

HANSARD

NOVA SCOTIA HOUSE OF ASSEMBLY

COMMITTEE

ON

COMMUNITY SERVICES

Thursday, June 21, 2007

Committee Room 1

Services for Persons With Disabilities

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COMMUNITY SERVICES COMMITTEE

Ms. Marilyn More (Chairman)
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[Mr. Gordon Gosse was replaced by Ms. Joan Massey]
[Mr. Stephen McNeil was replaced by Ms. Diana Whalen]

In Attendance:
Ms. Rhonda Neatt
Legislative Committee Clerk

WITNESSES

Nova Scotia League for Equal Opportunities

Mr. Ron Levy, Chair
Mr. Claredon Robicheau, Past-Chair
Ms. Bernadette McKeough, Coordinator
Ms. Joan Levack, Secretary

Abilities Foundation of Nova Scotia

Mr. Thomas Merriam, President & CEO
Ms. Faye Joudrey, Coordinator of Community and Client Relations

People First

Mr. John Cox, Development Coordinator
Ms. Nancy McKinnell, Support Person

HALIFAX, THURSDAY, JUNE 21, 2007

STANDING COMMITTEE ON COMMUNITY SERVICES

9:00 A.M.

CHAIRMAN
Ms. Marilyn More

MADAM CHAIRMAN: We'll get started. I understand one of the groups isn't here yet but we have an unusual agenda in that we have three groups presenting this morning. Since we have only two hours, I think we will start and people can join us as they arrive.

I'm Marilyn More, Chairman of the Standing Committee on Community Services. We're delighted to be continuing with our topic of services for persons with disabilities. We have three excellent organizations presenting to us today. So perhaps we'll start with introductions of the committee members. Keith, would you like to begin.

[The committee members introduced themselves.]

I just want to remind the presenters that the microphones do not amplify your voices, they just record, so it's important that everyone speak up so that everyone in the room can hear what is being said.

We're going to start with the Abilities Foundation. I just remind you that later on, as we get into the questions and comments by the committee members, you can use any of the four mics at the back of the room. You can be heard by Hansard if you use any of those four.

So if you'd like to start, perhaps you could introduce the representatives from your organization and we'll do that as we go through each of the groups, and we'll continue on.

MR. THOMAS MERRIAM: Thank you very much. I'm Tom Merriam, I'm the President of the Abilities Foundation of Nova Scotia. I have Faye Joudrey, who is our Coordinator of Community and Client Relations with me today. She will offer me help, if you ask a more challenging question than I can come up with the answer to.

What I'd like to do, if I may, is just move as quickly as possible through a brief presentation that will give you a little bit of background on our organization, its history and most importantly, the kind of work that it does right now, and some brief comment on future directions that we hope to pursue. I'll just move through these slides, hopefully the microphone can pick me up from this distance.

First of all, our mission in life is basically to work with people with physical disabilities, both children and adults, and overall to help them realize their individual potential, provide them with programming and support and opportunities that seek that goal. A key element of that is to provide the independence, particularly mobility, that helps them achieve those objectives.

From a history point of view, we've been around some 76 or 77 years now - not me but the organization - and we have gone through a series of benchmarks in our life. I won't go through those in detail but you can see that they embody a series of accomplishments over time that relate to the introduction of programs and that kind of thing.

The other thing I should point out is that as you'll see from our logo, we are the Easter Seals organization in Nova Scotia as well and, as such, are essentially part owner of Easter Seals coast to coast in Canada, so we're a partner organization. We sit on the national board of that body and we implement both programming and fundraising activities coast to coast, as part of that role. Here in Nova Scotia that name is known most in the context of some of the fundraising initiatives we do and we position Easter Seals primarily here as a fundraising entity that supports financially all the programs offered by the Abilities Foundation.

Just to give you an idea of the scale of operations, we have about \$2 million worth of programming a year that we provide here in Nova Scotia, literally from one end of the province to the other. What is unique about us is that we generate the funds to pay for those programs primarily from three sources, fundraising is the single largest source of those funds. We raise about 40 per cent of that \$2 million through fundraising initiatives. We have a very, I hesitate to use the word competitive but I suppose it is a competitive environment for fundraising. These funds come from individuals and companies and they are being obviously contacted every day by one of 8,000 charities operating in this province, looking for support of some sort or other.

Our approach to that in more recent years, under a strategic plan we developed, was to become as innovative as possible. Tonight and tomorrow we will rappel 85 people off the top of 1801 Hollis Street as a fundraiser and each person participating raises a minimum

of \$1,500 to participate in that. That is a sample of what some might consider a slightly bizarre approach to coming up with revenue but it works.

We have our 24-hour relay at Saint Mary's on Saturday and Sunday this year. Also, next week we're launching our Guardians of the Sea project. Some of you may remember the Lobsters in the City in 2005, this year tying into a partnership with the Tall Ships event, we're doing Guardians of the Sea which are ships' figureheads, seven-foot high fibreglass creatures that are painted by artists. These will be sold at a gala auction event in the Fall, which is where the fundraising component comes from. Meanwhile, we're able to help local artists get some profile. We give marketing opportunities to companies that are the sponsors of these pieces while they are out on display, so it is really a win-win scenario for everybody involved and it has been a very popular project.

The other funding, the 40 per cent from fundraising, is supplemented next by about 30 per cent in government funding. That relates primarily to funding of our skills centre training program and most recently to children and adults wheelchair demonstration project that we're doing right now and I'll come back to that in a moment. About 25 per cent of that income also comes from what we call earned income; our programs like New Leaf Enterprises sells businesses services, collating and other kinds of business support services, postal code sorting and that sort of thing. It has a significant food program and operates cafes in the Halifax area that generate revenue. So that's a quick, thumbnail sketch of where the money comes from to do what we do.

Now on the program side - I guess I had better change the slide here for you - we have an Active Lifestyles program that includes our Camp Tidnish summer camping program and a new initiative called Take PART, which I'll talk a bit more about in a moment, New Leaf Enterprises skills training, community and client services and health services.

The Active Lifestyles, Camp Tidnish may be known to many. It is celebrating its 70th year this year in operation near Amherst, out on the Amherst shore at Tidnish. It is a very successful program, it accommodates about 300-plus campers a year. There is a fair mix of campers at Camp Tidnish, it is serving both people with physical disabilities and some with intellectual challenges, so that's a history that we continue to this day, even though our primary mandate relates to serving people with physical disabilities.

[9:15 a.m.]

The Duke of Edinburgh Program will be known to most of you. The difference is that until very recently, it has not had an orientation toward people with physical disabilities. We worked with the Duke of Edinburgh folks and developed a program that developed goals and benchmarks for achieving the various levels of award that embodied events and activities that people with disabilities could do. We've had a number of graduates of that program and continue to have people moving through that, mostly very young people obviously.

Take PART is a new initiative that is all around participation in sport and recreation activities. The single biggest problem, particularly for young people, is that they don't have opportunities to get out and get involved, they get stuck in front of the video screen or the TV and that produces all kinds of related issues around obesity and other things, to say nothing of not being able to develop social skills and other skills that are important as life goes on. The Take PART Program is designed to provide those opportunities. It has been launched in the Halifax area very successfully, we've worked with HRM.

It is in a fledgling state but is coming along very well. We've operated for about a year now, we want to move on to the next level which we hope to do starting this Fall. We've also worked with sport camps in the summer, through the university system, and we also have a fundraising component called Stars on Wheels, which is a demonstration wheelchair sports event that ties into the university athletes pitted against some wheelchair athletes who, of course, in a basketball game they pretty well decimate the university athletes, so it's an entertaining thing. Then they mix the two teams and go from there in the game. That's a very important program for us for the future.

New Leaf Enterprises, I've spoken about already but basically it has two key components: one is training around food services and the other is around business services. Those are important for two reasons, they provide real job opportunities. We have 34 trainees in that program. They are working both within New Leaf's own facilities and out in the community at the various New Leaf cafes. The largest one of those is at the rehab hospital here on University Avenue. It has been a tremendous success.

The business skills side, as you can see, involves a variety of services we offer to businesses. We have a clientele of firms that have supported us for some time. They tend to focus on small volume, specialized kinds of tasks that are not automated and therefore we can compete, in terms of pricing, because we bid on these jobs like any other private business would.

Community and Client Services is Faye's area. I think the key part of it is that there's an information void out there. If you're confronted with a disability or, for instance, you've had polio and you are now in your 50's and suddenly you have polio syndrome, which is a recurrence of the disease or symptoms of the disease, then you're looking for help to know where to go to find out more and get services and so on. Faye does a good deal of that sort of activity in her day-to-day work.

We are involved in issuing a disability travel card. There's a theatre card that complements that, that we hope to get in place here in Nova Scotia this year. We are the secretariat to Polio Nova Scotia, which is a group of 400 to 500 polio survivors here in this province, and obviously we work with other groups, like you are hearing from today, and do a lot of liaison work and partnership work.

On the health services side, as you might expect most obvious of all we're in the business of trying to help people get assistive devices; that can be prosthetics or various

kinds of medical equipment or equipment to use in the home to facilitate working there. We are in the process now of working very enthusiastically on a wheelchair program that we'll come back to in just a minute - I may as well move on to that right now.

The wheelchair program is a major partnership initiative. It has taken years to launch. It began with a program related to children and has added an adult component. It's a partnership of a number of different organizations. We started out with a wheelchair initiative group that had the Disabled Persons Commission, LEO, CPA, the IWK Hospital, a number of organizations that were all part of that process.

The government listened to our proposal which was done on the basis of a principle that while we might not be able to do everything we wanted to do on the front end, that we wanted to start somewhere in providing those who cannot get wheelchairs with the ability to get them. That program has, in our view, been very successful in a demonstration stage. These were all the objectives but at the end of the day, it boils down to trying to provide a model for providing equipment that does not involve the so-called charity model. If you are the person with a disability and you have to go begging for money to get a wheelchair, that's not a very pleasant experience for anybody to have to go through. Our belief is that you shouldn't have to go through it. So the whole concept of this program is to provide some sort of help, at least for those most in need, to be able to do that. There are many challenges in that because obviously if you paid for every wheelchair in the province, it's an extremely expensive proposition. Our belief is that if we can help those most in need, then we're making a significant contribution.

The Abilities Foundation was asked to be the actual administrator of the program component itself. We work under a steering committee that involves those organizations I mentioned and it is co-chaired by the foundation and a representative of the Department of Community Services.

We are just now coming to the end, as you will see, of the children's component. It was to be about a 30-month initiative. It was funded to the order of \$500,000. It has been operating now for a little over 24 months and we are well along in the expenditure of those funds. Right now we're beginning to put together the evaluation report. Our hope is that the government will see merit in continuing on with that initiative in some form, hopefully permanent in the long-term, but for the time being, at least a continuation of the current work.

By the same token, more or less a year later, we introduced the adult program, it was funded to the order of \$1 million. Needless to say, there are a lot more adults out there than children, needing chairs. Its timeline was about 24 months.

One of the challenges in this program is that statistics on need are very hard to come by and you're really groping in the dark a little bit in this exercise and that obviously is a concern to government when they're trying to budget for it. So we've done a fair bit of work and we based it on a series of research tasks. It has proven to be fairly well tracked,

if anything we might have been just a little bit stringent in the conditions, in the desire to have enough money to do what we were trying to do, and that will be part of the evaluation.

In terms of the actual costs of items, as you can see, we went on estimates and research that said the average manual chair would cost about \$3,000 and the average power chair, both for children and adults, would cost around \$10,000. You can see we're a little over on the children's manual, that relates primarily to rather more sophisticated seating requirements in the chair than we allowed for, but the other numbers are just a bit below the estimates, so overall it's moving along.

In terms of applications, we're tracking fairly close, we're a little low on the adult side and that may be a product of two or three issues. Indeed, our steering committee is going to be asked to look at some thoughts on that, to see if there's some tweaking we might be able to do even within the demonstration project, to bump those numbers up a little to coincide with the resources we have. So that is that program, and in the future our goal is to put a lot of emphasis on wheelchairs and the ability to have an ongoing program that is available to Nova Scotians.

The other initiative that we have in the works is one around interactive community-based day programs. We offer such a program in our New Leaf Skills Training Centre. We think we can suggest to the government that we can offer a broader program and save them some money, in terms of costs of personal care workers for people who are at home with an individual personal care worker, whereas we can draw them together at least for eight hours a day and have obviously a ratio of care worker to client that is better than that. That saves some money but, more importantly, from our point of view, the program we offer is a very interactive and entertaining and useful program for the people involved. So rather than having someone sitting at home watching TV, we can have them and have them involved in creative endeavours that they'll find have a lot of value to them. So that's our focus for the future, a couple of program areas that we want to emphasize while we continue to build some of the others that I've told you about.

I think I've likely used up my time and then some, so I'm going to stop at that point and let others have a chance, and I gather we'll have questions later, potentially.

MADAM CHAIRMAN: Thank you very much, Tom. I'm just going to give committee members a chance. Are there any questions you have to actually clarify the factual information that was presented? If not, we'll save your comments and questions for later in the meeting.

No, I don't see any hands. Thank you very much, Tom and Faye, I appreciate it. So People First are going to go next?

MR. JOHN COX: Hello, my name is John Cox and I'm the development coordinator for People First Nova Scotia and this is Nancy McKinnell, who is a support coordinator for People First.

People First is a self-advocacy group for people with a label of an intellectual disability. The term was phrased when there was a symposium in Salem and someone asked, well, what would you like to be named as, and someone said I want to be known as a person, people first. So that's how the name came about.

Every member of our organization is a person with a label of an intellectual disability. We are the only self-advocacy group in the world for people with intellectual disabilities. There's a chapter in every province and territory in Canada now, which has local chapters, and we have nine local chapters throughout the province, everywhere from Yarmouth to Sydney.

One of the key factors in achieving equality is the elimination of physical and social isolation. Therefore, there are certain specific issues that the membership of People First Nova Scotia have taken up. The first one is deinstitutionalization. People First believes that all people with disabilities should live in the communities, despite the severity of their disabilities. With the right supports, people can live full and productive lives in their own homes.

I'm just paraphrasing this, I'm not reading it word for word. All people need to live free of incarceration. People are locked away because of their disability and are denied what most people would consider basic life experiences. Many People First members have the experience of living in an institution and everyone would tell you of the living hell they experienced and how their lives are different now that they are living in the community, and people are now living instead of just existing.

This province has the highest number of people incarcerated in institutions, except Ontario. This is not per capita but it is an actual number. Ontario has made a commitment to close all institutions by March 31, 2009. Nova Scotia needs to put a moratorium on creating any new institution beds and lift the moratorium on small options homes so that people can start getting the appropriate supports they need to live in the community.

[9:30 a.m.]

People First Nova Scotia and the Nova Scotia Association for Community Living have a joint task force on deinstitutionalization and will welcome the opportunity to work with this government in developing a plan to begin this process. People are living in extreme poverty in this province, people are being turned away from receiving supports or they are receiving inadequate supports from the Department of Community Services. One of the most confusing things is that people are turned away from the services for people with disabilities because they are not disabled enough or unclassifiable but they are receiving the employment supports and income assistance which is based on the old welfare model, because they have a disability. So it's a case of two sides of the same department saying, you have a disability and one saying you don't, and that's in my mind.

History tells us that the community supports improve when there's a solid plan to close institutions. For example, the in-home support program started after they closed the children's training centres. Before that, families received \$52.50 per month for respite care. The 21-hours-a-week cap on support hours does not work for some people. As a person with a disability, you either qualify for 24 hours a week or 24 hours a day. There is no middle ground, there is no in-between, there's no flexibility in this policy.

The Department of Community Services needs to work with people where they are at. Policies, although important, do not work when you are dealing with people's lives. Every person is unique. The inflexibility of policy to deal with our own uniqueness and individual needs, needs to be re-worked. There is the perception that this will create more costs and work on the system, this will create as many programs as there are people receiving your service. This is not true. By creating a system that meets my needs instead of trying to fit me in a system that may not meet all my needs or meets the system's needs, then it is going to cost the department more money, more both financially and with human resources.

This classification system that they have does not work. We don't even know what classification system they are using. At one point the department was going to use the InterRAI classification tool, which asked really inappropriate questions, like do you have scheduled toileting, yes or no? Who schedules toileting? Or, have you had sexual activity with a partner in the last 90 days? Unless this is part of my support plan, then it is none of your business.

When asked about my home environment, every question around it states about the disrepair and upkeep - it assumes that I am unable to maintain a good home. It never asks if my home is in immaculate condition, and I think this is the problem with the entire support system, it assumes that I, as a person with a disability, am coming there from a deficit, that I am unable to take care of myself, I am unable to take care of my home. It is not about that, it is about my disability. So the system treats me, before I even come into the system, as a person who is lacking in a lot of ways, and all I need are supports for my disability, which may or not include, and that would actually benefit in terms of my other personal stuff.

We also know that people are being turned away from services because they are unclassifiable. How can a classification system work if one of the classifications is unclassifiable? This is not an appropriate response, it is a cop-out.

One of the major areas is a moratorium on small options. This needs to end, just because people are not receiving supports in the community, and again they are being offered institutional life, institutions instead of community supports.

The major barrier to employment is the policy created by the Department of Community Services. The proposed changes coming out of the renewal initiative defines independence as no longer needing the supports of the department. Loosely stated, I no

longer have a disability if I am able to work. One of the biggest confusions, again, is that I am denied services for persons with a disability, which is the support I need, because I don't have a disability or I am unclassifiable. So people with disabilities are living on the income-supports model which basically just gives them a home, a house, and the basic living allowance.

The ESIA, the Employment Support and Income Assistance rate of \$200 a month is too low even to meet the basic needs of any person. Also, the rent allowances are too low if someone is looking for a safe place to live. The rental rates usually ensure that people find places in unsafe neighbourhoods and some may be subject to slum landlords.

I was just talking to a member last night who gets \$535 for rent and his rent is \$562, so he has to come up with the other \$30 or \$40 out of his Project 50 to pay for his rent. The \$200 a month that people are given is used for food, personal needs such as razors and feminine hygiene products; this is also used for cleaning supplies such as soap and shampoo and dish detergent and other household cleaning items. Then Community Services complain if I am not following the Health Canada's Food Guide or have less than a perfect house - rock meet hard place - and it is being held against me.

The continuum of services doesn't work. The department's idea for independence means not needing any services from them; they define disability by ability to work. Every People First member in this province has told me they want to work, that is not the issue. The issue is when people say they can't work because the supports they have will be taken away. We applaud Premier MacDonald and this province for the proposed low-income Pharmacare plan, it's a great start - this may help with some of the problem, but not all of it. People need other supports that will enable them to continue working, but these are all in jeopardy when I start to earn a paycheque.

The staff person in charge of the renewal initiative once asked me: What if people were offered a \$50,000-a-year job? If you were going to offer me that, that's fine but the reality is that there are very few people in this province who will be made that offer and if you have a label of an intellectual disability, that chance is even less - probably nil. Yes, there needs to be a system in place that allows for a person to contribute, but it cannot be an all-or-nothing situation. It needs to be fair and equitable to the person with a disability.

Poverty leads to other problems and is a general barrier to social and physical integration. Throughout this province there is a lack of affordable and accessible transportation. For so long we've heard from people outside of HRM about the inadequate buses. I know of one person who spends two hours in the morning getting to the sheltered workshop in Sydney because that's the schedule of the buses.

In metro, the Access-A-Bus has to allow for two weeks to plan and if you wanted to go to a movie, a show, you have to plan that two weeks in advance. One guy said to me the other day that you can plan to go out for your birthday party, but if they decide to cancel

at the last minute you can tell people, go to my birthday party but you may not see me there, right? That's the fallacy.

Accessibility is more than just physical access. Getting into a great recreation facility such as the Sportsplex and/or the Metro Centre means nothing if you can't afford the membership fees. People with intellectual disabilities need to have access to year-round, inclusive and affordable community recreation programs. Communities across the province must encourage the participation of people with disabilities in the recreation programs. Not only does this contribute to the diversity of the community, but it allows people with disabilities to become comfortable in their communities and is the first step toward socializing outside of segregated settings.

Many people are denied education that meets their needs. Access to education is a basic right in Canada and people with intellectual disabilities need to be included in the education system. Educators and administrators need to understand that people who have been labelled can learn but often learn differently than others. However, if a People First member has completed only Grade 6 and has been out of school for some time, there are no clear services presently available to assist him to get the Grade 8 level which is required for him to enter a GED equivalency program. Without the GED, a person is prevented from attending community college or university.

One assumption that the Government of Nova Scotia has is they define disability as an illness. People with disabilities are not sick. That is why bringing people back from the Department of Health to the Department of Community Services is important. The Department of Health is great in providing home care services to those who need it but they are not equipped to provide services to allow people to be part of their community.

It is not easy to understand doctors at the best of times. One important thing that underlines this entire process is plain language. If we cannot understand the written stuff that is given to us, if we cannot understand the words that are coming out of your mouth, then that is an access issue. It is an issue that we talk about all the time, especially when we talk about the medical profession. Some doctors see us as not being able to understand if we need an operation; some may even think our lives are better off if they deny us lifesaving procedures. The health care system must better accommodate the needs of people with all sorts of disabilities and respect their right to make informed decisions so that they may live full lives.

Last year Minister Streach testified in court that she was a guardian of a woman in one of her homes - this is true of every person receiving services from the department. This creates absolute control over a person's life. If an agency says they give control to a person, that only happens when the decisions I make are their decisions. Allowing people to make their own decisions does not mean you have to agree with that decision, but are giving me the tools to make an informed decision. There is no dignity of risk built in that allows one to grow as a person.

People with intellectual disabilities need people in their lives who they trust and know can provide them with the appropriate tools to make informed decisions. It is not as cut and dried as a wheelchair for people with physical disabilities, for example. Don't get me wrong, there are other supports that people with physical disabilities may need, but my point is that people with intellectual disabilities need less obvious supports and these supports may lessen or increase, depending on what that person's life circumstances are at the time. We are aware of one person who was forced out of a group home and into an institution because she broke her leg and the group home was inaccessible for her to get to her bedroom. She is now back in her home because her leg mended.

We are also aware of another person who had a hard time when his mother died. Instead of treating him as a real person with real feelings and providing him with the appropriate supports to help him deal with his loss, they carted him off to an institution because he became too hard to deal with. Who in this room has had to deal with that kind of loss without support either from co-workers, friends or family? It just boggles my mind that an agency that is paid to provide support to someone refuses to do that and finds it easier not to provide support.

It is my conclusion that people who receive services from this department have to be perfect. If they mess up or make a wrong decision that is not okay. Who here can say that they have lived near perfect lives, that they didn't learn from their mistakes and went on with their lives? I wouldn't know how that feels because I am a person with a disability who once lived under the regime of the Department of Community Services.

[9:45 a.m.]

Thank you for this opportunity to speak about People First. We appreciate being able to talk frankly about some of our concerns regarding the department. Thank you very much.

MADAM CHAIRMAN: Thank you, John and Nancy.

Again, do any members want to clarify any of the factual information in the presentation? No? Thank you very much.

So next we have the Nova Scotia League for Equal Opportunities.

MS. BERNADETTE MCKEOUGH: Good morning, my name is Bernadette McKeough. I am here with the Nova Scotia League for Equal Opportunities. I would like to introduce several of our representatives who are here today who are going to speak quickly on some of the issues that NSLEO identified or has been working on the past couple of years. First is Joan Levack, and Joan is our secretary of NSLEO; next is our chairman, Ron Levy; and next is Claredon Robicheau, who is our past-chairman as well as our Council of Canadians with Disabilities representative. Not with us is Ralph Ferguson who was supposed to attend the meeting today to discuss some of the issues on housing.

All of you have copies of the written material presented today. Some of the issues that we will not have time to talk about today that NSLEO has been addressing in the most recent year has been emergency preparedness for vulnerable populations, as well as universal accessibility in design in business and tourism, and access to information. So I'm going to wrap it up and pass it on to the representatives.

Ron, would you like to go first?

MR. RON LEVY: Sure. Good morning, Madam Chairman, and committee members. Thank you for the opportunity to meet with you today to discuss issues and services that affect the lives of persons with disabilities. Those same issues affect the lives of seniors and low-income families as well and need to be addressed and solved with a united front. Affordable and accessible transportation is at the forefront of these issues.

Each year, after research and consultations with our affiliates and other organizations, we prepare position papers on key issues and present them to all three provincial caucuses. In these position papers we make recommendations we hope government will seriously consider as possible solutions to some of the problems we face today. Last year we made six recommendations on transportation issues. Time does not permit us to review each of these recommendations today; however for those of you who missed our presentation last Fall, copies of that presentation are available here today.

Our front-line people include all six affiliate groups spread throughout the province; two of our affiliates run a quality, affordable, accessible transportation system in their area. At a recent meeting of the Nova Scotia Community-based Transportation Association, a discussion was held on barriers that must be overcome to run a successful transit system. Some of the barriers noted are:

Lack of infrastructure and funding to support transit systems, both regular and accessible; Accessible transit systems across Nova Scotia, including Halifax and Sydney, are turning clients away because they cannot guarantee a service to them;

In some areas, particularly in Halifax and Sydney, travellers must pre-book their travel needs as much as two weeks in advance of their required time of travel - this is not acceptable as many travel arrangements need to be determined and arranged at a time closer to the actual time of travel, such as 24 hours in advance, which should be sufficient time for any service to book people;

Individuals seeking gainful employment or students attempting to improve their skill level, whether to attend adult high school, community college or university, are hard-pressed to find suitable and affordable transportation to and from their place of learning;

A large number of people who require regular transportation for medical reasons are having extreme difficulty finding it - for example, at the meeting we spent

considerable time discussing the lack of transit service to accommodate dialysis patients who sometimes need to travel to and from Halifax upwards of 13 trips per month, and this is a necessity of life;

Lack of accessible taxis in the province, particularly in Halifax;

Lack of support of individuals to assist with the cost of retrofitting their personal vehicles to make them accessible; and

Lack of accessible rental vehicles - currently there is only one accessible vehicle available for rent in the whole province, and I believe that is out at O'Regan's here in Halifax.

The list goes on. We at NSLEO are aware of many issues and on a regular basis - whether it is at the NSLEO office, working with another community organization, or at the location of an affiliate - we spend a considerable amount of time attempting to find suitable solutions to transportation problems. NSLEO, the Nova Scotia League for Equal Opportunity, and NS-CBTA, Nova Scotia Community-based Transportation Association, work closely together. We plan to prepare a position paper as a joint effort to present to caucuses this Fall. We are a working board and, in particular, all members of our executive make major contributions to the success of our organization. Thank you.

MADAM CHAIRMAN: Thank you, Ron.

MR. LEVY: If I can answer any questions . . .

MADAM CHAIRMAN: Claredon, are you part of the presentation?

MR. CLAREDON ROBICHEAU: Yes. Thank you. I want to go a bit everywhere in this context of technical aids and wheelchairs, but at the end of the day there are around 1.4 million persons with disabilities in Canada; in our backyard here it is over 150,000, I do believe, in Nova Scotia.

In that context, on top of that, there are 600,000 people in Canada with disabilities living below the poverty line. Those 600,000 people living below the poverty line are compounded by the fact of the cost of living with a disability - wheelchairs, home care, technical aids, transportation - which is two or three times what yours is. So when you are seeking the services or you do your income tax, you can't take off your disability, a wheelchair loan or all this stuff. So combined with all that, a lot of people have to choose between food and that.

We've made little strides, but we're at a very low pace. In that context, too, some of the stuff I'm talking about is this graph at the end of your presentation - it talks about the disability rates. I know it is old data but it is probably very relevant today and to the Nova Scotia Centre on Aging through Mount Saint Vincent University. When you're

talking age 55 to age 64, the disability rate can go up to 14 per cent; 65-plus, you can talk about a disability rate in the 50 to 60 per cent rate. With the aging population, this is something we had better pay strong attention to and it is a no-brainer as far as being a doctor, it is cataract surgery, hip replacements, arthritis, it is the whole gamut. As far as technical aids, wheelchairs, housing, affordability, the whole nine yards, it's an investment we need to look at.

Disability supports - they vary in a different myriad of programs, be it federal, provincial, and even probably some municipal ones as far as transportation funding. Unfortunately, it is such a myriad of scale, it is piecemeal and it takes a lot of work and energy for people with disabilities, and seniors, to navigate through the system that is just piecemeal, all over the place, and those who know, get, and those who don't know, don't know. MLAs like you guys, I'm sure your phone rings every day. I heard up to 800 phone calls a month, of people with this problem. It's just a piecemeal that you have to put together and sometimes people fall into the cracks, and we need to seam that crack.

As far as the wheelchair program, NSLEO was talking about this for my fourteen years of advocacy, research, and education. I don't consider just myself an advocate, using the "A" word, or lobby. It's a very non-partisan subject when it comes to my grandparents, my parents and my siblings, and my friends.

Technical aids - we can talk about glasses, computers, screen readers for the blind, closed-captioning and personal lists. There is a long list out there. The three main issues I personally think these supports improve are the quality of education, the quality of employment, and at the end of day the quality of life. You can balance this between the Department of Health and the Department of Community Services all you want, but at the end of the day that's what it's about.

Again, in closing I'm going to touch on a few things about the cost that we need to invest now, and the research we need to do together that's being explored. In my home office I've got about a trunk full of research papers that could fill the trunk of your car. We've been researched to death - people with disabilities, seniors and all - 15 years, there's research upon research in Canada and in Nova Scotia.

Going on one that's not that old, in 2003 Mount Saint Vincent University, Building Policy Frameworks for Older Parents Caring for Adult Sons and Daughters with Disabilities, and I was on this committee from the three Atlantic Canadian Provinces. You can imagine the 70- and 80-year-old parents taking care of their 40- and 50-year-old child now. They are saving our tax dollars, from preventing those adults with disabilities from being institutionalized, \$3,000 to \$4,000 a month, yet we're worrying about should we increase their housing allowance and this and that. It was happening way back when, and it is happening today. The burden these parents have on their shoulders is horrendous. I can speak on their behalf, I know some of them personally, and again it is a web of piecemeal services out there.

A lot of solutions in here, unfortunately NSLEO, we have only so much funding, we're low on funding. We hope we're not the advocacy gurus that you think, we haven't burnt any stakes on the Legislature yet, but at the end of the day I think we'd like to be considered as the solution people. We can't have something like this collecting dust. It's too bad, it was \$150,000 research that was done across Atlantic Canada, here in our own backyard by Mount Saint Vincent University. I'm a SMU fellow so I'm not bragging Mount Saint Vincent.

Other than that, another one collecting dust: 2005 Strategy for Positive Aging in Nova Scotia. That graph I just showed you, in 2026, we're going from 130,000 seniors over 65 to 260,000 seniors. What's going to happen? We can't put them all in long-term care facilities, we don't want them there. We need supports. It is in here, it's about transportation, which Ron touched upon, and housing. They talked about inclusion in society and participation and empowering. I'm not 65, but I assure you the ones I speak to, they want to live in their community and that's where they should be, as anybody else, and to contribute.

On the good news, we're going to have the most articulate, educated in computers and research ever that's coming, so as far as volunteers, I hope they come and join us on our side.

[10:00 a.m.]

It's not rocket science, it's in there and much of this stuff is repeated in other research, NSLEO position papers and, in closing, just a recent one, in 2006, and I just got back from Winnipeg with the Council of Canadians with Disabilities, the Caledon Institute and CCD are doing research on poverty, and just to look at a minimum guaranteed income for Canadians across Canada of \$13,000 a year - where did we come up with \$13,000 a year? It's from the Old Age Security allowance, that's the benchmark, Old Age Security is the benchmark \$13,000 - it would cost \$1 billion across Canada to eliminate poverty, snap a finger, and I can't snap my finger right now. That is equivalent to the GST, the 1 per cent they just took off, which didn't change my life much.

We're still crunching the numbers but just the idea, and the federal lobbying we need you guys to do when you stand and they have Premiers' meetings or First Ministers' meetings - we need you guys to put these issues on the table. Just the idea of talking about seniors' income splitting would cost anything over eliminating poverty or disability supports in this province. Thank you.

MADAM CHAIRMAN: Thank you, Claredon.

Joan.

MS. JOAN LEVACK: I'll be quick. This has been very interesting listening to everyone and almost everyone has touched on something I wanted to talk about, so I'm going to be very quick and just kind of wrap it up.

I come here as the executive of NSLEO and as a parent of a child with a disability, and I work with people with disabilities every day as an employment counsellor so I'm working with the Department of Community Services consumers every day. The thread that I find runs through my life and through all of these conversations we've had today is that it's really difficult for people to navigate through the system. When you're lost and need a navigator, you make bad choices - you are poor, you are desperate, you make decisions out of frustration and you're dependent. You are put in a position where you cannot find your way to the solution.

I remember when I was researching the job I have, I went to the Department of Community Services Web site and I thought, oh my God, we live in Eden, everything we need is here, it's so wonderful. Then I actually started to get into the reality of it, and there are regional differences in what happens and what services are available. There are people in the Department of Community Services who aren't quite sure of what they can do, my clients don't know what they can do, I don't know what the Department of Community Services could be doing, and there's got to be a way that we can, without a lot of bureaucracy, manage to navigate all of these people through so that they can become independent, because on paper we have everything that we need - we even know what we need, but we need to find a way to get there. So this is what all of us are here for today, to help find a solution for that, so I thank you for your time.

MADAM CHAIRMAN: Thank you, Joan.

What I'd like to suggest for the question part of the meeting is perhaps Ron and Claredon, you could stay put, and if we could put the mic down, a representative from each of the other two organizations might at least sit in front of the mics and then we can change people as questions arise, and you may want to designate someone else to answer that question.

Okay, we'll see how this works. Thank you for your patience. I have Diana, and I neglected to introduce Diana when she joined us. She's the MLA for Halifax Clayton Park and she's going to ask the first set of questions.

MS. DIANA WHALEN: Thank you very much and I do apologize for being a few minutes late, and I actually have to leave before 10:30 a.m., which is why I appreciate being the first to ask some questions this morning.

Again, we certainly have learned a lot. I think, once again it is really important for us to look at the many issues and the many challenges that are faced by people with disabilities and how we can help, how we here at the Legislature can look for changes in legislation and advances that other jurisdictions have begun to take that I think we should

be on board with and leading the way, if we could. I know one of them is the accessibility to public buildings and we did introduce a Private Member's Bill this year from our caucus to set a date - I think it was 2020 or 2025 - to make the public buildings accessible. I think we need to start setting goals like that so that we can actually see some progress. I'm sure that for those of you who have been working for many years, to see progress, it seems very slow, so we've got to get the ball rolling.

There are a couple of questions I have that I'm very concerned about. I wanted to start, if I could, with John. John, you mentioned from People First the issue of the moratorium on small options homes. If you could help me understand how long this has been in place. I know from people calling me that there are no places and you can be on a waiting list for ages, but could you give us a little snapshot of what is available now and how long this moratorium has been in place.

MR. COX: I can't give you the specific amount of years, I think it is around 12 or so. It's been . . .

MR. ROBICHEAU: Yes, I agree with you, 12 to 15.

MR. COX: Yes, it's quite a while, 12 to 15. What the moratorium does is it stops the creation of new small options homes. So what happens is as people move out of small options homes, the only time you can get into a small options is if someone moves on or moves out or whatever. So there are people waiting in group homes or whatever, waiting to be placed in small options homes and can't go because they're being refused to be created. So the moratorium needs to be so that agencies who are dealing with small options homes can create more homes so that they can either buy or rent a home somewhere because people need those homes.

So, yes, there's no new people coming in. The only new people coming in happens when old people go out, I mean people leaving the small options system. So it's been going on for too long and for whatever reason.

MS. WHALEN: Can I ask you a question? The small options homes, because you mention them as something that should be expanded, I assume they are something that people who are living in them find to be a good environment? It is something we should be encouraging?

MR. COX: Traditionally when deinstitutionalization is only new, it started I believe in the 1960s in a lot of places and the original progression was when you left the institution you would go to a larger group home facility. In my case, when I left I went into a group home, then I went into a small options and then my own apartment. So that was supposed to be the progression, in terms of growing as a person with a disability. But if you take one of those steps away, which is a crucial step, you've got nothing to transition from an 8 to 12 or 15 bed group home to a one or two room apartment, with a roommate or whatever. So there's that step that's definitely missing in terms of supports.

MS. WHALEN: I understand in at least one county, in Guysborough, there are no small options homes at all, is that right? Are there other areas you could point out where there are real gaps?

I had spoken to a family member in Guysborough whose son is somewhere in Cape Breton in a small options home and she really raised this as a big issue recently. There is a concern that family can't visit, it becomes very inaccessible.

MR. COX: And someone mentioned around the regional stuff, there are five regions in the province and each region is in charge of creating their own supports. When I was in Halifax, my social worker - you know you can get a home maker and a support person for a person living in an apartment and that would be directly paid for by the Department of Community Services. So they'd work, actually they're an employee of the department.

When you move to Windsor or down to the Valley, you had to be part of an agency, which may or may not be appropriate, and also adds a number of costs to it. Instead of having someone come into your home from the department, now you've got agency costs. I was told you had to be part of an agency down there. They're not set up to do supervised apartments as they are in metro, for some people. There are people in metro who have agencies also, also there's RRSS, and Metro Community Housing and other agencies.

MS. WHALEN: But it's an example of the sort of disparity between areas of the province.

MR. COX: Yes, and I was told until recently that small options homes were not in Cape Breton, I believe, and that just started as part of the plan or the direct family supports was another thing. Now I could be wrong about that - or supervised apartments in Cape Breton are not around, or there may be very few now because of the new initiatives around that.

So each region has, you know - so I've been told that Cape Breton doesn't have supervised apartments. Guysborough, group home or nothing, or an institution, right? There's nothing below that. So the regionalization stuff in a lot of - and I know people. I have a friend who is now in metro because he can't get the supports in Guysborough. He's in his own apartment in metro.

MS. WHALEN: Again, I think that's terrible for the families, though, being taken out of a community where you're closely - it's home and you have to move from home, really, and that's not right.

MR. COX: And another issue is the regionalization. We fought for two years for a young man to come to metro to get the same supports. If you leave a region, one of the regions, that money stays with the region so in order for you to get the supports, it is only

dependent on if there's money in the Halifax region. You move from the Valley to the Halifax region, so that money doesn't follow you.

One of the things that I find confusing, it's all the same pot of money at the end of the day, in terms of community services, but it's all regionalized. So you can move but you may be in jeopardy of losing your supports because of . . .

MS. WHALEN: I have a similar question to that and I'm not sure who is best to answer it. There is a group of people in the province currently under the in-home support program. Again, from a constituent call, I'm understanding that that is going to be switched and I think the in-home support program is currently with the Department of Health and in the presentation somebody mentioned that it is true, if you are disabled you are not sick and the Department of Health may not be the right place to be administered or managed through.

My concern is that if they're in a transition program right now, going back to the Department of Community Services, it might again be taking people and trying to push them into a program that doesn't fit, that doesn't provide the extra funding and recognition of the extra costs of being disabled, which I think the in-home support program was fairly flexible in that regard. In terms of talking to my constituent, the person I'm talking to has been happy, at least reasonably, with what she's got in terms of her supports and is worried about the transition back to Community Services.

Claredon, maybe you know something about this.

MR. ROBICHEAU: There are just a few families that I know in the Municipality of Clare, which I am from, who are fairly happy with it, as far as the supports, the holistic disability support versus the medical model of transition. No consultations have ever gone to us about this transition. We don't see the benefits of it but it's very behind-the-door-scenes stuff. I can't quote it more than, you know, what the press has said and what I've heard in the Legislature.

I think it needs some tweaking but I agree with you, as far as the persons I do know. Many of them are parents of children with disabilities, are fairly satisfied. Who is more better to care than their parents themselves, in their home and a home environment? That's where it should be.

Home care is there and they could do the wheelchair stuff and the medical stuff but it definitely doesn't belong in this support area and it should stay where it is.

MS. WHALEN: In the case of my constituent, the talk is that she'll be moved to income assistance, I think that's it. So that's a Department of Community Services one. They're not calling the employment support but the income assistance part of that. I'm really worried that if this is being done, especially if it's being done quietly and case by

case, that people may lose some of the support they currently have, which would be a step backwards for people with disabilities.

MR. ROBICHEAU: Then you are going to amalgamate all this good staff together who's going to be lumped in this big black hole. It's pretty hands-on, individual cases.

MS. WHALEN: I certainly wanted to mention it today, to be sure that you're also looking at it because I know you advocate for all.

MR. ROBICHEAU: In closing, our Department of Community Services caseworkers are the most burnt-out per capita in Canada. We had a public forum here in Halifax about three years ago and people went to the microphone and there was a huge applause when somebody said the best thing that the Department of Community Services could do is remove answering machines. It was a fact, you call them and it takes about four days. So to go from that to a home support worker who is in Yarmouth, not that far away, if we're going to go back to that system. They are overburdened as is and I don't think the Department of Community Services can take on - these are good staff we're talking about, Department of Community Services, they're really good people. I don't know how they sleep at night but again, I'd be worried about that part.

MS. WHALEN: I know my time is up so I'm going to defer to the next. Thank you very much.

[10:15 a.m.]

MADAM CHAIRMAN: Just for the benefit of the members, the speaking order is Pat, Joan, Leo and Keith. So Pat.

MR. PATRICK DUNN: Thank you, Madam Chairman. Just perhaps one question for you; you mentioned I think in your earlier comment about the Take PART program and I believe you mentioned running maybe approximately 12 months or 14 months or so, primarily in the HRM.

MR. MERRIAM: That's correct. It's done in the HRM and it's a program that we've struggled to find some money to do and so far have gotten a little bit of corporate funding and a modest amount of Department of Health Promotion and Protection funding.

We believe it is really important because the first thing that happens to a child in a wheelchair is the danger of obesity that springs from inactivity. The reason they are inactive is based on really two factors: the opportunity to get out and do things, and the other is having the social skills and setting to be willing to get out and do things. Also, you have to offer a program that addresses all ranges of activities. Not everybody is going to be a wheelchair sports athlete, obviously. So some of these things are as basic as just teaching wheelchair skills to people, to young people in particular, because your first time in a

wheelchair, you get the basics obviously but there are all kinds of life experiences you have in a wheelchair that you're not prepared to deal with.

We have an excellent staff member who is a young chap who experienced a disability in his late teens and he is now only 25, so he has that first-hand experience and therefore he relates really well to the clientele of that Take PART Program.

Our goal is to spread that out across the province because if you're in most communities in this province and you want to go out and become active, particularly as a young person, there is essentially very little, if anything, in most of those communities for you to do. We've partnered with the universities in particular. Our belief is that we have a lot of these facilities there. We have gymnasiums and we have athletic departments of the universities that are quite willing to get involved in these kinds of things. So it's a matter of drawing together the partners so the cost of this initiative doesn't have to be that significant to make use of the infrastructure that's there.

So far it's gone over really well, the people in the HRM we've worked with are very supportive of it and they found it a good experience and our staff and volunteers that we bring to it have found it a very productive thing to do. So right now we're developing some proposals to draw us some more corporate support, hopefully a little more government support, so that we can take it beyond HRM to successive communities across the province.

MR. DUNN: Thank you. That was my second question leading up to the university spreading out beyond, so you've answered that also.

MR. MERRIAM: Oh, it's a priority of ours and we're going to work very hard to find the money both internally and externally, to make that happen and it's the rate of progress that we can do it that's affected by the money we can find to launch it

MR. DUNN: Thank you. A question, John, just maybe a clarification. When you were talking in your initial comments you were talking about education and that people with intellectual disabilities need to be included in the education system. Are these isolated cases or - I was a little confused, I wasn't sure if I was agreeing with that, I guess, after three decades of education under my belt, so I just wanted some clarification there. Are these isolated incidents or are they - is it just, in your opinion, a general happening?

MR. COX: It's been my experience talking to People First members and others that there's a definite lacking. Each school board is unique in my understanding so that becomes problematic and each school, that if you have a good principal who is willing to provide those types of supports, the teachers' assistants and all that, then you'd have a great school program. But if not, then people are lacking.

There's a perception that people with intellectual disabilities can't learn and it's around how people learn. I have a great friend, who has now passed on, who once said to

me, is it because I can't learn or you can't teach? That sticks with me to this day and there's a perception among not just the teaching profession but around everybody, that people with intellectual disabilities cannot learn, yet my computer guru is a member, down in the Valley, he's a guy who, if I need computer assistance, he's the guy that I would call upon, and other things.

Each one of us has different skills. You may not be - you know I have a friend who has a political mind and has keen political analysis but other people are not like that, people who have computer skills, people who have other skills, people who are great at child care and other things.

So in terms of the question, yes, it's my understanding that most people that I know and I am aware of don't have a high level of education but a lot of our members are at least 30 or 40-plus, so we're talking at least 20-odd years ago. So a lot of people now, that I'm aware of, don't have even a Grade 6 education because of the sign of the times. Now that may change but again, I think it is dependent on the school board and even the school itself.

MR. ROBICHEAU: John, may I add to that? If I may add to that - one of the biggest cracks that needs to be filled urgently is the age 18-to-21 thing, and that is horrendously happening today still. Once you are 18 and you're graduated or booted out of school, there's a two-year gap before you can touch onto the Community Services funding.

Cases and cases, especially two or three that I know down home, where it's again that navigator situation, where the parents know and those that don't know, the have and the have-nots, they have to make sure that their 19-year-old child is missing two credits so that they can go up to age 20 to get through that school system. We heard in the papers - I don't know if it was in New Brunswick or Nova Scotia - where they didn't know and at 18 that young child was out of school and on the streets and home.

You quickly become unemployable, even maybe unsociable, if you spend two years watching TV and Oprah. When that person is 21 and goes into a handicapped, sheltered workshop or a training centre, it's almost too late. The stats I just got from Service Canada yesterday was that it can take up to five years of expenses to get that person back into the life skills - life skills is first, because they're watching TV for two years - into employability and then back into the community. That two-year gap can cost five years of investment, so again to that aspect. Thank you.

MS. LEVACK: Can I add just one thing?

MADAM CHAIRMAN: Sure.

MS. LEVACK: I have several clients who have gone through the system and are educated, at least up to the 10th or 11th grade, but they spent most of their time emptying recycling bins in the classrooms as some sort of work project, and it was training them in life skills. There's no dignity in that, so I have them coming to my office asking can you

please get me into some sort of classroom so I can actually learn. So sometimes it's not a question of whether or not they, on paper, have the education, but in reality they do. There are cross-disability issues in one resource room with one resource teacher, there will be people with physical disabilities and learning disabilities and intellectual challenges. All of those things are really difficult and I feel for the resource teachers and the Department of Education and everybody else who is taking care of this, but they need to do more than empty garbage cans and ferry notes back and forth.

MADAM CHAIRMAN: Thank you, Joan.

Joan Massey.

MS. JOAN MASSEY: Thank you, Madam Chairman. Thanks to Ron for bringing that up - that was one of the questions, so you've covered my first question on the issue of the people who are 18.

MR. ROBICHEAU: My name is Claredon. Just for the record.

MS. MASSEY: Sorry. First I would like to say thank you, folks, for coming in this morning. I am just wondering, on a personal kind of note, what time did you folks get up this morning to get here?

MR. ROBICHEAU: At 6:30 a.m., and that was late. It is a three-hour drive.

MS. MASSEY: Thank you very much for making the effort to come in here. I was thinking that this morning when I was getting ready, I was thinking we probably should have bumped it up a little bit because there are a lot of transportation issues and we've heard about those things this morning, so I know it's a little bit harder for mobility.

I would like to talk about a couple of issues - one is back to the issue of wheelchairs and accessibility to equipment, and the other is the self-managed attendant care program. I know that when we saw the presentation from the Abilities Foundation you were talking about all the great, fantastic fundraising endeavours you do. I sort of had a chuckle to myself because my husband did the Drop Zone twice and my heart was in my throat while he was going down off the building, but I think it's fabulous.

I guess what's happened, though, in the province is we are seeing a fall in numbers of volunteers, I think, and everybody is very busy and it does take these kinds of innovative, fundraising ideas to get people out there. You're right, there's a lot of competition going on here, I know, and if you've got somebody behind you maybe who knows people with deep pockets, sometimes certain groups do better than others. I believe the competition is really fierce out there.

What I'd like to talk about, as far as equipment and everything goes, I guess is the whole feeling of what we're talking about here - is it right for people with disabilities to

have to go to charities, or organizations like yours, to get equipment that will let them be successful and be part of our community? Everybody in this province has something to give back to the province and I think we're doing the province a big disservice by keeping a huge number of people, because we've heard some staggering figures here this morning, 150,000 people with disabilities in Nova Scotia, and we're keeping these people behind closed doors, almost locked in their own homes and in the wrong facilities that they shouldn't be in.

You are doing a great thing, I want to recognize that, but in a way you shouldn't have to be doing it. So what kind of help should be in place? What do you think the government should absolutely be doing that might put you out of work?

MR. MERRIAM: If I could start, but I'm sure Claredon and others have points to make, too . . .

MR. ROBICHEAU: Probably the most aggravating subject I have to talk about today. Tom, go at it.

MR. MERRIAM: We would obviously love to be put out of work, although we're not very fearful that is going to happen in any immediate timeline. We believe that mobility and independence are at the heart of all these issues you're hearing about, and that's why it is in our mission statement that that is what we try and do.

The flip side of the coin is that one has to be realistic. So for our organization we take the approach that we know where we'd like to get to but we have to start somewhere. So that's why we think things like this wheelchair program that Claredon and I, and others, have worked on now for some time is so important, and we're fearful, quite frankly, that the demonstration project would end, literally end, because we think it is just crucial, that it is only the first step in a succession, and I should say I believe the Department of Community Services believes that, too, and it's a matter of resources.

[10:30 a.m.]

So you mention our efforts on innovative fundraising, and I guess our response is that it's unlikely the government has the resources to do everything we want them to do so we're saying well, we'll put our money where our mouth is, or the money of others who we can convince to come forward. So it's very much a partnership approach and that's the model that this particular wheelchair project has followed.

We'd like it to move faster, there are issues within it that need to be addressed, obviously in terms of any ultimate permanent program that springs from it. We're going to be pressing very hard, I can assure you, and I know our steering committee members are likely not to accept anything short of some sort of respectable program that carries on, because we know it's a building block to deal with a whole series of other challenges in the system that will be better because of resolving some of those primary mobility issues.

You asked in your opening comment about really the rights of individuals. Right now, depending on the nature of your disability, you may well have it addressed by government programming. If you lose a leg, odds are that you'll get a prosthetic leg through the government-funded system, but if you need a wheelchair, you likely won't. So there are fundamental inequities in there, too, that mean depending on how lucky you are, you may or may not qualify for help, and we think that's an inequity that needs to be addressed.

So we're highly committed to it. I know Claredon has done a tremendous amount of work and he's had the benefit of being in some other provinces, seeing what they do. We don't anticipate that we'll have the best system in the country any time soon but we'd sure like to work in that direction, and mindful of the resources available we've been prepared to be quite creative in how we bring that to the table.

So in our case our organization is expanding its assisted devices budget, apart from the wheelchair initiative, because we believe that there are things we can do that will encourage government, and we need to make sure all the players are contributing what they should. Our view right now is that the government has a ways to go to deal with its share of that project.

MR. LEVY: Can I make a comment about the wheelchair recycling program and whatnot? I haven't been involved much with it, except as chairman of NSLEO I know what's going on. I really think this subject we're avoiding is the income level for somebody to qualify for a chair. Right now it is at \$22,000, family income. I have an income that is much greater than that, so there's no hope. It doesn't matter that I spend maybe a minimum of one-third of my income to provide for the needs of my wife and myself - \$22,000 for a couple is at the poverty level. If you're paying \$700 or \$800 a month for rent, et cetera, \$22,000 is eaten up so quickly. These people who are earning \$30,000 or \$40,000 or \$50,000 a year still have to go to some service club or some place else to attempt to find the money to buy, particularly, new electric chairs. So I think it is a subject we do need to address.

MR. ROBICHEAU: I'd like to finish on that wheelchair initiative because it's so important. Tom is being very politically correct, but I'll be nice but factual in the best capacity I can. It is, on my banking days, really hard to see parents and adults, but mostly parents, saying I can't buy an RRSP this year, we can't go on vacation, or I have to double my car payments because I have to invest half, like \$5,000 on a wheelchair for my daughter.

It is not fun for parents, and we're not talking about a parent with just one sibling all the time - there's another daughter or son involved - who says we can't go to Disney World this year because we bought your sister a wheelchair. Those are the things we're dealing with; we're dealing with parents living in Nova Scotia who live with dignity at salaries of \$30,000, \$40,000, who had posters on the wall "Benefit Dance for Jane and John Doe's Son." That is as humiliating as you can get. It's worked in a welfare model, it's a charity model.

Keep in mind the charity model right now, the most competition we're having right now is hospital foundations, MRIs, QEII's, the Cancer Society, they're all great but there are a lot out there in a very competitive world. Hospital foundations are very, very attuned organizations for MRIs - and I'm not downing them, they're doing a great job, and we need hospitals.

Age 2-to-18 pilot project - I've been at this 14 years with NSLEO and other organizations like CPA, the Abilities Foundation - from age 2 to 18, with the Disabled Persons Commission, and they have great staff, we dissected numbers after numbers. We do respect that the days of government writing blank cheques are gone, we can't do that, but the numbers are out there, and I think on your power point presentation were awesomely good numbers to say we know what we're doing and the numbers that we have dissected, with the help of the Disabled Persons Commission, from ages 2 to 18 the \$0.5 million is just probably exactly what it needed for two years.

We have a problem where some parents, for \$10,000 wheelchairs, have a \$1,000 insurance payment which, when you have only X amount of dollars to deal with, we had to say well, are we going to subsidize insurance companies? I said no, I was the first one to say no. I didn't realize that some people had five or six different insurance companies that I know. I've got four siblings in my family in wheelchairs, so it almost makes me an expert. All of our four, plus my cousin, have different insurance - Manulife, Blue Cross, whatever, whatever, and I couldn't believe that an insurance company would even do that. They would be a lot better off to say there is none.

So we had to balance - are we going to subsidize with taxpayers' dollars, insurance companies? And we had to look at our province, what will happen. So we're going to review that and say okay, maybe it was wrong, let's go back and we'll accept the \$1,000 from the insurance companies, okay? So maybe that's what will happen. From ages 2 to 18, we're pretty well on target and I'd say the parents are pretty satisfied and we up the income level - this is something two of us on the committee really said, that you can't cut it at a \$20,000 income level for parents. Young parents have mortgages, car payments and that, whereas somebody 50 or 65 years old hopefully doesn't have a mortgage payment.

The pilot project from ages 19 to 64 right now with the income level of \$21,000 is not sufficient, especially with the Abilities Foundation that runs a darned good program for the money they have, and I'm glad we took them. In Saskatchewan, they run the program down there and (Interruption) yes, and Manitoba.

It was announced, and this was with flair, about two years ago, a \$1 million program. We were saying it's a \$2 million program for Nova Scotia. This is what we estimate from two to a hundred, whatever, life, is a \$2 million program. The \$1 million program was announced at Easter 2005, with much fanfare. Then we find out in the fine print that, oh, that \$1 million is for two years. So whoops, there's \$0.5 million because we had that \$2 million benchmark. Then we find out that \$0.5 million a year is not new money. The Department of Community Services spends about \$300,000 a year to buy wheelchairs

in Nova Scotia. Whoops, well then we're down to \$200,000 a year. So having a \$200,000 cheque on the table to the committee and with the Abilities Foundation managing it - and we can't blame them for managing it, they're dealing with what they've got - we, as the committee, were pretty upset that we had to set that \$21,000 limit, that we couldn't touch insurance companies at all.

It needs an infusion of - and it's called a pilot project, fine, but hopefully it is time to move on. I know we couldn't be in this budget because it's a pilot of two years, but the two years is coming and I hope all three political Parties are going to say it needs an infusion of at least \$1 million per year. It exists in Saskatchewan.

It is really not fun, as a Canadian citizen, to live in debt. You choose where you live. In Saskatchewan, Manitoba, Quebec, or Ontario, you can win the 6/49 and the next day those four provinces will buy you wheelchairs. We're all Canadian citizens and I know it's a provincial jurisdiction and I've heard that story in Ottawa, we've been there, done that, it's a provincial jurisdiction. It's an investment in the lives of people in education, employment, getting them out, spending money, paying GST, paying taxes, this is what we need to do - it is an investment, not a cost.

We did play with the money of around \$3 million in Nova Scotia, but in Manitoba it's \$2 million. The reason is after a program that has been there since 1978, a lot of wheelchairs are being recycled, refurbished and reused, and put back on the street. So it's out there, we don't have to reinvent the wheel, literally it's there. NSLEO has done a presentation, your committee has done a presentation as a group, and I think we'll just move on. Thanks.

MS. MASSEY: Thank you, very informative.

MADAM CHAIRMAN: Thank you, Joan.

Leo.

MR. LEO GLAVINE: Thank you very much, Madam Chairman, and certainly thank you to all of our guests who are here today representing different organizations. It is one of those days where the two- hour timeline is probably a bit short, so I'll get right at it.

First of all, John, I truly am fascinated with the concept of deinstitutionalization that is going on across the country. Have we waged even the philosophical battle here yet in Nova Scotia, or is that really yet to come? What stage would you see us, as a province, and government's engagement in that concept at this point?

MR. COX: I'm not quite sure what you mean by philosophical.

MR. GLAVINE: In other words, I mean, are we prepared to let go of our major institutions, our rehab centres and so forth? Are we going to go down that road?

MR. COX: Well, no. From the government side of things, no. We're seeing that in the creation of Cobequid Centre. I'm also told, through the grapevine, that there's going to be a renovation of an institution - lots and lots of money - in Pictou County I believe, so we're not seeing that. We believe that the money can be better invested in people, in the supports in the community, instead of renovating buildings.

MR. GLAVINE: That's really where I wanted to go. Very often government will make decisions based on the economics. Is it economically beneficial for government to deinstitutionalize? We all know the humanization that goes on outside, perhaps, the institution to a greater enhancement of a person's life. Does it make economic sense here? I think that could be the killer.

MR. COX: In the long term, yes. My experience is that governments have four-year visions, in the sense that governments are elected every four years. But in the long term, when you've got someone who has been incarcerated - and that's all it is, and I loosely call it incarceration because it is like a prisoner except there is no due process, there is no mechanism, there is no lawyer, there is nothing there for people, no avenue for people to appeal institutionalization - in the long run, over a number of years, when you've got a person who has been incarcerated for 30 or 40 years, yes, his supports are going to be greater when he comes out initially, but over time those costs lessen of course as you learn the skills that are needed to live in the community, which you haven't had for all of your life - since birth for some people, or close to it.

So initially I believe that there's definitely going to be a cost in terms of providing the skills needed for people to learn to live in the community, but over time those skills lessen. As I learn a new skill then I don't need those supports any more, when I learn banking, when I learn how to cook for myself. That was the history of the group homes, they were created as a stepping stone for people to come out of institutions. So you learn the basic life skills in a group home, then you go to a small options home where it is a smaller setting and you learn more - I want to say intimate skills - you learn more cooking skills and you learn more about being integrated, then you move on to your own apartment, and that's the progression.

MR. GLAVINE: So in a sense, with the 12-year moratorium on small options homes, we actually have a regressive policy, perhaps, in Nova Scotia.

[10:45 a.m.]

MR. COX: Yes, and I believe it's an investment in people's lives, as people become mature, the policies around that people need to get off assistance and all that. But people are participating in the community no matter what the severity. Part of the package I gave you was, at the end was a page written by Judith Snow about the contributions - and don't be confused, contributing to society doesn't mean you have to have a paycheque or like when you go on the street, what do you do? That's the first question when you see someone you haven't met. Don't define a person's worth by that.

People do contribute to society, people do contribute to their communities, and people need to be a part of that. The philosophical debate for me would definitely be around the incarceration and what that does.

MR. GLAVINE: We don't have a lot of time left. I want to bring two points together: one that Joan made, and then Claredon. Joan talked about how very often the education system does not bring the greatest level of support and challenge to children with mental disabilities and mentally delayed children, and very often it's demeaning tasks as opposed to challenging them at the intellectual level they are.

There's no question that right now in our system, for example, an EA can be assigned to a child with a behaviour problem, but the child who is two years developmentally delayed in their education, you have to fight beyond belief to get somebody to help them, that will enable their education to proceed, I think, at a much stronger level, but the real crime in this province is, no question, between 18 and 21. Those children, if you read the Education Act, it says that we have to provide for them.

I've had two or three of the most disheartening letters, in my four years as Education Critic, from parents who saw their child leave at age 18 and regress through 19 and 20, until they reached 21 years of age. Assistive technology is taken away from them and they are basically, as you said, at home and it's the TV and possibly a computer, if they're able to afford that, but yet right in our Education Act it says we need to take responsibility for continuing those children in the education process. So it is a huge vacuum piece.

I must say that I did teach at a school where we made every effort to keep children until they were 20 years of age who were, especially severely mentally challenged. So what more do we need to do there, Claredon, to bring that change about?

MR. ROBICHEAU: It is very, very expensive that the Department of Education is dumping these kids on the street. Somebody is picking up the tab. It is the Department of Community Services, the Department of Health, home support, the whole nine yards. So those very little savings for those one or two years that that person is out of school, saving teachers and school buses and all that stuff, is a very short-vision idea. It is going by the rule book - it is mean, very mean.

The word "regionality" was talked about. In the Municipality of Clare last year, a teacher's aide came to see me about transportation and I said no problem, it was done on a dime. I said see you in September. We've brought some of those who were in the 18 to 19 age bracket out during field trips with coaches or teacher aides, outside the school area, brought them to Tim Hortons, serving coffee, washing the floors, whatever - any life skills they could imagine. Just having someone with Down's syndrome being seen in downtown Meteghan, washing the floors at Tim Hortons, was a very, very nice thing to see, there were smiles everywhere, versus that person in a classroom emptying garbage cans.

We brought three of them, twice a week, from the school to the gym with a teacher's aide - to the gym, a private gym, not the school gym but a private fitness centre. What's my charge? Zero. There has got to be some empathy in there in the system, we're not all there for the buck.

Some are not going to graduate this year. They're going to graduate in two years. One day a week we're bringing them to the sheltered workshop to get to meet the other people and what this is about. What's life after the school thing out there, and employment and life skills and all that stuff? I praise that teacher's aide and the principal for allowing it. You know it's like the schoolyard stops there and, boy, you can't pass that. But yet people with abilities can go to Cape Breton on an eight-hour drive to play soccer and we don't question insurance, we don't question the cost. It is a volleyball varsity league. They are in Grade 12 but they're able-bodied, and there's this hockey team and all this stuff. We don't question that as taxpayers, do we? But yet if we're going to spend \$400 a year on a student to get him out somewhere in society, where Tim Hortons was glad to take that person, it was free. That is not rocket science. Anyhow, thanks.

MR. GLAVINE: I have ten more questions, but I'm going to pass it over to Keith.

MR. KEITH COLWELL: Thank you very much. I really do appreciate your coming in today and, as it was already said, it is too bad that you have to come, it's too bad that these problems weren't all resolved and that people had the resources they need to ensure they can live a full and complete life. I am pleased to see that your organizations are heading in that direction and, with our help as politicians, hopefully someday that will be a reality.

There are a couple of things that really concern me. You mentioned that the funding of individuals moves from one area to another area. This is an issue that doesn't make any sense to me. Why isn't the funding attached to the person so they can move anywhere within Nova Scotia that they prefer and, indeed, which may improve their lifestyle, get closer to family, to employment opportunities, to treatment options, whatever the case may be?

What would you think about portable funding that was attached to the person rather than a location?

MR. COX: Hear, hear! Welcome to my world when you say I don't understand that, because I don't either. It's around the individual and the individual needs, right? I've often said - and when we advocated for this gentleman to move from the Valley up to Halifax, you know I said to the department that it all comes from the same pot of money anyway, what's the big deal? But it took two years for him to move.

One of the arguments I used was that it is a violation of the Charter of Rights. I think that might have done it, I don't know. Everyone has a right to choose where they live in Canada, but that's not happening with this unportability of funding, I guess.

MR. COLWELL: It's just strictly a government policy, that's all it is.

MR. ROBICHEAU: Probably budgets, regional budgets . . .

MR. COX: And the budgets are stuck with the region, not the person. So if I leave Yarmouth County or if I leave Halifax to go to Yarmouth, the money stays here and Yarmouth has to find that money to provide those supports. So the budgets are attached to the regions, not the person.

MR. COLWELL: It doesn't make sense to me, because basically if the person goes then the cost of that person, whatever cost it is for that budget, is gone too.

MR. COX: Then we said earlier, there are other people who are forced, who are told that they have to move to a group home or other places in another part of the province, away from family, and the department is demanding that, you know there are no supervised apartments down in - there was a woman who wanted a small options or group home down in Shelburne County, I believe, (Interruption) the Bridgewater area and they were offered a placement a couple of hours away for their son and daughter and they provide real supports for the son and they want a great placement but they don't want him to leave his community where his friends are, and that's fair ball. So the department is also offering other placements, outside of the area because there's nothing in that area, in that region.

Each region is structured differently; each region has different services. Up until recently there were no supervised apartments in Cape Breton. There are no group homes or there are no small options or other in Guysborough. So each region decides on what piece of the policies and what piece of the projects they can take on. So it is not a provincial jurisdiction. There may be group homes in every region, but there are not small options in every region and there are not supervised apartments in every region.

MR. ROBICHEAU: The Department of Health wouldn't accept it. It would be like somebody living in Yarmouth and the Yarmouth hospital may take an X-ray and they say well, this is wrong, we're going to transfer you to the Kentville hospital, and the Kentville hospital takes an X-ray and they're going to debate where to send the X-ray bill - to Yarmouth or to Kentville? One hospital board, they're not going to do that.

MS. LEVACK: Just an object lesson here - I have a client who was living in the Halifax region and was working with an LMAPWD counsellor who had set her up for a much-needed psycho-educational learning assessment, because in order to access other disability supports and get back to school and then get employment, she needs a recent assessment.

So that was fine. She couldn't afford to live here, so she moved back with her mother in the Valley and went to the employment support worker, in the Valley where we live, who said no, we don't do that here, we don't have money. So as an external service

provider, I'm trying to find money to get this assessment that she could have gotten two months ago if she had been able to live with her child in Halifax but just couldn't afford it.

So it is this kind of choice that she has to make and it is the kind of choice that all of us have to make, where do we find the cash? We're talking about charity, it's like maybe I need a fundraiser to get the money for this. She is now so disheartened that she's thinking, well maybe I just won't bother going back to school or looking for work after that because she can't access the support she needs, although she could have 75 kilometres away. So this is the regional difference that I find so mind-boggling and it has real, very serious effects on the people who are trying to access the supports.

MR. COLWELL: It always comes to me in all these situations that they don't really look at the individual, they look at budgets and what they've got planned in that area, and so many times, as you say with that lady moving with her mother, it might have been the best thing that ever happened to her and her family but if she doesn't have the supports there, and that will set her backwards and there is no need to and it shouldn't be the case at all.

I can't imagine what it would be like to have that taken away, when it was there before but you had to move for other reasons - I mean it is just mind-boggling; it is just unbelievable.

MS. LEVACK: Yes, there's no question that it's necessary, it's just that she can't get it where she is now. We're all problem solvers, so we'll find a way to do it but it would be really nice if we could just say, well head office, the Department of Community Services, has said she needs it, and get it regardless of which branch office we're calling.

MR. COLWELL: That would be a lot better. I think that's something that government really should look at. That's just policy, again, it doesn't change legislation or anything, it's just policy.

The second issue that I really picked up from your organization, which I've heard often from NSLEO and it is a very good point, is portability funding, again for travel issues so individuals can get - maybe if the lady had easy travel to Halifax to get that, it may resolve her problem.

MS. LEVACK: Well, she can't because she's not in that region any more. So she can't actually access monies, right? If she were able to get the money in the region where she is now, then we would be able to find somebody to do the assessment, but because she's no longer in the region where the money was attached, even if she could travel to Halifax to get it done, she can't.

[11:00 a.m.]

MR. ROBICHEAU: On your issue of transportation, there's a \$150 allowance for people on community services, in their budgets. Number one is for medical only, and

number two, they have to pay up front, except there are some of us who can bill directly the Department of Community Services, like Dial-A-Ride and probably a few taxis that are well-connected, they've earned the respect from the Department of Community Services to bill - we're talking about taxpayer dollars.

Unfortunately very few people on community services know that. Transportation, again it's the piecemeal of who knows and who doesn't know. Unfortunately that's happening, where you see some very sick people hitchhiking here and there today.

On a positive note, there's a little bit of federal dollars that just came through the transit fund to this province. So we're glad that Service Nova Scotia and Municipal Relations did come to bat to recognize the 2,000,000 kilometres a year that we log in Nova Scotia, in rural Nova Scotia, so we're glad to have it.

MR. COX: Just to follow up on Claredon, We're more than just a medical appointment and work. When you leave here you don't just go home and wait to go to a doctor and then come back to work. There is other social stuff that happens that needs - people are isolated because they can't access that \$150, first of all because they can't afford it up front but, secondly, they can't go and visit a friend down the road or they can't go play pool on a Sunday afternoon because they don't have \$10 to go back and forth to the pool hall with some friends. So we're more than just a medical appointment and we're more than just work - just like everyone else in this room you might play racquet ball, you might do a variety of stuff and those funds aren't accessible in terms of transportation.

In Halifax they are in some ways, because you have to be part of a day program to get a bus pass, and then away you go. When that monthly thing is up to you, you can go anywhere but you still have to be part of a day program - and how come you work and I'm part of a day program? When I was still on assistance and started my job, my co-worker was employed, I was part of a day program - and that was the language they used when I was on community services, in terms of starting my employment.

MR. LEVY: Even on transportation issues, there are a lot of people who are in the welfare system, they can't even afford funding to shop for their basic needs, whether they have to go to the mall for groceries and basic needs. Their allowance is so small each month for that type of service that they can afford it once a month. Well, most people can't shop - if you're on a limited budget like that and you spend all of your food allowance at one time, there's always the basics that you have to get to a store for, whether it be milk, bread, et cetera. So it's not feasible that once a month is what your allowance is for basic needs.

MADAM CHAIRMAN: Unfortunately we have run out of time. I didn't get to ask a question, so I'm going to throw my question out there, and if anyone has the answer perhaps they can let me know: How do you get barrier-free access complaints addressed in this province? I'll just leave it at that and perhaps I'll have a chance to talk to somebody afterwards.

I do want to recognize that we've been joined by Ralph Ferguson, who is the vice-chairman of NSLEO. Thank you, and good to see you, Ralph.

I think you can tell from our deep interest in this that we are in your debt for taking the time to come here today to give us this background information. Your presentations and your answers have been excellent. We want to say how much we admire and we want to express our appreciation to you and your other volunteers and your staff and your organizations for the incredible work you are doing on behalf of our colleagues with disabilities in this province. So thank you very much for all you're doing. Believe me, our committee is very interested in supporting your work. Many of us have relationships with your organizations and hopefully we'll have a chance to hear officially from you in the near future - so thank you very much for coming.

I just want to remind the committee members that we received a response to our letter to the Minister of Community Services regarding our recommendations from the Forum on Poverty, and perhaps we can add that to our next agenda. Our next meeting is another organizational meeting and it will be Thursday, September 20th, between 9:00 a.m. and 11:00 a.m.

So have a great summer, safe travel everyone, and thank you so much.

[The committee adjourned at 11:05 a.m.]