

# **HANSARD**

**NOVA SCOTIA HOUSE OF ASSEMBLY**

**COMMITTEE**

**ON**

**COMMUNITY SERVICES**

**Tuesday, October 4, 2016**

**Legislative Committees Office**

**Community Homes Action Group**

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## **COMMUNITY SERVICES COMMITTEE**

Ms. Patricia Arab (Chairman)  
Mr. Brendan Maguire (Vice-Chairman)  
Ms. Pam Eyking  
Mr. Bill Horne  
Ms. Joyce Treen  
Mr. Eddie Orrell  
Mr. Larry Harrison  
Ms. Marian Mancini  
Ms. Lisa Roberts

[Mr. Brendan Maguire was replaced by Mr. Joachim Stroink.]

[Ms. Pam Eyking was replaced by Mr. David Wilton.]

[Mr. Larry Harrison was replaced by Hon. Christopher d'Entremont.]

In Attendance:

Mrs. Darlene Henry  
Legislative Committee Clerk

Mr. Gordon Hebb  
Chief Legislative Counsel

## **WITNESSES**

### Community Homes Action Group

Dr. Brian Hennen,  
Co-Chair

Ms. Lois Miller  
Co-Chair

Dr. Paula Hutchinson,  
Researcher and Evaluator

Ms. Wendy Lill,  
Member



House of Assembly  
*Nova Scotia*

**HALIFAX, TUESDAY, OCTOBER 4, 2016**

**STANDING COMMITTEE ON COMMUNITY SERVICES**

1:00 P.M.

CHAIRMAN  
Ms. Patricia Arab

MADAM CHAIRMAN: I'd like to call the committee to order. This is the Standing Committee on Community Services. My name is Patricia Arab, I am the MLA for Fairview-Clayton Park and the Chair of this committee.

I'd like to welcome our presenters here today. I'd also like to welcome our new committee member, Ms. Lisa Roberts, who is the new member for Halifax Needham. This is her first committee meeting with us so we're happy to have her here.

Today we're going to be receiving a presentation from the Community Homes Action Group in regard to an update on the Choice, Equality and Good Lives in an Inclusive Society. Today we have Dr. Brian Hennen, who is the co-chair of this group, along with Lois Miller and Dr. Paula Hutchinson.

I do believe we have Ms. Wendy Lill in the audience with us. She won't be part of the formal presentation but maybe we'll be able to convince her to have a chat, maybe at the break if not in the more formal part of the committee.

I'd like to start by asking our committee members to introduce themselves and we'll start with Mr. Stroink.

[The committee members introduced themselves.]

MADAM CHAIRMAN: I'd like to welcome the people who are watching in the audience and remind all of you in the audience, as well as our committee members, to have your phones either switched off or turned to vibrate. As well, these proceedings are being recorded by Hansard so I would ask that our witnesses as well as our committee members wait until I have recognized them before they engage in a question and answer dialogue.

With that, I will pass it on to you, Dr. Hennen.

DR. BRIAN HENNEN: Madam Chairman, standing committee members and other Nova Scotians present, thank you for the opportunity to present our concerns about the adequacy of appropriate residential options for our fellow citizens who live with developmental disabilities and autism spectrum disorder.

The Community Homes Action Group is a voluntary group of health care professionals, academics, concerned citizens, parents and advocates formed in 2009 to draw attention to the crisis in residential options for persons with developmental disabilities and to work with the provincial government to find solutions.

I am a retired academic, family physician, and I am an emeritus professor at Dalhousie University. Lois Miller is a former executive director of Independent Living Nova Scotia, has been a member of their board and is a continuing advocate for people with disabilities. Paula Hutchinson is an academic researcher in educational psychology and educational principles and is our research person. I also acknowledge Jean Coleman is present in the audience, who is the current executive director for the Nova Scotia Association for Community Living.

Eight of us have direct experience with a family member with a developmental disability or autism spectrum disorder. There are 13 members in the organization. When we first presented our concerns to this committee in 2011, over 1,500 people were living in large care facilities. There were no community-based services for persons with complex health and behavioural needs. A moratorium had been placed on the creation of new small options homes in the 1990s and wait-lists for all residential services had grown to over 1,000. There was no flexibility in funding to allow for people to engage in self-directed care and to exercise choice and control.

The human and financial costs of being housed inappropriately were escalating. We met several times with the minister and her staff to discuss the urgency of the situation. We held demonstrations, we wrote op-ed pieces, we met with the MLAs and with the Premier. We met several times with the minister and her staff to discuss the urgency of the situation.

In 2013 we were pleased to see the government set up a joint government Community Advisory Committee to create a road map to transform services for Nova Scotians with disabilities. The committee of government represented service providers and members of the disability community, set goals, made recommendations, and created

timelines for action. Two CHAG members took part in the road map process, and Jean Coleman was there also as the executive director of the Nova Scotia Association for Community Living.

The committee report - Choice, Equality and Good Lives in Inclusive Communities: A Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program - was adopted and released by the Department of Community Services on August 29, 2013. The road map put forward three key goals: greater self-direction, choice, and controlled by people with disabilities and their families; a modernized delivery system of supports and services to advance social and economic inclusion; and increased capacity and involvement of generic community systems in enabling legislation. Ten recommendations were laid out to assist in achieving these goals. A five-year plan with timelines and outcomes outlined where we needed to go and how we would get there. The community was delighted and hopeful that real change was going to happen.

A year and a half and a change of government later, Community Homes Action Group represented again in February 2014 to this committee, this time with the Nova Scotia Association for Community Living, to talk about the importance of the road map and the need to move forward more quickly. People waiting in the community were again feeling frustrated at the lack of action. At that meeting, we were heartened by your committee's interest. We heard from your members that you, too, were dealing with families in your constituency offices desperate for assistance and frustrated by lack of action for their loved ones.

Here we are again, three years later, and what progress has occurred for people living with developmental disabilities and their loved ones? Sadly, we have still seen very little change. Still over 1,000 people are living in large-scale facilities, wait-lists continue over 1,000, insufficient emergency care exists for persons with disabilities in most communities, and aging parents continue to anguish about the future of their vulnerable offspring still living at home.

Over the last weeks we have met with others from People First, Autism Nova Scotia, the Nova Scotia Residential Agencies Association, and the Dalhousie assessment clinic for adults with developmental disabilities. We asked for suggestions for improving services, and encouraged comments on the survey and report card project.

We heard there was a need for staff development training, especially for executive level and administrative leaders, for board members, for providers of services to complex care clients, with a particular request for values-related programs for new staff, existing employees, and Nova Scotia Community College students.

Some who spoke to us are concerned about the lack of succession planning for senior administrative and CEO positions. We heard that nothing would change while the

Homes for Special Care Act and the Employment Support and Income Assistance Act - described as old and inappropriate - remain unchanged.

We were alerted to the aging-out process whereby, for example, a youth reaching adulthood was moved from a happy placement in a group home into a locked unit for adults where he was exposed to unhealthy behaviours and experienced unhappiness. Some reported that family members said they had seen a loved one move from cradle to grave without ever having seen a care coordinator. Others haven't seen a caseworker or had an assessment in over five years.

Clinical information about persons under consideration for a move was frequently outdated and not comprehensive. Families afraid of losing resources or waiting list ranking have been known to hold back information with substantial risk to their loved ones or their residential mates. Sadly, again, we heard decisions are frequently made according to what services and resources are available as opposed to what the client needs.

We received an invitation from the president and CEO of Housing Nova Scotia, Dan McDougall, to participate in a survey on October 21<sup>st</sup>, aligned with the National Housing Strategy, engaging federal, provincial, and territorial partners. His letter provided the quote which began this report: "Housing is one of the most fundamental needs for Nova Scotians. Our homes shape nearly every aspect of our lives from health, educational achievement, success in the workplace, the security of our retirement, to our dignity in old age." Let us incorporate this fundamental value into our discussion today.

We would complement the Department of Community Services on some things. There are lots of committees struck. There has been a lot of internal work accomplished. There are more streamlined wait-lists, improved communications with a newsletter in its second edition, and effective public presentations across the province. DCS has been conducting first voice consultations to drill down on what community means and how its needs are determined. We commend the department for their efforts at building these steps toward a foundation for action. However, we need to start building the structure and to increase the number of real community living choices for our fellow citizens with disabilities.

I'll invite Dr. Hutchinson to talk about CHAG's report card.

MADAM CHAIRMAN: Dr. Hutchinson.

DR. PAULA HUTCHINSON: Good afternoon. I'm going to direct you to the report card; you all have a copy. Last Fall, in 2015, CHAG sent out a province-wide survey asking families, self-advocates, social services professionals, and service deliverers to assess the progress, so what kind of real change did they see in their communities? Essentially, the respondents gave government a failing grade in all five areas. These areas are all lined up

with what the transformation road map promised to citizens. Among those were 1,000 comments. I'm just going to share with you the results.

Seventy-nine per cent said that there was poor progress on person-directed planning. One of the quotes that represents that is, "We don't see where people have choices that are not government-forced or mandated. If people had choices they would not live in institutions."

Ninety per cent said poor progress on providing community-based housing. The comment here was, "There are not enough supports for families to create flexible solutions that meet their adult dependents' needs. The system needs to be changed more efficiently and with a shorter timeline . . . there are too many people in crisis." Crisis was a main theme that we saw across the data.

Eighty-five per cent said poor progress on reducing reliance on institutions. A comment: ". . . it is fine to write reports but it is not matched with DCS walking the road and taking real action towards achieving the end of this model in Nova Scotia. As long as these institutions are seen as being the main provider of good, well-paying jobs in certain areas it will be very difficult to eliminate them without clear will of government." Leadership is required.

Eighty-two per cent said poor progress on increasing employment opportunities. Eighty-six per cent said poor progress on decreasing wait-lists. The comments for this were very dire. "To my knowledge nothing has been done to decrease waitlists. My own son has been on the list for over 20 years. How can this be?" Another one, which is heartbreaking: "Son died while waiting for appropriate care."

The sense of hope about the road map that was presented in 2013 - on the ground, I would say that people are in despair. They really don't believe that change will happen for them. Overarching, the main quote that sums it up is, "It is sad indeed, when NS was actually a leader in the area of closing children's institutions in our province. . ." - which is true - ". . . to where we are today even after DCS spending has increased so dramatically." And that's true.

"We are fighting the same battle as parents 20 & 30 years ago. We know the harm, neglect and abuse that individuals have endured living in institutions - this is no longer an argument. It is not difficult to support an individual to live a good life in their community. The fact that we have not moved forward with the Roadmap, in this day & age, with the UN Convention and the Charter of Rights and Freedom, is simply beyond comprehension." This is a human rights issue.

CHAG has committed to running the survey again this year. We will run it every single year to gauge what is happening in our communities and give our community members a voice.

I'd like to pass it over.

DR. HENNEN: Ontario has invested substantially in revising its programs directed at persons with developmental disabilities. In its health care assessment research in developmental disabilities project, health care utilization data have been profiled more accurately than ever before. An international visiting expert declared that Ontario was a world leader in its collection and analysis of such data. However, apparently having good data retrieval is not enough, as Lois Wilson would like to tell us.

MADAM CHAIRMAN: Thank you. Ms. Miller.

DR. HENNEN: Did I say Lois Wilson?

MS. LOIS MILLER: You did again. Lois Wilson is the former moderator of the United Church and I've met her. She's even shorter than I am, a lovely lady for me to be confused with but I am not she.

The Ontario Ombudsman, Paul Dubé, released his disturbing report called Nowhere to Turn just this past August. He called for a sweeping overhaul of Ontario's programs to support adults with developmental disabilities. His office reviewed 1,500 complaints, can you imagine? That's a lot of Ombudsman's complaints. Of course it's large, Ontario. They made 60 recommendations for reform, all of which the Ontario Ministry of Community Services has agreed to adopt.

The auditor found that many people with disabilities had been placed in inappropriate placements. He found them in hospitals, homeless shelters, seniors' homes and jails. They also cited two coroner inquests about two men who died recently in Ontario in obviously the wrong place: one drowned in a cistern while in an alternate family home, the other died in the custody of his brother who, by the way, is now doing 20 years for manslaughter. They also highlighted 18 other stories and here was one that touched me. It's about a young man named Tommy, from Toronto. They found him in hospital but not for medical reasons. He had been in hospital for 73 days at one stretch, at \$2,000 a day. Now don't even think about his quality of life there - just think of the cost and what his family could have done with that money.

These stories could have happened here. In fact I could have written them. When I worked at Independent Living, our information officer used to call them "end of my rope stories". Usually a Friday afternoon someone would call with a story like that. We've all heard about them in our local media and I think many of you will have heard some of those stories in your own constituency offices. I'm looking at you, MLA Horne, my local MLA. You and I met with a parent who was dealing with just this same kind of despair a year or so ago.

Here locally we've heard of the woman who was living at Quest and who ended up in police custody and in court when she threw a toddler-like tantrum; or the young man who got himself out to Alberta, found work and then actually got himself back home because he was trying to escape an institution where his parents wanted him to be living; or we've probably heard about the three patients who are still in Nova Scotia Hospital. Each one has been there for over a decade, not because they need to be in a locked psychiatric ward but because there's no place outside for them to go. There's a human rights investigation going on with the Human Rights Commission on that situation now.

The Ontario Ombudsman's Report and our own experiences bring home the importance of one of the key recommendations of the road map, that is the need for round-the-clock teams in the community to intervene before people get into a crisis. To date, this recommendation has not been acted on, so back to Dr. Hennen.

DR. HENNEN: Dr. Karen McNeil, who is the senior physician at the Dalhousie Family Medicine Adult Developmental Disability Clinic sees daily the hardships families are facing caring for their loved ones. She says that, "Parents of adult children with behaviours that challenge are tired; tired of advocating, coping and seeking solutions for problems that even the most experienced clinicians find daunting. There's an urgent need for behavioural supports in the community for these families in a seamless program that spans the life cycle."

She goes on to suggest that if we calculated the costs of effective community-based behavioural management programs and compared them with the accumulated costs of two on one support in group homes and institutions, one on one support in schools, medications, the replacement of property, inappropriate use of emergency rooms, the use of police and justice services, managing injuries to family and support workers, removing parents from the workforce to provide necessary care, and not facilitating persons with disabilities to work for pay, then we could show that a community-based behaviour program over a lifespan would prove to be cost effective and likely cost saving.

Another key recommendation in the road map is the reduced reliance on larger residential facilities. Such reductions must take place in concurrence with the development of the unnecessary community-based alternatives. The government has put a moratorium on new admissions to ARCs and RRCs as of July 2016. This is a start, although the use of a temporary placement time limit of three years does not promise a quick-moving process.

So far it appears as many as 300 folks are ready to move - if there were only 300 appropriate places for them to call home.

The 25 individual placements for which the \$2.2 million granted in this year's budget was to be spent have not yet happened, although we understand the individuals have been selected. We heard questions about these assignments, most particularly about how the formula of \$2.2 million for 25 places came about. Many felt the money was insufficient.

With over 1,000 people living in large-scale facilities, 25 is a very small proportion; it is one in 40. At this rate there will be many folks who will not get out into the community, ever.

Another \$790,000 was directed at Nova Scotia's 29 adult service centres. That averages \$27,000 per centre to generate, screen, and select best enterprise opportunities and to enhance employment supports and help agencies grow capacity. There is no guarantee in this year's budget increase announcement that the same level of investment would be ongoing. We have yet to hear assurances there will be any more.

Until we start seeing real community living alternatives being offered to persons with disabilities on Brier Island and Cape Breton and Rawdon and Dartmouth - when we start seeing people being able to live in the community and see the community involved in making it work, that's when progress can be said to be taking place.

More provincial consultations are planned by the disability services program and it's important that the department is asking for community input, but it must be continuously. Until we start really rolling up our sleeves, creating community, involving service deliverers with great track records in creating good community options, talking with and listening to individuals and parents who want to try their own options, continuing to engage the extensive expertise of effective service deliverers, applying the administrative know-how of department administrators, and receive real and continuing government financial commitment, we will not move forward. Government needs to make a commitment to long-term sustainable funding to provide a variety of community-based residential options.

The road map called for using the fiscal year 2013-14 to develop shared government-community commitment and leadership and detailed implementation plans, time frames, and actionable steps that would begin major rollout in 2014-15. It is now nearly 2017, and no major rollout is evident.

The road map stated we are fully aware that our proposed road map for change will require substantial investment beginning in 2014-15. We see this as a transformative investment that will lead to the creation of a sustainable, cost-effective system of supports.

We as Community Homes Action Group are here to urge the provincial government to honour the rights of persons with disabilities as outlined in the UN Convention on the Rights of Persons with Disabilities, and determine that the recommendations in our 2016 report card are fulfilled. Most fundamental is the assurance of continued substantive investment necessary to increase community-living capacity and fulfill the promises made to Nova Scotians with disabilities and their families.

Thank you for your attention.

MADAM CHAIRMAN: Thank you very much for your presentation. We're now going to move into our question and answer portion. We will start with the Progressive Conservative caucus with Mr. d'Entremont.

HON. CHRISTOPHER D'ENTREMONT: Thank you for your presentation, thank you for standing up for persons with disabilities in this province. My question revolves around a lot of the blockages or ineffectiveness of what's going on here in and around the department. There is unfortunately one department - we can blame government but I don't really want to go there - maybe later on - just because of what I am.

What have your discussions been with the department on where their thoughts are on the road map? Are they discussing with you? Are they working with you, or are they just providing you with a little bit of lip service?

DR. HENNEN: The department and the DSP have been open, have welcomed us to discuss with them things that are on their agenda. For example, we recommended a newsletter and a newsletter happened. Also we know that members of their staff are meeting with people from the Department of Health and Wellness and that's a key partnership. The Department of Health and Wellness has some resources, has data that could be used to clarify some of the issues involved. There is a collaborative committee between Health and Wellness and Community Services, and I think that's good.

We have other ministries that are similarly involved, like housing and law and so forth. I think I can say it's very co-operative. I think the frustration is that the resources they need to do what they really need to do aren't there.

MR. D'ENTREMONT: Thank you for that. We have been talking about the road map since 2013, early in 2013, in sort of what I guess we'd call the dying days of the NDP Government. I think they rushed it to get it there, and thanks to the minister of the day for getting it finally in place. The unfortunate part - and I don't have an indication of where the current government is on it, their feeling. You are saying that it's now nearly 2017 and no major rollout is evident, so as much as we're collaborating and talking, the actual capacity building that is required is not necessarily happening.

Have you had a meeting with the minister to find what her thoughts are around this? Have you met with the Premier? I have a suggestion to maybe write a letter to the minister here, just to find out what her side of the story is but I'll let you answer first.

DR. HENNEN: We have never had a meeting with the minister.

MADAM CHAIRMAN: Ms. Mancini.

MS. MARIAN MANCINI: Thank you all for being here. I think I've been trying to follow your history a little bit and you did outline it fairly succinctly here today, the plan

was drafted. I expect there was a tremendous amount of work that went into developing the road map and it must have been an exciting time in 2013 when you presented it to the minister and then it was adopted by the new minister in November 2013. I would think you were probably still feeling fairly optimistic because one of the co-chairs on the advisory committee became the deputy minister, so I think that would be cause for optimism and for encouragement, and even in April 2014 when you presented here you were still hopeful. You were further pushing the agenda on this.

I was just going to ask, how do you feel that's happening, but I think I got the sense from your presentation how you feel about that. In the road map itself, it's a road map but another word for timeline, there was a very detailed plan. Originally it was five years and then it went to a 10-year plan. I mean, reluctantly but it was accepted and a 10-plan was outlined.

You indicated there was some progress made by the department. Is that fitting in anywhere on the timeline or the road map? Is there any structure to what you're seeing coming forward now?

MS. LOIS MILLER: I'm wondering if you would be willing to hear, and if Wendy would be willing to speak on that.

MADAM CHAIRMAN: We would be very happy to have Ms. Lill speak.

MS. LOIS MILLER: Wendy Lill is on the advisory committee, which the province has set up, so I think she could tell more. I didn't make that cut, but I and two others from our committee here were, in fact, on the committee that developed the road map.

MADAM CHAIRMAN: Ms. Lill, could you introduce yourself?

MS. WENDY LILL: I'm a member of CHAG. I was the co-chair of CHAG, and proudly so for a long time. I stepped down from that last September because I was asked to sit on the Phase II advisory committee for the transformation. That's why I'm not sitting up here today, because I feel like it's better - I'm actually part of the advisory committee overseeing the process for DCS.

I guess the question is, what is going on now?

MS. MANCINI: Essentially, yes.

MS. LILL: I don't think I can really speak for the advisory committee, other than that I believe there is a great deal of work going on. I'd say there's a great deal of really important foundational work that is happening.

I think we all know that politically there needs to be a pressure and commitment continuing at the political level to move the work of the departments forward, and I think that's why we continue to come to this body. You are the elected representatives and you are the ones who are going to be asking the questions about where we are on these important issues that are affecting our population.

I am impressed with the foundational work that's being done at the department. I think they are listening, but they are dependent on the political will. I think that's what we all have to keep our eye on in the next budget, which is coming out not long from now and I'm sure a lot of the decisions are already made. We have to make sure that the money is there to make this promise come true.

Sorry, I just felt that it was a conflict for me to be sitting here with my wonderful colleagues, so I'll go back there.

MADAM CHAIRMAN: Would you entertain a supplementary question from Ms. Mancini?

MS. LILL: Yes.

MS. MANCINI: Thank you. I think it was in one of the 10 recommendations that you needed to develop a legal framework to ensure that the appropriate legal guidelines are in place. I think it was recognizing the legal capacity of individuals with supported decision making as opposed to substituted decision making - and that's in keeping with the UN Convention.

I do note - and it's encouraging to see this - that the Law Reform Commission did prepare recommendations, not in relation to this, but the Powers of Attorney Act, and they adopted that language in it. I was actually really pleased to see that it is no longer - it's a whole different concept, coming from sort of a legal background, to see supported decision making as opposed to substituted. It's quite a huge thing.

The thing is here, we were supposed to see some reform. I'm asking it because it should be a fairly concrete thing, and it was in the road map and there was a timeline. I can't remember now, but it seemed like by 2015 - the Homes for Special Care Act was going to be reviewed, and I think even the Fire Safety Act, the Occupational Health and Safety Act, the Incompetent Persons Act, and the Adult Protection Act - all of that legislation needs reform.

I'm suggesting that's probably not the most expensive part of this whole road map, so I'm just wondering if you can tell us if there has been anything moving forward in relation to that.

MS. LILL: The only thing I would be able to say to that, because that is not an area we've been dealing with, I do know there is this sense that we create the models that we want, that we believe should be in place and then we create the legislation around it. I think they made a decision early on to leave the legislative work until later.

That is certainly not acceptable to service providers who feel they are really hogtied by this legislation. I don't know whether there has been a real clear communication that has gone on between all the players on this front, I would simply say that.

MADAM CHAIRMAN: Ms. Treen.

MS. JOYCE TREEN: Nice to see you again, Brian. Thank you for all your information and all the time you put in for advocacy on behalf of persons with disabilities. It's a challenging situation, I'm sure, and I admire you guys for what you do.

I guess my question is, it's three years now, or almost three years, and it is moving forward but you don't feel quick enough and sometimes as an MLA I feel that, too. What do you feel are the real challenges that are slowing this process down, in your eyes?

DR. HENNEN: Well, to follow the continuity of the discussion, I think one of the big things is that the legislative policy has to decide what is the important thing about standards of care and standards of services.

The Accreditation Canada, which accredits all the major hospitals in Canada and a lot of nursing homes and all those things, has actually got standards of care for people with developmental disabilities in the community. No one seems to pick that up. The standards have been developed by a national group who are highly reputed, in terms of what constitutes standards of care, so I think that's one important thing.

I think I'm personally disappointed at the lack of attention that we had from the minister. I think we've had good communication with the deputy, and the deputy and Mr. Rudderham have gone across the province and have communicated well with the public and they continue to do that. They are going off again in another couple of weeks for another series of interviews. I think we're needing leadership at the political level.

MADAM CHAIRMAN: Ms. Miller, would you like to follow up?

MS. LOIS MILLER: I guess I'm just adding my own observation to answer your question. One of the biggest gaps that I saw - both when I was working and now as a retired volunteer - is lack of community supports and lack of funding for community supports.

If someone is going to be living, for example, in a small group home of three or four people or whatever and that person may have behavioural problems or issues, may need a lot of support, medical support, psychological support, behavioural support and so

on, I think we need to have mobile teams who are going to be available to provide that assistance in the home community, or wherever it is the person is living. We need to be able to provide that kind of help before a crisis develops and then it's in the newspapers and on television.

For me, I think the lack of planning and of funding for appropriate community supports, I see that as a very big gap.

MADAM CHAIRMAN: Ms. Treen?

MS. TREEN: I'm good right now.

MADAM CHAIRMAN: Mr. Orrell.

MR. EDDIE ORRELL: Thank you for your presentation. I'm going to shift a little bit from what we're talking about here to the housing situation. We heard, I guess two years ago now, a lot of people who are aging have persons with developmental disabilities who live at home are concerned about where their loved ones are going to live after they're done. We know that the government put a moratorium on admissions to residential care facilities, adult rehabilitation centres. But people are not going from those facilities into the small options homes at the present time.

Is that because we're not spending the money on the development of small options homes? Is it because there's not enough people staffing them? Is there a reason we're not doing more to move people from those facilities? The supplementary or second part of that question is, do some people still need to be in institutional-like settings, or can we eliminate them altogether?

DR. HENNEN: The administrative structure does not permit front-line decision making. People in discussion with a group home administrative staff may hear from them that they could handle this or they could do that if they only had this or if they only had that. No one's ready to make those decisions at the front line. By the time it gets back to central, the whole thing seems to get lost. I think there needs to be more authority placed in the people at the front line to make some of those decisions.

We heard from an administrator of one of the regional agencies who said of the last eight people transferred to his place, only one had come from an institution. The rest had come from community people who were in trouble or whatever. We heard others say, if I only had X dollars, or if I could only use my other bed, with a little bit of support, I could take care of that person and look after them, and it gets thwarted; something stops it.

I think that there's some front line work that needs to be done giving authority to people closer to the person in need.

MR. ORRELL: I have a shelter-type workshop in my constituency that is facing the same type of challenges. They're adults who are leaving high school, still living at home with their parents, having difficulty even getting into a day program, which is all part and parcel with the ability of a loved one to stay at home. What would happen if I was the adult of a person with a developmental challenge and passed away and that person became a ward of the province? Is that why people aren't going from the institutions to the small options homes because that's an emergency situation?

I guess I'm baffled because I know some people are supported by the Department of Community Services; others are supported by the health care system. It doesn't seem like there's any consistent application to how people are cared for. Can we talk about that just a little bit?

DR. HUTCHINSON: Yes, I think you've raised a really good point. There doesn't seem to be collaboration or cross-sectorial work around this issue. So what we see is that if a family member passes away, and a loved one is left without any kind of a plan, that person may end up anywhere - anywhere. You have the immediate family which is grappling with how to support that person. That person could end up in a nursing home. That person could end up in a hospital. That person could end up in an institution somewhere.

It's unlikely that that person would end up in a situation that was suitable to them because once a family goes into crisis, then all of our person-centred values and options run out and because often that perfect placement is not there for that person, and the people - the family, the parents - who love that person the most are no longer there to support that transition.

We recently supported a family here in rural Nova Scotia, a 78-year-old mother, and the father had passed away. She had been caring for her adult son, 42 years old, since birth, loves him, and continues to love him and treasure him and value him. She found a placement on her own - this speaks to Dr. Hennen's point - where she actually worked with a service provider. She wasn't allowed to do that. The process is that the recommendation goes from Community Services to the service provider, then the service provider decides if that's an adequate placement or not. Typically it's not.

Anyway, we had to advocate really strongly with her, supporting her to push many buttons, call many people, and write many letters. It took her over a year, a 78-year-old mother, over a year - well, probably over three years - to finally get the placement where the service provider was there, willing and ready and waiting to take this young man. He had been in their community, supported well, they knew each other. It was just a matter of funding and getting that going. It took a lot of work to get that to happen.

MADAM CHAIRMAN: Ms. Roberts.

MS. LISA ROBERTS: You referenced 25 cases, 25 situations where some progress has happened, and funding is allocated to those individuals. I wonder if you could share anything of those experiences and highlight what we should be learning from those first 25 of the 1,000-and-some.

DR. HUTCHINSON: Those 25 people, we have no idea who they are - it's 25 spots. We don't know who those people are, we don't know what their needs are, they are yet to be identified. They said, we have \$2.2 million of funding, we will choose 25 people, and those people will have that funding to be situated in community.

I think what is really important here though for us to be thinking about is, how are they evaluating that process? They're not evaluating the process, and I think that's one of the key problems. We can't learn from what's being done well and we can't learn from what's not being done well because we're not evaluating it.

I would think that if we were wanting to make sure that we were hitting our targets and our goals in a process way and an outcome way, that we'd be evaluating that.

MS. ROBERTS: So just to clarify, do any of those spots have a person in it who has moved from a not-good situation to a better situation?

DR. HUTCHINSON: We wouldn't know that. So as much as communication in the form of a newsletter has occurred for us and there is dialogue on occasion, we're actually not kept abreast of the progress.

MADAM CHAIRMAN: Ms. Miller, would you like to add to that?

MS. LOIS MILLER: Yes, I will. Just in the past week I read - and I can't remember where, I certainly didn't bring the document with me - but I did read one of the documents or communications from the Department of Community Services. From what I read, several of those persons of that 25 have moved out into the community. The others have all been identified. What I was reading said that the department plans to have all of those 25 persons placed by the end of November.

When I read that, I really was thinking about it. I was sort of putting on my hat as a parent; if one of my daughters were in that group of 25, I don't even know if I would want to go for that because the money has been allocated for only one year. I mean what if my adult son or daughter were to be placed somewhere and next year there isn't the ongoing funding - I would be very frightened. That could be even worse than having the person stay wherever he or she is right now, to move and then not be able to stay.

So Dr. Hutchinson is right - we wouldn't as a voluntary group be advised, but I do understand the process is moving forward and hope quite quickly. I doubt, from what we've

seen, to me there has been no history of adequate evaluation so I don't know how successful that will be.

DR. HENNEN: When we met with the residential administrators, there were two people around the table who both told a story. One said, I indicated an interest in taking one of those 25 and had no response. The other said, I am interested in taking those 25. They had an acknowledgement that they'd applied, but they hadn't heard back.

MADAM CHAIRMAN: Mr. Horne.

MR. BILL HORNE: Thank you for being here. It's quite an issue we have with what we're going to be doing in the next 10 years. One of the issues that I see is about employment for those that can work and how that is dealt with as you have seen it and how you feel it will be useful for the communities that they live in.

DR. HENNEN: The whole issue of employment is not - our advocacy is for residential placement, but to the extent that a good home is fundamental to anybody - to seek jobs, to seek education, to have leisure and enjoy themselves. It has to start with a good home. One of the problems is the homes aren't there to suit the needs of the people who need to be moved.

The training that's available is pretty good, I think. The \$790,000 went to the 29 agencies which fundamentally their job is to provide people with jobs and vocational activities and leisure activities and so forth. So they're sort of there and that's happening, but the business of what's a satisfying home for the individual is the problem. So we're focusing on residential placements.

MS. LOIS MILLER: Just to respond to Mr. Horne on that - the principle I always follow is home first. Someone really can't think about getting a job if he doesn't have a decent and stable place to live. That always has to be the principle, I think: homes first.

If someone is living in an institution, the institutions don't do take-outs. There's nobody going to go from that facility to take someone who is able to work, who has learned how to work. There's not going to be anybody who is going to be taking you out, making sure you can get on your bus or however you're going to get to your job. There's not going to be someone there to help make sure you get your lunch and all those kinds of supports that you may need. Those services are not available to people who are living in institutions. That's why we're focusing on home first. Once someone is in a stable and decent place to live, then you can start looking into finding appropriate work settings.

DR. HENNEN: On September 3<sup>rd</sup> there was an op-ed in *The Chronicle Herald* by Kevin Morris and Christine Aldridge-Morris, parents of an adult child. It's worth looking at. They talk about, ". . . options are severely limited for those living with autistic adults. The two most prevalent concerns for autistic adults are employment and finding

appropriate accommodations . . . As we parents advance in age, it will become increasingly more difficult for us to provide and care for our adult children . . . no two autistic adults are the same . . . Any system will require assessing individuals on a case by case basis . . .”

Those who do manage to secure housing will also require some level of supervision. So it isn't find a job and that's it. There has to be a continued commitment of supervision and support. “In many cases, supervision will be required in perpetuity.”

Solutions may include “. . . specialized accommodations . . . government-assisted housing for higher-functioning autistic adults, with some support and supervision . . .” and tax incentives. So there are two parents living with an adult child that they are worried about and they've thought about it carefully, they've talked about their colleagues, and if you're looking for a starting place for a discussion - that's from September 3<sup>rd</sup>.

MR. HORNE: Just to add to your thoughts about small options homes, can you give me a description of what you feel would be a workable model, or how you come about to have the small options homes?

DR. HENNEN: I think the small options homes are usually two or three, or maybe one person. If it goes into a larger group it's called a group home and so forth. The individual who is considering a placement or the family is considering a placement with them, has to have an opportunity to test it. Generally speaking, the group homes and the small options homes provide that opportunity, people can go in and spend an overnight, if they want, to get a sense of how they feel. They might have a meal with the other residents who are there.

It goes back to the thing that every individual is different. You might have somebody with autism who has no speech and maybe is a big guy, moving into a small options home with two or three people, which might include some smaller people who have different skills and strength. So there has to be some involvement of the supervisors of the group home and of the small options home to know what they think their residents are capable of doing in terms of taking on a new roommate or a new housemate. There are people here who have actually experienced that experience so maybe I should let them . . .

DR. HUTCHINSON: I just want to share with all of you, actually, that we're not locked into thinking only small options homes. I think what Dr. Hennen is also trying to say is that there needs to be a range of options for people. I mean if we're thinking about person-directed planning, we're really thinking about what do our constituents need, what do our family members need.

Essentially there are some people who, with a little bit more support, could live independently. There's other people who will require a great deal of support. Being flexible around that is really important, I think. So to sort of target just one type of option is probably putting a limitation on the potential that is out there.

Also, thinking about that particular family, they may in fact be quite well resourced, they may be prepared to partner with a service provider to provide some support that comes with that individual, rather than just looking for all of the support to come from the service provider themselves. I think we really need to be thinking creatively, especially if we're going to be reducing these wait-lists.

MADAM CHAIRMAN: Mr. d'Entremont.

MR. D'ENTREMONT: I'm trying to identify the gap here and why we have such a gap over such a long period of time. I wonder if I could make a motion here and we could discuss it later on, after we finish our questions. Maybe we can write a letter to the minister and just ask her to provide an update on the government's transformation of services for Nova Scotians with disabilities. Maybe a part two is how the department is going to meet the timelines set out in the road map.

I think it's a simple question to her. I'm sure in Question Period we'll be asking questions of her on this one. I think this is probably a more comprehensive request for an update, so I was just wondering if that's a reasonable thing to ask, just to try to fill in some of the blanks here, why there's such a time period going by.

MADAM CHAIRMAN: I think we can address that. So we have a motion to write a letter to the Minister of Community Services, asking for an update on the transformation process in detail.

Would all those in favour of the motion please say Aye. Contrary minded, Nay.

The motion is carried.

We'll make sure that comes from this committee directly to the minister.

We will move on to Ms. Mancini.

MS. MANCINI: I just wanted to follow up on your last comments about the different types of housing. When I did read the report - and I was new to reading it, not having been involved in this in any way - I was trying to figure out what the housing options are. Then when I read the Hansard from 2014, I noted Wendy Lill's comments when she said you could have somebody in independent living who needs 20 hours a week, but the next bump up from that is 24/7 care. So it's like we're lacking some flexibility in the current system in that regard.

The other thing is, I think there was a moratorium - maybe that's too strong a word - on small options homes. That goes back to the 1990s. I saw some stats, and I have them in my briefcase, but suffice to say that we're probably down to a quarter of small options

homes that were present in the 1990s. So there's a marked decline in that. We're also looking at the moratorium on the institutions, like in July 2016.

I guess what concerns me a little bit is that scenario of the aging-out person, a disabled person. Right now there is no small options home and they can't go into an institution, what's going to happen? I'm kind of wondering about that.

DR. HUTCHINSON: That's an excellent question. We're not aware of what is going to happen. I would expect that families will be going into crisis. We have families that are already in crisis, and so I would expect that we will have people in crisis, and we are not aware of the plan that's in place for families in crisis at this time.

We know what happens when families go into crisis when there wasn't - I think there's some talk that people can be temporarily placed and the temporary is three years. So although we're saying no more admissions into institutions; in fact, they have the caveat that if someone is in crisis, they can be placed in an institution for up to three years, which is a short-term placement.

I can imagine, as you can, that three years is a significant length of time. In my opinion, I wouldn't see that as a short-term option. That's the length of time it is to get a degree.

MS. MANCINI: My second question is probably a little off, but it certainly came up in the discussion so I think I can fit it in here. It was in relation to that \$800,000 for adult service centres. You figured it out to be about \$27,000 per. What I noticed in that press release from the minister, she says, "It will help them identify and create opportunities to increase their revenues and capacity." I don't know what that means. That's my question. Can you explain that to me?

MS. LOIS MILLER: When I read that, that stood out to me with a real red flag. From my own experience in the non-profit sector, what I think that will be used for, or is intended to be used by the adult service centres - and just to make sure we know, like in Sackville we have Building Futures, there's DASC, Prescott, those are the kinds of agencies. They used to be called - and you used the term, Mr. Orrell - sheltered workshops, but they don't like that term now.

I think those organizations will be using that money to enhance their own capacity, like for training, bringing in a consultant, and helping them explore ways they can set up additional businesses, like a Building Futures, one of the little services that they have. They do shredding. Actually, I took some boxes of my dad's stuff over there for shredding. They have a little shredding business. That's great. That's working well for them because many of the people - and they proudly told me - not only do they not read the materials that I left there, but even if they did look at them, they could not read. One of their men told me that very proudly. That was a bonus, he felt, for me.

They will be expanding and exploring different options there where they can be setting up little business ventures like that that will provide employment. But I have to say, that's to enhance their own capacity. When I see that, I'm sort of thinking, oh dear, down the road they may be getting less funding because now they will have enhanced capacity to raise more money on their own, so I think that's kind of a double-edged sword, actually.

DR. HENNEN: I just want to point out that that's once-only funding. That's not a continuing budget increase; that's once-only funding. What's going to happen after one year when they've blown their \$27,000?

MADAM CHAIRMAN: Mr. Wilton.

MR. DAVID WILTON: Thank you for your presentation. I'm just wondering a couple of things. The road map commitments that we have here, were you guys involved in any consultation with that? If you were, do you see this as a positive thing going forward? Are there any roadblocks through all these suggested roadways I guess we call them? Do you see it impacting this report card that you presented here today?

DR. HENNEN: Three members of CHAG were on the committee that established the road map. When it came out, they were very optimistic that something substantial had happened. The first thing that really happened in a public way was the announcement came out that we can't do it in five years, so we're going to set for 10. That just took the wind out of everybody's sails. There was no reason, no rational assessment that this could not be done in five years. It was just stated, we can't do it in five years so it'll be 10.

MR. WILTON: Just on that statement there, government has committed to a three-phase approach, I think. Phase 1 is done, from what I understand, and we're into the second phase. Wendy Lill had mentioned that here just before, I think. Wendy, is that where we're going? I don't know when you expect to finish that part. Do you have an idea?

MADAM CHAIRMAN: Ms. Lill, we'll ask you to come back up to your seat, and that way we can recognize you.

MS. LILL: My understanding is that Phase 2 is over at the end of November. At this point, I'm assuming they are going into the next phase, and the work of our committee will have ceased. That's my understanding.

MADAM CHAIRMAN: Ms. Miller, did you have something that you wanted to add to that?

MS. LOIS MILLER: The report card directly measured people's perception of progress on reaching the goals in the road map. We picked only five of the 10 goals. This Fall's road map will again directly be measuring what progress people are seeing on reaching the goals of the road map. The report card is directly related to the road map.

MR. WILTON: The road map that has been presented - my question is, going forward, do you see it, as a committee, directly affecting the negative output that has been put in here? In your second phase, I'm sure you're going to have a report on that. Do you see a result from what Wendy is doing there affecting this report card also?

MS. LOIS MILLER: We would hope so.

MADAM CHAIRMAN: Ms. Lill, do you have anything else to add? No pressure.

MS. LILL: I would say that the government has become better at listening to the community. I'm hoping that this report card process is having an impact. It is definitely front-line responses to the things that they are working on and it's clearly important that they're picking up on the importance of that.

DR. HUTCHINSON: At a public meeting recently I offered to partner with them on this road map so that it actually could be a way for them to garner feedback on the work that they're doing. We want to work with Community Services. We want to be collaborative. It's in our best interests to do that - all of our best interests to do that. However, there wasn't an interest at that time, but that's certainly something that I would like them to actually be taking up as well to understand better what their constituents are feeling, thinking, wanting. I think when you get close to what people want, then you do a better job of providing the services that you're mandated to provide.

MADAM CHAIRMAN: Mr. Orrell.

MR. ORRELL: We talked a few minutes ago about the \$27,000 that is going to the facilities to build capacity. My wife worked as a job coach and an employment support person in one of the workshops in Cape Breton. She was in charge of finding jobs for people who went to the institution and did a pretty good job at it - so that money could be used for that. To hire a person to do that kind of job with \$27,000 wouldn't go a long way. So a one-shot deal to get the hopes of people up wouldn't be the greatest thing we could have. So let's hope that they'll see the wisdom to improve that.

What some of the facilities are doing now, like the Northside Adult Service Centre, is getting involved in Chase the Ace. They've raised hundreds of thousands of dollars now to try to continue that, but that's a challenge and burden on those institutions, those facilities to do that.

We're seeing in your report that there are 300 people ready to move now from institutions, which would mean another 1,200 or so that were really not ready yet. Do we have a cost of - we know we face different challenges with different abilities and different supports needed. Is there an estimated cost of what that would be to move those 1,200 people from institution-based facilities to small options types of facilities?

Estimated, doesn't have to be perfect, but we're spending like \$790,000 on this and \$2.2 million on that. If we could take all that money and put it together, is there a cost that we may be able to say, okay, if we spend this much money today we could eliminate that or reduce the institutions to people who actually really, really need them and be able to put the people who could live independently or with supports in the community into those areas. So I guess my question is, is there an estimated cost to what that could be?

DR. HENNEN: I have not heard an estimate from the program. I think so much depends on the individual. I heard a regional authority CEO say, I could do that for \$40,000, and then someone else says, it's going to be nearly \$500,000 to deal with that person. That's a real number.

The whole business of categorizing or profiling the kind of client that's going to be making use of this group home, of these job-creating facilities and all that, it's so individual. They need a profiling formula that they could do it in. I've never seen an estimate, but I think it's a lot bigger than some people think it will be.

If we're averaging out, just off the top of my head - and I'm not a good accountant kind of guy - I'm guessing you're talking \$125,000 or \$150,000 per person on average, in that range.

DR. HUTCHINSON: When we talk about costs, we're actually talking about jobs. So when we talk about spending this kind of money, we're actually talking about investing in jobs for Nova Scotians. That's what we're really talking about. This isn't money that goes poof, up in the air, and it doesn't go anywhere. This is money that would create jobs for people in their communities, to support people and invest in communities. I would like us to think about it in that way.

MR. ORRELL: I guess that's what I'm thinking about, more that if we have 200 people working in an institution, those 200 people are going to go into the community with some more. The savings on institutionalized food and all the rest that goes with it, health care and the transportation and so on and so forth, I was just wondering if there was any combination of if we spent this much, we wouldn't have to spend that much, this would cost this much.

Going forward, all governments - and I'll exclude no government in that - without a cost to something, you're going to have a hard time getting the action done. It's a fact that no government wants to spend money but if we can spend money to save money, or to at least neutralize what's being spent, I think moving forward will be a lot easier. I don't think there's anyone at these tables who would deny the fact that everybody deserves a decent place to live, be it people with disabilities, people who are low income, be it seniors, or be it people with medical problems. We have to find a way to provide that in a cost-effective manner, or to save money.

That was the purpose of the question, not to say that we don't have the money to do that but if we could find a way to do it and do it relatively effectively with savings in other areas, I think it would be lot easier to move forward. So thanks for your presentation.

MADAM CHAIRMAN: With the permission of the committee, if I could just kind of ask a follow-up question to Mr. Orrell's question. Do you know of any province or any measuring tool that would - because there's so many complexities to people's needs, it's hard to imagine there would be some sort of cost-testing evaluation that would be able to give us an accurate number. Does that exist? Do you know if that exists, Dr. Hennen?

DR. HENNEN: I doubt it. Ontario had a lot of resources. We reported on it, they had the evidence that they knew how to describe the clients better, they had good data on that, the demography of the population. Then the Ombudsman's report said it doesn't matter. There are too many cases happening, too severe, and this is not good enough.

If Ontario with its resources can't come up with a formula, I doubt if there's one out there.

MADAM CHAIRMAN: Ms. Roberts.

MS. ROBERTS: You referenced in your initial presentation the need for community to be the care provider for these people. In 2015, a number of community organizations had their funding cut: Free Spirit Therapeutic Riding Association, the Schizophrenia Society, the CNIB, Deafness Advocacy Association, the Nova Scotia Association for Community Living, and People First Nova Scotia. I'm wondering, what impact have you seen of those cuts in the community related to the situation you're talking about?

DR. HENNEN: The closest I've been has been to Independent Living Nova Scotia because I was on that board when Lois was the executive director. I think the funding that supported Community Living nationally was mostly federal and it was in the previous government and it was really clobbered substantially. We didn't get any pickup or support from the provincial government either, so there's a not-for-profit that has done very well and made a lot of contributions that just lost its core funding. There are a whole lot of institutions across Canada that lost their core funding. There have been many attempts to try to bring some of those organizations back together as collaborative organizations, to make do with less.

I don't think that many people in high places really credit the not-for-profit, volunteer efforts in their communities. I think the work that volunteers do, you can credit it with an award once in a while to the person who stands out but the recognition of the contribution of not-for-profits and volunteer people by government needs to be really picked up and be given substantial support. I think that's fundamental in strengthening the community reception.

Look at how well we're doing with the refugees when there was money turned on and people volunteered. The volunteer work that's going into caring for refugees right now is substantial and it's not costing government. The federal government got away with a whole lot of stuff because the privately-raised money to support refugees became available much more quickly to the people who needed to use it and it was coming from the private sector. It was coming from people who were donating their time and it wasn't really acknowledged as well as it could have been.

MS. ROBERTS: Related to that, you may know that I was just recently working at a neighbourhood level in the non-profit sector so I think a lot about community resources and the strength of community to respond - exactly to your point - to refugees, to people with disabilities, to people who are lonely, to seniors, to the people caring for seniors.

I'm wondering if in your sector and in the context of this road map, is that part of what you are thinking about? What kind of communities do we need to create options, and the options that are needed by the people you are particularly advocating for are not necessarily a completely different sort of set of supports than many other people in our community also need?

MS. LOIS MILLER: That's exactly the sort of thing I was thinking of. My husband, who is sitting here I think still behind me, served for some years as a United Church minister in Rawdon and, by the way, it was because of me that name got in the report. I often thought of the situation in Rawdon.

At that time I was working as Executive Director of Independent Living Nova Scotia and there was a man who we were involved in supporting who lived in Rawdon. Now this was not a man with an intellectual or a developmental disability, he was a high-level quadriplegic, in fact a mouth painter, and sadly he has since passed away, just in the past year or so. At any rate, I would occasionally drop in to visit him when I'd be in Rawdon.

What I would see was just the sort of thing that would be my vision for many people with developmental disabilities living in the community. I would meet this man on a Saturday evening out at a concert or at a theatre presentation because he was able to access one of our, I think, very good provincial programs, self-managed care, but it's funded through the Department of Health and Wellness. It was modelled, by the way, on a program that Independent Living Nova Scotia developed so I'll just put in that little plug.

Anyway, because this man was able to be part of the self-managed care health program, he was able to have an attendant with him and tailor his attendant time to what he really needed. So his attendant could take him out on a Saturday evening and he could go to the concert; a close community like that. There were nephews, a couple of his nephews would help him get into the car. There was lots of volunteer support. There was a medical centre there at that time. We drove past it two days ago and it has a sign up now,

it's for sale. I don't know, they lost their funding through the Department of Health and Wellness, I don't know how that happened.

There were doctors in that community on a part-time basis, the foot care people were there, the nutritionists were there, the parenting experts. That's what we really need and a good case manager could put together a wonderful plan for someone, drawing on all those kinds of voluntary supports, as well as agencies that are putting their staff in. That's the way I see it, of something really working with the circle of support around someone so that that person could have a good life in the community as I saw with this man.

By the way, he was able to find a wonderful apartment adjacent to a home that had been built for a grandfather; it was a grandfather suite. Luckily for the man I knew, the grandfather passed away very quickly after moving into his suite, so this gentleman was able to move in - fully accessible. There are often wonderful resources in the community, but often it takes somebody paid by an agency to go in and pull that all together. That's the kind of vision I see for many people.

MADAM CHAIRMAN: Mr. Stroink.

MR. JOACHIM STROINK: Thank you very much for your presentation. I commend you for the work that you guys do in our communities. It can sometimes be thankless, but we do appreciate the dedication and what you do on a daily basis.

I guess with that, last year, the 2016-17 budget, we invested \$13 million in to the DSP. There is good stuff out there, and that's an indication that government is trying to work hard towards the 3-phase plan and working with people with DSP. Given the limited resources that this provincial government has at this point in time, where do you think is the highest priority to put funding forward? What areas do you think, with the limited resources, would have the greatest impact to people with disabilities?

DR. HENNEN: I would start with staff development and the training of people who are providing services and education of the community. The whole business of education, educating the community, educating the caregivers, educating the families - a real thrust in that area. I would give that as an emphasis.

I think one needs to look at how the money that has been spent is being used. There have been a lot of consultants hired in the last year or so to provide advice to DSP. When we were meeting with various groups, we had some people question the awareness of the consultants of the front-line issues. Maybe that could go in your letter to the minister: did they get good value from their consultants or not? That would be a good thing to know.

That's where I'd start. There's a whole series of things, but my number one would be staff development.

MR. STROINK: Anyone else there on that comment, with the limited resources?

MS. LOIS MILLER: I guess, if I were the decision maker, I would be seeking more funded spaces, more funded rooms, whatever, in community-based housing models, places like L'Arche. It always gets top marks for good quality of life. The people who have loved ones, and residents themselves, I have met with a number, and always it gets top marks. But that's one model.

Here locally regional residential support services - there are a number of very fine agencies across the province that would be able to make more spaces available if they knew they were going to be able to have funding to make those spaces available. They wouldn't necessarily be buying more houses or renting. They might be using apartments but providing support. They might be partnering with families where families would actually be putting some money into renting a space. There are just all sorts of good, creative, and flexible things you could do.

I would say more funded spaces and also more funding to supports in the community so that organizations that maybe are serving seniors could also be serving a different population, or a group that is serving young families might also take on additional areas of service. Those would be my top priorities.

MADAM CHAIRMAN: Dr. Hutchinson, do you have anything to add?

DR. HUTCHINSON: No, I think my colleagues have addressed this question.

MR. STROINK: With that, Dave and I own a few businesses and one of the opportunities that we have is to engage Nova Scotia businesses. What are some suggestions you have to encourage businesses to hire DSP or how can people support that in their business? I think that's an important question for Nova Scotians to start thinking about as entrepreneurs - how do we get people with DSP into the workforce within our own businesses because we all have a responsibility to make Nova Scotia a better place and that's one way of doing it.

MS. LOIS MILLER: There are excellent employment agencies pretty well all across the province. Mr. Orrell, you mentioned the one your wife had been involved in and I co-operated with her on a couple of services. The employment services network - I'm sorry, I've forgotten all the various acronyms and names - but here in the Halifax area, TEAM Work Co-operative, for example, those of you who are in the Halifax area would be well served. A business could be partnering with TEAM Work. There are ways that they could - for instance, if you were to hire a person with an intellectual disability, they could have a job coach who could spend some time with that person.

If you had a restaurant, someone might be coming in, for example, to do vegetable prep, which you're always going to need. A job coach could come with him to get him

started - make sure he really knew how to do it and check in with him from time to time and make sure he's on track, that there aren't communication problems with the supervisor and so on.

You could actually engage or hire a highly valuable employee who would love his work and get there every day, whereas you could be putting the same amount of money into somebody that you've hired who really doesn't want to be doing those dishes and is going to look for the first opportunity to move up or move out. So I think those are the things. There are good agencies in place that can work with employers, and if you have interest, I'd say get in touch with them.

DR. HUTCHINSON: I think it's important to raise what Autism Nova Scotia has been doing. They have been working really hard at creating jobs for people with autism in the community. They have training for the job coach people. They have infrastructure. They have found some amazing partnerships with business and so I think that we should be also noting the progress that they have made. They're very interested in partnering with businesses.

MR. STROINK: Have you heard of EDN, Entrepreneurs with Disabilities Network?

DR. HUTCHINSON: Yes.

MR. STROINK: That's a phenomenal program.

MADAM CHAIRMAN: TEAM Work is actually in my constituency and I work really closely with them. They have training specifically for employers so that business owners can come in and will know the best way to hire someone with a disability. There is so much support for them on that end of it. They're quite remarkable.

DR. HUTCHINSON: I think I want to pick up on Ms. Miller's point, which is that the people who receive jobs in this way or are supported in this way are very committed employees. I know people with autism that don't want to take a vacation. They don't want to take a day off. It's part of their routine to work every day, part of their code, and it's very difficult for them to take a day off, believe it or not. They really do value the routine and the environment that they're in and what has been created for them.

MADAM CHAIRMAN: Mr. Orrell.

MR. ORRELL: I guess I have one simple last question - going forward, what is your primary concern about how this transformation has taken place, how long it's taking and what can we as a group and as a committee, do to help move that along?

DR. HENNEN: I think the important thing is to get some solid and predictable funding increases, to DSP and the agencies that are providing the support. I think there are a lot of things that could happen with a modest amount of investment, if it was carefully directed.

I was going to connect with the last discussion, and I hesitate given what's going on south of the border, but I wonder about tax benefits to companies and whether some kind of subsidy support for salaries for persons with disabilities could come from government with a subsidy tax relief program for small companies particularly. If every small company hired one person with a developmental disability - full time or part time or whatever - it would make a tremendous step forward.

MADAM CHAIRMAN: Ms. Mancini.

MS. MANCINI: I was referring back to Hansard and at that time Ms. Lill had spoken about her own personal experience with her son Sam, who has an intellectual disability and who has three part-time jobs; this was in 2014. At that time she talked about after high school he became involved in a program called ACEE which is run by Independent Living Nova Scotia and was funded by the Department of Education and Early Childhood Development. It is for young people graduating from high school and it provides a sort of transitional opportunity for them to get into the program, to get some training in terms of, whether it's even getting the bus, getting used to the transportation system, I think there's a job coach available. She talked about Sam working at MacAskil's and if there are any challenges. It's similar to what you were describing earlier.

In the Spring, the Halifax Regional School Board withdrew the funding for this program and this had been in operation for 10 years, so it certainly seemed to be, at least from Ms. Lill - and I had an opportunity to speak with the executive director and she was devastated. She maintained that she hadn't really been consulted when the funding was cut and so right now the program is gone. It may have been absorbed into another kind of more generic type of situation funding arrangement, I'm not quite sure about that.

I'm just wondering if anybody here is able to comment on the impacts of losing this program?

MS. LOIS MILLER: I'm almost afraid to start. I don't think I am being boastful to say I was the founder of the ACEE program.

MS. MANCINI: I didn't know that.

MS. LOIS MILLER: I wrote the original plans, got the original funding. Dr. Hennen and I think also Ms. Lill were on our board at the time, highly supportive. It took a great deal of advocacy, research and development.

Ms. Mancini, when you said my comments sounded similar to ACEE, actually not, they were referring to ACEE. We had so many success stories - Sam, whom you mentioned, but so many others. One of the young men who completed the program, I occasionally bump into him and he has been working in a law library. He has autism, he does filing of law cases, I don't know. My daughter is a law student so I should ask her if she bumps into him there from time to time.

He also was a success story, someone who otherwise would have been very hard to place in any kind of employment. But with a job developer who ferreted out that spot, with a job coach who went with him and learned how to file those cases herself, that young man has been able to really have a very good career. That's what he does. He does it so well that his supervisor told us the only problem was she had to take him aside and make sure that he wasn't correcting the supervisor because occasionally he found things that had been filed in the wrong place years before. Of course, his communication - he doesn't respond too well to other people's feelings and he never will, and of course he pointed that out to the head librarian and couldn't understand why that wasn't a good thing to do - and he never will probably understand it, but he's dynamite at what he does. Those were the kinds of situations we dealt with at ACEE.

Yes, sadly, the ACEE program, as it was established, is no more. The funding came from the two departments jointly - the Department of Community Services and the Department of Labour and Advanced Education - through a structure that they set up that was very bizarre and awkward. The funds went to the school board and then to us, to Independent Living. The school board has decided this year to go with a different provider. So they are working now through the community college, which will be setting up a program.

I feel it's a sad loss - not just for the money. Well, we lost three employees, all of whom were themselves people with disabilities - but that was one of the joys of the program. The people who delivered the program were themselves people with disabilities and they became such wonderful role models for the youth in the program.

They would see the job developer in a wheelchair, their teacher was blind, another person deaf. That was just itself the most wonderful feature, I think - being able to see people reflecting themselves and see these people successful and leaders. So it is a sad loss, but another transition program will be offered by the community college.

MS. MANCINI: So there were at the time then people who were maybe halfway through who had to move on to the community college program or do you know?

MS. LOIS MILLER: Most, by the end of June, were close to finishing so it's just that Independent Living wasn't - I mean, that was unfortunate of course, but we were able to make sure those people were able to complete the program. Some may have chosen to apply for the new community college program, others will not. Some, of course, have gone

on to paid jobs - so it really depends - but we weren't able to accept new people in for September.

I understood from our executive director that she had 85 people who had picked up information packages. I don't know what's going to happen to those 85.

MADAM CHAIRMAN: Ms. Treen.

MS. TREEN: I just want to talk about a little situation and get your feeling on it. I have friends that have children who have disabilities. They're in their late 20s and they are starting to think to the future, about where they're going to live if something should happen with their health.

I know the mother - she's quite a good friend of mine - went to a small options and got on the list, waited. She discussed it with her daughter who lives with her, and her husband. They went to the small options and had a visit and then they came back. They were hemming and hawing on what to do and the daughter ended up breaking down, crying, did not want to go - wanted to remain living at home. She describes similar stories with similar friends. They go to The Club in Halifax. So she has a lot of buddies over there and similar situations.

I've had people come in my office, one in particular had someone living at home, a son with a disability who she just couldn't handle anymore. He was a bigger man now and had violent outbreaks and different stuff. She was begging to have him put in a confined institution or whatever and was looking to figure out what to do.

My question is, people with a disability, parents of children with a disability or families or caregivers - who makes the decision or helps them make the decision on what the best thing is and where they are to go? That's a hard decision. I know it's individual of course, depending on the need. Do we create a team of people who work with them? What would your idea be for people trying to make that decision?

DR. HUTCHINSON: I think that's a support that can come from the community as well. You mentioned The Club as being an option - that's a great example of a community of people who come together and spend quality time together. Through different organizations where people come together, we often hold meetings, information meetings, to share with families what to expect when they're thinking about transitioning their son or daughter.

What you're hearing from your friend whose daughter is reluctant to move, often it's not really understanding what the choice in front of that individual is. That's the reason why we talk about it as a transition, not as a move. That's the reason why I'm trying to caution us around crisis because crisis makes that happen much faster than it should happen. For every single family, if you have a family that's in crisis, then you need to take

the heat off so that that family can breathe again and reconnect with their son or daughter because essentially that's our experience.

Most parents who have been caring for their adult children have significant health and mental health issues as a result of the care because it's 24/7, and it's extremely difficult to do, more difficult than anyone can possibly imagine. I did a study on that, and it wasn't good. But with the right supports, then what happens is the individual gets to have a life that their typically developing children have. That, I think, is the biggest part.

We have a lot of families that are very socially isolated. Their children are socially isolated. They're not able to get out into the community because they don't have the support to do that. I had a family member who said, I close my curtains so my child can't see what's happening outside because I can't be out with my child all the time. Families are doing the best they can, so I would say for that family member who's thinking, just put him anywhere, that is a big red flag for us. That's a family that needs our immediate attention and support.

However, for your friend who sounds like things are going really well, for them it's a natural transition at some point in time where their adult child will be moving out. So how do we provide those opportunities? Investing in people who can actually support that transition I think is a really smart step.

MS. LOIS MILLER: I would say a first good step would be to get in touch with some of the community-based organizations that have proven track records, for instance, the Nova Scotia Association for Community Living. I think Jean Coleman is here today or she certainly was. They are able to provide a lot of planning and support and I think help open doors to help the family dream big.

That's what I would love to see, when a family and their adult son or daughter would actually be able to develop plans. I would suggest that should be as early as possible, but you start wherever the person is. If he's 29, there's no point for somebody like me to say, gosh, too bad you didn't do this when he was 9. Yes, it is too bad you didn't do this when he was 9, but you have to start where the person is.

Autism Nova Scotia would be another, if the person has been identified as having autism. All those kinds of organizations could help the family in a non-threatening and not a crisis-driven situation to make good plans and help with the transition. I've seen that many times, it is possible.

MADAM CHAIRMAN: Thank you. I know that we have gone over our questioning. I know that Mr. Horne has one last question, if we could just keep it brief.

MR. HORNE: First of all, I'd just like to say that what you've been talking about all day has been very good for us to understand. The last 45 minutes to an hour has been

awesome, I think, as far as getting into the discussion and the real bites of what we're dealing with.

I live in a community where we have over 120 different community groups, volunteers. I could see like an advisory board being set up in our community. I know of people who have DCS or DSP and I'm just wondering, do you see that we could work out a system, have community groups so we could get engaged with the community and with the individuals?

MS. LOIS MILLER: I would certainly say yes but remember, those kinds of things don't just suddenly spring up. If there is a case manager, for instance, or a case supervisor who should be meeting on a regular basis with a participant in a program and his or her family, certainly we need to be working through well-established organizations because you don't just grab volunteers. We need to make sure these persons are well qualified, have been well vetted and trained.

Certainly I see a big role for volunteer groups in the community. As you mentioned, where we are in Fall River, think of, as you said, over 100 organizations that we could be drawing on to provide support. So yes, I certainly see that as possible.

MADAM CHAIRMAN: Thank you so much. Do you have any closing remarks?

DR. HENNEN: I'll just say a couple of things just for information. The IWK is doing an internal review of autism and is bringing in experts at the end of this month. They will be here for two days and they will be looking at that. Autism is an interesting phenomenon in the way it has been going, whether it's because we are better at identifying it or not, it is growing hugely and we need some solutions.

One of the big issues with the IWK is this business of the aging-out, when you become 16 or 17 years old, you are no longer a pediatrician's responsibility and where do you go? So we're in the business of trying to train family doctors better so they will comfortably accept responsibility of providing continuing primary care to people with developmental disabilities. That's one point.

The second point, there is a Dartmouth club. We are partnering with The Club and out of Grace United Church in Dartmouth we run four programs a week now for people with developmental disabilities, in terms of choir and music and games and leisure activities.

The other point, we just touched on it very little, one of the big problems in the community is for those communities where an institution sits, that provides good work and employment for individuals and for the staff and all that stuff. We need to be able to convince the employees of those institutions that there will be good jobs for them in the

community and we'll prepare them for that as the system changes because the system is going to have to change and it is changing.

The person who is 45 and has got 20 more years to go, sees their job on the line, goes to talk to their MLA and says, you can't let them do that, we've got to be able to say to them, we'll provide you with a different kind of job in the community. You've got lots of talents to give and lots of experience to work on. So we've got to deal with that in a provincial level, in terms of supporting those kinds of changes.

I really thought your questions today were right on and very helpful to us, in terms of making us understand a little better what we can do better. I think that was very helpful. I do just want to say to Joyce Treen I thought her work on the service dog legislation deserves a real credit and I was sorry I wasn't there to wave the flag at you. It was a great thing to happen.

MADAM CHAIRMAN: Thank you so much. Since we've gone over so much on our time, you can tell how important this discussion was to us and we really appreciate you being here. I think all of us around the table have a better understanding as to what we can be doing to support you and support those with disabilities.

We're not going to take a recess because we do have a bit of committee business. Maybe I could ask our witnesses, even though you can leave the table, if you could just kind of stick around because I'm sure some of our members would like to speak to you, once we wrap up here.

Going straight into committee business, we received correspondence that was all sent to you electronically and we have it here in hard copy as well. This committee will be requesting that information and then getting back to those individuals. Is there any discussion on the correspondence we received? It's quite straightforward and we will be looking for those answers to get out to the groups.

There is a typo as to our next meeting date. It is Tuesday, January 10<sup>th</sup>, not the 9<sup>th</sup>. We will have our clerk send out confirmation that that date works for our witness. We know they are free on the 9<sup>th</sup> but the committee meets on the 10<sup>th</sup> so we're just going to make sure of that and we will let you all know if that is the case or not.

If there is nothing else, then we are adjourned. Thank you very much.

[The committee adjourned at 2:57 p.m.]