

HANSARD

NOVA SCOTIA HOUSE OF ASSEMBLY

COMMITTEE

ON

COMMUNITY SERVICES

Tuesday, November 6, 2007

Committee Room 1

Presentation on Autism

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COMMUNITY SERVICES COMMITTEE

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[Hon. Ron Chisholm was replaced by Mr. Keith Bain.]

In Attendance:

Ms. Charlene Rice
Legislative Committee Clerk

WITNESSES

Valley Autism Support Team
Mr. Norman Donovan - Director

Autism Society Nova Scotia
Ms. Vicki Harvey - Executive Director
Mrs. Tracey Avery - Parent Representative

Autism Society of Cape Breton
Ms. Michelle Gardiner - President

HALIFAX, TUESDAY, NOVEMBER 6, 2007

STANDING COMMITTEE ON COMMUNITY SERVICES

1:00 P.M.

CHAIRMAN
Ms. Marilyn More

MADAM CHAIRMAN: I call to order the meeting for the Standing Committee on Community Services. Our topic today is autism and we're very pleased to have with us representatives of the Valley Autism Support Team, Autism Society Nova Scotia, and the Autism Society of Cape Breton.

I think we'll start with introductions of committee members.

[The committee members introduced themselves.]

MADAM CHAIRMAN: Thank you. I wonder if you'd like to introduce yourselves and those that you've brought with you.

MS. VICKI HARVEY: My name is Vicki Harvey, I am the Executive Director of Autism Society Nova Scotia and I'm very pleased to be here today.

MR. NORMAN DONOVAN: I'm Norman Donovan, I'm a Director with the Valley Autism Support Team. My grandson has autism.

MS. MICHELLE GARDINER: I'm Michelle Gardiner, President of the Autism Society of Cape Breton and I have a child with autism.

MADAM CHAIRMAN: Welcome. So I believe you're going to start with a presentation. We've made copies of it available to the members, if you want to take notes on it. Then we'll have a chance to ask questions and points of clarification. Thank you.

MS. HARVEY: Thank you very much. We're really pleased to be doing this today. I'm going to start off. We're trying to do a joint presentation to you, because this affects all of Nova Scotia and all Nova Scotians. So we've worked very hard together and it's been lots of fun, so we're really pleased to be able to start with you today. I will do part of this and then we'll move on to the other two participants. Please bear with me with the technology; I'll do my best here to present this in an effective manner.

We're going to start off with a short definition of what autism spectrum disorder is and for anyone who has anything to do with autism spectrum disorder, short is one of the - it doesn't really fit with the definition, but we'll do our best. One of the things we've always tried to do is how to come up with a definition of autism in 50 words or less. We haven't been able to find that yet.

Autism spectrum disorders - these are the most common neurological brain disorders affecting children. We don't know why autism happens - if we did, it would certainly help us in trying to develop proper strategies or even helping us to eradicate it, but at this point in time we do not know. There are some very promising genetic studies going on, but there are a multitude of theories as to why autism happens.

It used to be known as just autism. What we have found is that expanding that to spectrum disorders takes in a lot of people who fit the definition, but perhaps were a little more subtle in their characteristics. Autism certainly does present as a spectrum and we'll talk a little bit about that as we go along. It changes the way that we process information. People who have autism receive information differently and process it differently and utilize that information differently, and it does affect all aspects of development.

It is, unfortunately, what we consider to be almost an invisible disability. People with autism don't typically look physically disabled. They seem like everybody else, so that can really make it much harder for us to try to create awareness about this disorder. Often what happens is, people tend to look at the characteristics as weird or odd behaviour. It can be very misinterpreted, so that the child who seems to be having a temper tantrum because he may be overloaded with sensory information or one of his routines has been upset, just appears to the local public like a child whose parent cannot handle him. He's just having - you know, behaviour that if you disciplined him properly everything would be fine.

This is not a disorder that discriminates, it happens in all racial, ethnic and socio-economic groups, so this is a worldwide disability. It does happen in both genders, but we do see it happen four times more often in boys than in girls. We have a picture of a number of young people, these are people who have been involved in our camp program, lovely kids, and they all have a diagnosis of autism and that is almost the spectrum right there, because we have all presentations there.

When you see someone who has autism or when you meet with them and get to know them, it's important to remember that each person with autism is an individual. Just

like the rest of us - we all have our own characteristics and our own personalities. Each person with autism presents differently. It's always very important to remember that if you've met one person with autism, then you have gotten to know one person who has autism and you're next interaction with a person with autism may be very different.

It is a brain disorder, it begins early in childhood and it is a lifespan issue, so it is something that affects us - excuse me, I have to go back there. It affects individuals - okay, it doesn't want to go back, sorry about that.

It is a lifespan concern. Once you have a diagnosis of autism, it is something that will affect you for your life. With appropriate strategies, some people can become able to do things in a more normal way, but there is always going to be some effect from the disability.

It affects people in three main areas of development. Communication - and that would be in our ability to utilize language, to understand language. It isn't strictly just verbal language, it can also be non-verbal, which is a very important part of the way we communicate. We all use non-verbal language in our interactions with people. When we talk about the spectrum, you can see all ranges there. On one extreme there can be an individual who does not ever learn to use verbal language; the other extreme, you can have individuals who are very verbal and very able but struggle with comprehension. They do not fully understand what is being said to them and are not perhaps able to use the social components of language effectively.

The next area would be social interaction, which is really a key and important thing for all of us - we all want to be able to interact socially. People with autism do have a significant lack of ability with social communication. There's an inability to learn the social rules that we have picked up quite naturally as we have grown up. These are things that need to be specifically taught to people who have this disability. There's a lack of understanding of emotions, facial expressions. All of those things that you've picked up through osmosis, these individuals need to be taught and if they're not taught they are left at a huge disadvantage trying to navigate what's going on in the world.

The third area would be in rigid or unusual behaviours, and this is reflected in the need for routine and structure in their days. Routines are very important to people with this disability. Also, having fixations on odd objects or very strong interests in particular areas can reflect some of those behaviours. Again, if you're looking at the spectrum, on one end of the spectrum you might have someone who has very significant behaviours they have to do over and over again. They may flap their hands or they may tap things, to the other extreme of much more subtle behaviours which, again, the person needs to do, but are not as obvious. If someone is pacing up and down in a room that's something a lot of us do, so it does not seem to be as extreme and there's quite a variation in between.

How common is this disorder? When we talk about prevalence rates - and that's what this slide is about - we're looking at how often we see this happen in the population.

There has been a significant increase in the prevalence rate over the last 20 years. As you can see there from the slide, we've gone from 1 in 5,000 up to - well, in 2005 we were at 1 in 166. The current estimate from the centre for disease control this year is that we see 1 in 150 people who would have some diagnosis of autism.

So what does that mean to Nova Scotia? If we look at the total Nova Scotian population based on our 2006 census, there you see there's 914 - roughly 1,000 people - so we can project based on 1 in 150 that just over 6,000 people would have a diagnosis or would be affected in some way by autism. We did have a look at the population breakdown again based on the census. You can see the preschool age and adult members there and if you apply that statistic, those would be the numbers we might expect to see of people with autism. Again, that projects out to be about just over 5,000, and remember that population breakdown is only to age 64, so we're not taking in the full population.

Those figures we've calculated are based on census and prevalence rates which come from the States. The reason we've had to use those kinds of figures is there's no central location to keep information or statistics on autism and people who are diagnosed - people who are out there in the community. So we have no surveillance mechanism; there isn't anything federally and there isn't anything provincially. That kind of information is so important in order to help us plan for the future. If we had that data, it could help project the needs - our community is growing up and these numbers are really increasing. There's certainly a wave of service that's going to be required and the lifespan needs will not be going away.

So let's take a look at a little bit of information we have around the school boards. In the Halifax Regional School Board, these are numbers we know as of September 30, 2006, according to the Department of Education, so that's the enrolment we've had at those different levels. Again, if you apply the ratio of 1 in 150, we should expect to see 173 elementary students, 87 junior high and 96 high school, for a total of 356 students within our Halifax Regional School Board. So remember that elementary statistic of 173.

[1:15 p.m.]

We do have some numbers that are being collected now within the HRSB. Since 2001, there have been numbers kept of the children entering Primary who are diagnosed with this disorder and you can see the table there of the kids who are coming in. We do know that in total, from Primary to Grade 5, there are 235 students in the HRSB diagnosed with this disorder. Remember I asked you to remember the number that we projected, based on the ratio, which was 173.

We do have some numbers, too, from the Annapolis Valley Regional School Board. Again the breakdown, according to the Department of Education statistics, and if we apply the ratio - there are the numbers we would expect to see, and the projected number would be 102 students. The reported numbers we have been able to get from the Annapolis Valley,

there are the numbers currently in the breakdown of the grades, and the estimated number is 1 in 126. So again, we're over what the projection would be.

In Cape Breton, the school breakdown, according to the Department of Education, is there. If you use the ratio, we would expect to see 111 students, approximately. Unfortunately we are not able to get any data from Cape Breton. Again, there's no central place to collect that data, so we're unable to actually get the proper statistics.

So what does that mean? If you're living with and caring for someone who has an ASD, it really changes the dynamic of the family. One of the things that families say to all of us when they come to us is, when you have a family, when you have your children, you are expecting something. You start to dream about what your family life is going to be like, how your life is going to progress. To be given a diagnosis of this is very devastating to the families in lots of ways, particularly around nobody can really say what the future will hold, and suddenly you have to change what your family life was going to be and change it in many, many ways. Parents suddenly have to take on increased roles: as educators, as advocates, caregivers and financiers. This is not something that is easily managed in a family budget. So advocating is so important to our children.

Unfortunately, because awareness is low and because there's not a good understanding of this disorder, parents are constantly having to explain, to defend, to express what it is to be with these children and how we can best help them.

These roles are in flux; this is not something that we don't say, okay, you're going to look after advocating and educating, and we know that when he gets to this age we should expect to see this. We don't know that, we don't know what the prognosis is going to be. Early interventions really help, there are lots of strategies we can use, but each person is individual and they respond individually. So not every therapy works for every child. You have to really look at the individual and try different strategies to see what works best and see what you can achieve for that individual.

This is not something that goes away, unfortunately. For most families, this is something that continues into the adulthood of the child, and the families must really consider what is going to happen as their family member ages and as they age; we have to think about what we're going to do and how we're going to plan.

What I would like to do now is turn this over to Michelle Gardiner. She is going to talk to you a little bit about some stories and some families that she knows and give you a sense of what their life is like.

MS. GARDINER: Thank you, Vicki. I come here today to just bring some stories from three families in Cape Breton, but I think these families really demonstrate the depth and breadth of what families in Nova Scotia are dealing with when they live with autism. They're specific but we've tried to make them look at age, look at the different issues that come throughout life. So it's very nice to be able to bring their stories and it's an honour.

We're going to start with the Baldwins. We have a picture of them. This is Tracey, Fred and Callum and his baby sister Carly. Callum is three years old and Fred and Tracey would describe Callum as a loving and very cuddly child. Callum was diagnosed in October 2006, just a little over a year ago, with Autism Spectrum Disorder. Some of the signs that led to the diagnosis was that he was demonstrating very poor eye contact, he was unresponsive to his name when called or when you were trying to speak to him. He had no words by the time he was age two, he just didn't speak. He had quite severe sound sensitivities, anything from hearing a crow caw when you are out in the field or in the yard to an ambulance, which would send him into a meltdown, which would mean he just couldn't get out of the fear and frustration or whatever.

He also had a certain kind of behaviour which is called stemming. It is a stereotypic coping behaviour. He would sit on the couch and he would rub his head for, say, 20 minutes against the back of the couch. Or when he was out in a playground he would always be going around the perimeter, so he was always going in circles around the perimeter, rather than being in the middle and interacting.

Callum was one of the lucky kids in this province. He got early, intensive behavioural intervention. He began in June, so it has only been six months, and it is amazing what has happened in those short six months. He has a vocabulary now that includes 80 words in six months; he shows great improvements in his interest in other people now, and he is able to respond much more to his name. It is still coming but it is getting much, much better. He likes to interact with other people. His sound sensitivities have completely disappeared - as his Mom said to me, the crows all went away. She said as soon as she went outside and saw a crow, you were looking for it, right? But now she said we just don't think about it anymore. He has fewer tantrums and less stemming because he is able to deal with his anxieties.

When I talked to these three families, I asked them what they wanted me to tell you. I said to Fred and Tracey, what do you want them to know about your experience? They said, getting the autism diagnosis was absolutely nothing short of devastating; discovering that treatment was available brought, as you can imagine, quite a bit of hope. The hardest part was realizing that Callum may never receive this treatment. The seven months of waiting for an answer was an absolute nightmare for them. They told me, we lived in frustration and fear until the day his name was drawn from the proverbial hat. They want me to tell you that no child in Nova Scotia with Autism Spectrum Disorder should be denied this treatment because there is only enough funding available to treat the lucky few.

The next family I am going to introduce you to are the Mathesons. This is Paula, Donnie and Justin. Justin is nine and he is in third Grade. They live in Coxheath, just outside of Sydney. Justin is a vivacious nine-year old who loves to read and learn particularly about insects. Justin was diagnosed with Autism Spectrum Disorder at the age of six, in 2004. The biggest challenge that Justin faces is his anxiety-based behaviours brought about because of his Autism Spectrum Disorder. Justin cannot deal with any issues dealing with eating, digestion or toileting. His mother can't even use the word "washroom"

because this is one of the many trigger words that will result in a meltdown that could last for minutes or even hours and usually ruin his whole day, if it does happen.

Paula and Donnie and Justin follow an extremely stringent routine that begins from the moment he opens his eyes in the morning until he falls asleep, usually late in the evening, their whole world is just all about regimen.

Justin requires constant one to one supervision every hour of his day. It's like having a three-year-old with the intelligence and strength of a nine-year-old, but no common sense. He is a flight risk and a danger to himself. Justin can only attend school three hours a day, during which is the only time she's away that she can actually work. She has a part-time job, she works at Value Village, she does that three hours every day. He only attends school three hours a day because that's all he can deal with. Because of his anxieties, particularly around food, he must be isolated during recess and must go home before lunch. He can't handle watching other people eat.

Paula and Donnie asked me to be very candid about the situation the family faces. Because Justin has severe reactions to babies because of the diapering issue, Paula and Donnie cannot have any more children. Even taking him into a public place becomes impossible because you can't predict when a baby is going to show up.

I also asked Paula and Donnie what they would like you to know about them. "The hardest part is, we never get a break. We can't leave Justin with anyone because they just can't handle him. Our families can't deal with him. We keep trying unsuccessfully to have play dates but they usually end in an episode. I just wish we could hire someone with training that could take him out, to be a friend; his world is so small. We haven't been out as a couple for seven years now. No movies, dances, dinners or even going for a coffee together - it just isn't possible. We don't know how to relate to each other anymore outside of the context of Justin. We applied for direct family support from the Department of Community Services. We were denied because Justin's cognitive function is considered too high for us to qualify. Basically, because he is intelligent we are not considered in need. We just keep hanging on, but our marriage is failing. We are so busy caring for Justin that it is just hard enough to carry on and not think about ourselves. We use all the energy we have to help our boy. We feel very alone and forgotten by society and we are terrified for Justin's future."

The final story I'm going to tell you about is the Mills family. This is a picture of Reverend Stephen, he's a First United Church minister at St. Andrews in downtown Sydney. His wife, Norma, his daughters Alice and Karen and Gordon. Gordon is 19 years old now, so this picture is a little dated but it was the only family picture they could dig up for me. Gordon is an accomplished special Olympian, he has three gold medals provincially under his belt. Gordon was diagnosed with Autism Spectrum Disorder at the age of two and a half in 1990.

Gordon benefited from an intense day care program to which his parents attribute much of his success. At diagnosis he could only speak two words. By the time he entered school at age five he had age appropriate vocabulary. Gordon did very well in school with supports. He graduated from Sydney Academy in 2006 at the age of 17.

Stephen and Norma began planning for Gordon's post-secondary education in January 2006. A full psycho-educational assessment was completed and Gordon received letters of support from both his pediatrician and his psychologist. Everything just seemed to be falling into place. Gordon was looking forward to attending college to learn more about computers and office software, which he has an aptitude for. Gordon didn't get to go to college as expected because the system wasn't able to accommodate or follow through for him. Gordon was very disappointed, he just couldn't understand why he couldn't go to college like his older sister did.

When I asked Norma and Stephen what they would like you to know, they said not to forget about the adults with autism who are looking to find a contributing role in our society. The only real option for Gordon until he turns 21 was for him to go back to high school, which he reluctantly did. After he is 21 he will be put on a two to eight year waiting list for vocational training. Norma and Stephen wanted me to let you all know that this is only going to get worse - Gordon is at the head of this wave. There's so much more to come as the increased incidence of autism puts more and more stress on all of our systems.

[1:30 p.m.]

So those are my stories. Like I said, it has been an honour to be able to come to you folks and share some of the people that I have the pleasure of knowing. I pass it over to Norm.

MR. DONOVAN: Thank you very much, Michelle. So far we have presented you with an overview of autism, statistics of incidence of autism in our schools and have opened the window on the social impact that autism is having upon our families. I will discuss the economic impact associated with autism.

The costs associated with this disorder are numerous. First of all, we could take a look at the medical costs. This is a list that some, maybe not all people with autism will access, but the one thing I would like to point out here is that each individual with autism should have access to any medical service that they require; that is not the case at present. Some children have allergies, some have diet problems and many children with autism experience severe seizures.

The non-medical costs, however, far exceed the medical costs. When we look at the non-medical costs, you can see they cover all these areas. Talk about special education in the schools with the teaching assistants, many of these children require a teaching assistant full-time, 190 days a year, six hours a day. Transportation can be a problem. We have one little boy in our area who has to use a taxi. His TA picks up the taxi, goes to his

house, picks the boy up, brings him to school, takes him home in the taxi, because he cannot use a school bus.

Child care, respite care, naturally, out-of-home placement, home and vehicle modifications - these are unique to the ASD society. We have one house in our area which is literally a fortress. It has an eight-foot fence around it, double locks on the doors - lock in, lock out. Glass was removed, Lexan was used in the windows. Fire departments just love it when they hear that story. Vehicle modifications. Some of these children cannot use the normal car seat, they have to have a special harness; \$175 for that harness and so on.

Indirect costs - loss of income to that family. Many of the families were two-income families before their child was diagnosed. My son and his wife were one case; she was an RN earning \$60,000 in Ottawa, had to give that up. She could put in a few hours on the weekend to keep her licence going, but it's gone. Others that we know in the Valley cannot go out of the house to work, not possible, they must stay with their children. Along with all that you lose your benefits, whatever you had with employment. You might be able to go to work - as Michelle mentioned - with reduced hours, switching to flexible, lower paying jobs and leaving the workforce, as I mentioned.

You'll notice that we're using a lot of data from the United States. You will find that these studies in your binders, we have to use these because we don't have the data from Canada. Also in the binder you're going to find the Senate report, Pay Now or Pay Later, that was issued in March of this year. The Senate committee recognized that money spent in early intervention will save considerable expenditures in the future. I recommend this study to you; it's well done.

There is a small window, when the child is between 2 and 6, when intervention provides the most benefits. This has been recognized by the Department of Health with the Early Intensive Behaviour Intervention Program, or EIBI as we know it. Right now \$4 million per year is providing limited treatment for approximately 60 children, and we certainly thank this committee for initiating this program three years ago. However, we need this program for every single child in Nova Scotia, not just 60.

The children who do not receive early intervention require full-time teaching assistant support during their entire school career. Some of these children stay in school until 21. The cost of a TA support alone is approximately \$220,000 in Nova Scotia per child. This slide gives you some idea of the costs associated from the preschool, school-age, right through adulthood. If you'll notice, the estimated lifetime cost for an individual who has not received early intervention, according to the United States, is about \$3.2 million. Remember the figures we gave you earlier of over 6,000 Nova Scotians - it's quite an expensive proposition facing us.

The significant costs required to support an individual throughout the entire lifespan, we're talking from birth to death for some for these individuals, under the care of the government. The families try to support but they can't do it - \$3.2 million, not a hope.

Often the services of the day or residential service provided is required. You start talking about residential homes now.

It increases the cost of caring for an individual with ASD significantly at this point. Looking at these costs, a person with a high level of need, it's about \$200,000 a year and lower level, about \$140,000. These are U.S. figures now, because we don't really have them for Canada. When you project that ahead, \$18 million for one person over the lifespan, or \$12 million. This is for individuals who do not receive intervention, it puts a significant pressure on our social support programs - health, education, community services - tremendous pressures coming upon you. However, with appropriate interventions, these costs need not be so extreme, and this is really the point we have to make here.

I've painted you a very dismal forecast, financial forecast, but it doesn't have to be. I'm going to tell you the story about my grandson. He was diagnosed at 38 months, severely autistic, failed every element of the diagnostic test. He commenced very intensive intervention at the age of 41 months. He got between 25 and 40 hours a week during the first year; the second year it was reducing down to about 10 hours at the end of year two. At age 61 months he entered the school system, no TA required, no extra school supports requiring financial expense. He travelled on the school bus by himself.

The financial cost for his intervention was \$47,000 for two years, of which the Ontario government contributed \$26,000. What a bargain for the Ontario Government. What a bargain for the Ontario taxpayers.

I expect that my grandson will be a taxpayer and not a tax-taker. Before we Nova Scotians can plan and institute a system that will allow our people with autism to become taxpayers and not tax-takers, we need to conduct a census of our population to determine the extent of autism throughout this province and what is required to provide the necessary treatment and supports.

We submit, for your consideration, our community needs. Today, we call upon you to put forth a motion to call upon our government to form a working group that will address the lifespan needs of individuals and families affected by ASD. The idea of this working group is not unique. In your binder, you will find the Chronic Pain Working Group report. Their recommendations were accepted and we now have chronic pain clinics established throughout our province. Let us do the same for our people who are living with the challenge of autism. Surely we can do no less for these faces that you see appearing before you now. We thank you for your kind attention and we welcome your questions.

MADAM CHAIRMAN: Thank you, Vicki, Michelle and Norman. I think I have to say on behalf of the committee, that's been one of the best presentations that I, personally, think the committee has heard in a number of years.

Now mind you, we gave you a lot more time than we usually give groups, but that's because we had three organizations represented here today and so we multiplied our usual

10 minutes by three-plus. The information you provided is excellent and I think it's going to be a good basis for a bit of a discussion. I'd like to have that discussion and some questions before we actually put any motion on the floor. So thank you again, you are very able advocates for your children and for all families suffering from this spectrum disorder in Nova Scotia. So we really, really appreciate your frankness and the time and effort that you put into your presentation. Thank you so much.

Who would like to start with questions? Yes, Keith.

MR. KEITH BAIN: Thank you very much, that certainly was an excellent presentation. I listened to Michelle and I was able to meet Gordon Mills just last week, as a matter of fact. I guess I had a special interest, because I have a niece who has a son who is also autistic. It provided the opportunity for Gordon's mother to speak to my niece and I think that, in itself, is a great relief to families out there, having someone else to talk to, and I think she has offered herself at any time that my niece has problems, to give her a call. So I think that's part of the right way to go.

I just have a few questions based on the information you provided us. The early intervention, Early Intensive Behaviour Intervention Program - that's quite a name . . .

SOME HON. MEMBERS: EIBI.

MR. BAIN: Maybe that's what I should be using. It's only a couple of years old, but I wonder if you could comment on the success of the program.

[1:45 p.m.]

MS. HARVEY: The success of the program - it was really for families. It was such a godsend in so many ways to hear that there was going to be some kind of program to address those early intervention needs, because certainly research has shown that early intervention is very key in helping individuals with this disability achieve potential, move towards potential.

The strength of this program has been that it has been done very carefully. Lots of research went into what would be the best approach for the most children and remember, I did say earlier on that not every intervention works with every individual, so we really have to think about what strategies we're developing. So there was a great deal of research that went into what type of therapy to put into the EIBI Program and then there was a lot of thought around how we effectively create capacity, because that was a key component here.

Prior to EIBI coming in, there wasn't capacity within Nova Scotia to provide supports around some of the gold-standard strategies that are out there, so there weren't people trained to effectively deliver those supports and those strategies. So part of EIBI has been to train people - train the trainers as well - so that we can gradually build that

capacity up, and the intention is that eventually we will be able to provide to the children that are there.

What we're running into now - and there has certainly been some wonderful success. I know that there is a document just out talking about the first bit of research that has been done, I think it's on the first year of the program - there was a release that the Department of Health just put out. Part of the issue though is that the pot of money we have right now is limiting. It is providing, we are developing, but putting more money into this would help that program to grow more and would help the families that currently are not accessing services and perhaps won't.

This service is provided to children up to the age of six. Once they're heading for the school system, they do not get access to this program. Right now, this is a lottery-based program. Your name is put into a hat, is what happens, and you hope that your name is the one that's pulled out. This is given to the children for one year only. Part of the strength of the program is that it is training the families to use the strategies themselves, so they're trained in pivotal response therapy, which is the main therapy that we're talking about here, hoping that the families will be able to continue that as the therapists are gradually phased out and that it will translate over to the school as they get older. So there are lots of wonderful strengths to this program - we were really thrilled with the fact that government has stepped up to the plate to do that. The glass is half full here. What we want to do is we want to top it up.

MR. BAIN: Thank you. I had another question - and you answered it - as to who determines who participates. It is a lottery, I guess, is basically what you're saying.

MS. HARVEY: It is a lottery, unfortunately.

MR. BAIN: So in this program is there training and support for the parents as well?

MS. HARVEY: Yes. This process is a very naturalistic process, so the interventionists who are assigned to the family start off by coming into the home and talking to the families, getting to know the child and following the lead of the child, so looking at what the child is interested in. What you're trying to do with these early interventions, these kids are lacking in lots of skills, skills that typically developing children would learn naturally; they have gaps, they learn differently. So what you're doing is assessing what those gaps are and then you're trying to address, how do we teach that to them?

This particular approach, as I say, is done sort of within the home or the day care setting, or whatever is conducive to the child's learning, and the families are active participants in the program. They are trained, as well, by the interventionists to come in and to learn how to apply the techniques so that the child, even though they're getting the intensive piece of it for roughly 15 hours a week to begin with, that gradually decreases, the family is gaining the skill to be able to apply those things throughout the day.

MR. BAIN: I'm sure there are support groups out there for parents of autistic children.

MS. HARVEY: All of our organizations provide support groups for families.

MR. BAIN: I guess my question is, what about participation in these support groups by the parents?

MR. DONOVAN: Well, I could speak for the Valley. We have 30 families in our support group and they have 33 children on the spectrum. Basically it was started back in 1995 by mothers wanting to talk to other mothers saying, what's going on, why me? In fact our founding member is Linda Ettinger over there - she started this in 1995, and it's still going. So that is our support, and we try education programs and discuss strategies that people have found worked or have not worked.

MR. BAIN: I guess it's gone circle, is what I mentioned before. It just happened that my niece met Norma Mills and . . .

MS. GARDINER: I would say that's where 90 per cent of the support in this province is coming from - it's one to one, it's meeting with somebody. We found support groups in Cape Breton very tricky business. I had a support group meeting we called a month ago and I had three people show up, one was my sister and the other was Erica and Erica's father, so you know, we weren't getting the response. I think there are a few reasons for that. I think one is that as you go through what we call grieving for the normal child, your needs change and because of the nature of the spectrum, the broadness, people have very different experiences. Plus, as they age, different things come forward.

Often we'll get a group of parents - it seems like the ones who start to congeal are the ones that are with 9- and 10-year olds and then through the teen years, but we have all these families who are in most need when they're just diagnosed and we're having a hard time reaching out to them. Often, you'll have some step forward that come to our meetings and quite frankly, we scare the heck out of them because they hear our stories and here they are in a roomful of war veterans and they've just walked in. That's why we're really, as a society, trying to figure out how we're going to deal with support.

It's very difficult for people to get their heads around this, they blame themselves. We're talking about people who are moderately educated. I really worry about the poor children with autism, with the parents who don't have the coping skills. I fully expect at some point to wake up in the morning and find - and this sounds horrible - the front page with a police car and I can tell you which houses it might be where a mom or dad just lost it because they can't deal with it. The doors are locked, the plexiglass is on the windows, they don't know how to help themselves. It's that these people are socio-economically challenged and sometimes intellectually, as any part of society is. That's what I really worry about right now.

I often caution in community development - and that's what we do in support groups. It's very easy to preach to the choir, to the keeners, but I think our biggest responsibility is to those who really can't speak for themselves - not only the children, which are the most vulnerable, but the families.

MS. HARVEY: I would also like to say within the HRM, we now have two chapters of our support group. The Halifax one is a little more sedate, and that's where we tend to bring speakers in, but the Sackville-Bedford group is just a going concern. They have loads of people coming in and they seem to have found a trick to really support families in a very comfortable way, so we're really excited to see that and we're hoping to branch that out into the Dartmouth area.

MR. DONOVAN: On the other side, the areas where there are no support teams, during this past month, October was Autism Awareness Month, and we put on displays in various areas up and down the Valley. I was at Tools For Life last week where they had a display. I met families from one end of this province to the other and the ones that really got to me, a family down in Shelburne County, all by themselves, no support, no help, didn't know where to go. I met a lot of families that have adult children and this is the one that really bothers me, the adult children are still at home: 21, 28, and 32 that I can think of right now.

MR. BAIN: Thank you, Madam Chairman. I'm sure there are lots of other questions.

MADAM CHAIRMAN: Pat and then Leo.

MR. PATRICK DUNN: Thank you for your presentation. I had the opportunity, and I'm sure my colleague who has been in education for many years, to be introduced to children in the school system with autism. Michelle, you mentioned earlier in your statements about finding it very difficult to obtain data. Were you referring generally across the province or within the school system?

MS. HARVEY: Generally across the province. You know we have some limited figures we can get through the school system, as we showed you. Throughout the province, we can't - for instance, we can't go to the IWK and say, what are the numbers of people you've diagnosed? There's a privacy Act around that.

MR. DUNN: I know the data should be available, certainly within the school system, because of guidance and special services intervention within the school. They certainly - at least my understanding and experience has been that within the school system itself we certainly have that.

Another item, like dealing with inclusion within the school system and so on, I find that there needs to be more training, awareness. I mean we certainly have our EAs - formerly TAs - who work with a variety of children and so on, but do you know if there's

any move afoot within the training of teachers at the university level, the two-year program, where special - you know, there are specialists coming out, but I'm talking about the average teacher who is teaching classes in our school system, are they receiving any training in the programs now?

MS. HARVEY: I'm wondering if we could ask Kym Hume just to answer that first, and then you could . . .

MADAM CHAIRMAN: Certainly, we just ask others to step up to the mic so that it's recorded for Hansard.

MR. DONOVAN: Kym Hume is the autism consultant in the Annapolis Valley Regional School Board.

MADAM CHAIRMAN: Thank you. If you could speak right into the mic.

MS. KYM HUME: Am I close enough?

MADAM CHAIRMAN: Yes, it doesn't amplify but it records.

MS. HUME: Okay, great. Your question was, training within the school system - I think you had two questions there.

MR. DUNN: Well, one was teacher training at the university level and the education degree.

MS. HUME: I can talk a little bit about that. At this point there is not. Of course our universities that are preparing teachers do have special ed components within their training, but they do not have specified courses on autism. There are some universities outside our province that do; the University of New Brunswick offers a full program on that and they're seeing some really good successes with that. But within our province there is not, which would be a goal that I would like to see at some point.

The statistics that we talked about earlier are actually misleading in a way. If we had more psychologists in this province, our statistics, the numbers of kids would be quite a bit higher than what the actual diagnoses are. We have children in our school system in the Valley, for example, that I know have autism but they've not been diagnosed. The waiting list to get in to see a psychologist is so long that they just are not diagnosed, so we put supports in place anyway. But the statistics that I presented for this presentation, there are more kids than I was able to show because I can only show the kids that have a diagnosis, I can't show the kids that I know have autism but don't have a diagnosis. So that at least answers the question about the statistics a little bit and also about universities. Do you want me to go on with the school training issues?

MR. DUNN: Sure, please.

MS. HUME: The Department of Education has really put a lot of emphasis on training in the schools around the issue of autism. A number of years ago, way back in 1995, at Annapolis East Elementary School in Middleton where I was the vice-principal at the time, we had a large number of students with autism come into our system. There were lots of reasons for that, but we had lots of kids. We had no choice but to learn what to do, because we were really floundering and we had a huge population - it was an atypical population of students. So we became trained within that school by going to Division TEACCH in North Carolina, and I was there and had quite a bit of training at that time.

Since then, of course, we've seen the population of kids with autism just grow unbelievably so that in our little district of 16,000 students, we have somewhere around 135 students diagnosed. We know there are more and we know every year we bring in around 15 students - a year - who are diagnosed. There's always another five who come in who are not diagnosed, because they never got into the right queue to get the diagnosis. So we're looking at roughly between 15 and 20 every year now, and that's just in our district. So if you multiply that with the really large districts like Halifax and Cape Breton and so on, there are an awful lot of kids coming into the system every year now.

[2:00 p.m.]

The Department of Education, I think, has done an admirable job of recognizing that, to the point where they have funded positions as autism consultants, which is the position I hold now for our school board. Most of the boards have designated people and that's their responsibility for their board. They also designated a position at the department level and Lori Logue is our autism consultant at the department level.

I sit on a provincial working committee called PIAT, as does Vicki, and I think Jo-Lynn Fenton is there as well. What we do is, we're an advisory group as to what the training needs are around the teachers in the classrooms to support students with autism, as well as the EAs and what their level of support is, to even our school psychologists and our speech language pathologists, who also require that level of training.

To date, we've done a number of intensive training programs, the newest one being the STAR program. It's an intensive behavioural program that we've initiated and we just started last year. We had Dr. Joel Arick, who is the creator of the program, from the University of Oregon, come and do training with each of the boards. We all came to Halifax and had training. We've had ongoing training with him for two years now and we've had a lot of success with the students who we've started on that program. It is intensive, though, I can tell you. It's not the whole day of every student with autism, but it's a good proportion of the day, because these kids need intensive programming - you can't waste time with them. You have to use every possible moment you have to be teaching these kids, because they need that time.

That's one thing we've done and that's been very successful in our board. I can't speak to all the boards, but I do sit on this committee and everybody is saying the same

kinds of things, that we're very pleased with the STAR program. What we need is more people like me, to be able to be out there training, because there's only one of me and I depend a lot on my speech language pathologists in our board to help with that training.

One of the other things the department has done, and credit to them, is we've brought in a couple of folks from Division TEACCH, which is at the University of North Carolina, which is a level one research station and known as really one of the premier places in all of North America with successful strategies around autism. We have - and this speaks to the other end of the spectrum, so this is why I'm very pleased about this, because my worries right now are the kids who are in middle and high school. This big bulk of kids that we're talking about, they are coming up and they are sitting in middle level and high school right now, and most of my time is spent now in middle level and high school because I have teachers and EAs who are just now learning about autism. It's a real struggle for middle level because it's very different from elementary, as you probably know.

The two new things that we've done with the high school levels is some training on something called the TTAP - the TEACCH Transition Assessment Profile - which is an assessment that we would use to assess the adaptive skills or the abilities for students at the middle level and high school, in preparation for transition to community.

The other program that we've been training on just recently is called The Factor, which is teaching functional, everyday routines. So we've done that with our middle level and our high school. So we've moved in that direction of seeing that, you know, we've done an awful lot of really good work at the elementary level around the province - not just in our board, but around the province.

Is it everything we want? No, it's not, we need sensory rooms in all of our schools. All of these kids, for the most part, have sensory needs that you cannot ignore, because they'll let you know if you do, and you need to have those supports in place. Yes, we really need more of that. We need more of my role, for sure, there's not enough of me.

My main concern, really, is at the high school level. We have a number of students who never had the benefits of early intervention. They've had good, supportive school program planning teams, but now they're in high school and what's really kind of sad is that we're teaching them really good work skills, we have them in work placements, but when they leave our system there's nothing for them. That, for me and my life's work, is demoralizing. I'm looking at these kids and I'm thinking everything that I know they can be and do might stop as soon as they leave us, because most of them stay with us until they're 21 and to go from there to the community is the next big step.

I'm thrilled to be able to say to this committee that this is the area where there is a huge need around the province. Living arrangements, supported living, as well as work placement in their own communities so that they're not having to move out of their communities and live in residential areas away from their families, like other children.

MADAM CHAIRMAN: Could I ask you to repeat your name and your position within the school board just for our recording purposes?

MS. HUME: Yes, I'm Kym Hume and I'm the Autism Consultant for the Annapolis Valley Regional School Board.

MADAM CHAIRMAN: Thank you.

MR. DONOVAN: To follow up on your question, if you create this working group we would sincerely hope they would get all the statistics, the numbers that you're looking for. They would, I hope, take a look at what Kym Hume is doing in the school system and try to cost it out, because remember I gave you figures from the United States and the school costs seem really high. When you think of what Kym is doing, you can see the costs starting to go up and up because of all these new things that she's bringing in like the STAR program. I would hope the working group would take a good look at that and say, yes, we need this in every school and this is what it's going to cost.

MS. GARDINER: I'm from Cape Breton and I'd just like to note that I became President of the Autism Society of Cape Breton in 2001 and it was because I had a real grievance with the school board. I have to tell you as president, since then and today, I never would have thought we would be where we are today. Our school board in Cape Breton has done amazing things, they've spun straw into gold. They have a coordinator similar to Kym, I'm very proud of them.

The conditions my son went into and the conditions he went into in junior high, I was terrified of him going to junior high. I just thought he's going to get lost, because we're not going to have what we have at elementary and they're doing it, they're doing it in Cape Breton. My concern in Gordon's story is, we have a youth program and our kids get together once a week, there are about seven kids in the program. We parents leave them with volunteers and a coordinator that we have and then we all go to Tim Hortons and chat. Of those 10 parents, nine of us fully expect our children to go to college, we expect that there will be a place perhaps at community college for them. Gordon's story tells us there's not, so there's obviously a gap here whether the parent's perception is not right or whether we're not somehow accommodating, but this wave is coming.

Right now you're just at the beginning, but we're going to go here and hopefully with early intervention we're going to see the bottom. My son is right in the middle, I'm terrified for his future. He wants to be an engineer and I can't tell him he can't be and maybe he won't be, but in Grade 8 I'm not going there right yet.

Anyway, I just wanted to say that and that I am proud of our school board. I'm not saying we don't have issues, but I think we've come a long way with very little and I get less and less calls every year from parents.

MR. DONOVAN: In preparing for this presentation, we tried to get information about the community colleges - we couldn't get anything. There were two aspects to the community colleges. What happens to the child who has autism, who finishes high school and wants to go to a community college and is capable but needs some support, i.e. a TA? We don't know. The other one is the community colleges should be training the autism support workers to enter the EIBI program. I would really hope that this working group would get into that area and find out what's going on - why aren't you doing it, what can we do in the future?

MADAM CHAIRMAN: We will get to a discussion of the working group, but I'd like to at least have one go around of questions before we get a motion on the floor. Just be patient. I will move on to Leo.

MR. LEO GLAVINE: Thank you very much, Madam Chairman, and certainly to all presenters - of course, Norm I know very well personally - just a fabulous presentation today. I know there's quite a bit of expertise actually in this room and I'm not going to quite let Kym off the hook here yet.

Being introduced as a consultant for the AVRSB, yes, is her current role, but Kym in many ways has been a pioneer in this field at the Annapolis East Elementary School. When she talks about an atypical population in our area she, in many ways - I guess we'll say - is to blame, or is responsible. Actually, military families started asking for a transfer to Greenwood because of some of the positive things, some of the early initiatives that were taking place at Annapolis East. I knew there were some things going on, but it was actually during my first campaign that I went to five homes on the base, three had autistic children, and it was because of some of those early things that were going on.

Kym, I have one question for you. We know that there's certainly a vacuum, if you wish, at the junior high and high school in terms of giving a full program to children, perhaps not comparable to where you are with the STAR program. What are some things that are being done? Could you give us a few examples of things at the junior and senior highs that hopefully will keep these children in school, engaged, and to be able to be on a continuum of learning and dealing with really their life sentence of autism?

MS. HUME: I think that one of the things happening now that would not have happened before the position that I hold existed, and my position now is only in its second year, so it's only been the last two years and before that as coordinator of student services and the principal of a school, I kind of tried to do both and couldn't. Now with the number of kids, it would be impossible.

So fortunately having a dedicated position, Leo, has meant that I'm able to go into the schools and have a group of teachers together and meet with them - particularly a program planning team, which is the name we give for a group of people who surround that student as they move through school. So it would include the classroom teacher; the resource teacher; the parent - pivotal without the parent, we don't meet without the parent

there at the table; generally the EA, if the EA is there, we always invite the EA to all of our meetings; and the administrator of the school. So meeting with those teams I think, Leo, has been a huge step forward in helping teachers understand autism.

It's really hard to program if you don't understand the syndrome, because this is not like the other disabilities I've ever worked with, it's different from the rest. So having the position and being able to go in and give individual support to teachers and teams has been one thing, and I've done that all throughout the schools. I've done specific in-services aimed just at middle level and high school resource teachers, because they're the ones often that have responsibility for these students on their caseloads. So they're the ones who have a lot to do with preparing materials or delivering resources to the classroom teacher, so a lot of that kind of training has gone on.

For example, I've done a lot of work at Avonview High School, because they have a number of students there. I've done in-servicing with the staff there and it's one thing that has happened in the last couple of years that would not have happened before, so that's one difference. Of course, the Factor training and the TTAP that I referenced earlier, those are two things that are specific to autism. However, the thing about autism strategies is that they are highly successful with other children who have developmental disabilities, all the kinds of visual strategies and supports and routines that we put in place have been really helpful for many, many of our other students. You'll often find that teachers will say, you know, that would really work with so and so, and so and so, so a lot of good teaching strategies have come out of the research of autism.

MR. GLAVINE: Thank you. One other question, if I have time. This is going to be for Norm or somebody here. Thank you very much, Kim, I appreciate that.

One of the real missing pieces still for Nova Scotia, and really for the country, is a national strategy. Denmark is in the process of developing a national autism strategy and the United States has a five-year research plan with millions of dollars being put into it, \$945 million to be exact, almost \$1 billion. Two bills have been introduced in the House of Commons, but they really haven't brought the results that we need. I was wondering if you could give the committee a little bit of an idea of where that is, where things are nationally and also, should we be playing an advocacy role, as members of the Legislature, to try to push all Parties and all MPs to embrace a national strategy?

[2:15 p.m.]

MR. DONOVAN: I think when you look at Nova Scotia, when all the data comes in and you realize the funding that you're going to need, we're going to have to go to the federal government. If we had a national strategy, it would make life much easier, it would open that door.

We don't have one. We have tried time and time again, and I really think it's up to the provincial governments to put the pressure on the federal government to come up with

a national strategy. I think Nova Scotia could, if this working group was formed, come up with a gold standard for the rest of the country. We're small enough, less than 1 million people. We can access the data, come up with a plan and say look, this is what is required, this could be done across the country, and put the pressure on the feds to come up with a national strategy. Vicki, would you like to comment?

MS. HARVEY: I would like to just - actually I might just invite someone to come up for a moment to speak. There has been some movement in the federal level to look at a national strategy and that has been called for by a number of organizations, federally, within Canada.

We happen to be lucky today, because we have Jo-Lynn Fenton here who is Past-President of the Autism Society Canada and she was present when Tony Clement actually made some announcements in November of last year. I'm wondering if you might just come up and speak to that.

MADAM CHAIRMAN: Again, would you mind repeating your name and your position. Thank you.

MS. JO-LYNN FENTON: I'm Jo-Lynn Fenton and I am a parent of two individuals on the spectrum and I'm Past-President of the Autism Society Canada and I'm Past-President of the Autism Society Nova Scotia.

I guess where we run into problems when we try to move forward towards a national strategy, our community is really fragmented and without gold standards and without really good systems to support interventions and supports and accommodations for individuals, as Vicki pointed out, not every intervention works for every individual. So when you set up a system, you have to make sure that your system is really holistic and some of the bills that have come forward have been more narrow in scope. I think that has been one of the issues that's kept them from being able to move forward.

Where you're sitting right now again, without the surveillance mechanisms in place and the ability and research to know what types of interventions meet certain gold standard levels, because obviously we don't want to just throw our money at any type of intervention, we want to say okay, here are the interventions that we know. We know that most interventions that employ the strategies of ABA - or applied behaviour analysis - are good strategies. They are made up of a number of components, one of which would be Lovas ABA, which is a discreet trial format, and PRT - there are lots of ABA-based programs. However, are they the only types of interventions that are going to work? Some kids need different types of things; maybe more pragmatic social language, things like that.

There needs to be some research done and there is a symposium happening later this week that the Minister of Health called for last year. He's bringing together all the Canadian researchers and they're going to sit down and talk about what types of interventions might we need or should have in a strategy that might address the national

issues. But again, we're talking about lifespan, not just simply interventions, because we need supports, we need accommodations for this spectrum of disorder. What one person needs at this end who has maybe significant cognitive impairment, and someone at this end who maybe has some social eccentricities but can go on, like Temple Grandin, and develop cattle slaughtering and handling facilities and can do all kinds of really wonderful things, but still needs some supports and accommodations to get through her day.

So how do you marry those things together - that's why I think we need to sit back, look at it and say, right now autism hasn't found its rightful place in health, education or social services. We need to figure out what components we need from each one of these departments or divisions to help us move forward, and that's an integral component of the national strategy.

MADAM CHAIRMAN: Thank you very much. Trevor, you're next.

MR. TREVOR ZINCK: Thank you, Madam Chairman, thank you to all the presenters. I can tell you today that in October, and mostly on the U.S. stations, there was a lot of coverage on the topic; a lot of celebrities who spoke, in particular with Larry King on CNN. So it was interesting to get some feedback on how they were dealing with it.

One of the recent studies that came out in the U.S. was the emphasis being put on early intervention, and not to dispel those adults and individuals in junior high and high school, 21 years of age, but in particular the emphasis that the United States Government - or the push that parents are putting on the United States Government - to have some early intervention stressed. I think here it would have to be initially a ground root foundation building situation that we would try to perhaps have the working group implement.

I want to talk about the EIBI Program, to start with. It began in 2005 with, I believe, 27 individuals. Norm, you had made mention of 60, is that where that program is now?

MR. DONOVAN: Right now.

MR. ZINCK: Right now. Have any of the organizations been alerted to potentially how many more people will benefit from that program in the upcoming year or in the years to come?

MS. HARVEY: Well we haven't really been given firm figures on that. Certainly each year they try to find more interventionists, train them so that they can take on more children, but that number is going up very slowly.

MR. ZINCK: And that's due to the fact that they don't have people to train?

MS. HARVEY: Right.

MR. ZINCK: Or they don't have enough people trained. (Interruption)

MS. HARVEY: Or the money, thank you.

MR. ZINCK: So it is capped at \$4 million, okay. I can tell you I've got one constituent who was very fortunate to have the lottery ticket drawn and had her young child put in it and Teddy has benefited. However, there were some early frustrations with the level of care that he was getting, the training in particular. So there are still some concerns. I have to agree, 60 is a very minute number, compared to what we're dealing with and what families are dealing with.

Michelle, the presentations on the families - I mean that's really where it's at, for us to discuss this and support it, actually getting out and visiting with some of these families and hearing their stories. Unless we're affected by an individual, we can't really speak to it.

Back in June, I had an opportunity to go to the Valley and visit with what I thought was going to be just the executive director of the Valley Child Development Association. What happened was, I walked into a meeting where they had all their staff and they invited all the parents, or at least six parents who showed up, and four of the six had children who were autistic. To hear the presentations and how much they benefited from that program, it was just amazing. The fact that somebody would go to their home and support them and help them and teach them at that point and the early stages where a lot of people don't know what to do, don't know what's out there - they had really benefited.

However, the frustrating part for the parents and the executive director was the level of funding that we do put into that program in particular. It services and crosses over many different parts of the province, so there are a lot of people who could benefit from it.

Not a lot of people know about it and one of my points to them was, geez, what if they knew how many parents were benefiting from this program? We'd have a big problem because more people would want to be part of that. So I think that's part of the challenge that we would have to take on.

It is kind of like fighting crime now - we want to deal with the grassroots problems but we can't forget about the criminals who are out there doing it now. With autism, I think the early intervention is key in the process of saving money in the long run. However, I don't want to forget about the individuals who - because they deserve the dignity and the respect to go on and have something in their future, instead of just staying at home because parents get older, too. That's a lot of what we hear - that I can no longer care for my child with special needs. Where are the programs, where is the funding to continue on, to allow that person to have that dignity and respect and to go on and have a decent life?

I am confident that we, as a committee, would support the efforts if we can go on. I think it has to be the continuum because you get to the age of six and a parent has to deal with their child going into the school age with teachers and boards and if we don't have the support there then they run into a problem again, then at the junior high and the high

school level, and all of a sudden they're out in the real world. I definitely would support some sort of continuum of services, for sure.

MS. HARVEY: We really appreciate that. It wasn't mentioned at the beginning - I am also the parent of a child with autism and my son is 16, he'll be 17 in January. He has entered high school. We have been extremely lucky - he's very high functioning and we've had really excellent support through the school system - but I am looking forward to what is going to happen when he leaves the school setting. Your son wants to be an engineer, mine wants to be an archeologist. His special interest is in mythology and dinosaurs and that kind of thing and I have not actually got to the point where I've said to him, because he's not going to go to university, he can't, what is going to happen to him? What is going to happen to us? We have been struggling trying to figure out how we will plan and how we will accommodate everything for him as we grow older and he grows older.

MR. ZINCK: But you shouldn't have to tell him that he can't be anything, you know that? That's the difficulty.

MS. HARVEY: No, you're right, I think that's why I haven't yet.

MR. ZINCK: That's the difficulty. Don't tell me I can't do something or can't be something because I'll prove you wrong and some of these kids that are benefiting from the supports, they're growing and they'll want to go on . . .

MS. HARVEY: I can't believe - I'm sorry to interrupt you - my son is doing English without support. He does have a program assistant with him all the time - a teaching aid - but he's doing the regular curriculum with adaptations. He is not on an IPP for his English, for his language. I am astounded, I am thrilled, I never expected to see that from him. So yes, we shouldn't shut off that valve, we should always expect the most we can from everyone.

MS. GARDINER: And they can develop throughout life. Most of us develop until we're 30, our brains stop growing - some of us at 40 (Laughter) - but Dr. Susan Bryson told me there are people who couldn't live independently at 50, but by the time they were 55 they were living independently, so the development continues. When I spoke with someone in the community college system about this yesterday I said, we have to think about that, because they love the term lifelong learning and that's kind of what we're talking about, too.

I still haven't come to terms with the fact that he's not going to be an engineer and I don't know if I'm realistic or not and that's kind of part of it, right?

MR. ZINCK: What we need is a system that would actually allow all individuals to have that opportunity, not to come to a situation where they're being told, well we didn't think about that, there's nothing in place. That shouldn't be the norm - opportunities should be there.

MS. GARDINER: And educational institutions - pardon me, I'm sorry, they're not just about granting degrees and diplomas, they are community-based institutions. I know the president of CBU spoke at an awards night at Sydney Academy last week and that is one thing he spoke of, that it is really important that our educational institutions serve our community in more ways than just granting degrees and diplomas. That is where I think maybe autism could fit in this and if we had the working group perhaps they could help them find their way.

MADAM CHAIRMAN: Thank you. Len.

HON. LEONARD GOUCHER: Thank you. I guess in light of the time, Madam Chairman, I'll try to be very brief. I have a nine-year-old grandson as well and he has his challenges in life. One of them isn't autism, but I have friends, some of whom I worked with, some of whom are acquaintances through my work who have autistic children, some are more severe than others, as you say. I couldn't even imagine what it would be like and I don't even pretend to sit here and try to imagine what it would be like. I have been in the classroom with my wife as a volunteer in her school dealing with a couple of situations with autistic children with TAs and even at that it can be very difficult at times. One poor little child has a multiple issue of hearing and sight as well as being autistic - a wonderful little fellow.

[2:30 p.m.]

I was watching a program the other night and the number that was bantered around was one in 140 for autistic children which is about the same as you have, but it still seems to be going the wrong way. I guess my number one question, Madam Chairman, which was answered was the whole issue of diagnosis and how many young children are walking around right now and somebody is thinking they are ADD, like I am. I'm ADD, but I didn't find out until quite a bit later in life because they didn't know what they were dealing with when I was a child, they thought I was very different, and I was. (Interruption) Yes, still am. (Laughter) But I don't mind saying it, that's life and I just wonder how many young people - because autism, I don't know how else to put it, is something that people are finally starting to realize is there and diagnoses are going to start improving.

I guess my question was already answered, we really don't have an answer for it, as to how many young children are out there with this affliction, but really being diagnosed with something else, or parents thinking it is something else. I guess that brings me down just to a question. I look at MS and I look at Lou Gehrig's and some things and I've had a little brush with that myself at one point in time, while that was a different diagnosis, but the Province of Nova Scotia at times with MS and Lou Gehrig's is significantly higher than many areas in North America, probably one of the highest, actually. Are there any regional disparities with autism in Canada and even more specifically within the Province of Nova Scotia and forgive me, is Cape Breton a higher area of incidence than say, the Valley or the southwest part of the province, or even Halifax?

I know you may not be able to answer that and just one other quick comment, too. It really worries me about your data, the whole issue of data collection and being able to substantiate a lot of this because it must be very difficult for you, but I'll leave that for another time, but just with regard to the issue of autism with regard to regions?

MS. GARDINER: I think you went right back to data and I guess that is what it is based on. We don't have data.

MS. HARVEY: We can certainly speak to - Dr. Susan Bryson did a study back in 1988, because there certainly seems to be pockets somehow of areas around the world actually where we see perhaps a larger incidence of autism for whatever reason. When she did that study - which was internationally recognized - there seemed to be pockets within Cape Breton in particular where all of a sudden, there seemed to be quite a number of kids and so she did a whole research piece on it. There have also been things in the news, particularly around Silicon Valley in the California area - why does there seem to be all of a sudden more kids with autism there and what is the function?

Again, I think that goes back to why does autism occur? Is it a genetic component? Is it something that is environmental? Is it something that just hasn't been well recognized? We don't know and if we could answer those questions we might be able to figure that out.

Whether that is still the case now, that Cape Breton seems to have a pocket, I think that across the province we all seem to be hitting those prevalence rates that we quoted earlier.

MS. GARDINER: I spent a fair amount of time as Chair of the Health Studies Working Group for the joint action group looking at the cancer issue in Cape Breton and it was like trying to herd cats. When you start to talk about these kinds of things, it is a very delicate business. I mean the cancer thing - I still walk the streets of my community and am told on a daily basis that we have an increased case of cancer. I spent three years as Chair of that working group and I never saw any evidence of it simply because the right questions, in my opinion, weren't being answered, but that is the stuff of folklore. I think that is what we need to really take a look at what is going on here and if there are pockets, well let's not talk about why, let's talk about what we can do. I'm not interested in knowing what has happened anymore in my world, I want to know what I can do to help us tomorrow and those coming.

MADAM CHAIRMAN: Thank you. Gordie.

MR. GORDON GOSSE: Thank you, Madam Chairman and thank you for your presentation today. I can go on, I guess, and say that everybody has a tie to autism, but I have an adult son who is 31 years of age who is epileptic and severely mentally challenged and back in the 1970s and 1980s, I didn't have the support or anything else - I had my family's.

I'm pretty well aware of most of the programs out there. Being elected as an MLA for the last five years you get a lot of calls and one of the main calls I get - and I pretty well know everybody in the autism group in Cape Breton. I've been to every one of their functions over the years, I never miss it and I've actually taken my son to some of their walks and other stuff, too. The reason I say this today is that I have some questions I would like to see if you guys could answer for me in a sense that when you did your presentation earlier, you talked about direct family support, the cognitive ability based on the child. Now the most complaints that I get as an MLA is that the cognitive ability - they're refused and denied direct family support because of that ability, but when I go to the home and I see the child and his interacting with the family and everything else, I'm saying God, if that child doesn't need direct family support, what am I seeing here? So to have somebody come in, I would like to know what the policy is in the province. Has anybody seen the policy in the Province of Nova Scotia to deal with direct family support?

MS. HARVEY: There are certain criteria that the Direct Family Support Program bases their selection . . .

MR. GOSSE: Every time you call, it's always under review.

MS. HARVEY: Yes, that's correct.

MR. GOSSE: Maybe it's just me.

MS. HARVEY: Yes, it's really hard to get that.

MS. GARDINER: Does anybody have that? Does it exist?

MS. HARVEY: Oh yes, I'm sure it exists. It's always under review so it's very difficult to . . .

MS. GARDINER: My parents can't get it because they're always told it's under review.

MS. HARVEY: Yes, that's right. And there are a number of families here today that do receive some sort of funding from that particular program. It's a program that was originally developed for families that had family members who had severe medical issues and needed 24-hour care and the families were providing that. So it was some opportunity for those families to get a little bit of a break.

As the program started to build, it was realized that there were a lot of other people with disabilities within their family that would benefit from it. Everybody needs that sort of form of respite. I mean you get exhausted, you have to have something.

I'm not someone who has been able to access that particular service, for a number of reasons, we just don't meet the criteria at all . . .

MR. GOSSE: Financial criteria, \$40,000 or . . .

MS. HARVEY: Oh yes, financial yes. It is income-capped, income tested, as they say, so for a family of four I think that the income cap right now is \$47,000. Yes, that's net. So you know that's not a whole lot of money, a lot of people.

The concern I always find with families, when we talk about that cognitive component is people with autism, kids with autism, individuals with autism, they might cognitively have pretty good ability but their behaviours can be quite extreme. For the family member who is trying to manage that child who is climbing up on to the window and bashing against the glass and they are three stories up, how do you manage that, and with kids who are so hyperactive that they are whirling around the house. They might have a cognitive ability that would be considered closer to normal or beyond those levels but it is exhausting for the family to try to manage that.

I'm wondering, Tracey, if you might just say a word there. This is Tracey Avery who is the Co-President right now of the Autism Society of Nova Scotia and she has twin boys with autism. I wonder if there's something you'd like to say. Come on up to the mike. You are a consumer of direct family support.

MS. TRACEY AVERY: I get direct family support. I have twin boys who are seven. They are in Grade One and they both have autism.

MR. GOUCHER: They are beautiful too.

MS. HARVEY: They are gorgeous. They came to our camp this summer and everybody wanted to have a hug, they are beautiful children.

MS. AVERY: One of them doesn't speak at all, he has maybe four words so he still has no language. He has a lot of behaviours, like Vicki is talking about. My other son only started talking when he was five and a half, so he is limited in his language and a lot of what he says, he doesn't understand fully what he is saying. A lot of times I'll say things like, what do you want, Kyle, and he'll look at me and say, what do you want, Kyle? I just say, okay, do you want to have supper, yes or no? He'll say yes, so he understands it when you break it down but he doesn't understand the whole social speaking.

As far as behaviours go - oh my God, my house is like Fort Knox. I have things locked with keys, deadbolts everywhere, plexiglass because it's like having a two-year old or a three-year old in a bigger body, so they're quite capable of doing a lot of damage quickly but the things they're interested in are so two-year old-ish. They want to get into cupboards - it just makes no sense, the things that they want to do. Once they open a container, they want to just throw everything all over the house. A lot of time it is safety concerns - they don't understand traffic, you can't take your eyes off them for even a minute. I've got two, so one goes this way and one goes that way, what do you do?

I had a moment one time where I had to leave Kyle to chase Brandon, running towards the highway and it was the hardest thing I ever had to do because to leave him behind while I went running after, I had to take a gamble - I knew that Kyle doesn't usually run so I had to chase the child who was. So I guess - I don't know where am I going with this.

The family support you really need because to have that kind of stuff going on in your family, it not only takes a toll on yourself, your marriage, your family, it causes so much ruckus in your family and your whole - your friends, everything you do is changed when you have children with autism in your life. Some things are good - I don't want to paint a terrible picture, but you do need a break from it and having that support means the world to our family. I have someone right now with them so I can be here. Otherwise I would have to be home with them and to me, this is a break, I would be home with screaming kids.

MR. ZINCK: How many hours of support do you get?

MS. AVERY: It's done by dollar figures so I have never really worked out the hours.

MR. ZINCK: How much . . .

MS. AVERY: It's, God, I don't even know if I can figure it out. They give you . . .

MR. ZINCK: More than \$400 a month?

MS. AVERY: Yes, and I have two children, and they'll give you some support for transportation costs and stuff like that, too. So depending on the family, they'll look at what your needs are and assess you.

The first time I went for direct family support, the woman came out to my house and she talked to me for about an hour and the kids were there. It was distracting; she was asking me questions like, how difficult is it around mealtime, and the forever optimist, I'm like oh, it's not that bad, it's okay, you know we get through. Then she's like, well how's bath time, and I'd say oh, it's okay, we get through it, and then she offers me \$200 a month.

I know you can get more money than that and that's not going to go very far, it might give me a Saturday afternoon, so . . .

MR. ZINCK: So the individual who is looking after your children today . . .

MADAM CHAIRMAN: I'm sorry, but I don't think the recording is picking you up because it's not your turn.

MR. ZINCK: Okay, sorry. I've just had a case that's really interesting . . .

MS. AVERY: Well then I called the woman and I asked her to come back and I just said, do you know what, I'm going to tell you what it's really like. I'm not going to hold back. I'm going to tell you everything that I live and go through, and it changed everything.

MS. HARVEY: It's so important to think - I mean, Tracey is lucky that she is able to access this particular amount of money. So many families cannot and do not, and it is something that should be accessible in some way to all families.

MS. AVERY: Well the income cap really upsets me as well because I didn't go back to work because of this. I work part-time now but it's - I work for minimum wage, or a little more than that, but it's not much and it's more to get out of the house than anything. So as far as the income goes, it shouldn't even be a factor because the things that you live through when you are caring for a child with autism, nobody can really understand it unless they live it. Everyone deserves to get a break, for your own sanity. They say marriages break up, you know it is 90 per cent, 80 per cent. It's really high and I can certainly understand how that can be because it really puts a strain when you're caring for children - in my case it's two, so you're constantly one's with one and one's with the other - it's a lot on a family.

MS. HUME: And you have to find your people.

MS. AVERY: Oh, definitely, that's another thing that should be looked at, they should really try to find reliable people. I've been lucky, I've accessed some really great students in my travels and I latch onto them and keep them working for me, but not everybody has that, there's a lot of issues with families trying to find adequate respite workers, people who are trained or who will understand how to look after their children.

[2:45 p.m.]

MADAM CHAIRMAN: Thank you very much, Tracey. One quick question from Gordie, then we're going to Keith, then we can entertain the motion.

MR. KEITH COLWELL: Madam Chairman, before you do that, I haven't had a chance to ask any questions yet.

MR. GLAVINE: No, she said Gordie one and then back to you.

MR. COLWELL: Okay, Gordie has already asked questions, though.

MR. GOSSE: I've asked one.

MR. COLWELL: Okay, go ahead then.

MADAM CHAIRMAN: I've been timing, so one quick one, Gordie.

MR. GOSSE: Is that okay?

MR. COLWELL: Yes, just highly unusual.

MR. ZINCK: To ask two questions?

MADAM CHAIRMAN: Okay, let's not waste time on this. Gordie, a quick question and then we're going to Keith.

MR. GOSSE: I do understand the problems because I have a friend of mine who is after mortgaging his house twice now to spend \$100,000 for the program itself. My second question would be to Kim, who was at the microphone about not having any stats. I'll give you some stats from the Cape Breton-Victoria Regional School Board: there are 229 children between the ages of 15 and 19 who are going to be finishing school in the next five years with cognitive disabilities, mentally challenged, autism and it is a four-year waiting period just for the adult day activity programs in our area. They have never had any core funding or money for those programs, you're talking about when they're 21, they've never had any money for those programs in my area to access core funding so they can handle these 229 children in the next five years coming out with disabilities.

You're talking about community colleges, you're talking about college, we are talking about adult day activity programs. Where are they going to go? What is the prognosis for those children? So that is what my point is to you: Are there any programs that you know of in Nova Scotia that have been funded in recent years by the government to alleviate some of this problem or help with this problem?

MS. HUME: Not in my area, in the Valley, but I know that there are some in the city. There are more in the higher populated areas of the province, but we don't really have any of those kinds of things. The population we have coming out - I only talked about the kids with autism, but like your area there are a huge number of other students as well with Down's Syndrome and so on, so it's big. That's the area that I think we are worried about is that we've got this huge number of kids with disabilities and they are ready to come into the community and there's just nothing, that's a real need.

MADAM CHAIRMAN: Keith, we'll let you finish off the questioning.

MR. COLWELL: I want to thank everybody for coming today, the parents and everyone else who is here. It is a real education, I think, that is needed outside the community you live in and I think that is probably part of your problem. It must be extremely difficult to live with this every day, it has to be almost impossible.

You talked some about support for parents and when you talk about the Mathesons who spend all their time with their child and the support that is needed for parents, even training in how to deal with this situation, is there any training there for parents to take

outside of what Community Services may do or they can do on their own - although I realize it's very difficult to go to training - are there any programs like that available?

MR. DONOVAN: I would like to answer that one. The answer is no. We have the families in VAST, Valley Autism Support Team, who have been begging for training. Why can't the trainers who are training the EIBI people come and train me how to use the PRT system for my child when I know my child will respond to that if I knew what to do? The answer is no.

MR. COLWELL: That's very discouraging and it must be extremely discouraging for the parents. How much would that cost? Do you have any idea what it would cost to do that training on a realistic basis, say for a parent or per family? Is that a huge cost?

MS. GARDINER: I think the family that Gordie alluded to who has remortgaged - they have someone working with them and they're talking about \$40,000 a year aren't they? I know in Cape Breton we have a couple of programs through Child and Adolescent Services which is quite robust. We have an intense ICBTT - it's a program where they go into the home for all things under the scope of Child and Adolescent Services, but to get into that program you have to be quite severe, but that is outside of autism, I don't think they even deal with autism. My daughter has a brain injury, so I have them come in with that and they kind of taught me just very basic parenting skills. I'm a pretty smart girl, but I really learned a whole lot about schedule and all of that. I think that even that rudimentary form would go a long way for a lot of families and we obviously are able to do it, it's about access.

MR. COLWELL: And that type of training wouldn't be terribly expensive, would it?

MS. GARDINER: I think it is kind of there, I think we just have to make it more available and help families to come to it. There's an awful problem as well with people coming to terms with this. You want to deny something so difficult and like Tracey said about her home life in talking about it, I see other people's situations and go, how do they do it, but I don't see it in my own world and I don't even really see the autism sometimes because I have no context to put it in, it is just the way life has always been.

MR. DONOVAN: I think the working group would clearly identify this area.
(Laughter)

MR. COLWELL: Yes, I can sort of gather that. (Laughter) We don't make decisions on where money goes, it's the government and we have a government Cabinet Minister here today, luckily and I'm glad to see him here and I know he is very concerned - I've known him for a number of years - about issues like this.

How can we as a committee help you? I know we talked about passing a resolution which I'll gladly support without question. How can we help you with other things that you

need like training for parents, some things that may not be very expensive to do but can have a major impact on the families and the lives of the children that they're dealing with? Not only that, but as they get older and older, and Gordie identified in his question that I questioned, but anyway, it was a very important question to put forward, how do you deal with these young people when the parents are no longer there? What happens then? And they haven't had the opportunity for the early intervention, they haven't had the opportunity to do and achieve what they can to the maximum of their ability, which is a crime as far as I'm concerned. What do you do?

MS. HARVEY: It's a good question.

MS. GARDINER: If I could ask the government to do one thing today and I know this is just pretend, not that you couldn't, but I'm just saying that this respite care issue is huge. It just really bothers me when I hear about people like Paula and Donnie. I'm so afraid that I'm going to wake up tomorrow with - no offence - a reporter's microphone in my face saying who knew that this could happen to a family, it was autism? We were saying, our families are suffering.

This program has the potential to help these families and I really believe that yes, we have to look at the criteria and all of those things, but we were fitting in for a long time and then the rates went up and the rules kept changing. I don't know if anyone deliberately meant to do it, but it was kind of like autism got pushed out because autism was such a big monster to deal with. If maybe even the government could go back and look at that in the Department of Community Services to see how can we serve these people, because that's what I'm getting most of my calls on, people who are just so desperate and they're having a really hard time. The Mathesons - I didn't embellish. I actually played some things down and that's the reality, so that is my wish list.

MS. HUME: Can I make a comment on that?

MR. COLWELL: Sure.

MS. HUME: I work with the families that are sitting behind you. There are three moms sitting behind you and a grandmom sitting behind you, as well. I work with all the families in our district and the number of stories that come to me about safety issues within the home really scare me tremendously. If I had one wish, besides all the training and so on, it would be that the families who call me or the families who end up in my Autism Centre at Kingston District School and are telling me that last night someone escaped and ran across the road, I had to chase him across the road into a house and so on and so forth, what does not exist for these families is that there is nobody who can go into the home and help with severe behaviour problems in the home.

The respite workers that these folks have to find on their own, somehow, these are not people necessarily that have any skills whatsoever, so if you have a child that has extraordinary and exceptional behaviours, many times you can't keep the person because

they just simply don't know what to do, so your respite worker leaves. So if there was one wish for me it would be that we have people who were trained to go into homes to help with severe behaviours and even the low level behaviours.

Just because you have a child with autism doesn't mean you necessarily know about all of those strategies. You love your child and you know your child. You may not necessarily understand everything there is to know about autism and what the newest techniques are. We don't have this cadre of people who can go into a home and help families when they're struggling with behaviours. So, if there is a family that has this problem and they contact their mental health, if they are able to get in to see a psychologist in days and day or weeks, it is an office visit. It's not that anybody comes out to the home and helps that parent in the home and if you're not in the situation, you can't put strategies in place until you know the function of the behaviour. Families aren't in a position of being able to assess that, because they're so caught up in the emotional trauma of what's going on, they can't see rationally around that.

So if I had a wish when I talk to these desperate parents, it would be that there are people who we could access who are trained to go into homes to help set up visual schedules, to help put the supports in place - often the same ones that we use in schools - in the home setting. That would be something that I think would help all the families. Thanks.

MR. COLWELL: Great. Is my time up?

MADAM CHAIRMAN: Possibly, if you're willing. (Laughter)

MR. COLWELL: Yes.

MADAM CHAIRMAN: So who's prepared to put the motion on the floor? Yes, Leo.

MR. GLAVINE: In fact, I wrote it out - they were so intent on wanting this motion. It reads: That the province create a working group of health, education and community services professionals who can investigate the scope of issues surrounding the autism community, and produce a report that develops and implements a plan that addresses the intervention, support and accommodation needs across the lifespan of individuals living with and affected by an autism spectrum disorder. I can pass that on to the clerk.

MADAM CHAIRMAN: Thank you. Do we have a seconder?

MR. COLWELL: I second it.

MADAM CHAIRMAN: Thank you. Speakers on the motion? Yes.

MR. GOSSE: I would like to speak on the motion. I would like to see it amended, that it have participation from advocates and parents in the group. I would like to see it amended to have the people who came here today, and parents . . .

MADAM CHAIRMAN: Do we have a seconder for the amendment? Okay, any discussion on the amendment?

Would all those in favour of adding parents and advocates to the motion - yes.

MR. GOUCHER: Should we define that a little bit? I mean I think it's very good, but what's the wording?

MADAM CHAIRMAN: Okay, the working group currently includes health, education and community services professionals, and the amendment is to add parents and advocates to that group on the working . . .

MR. GOUCHER: At the determination of the Autism Society Nova Scotia? The Autism Society Nova Scotia would determine that?

MADAM CHAIRMAN: Well, we have a . . . (Interruption)

MR. GOUCHER: Well, I'm just asking because there are several groups and I would think the Autism Society Nova Scotia would probably know who maybe they'd want to put out - does that seem reasonable?

MADAM CHAIRMAN: So you're amending the amendment?

MR. GOUCHER: No, no, he can just - this is just a friendly amendment.

MADAM CHAIRMAN: No, there's no such thing as a friendly amendment. (Interruption) This is doable, just hold on a second. What we're suggesting is amending the amendment on the floor to say the parents and advocates would be determined by Autism Society Nova Scotia. Are you ready for the amendment to the amendment?

Would all those in favour of the motion please raise your hand. Contrary minded, please raise your hand.

The amendment is carried.

So the amendment as amended is that we would add parents and advocates to the working group, as determined by Autism Society Nova Scotia. Are you ready for the amended amendment?

Would all those in favour of the motion please raise your hand. Contrary minded, please raise your hand.

The amendment is carried.

Okay, are you ready for the main question? Do you want to hear the full - okay, everyone understands what we're voting on.

Would all those in favour of the motion, as amended, please raise your hand. Contrary minded, please raise your hand.

The motion is carried. Wonderful.

MR. DONOVAN: Thank you very much. (Interruption)

MADAM CHAIRMAN: You're quite welcome. I'm not going to repeat what I said earlier, but this has been one of the best meetings I think we've ever had. I thank you, I thank the audience and I thank the members of the committee who are taking this so seriously. It was dealt with in a non-partisan manner and that's one thing I really, really appreciate about the Standing Committee on Community Services. We deal with such important, complex and emotional issues, and I want to thank the members for the very professional way that they deal with this. I think this is something we can all be very proud of and have a stake in its future and its success. I'm sure this process is going to work out very well, for the best interests of families and children that are so important.

Before we move out, there are two quick business items. The annual report for last year was distributed to the committee members. Are you able to vote on that so that we could present it to the Fall session of the Legislature?

[3:00 p.m.]

Okay, would someone like to move adoption of the annual report? Keith. A seconder? Pat.

Would all those in favour of the motion please raise your hand. Contrary minded, please raise your hand.

The motion is carried.

Another issue is that our next meeting is scheduled for Tuesday, December 4th, and as we all know, we're going back into session. What is your wish in terms of meeting during the Fall session?

MR. GOUCHER: It's probably going to be an erratic session, so I'm thinking probably we'll need the time, unless something really urgent comes up. (Interruptions)

MADAM CHAIRMAN: Okay, so I'm getting a consensus that we postpone that meeting to January. Is everyone in agreement? Thank you.

MR. GOUCHER: Unless something - you know, I still think it's fair to say if something really urgent came up that had to be dealt with, then I think . . .

MADAM CHAIRMAN: Before you leave, we need to get our signatures on the signature page for the annual report, if you could start that around.

I declare the meeting adjourned, thank you very much.

[The committee adjourned at 3:01 p.m.]