HANSARD

NOVA SCOTIA HOUSE OF ASSEMBLY

COMMITTEE

ON

COMMUNITY SERVICES

Tuesday, September 23, 2008

Red Room

Forum on Disabilities - Presentations

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COMMUNITY SERVICES COMMITTEE

Ms. Marilyn More (Chairman)
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Mr. Patrick Dunn
Mr. Gordon Gosse
Mr. Trevor Zinck
Mr. Keith Colwell
Mr. Leo Glavine
Mr. Manning MacDonald

[Mr. Manning MacDonald was replaced by Ms. Diana Whalen.]

In Attendance:
Ms. Kim Leadley
Legislative Committee Clerk

WITNESSES

Abilities Foundation
Mr. Tom Merriam - President & CEO
Ms. Veronica Dale - Manager, New Leaf Enterprises

Brain Injury Association NS
Ms. Harriet McCready - Past President
Dr. Richard Brahma - Acquired Brain Injury Coordinator, Capital Health
Ms. Margo Dauphinee - Executive Director
Ms. Jane Warren - President

Canadian Mental Health Association
Ms. Angela Davis - Coordinator

Canadian Paraplegic Association NS
Mr. Dave Shannon - Executive Director

CNIB
Mr. Duncan Williams - Director of Service & Operations NS/PEI Division

Independent Living Resource Centre
Ms. Lois Miller - Executive Director
Mr. Brian Hennan - Incoming Chair
Ms. Gail Giles - Past Chair

Community Inc
Ms. Cynthia Bruce - Chair
Ms. Joan Levack - Employment Counsellor

Deafness Advocacy Association NS
Ms. Linda Quigley - Executive Director
Mr. Elliott Richman - President of Board of Directors

Disability Rights Coalition
Ms. Dorothy Kitchen - Communications

Nova Scotia Association for Community Living
Ms. Mary Rothman - Executive Director

Nova Scotia Community-based Transportation Association
Mr. David Mooney - Chair
Ms. Dodie Goodwin - Executive Director, Pictou County United Way

Nova Scotia League for Equal Opportunities (NSLEO)
Mr. Ralph Ferguson - Chair

People-First
Mr. John Cox - Development Coordinator
Ms. Samantha Butler - Support Coordinator

Provincial Autism Centre
Ms. Cynthia Carroll - Executive Director

TEAM Work Cooperative Ltd.
Mr. Murray Vandewater - Board of Directors

HALIFAX, TUESDAY, SEPTEMBER 23, 2008

STANDING COMMITTEE ON COMMUNITY SERVICES

9:00 A.M.

CHAIRMAN
Ms. Marilyn More

MADAM CHAIRMAN: Good morning. My name is Marilyn More and on behalf of the Standing Committee on Community Services, I want to welcome all of you here today to Province House and to thank you for taking time out of your very busy schedules to join us on a discussion of some very important issues to all Nova Scotians. As you well know, approximately 20 per cent of Nova Scotians have a disability so it impacts not only on those people but indirectly on their families, their workmates, their colleagues, their neighbours, and the whole community. So what we're about to discuss today is very important to all of us.

One of the reasons that we have our annual forums on a particular issue here in Province House is to both recognize the importance of the issues that you're going to present to us, but also to recognize and honour the work that you do every single day, both in your families and communities but also in your organizations. We want to say thank you to each and every one of you for all the contributions you make to make Nova Scotia a better place to live and play and work - thank you very much.

We have a very busy agenda today. I think you have the agenda in front of you so I'm not going to review it in detail. We ask that each organization, when they come to the seats opposite me at the table, once the red light comes on - which will come on automatically - if you could introduce your organization and also the individuals who are representing your organization today.

As you know, everything that's said here today is going to be recorded and put in Hansard so that there is a permanent public record of everything that is said and discussed.

In terms of housekeeping details, there are accessible washrooms - male and female - downstairs. There are also a couple of washrooms that are somewhat accessible at the end of the hall here, just next to the Chamber, that you can also use. We'll be breaking at approximately 12:00 noon for a light lunch which will be served here.

So let's start with introductions.

[The committee members introduced themselves.]

MADAM CHAIRMAN: So let's invite the Abilities Foundation to come forward.

MR. TOM MERRIAM: Good morning. I'm Tom Merriam, President and CEO of the Abilities Foundation. This morning I have a colleague with me, Veronica Dale, who is the manager of our skills training centre, New Leaf Enterprises. We very much appreciate the opportunity to be here this morning. We know you have time constraints so my thought is that I would speak more conversationally, you might say, than to read the prepared material that has been made available to you. I'll try to stick to my time limitation so that we enable the day to progress smoothly.

The Abilities Foundation, as many know, is an organization that has as its primary mission the offering of services and programs that help individuals with physical disabilities achieve their individual potential. That provides for an exciting mandate but also a broad spectrum of what we do.

Very briefly, our programming is basically divided into four areas. One of the leading ones at this point is in the whole area of active lifestyles and wellness and working particularly with young people with disabilities, to try to help them become more active, be more involved and develop their independence, their social skills and a variety of other life skills that will stand them in good stead for the future.

Another important program, and indeed the largest program we have, is New Leaf Enterprises, our skills training centre, and I'm going to talk a little more about it in just a moment. We have our Community and Client Services program which covers a range of information services and help and assistance to individuals looking for direction to all the programs that are available to them across the province, depending on where they are and what their needs are. Faye Joudrey, who is with us today, manages that program as well as an important Health Services program, which deals with the funding of assistive devices and wheelchairs and things of that type. Again, I'm going to come back to wheelchairs in just a moment.

The business plan of the Abilities Foundation has us concentrating our efforts on a number of very specific targets, primarily around the concept of program growth. We're looking to offer services that through our work we know are needed badly and we've made some significant strides in the last few years in doing that. In fact, we've likely more than doubled our program spending over the last three to five years and we've done that with the help of a lot of partners, and we do follow a partnership model. Perhaps one of the best examples of that recently is, in fact, the Wheelchair Recycling Demonstration Program that we undertook with funding from the Department of Community Services and that was a partnership of several charitable health care organizations and interest groups. In fact, you'll hear from a number of them today on other subjects.

The wheelchair program started a little over three years ago as a demonstration to prove up the need and the scope of that need in Nova Scotia. We have now completed that demonstration project, having done one targeted on children and another on the adult population.

We've had a very successful project, we've provided the Department of Community Services with an evaluation report on each project, and we've agreed in principle with them that we want to move forward now to a permanent program in Nova Scotia that will fund wheelchairs for those who are most in need and don't have the economic means to acquire chairs for themselves.

[9:15 a.m.]

In the process of doing that, we are sitting down with the department this Fall and we're anxious to expand on the scope of those individuals who might be eligible for chairs and our demonstration project proved up a couple of issues that we want to focus on in particular - actually three issues.

The first is that the program had an insurance exclusion criterion that said if you have private insurance, you're not eligible for the program. We believe that's still a valid issue, however, we think we need to have the ability to modify that to some degree for certain individuals. What we found was that some individuals with disabilities use up their insurance benefits very quickly and therefore have no money left in their insurance plan to pay for a wheelchair. We believe those people, if they qualify according to the other criteria of the program, should be eligible and not excluded simply because of the insurance issue. So we're working with the department to define that so that we can clarify who might qualify in that situation, so that's a change that we'd like to see.

Another is the whole issue for the adult population of the income qualifying level. Presently, we have been using a $21,000 per year family income criterion. That obviously is serving only the absolutely most needy and not all of those who should be assisted. We'd like to move to some other method that might have a little more flexibility. The challenge, of course, is that you could spend several times what we spend now on adult wheelchairs and if we follow the principle, at least for the time being, that we're trying to ensure that the most needy get served, then we believe some sort of sliding scale that might have a co-pay component in it might be a better way to address that.

The third area is the project name had "recycling" in its title, and that endeavour has proven to be quite an interesting challenge to address and to evaluate what is the opportunity for using recycled equipment, rather than new equipment. There are many issues around that, we've learned along the way in talking to both applicants, occupational therapists and the equipment suppliers themselves. Obviously we want to be providing high-quality, usable equipment to people, not something that has lost all of its useful life.

That's a complex area but one of the elements of it that we think is needed is a very solid process of being able to inventory available used equipment so that we can - not only we, but occupational therapists and others in that circle of providers - we will be able to know what's available. It's much cheaper, obviously, to refurbish a piece of equipment, if it's a good piece of equipment, than it is to buy a new one. So it's another way of stretching dollars.

On that issue, we would like to obviously see the department work with us and move ahead as quickly as possible to come up with those new program criteria, to launch the new permanent wheelchair program. I should say that right now we are continuing under the old criteria, so the department has been very supportive and has provided us funding for the current year. We expect to spend about $1 million on wheelchairs this year for adults and children in Nova Scotia under the old criteria, and then hopefully move forward from there.

The second area that we're putting emphasis on and that we will continue to do, which we think is a very significant one, is in the area of a vocational personal development day program. In your material, there you see we've described that initiative. Basically we run a portion of the program at New Leaf that offers that program to eight to 10 of our current clients. We believe there's an opportunity to offer that program on a much broader scale and initially we put a proposal forward to the Department of Community Services to add 40 slots in that program, to expand it and build on it. We've developed that program over the last several years and it provides a very valuable day program for individuals who are looking for the ability to get out, be more independent, develop socialization skills and have other benefits from the program. That is a significant undertaking but we know the demand is there because we, of course, field the calls every day from people looking to seek it and particularly young people who are in some sort of transition from the educational situation to a work environment, be it community work or otherwise.

New Leaf has been in that business for 48 years now, it knows how to do that and it, indeed, is the only skills training centre of its type in Nova Scotia, serving people with primary physical disabilities. We believe we are well positioned to do it, we put a proposal forward that calls for creating those 40 spots.

What I would like to do just for a moment, if I can ask Veronica Dale just to comment on what the outcome of that proposal would be, just to help you appreciate a little better what the value of that program would be. But before doing that I'd like to just highlight that our analysis indicates to us that the province is currently paying for services of personal care workers in support of what would be some fair percentage of those individuals. We're suggesting not new money is required for this, but rather redirecting current funding from those personal care workers to support the cost of those individuals going to New Leaf every day and having the benefit of a far more helpful program, rather than sitting watching TV all day for instance, which unfortunately is the primary activity of some of those individuals. We can offer them significant benefits and Veronica, if you would just briefly run down what you see those benefits as being.

MS. VERONICA DALE: I guess some of the main benefits would be just the group interaction and the opportunity to develop relationships, build life skills, socialization skills and just having the meaningful daytime activities of being able to leave the home and go out into the community in an interactive community-based program. I don't think it can be understated the benefit of having that interaction with a peer group and having goals and challenges in your day to day life.

I guess some of the outcomes that would mean the most to me to bring to your attention today are the ones that can be achieved by an individual leaving the residential setting and going out and meeting with a group. Life skills, functional literacy skills, access to community activities, access to community programs, some level of recreation, are all very important. Having the benefit of being at New Leaf for a number of years and seeing the benefits to the people who I have the pleasure of working with, to be able to go out into a setting in the community, it's something that I know very well that we can offer to 40 new people who I can put names to a great number of those people because I've met them, I've met their families and I've met their caregivers, and it's a very real need in the community. It's something that I certainly have passion for because it's hard to look at people who want something in the community and there's nothing there right now because they're on a wait list for a program. So that's I guess the main thing.

I'm waiting for bells to go off, if my husband ever knew a bell would shut me up that would be it, there would be one in my house. So I guess those are the main things, social interaction and peer groups.

MR. MERRIAM: We'll just conclude on that note. We're obviously here, in a sense I suppose, to keep the pressure on the Department of Community Services to work with us to do what we can. We're quite good at . . .

MADAM CHAIRMAN: Just a minute, the microphone is not on, Tom. Just wait until the red light comes on and then perhaps you could start your comments again.

MR. MERRIAM: Okay. The Abilities Foundation has spent a lot of time learning how to stretch a dollar, we do it every day and we do it in part not through great wisdom but just sheer determination and a lot of really good partnerships and that's what we see our role with the Department of Community Services being, a partnership where we take scarce resources and find a way to use them to maximum advantage. Our goal is to encourage them as strongly as we can to work with us on a timely basis and move forward, on these two projects in particular right now are our priority, so we welcome the opportunity to talk about that and report on our progress. Thank you for your time this morning.

MADAM CHAIRMAN: Thank you very much, we really appreciate you coming. For the committee members, we haven't had an chance to discuss - we really don't have time for questions in between presentations, but if there is a point of clarification that really needs to be cleared up, I would certainly allow that. Yes, Leo.

MR. LEO GLAVINE: Thank you very much, Madam Chairman. I was just wondering why the emphasis up to 64 years of age, why wouldn't there be more continuum in your program especially to provide wheelchairs and programming?

MR. MERRIAM: There are a number of issues we're talking about with the department. The simple answer to your question to date has been that the use of wheelchairs, as you appreciate, after age 64 the escalation in demand is really very dramatic. Unfortunately, we're all going to experience that sooner or later, so it's purely a cost issue to date, however, that is one issue on the list. The department is certainly sensitive to the fact that there is a significant group of people out there who need service as well, so that hopefully will come. We will be pressing to hopefully expand a range of people who should be served under the program in future.

MR. GLAVINE: Thank you very much.

MADAM CHAIRMAN: Thank you very much. I'd like to invite the representatives for the Brain Injury Association of Nova Scotia to come forward, please. So if you could introduce your association and your representatives, please.

MS. HARRIET MCCREADY: I'm Harriet McCready, I'm the Past President of the Brain Injury Association of Nova Scotia.

DR. RICHARD BRAHA: I'm Doctor Richard Braha, Acquired Brain Injury Coordinator at Capital Health and member of the Advisory Committee for the Brain Injury Association.

MS. MARGO DAUPHINEE: Margo Dauphinee, Executive Director of the Brain Injury Association.

MS. JANE WARREN: Jane Warren, President of the Brain Injury Association.

DR. BRAHA: Madam Chairman, committee members, we want to thank you for this opportunity. It is our pleasure to be here to speak to you today about acquired brain injuries. Thousands of Nova Scotians deal with the devastating effects of brain injury as we speak right now and yet there are very few community services and supports for this population.

I'd like to tell you a little bit about acquired brain injuries. They are injuries to the brain that aren't due to hereditary, congenital factors or degenerative factors. There are two broad classifications. There are traumatic brain injuries - those are the injuries that used to be known as "head injuries" as a result of open, closed, penetrating injuries to the brain from motor vehicle crashes, assaults, falls and the like, sports related injuries and so on. There are also non-traumatic acquired brain injuries from events such as strokes, aneurysms, infections such as meningitis and so on.

We believe that there are about well over 18,000 families in Nova Scotia that are currently dealing with the effects of brain injuries. There were close to 9,000 new cases over the past six years in Nova Scotia. The numbers probably underestimate the actual incidence and prevalence due to a number of factors such as the way these injuries are coded on admission to hospital and on separation from hospital. Acquired brain injury is a kind of umbrella term that describes numerous medical ideologies, and for that reason it's hard to get a precise number of the incidence and prevalence.

[9:30 a.m.]

Apart from the devastating personal consequences of these injuries - changes in thinking, cognition, emotional function, behavioural function, social functions - brain injuries impact families in a big way. We believe that families are impacted as much or more as survivors of these injuries. There's interruption to the education of survivors, to the education of siblings and family members, and survivors have a very, very difficult time being active in society, reintegrating in society because of the lack of services and supports once they leave the hospital.

There's a massive loss of personal income, but also income for family members who take time off work or may leave employment in order to care for their loved ones - again, because the support structures just aren't there for survivors once they leave the hospital. There are devastating effects of being marginalized in society, being isolated and, of course, in large part due to the stigma that's still associated with acquired brain injuries.

MADAM CHAIRMAN: Thank you. Could I suggest that you pull the microphone over, or perhaps your chair, so that you're speaking directly into the microphone.

MS. HARRIET MCCREADY: Certainly. I'm just going to speak briefly about the perspectives of the families, the professionals and the survivors partly from our own experience in the Brain Injury Association, but largely from a needs assessment survey that we had done recently, which was funded by the Department of Health, and we're very grateful for that.

From a family member perspective, which is my perspective, all the impacts that Dr. Braha mentioned impact the survivor and they impact us as we try to care for the broad range of survivors with their particular issues. Whether it's somebody who is mildly impacted but who can't keep a job because of emotional outbursts or whatever, or whether it's somebody who is so seriously disabled - in fact, we have one particular situation where that survivor has had to be placed in a long-term care facility outside the province, and you can imagine the costs and heartache that brings. Our needs assessments show that 70 per cent of family members supporting a survivor were not satisfied with the current level of services available in the province. There were about 20 per cent who were overall more or less satisfied, and that would depend on what the particular situation was.

The professionals who were surveyed as part of that assessment also had a very high level of dissatisfaction, it was actually 80 per cent. The professionals see a different role or situation than we as families or survivors do. They had mentioned particularly, as Dr. Braha has mentioned, a lack of services, unmet needs, increased costs, very difficult for them to access the kinds of things that they know their member needs.

From the survivor perspective - and I certainly can't speak for survivors specifically - their issues were very broad-ranging. Everything from the stigma to not being able to get a job, not being able to contribute to society even to the extent that they can, even if it's not fully, and 45 per cent of them were not satisfied with the services that were available. We think that number is probably low because they simply may not know what they don't know.

I'm going to go back to Dr. Braha, who can speak to what is needed to try to resolve this situation.

DR. BRAHA: We've known for a long time that this patient/client population accesses the health care system, as well as other systems, in a big way. The lack of delivering services to support survivors in the community once they're discharged from hospital results in huge costs to the Department of Health, but as well as other ministries - Community Services, Education, Justice, and so on and so forth. The 1999 Department of Health report from the working group on acquired brain injuries illustrated this.

The Department of Health's 10-year Continuing Care Strategy, which I believe was presented to this committee in January 2007, stated that the department, to quote an excerpt from the report, will respond to acquired brain injury needs by incorporating ". . . the needs of persons with acquired brain injuries in continuing care services.", slated for years four to 10 in their strategic plan. This just sort of illustrates how this patient population is well-known and has come to the attention of many ministries.

Just to be brief, we believe there are a number of things that need to happen in this province in order to move this agenda forward. First, we strongly believe that we need an integrated Nova Scotia strategy for acquired brain injury education and injury prevention. There are a number of injury prevention initiatives, but to our knowledge there are none that are comprehensive and provincial in scope to deal with this specific issue.

We need to target health professionals in this strategy; we need to target children, in particular; educators; and, of course, the general public. There remains a need for a comprehensive and coordinated provincial brain injury program. The vast majority of our services are clustered around the Halifax region and brain injuries don't differentiate. It's a provincial problem, there are survivors in every district.

We need to establish a multi-agency mechanism for planning and coordinating acquired brain injury programming in this province. We need to develop a comprehensive and coordinated brain injury program to support research, the recruitment of health professionals in this area, which is an area that we're really struggling with, and in particular the seamless transition to support survivors and their families as they move across the continuum of care from acute care to rehab, to outpatient care into the community, and into full integration in the community.

We need to develop an employability approach for survivors of acquired brain injury that considers employability within the context of survivors' needs and what they can contribute to the employer and to society. We need to build upon existing work and practices and we need to train professionals to learn how to support survivors as they try to make that transition into the employment sector.

We need to develop outreach services across the province, crisis support, prevention, education, employment support, transition support and so forth, and we need to support participation by community-based organizations. In particular, as we all are aware, community-based agencies struggle for sustainable funding and I think if we're really going to move this agenda forward, we need to find some core funding for some community-based organizations because they are the ones that are currently carrying the load in supporting these folks.

We need to develop an acquired brain injury resource centre which, again, can be an instrumental support for families, survivors, employers and health care professionals as well.

Finally, because we have such a hard time tracking what happens to these folks, we have such a hard time monitoring their access to the system and so on, we need to develop an acquired brain injury registry so that we can put into place a surveillance mechanism to evaluate the effectiveness of our programs. Thank you.

MS. MCCREADY: I realize we're out of time so I would just encourage you to have a look at the handouts. We have some slides with a little background about us. One final comment; I'm sure you're all aware of the determinants of health. I can tell you that brain injury survivors and their families are impacted or impact almost every one of those in a negative way, so we're hopeful that we'll make some progress with the support of all the Parties. Thank you.

MADAM CHAIRMAN: Thank you very much. Any points of clarification from committee members? Thank you.

The Canadian Mental Health Association.

MS. ANGELA DAVIS: Good morning, Madam Chairman and committee members, thanks for having me here today. My name is Angela Davis and I'm here on behalf of the Canadian Mental Health Association, Nova Scotia Division. It's kind of lonely being up here all by myself.

I'm speaking on the needs of the people we serve and we do our work through education, advocacy, and provision of on-the-ground services. What I'll say is there are many types of mental illnesses that affect Nova Scotians. I won't go into the specifics of these illnesses, but I will say that one in five Nova Scotians will be affected personally by mental illness in their lifetime. For many people mental illness will make it difficult for them to manage day-to-day living.

The three most important issues of concern for persons who are living with mental illness in Nova Scotia are these: they need a home, a job and a friend. This is what individuals living with mental illnesses have told us is most important to them. The CLEAR project in the 1990s was the first to tell us this formally, but there have been many research initiatives since that time that have also served to show us that again and again.

I'll start with a home. It's not just somewhere to live, it's a place an individual has chosen to make theirs, a place they feel safe, a place they can take pride in making it their own. A person feels pride in sharing their home with friends and family. It's where they develop friendships and nourish relationships. A home does not mean having to move on when assessed to be doing better. Home is where a person has the support they say they need, support that ensures their ability to maintain their tenancy.

Some of the most important types of support include an opportunity to learn what it means to be a good neighbour, understanding the responsibility of having to pay one's rent on time and the typical consequences of not being responsible to these issues that each and every one of us would face if we were not to live as a citizen.

A home is a safe, secure and affordable place to live. It's where each of us has the opportunity to live as a full citizen of our society.

My No. 2 on our wish list is a job. "What is it you do?" is most often the first question you're asked when you meet someone. What we do defines us. The reality is that being part of our society does not happen just by living there. An individual needs to feel a part of the community to feel that they are contributing. I work, I pay my taxes, thinking that brings with it the entitlement to have a voice and to use it. It gives us a say in what happens.

Without a job, all the opposite realities are true. Individuals who are disabled because of a mental illness need the opportunity to work. Our current social assistance program is called Employment and Income Assistance. Why don't we start from the perspective that everyone is employable and that they can work and that support will be provided at various levels over and above the wages and salaries earned, to ensure a livable income?

For example, someone who works in-house at LakeCity Employment works between 35 and 40 hours a week and earns $50 per week. This is a disincentive; people think, why should I work full time for so little money and rely on other community services and resources to meet my needs? The individual isn't proud of the job, they start to feel they're being taken advantage of and often have a hard time holding down jobs because of this.

Imagine a system that says, we will pay a fair wage when you work if, because of your disability, you can only work part time or on a casual basis. Imagine the difference this would make for the individual and in how the community views income support.

Third and final on our wish list is a friend. It's not necessary to expand on the importance of relationships in an individual's life. We can all attest to the fact that friends have played a valuable role in our own life. Can you imagine a life without friends, without the supportive relationships that allow us to be ourselves and to give to others in a personal and meaningful way?

Within the Canadian Mental Health Association's branches and offices across the province, one of the most consistent services provided is that of social support - providing individuals the opportunity to meet others, to participate in community activities and ensure community inclusion. I'm willing to suggest that if we move forward with the first two suggestions that this one would take care of itself. Individuals would have opportunities on their own to become involved with others and develop close friendships, based on the fact that they had a safe place to live and felt like they were part of society.

I recognize that each of the items on our wish list is a simple concept, yet for many people in Nova Scotia it's unattainable, especially for many of those who are living with a mental illness.

At the Canadian Mental Health Association, we believe that only through systemic change in policy and a shift in the way we see people with disabilities will all Nova Scotians have a home, a job and a friend. Thank you very much.

[9:45 a.m.]

MR. CHAIRMAN: Thank you, Angela. We have a little time here if any committee members would like to ask a question of Angela or make a comment. Thank you very much, that was most interesting.

I neglected to say earlier that we've been joined by Diana Whalen, MLA for Halifax Clayton Park, welcome.

The Canadian Paraplegic Association of Nova Scotia.

MR. DAVE SHANNON: Good morning, Madam Chairman. I'd like to say that the Canadian Paraplegic Association of Nova Scotia is pleased and honoured to be here before the standing committee. We believe it is through this forum and the ideas that we shall generate today that we can move toward a new era of meeting the needs of Nova Scotians with a disability. We would also like to acknowledge our profound appreciation for the ongoing funding and support from the Department of Community Services, in order to assist Nova Scotians with a spinal cord injury.

At CPA Nova Scotia, we improve lives. We provide an important contribution to Nova Scotian society and reduce health and social service costs. As an organization that is dedicated to assisting persons with spinal cord injuries and other physical disabilities to achieve independence, self-reliance and full community participation, our organization has direct links with a broad spectrum of Nova Scotians with spinal cord injury, their families and caregivers, through our client services and peer networking programs.

Our organization continues to address the needs of our members throughout the continuum of their lives after injury. We meet a newly-injured person and his or her family in the hospital, provide counselling services during rehabilitation, and continue to advise and assist as our clients navigate the community in order to become productive members of society. It is through this one-on-one and group interaction that we have noted evolving needs of persons living with spinal cord injuries in Nova Scotia, and I'd like to talk briefly about those evolving needs.

Our client services remain the centrepiece of our activities. We have also met success in bringing peers together to socialize and participate in recreational activities. With this we take a ground-up approach and that's critical to the principle. We don't dictate to our members what they need as peers, they dictate to us what their priority needs are and we respond.

We work on the principle that lived experience will allow persons with spinal cord injury to jointly devise strategies for greater community participation, meet their health needs and find empowerment through friendships. In addition, we have seen a change. We have seen an increase in the needs of persons who are aging with spinal cord injury. Not only are our clients developing more complex needs as they age with a spinal cord injury, but more elderly persons are now having spinal cord injuries. Therefore, going forward in this next year and next decade our priority areas of concern at the Canadian Paraplegic Association are:

- Continued outreach to all Nova Scotians living with spinal cord injury through our peer program and client services;

- Realization of a pan-provincial peer program; and

- Development of an action plan to meet the needs of seniors with spinal cord injury.

This funding can help us collaborate with governmental, non-governmental and the private sector to realize an inclusive Nova Scotia. Together we can succeed in the removal of barriers and promotion of the full and equal participation in society of Nova Scotians with disabilities.

Initiatives under the above objectives may include enhanced service delivery, policy reform proposals, research, promotion of best practices and new service delivery models, capacity building and knowledge sharing and dissemination. Initiatives supported will have outcomes that either address provincial responsibilities or have provincial significance. Again, client services, peer programming, meeting the needs of persons who are aging with spinal cord injuries. We can work to support that and develop new and comprehensive strategies to create an inclusive Nova Scotia. Thank you so much for your time.

MADAM CHAIRMAN: I have a question, Dave. Could you just elaborate a little bit more about the need to expand into the senior population in terms of your service delivery?

MR. SHANNON: Yes, as you know, our organization is now 57 years old. Traditionally persons with spinal cord injury are men between the ages of 18 and 25 years, the newly injured. So you are captured right at the start of their career and education and that has been the tradition.

Now we’re finding more and more injured persons are over the age of 40, we think that might be because there are more slip and fall accidents and that sort of thing as people, for example, are having some mobility difficulties and then they go and take their stairs, or when walking outside their home they’ll slip off the steps, those sorts of accidents are happening more often. Also, a person with a spinal cord injury now - due to improved health care and technology, so many more people with a spinal cord injury who may have passed away by the time they were 50 are now, of course, living longer but now they’ve had a spinal cord injury for 30 or more years. Their needs are becoming more complicated at a health care level, but also at a social level because of the complexities of life and finding support systems and family issues and that sort of thing, so there is a changing trend.

MADAM CHAIRMAN: Thank you. Are there any other questions from committee members? Thank you very much, we really appreciate that.

MR. SHANNON: Thanks so much.

MADAM CHAIRMAN: Next we have the representatives from the CNIB. Please come forward.

MR. DUNCAN WILLIAMS: Good morning, Madam Chairman and committee members. My name is Duncan Williams, I’m the Director of Service and Operations for

CNIB Nova Scotia, P.E.I. and New Brunswick. I would like to talk to you about a few of our key concerns, I guess, from the point of view of our clients.

In the Province of Nova Scotia, there are approximately 25,000 people who have some sort of vision loss that affects their day to day functioning. Right now, we see about 5,000 of those individuals who come through our doors on a regular basis. The reason there is a gap between the number we have and the number that could benefit from the services is we simply don't have the resources. There's a number of common themes that I'll address here. I do want to acknowledge, first and foremost, though, that we have had generous support from Community Services for many, many years for CNIB services in the Province of Nova Scotia. However, as has already been alluded to, the demands and the requests that are placed on us as a community organization have changed and with that, the demands on our financial capabilities also change.

There are several key areas that I'm sure you will hear more about today from other agencies and you've already heard about the need for a universal adaptive devices program. Technology has made the lives of people with vision loss very, very different than what it was even 20 years ago. The problem is right now there is no program that helps support the purchase of that equipment, which means that a perfectly capable individual may sit at home, watch TV - listen to TV, whichever - when they could easily be working, employed and contributing members of the community but for the sake of maybe a few hundred dollars or even a few dollars, to purchase devices that would enable them to work and participate in the community.

Another common theme that I'm sure you'll hear about today is seniors, of course. Our population is aging very quickly. That does not differ from the population the CNIB sees on a daily basis; one in four people over the age of 65 have some kind of vision loss and as our population lives longer, we see more and more people with vision loss come through our doors.

Transportation, of course, is another common theme that I'm sure you'll hear more about today. For our clients who live in remote parts of the province, or for that matter here in HRM, transportation is a key issue to get to and from employment, to and from appointments or to perform daily activities associated with being a citizen - picking up groceries and so on.

The CNIB has been around for 90 years. We've had a very fortunate management structure, a very wonderful support system from our volunteers and we've had significant support from governments at all levels across the country. However, our ability to continue our services is threatened at this point.

I would like to focus on two key areas. Our library service is a service provided from a central point. It's a central library that CNIB funds 100 per cent itself, at about $10 million per year. That cost is distributed across our divisions throughout the country. You and I - as taxpayers, property taxpayers and provincial taxpayers - have the luxury of walking into our local library which is funded by both the municipal and provincial tax base. However, the library services that so many of our clients turn to is not supported by the province and/or any government level. For the people of Nova Scotia, at this point that service is in peril because we are no longer capable to raise the funds to support that service effectively. We see it as a human rights issue, the right to read, the right to access information is critical for educational purposes, the ability to participate in the democratic process and the very ability to take part in any activity in our community.

Another issue that we have and our clients have identified significantly - or is of significance to them - is that they haven't got access to timely service provision. They are put on wait lists at our agency because we simply don't have the resources to provide the specialized services that are required. I'm going to give one very crude example, and you'll pardon me for it, but I think it will highlight the difference and highlight where the gap is; if, God forbid, one of us walks out of this room today and falls down and breaks a leg, we end up at the emergency room, our cast is set and eventually we're sent home. In a few weeks we go back, the cast is removed and if there's a need for physiotherapy and other rehabilitative services, for the most part those are part of the health care continuum.

If somebody with vision loss walks out of their ophthalmologist's office or optometrist's office after receiving the best care they can possibly provide through the medical system, they then have one choice, unfortunately, and that's CNIB.

I say "unfortunately" because we are the only game in town and that's sometimes a good thing, sometimes a bad thing. The bad part about it is, we are largely dependent on the generosity of the public and the number of people who purchase everything from our lottery calendars to our lottery tickets and so on. Imagine if you had to depend on the generosity of your neighbour to get access to the same physiotherapist, so that you could get back to work, so that you could participate in the community and so that you could become independent once again. This is a situation that our clients face.

[10:00 a.m.]

Without rehabilitation services, we know from our research that clients are more likely to have mental health issues, for example, three times more likely to suffer from depression. They are more likely to slip and fall, break a hip, for example. Imagine the cost of hip replacement when with a small investment up front, from a preventive rehabilitation point of view, we could have taught somebody independent, safe mobility skills, thereby they would never enter the hospital, or we would hope.

My final comment would be around the need for our volunteer programs and supports. As has already been identified by other agencies, the need for companionship is important for functioning at a level that we deem to be social, that we deem to be part of a society that is very social. We have seen our clients, unfortunately, sit at home because we are unable to coordinate a volunteer program that provides friendly visiting services, for example, or something as simple as having one's mail read aloud to them because, unfortunately, legislation does not dictate that a home mail has to be in an alternate format. Therefore, someone who has significant vision loss must rely on somebody else.

We would hope that we could access funds to support that program as well. However, at this point we've not been fortunate.

I said "finally" once but I do have one point left - sorry, I lost count. The final point I will make is around the health continuum and prevention. There has been a significant amount of talk and effort and research in the last 10 to 15 years to talk about a new way for health care. What we believe is that CNIB has an infrastructure and it has the expertise to assist with a new way of health care to keep people out of long-term care, for example. Another example - we know that by providing rehabilitation services we can keep people out of long-term care up to three years earlier. If you do the math on that really quickly, that's a heck of a burden lifted off the health care system.

We would hope that as part of that new way of thinking about health care, that CNIB would be viewed for the infrastructure and expertise it has. What we lack is the will at this point - political will, legislative will - that makes these programs part of our health care system and we also lack the most basic element to any program funding and that is finances.

I thank you very much for your time and I will submit our formal presentations at a later point but I prefer that you not have access to information at this point, so that you get just a wee glimpse into what it's like to have a vision loss. Thank you very much.

MADAM CHAIRMAN: Thank you, Duncan. Are there any questions? Len.

HON. LEONARD GOUCHER: Thank you, Duncan. Mine is more of a statement than a question. I've lived with a Dad who is blind for the last 10 years - macular - and I'm sure that as seniors get older that is something that you run across on a fairly regular basis. We don't often get an opportunity, Madam Chairman, to thank individuals in a public forum and that's what I want to do. Duncan, I know on behalf of my Dad, and myself who also have vision issues - I've got retinal tearing and I've got about 20 in each eye right now and I'll probably come to see you in a few years myself as well - I hope not but I think I probably will be.

I just want to take this opportunity, Madam Chairman, to thank you for the services that you've given my Dad. I am fully aware of the issues surrounding the library services and you do provide them to my Dad, but I do want to thank you and just be on the public record as saying that. As politicians, really quite frankly, we don't get to do it very often, but you do provide an excellent service and I am one person who is very, very familiar with it, thank you.

MR. WILLIAMS: Thank you for your feedback, I'll be sure to pass that along to the staff and volunteers and for all of the right reasons, I don't want to see you come through our doors.

MADAM CHAIRMAN: I actually, Duncan, have a couple of quick questions. What would Nova Scotia's share of the National Library Program be if you were supporting it in terms of usage and availability?

MR. WILLIAMS: We basically use a model that's similar to, dare I say it, the federal model that's used within our government and that's through the tax base dissemination across the country. We represent about 3.5 per cent to 4 per cent - it fluctuates - of the overall budget for CNIB's library service. Therefore, if I had to do straight math the equivalency would be around $350,000 for the service provision and the actual talking book machines would be an additional $400 per person, multiplying that out for new clients would give us an additional $35,000 to $40,000 per year for those who come to us.

MADAM CHAIRMAN: One other quick question. In terms of your current program delivery, what percentage would you say is metro based and how well are you able to serve outside HRM?

MR. WILLIAMS: Approximately 50 per cent of our client base would be in metro, representative, of course, of the population of Nova Scotia. We are able to service across the province - however, I would be telling you a lie to say that it's an equitable service, it certainly is not. Cape Breton, for example, we would have about 900 clients on Cape Breton Island and we have staff that on a fairly regular basis make it to that area and provide the service.

If you asked me whether I believe it is adequate, no, I do not believe it is adequate. I believe that our clients are getting a minimal service mainly because we just don't have the bodies and the resources. We receive - and at the risk of offending somebody - about 17 per cent of our provincial budget from provincial funds and that is one of the lowest in the country.

MADAM CHAIRMAN: Great, thank you very much, I appreciate that. Any other questions? Thank you.

MR. WILLIAMS: Thank you.

MADAM CHAIRMAN: Lois, do we have your representatives here now? Okay, let's go to the Independent Living Resource Centre.

MS. LOIS MILLER: Madam Chairman, would it be possible to have the upper windows shielded, it's difficult to see.

MADAM CHAIRMAN: Sure. Kim, could we arrange to have that done shortly? Thank you. So again, if you could introduce your organization and your representatives today for the purposes of recording.

MS. MILLER: Thank you very much, Madam Chairman and members of the committee. I'm Lois Miller, the Executive Director of Independent Living Nova Scotia Association and I welcome the opportunity to address your committee this morning.

Let me introduce from Independent Living Nova Scotia, Brian Hennen, who is our new Co-chairman and Gail Giles, who is our one of past co-chairs. We're especially pleased to be able to make this presentation because it's the first public presentation we've made using our new name. We are now Independent Living Nova Scotia Association, the association part is the idea of the Registry of Joint Stocks.

We've recently changed our name and our bylaws to implement a decision made in June by our members to extend our mandate province-wide. We've taken that action because we are the only independent living organization in Nova Scotia, we've been getting many inquiries from people around the province, and because the issues that we deal with are really provincial, not local. We are, of course, going to continue operating a resource centre in Halifax and we'll continue providing core programs in the areas of information and networking, peer support, independent living skills, and research and community development.

Since our time is limited, we've chosen to address several issues that are raised in the two reports that were recently issued by the Department of Community Services - I'm assuming most of your committee members will be familiar with those. One is on vocational and day program services and the other is a report on residential services - these two reports were recently released by Community Services.

Our first recommendation is that programs be developed to provide vocational and pre-vocational services to young adults with disabilities in the 18- to 21-year range. This is a recommendation, it's given high priority in your department's vocational and day program report and we endorse that. We speak with some knowledge and experience on this issue as we offer one of the few programs available in Nova Scotia to this population group - it's called Access to Community Education and Employment and we call it ACEE. It's now in its fourth year, although it took us about 10 years to get to this point. It's for young adults who have finished high school, but they're not yet ready to move on to work or further education. Our report is mentioned briefly, just with a brief reference, in the Department of Community Services report.

Our ACEE program is jointly funded by the Departments of Education and Community Services, and we certainly thank those departments for their funding for this program. During each of the past three years that we've been offering ACEE, however, we have had to turn down many applicants, young adults with disabilities who finished high school, but unfortunately they can't demonstrate the capacity to work independently or with minimal supervision. We have seen these youths and their parents frustrated, disappointed, sometimes in despair because there are almost no other options for them. They can't go back to school, they've already been given a certificate and yet there are no vocational or pre-vocational programs that have the capacity to accept them.

We assure your committee that we want to be part of the solution to meet this need. About a year ago I met with a representative of the DIRECTIONS Council that represents the various vocational day programs, to assure her of our support if they are able to extend their capacity to meet the needs of these youths. Now that we've extended our mandate province-wide, Independent Living Nova Scotia is looking forward to having a seat at the planning tables as programming is developed for these young adults so that we can contribute our knowledge and experience.

Our second recommendation is that support options for clients - and I'm quoting here pretty well from the report on residential services - be determined by the person's need for support, and that's in Recommendation 11 of the report on residential services. That recommendation is discussed at some length in that report and the authors, the consultants who put it together for the department, acknowledged and commented strongly that currently it's the placement, the place that people get put that drives the support they get, not their need for support, and that is stated strongly in that report.

We urge instead the Department of Community Services, as recommended in this report, provide choices for people with disabilities as to where they live and that would, of course, be in keeping with the UN Convention on the Rights of Persons with Disabilities which, in fact, says that people with disabilities can choose their place of residence and where and with whom they live, on an equal basis with others, and that they should be able to receive the support they need to do so.

[10:15 a.m.]

We urged the Department of Community Services to provide this choice. There are several ways the department can do that. It could extend its own community-based programs to provide more than 21 hours a week of care - that's only three hours a day, not enough for many people. It can work with the Department of Health to extend the cap on the provincial self-managed care option so that people can have more hours of care.

Once again, we would like to be part of that process to enhance and extend these programs, because for over 15 years we have been offering a self-managed attendant care services program and we can bring that experience to the discussion.

Another way our province can provide choice in residential and community supports is by making a commitment to exempt contributions to the new federal registered disability savings plan from clawbacks. I don't know if some of you are familiar with this but the federal government is in the process of bringing in new, registered disability savings plans. They are going to be something like our ESPs only actually better, I think, for persons who participate.

The problem is that our province has not agreed to exempt money that people might then take out of their RDSP, to exempt it from clawbacks. Other provinces have - Newfoundland and Labrador, Saskatchewan, B.C. and the Yukon - and we are calling on

Nova Scotia to support that program. Otherwise, people might find that they have been contributing to RDSPs which then are being used, essentially, to maintain their other provincial supports, so the people could find themselves really donating to the Province of Nova Scotia, which itself is maybe not a bad idea but that isn't what families and people will be trying to do.

The final recommendation is that an aging-in-place strategy be developed and that is also recommended in part in the Community Services report on residential services. But unfortunately the report recommends an aging-in-place strategy for elderly persons with disabilities who require nursing home care. We are asking that an aging-in-place strategy should include strategies for people with disabilities in their middle to senior years who require increasing support but not necessarily nursing home care.

In the past couple of years we've had two members of our small self-management program - both women, middle-aged - who, because of the cap on self-managed care funds, have had to move into nursing homes where the care is not appropriate to their age and where they don't have access to disability supports that they had while they were at home. Now they are receiving a level of care that is far beyond what they really need, without the supports that they had in their own home, at much more cost to all of us. That is an issue that we wish you will address.

I'll now ask if Mr. Hennen or Ms. Giles have some comments to add.

MS. GAIL GILES: I would just like to follow up on - Lois was speaking about more services for people who need attendant care and, you know, people who are in mid life who have disabilities and need support, they do not need to end up in institutions where they are getting levels of care that they don't need. They don't need to be removed from their homes, Community Services needs to keep them in the community. They can stay there if they have a higher level of attendant services. They can continue to contribute to their community and be part of the diversity of their community.

If they're put in an institution, they are cut off from friends, they are cut off from their community and they are receiving health care, nursing care that they do not need. If they can manage, with an attendant, to provide for themselves for 12 hours, it's cheaper to allow them to provide for themselves for 24 hours than to put them in an institution where they receive levels of care that are far higher than they need.

As well, these are many people in mid life who don't want to be with people who are 20 and 30 years older, and they have become a part of their community. I think that we do the community a service by keeping them in the community.

Also, I would like to recommend, and I don't know if Lois mentioned it, that the Department of Community Services, along with the Department of Health, investigates things like a circle of friends so that people with disabilities - often we live alone - can have some kind of supports around, government services. So when issues that may happen in our lives, health issues, as can happen with anyone, a hospital visit, a stay for an operation, whatever, family circumstances, there is a circle of support around people that they can navigate through.

I have just been going through the process of a self-managed attendant care program and it is a process. You have different people going through different - yesterday or last week I ended up with a stack of papers and a full CD of information about labour laws and financing, and do you know what? There was nothing warm and fuzzy about what's been going on. This is it - if you want to be a self manager, learn and go and do it. I think it can be handled in a much better way.

Having circles of friends around people, it's not costly - you need a few facilitators - and that's all because it's the people in the community who are the circle of friends and that, I think, heightens community. Thank you.

MADAM CHAIRMAN: Thank you very much. Brian.

MR. BRIAN HENNEN: Madam Chairman and members of the committee, I just want to make two points. The first point is simply that the people who are currently accessing services as people with disabilities, constitute a very small proportion of the disabled people in this province. Nova Scotia has the dubious distinction of having the highest proportion of disabled people of any province. Of a population of 950,000, probably 192,000 have disabilities, of which one-third are severe or very severe.

The population of people with intellectual disabilities, at the lowest estimate, is in the order of 5,000 or 6,000. The program report indicates that the government, through Community Services, is servicing 4,800. So there's a large proportion of people with disabilities who are not formally accessing the services that are available to them.

The second point I want to make is about improving the quality of programs at large. I really commend the Services for Persons with Disabilities Program for the frankness and openness of their report. I want to raise particularly the issue of quality and accreditations. I come from a background that makes me a very strong believer in accreditations of health services, of social services, of educational programs, and accreditation processes that involve self-assessment, looking at how you're doing yourself and then presenting it to peers for either confirmation or otherwise.

The report says there are 211 small options homes of three persons or less and others being provided independent living support as individuals which are not accountable to the Homes For Special Care Act and are not licensed, subject only to interim standards which were set in 1996. Standards can last for a while, but interim standards that have been used for over a dozen years seems to be a little bit lacking.

In the report it says that in an environment largely devoid of standards, what incentive, other than altruism, does a provider have to go beyond the minimal licensing requirements? Also in the report it says, the residential sector operates in silos of 25 interviewed organizations, and none met with other boards or operators. There are separate local governance mechanisms in all but three for the residential and adult service centres - this does not sound to me like a glued-together program.

In the Department of Community Services Business Plan for 2008-09, it refers to strategic goals, and three of those six strategic goals talk about creating ". . . an integrated, client focused, quality service delivery system; to strengthen service provider relationships and leverage opportunities for collaboration; to develop and demonstrate leadership in the continuous pursuit of excellence."

So I would encourage all of you to ensure that one of the things the department is doing this year is reviewing its strategic goals and I would encourage you to encourage them to look at their standards, their self-accreditation, and their ability to make and encourage people to collaborate with one another and learn from one another. Thank you very much.

MADAM CHAIRMAN: Thank you all very much, we appreciate that. Any quick questions or points of clarification? Leo.

MR. GLAVINE: Thank you, Madam Chairman. I was wondering if you are proposing that when a student reaches 18 years of age and is generally leaving school that it almost be mandatory or that there be full programs available and integration into work or future additional vocational training. Or do you see a combination whereby those schools that do make the school program available up to 21 years of age that, in fact, that be fine for them to continue to engage in?

MS. MILLER: We would like to see options available so that people could make wise and informed choices. My own observation, based on some years of providing this kind of programming, is that if the youths - and these are generally youths with multiple disabilities we're talking about here, including probably intellectual disability, dealing with mental health issues, perhaps with significant learning disabilities, as well as physical disabilities and all of the above, so these are youths with very complex needs - my observation is if that youth has completed high school and has received his or her diploma which indicates, I think, that they have gotten about all they're going to get out of school, we have observed that those youths do much better in a program that is outside the school that can be much better integrated into the community.

Our ACEE program does include job-related literacy and numeracy so there's a good educational component, but it's all related to the workplace. It also includes learning, career development, career facilitation, getting ready for the workplace, and job placements in real-life work settings. We find that the youths learn a great deal more by being in that kind of a program than going back for yet another year of school. It just seems to me if something hasn't worked for a young person for four years, why put him back into that for another year and another year? But people seek that because there are so few alternatives and families are often in despair to find a placement. So that’s why we are asking for a range of programs for youths in that age range. But you’re right to pick up on that, it’s a very big issue.

[10:30 a.m.]

MR. GLAVINE: Thank you very much.

MADAM CHAIRMAN: Thank you, again.

Cynthia Bruce with Community Inc. Yes, if you would like to start.

MS. CYNTHIA BRUCE: Good morning, my name is Cynthia Bruce and I’m the chair of the Board of Directors of Community Inc. With me is Joan Levack who is an employment counsellor in our Middleton office and generally serving as my eyes this morning, mostly to tell me when the light is red.

It’s a pleasure for us to be here and to be able to present to you on what we believe are the issues facing many Nova Scotians with disabilities and on what we believe to be at least some good steps towards solving some of those issues and addressing them in a holistic manner.

Community Inc. is a non-profit, community-based organization in Kings and East Annapolis Counties. Our vision is to create a world where equality is assumed and not earned, and where full citizenship is a right and not a privilege. While our current mandate is to provide employment counselling services to persons with disabilities - and it’s true, a much-needed service - our guiding mission is to create a fully inclusive society through building community capacity. We absolutely believe that communities want to become inclusive, but they need the supports in place to facilitate that process.

Persons who identify as having a disability make up almost one-quarter of this province’s population - it’s a demographic that I always find astounding. They face many barriers on a daily basis to living, learning and working, including access to affordable, accessible transportation, access to adequate educational, living and employment supports, and access to appropriate assistive technology that actually will facilitate living, learning and working.

We fully recognize the work that government has done to create a variety of programs to attempt to address the needs of persons with disabilities, but they’re often scattered across government departments. It makes it very difficult to access them and it makes it even more difficult to access the appropriate ones to meet the needs of anyone who requires these supports. We believe that persons with disabilities are not segmented, scattered human beings and that we need to recreate our programs to address their needs from a more holistic perspective.

As citizens of this province we are multi-faceted, multi-dimensional human beings who are not and should not be defined by our disabilities and by what we can achieve. We need to be recognized for what we can contribute and not scrutinized for the accommodations that may need to be put in place to facilitate inclusion.

In other words, we feel that governments and communities need to recognize that inclusion is everyone's responsibility and that barriers to inclusion are not necessarily only inherent within the persons striving for inclusion. Sometimes these barriers are socially constructed by society, not through a desire to be exclusive but more through a lack of experience with and exposure to inclusive practices.

At Community Inc., we recognize that a lot needs to be done to facilitate fully inclusive communities but we have three priorities that we would really like government to focus on that we believe would then allow us to address the needs of persons with disabilities in Nova Scotia, as well as to address the often unidentified needs of communities that would like to become inclusive. Firstly, we believe government needs to support community-based organizations through providing sustainable fiscal funding, along with flexible programming activities. It's basically at the community level that a lot of meaningful connections can be made that will make really long-lasting changes in the lives of persons with disabilities and in the lives of people who need those supports.

In terms of fiscal support, we would like to see policies that allow for core funding, which will then allow for sustainable program development rather than project-based activities. People with disabilities are not projects; we have the same objectives and goals in life as any other person in this province. We would also like to see some flexibility in programming so that not only can we direct our programs to meet the needs of persons with disabilities, but we can direct some of our programming energy toward meeting the needs of communities who would like to become inclusive but do not really have adequate support to facilitate that process.

The second thing we would like government to focus on is that in conjunction with community-based and provincial organizations, developing a comprehensive strategy to begin to address the needs of people with disabilities and the communities that wish to become inclusive. This strategy needs to be based on sound research that will then lead to the development of policies and programs that will allow every Nova Scotian to embrace both the rights and the responsibilities of full citizenship.

The final point we would like to make and the final priority that we feel is important is that in order to research and develop and implement the strategy, we believe there needs to be a government department of disability issues. We recognize fully the work that the Disabled Persons Commission does and we applaud them for it but their ability to make real change in the lives of Nova Scotians is significantly restricted by the parameters of the Disabled Persons Commission Act. Essentially the mandate allows them to research and to educate the government on issues facing persons with disabilities on a daily basis.

Unfortunately, education is not always enough. We believe that there needs to be a government department whose mandate it is to research, create and implement policies that will not only allow us to move toward meeting all the needs of Nova Scotians who have disabilities, but also allow us to move towards becoming a fully inclusive Nova Scotia.

We'd like to thank you for the opportunity to be able to present to you and bring our issues to you.

MADAM CHAIRMAN: Thank you very much, Cynthia. I'm just curious, when was your organization formed?

MS. BRUCE: We were incorporated in 2001.

MADAM CHAIRMAN: Are your members individuals or other community groups? How does it work?

MS. BRUCE: The members of our board or the members of our . . .

MADAM CHAIRMAN: Of your organization.

MS. BRUCE: The members of our organization are essentially citizens who identify as having a disability. We originally developed as a partnership committee which, before we provided service, was made up of a board of directors comprised of other community groups. We've sort of evolved out of that. We have a significant representation on our board of persons with disabilities from the community but it's certainly very much a community-based organization.

MADAM CHAIRMAN: Thank you, that's very helpful. Any questions or comments? Leo.

MR. GLAVINE: Thank you, Madam Chairman. I was just wondering, for the benefit of the committee, if you could maybe just outline a couple of action-oriented, I guess, programs or advocacies that have indeed paid dividends for people of disability, helping them to integrate better into our community.

MS. BRUCE: We have a fabulous team of employment consultants in our office and they do phenomenal work providing employment services to persons with disabilities. I think the statistic that always sticks out for me, and Joan could speak a little better to the stats, but the one that sticks out for me is the fact that we - and particularly in our Middleton office - have facilitated and empowered persons to gain employment who DCS would actually consider to be unemployable. There are a number of those who we have been able to work with in the last eight or nine years. Maybe you'd want to speak a little more to that, Joan.

MS. JOAN LEVACK: Our goal for the Middleton office was to find employment for six persons with disabilities in East Annapolis. We found employment for 410 per cent over that goal last year. It's very simple because there is work for every single person. It's a matter of finding the right work for the right person, finding the right employment. It really is a matter of doing it one person at a time, that's our goal.

I have an active case-managed load of about 80 people, as does our Kentville office. If we had money, we could probably serve twice that many people and employ twice that many people. Again, it's very simple.

MADAM CHAIRMAN: Thank you, we really appreciate that.

The Deafness Advocacy Association, Nova Scotia. Just a reminder to speak directly into the microphone as much as possible. So, if you'd like to introduce yourselves and your organization.

MS. LINDA QUIGLEY: Just before we start, Elliott realized he handed his copy with his notes on it to the person who is distributing them, if we could have that one back and exchange it for one that is not written on, it would be appreciated. Thank you.

Good morning, Madam Chairperson and committee members. My name is Linda Quigley, I'm Executive Director of Deafness Advocacy Association, Nova Scotia.

MR. ELLIOTT RICHMAN: And I am Elliott Richman, I am a volunteer with DAANS for 28 years thus far. My wife and I have been foster parents to an older student with special needs as well.

MS. LINDA QUIGLEY: Over 58,000 Nova Scotians have a hearing loss. Statistically that means that almost 33 per cent of persons with disabilities in Nova Scotia reported hearing loss as their primary disability, according to the 2006 Healthy Active Living Lifestyle House Report conducted by Census Canada. Despite their significant numbers, people who are deaf, hard of hearing, late deafened and deaf-blind, continue to be underserved and undersupported by this province. We welcome this opportunity to present to you the three areas where, after 32 years of service delivery to the people of this province, DAANS has found the greatest need.

The first area that we wanted to talk about is the need for broader policy on providing financial aid for technical devices. Hearing aids are essential assistive devices to some people who are deaf or hard of hearing but they cost $1,200 to $5,000 per ear every three to five years depending on need. Additionally, the ongoing cost of batteries, tubes, ear moulds and cleaning items can run up to $1,000 per year. Even in a two-person income household, the need to spend up to $15,000 every five years just to hear places a huge financial hardship on the average family. For many, this cost is simply too great so they choose not to correct their hearing and end up losing their jobs, their social support network, their self-esteem and even their families. When this happens, as we have seen time and time again, the person ends up on social assistance and ultimately will cost the government far more than the cost of that hearing aid.

[10:45 a.m.]

DAANS receives 10 to 15 telephone calls every week - and we've been keeping statistics for five years now - from Nova Scotians who are looking for funding for hearing aids for themselves, their children, their spouse, their parents and their friends. Hearing aids, however, are not the only technical devices required by a person who is deaf of hard of hearing. They also require: a special telephone including a TTY, a video phone or a volume-controlled phone; a device that will provide a flashing light or a very loud sound when the telephone rings, a doorbell buzzes, the smoke, fire or carbon monoxide alarm rings, or an alarm clock goes off. Devices are also needed to hear a child cry, to know when someone is breaking into the house or coming into their office, as well as devices to listen to television, to hear in church, a meeting or an auditorium, to pay attention in a classroom and on and on.

A child attending school can be provided with many of these devices while attending school through the Atlantic Provinces Special Education Authority, but these devices belong to the school and must be returned at graduation. A working adult can apply for federal assistance through the Opportunity Fund for some technical devices required for work. However, a non-working parent, a person on Canada Pension who is unable to work, or on social assistance, disability assistance, a young person living at home searching for work and a senior citizen have no access to financial aid.

While Community Services does provide some assistance to individuals, that assistance is being tested and limited by age. Additionally, policy varies across the province, with people in some areas receiving support while people in other areas requiring the same support are being denied.

We respectfully suggest that the province must adopt a uniform, broader and more inclusive policy or program providing all persons with disabilities assistance for essential technical devices, including but not limited to those required by persons who are deaf and hard of hearing and such provision must not be limited by age or be means tested. DAANS requests that the Department of Community Services join with the disability organizations in advocating that the Government of Nova Scotia adopt and support an assistive devices program similar to that in Ontario which provides 75 per cent of the cost of any assistive device to a person with a disability regardless of income, family status or age.

MR. RICHMAN: Now I would like to discuss the greater support for disabilities in organizations. As reported in the September 12 to 14, 2008 issue of Metro, Alberta Premier Ed Stelmach said it best. He acknowledges that even in Canada's economically strongest province there were Alberta families struggling to get by and the charity organizations can address their troubles much better than his government can. Premier Stelmach also said, voluntary organizations identify need much better than a government can and they also deliver those services much more effectively and efficiently.

MS. QUIGLEY: As we know and as this province has recognized, certain cultural groups have proven to be far better at providing assistance and support to those within that specific cultural group. So too are disability groups better at recognizing and supporting the unique needs of their consumers. Cross-disability employment programs are not working for deaf and hard of hearing people who still face 40 per cent unemployment. Supportive housing programs are not taking into consideration the visual needs of those who are deaf and hard of hearing as they are still being offered geared to income rentals with wheelchair accessibility.

People who are deaf-blind have been told that they are unable to access the activities of daily living supports offered through the attendant care program because this government has disallowed deaf-blindness as a class of disability.

MR. RICHMAN: The Province of Nova Scotia must do more by granting organizations for, of and by the disabled communities the increase in grants that will truly allow people with a disability to take advantage of housing, transportation and employment on an equal footing with every other Nova Scotian.

DAANS requests that the Department of Community Services recognize the true value of the contributions made by the disability specific organizations and provide appropriate financial support to those organizations supported by the department.

Now our third point - how much time do I have left?

MADAM CHAIRMAN: Probably another four minutes.

MR. RICHMAN: Great, so be it then. Now we'd like to talk about our third issue and that would be interpreters and intervener services. The federal Government of Netherlands provides deaf citizens with 200 hours of free interpreting services to use for whatever each deaf consumer requires for their lives, whether it's a want or a need. Those 200 hours are separate from interpreting hours used for employment, education and health. That means they separate it from schools, universities, the hospitals, or whatever - they're separate hours allotted to each deaf individual. Those hours can be used when dealing with their landlords - especially when sourcing new apartments or requesting repairs or late rent payments. Those hours can also be used for workplace meetings, either for the future positions or for social interactions with their colleagues, socializing with their employees after work hours.

Deaf individuals have the right to take advantage of perhaps going to a car dealership or taking their car in to be repaired, having repairs done and having negotiations with the mechanic or in their homes. When contractors call and hang up on deaf individuals, it's because they do not want to deal with a deaf individual for the purpose of the relay services, so therefore an interpreter can be afforded to go in and speak to them directly.

The Province of Nova Scotia must introduce a policy or program that would allow deaf and hard of hearing Nova Scotians to be granted, on an annual basis, a specific number of free interpreting hours to be used as needed and qualification of such programs should not be means-tested. DAANS requests that the Department of Community Services recognize the vital communication link provided by interpreters and interveners and provide financial support to these programs. How did I do time-wise?

MADAM CHAIRMAN: Right on time.

MS. QUIGLEY: Thank you for allowing us the opportunity to present to you today.

MR. RICHMAN: And thank you very much for your time.

MADAM CHAIRMAN: Could I just clarify something? There was a comment in there that deaf-blindness was disallowed by the government as a category of disability . . .

MS. QUIGLEY: As a class of disability, preventing them access to the attendant care programs offered by the department.

MADAM CHAIRMAN: Oh, it was just in relation to that particular program, was it?

MS. QUIGLEY: Well, Community Services also denies deaf-blind individuals their specific needs, access to supports for their specific needs as well. It seems to be a policy right across the board of this government. We've taken it up to the ministers and they have also agreed that deaf-blindness is not to be considered separately as a class of disability.

MADAM CHAIRMAN: Thank you. Any other quick questions, points of clarification? We appreciate your presentation, thank you very much.

MS. QUIGLEY: Thank you.

MADAM CHAIRMAN: The Disability Rights Coalition.

MS. DOROTHY KITCHEN: Good morning. My name is Dorothy Kitchen, I am presenting on behalf of the Disability Rights Coalition. I'm going to be speaking and focusing on the United Nations Convention on the Rights of Persons with Disabilities and its relation to policies and legislation.

As you may all know, the United Nations Convention on the Rights of Persons with Disabilities has been ratified by enough nations. It went into effect on the 3rd of May and is now legally binding internationally. Canada has signed this but they haven't ratified the convention and we would urge that the Nova Scotia Government encourage the federal government to do so. To date, 37 countries have ratified, including China, Brazil, Chile and Argentina, countries not exactly known for guarding human rights.

On the presentation, I've kind of put things that I've cut from the United Nations Web page, so that's the information where it came from. A big problem in Nova Scotia is there's no legislation governing the Services for Persons with Disabilities Programs and we need legislation consistent with the UN Convention now. The lack of legislation allows for discretionary and often discriminatory policies and decisions in individual cases. An example of this recently was an attempt to move a young woman with disabilities from her community-based foster home, where she was flourishing, into the Cobequid Centre, a new institution for 25 people, against the wishes of her family, a doctor, the foster parents and, most importantly, her own - a clear violation of her rights under the convention.

The Nova Scotia Department of Community Services states it is committed to a sustainable social service system that promotes the independence, self-reliance and security of the people it serves, through excellence in service delivery, leadership and collaboration with their partners. The Services for Persons with Disabilities Program is a voluntary program that provides residential, community-based vocational day program support to individuals with intellectual disabilities, long-term mental illness, physical disabilities or a combination of disabilities. Residential services include a continuum of options ranging from support to families, caring for a family member with a disability in their own home, to full 24-hour residential support. The goal is to create a range of programs that can support people at various stages of their development and independence.

[11:00 a.m.]

Unfortunately, the DCS policy above is not supported by its own community-based options policies and decisions. For example, the moratorium on community-based options since 1996, which does not give opportunity for people to have choices where they live; the failure to reform the system as per the government-sponsored Kendrick report; housing persons with disabilities in institutions, hospitals and RRCs because community-based options are not available; and providing persons with disabilities living at home with inadequate supports or services leading to caregiver collapse.

The most recent residential review report will result in more institutions and social exclusion, and does not conform to Canada's international obligation - see Article 19 (a), (b) and (c) of the UN Convention. I have printed that out, so do you want me to read it or do you want me to just leave it for you to read?

MADAM CHAIRMAN: No, I think the members can skim through it. Thanks, Dorothy.

MS. KITCHEN: Okay. Congregated living arrangements such as group homes, institutions and nursing homes, do not promote independence, self-reliance or security for the people they serve. Support to families is not adequate to meet the needs of many families. It should be assessed in each individual family's needs.

This is evident with the following e-mail we received from one of our members: Mary recently had some orthopaedic surgery. As we are not set up at home with lifts, accessible showers, et cetera, and since both my husband and I weren't going to be able to stay home indefinitely to do all the lifting until Mary was once again able to bear weight and assist with transfers, we started working on some type of convalescent care, only to learn that the only option was an Alzheimer's unit at Parkland's - a private seniors' complex - for $215 a day. Oh, we have a long way to go. Mary, by the way, is only a teenage school girl. She's not an adult and this was the placement they were offered, a temporary placement.

This is a quote again from the DCS: Full 24-hour residential support, a translation of that means group homes with eight or more residents, large institutions and nursing homes. This has nothing to do with persons living in their own homes and communities.

The following is a DCS definition of a physical disability: physical limitation that substantially limits independence and requires ongoing supervision, support or skills development but not nursing care, 21 hours per week. The physical disability does not limit independence, the absence of adequate support limits independence.

Discrimination in Nova Scotia takes place when the level of support is based on the hours of support required. You should be able to obtain the right kind of support, whether it is two hours or 24 hours, based on need, and still have the choice of where you live and with whom. People do not require the range of programs in their homes.

I'd just like to ask, does anyone here have a program in the home? I don't. That's just a comment.

This means persons with disabilities are to be included with the right kind of assistance, in community programs and activities that are available to the general public, not segregated. This includes support to live in a home of their choice, education, recreation, employment, et cetera. It has been proven that some of the policies around segregated living for persons with disabilities are not economically sound. Studies show that when congregated living arrangements were closed down across the country and around different parts of the world, the result was cost-neutral.

To give an example of what some institutions cost in Nova Scotia, the recent renovation of the Cobequid Centre in Sackville cost $4.180 million - that's without overruns or design costs. This facility is to accommodate 25 persons. According to government officials, the per diem rate is $450. It goes on to say that it will provide highly specialized service for people with complex needs, and that includes providing assistance with all aspects of daily living, getting dressed, bathing and eating. I would just like to ask, what is highly specialized about requiring help to bathe, get dressed and to eat? As a matter of interest, Ontario is closing the last of its institutions this year.

Also please note that initially, the Cobequid Centre was proposed as a possible site for the area Motor Vehicles branch and was turned down. To quote Minister Jamie Muir, "Last Spring we were considering the Cobequid Centre in Lower Sackville. After investigating the centre, we found that this location did not adequately address our needs. Some of our concerns included the lack of sidewalks, no bus service to the centre, and there was not enough space for parking." That doesn't say very much for the people who have to live there.

In conclusion, just as orphanages are no longer acceptable and residential schools for Aboriginal children are no longer acceptable, as is obvious from Prime Minister Stephen Harper's recent public apology and the compensation awarded by the courts to former residents, it is not acceptable to take persons with disabilities out of their homes, away from their families, friends and communities and place them in institutions. People are not pawns to be moved about at the whim of DCS.

I also received a letter yesterday from another member of the coalition and it says:

> Dear Mrs. Kitchen:
>
> I understand that the Disability Rights Coalition will be presenting to the all-Party standing committee on September 23rd. I am hoping that you can add my voice to the many dedicated people who will be presenting on behalf of the thousands of people in Nova Scotia who either have a disability or are affected personally by someone who has a disability.
>
> My husband and I have been blessed with two wonderful, beautiful sons, both of whom have autism. We are gravely concerned about their futures. We fear that our sons could live a life of poverty or, worse yet, be homeless. The federal government has finally given society a tool, the registered disability savings plan, the RDSP, to start addressing the huge financial challenges that people with disabilities are given as a result of society's ongoing biases about what they can and cannot accomplish and contribute.
>
> The RDSP allows families to invest up to $200,000 in a tax-free shelter, much like the education savings plan. Some families, like the families of children with autism who have already had to invest life savings in early intervention treatment or, worse, have gone bankrupt trying to fund autism-specific supports, can no longer afford large contributions, in this case the RDSP supplemented by a grant and a bond that would provide cash contributions to RDSP plans. Over time RDSPs will provide billions of

> dollars to supplement income which is often below the poverty level. This income will enable home ownership and provide hope for access to a quality of life, as is intended by international and provincial human rights legislation.
>
> I'm not a Conservative by nature, so it pains me to say that the federal government has shown leadership in this area, but credit is due. They have shown leadership by agreeing not to claw back benefits received by people with disabilities who benefit from the RDSP. Four provinces have also shown leadership. For anyone living in British Columbia, Newfoundland and Labrador, Yukon, and Saskatchewan, the plan is an exempt asset and you are free to use any income from your plan in whatever way you choose without affecting your income assistance. I beg our province to follow the leadership shown by the federal government, B.C., Yukon, Saskatchewan, and Newfoundland and Labrador.
>
> If the government is looking to do the most responsible thing for their taxpayers and people with disabilities, then do not claw back the RDSP income and do not restrict its use. Many of our sons and daughters will be taxpayers if they are not penalized for trying to start a life. Give our sons and daughters access to life.
>
> My husband and I are taxpayers, we started a business to try to build enough income to keep us from being bankrupt from the costs incurred by financing treatment not covered by our province. We now employ 30 persons, those people are taxpayers. I ask the province not to give us any more reasons than they already have to move to another province that is more progressive in building an environment that will allow people with disabilities access to life. Thank you for listening.
>
> Regards, Chris McAllister and Jack Knox.

I didn't get that onto my presentation because it just came yesterday after I had printed them out. I thank you very much for allowing me to present today.

MADAM CHAIRMAN: Thank you, Dorothy. Are there any questions or comments from committee members? Leo.

MR. GLAVINE: I was wondering, Dorothy, what in your view do you think is the rationale or the philosophical position of our province and government that seems to be going in the opposite direction of many provinces, around greater independent living?

MS. KITCHEN: I guess ignorance of what people are capable of doing and that they're capable of living in the community. It's lack of support, that's the problem - lack of funding for support. If they had adequate support then most of these people - well, I'd say all of the people because I don't believe in institutionalizing anyone and I think it's wrong. People belong in the communities. I actually can speak from experience because I have a daughter who is present here today and she lives in the community because she's had the support that she needed. It doesn't matter on the severity of the disability, if the supports that you need are put in place - and I think I have to stress the word "need" because you can't just do a blanket statement for every person. Just like you and I have different needs, a person with a disability has different needs.

MR. GLAVINE: Thank you.

MS. KITCHEN: Thank you.

MADAM CHAIRMAN: Next we have Mary Rothman from the Nova Scotia Association for Community Living.

MS. MARY ROTHMAN: I want to begin by apologizing to members of the committee. I had a mini personal crisis first thing this morning and did not bring copies of my presentation. I'm not going to give you details to be read into Hansard, but if anybody wants to talk to me at lunchtime, I'll tell you. So I'm here with my personal speaking notes.

The Nova Scotia Association for Community Living has been in existence for over 50 years. We are part of a federation of Associations for Community Living in every province and territory of Canada. Our membership is made up of families that have a person with an intellectual disability as part of their family, people with disabilities, service providers, friends and supporters. That cross-section of people is reflected on the makeup of our board. We enjoy a respectful relationship with the Department of Community Services, although we have deep and abiding differences in some of their policies.

Our membership has named several priorities of concern to them. They have done this, the same priorities, consistently over the last several years. The very first one is the institutionalization of people with disabilities in Nova Scotia; the second one is poverty; the third is employment or access to post-secondary education for people with intellectual disabilities; and the fourth is adequate and flexible and appropriate supports, to allow people with intellectual disabilities to live in their communities and be part of their communities and be good neighbours.

[11:15 a.m.]

The issue around poverty - we would echo those people who have already asked that Nova Scotia declare the new savings plan announced by the federal government to be exempt. Families cannot leave money right now to their sons and daughters or provide for them after their death in any meaningful way because those assets will be clawed back by the Department of Community Services and they will continue - their sons and daughters will continue - to live in poverty.

If you are poor and your mom and dad are still alive, or your Aunt Suzie or a good friend, you can go there for Sunday dinner and you can get some pretty nice Christmas presents. But it is heartbreaking to hear family after family after family say to me that they hope their son or daughter dies before they do because then they will know they are safe. That is not what we want for our children, so we strongly, strongly urge the Government of Nova Scotia to make this disability savings plan exempt from asset considerations.

Employment - the Department of Community Services has recently issued two reports and this one is called Vocational and Day Program Services for Adults with Disabilities in Nova Scotia. It only lists six recommendations, we would basically support them all.

Vocational programming in Nova Scotia is in a crisis. I left that field 20 years ago in this province and I have seen very little improvement in the kinds of services that are offered to people. Not because the staff don’t want to and not because there are not dedicated staff - there are some innovative and dedicated staff in that sector - but the funding formulas are ridiculous. People with disabilities, quite frankly, in most of these centres have to work and get paid a pittance; usually a stipend of maybe $50 a week, maybe not that much. What they are doing is working in small cottage industries that are generating the money, so they have a place to go tomorrow. In some places that would be called slavery.

Most of these adult day programs don’t even keep waiting lists because people would be waiting for years and years and that’s just too discouraging. We also would support those recommendations and the recommendation of the department that they begin immediately to look at the problem of those young people 18 to 21 years of age coming out of school. Those young people have been included in their communities, they have been included in their schools, they don’t really want to go to a segregated program and even if they did, they can’t get in.

So we have two examples of partnerships with community agencies and community colleges in Nova Scotia. One is the ACEE program, which has already been talked about, which serves that 18- to 21-year old; and the other is in Port Hawkesbury, just starting this year, and it’s called Strait to Work - I think it’s a great name - and it’s a partnership with the community college up there as well. We would encourage the exploration of other types of partnerships that more adequately meet the needs of young people with intellectual disabilities. They want a job, they want a real job and they want to get real pay for the work that they do.

The issue of adequate and flexible supports in the community is tied to the issue of the institutionalization of people with disabilities in Nova Scotia. The second report that was released in June is a report on residential services. It’s a very confusing report, quite frankly, and I don’t - although they say within this report that they haven’t really costed what they’re saying here, we’re presuming that this is going to be setting the policy for the years ahead for the department, although there has been no statement by the minister.

There's no author on this report - it's simply a report that showed up on the Web site of the department.

There is a real disconnect, in our opinion, between some of the rhetoric and some of the quotes and some of the visioning statements within this report, which are great. We certainly support the UN Convention; Nova Scotians, in fact, had a real part to play in developing the UN Convention on the Rights of Persons with Disabilities. Minister MacKay was the lead minister from Canada on this issue and we had two Nova Scotians - Dulcie McCallum and Steve Estey - who were part of the NGO delegation to the UN and had real influence on this convention.

The report by the department quotes Article 19, which you already have copies of, and, at the same time, it entrenches for generations to come the institutionalization of people with disabilities in Nova Scotia. The figures that I received last week from the Department of Community Services indicate that there are 691 Nova Scotians housed in adult residential centres and regional rehabilitation centres.

There happen to be two types of institutions that the department and my organization agree are institutions. That does not include those people with intellectual disabilities who are housed in nursing homes, and we know that there are people in nursing homes but the Department of Health can't tell us how many people live in nursing homes with an intellectual disability. It does not include those people who happen to live in 30-bed community homes around the province, it is simply the adult residential centres and the regional rehabilitation centres - 691 people, that is more people placed in institutions than in any other province or territory in Canada and it is simply unacceptable. Some provinces have closed institutions, others have made commitments to do so. Most of the rest at least have plans for downsizing by x number of people a year.

In our province we just opened, in the last two weeks, a new institution. You can tell I'm passionate about this one. But you know we have a precedent here in Nova Scotia, we used to be leaders in closing our institutions. We were leading the country, along with B.C. in the 1970s, and it came to a grinding halt.

The other things that concern us about this report is, although the rhetoric talks about choice and the rhetoric talks about people having the ability to choose where they want to live, it's not what the recommendations really, really say. It talks about assessment but the department has not decided what the new assessment tool is going to be, but that assessment basically puts a price on your head and says where you can live. If you need more than 21 hours a week support, you're going to go and live either with another family that you may not want to - you may already have a family and, quite frankly, want to have some more independence - or you're going to go to an institution or you're going to go to a large group home.

Small options, which used to exist - they're gone from this report. The department is now building six- to eight-bed group homes. We stopped doing that in the 1980s. So there needs to be a lot more work done if this is the vision for the Department of Community Services - there needs to be more conversation, there needs to be more work done.

The consultant who wrote the draft of this report did not talk to people who were receiving services unless the service that she was speaking with invited one of their clients to come along to a meeting. Nor did the consultant go and talk to people who were on waiting lists, and there are people who have been on waiting lists for over 10 years for community living support in this province. None of those people were consulted to ask what their dreams and aspirations were. So there's still a lot of work to do.

I have to say that some new money is flowing, there are new people now being supported in the community and we are very, very grateful for that, but it's not enough. The minister announces $6 million to go to community and $19 million to renovate an almost 100-year-old institution outside New Glasgow. I don't think that's justice and I'm probably running out of time, so I guess I'll stop there.

MADAM CHAIRMAN: Thank you very much, Mary. Any points of clarification? Thank you.

Next we have David Mooney and the Nova Scotia Community-based Transportation Association. Whenever you're ready you can start, David.

MR. DAVID MOONEY: Thank you. My name is David Mooney, I'm the chairman of the Nova Scotia Community-based Transportation Association and I have Dodie Goodwin with me, executive director of the Pictou County United Way.

Madam Chairman Marilyn More and Members of the Legislative Assembly, for many of you this may be your first encounter with the association but for others it will be a reconnection with this provincial entity. Since 2006, a dedicated group of directors have worked diligently to create a new strategic plan and vision for our organization.

Community Services is no stranger to the transportation disadvantaged. Community Services supports community-based transportation every day through rural Nova Scotia. Service Nova Scotia and Municipal Relations funds provide valuable spinoff support when it provides your DCS clients with affordable and accessible rides for school and work opportunities. Today, our board consists of 12 people. They agreed from the onset that there was a need to clarify the purpose of the association and strengthen its position as a leader in the field of community-based transportation. These board members represent many communities and groups, all of which understand the need for accessible, affordable transportation.

[11:30 a.m.]

In your handout, there's a list of our board members and the significance of it is that all of these community members themselves are responsible for independent organizations in the province and all of us have a need and envision that transportation is really for everybody.

The board felt that, as an association which was representative of many different communities, a broad vision was required to assure that community-based transportation was reflective of this wider population that is or could be served. The vision of the Nova Scotia Community-based Transportation Association is that all Nova Scotians have access to affordable, community-based transportation.

So what is community-based transportation? For the purpose of our work, we define community-based transportation as those services which are community-owned and governed and enable consumers' involvement in community engagement. It is the mission of the association to promote and stimulate and support the development and sustainability of community-based transportation throughout Nova Scotia.

As a provincial association, we believe that accessible, affordable transportation is a fundamental right. Community-based transportation should be supported and funded by the community and all levels of government. All those who are contributing to the vision of the organization are valued and supported, and community-based transportation contributes to an overall positive impact on the environment.

MS. DODIE GOODWIN: Using these elements as a framework from which to build and strengthen the association, the board developed key action areas and goals. The four are: governance and membership, community mobilization and support, government relations and marketing. The board really felt that solidifying itself as a viable organization with a structured membership base was its top priority. The membership would strengthen the work of the board and create a broad vision that was representative of the many sectors within the population who could benefit from the community transportation model of service delivery.

Board meetings are being held around the province so that we can actually encourage local participation and after a board meeting there is an open forum so that we can build awareness and work together as a provincial force.

Community mobilization and support - the association currently has on its board, as David has said, many long-time service providers and many people with different backgrounds. Currently two of them - Claredon Robicheau, Le Transport de Clare, and Ron Levy, Central Highlands Association for the Disabled (CHAD) - are both here today and their willingness to share their expertise is incredibly generous and it's quite ironic that they both started their services, totally at different ends of the province, at the same time and then were able to meet and share their experiences. It has been amazing for both sectors of our province to have those services.

It is through their ongoing work and information-sharing, as well as events such as the one we're attending here today, that the association is able to provide a level of expertise and guidance. The goal is to make information and resources available to other groups who are trying to mobilize communities, to support the development of community-based transportation throughout the province to get Nova Scotians where they want to be.

Government relations - the Nova Scotia Community-Based Transportation Association works closely with Service Nova Scotia and Municipal Relations. The board wishes to recognize Karen Ramsland, who has just retired, and now Georgina Dimock, who have been an excellent resource to us and who have provided insights into community-based transportation on a provincial level.

The Community Transportation Assistance Program (CTAP) and the Accessible Transportation Association Program (ATAP) funds continue to provide ongoing support for community-based transportation providers in Nova Scotia. Recent federal funding has also shown a commitment to community-based transportation through the Canada-Nova Scotia Agreement on the Transfer of Public Transit Funds. NSCBTA looks forward to continuing its involvement in the consultation process for programs such as these.

As many of you know, the transfer did include the dial-a-ride programs and that was a precedent and we were very pleased with the Nova Scotia Government's direction on that. We also applaud the provincial government for its last budget in establishing funds to assist with the initiation of new public transportation systems, as evidenced by the recent input of $125,000 to the newly-launched Strait Transit that launched yesterday and we're very pleased to see that launch and service that area. As said, only by engaging all levels of government and community, can we get all Nova Scotians where they need to be.

Marketing - to ensure that the work of NSCBTA will move forward, there is a need to work collectively to increase awareness and public understanding of what is community-based transportation. It is important to highlight the benefits it represents to every community that is fortunate to have access to such a service. In order to develop a consistent message in a timely fashion, NSCBTA retained the services of Jen Powley last summer, a master's student from Dalhousie, to work with us. She created learning modules and assembled a document of best practices. We are able to bring this workshop to communities with a vision of community-based transportation.

The board's vision of community-based transportation adopted by NSCBTA represents a direction that could be described as thinking outside the box. Far too often, the idea of accessible transportation is linked primarily to the disabled population. Although this represents a large percentage of the users for whom this service has proved to be most useful, we are now looking beyond these traditional users to anyone who needs a ride and does not have access to transportation services. We all know if we can get people to programs, programs are great but we've got to figure out how to get them.

We were extremely pleased with the support we had in the spring workshop with the rural municipalities when we spoke to them about the need to keep people in their communities and transportation is a key issue.

Community-based transportation programs are working with individuals to service the needs of adult learning centres, recreation and after-school programs, community services and support for daily living activities. Some dial-a-ride services are partners with community school boards and also provide rides for patients who may otherwise use EHS for hospital trips for dialysis or medical appointments.

Rural Nova Scotia - and most of Nova Scotia, except Halifax, is considered rural - is in need of services that keep people in their communities and help prevent the out-migration of people who require basic supports, as evidenced in the Nova Scotia Strategy for Positive Aging, in the age-friendly rural communities that was done in Guysborough and the framework for a poverty reduction strategy for Nova Scotia. Every one of those has a goal of creating community-based transportation to keep people where they want to live.

Our board is supportive of other real partnerships, such as Pictou County's quest for public transit, to work together with the dial-a-ride service already operating. This will mean the new, fixed-route transit could exist with a door-to-door dial-a-ride program, encouraging everyone to look at how we can look at the resources we have and use them to our maximum efficiency.

MR. MOONEY: Environmental issues are also moving to the forefront of community development and strategic visioning. NSCBTA can be a leader in promoting community-based transportation as a means of reducing the environmental impact on the province. We would like to commend the work of the Ecology Action Centre - a partner of NSCBTA - and their green mobility strategy. In your handouts, I've given you their recommendations along with our presentation.

Although our interest in transportation has gone beyond the dial-a-ride system, CTAP and ATAP have been in the heart of community-based transportation and support still needs to be directed their way and improved continually. I hope this overview provides you with some background regarding the association and how we have reached this point in our evolution as a provincial body. I hope that you will take this message of community-based transportation back to your constituents. We hope that as a result of today's session, you will endorse our three recommendations:

(1) Community Transportation Assistance Program, CTAP, funding of $1.60 per capita is not enough for medium-size services. Increase CTAP operating funds by $20,000 for services with three or more on-the-road vehicles.

(2) Increase ATAP, which is Accessible Transportation Assistance Program, funds to $40,000 for new vehicles. By doing this all we need to do is increase the ATAP program from $100,000 to $200,000. These vehicles that we're using today, which are smaller or diesel, more environmentally friendly, are becoming very, very expensive.

(3) Endorse and support the Ecology Action Centre's green mobility strategy, particularly with respect to funds related to public transportation.

We appreciate your interest and applaud your decision to allow NSCBTA to participate here today, Madam Chairman.

MADAM CHAIRMAN: Thank you very much. I'm just wondering, do any committee members have any questions? That was a very thorough . . .

MR. MOONEY: We'll be here this afternoon for the round table, too, Madam Chairman.

MADAM CHAIRMAN: Excellent. So thanks very much, David and Dodie.

We'll move on to the Nova Scotia League for Equal Opportunities. Welcome, Ralph.

MR. RALPH FERGUSON: Thank you, Madam Chairman, and members of the Standing Committee. I'm here speaking on behalf of the Nova Scotia League for Equal Opportunities. My name is Ralph Ferguson, as most of you know.

Before I go on I'm going to tell you that I'm not going to use that big, long name, I'll probably be referring to it as NSLEO or Nova Scotia LEO in my talk. I'm here, as you see, by myself but I want to assure you that I'm not by myself in the room. I've got my Past Chair and my Past, Past Chair in Ron and Clarendon here. Our staff - Bernadette in is in that corner and our Vice Chair and Chair-in-Waiting, Joan Levack is behind me there, too, and she is going to be joining us this afternoon, too, I think, at the round table, so we're very pleased to have this opportunity to come before you and speak to you.

I had better get on with it because I'm timed, aren't I? NSLEO is an organization for persons with disabilities. The governing body of NSLEO, as well as the governing body of our member groups, consists of persons with disabilities. Our member groups are affiliate groups around the province and we have six of them.

NSLEO provides a consumer perspective on provincial issues which affect the daily lives of Nova Scotians with disabilities. NSLEO believes equality can be realized when all facets of our community are readily accessible to persons with disabilities and lead to complete and genuine independent living. The facets of community of chief concern to our organization are human rights, employment, education, housing, public accessibility and technical aids.

To put the situation in perspective, I'll give you the figures which we use, which are similar to figures that you've heard around the room today but, depending on the source, you'll be told the rate of disability in Nova Scotia is anywhere from 17 to 20-plus per cent. That means that 152,000 Nova Scotians are living with that disability. Another group said 192,000; now that may be the new census, you see, because we know that figure is growing, that 152,000 - it has to, with the aging population. Add to that the number of caregivers and family members of those persons with disabilities and you have a significant number of citizens here in Nova Scotia whose lives are directly impacted by disability issues. Also, when you consider that we're aging, as I say the number is growing.

As I mentioned earlier, our mandate at NSLEO is to provide a consumer perspective on provincial issues. As such, we have, over time, come to enjoy a good relationship with all the Parties in this province and have, for many years, been privileged to come before groups like this, and the caucuses, and have our positions taken seriously and we really appreciate that. Therefore, it is difficult to follow the mandate of this presentation and only focus on two or three priorities. Of necessity, our day-to-day operations involve trying to understand the totality of the issues that persons with disabilities face. It does a disservice to those citizens with disabilities who find all facets of their lives implicated by a multitude of issues for us to kind of stick to three, but that's the mandate - we're going to try. We can provide you with copies of our position papers on various particular issues so today we will focus on just a few important priorities.

[11:45 a.m.]

First, in order to solve any problem one must have a strategy. This province does not have a disability strategy. The issues are spread out through various departments which do allow to have a clear picture of the issues. Energies are scattered if there is no central focus. Our province subscribes to a population health model which strives to see the whole person and the totality of their key determinants of health.

If there were a clear-cut disability strategy or even a department of disability issues, it would go a long way towards taking the knowledge that all of these organizations speaking today have and using it to implement a policy that leads to full citizenship for all Nova Scotians. Leadership is what we need, the creation of a legitimate space for these issues and the implementation of solutions to these issues. That's what is missing now in any kind of a formal way and we'd like you to consider that.

As a result, each already existing department deals with siloed issues and does not have the opportunity to marshal all of the resources at hand to understand fully the implication of each issue and how it interacts with the other issues. We have knowledge, we have passion and commitment and what we need now is formal leadership and legitimacy of purpose. In this room alone we have the combined power of the not-for-profit, the provincial, and community-based groups necessary to begin such a task.

So I guess it is possible after all to give this presentation without mentioning specifics, such as more for wheelchair initiatives, more ATAP funding, a poverty reduction strategy, technical aid funding, low-cost accessible housing, better standards, support for specific education initiatives and the necessity of affordable, accessible public and rental transportation.

I thank you for your time and consideration. We appreciate very much this forum and the opportunity to come before you, but we look forward to a day when forums like this aren't necessary. Thank you very much.

MADAM CHAIRMAN: Thank you very much, Ralph. Any questions from committee members? We'll have a chance to pursue a lot of those issues this afternoon in the round table.

MR. FERGUSON: Thank you. Before I close, were the copies of this provided? Okay, I'm sorry.

MADAM CHAIRMAN: I'm just wondering if People First would be prepared to present now instead of after lunch? Are you comfortable with that, John, or would you prefer to wait? (Interruption) Okay, let's do one more and then we'll break for lunch and reconvene at 12:45 p.m., I believe.

MR. JOHN COX: Hello, my name is John Cox and I'm the development coordinator of People First Nova Scotia. To my left is Samantha Butler, who is the support coordinator for People First.

People First Nova Scotia is a self-advocacy group for people who have been labelled with an intellectual disability. Our entire membership is people who are labelled with an intellectual disability. Most of our members are receiving funding from the Department of Community Services, either through ESIA or the Services for Persons with Disabilities Program. There are eight chapters throughout the province, going anywhere from Cape Breton, all the way down, to Sydney to Yarmouth.

People First Nova Scotia and the Nova Scotia Association for Community Living have created a joint task force on deinstitutionalization. Our national organizations, People First Canada and the Canadian Association for Community Living also have a national task on deinstitutionalization. I have the privilege of sitting on both these task forces.

Many members of People First Nova Scotia used to live in institutions and are horrified that this government is making a move to reinstitutionalize its most vulnerable citizens. Nova Scotia was once a leader in Canada around deinstitutionalization and is now showing itself as taking a terrible step backward, by creating large facilities to house people with disabilities. In fact, Nova Scotia has more people incarcerated in larger institutions than in any other province in Canada. That's not per capita, that is numbers period.

As one member said, nobody who lived there and got out ever said boy, I'd really like to go back and live there again - nobody, not one - and that tells us something. Ask anyone who has lived there what it was like and all you'll hear is horror stories. Some refuse to even speak about their experiences - that tells us a lot.

Institutions are not new, they've been in existence for hundreds of years. At one point our society viewed them as a primary, perhaps preferred residential option for people with intellectual disabilities who could not live at home. This response by society assumed that services could be best and more cheaply delivered in large settings, that individuals did not have the necessary skills to live in the community and that they were not capable and needed to be cared for. We now know that these assumptions are false.

What we do know is that when asked, people with intellectual disabilities choose not to live in institutions. We know that institutions deny basic rights of citizenship, personal control, decision making and independence. Based on personal stories, as told by people who have lived in these facilities, we know of the abuse, isolation and personal suffering that more often than not occurs in these facilities.

Since the 1970s, we have witnessed institutional closures in all of our provinces and territories. In fact, at one time Nova Scotia was a leader in closing institutions in all of Canada. Deinstitutionalization started but did not finish. It has only been in the last several years that we have again placed emphasis on this issue, but an analysis of research findings provides these conclusions. There are multiple benefits to community living. Deinstitutionalization for people with intellectual disabilities is clearly different from deinstitutionalization for mental health consumers. Family attitudes changed dramatically, the theory of the must-stay group is not supported. Community support systems are more cost effective than institutions. Research findings are remarkably consistent and community living is not without problems and requires protections.

I do want to quote from some of the research which says for the must-stay groups, the four classic reasons for keeping people in large institutionalized settings - severe disability, challenging behaviours, medical fragility and advanced age - have been more convincingly discredited by carefully controlled studies of community placement by the evidence from total closures over the past 25 years. In fact, other research says that summaries of this research noted that overall, adaptive behaviour was almost always found to improve with movement to community settings from institutions and that parents who were often, as a group, initially opposed to deinstitutionalization were almost always satisfied with the results of the move to community, after it occurred.

In a time where all governments are demanding increased accountability and transparency in the expenditures of public funds, where the demand is for evidence-based practice as a target for public investment, why do our public dollars continue to support an institutionalized system that has been shown to be inferior to a community-based system? Perhaps it is time that these policy-makers actually review the research and act accordingly. In fact, the Director of the Services for Persons with Disabilities Program has said she has done this research, but our research shows different. We're asking the department to show us the document, show us the research that actually proves that institutions are better than the community.

This government says that the Services for Persons with Disabilities Program is a voluntary program, that if I as a person with a disability refuses what they offer, then I'm refusing any services. Being disabled is not voluntary, I have a disability and as such may need supports around my disability. Recently we have seen this in action.

I am aware of at least three people being offered placement in the new Cobequid Centre. Even when these people have medical professionals supporting their claims that they are better served elsewhere, even when they are already in the community and were told that the Cobequid Centre is a transition to help people get ready to go into the community, even when families, friends and other supports say that people are better served in the community, the department is saying otherwise. My question is, what credentials does the department possess to make decisions that go against family, community and other professional opinions?

Just to note, on the Employment Support and Income Assistance Program, there are 28,000 on that program - 13,000 of them, almost half, are people with disabilities. My concern is that these are people who are not getting supports for whatever reasons, probably turning down because you're either offered 21-hour-a-week or 24-hour-a-day services. There's a big disconnect when people have to either go from three hours a day to 24 hours a day, there's a big disconnect from this department on the needs of people with disabilities.

In a country so rightfully proud of its diversity and tolerance, it makes sense that Canadians should have the right to choose where they live, doesn't it? Why is this province systematically violating the basic human rights of people with disabilities? The residential review claims that it is trying to protect the rights of its most vulnerable citizens and I would argue that by implementing some of the policies and by taking away choices of where you live and with whom, the violation of those rights are being placed on by this department.

I would caution the province around their current policies. In Manitoba, a human rights complaint was issued toward their current government - it was when they committed to putting $40 million into renovating the Manitoba Developmental Centre. This is a real concern that institutions discriminate against people based on disability.

This standing committee needs to push this government for a deinstitutionalization plan. We've heard about a disability plan, part of that needs to be a deinstitutionalization plan. This plan must ensure that people have the right to choose where they live and with whom, services and programs that are directed and controlled by the person and that they are respected - a respect for his or her rights to make choices and to take risks; the right to individualized living arrangements and control over the required individualized funding; the necessary disability-related supports needed to fully participate in the community;

support as necessary from families, friends and advocates to assist in decision making; and supported decision making and services that meet all of the needs and are high-quality, portable and accessible.

The Province of Nova Scotia needs to create a comprehensive disability strategy, it is one of the recommendations that the Poverty Reduction Working Group put forth earlier this year. Without a clear plan to support people with intellectual disabilities, this and future governments will continue to fail many of its citizens. When Nova Scotia was a leader in deinstitutionalization, it was under a Progressive Conservative Government. It is time once again to show its citizens and the rest of Canada that you have once again become leaders in providing supports for people with intellectual disabilities in Nova Scotia. Thank you very much.

MADAM CHAIRMAN: Thank you. Samantha, were you going to add anything?

MS. SAMANTHA BUTLER: No, I wasn't, I'm supporting John.

MADAM CHAIRMAN: Okay, thank you. Any questions or points of clarification from committee members? Thank you both very much.

So we're going to break now for a light refreshment break which will be provided here in the Red Room. We'll reconvene at 12:45 p.m., we'll finish the presentations and then we'll continue on with our round-table discussions. Sorry, the lunch is provided in the foyer just outside the door.

[12:00 noon]

Are there any questions regarding the arrangements? I just wanted to ask in case there's anything we need to do for this afternoon's session. Is everyone fairly comfortable? Sorry, John, could you just come up to the table and . . .

MR. COX: It's really hot in here, is it possible to bring in a couple of fans or something to cool the place down?

MADAM CHAIRMAN: We'll look at reducing the temperature, thank you very much for that.

Okay, enjoy your lunch and we'll see you at 12:45 p.m.

[12:01 p.m. The committee recessed.]

[12:55 p.m. The committee reconvened.]

MADAM CHAIRMAN: I think we'll restart. We may have some people this afternoon who weren't here this morning, so again I would like to welcome everyone. I think we'll begin with introductions again from the members of the Standing Committee on Community Services.

[The committee members introduced themselves.]

MADAM CHAIRMAN: Okay, well, that was probably a little confusing to people in the audience as we bounced back and forth, but okay. So we have two more presentations, then we'll perhaps take a five-minute break to get a representative from each of the organizations that presented around the table. Then we'll do introductions for the round-table discussion and continue on this afternoon.

So thanks to everyone for coming back or for joining us. Our next presenter is the Provincial Autism Centre, Cynthia Carroll.

MS. CYNTHIA CARROLL: Thank you, Madam Chairman and members of the standing committee. My name is Cynthia Carroll and I'm the Executive Director of the Provincial Autism Centre. The Provincial Autism Centre was founded in 2002 as a non-profit, registered charity and was the original vision of Joan and Jack Craig, parents of an adult son with autism who is now 50 years old.

Today, funded entirely by private donations, the centre supports individuals with autism, their families, educators, health care professionals, and the community by providing information, materials, social program opportunities, and services throughout Nova Scotia. We believe that by providing parents with information that can help them seek more effective therapy options, a teacher with a strategy that can foster better inclusion in the classroom, or an autistic adult with a lead to an employment opportunity, greater success for individuals with autism and their caregivers can be achieved. That is why at the Provincial Autism Centre, we believe that support means success. Our vision is a world where all individuals with autism spectrum disorders can lead their lives fully.

In six short years at the centre we have developed a variety of programs and services. They include the largest autism resource library in Eastern Canada, with over 1,000 books, DVDs, and articles on autism and autism-related issues; Autism Online, a moderated on-line discussion forum that overcomes the traditional communication and social barriers of autism; and teen and adult social groups, which was one of our original programs in 2003, with now over 50 teens and adults coming to our centre on a monthly basis just to find a sense of belonging and communicate with one another.

We have a summer volunteer program which provides meaningful volunteer opportunities for people with autism. It helps young people gain work experience which then helps to form career choices later in life. In our first year, over 70 per cent of the individuals who participated in this program either returned to the original place they volunteered the following summer, or actually were hired by those organizations.

Autism Arts, which is actually a new program for our centre, was developed last year in partnership with the Art Gallery of Nova Scotia. It includes children and adolescents who have autism and it helps to explore therapeutic and creative opportunities through art. Last year when this program started, it started with two classes on Saturday. By January, we had to increase those classes to three classes and this year it will be starting just after October and we already have waiting lists.

[1:00 p.m.]

We have an adult self-advocacy network. This is a group of adults with autism who meet weekly at our centre to discuss critical issues related to autism that matter to them most. Their main mandate is to discuss employment, affordable housing and relationships. This groups also prints a newsletter called Autistics Aloud. It's written by and for people on the spectrum. You also have copies of that in your packages.

Coming, hopefully in January 2009, is a supported employment program for individuals with autism. To help identify the priorities of individuals with autism, I think it's important to talk a little bit about what is autism. If you research autism on the Internet, even on leading sites about autism, you will find that the majority will speak about the triad of impairments. They will state that autism impacts three main areas of development: socialization, communication, and the presence of restrictive behaviours or interests.

I can tell you that's not what autism is, but rather how it is diagnosed or identified. What autism is, is a profound difference in how information is processed by the brain and analyzed. This leads to challenges in socializing, communicating, and restricted interests, but also to many strengths like logical decision making, enhanced visual acuity, faster sentence comprehension, enhanced auditory pitch recognition, and accuracy in graphic recall.

Autism is a neurological disorder that you're born with. It is pervasive, affecting all aspects of development. There is a genetic component to autism, with boys four times more likely to have autism than girls and it currently affects one in 150 people, so in Nova Scotia that would be over 7,000 individuals who fall into the autism spectrum. It is a broad spectrum that encompasses everything from someone who requires two support workers to go to the dentist, to your favourite university professor. That is one of the difficulties in implementing services for individuals with autism - everyone is unique, making generalized disability support programs non-effective.

Autism is not a psychiatric condition or an intellectual disability, though people with autism can also have some of these conditions. One of the most important messages I can leave you with today is children with autism grow up to be adults with autism. Society needs programs and services in our communities to reflect that.

Our understanding of autism is new and emerging but autism itself is not new. We can attest at the centre that there are many teens and adults in our community with autism.

Many have different labels, and some have no labels at all because they have missed the generation of early diagnosis, but they all struggle to find understanding and acceptance in their peer groups, in the workplace, and to have relationships and to live independently in a world that only sees autism as a childhood disorder.

The Autism Centre strives to fill a gap in services offered to people with autism. While much attention is given to early interventions and support in school, this support significantly trickles off over time, leaving teens and adults with autism without services that respect their needs as autistic people. Our programs are respectful of the strengths of people with autism, and our unique and inclusive approach at the centre has gained international recognition by autism groups that share our values.

Our autism self-advocacy network, which is the individual group of adults I spoke about earlier, has been working with an adult self-advocacy group in the United States and has just been sanctioned as the first Canadian adult group in Canada to start to talk about some of these adult issues with autism. Their newsletter, Autistics Aloud, in January will actually achieve international publication, it’s actually going to go international which is a huge accomplishment for this group of individuals.

Society has indicated that we value what people with disabilities have to offer. We have things like curb cuts and ramps for people in wheelchairs, Braille on elevator buttons for the sight impaired, closed captioning on TV for the hearing impaired and all of these things tell people with these disabilities that they are included in society, as they should be. People with autism do not see themselves accurately reflected in society at all. We put the onus on them to overcome or mask their disability before we accept them. Do we tell someone who is sight impaired that they must learn to give eye contact in a job interview, even though it could be equally as impossible for someone with autism? Do we tell someone in a wheelchair that we will put all of our effort into helping them to learn how to walk or do we accommodate their disability so that their abilities can shine through? By meeting people halfway, through understanding and support, we will motivate people with autism to be the best person that they can be.

So what are the real issues for adults with autism? Autistic adults want to contribute. Adults want to work and have many strengths to bring to the workplace, but are marginalized by society who doesn’t understand autism in adulthood and by disability support services that don’t meet their needs as autistic people.

Support funding is often determined by intellectual functioning. Many adults with autism are denied services because they are clearly intelligent. Intelligence is not the problem in autism, it’s a social communication disorder first and foremost, but many make false assumptions about their abilities and their disabilities.

Support services are rarely informed by best practices in autism. Many approaches to things like teaching social skills, for instance, take approaches used for children and adapt them to adults, with no scientific basis or understanding about the real issues of adults with autism. As a result, these approaches can do more harm than good, giving the autistic person the message that they just don't belong.

We need to be informed by autistic people. Many autism groups are not informed by people with autism and don't respect that autistic people are key stakeholders in decision making that impacts their daily lives. The Autism Centre has established a reputation as a non-biased resource and a place that can be accessed by everyone affiliated with autism, but first and foremost we have gained respect by including people with autism in our decision making. It is because of this relationship with the autism community that the real issues in autism inform our practices at the centre.

Is early intervention important? Absolutely, but so is middle childhood, the teenage years and adulthood which is where we spend most of our lives. If there's no continuum of care of support and service, what is the long-term impact of an early intervention program when we know autism is a lifespan issue?

As more and more children are diagnosed through early intervention, how does the system support them after age six as they move through their life? The centre strives to fill these service gaps, but even with three full-time employees - one who is designated to administrative tasks and bookkeeping - we cannot keep up with the demand of service. Every day, we take calls and meet with people with autism, parents, teachers, education officials, health care professionals, employment programs, businesses and even calls from government offices about autism, about sharing our social program models in cities and towns across Nova Scotia. Although we try to accommodate as many requests as we can, our waiting lists continue to grow and need to be managed.

What am I proposing to this group? I think the themes of my presentation were, you know, autism is a lifespan issue, that there are significant gaps in services that really need a call for action. If we can accomplish all of this in six years, which I feel is a significant amount of programming opportunities and support to the autism community, imagine what we could do in partnership with the provincial government and partnerships in the community?

Fifty years ago, people with autism were institutionalized and hidden away from society. Today we have early intervention, but teens and adults with autism continue to be excluded and isolated in their communities and are in need of programs and supports. In 50 years, it is our hope with the provincial government, community organizations and the growth of organizations like the provincial Autism Centre, that all people living with autism spectrum disorders will live their lives fully. Thank you for your time.

MADAM CHAIRMAN: Thank you, Cynthia. Any questions? Leo.

MR. GLAVINE: I was just wondering, Cynthia, if you could speak for a moment about the centre's relationship to the Autism Society?

MS. CARROLL: The Autism Society of Nova Scotia is also a non-profit organization. We are two separate entities. They are well known for their parent support, we are actually known for the programs and services to actual individuals with teens in autism. They do run a very successful and very valued autism summer camp, which is a huge asset to our community. They don't physically have a structure right now that I'm aware of in the city, so they're not able to offer ongoing programs and services. Our programs and services have been ongoing since 2002. I think the difference between us and the Society - there is always going to be the overlap because there are very limited programs and services out there. I guess I would say the largest distinction is that they are a parent-driven organization. I believe all of their board members are parents. Our board members are comprised of parents, but also of professionals in the community and our programs and services, like I said, are for teens and adults. Does that clarify?

MR. GLAVINE: Yes, thank you very much.

MADAM CHAIRMAN: Thank you very much, we appreciate your presentation. Next we have TEAM Work Cooperative.

MR. MURRAY VANDEWATER: Hello, my name is Murray Vandewater, and with a name at the end of the alphabet I'm used to being last. It caused me some concern when I was a child in the 1950s in school in Nova Scotia and you had to get in alphabetical order during a fire drill. (Laughter) But it did teach me patience and trust in our leaders.

Following along that theme, I think there is an alarm sounding and it's going to be hard, quite honestly, for me through our organization to add to the comments that have been made today. I think there is some impatience being expressed on behalf of the disability community. I think in many parts it's because, looking at my role as a volunteer, that essentially there is a change in the paradigm on how society views persons with disabilities, in my own personal experiences, and how persons with disabilities view themselves. There has been a move from the charity model good works that many of us were brought up on and right now there is a significant move toward a rights model.

My view is, I think social policy is lagging in many aspects because of this change in paradigm. In many ways, I don't think that it is necessarily the fault of policy makers and leaders such as yourself because technology is moving so fast. There are significant advances in medicine, applied engineering, pharmacology and I think that, in large part, has invigorated the disability community.

With that lead-in, I'll go directly to my presentation on behalf of TEAM Work and we, essentially, are looking at the aspects of employability. A lot of these themes are common, I'm just putting in our two cents worth to add to the discussion.

The fundamental assumption I think many and all agree with is that employability is a cornerstone that contributes to a person's feelings of independence and societal participation. With that in mind that's what TEAM Work is involved with indirectly - it's looking at issues of employability across disabilities. We offer a case management service within HRM. TEAM Work is an umbrella group of about 31 shareholders and affiliates. Again, we deal within HRM, with about 800 to 1,000 clients.

We had three discussion points to offer here and I think some of this - again, listening to everybody ahead of me, I'm saying, oh, what am I going to say, everybody said it before. I think it's reasonable to understand that there is an inconsistency of employment services for persons with disabilities across the province. Why do we say that? I think the reason why we say that is we're looking at partnering and working outside our total mandate, which is HRM. Recognizing that, we're working with a group that is called a Collaborative Partnership Network which was formed in 1997, that is looking at, together with our partner group WorkBridge, a province-wide network of specialized services aimed at employment.

With all of these different groups and agencies, we believe we have expertise and experience and understand the need of support for persons with disabilities and that looking at ourselves, that we need to look at issues of continued equality improvement and aspects of accreditation in our own work. Accreditation was brought up in an earlier presentation.

[1:15 p.m.]

There is an 11 member network that has worked together to understand and try to define and articulate, what are the best practices, policies and programs that can promote greater access to employment support to assist individuals with disabilities. We believe there is a need to have access to comprehensive employment programs and services no matter which region of the province they live. There is a shortage of - qualified to work with persons with disabilities - job developers who are specialized in advocating to employers each individual client's needs.

The second discussion point. That is something I thought would be brought up. There's a devolution of employment support and assistance from the federal government to the provincial government. We, TEAM Work and Collaborative Partnership Network - and I don't want to presume to speak for all disability groups, but I would suggest they probably would join me in this - we want to be part of the decision making process.

I note that this kind of meeting of the all-Party group is lending us some ears to that effect and I like the fact that this kind of discussion between our politicians and ourselves is inclusive. I think in our entire thematic aspect of working with persons with disability, that terminology inclusiveness repeats across all disabilities and across all. I'd like to commend this group for including us in your discussions. We understand that essentially you're a group of ears and we appreciate that quality of ears that I see here today.

I think it's crucial that representatives from the disability community and partnering agencies contribute and participate in a decision-making policy that's accompanying this devolution of employment assistance and related programs for persons with disabilities.

Third and last point, so we can get into the round, and I think it's reasonable to say that you've heard a lot of different types of programs offered here today, one size does not fit all, except maybe me. But anyway, the issue is it takes a great deal of coordination of service providers, clients and employers to reach a successful agreement of what is suitable for a person with a disability.

It's an understatement to say that funding is lacking to effectively provide all the types of intervention which are suggested. Within the framework of what we offer within TEAM Work, there's a lack of trained job coaching, let alone noting that we have to look at again, issues of entry to practice of our own professionals and that passion is not enough, we have to do a job well and responsibly. We need to look at training and qualifications in determining what is appropriate to the needs of a person with a disability and listen to the person with disability to understand that need. Funding agencies often focus on the issue of paid employment as outcomes only.

I'm wearing another hat, I've often used the term "active community engagement". Again, I think this has been alluded to by many presentations. It can be defined as somebody being actively involved in our society. It can be involved in their own personal education and training, it could be volunteering with their own group, as well as paid employment. Active community societal engagement, I think, is what is key to persons with disabilities and employment is a very important part that we're focusing on.

Assistive technology or accommodation; these can be very simplistic through to the more complex, simplistic in that the accommodation may be some adjustments to a working day. On the other side, it can be very complex in that assistive technologies are somewhat complex. There's limited funds available to purchase assistive technologies and I think this is a recognized gap in services that have been enunciated several times.

There's a fragmented system of financial-related support to clients who are attached. You're eligible, ineligible, again that was alluded to earlier on today. It is challenging for support workers and the professionals and volunteers with whom I am working to provide - again we heard this term "seamless approach" to employment for persons with disability. I think that is an understatement but it is something, again by our participation here today, we recognize that that is something that is worthwhile to strive for. Thank you very much.

MADAM CHAIRMAN: Thank you, Murray. Any questions? Okay, we're going to take a five-minute break while we set up, so would the representative from each of the organizations who has been either volunteered or chosen to sit at the round table, would you come forward and we'll get everything organized. Thank you.

[1:21 p.m. The committee recessed.]