres be accredited and ensure that accreditation is carried out by a distinct third-party group, rather than a peer review system, which leaves the system open to abuse.

Many important details on how Bill 77 will actually operate on the ground are unknown and really must be specified in regulation and/or policy. One of the enormously significant details of concern are the qualifications of the persons conducting assessments and the methods and criteria they employ. Assessment methods are of immense concern to families and to the professionals and paraprofessionals who provide services to individuals with developmental disabilities.

Our recommendation is to establish clear specifications of the qualifications for the professionals who will be providing assessments. We believe these criteria should be set centrally and not vary substantially across the province. However, we understand that there will be some cultural concerns that may be reflected in the composition of the staff given prevailing geography.

OARTY is concerned with sections 26 to 28, which allow for the inspection of premises of services. We are not concerned with the inspections per se; we frankly encourage them. What OARTY believes is that more parties watching everyone is a better system. Presently, the transfer payment agencies providing care to adults do not get scrutinized in this way. In fact, there is also no outside case management.

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The children's model of inspection should not be replicated, as it does not work in a meaningful way to ensure centrally set standards are being applied. This is due to the deficits in the inspectors and in their training.

Recommendation: Implement a uniform skill set across the province for inspectors and a uniform code of conduct to be determined centrally.

Section 22 notes that the service agencies shall comply with prescribed requirements with respect to the operation of a service agency, including any requirements relating to the composition of its board of directors. The director may appoint inspectors who are able to set standards for service providers and their boards of directors. There are a significance number of private providers that offer a much-needed service but do not have boards of directors. Therefore, these operators may be excluded from participating in the developmental services framework as conceived in Bill 77. Is it the intent of this bill to exclude these resources?

Recommendation: Consideration is to be given to service suppliers of all sizes for the efficacy of the legislation.

The private sector is currently providing a large portion of services to adults, and it is vital to continue to support the private sector where clients and their families purchase services that are needed. The private sector supports programs without capital costs and is able to work directly with families and clients to provide programs that clients and families need and want in a timely manner.

Thank you for taking the opportunity to allow me to participate. It is a privilege to be here to speak for those who cannot speak for themselves.

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

Mr. Dave Levac: On a point of order, Mr. Chair: Given that recommendations were specific, is there a chance that we can get a hard copy for the committee?

Ms. Christine Rondeau: Yes, I will do that.

Mr. Dave Levac: Thank you.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We'll start with the government side.

Mr. Dave Levac: Yes, thank you very much for your presentation. You had indicated earlier, and I just need some clarification: Partners in Parenting is one of the groups—what's the second group that you represent?

Ms. Christine Rondeau: ACEworks. It's a private day services program for adults with developmental disabilities here in Ottawa.

Mr. Dave Levac: And your other concern I picked up on—not that I didn't hear the other ones, but the main concern I picked up on was the fact that you had indicated that according to your reading of Bill 77, it indicates that if some of the organizations that you pointed out do not have a board of directors or a director, they would not be qualified to purchase services by an independent.

Ms. Christine Rondeau: That's a concern of the small organizations that perhaps only run one or two facilities like a group home, where there is no outside board, yes.

Mr. Dave Levac: Okay. And you believe that the bill, the way it is written, specifies that, which would negate them.

Ms. Christine Rondeau: It does talk about the board of directors and is vague about smaller—

Mr. Dave Levac: I'll point that out to staff to make sure that we can clarify. Thank you.

The Vice-Chair (Mr. Vic Dhillon): Ms. Jones?

Ms. Sylvia Jones: I don't have anything to add. Thank you very much for your presentation.

The Vice-Chair (Mr. Vic Dhillon): Mr. Prue?

Mr. Michael Prue: The question goes to me—the very last one of the whole thing.

I was intrigued because you were the first person I heard who talked about accreditation and quality control. You obviously think that's necessary for the entire service sector. What about accreditation and quality control for private hires, contracts, employees, where people now have the option to try the other side?

Ms. Christine Rondeau: I think it would probably be a difficult thing to do, to have a private contractor accredited, but I do feel that private contractors could fall under private agencies or other agencies that are accredited and therefore be looped into accreditation.

Mr. Michael Prue: You do believe, though, that they should be accredited as well.

Ms. Christine Rondeau: I would think so. I would think that at some point—it depends maybe on the level of service or level of support, but in-home support services, which are basically what they're looking at, need to be challenged. The amount of professional training that's given to those people is very slim, so it would be good to bring it up a notch, for sure.

Mr. Michael Prue: Thank you so much.

The Vice-Chair (Mr. Vic Dhillon): Thank you, ma'am.

Mr. Yasir Naqvi: On a point of order, Mr. Chair: I believe in an earlier deputation a presenter mentioned that we are currently located in Minister Meilleur's riding. I just wanted to correct for Hansard that we are currently located in the riding of Ottawa Centre, which I have the privilege of serving. I just want to make sure that is properly recorded in Hansard.

The Vice-Chair (Mr. Vic Dhillon): You're some host. You're telling us on the last—

Mr. Yasir Naqvi: And I also wanted to take this opportunity to thank the legislative staff for their excellent work over the last four days in making these hearings very accessible and effective for all of us. On behalf of all the members, I'd like to thank the staff for their efforts.

Mr. Michael Prue: Mr. Chair, before we conclude, I have another request to the beleaguered and overworked research officer. One of the deputants today, Marcel Walsh, talked about his experience in Alberta with a system which allowed for him to be both an employee at one point and a contract employee at another. I'm just wondering whether the researcher, in her excellent role, could tell us whether or not the legislation that is being proposed here on that issue is identical to the Alberta one and whether or not people here could be either an employee or a contract employee.

Mr. Dave Levac: Further to that, I have heard over the week something that is tweaking my thought process towards finding this out: There seems to be a very large number of agencies, organizations and companies that provide services in this area. I don't know them all. I'm wondering if we could try to get a master list created of those groups and organizations that provide that type of help. I know that's onerous, and I hate to ask that, but I think there would be concurrence to try to find that out, because they will all be affected by Bill 77 in one way or another. There's been some discussion about negative and positive influence, so I'd like to see if we could get a master list of those organizations and groups that are, I think to be fair to research, registered and/or licensed in some manner. Am I diminishing that in some way?

Ms. Elaine Campbell: This may be something we would talk to ministry staff about. We'll get clarification on that.

Mr. Dave Levac: Ministry staff for that, please. That's great.

Ms. Sylvia Jones: One final request of research: Regarding Mr. Kinsella, there seemed to be some debate and confusion about whether relatives would receive any financial support if they looked after a relative. I wonder if we could get research to clarify how Bill 77 sets that out and maybe how it is currently done.

The Vice-Chair (Mr. Vic Dhillon): Okay. Just some notes before we finish: The written submissions are due by August 12 at 5 p.m.; amendments are to be filed with the clerk by September 3 at 5 p.m.; clause-by-clause consideration of Bill 77 will be September 8 and 9.

The committee is now adjourned.

The committee adjourned at 1617.

Continued from overleaf

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