

HANSARD

NOVA SCOTIA HOUSE OF ASSEMBLY

STANDING COMMITTEE

ON

COMMUNITY SERVICES

Thursday, October 28, 2004

Committee Room 1

Valley Autism Support Team

and the

Autism Association of Nova Scotia

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COMMUNITY SERVICES COMMITTEE

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[Mr. Jerry Pye was replaced by Ms. Maureen MacDonald.]

In Attendance:

Ms. Mora Stevens
Legislative Committee Coordinator

Ms. Sue Wolstenholme
Executive Director of Operations, YWCA Halifax

WITNESSES

Valley Autism Support Team (VAST)

Mr. Norman J. Donovan
Director

Ms. Janet Kroetch
Member

Autism Association of Nova Scotia

Ms. Vicki Harvey
Executive Director

Ms. Jo-Lynn Fenton
Vice-President Autism Society of Canada
(Nova Scotia Representative)

Ms. Michelle Gardner
President, Autism PDD Society of Cape Breton



HALIFAX, THURSDAY, OCTOBER 28, 2004

STANDING COMMITTEE ON COMMUNITY SERVICES

9:00 A.M.

CHAIRMAN
Ms. Marilyn More

MADAM CHAIRMAN: We have a very busy agenda this morning so I think perhaps we should start. I'm Marilyn More. I'm the MLA for Dartmouth South-Portland Valley and I'm the Chairman of the Standing Committee on Community Services. We will start with introductions but I just want to mention to the committee members that the topic of autism will run from now until about 10:30 a.m. and then we have a fairly heavy agenda, just some housekeeping items in terms of who we are going to meet with next and meeting dates. So we will probably need about a half hour so I am scheduling that from 10:30 a.m. to 11:00 a.m., just for your information.

I am very pleased today to welcome members of the Valley Autism Support Team and also Autism Association of Nova Scotia. I'm pleased also, we have representatives from a third group here today, the Families for Early Autism Treatment as observers. Welcome to all of you.

Perhaps we will start with introduction of committee members. Stephen, would you like to begin?

[The committee members introduced themselves.]

MADAM CHAIRMAN: Would you like to introduce yourself and the members of your two organizations?

MS. VICKI HARVEY: Certainly. Thank you very much for having us here today. We are very pleased to have this opportunity to address the committee. My name is Vicki Harvey and I am the Executive Director of the Autism Society of Nova Scotia. Behind me we have two other representatives today. I have Michelle Gardner here who is the President of the Autism PDD Society of Cape Breton and Janet Kroetch who is with the Valley Autism Support Team as a parent. Also, we have Jo-Lynn Fenton here who is the Vice-President of the Autism Society of Canada and the Nova Scotia representative on that association, and we have Norm Donovan who is with the Valley Autism Support Team and who will be doing most of the presentation this morning.

If I could just address the committee for a moment, Madam Chairman, we just want to say we hope to help you to become more aware and better informed about the situation which exists in Nova Scotia regarding treatment services for individuals with autism spectrum disorders. So we hope this will be very informative and a great opportunity for you to learn more about us.

MADAM CHAIRMAN: I'm sure it will. Now, Norman spoke to me just before the meeting to say that they understood that they had 20 minutes to 30 minutes presentation and I explained to him that we try to save more of the meeting time for interaction questions and answers back and forth. So he is going to try to shorten it down to approximately 15 minutes to 20 minutes. So I'm just wondering, do we have the permission of the committee to extend the usual presentation time to accommodate that?

SOME HON. MEMBERS: Agreed.

MADAM CHAIRMAN: Thank you. Thanks, Norman, if you want to begin.

MR. NORMAN DONOVAN: Thank you, Madam Chairman, and gentlemen of the committee. Our position within the autism society is that really there is no effective treatment program in Nova Scotia.

MADAM CHAIRMAN: Okay, just a minute. We are having a problem with sound.

MR. DONOVAN: I am no longer shorted. (Laughter) We recognize the EIIS Program but it is a support program and not a treatment program; 43 children yearly, we believe, are born in Nova Scotia. This, we feel, is the major problem and we have a solution for you. What is autism?

MR. WILLIAM LANGILLE: Can you slow that down?

MR. DONOVAN: Okay.

MADAM CHAIRMAN: I will just remind members that they do have copies of the transparencies.

MR. DONOVAN: You have copies of the slides. It's a neurological disorder. It is treatable. It is definitely a lifelong disability and it is not curable. It is our submission that only the Department of Health can handle this problem. However, this, we feel, is a very important point; no child must be forgotten, no child must be excluded. It is not the Canadian way to do that.

What is our goal? Our thrust is treatment. Independently, in other words, no caregivers when they leave school. That's the goal. Effective treatment programs, yes, they do exist. Let's not reinvent the wheel. This is our vision. I think it stands alone.

So what is this treatment program we are proposing? It's not just preschool. It's from the time the child is diagnosed until that individual departs this life. We said it's a lifelong disability. Therefore the Canadian way is to look after our people throughout the entire life cycle.

We see four phases. Phase 1 - Diagnosis. Very important. Diagnosis occurs within 30 days of referral. I think it's doable. We're talking about 43 children a year, one a week. Perhaps the most important is Phase 2 - Preschool intervention. You must get the children early. Between the ages of two and five, they are most receptive to treatment. Fully funded by the government - once you start a treatment program, you don't stop it. You will get regression. Think about this one, Phase 3 - Formal education. You can have a child in your school system for 16 years, entering at five, leaving at 21, if they're disabled. Autism is a disability. You should be prepared to treat them during those 16 years.

This is the one I have the most difficulty with. Phase 4 - Long-term care and treatment. It's sad. You have to recognize that some will never be independent. So when they leave school, what are their options? Remain with their parents until the parents die, then what? On the streets, in the prison systems, in the mental institutions, or meet a violent death? We can do better.

Within all that documentation I gave you, all 58 pages of it, there's a case study. It's very detailed. It's about my grandson, Marc Donovan. It's quite remarkable. It shows you what can be achieved. I'm just going to highlight a few points. We first noticed problems with Marc when he was one. By two we were pretty certain we were going down that terrible path. At three he was diagnosed autistic. There are many treatment programs, many therapies that can be used, the Ontario handbook lists 34 of them. Marc's parents, his psychologist and his senior behaviour therapist selected these 10. Not every child would go through these 10, there could be 10 others.

The results, besides being non-verbal, eye contact, communication, typical autistic, head-banging, frustration, tantrums, fixations, a lost child. Look what happened two years later. How did we do this? Here's the cost. I would point out provincial funding was \$25,500. Marc started school in September this year. He did not need an EA. He's by himself. He gets on and off the school bus by himself. What's an EA cost? About \$20,000 in Nova Scotia, probably \$25,000 in Ontario. Consider that. However, the financial cost to his parents - Marc's father works Monday to Friday, Marc's mother works Saturday and Sunday. That's their life. It ain't going to change for a long time.

[9:15 a.m.]

So what are we suggesting to you? I'm giving you an example here for the early intervention treatment program, just something you can start with, a baseline. So every year there's 43 children who will need \$1 million before they get to school, \$3 million over three years.

Now, what do we mean by an effective treatment program? This is what we submit can be an effective treatment program. This is what Marc went through. A very important point, these three: nutritional, psychological and medical. Many parents, the first time they hear the word autism is when the psychologist says, I'm sorry, ma'am, your child is autistic. What is that? Education is an essential part of the treatment program. After you diagnose, evidence-based therapies; as I mentioned, there's 34 listed in the Ontario book.

Diet intervention. The two principal components of Marc's treatment program, which led to his recovery, one might say, was ABA and diet intervention. He responded very well to diet intervention. He is on a gluten-free and casein-free diet. Within 90 days of starting that diet, we had eye contact. It's a medical problem.

Throughout the child's life, evaluation every six months by the autism team - not by the school principal, not by the teacher, not by the EA, but by the autism team, the psychologist, the behavioural therapist, the doctor. Take him right through school, and let's face it, at the end of school, there are some who will need lifelong supports. We have to provide that.

How are we going to do this? We submit we need a Nova Scotia task force on autism. If you want to come to grips with this problem, let's get a team together, let's attack it. This is a team we're suggesting. The representative at the bottom, from our society - we submit that people in this society have the most knowledge, the most experience with autism, and also the burning desire to come to grips with this problem. We want to be included. One thing we should do - I said task force - I think out of the Premier's office, they have the authority to question any Nova Scotia provincial department to get the answers. The answers are out there. Also, go across Canada and look at the other provinces.

What's their tasks? There are three of them, the first one - how many autistic children are there in Nova Scotia? Nobody knows. Certainly our societies have not been able to get that answer. It's there somewhere. We can dig into it. Adults, very difficult. I'm not sure you'll ever find out, but you have to make the attempt. The second task is to create a treatment program, not an individual plan for each child but, globally, how are we going to treat the autistics? Then, once we've done that, create an implementation plan. How are we going to do this in Nova Scotia? You can look at Ontario and you can see how not to do it. Message there. Schedule. Pie in the sky? No. The data is out there. All we have to do is bring it together. We don't have to do research. It's there. I think we know where to go to find it.

Now, why am I standing here before you today? I have no children in Nova Scotia, I have no grandchildren in Nova Scotia, so what am I doing here? August 2002, two years ago, I was on the beach in Lockeport with my grandson and as grandparents are wont to do, I want to play in the sand, making highways, digging tunnels with my grandson, so I'm down in the sand with the toys and I say, Marc, come on let's go. Silence. I thought that's strange. So I got up and moved over and there is Marc standing absolutely still and he's fixating on a blade of beach grass. Right there at his eye level. So I get down on my hands and knees and I look at him. What are you doing, Marc? Nothing. Absolutely nothing. He's not moving, he's not blinking, he's not seeing me. He's looking at that. I suddenly realized that was the face of autism. I was heartbroken. Not just for Marc but for my son and his wife. What did the future hold for him, them, Marc, me? Nothing but darkness and despair.

Advance forward two years after Marc's treatment. We're on the beach again, Marc is in the centre, he's playing with his dad, he's playing with his sister, we're playing with toy trucks and Marc and myself, his old granddad, we're going down and we're going to build roads, and we do build roads and Marc is communicating. He's looking at me. Is that a miracle? No. That's the result of effective treatment. It's possible. We achieved it with Marc. The reason I'm here is I think you can achieve it with Nova Scotia children. I think this committee has the power to do that. I want you to think about the Nova Scotia children and what you can do for them, that you can put them on that beach with their grandparents and you can play in the sand. Thank you, Madam Chairman, gentlemen.

MADAM CHAIRMAN: Thank you, Norman, both for the overview and for that very dramatic personal story, we appreciate that very much.

We usually do a couple of rounds of questioning, depending on the length of time available and we have two people on the list, Stephen and then Mark. So Stephen would you like to start?

MR. STEPHEN MCNEIL: Thank you, Norman. I've had the good fortune of meeting Norman in my office and having a first-hand recount of his personal brush with autism and I'm very fortunate in my constituency to have a number of parents who have been pushing this, not

only for the children of western Nova Scotia but across Nova Scotia. So thank you very much for coming in today.

You had talked about 43 children being diagnosed or being born yearly in Nova Scotia with autism. How many children do you think have gone undiagnosed in Nova Scotia?

MR. DONOVAN: I think I'll let Vicki handle that one.

MS. HARVEY: Ooh! A difficult question to start off with. I think it would be a bit difficult to say how many go undiagnosed. We are better able to identify earlier, but there are children who are missed and are picked up later. There are not a lot of good surveillance mechanisms to record who is diagnosed within the Province of Nova Scotia. So it makes it very challenging for us to be able to determine what the actual numbers are of people who are assessed and people who are suspected, because there isn't really a record kept, certainly not province-wide.

MR. MCNEIL: If my child was starting school tomorrow and at some point in the next year or two the teacher suspected that my child may have autism, what mechanism would be in place for that teacher to diagnose my child?

MS. HARVEY: The teacher would not be in a position to diagnose. What they would do would be to recommend to the administration that they felt the child needed assessment. The parents would be contacted. It would be discussed with them. It depends on the school boards. There certainly is an assessment procedure within the school board system with a psychologist who would be able to perform an assessment, however, waiting lists for that are very long. Children can be assessed through the IWK from the age of six and under, and waiting lists for that are very long. For a number of parents, if they are able financially, they can go for private assessment and usually have an assessment quite quickly, within about six weeks. But for the average parent in the school who is waiting for the assessment to come through the school system, they might wait well into a year for that assessment to come.

MR. MCNEIL: How does that vary from board to board, I'll use the Valley and maybe HRM?

MS. HARVEY: I can't speak for the Valley, I would ask Janet to give me a little bit of help on that. Certainly in the HRM, I can tell you that we're all parents of children with autism, to begin with. I have a 13-year old. When he was in Grade 5, we wanted to have a reassessment of his diagnosis. So I went through the school system, I went through the procedure and I was told that it would be a year and a half before I would receive a new assessment. So we were lucky enough and we went without a couple of different things so that he could have an assessment that was current, that could be used by his Grade 6 teachers to plan what would happen for him in Grade 6 and his transition into Grade 7. Transitions are really important that they be well planned for these children and you need proper information to be able to do that.

Janet, could you perhaps just speak to that.

MS. JANET KROETCH: With regard to the children in the Valley, my son wasn't diagnosed here in Nova Scotia initially, he was diagnosed in Australia, because my husband was working contract work away in other parts of the world, so we went through quite an ordeal in having him diagnosed, but when we returned to Canada, during a Summer, I had him diagnosed again because I wanted confirmation, I was getting differing opinions. I paid for that privately. Since then, now that we have been in the province for the past five years, I still have to contact the IWK to have reassessments done on an ongoing basis. It's not done automatically. I do have to wait. At times, I've waited two years to get in to see Dr. Shea, even though he is a former patient, so there is a substantial waiting time for those kinds of services, even for people who are already in the system. So you can imagine what kind of a wait is there for the children who haven't been diagnosed and those who are missed.

[9:30 a.m.]

MR. MCNEIL: Norman had mentioned the cost of treatment would approximately be about \$46,000 for Marc. Maybe you could just elaborate a little bit on the cost of not treating Marc or other children with autism.

MS. HARVEY: Certainly, the cost on the system, and I'm going to ask Jo-Lynn to help me with this question, because she has some of those statistics more at her fingertips, but I'm just going to say something quick and then I'm going to get you in there. Certainly, when you think about the support that would be required through the system, to manage someone with this disability throughout their life, and it is certainly dependent on how severely they are affected, but if they have not had any treatment, you're looking at the cost involved in constant care, helping the families with respite, because it is quite exhausting to have a child with autism that you have to look after 24 hours a day. Respite is very important to families.

In the school system, there would be, just starting off, an EPA or an EA to be with the child in the classroom. There would also be all of the team supports from the school board. In assessment, in trying to develop programming for the children, often the children need assistive technology or need particular materials for their programs. It goes on and on. Then, when they leave the school setting, if they haven't had proper treatment, you are looking at constant care in some form, whether that be a group home or whatever other institutions. Jo-Lynn, do you have some?

MS. JO-LYNN FENTON: I guess that brings us back, again, to the surveillance mechanism. Again, we have no great surveillance mechanism in place to determine how many individuals are affected by autism. When you try to extrapolate financial costs out, it also makes it very difficult. The Autism Society of Canada has done some preliminary numbers using educational data from three provinces, I do believe it's Saskatchewan, Quebec and British

Columbia. They've tried to work numbers that say basically you can assume that someone without treatment would have a lifetime cost of \$2 million.

If you put in an effective, valid treatment program, that cost could be reduced almost by half, again, taking into consideration all the supports an individual would need, depending on the severity of their disorder. Certainly individuals who are less affected, in the Asperger's range would require less supports, but someone like my youngest son, who is classically autistic, is going to need a great deal of support throughout his life, 24-hour care in addition to supports at school, and just basic functioning. He has no cognitive understanding of danger, and that doesn't look like that's going to change.

MADAM CHAIRMAN: Mark.

MR. MARK PARENT: Thank you for appearing before us and for bringing such an important issue here, and thank you to the member for suggesting it. Just some factual information to help me understand a little bit more about autism, since that's one of the things you're here for. I understand it's more common in males than females, three to four times. Are there any reasons for that?

MS. HARVEY: Part of the problem is we don't really understand why it happens. There's a lot of research going on. There are some suggestions there are genetic connections. Right now the research is very early, and they aren't too sure why. Also, as in other disabilities, you often find there's a higher ratio of boys to girls.

MR. PARENT: We clearly need more research on the subject.

MS. HARVEY: We certainly do. You have to remember that autism really has only been identified in literature since 1943. So it's really young. We've done a lot in a short period of time, but we need to do so much more.

MR. PARENT: I understand about 15 per cent to 20 per cent can live independently and work independently, worldwide. Does that figure fit for Nova Scotia society, or do you know?

MS. FENTON: I think we get back into the not a good surveillance mechanism. A lot of information is extrapolated from other sources, and whether or not that's accurate, one cannot determine. You have to remember that autism is a spectrum disorder, and when you look at someone who's more classically affected, obviously they're going to need supports, but there would be a group of individuals in the high-functioning Asperger's range. That wasn't added to what they call the diagnostic manual, or DSM4, until 1993. If you're looking at someone, similar to having really high skills, they might be socially aloof but quite good at their job and certainly able to care for themselves and manage in society. If you want to look

at those numbers, then how many are there? Again, we don't know. It would be basically guessing.

MR. PARENT: In terms of treatability, I'm a little confused about it because it's a lifelong neurobiological disease, so, really, that's not treatable in that sense. By treatability, you mean ability to interact with society in a productive way? Help me out a little bit there. The neurobiological disorder is not going to go away, right?

MS. HARVEY: No, it's not. That's right. You will always have autism. Did you want to say something, Norman?

MR. DONOVAN: Basically, treatment is to bring the child functionally into our society. Part of his brain has been destroyed, we know that. You can't do anything with that part. But if you start at a very early age, two to five, you can train other parts of the brain to take over that part that is missing. So, yes, they become functionally able.

MR. PARENT: So early intervention is absolutely critical.

MR. DONOVAN: Absolutely critical, because the brain is developing at that time.

MR. PARENT: I agree about the silo, and I see it in all forms of government programs. You have government programs, Health looking at a bit, Community Services, I think that's incredibly important, to try to get it in one area, so that progress can be made. I'm trying to hurry because of time. ABA, you mentioned it, I've read some of the literature on it. There seems to be some question of whether it's the model, or whether it's just one model amongst many.

MR. DONOVAN: It is a model, but it is a model that has been quite successful. The latest figures that we're getting, the latest opinions, shall I say, that we're getting, just two weeks ago, it appears that if the children are subjected to ABA, there is some improvement in all of them. In about 60 per cent to 75 per cent, there's a dramatic improvement. Marc is one of them. The figures are coming up.

MR. PARENT: Is it a fairly new treatment, ABA?

MS. FENTON: Maybe I'll go back to this, it actually is probably the premier, best-practice treatment. It's scientifically validated as an effective treatment. There are no other methods of intervention that have enough evidence to support them. When you look at possible treatment options of that list of 35 that Ontario has, the only one with validated evidence is ABA. A lot of principles we use are applied behavioural analysis principles. Really what they're talking about is more of a form of discreet trial teaching, which is a very stylized form of teaching these children that breaks down tasks into simple steps and builds it up to teach them step by step.

I guess when you look at it, they just perceive and process information differently than you and I do. They often, as in the case of Norm's grandson, focus on a blade of grass. They might have a hyper-focus to an activity and not be able to filter out or take in other things in their environment. So we really need to examine each child, each individual with autism is very different. The therapies that they would need to help them normalize their world or become accustomed to functioning within our world are unique to them. This treatment is the most scientific, evidence-based treatment available.

MR. PARENT: Is it fairly new?

MS. FENTON: No, it's not fairly new. It's been around since 1972 or 1973. Lovaas had started it in California. It has gone through some metamorphosis in the sense that it has been changed and stylized, but, again, it needs to be looked at in relation to how each child learns and what's specifically set up for them. That's why a team approach of specialists is so important to determine what that child needs. Because you write a program to teach tying your shoes, for example, it doesn't mean every child is going to learn to tie their shoes using that program.

MR. DONOVAN: It's also a team approach. Marc's ABA team consisted of five people, five therapists.

MR. PARENT: Just a comment on the figures that are needed for Nova Scotia, I would just encourage you to look at - I was just looking at the Ontario figures. Clearly not everyone has insurance plans in our province. There are those who couldn't afford the \$6,000. I have many constituents, and if they had to get \$6,000 out of their pocket, it would mean that their child wouldn't get treatment. I'm just not sure, you have to start somewhere, and you have to have some figures. I just have some concerns about the figures. I suspect, to really do the job properly, it would be significantly higher.

MR. DONOVAN: I agree. That was just a baseline.

MS. FENTON: Also, I might draw your attention to the fact that although it appeared to be only \$6,000 out of the parents' pockets, a lot of that money was actually put out by the parents and then they had to wait, because it was an income tax recovery. Also private insurance plans often require you to pay up front and then get it back. Probably they put out more in the range of \$20,000, and once they recouped from all the areas they could get money back, the cost was \$6,000.

MR. PARENT: I have many constituents who make only \$20,000. So whatever scheme we put in, I don't want to leave those people out.

MS. HARVEY: Absolutely, and I'm glad you brought that up, because I often get

phone calls from parents, saying, well, tell me now, can you talk to my private insurance server to see if they will cover the cost of this. Typically, they won't.

MS. FENTON: In a lot of cases, private plans do not cover ABA therapy because, again, it's not a medically recognized treatment. That's one of the reasons why . . .

MR. PARENT: It's not medically recognized?

MS. FENTON: Well, it's not as far as health plans are concerned, that it is medically necessary for these children, but health plans don't recognize it as an insured cost.

MR. PARENT: Even in the provinces which have more advanced treatment?

MR. DONOVAN: That's true. The insurance money that they recovered was not for ABA therapy. It was to pay the psychologists, to pay for the blood work, the other tests, that sort of thing.

MS. FENTON: Speech language pathology.

MR. DONOVAN: Yes, all of that.

MR. PARENT: But currently there is no jurisdiction that recognizes that?

MS. FENTON: You can claim it on your income tax with a letter from your doctor, but I don't believe that any private insurers would pay the cost of therapists sitting and working with your child.

MR. PARENT: Sorry, I've taken more than my time, but thank you very much.

MADAM CHAIRMAN: Maureen.

MS. MAUREEN MACDONALD: Thank you very much for coming today to speak with us. This is an issue that in fact has been before the Legislature, before the members of the Legislature, you'll know this, for quite some time. Not so long ago, the families for early therapy, who are here as well, brought a petition with 12,000 signatures, which has gone to the minister, which is pretty significant, I would say, in terms of what we generally see in terms of petitions in the Legislature, asking for early interventions.

I have some questions around wait times for diagnosis. You say it's two years, that's on average?

MS. FENTON: It depends on where you enter the system and how you enter the system. If you're a parent who has a two-year-old child and you think that there is something maybe amiss, depending on how you enter, if you go to your GP, if they give you the talk

where they say, well, boys talk later and let's wait and see. You could lose a whole year just on the medical profession going, well, let's wait. If they're students, they say, okay, now we should refer you, again, wait times in that area could be about 12 months, anywhere from nine to 12 months.

Again the IWK, it depends on the psychologist they have there and the services being demanded of them at that moment. So getting a range from them is about nine to 12 months. If you've reached school age, you're no longer eligible for a referral to that team directly, so then you must go through your school program planning team and get your assessment from them and determine whether or not the school psychologist can do the assessment or whether or not they want to refer you to the school-aged assessment team at the IWK.

Again, each one of these processes takes months, not days. So, as you look at that, the calculation of how long it takes just keeps growing and that, again, can get to be one to two years, depending if the team feels that the school can handle it, you could have two years. These children need reassessments to determine where they are and what level of intervention and therapies they need. Those types of assessments at school can definitely take two years.

MR. DONOVAN: May I add to that? If you create this task force that we're asking for in the implementation plan, that would form probably a major portion of it. I'm sure we can get it down way less than what it is now, because the team creates the atmosphere of doing diagnosis.

MS. MAUREEN MACDONALD: You indicated earlier that people can do private assessments, get them in six weeks, what does a private assessment cost?

MS. HARVEY: Right now, it depends on the psychologist that you are seeing, but it's roughly between \$130 and \$150 an hour and an assessment can be about 10 hours, roughly. So you're looking at maybe \$1,500.

MS. FENTON: If you want a report, then that's going to cost you another few hundred dollars and you can't access any service without a written report. So the costs just keep compounding.

MS. HARVEY: Then one of the major therapies that is used with the children as soon as they're diagnosed, well, prior to, in fact, is speech therapy. Again, there is a waiting list for the public system for speech therapy, so parents will try to opt for private and that will cost \$80 an hour.

MS. MAUREEN MACDONALD: So these therapies are very expensive.

MS. HARVEY: They are.

MS. MAUREEN MACDONALD: Just getting the assessment is very expensive if you have to go through the private system?

MS. HARVEY: Absolutely.

[9:45 a.m.]

MS. MAUREEN MACDONALD: You're probably aware that applied behaviour therapies are available in all provinces in Canada except for Nova Scotia and Saskatchewan. We have had, since April 2000, an interdepartmental working group, under the auspices of CAYAC, the Child and Youth Action Committee, looking at this issue and, in fact, they concluded that ABA therapies are, in fact, evidence-based, effective therapies for children with autism spectrum disorder. I want to ask whether or not you've been able to meet with members of this interdepartmental working group, whether you've had any communication with them, if you have any way of explaining why we don't have a program in place, given that they've already established that this is internationally recognized and does exist, in fact, in the other provinces for parents and for families, and for kids with autism?

MS. FENTON: If I may answer that. The province does have a plan, the Minister of Health has informed us that the standards for mental health services in Nova Scotia were revised and approved on March 22, 2004, and I do believe Vicki has provided you with a copy of the specialty services subsection, which is Sections E7-B and C. This was drafted by the core program standards working group of the mental health steering committee. The standards were put in place and intended to provide guidance and quality of service delivery and reduction in variations across the province. They have said, yes, intensive behavioural intervention is the best recommended therapy. The Minister of Health has informed us that this was brought to the budget table and it was not funded.

So our argument would be that, in fact, we now have more health dollars, it is a priority, it's under their best practice standard of care for these children. We would ask the government to fund this and provide the treatment that these children need.

MADAM CHAIRMAN: Hopefully, we'll have a second round, thank you, Maureen. Next we have Leo.

MR. LEO GLAVINE: Thank you very much for being here today. Having experienced autistic children through my teaching career, I certainly know how important the early diagnosis is from having experienced children also who did have some interventions along the way, who came to our area from other provinces. That being said, and diagnosis being so critical, do you think the medical community, who are very often the first ones to have some information and knowledge conveyed by parents observing the child from birth and so forth, I mean, is the medical community, are they well aware of some of the early signs that are going

to be able to get the kind of assessment to definitely give a diagnosis here and start the process? I was just wondering about a comment on that, please.

MS. HARVEY: I think the feeling from most parents in the province, I think there needs to be more education in general for the medical profession, certainly at the GP level. As Jo-Lynn alluded too, often parents go in when their child is not speaking or is perhaps very limited in their language and they hear, usually they start to talk a little bit later, come back in a year and we'll look at it again. Which is not the approach to take unfortunately. I always encourage parents when they call, if they are concerned, you can self-refer to the Nova Scotia Hearing and Speech Clinic, have an assessment done, get on the lists for some therapy, because if the child does start to speak and seems to be fine, you can sort of say, okay, I don't need to be there, but if not, you need to start that therapy as soon as you can.

So we would certainly support the encouragement, the further education of the medical profession surrounding this disability. Certainly, the specialists are more equipped, pediatricians tend to be quicker to pick up and to get the referrals going for the children, we find the general practitioners less so. They have a lot on their plates, I understand they are trying to cover so many things.

MS. FENTON: If I might add, this is not unique to Nova Scotia. The American Pediatric Society has just undergone a huge awareness campaign - they have called it Autism Alarm - that basically gives pediatricians and doctors markers to look for when they are doing office assessments of children when they come in to say, okay, if any of these markers appear, this is a child you should send for a referral.

Again, as Vicki had pointed out previously, this is a very young disorder, only 50 years. A lot of information, it's drastically changed from its initial conception of what causes the disorder to now really understanding that it is a neurological disorder of which this individual is born with. So when we look at how far we have come, we just keep trying to raise awareness and the medical communities are trying to catch up.

MS. HARVEY: And if I might just add one quick little story there, when my son was just over two, I took him to my doctor and said I was a bit concerned. He checked a list and said well, let's send him for audiology and speech assessment and come back to me. My doctor left the office that day and moved to the States. The doctor who came in, in his place, when I went back, I said, okay, he is certainly delayed in language. I'm seeing some other things. I would like a referral to the Developmental Clinic at the IWK and the doctor said, he looks fine to me, I don't think you really need it but if you really insist, I will do it. Huge difference right there. The doctor I initially had at least recognized that I had a concern and was trying to take steps. The other one wasn't very interested, didn't really have the knowledge base.

MS. FENTON: Another bit of information, I have two children, one with classic autism and one with Asperger's. My Asperger's child, who is very mildly affected, at two I started seeing concerns, at three I went for a referral to a psychologist and said look, here are the behaviours I'm seeing. This seems rather abnormal. He said, his behaviour is extreme, not abnormal. Go home and be a better parent. He was diagnosed just short of his fifth birthday. These are the types of things that block your access to systems and parents think, okay, it must be me and they go home. Of course, you know that there is something just different about them.

MS. HARVEY: And you are wasting time.

MR. GLAVINE: Thank you very much for recounting some of those experiences because I know that's very important that, again, the medical community and perhaps greater education is part of the process. Speaking of education, are the greatest number still diagnosed when they enter the school system, that the teacher is picking up on a whole number of cues that the range of behaviour here, certainly there must be something underlying the condition that is presenting through the child because I know at five we are being told already we have missed an enormous opportunity to change this child forever.

MS. HARVEY: Again, where we fall back to is it's very difficult, we don't have a lot of statistics because we really don't know when children are being diagnosed. However, we can tell you in the HRM School Board, and certainly there has been work trying to enhance services here and trying to pick up the children younger, three years ago there were just over 20 children who entered Primary in September diagnosed with ASD. The year following that, there were 38 children who entered. This September past, there were just over 40, 42 children who entered Primary in the Halifax Regional School Board. Those are children diagnosed. There are other children who will be picked up in the next few years who are in school now so the numbers are increasing and we are picking up earlier.

MR. DONOVAN: Madam Chairman, the task force that you are going to create, their first task is to get these numbers. It's not that difficult.

MADAM CHAIRMAN: I have to caution you, I'm not sure that this committee has the power to create a task force.

MR. DONOVAN: Oh, we think you do. (Laughter)

MADAM CHAIRMAN: But we can make recommendations to various departments and that is something we can discuss at the end of this session. Leo, your time is up, actually. Can you save that for the second round because I have actually been a little lenient.

MR. GLAVINE: Just in case there isn't a second round, can I pick up on what you just said a moment ago because I would like to make a motion that this committee recommend the

formation of a task force to look into and to expand the process of autism support in Nova Scotia.

MADAM CHAIRMAN: I'd like to suggest that perhaps we finish the questioning and then we can agree . . .

MR. GLAVINE: Okay, sure, not a problem. I didn't know if you would get back to me or not.

MADAM CHAIRMAN: . . . on what would sort of summarize our main concerns. That way, everybody can have a chance to get the information they want out on the table, if you don't mind.

MR. GLAVINE: Sure, not a problem.

MADAM CHAIRMAN: Russell.

MR. RUSSELL MACKINNON: Madam Chairman, I want to pick up on this issue with the Halifax Regional School Board and the figure of 40 children - well, you used 42 but we'll round it off at 40, if that's okay. They've been allotted \$14 million for special needs children. That works out to \$350,000 per child.

MS. FENTON: For the 43?

MR. MACKINNON: Yes.

MS. FENTON: They have more children in the school board who have needs, besides children with autism.

MR. MACKINNON: I want to focus on that, because in the Cape Breton-Victoria Regional School Board, I know of several cases of children, one in particular I know because he's my grandnephew, and he's an autistic child, and his brother suffers from ADD, and I have permission to speak on this because they've been very vocal on this issue. I don't know a lot about the technicalities of this, but I do know I've seen a lot of what I would perceive to be cases of ADD, autism and the more severe cases that years ago were referred to as severe mental retardation. Somewhere in between it jumps, each case is different. One may have a touch of ADD but also autism, or any combination.

What bothers me the most is that when these children go to school, and the point was raised about missing four or five years of critical time, there isn't sufficient expertise within the school system to be able to readily recognize these cases. I speak of this particular case.

What efforts has your organization or your group made in trying to convey that message to the provincial government and to the school boards, that this is a real issue?

MS. FENTON: I think within the Halifax Regional School Board, we've done a great deal of liaising with the school board to increase their awareness. They now have an autism team within that school board. They do a great deal of in-servicing with their staff members on autism. Vicki, herself, has done many presentations within the schools, both on in-service days, we've appeared and spoken to teachers about raising the awareness of autism - other disabilities, I do believe, have done similar things - and we have also now started to reach out to the children within the schools, and done presentations to the children, to help them realize why their peers are unique and different, and what things they can do to accommodate them.

I'm sure, like most provinces, we're not unique in the sense that we lack capacity, in the sense of the amount of people who know about this disorder and who can diagnose and who have readily available interventions at their hand to help them make their way in this world. It's limited.

MR. MACKINNON: I want to tie that into the issue that you raised a little earlier, it's a budgetary matter and the recommendation that was made by the Minister of Health to his Cabinet colleagues. What was the proposed budget figure that was brought to the Cabinet Table?

MS. FENTON: At this point we have not been given that information, and that was the Families For Effective Autism Treatment that had met with the Minister of Health and asked him why they did not provide this type of therapy. He was the one who drew our attention to the fact that the mental health services standards were set in place, and that the specialty services section does exist. He was the one who said that it was brought to the budget table and, again, competing resources and all of that.

Certainly, we understand that priorities must be set in allocating scarce resources. However, the allocation decision-making process needs to be transparent. Citizens have a right to know how these decisions are made and by whom. Certainly that's not a piece of information that we've been provided with.

MR. MACKINNON: I find that a little concerning, because you can't bring a budgetary matter to the table unless you know what the figure is, and if you know what the figure is, then you know, obviously, what you're going to use the dollars for, ergo you must know approximately what the population is that you're dealing with, or at least the magnitude of which you are going to deal with or attack the problem.

MS. FENTON: Again, getting that information from the Department of Health is very challenging.

MR. MACKINNON: Have you made any formal request for that information?

MS. HARVEY: We have asked different organizations. We've certainly asked the IWK, we asked the school board, nobody will give out the figure.

[10:00 a.m.]

MR. MACKINNON: Again, I'm not going to ask a question, I'm just going to make a closing comment, Madam Chairman, that being that I'm very concerned about the fact that there's a considerable amount of downloading from the Department of Health to the school boards to do kind of a quasi-assessment of the situation, but not with an in-depth analysis. Many children are falling through the cracks. I see this, not just in my own family's case but with a considerable number of others. At some point, unless it's dealt with at that level, whether it's through the Department of Health, the Department of Education or collectively, to paraphrase the comments of my colleague, to eliminate the silos, it's going to continue to escalate.

MADAM CHAIRMAN: I have Gordie and then Bill.

MR. GORDON GOSSE: Thank you for coming here today. I guess in my case as a parent of a child with a neurological disorder for many years, 26 years to be exact, I feel, and I know the struggles you've been going through, because before I ever became an MLA, I struggled for many years for funding, and in school, like my colleague, the member for Cape Breton West said. My son has epilepsy and is mentally challenged. This was through the 1980s and 1990s, so things have really progressed to now. I wish I had the support of committees that I see here today, but I didn't at that time in my life.

To go on on that issue, there was something in the report that I saw, regardless of status of income. I would just like to ask Michelle, the President of the Autism Society of Cape Breton - like my colleague just said - how is inclusion in the school system working for children with autism in the Cape Breton-Victoria Regional School Board? I'm just wondering how that's getting along, because I know that's the focus, inclusion. I'm wondering what supports are in place for children with autism in that education system. I do see that it's not just - as my colleague mentioned - the Department of Health and the Department of Education, but it's also the Department of Community Services, because they're the ones that are ultimately responsible for the in-home support programs. I would just like to ask you that, and how inclusion in the school system has been for children with autism.

MS. MICHELLE GARDNER: Well, I'm a parent of an autistic child. He's in the higher realm, somewhat Asperger's, we're not quite sure right now. We've had a lot of experience with this, particularly with the school system, because my son, although we knew at a year to a year and a half that something was gravely wrong, at three - he's 11 now, I might note - we began looking for answers. We were sent to Halifax, from Cape Breton, and told basically, there, there, dear, you're new parents, you're young parents, you're just not knowing what to do. Here's

a behaviour modification program, go home and try it. Well, thank God we didn't listen to that advice very well, or we would have done a lot of damage.

At five, when most children go to school, my son was simply not ready. He was not potty trained. I could not send him. Although parents told me they never go to school not potty trained, it didn't happen. We sent him at six, and a teacher promptly told us during the couple of days they do in the Spring, I can't take this child without an aide. You can't? We were struck with our grief. We then began to pursue, aggressively, to find out what was going on with this child. And that was because a teacher said that.

He was diagnosed at six with PDD-NOS. From that time on, he was in the school system, and I can't tell you it's been an easy journey. He missed six weeks of school at one point, because the TA was ripped, at lunch hour one day, from him. We spent the next six weeks of our lives in complete and utter turmoil. Now the school board, I find, has come a long way. I find that teachers are genuinely interested. Autism, for lack of a better term, is a little sexier now. So we talk about it. I just did a presentation on Friday to a group of junior high school teachers, who basically realized that we're seeing more of these kids. They just invited us of their own accord. It was wonderful, the compassion in that room. Teachers are really on the ground and they're trying. That gave us a lot of hope.

We have huge issues in our school board, and I would assume in other parts of the province, around transitioning. Transitioning is huge for these children, I can't tell you. Even as the parent of a higher-functioning child, transitioning has floored us on many occasions.

I would like to bring up the point that there are a few pearls out there and you folks are in control of one of those pearls. It's the respite care program. You have a Summer respite program, which I encourage parents within our organization to use to help us with the transitioning. We have transitioning issues from year to year particularly from going into school, which EIIS is doing, and despite it's a grotesquely underfunded organization it's doing an amazing job. From elementary to junior high, a lot of these kids were lost in the past, they dropped out in Grade 6. We know they're intelligent quite often, enough to go on but they don't, again from junior high to high school. We refer to it as a wave. There is a wave moving through the school system in our province. Right now it may be hitting junior high, maybe that's why those teachers asked me to come.

One of those pearls you have control over is the respite care. I can't underestimate the power of that program. There is one problem that my families are telling us and my family deals with it. You have a \$42,000 a year cap on that. When you have a family that has a child who is non-verbal, who needs diapers maybe at 15 years of age, I know very few mothers who have autistic children - and maybe it's because of where I'm from - who can work. I can't work. It's just not possible. My job needs me to be there. I can't be if I'm called out of school to deal with a school board matter, which is a reality.

That program is not in line with current standards; \$42,000 a year is very minimal. I did a little research last night on economics around that and at least a 25 per cent increase is needed in that. I implore you people to work with your staff to do that. That would bring us up to \$52,000, which I think is about what an MLA makes. I'm sure many of you would realize that that is not a whole lot of money. For a lot of these parents, it might be \$43,000 a year and they don't have diapers. Diapers are a lot when you have a child who's 15.

Anyway, the other issue that we're seeing a lot of around the respite care is a lot of these families, and my own included, I'm diagnosed manic depressive/bipolar. I was diagnosed six years ago, right around the time that this all started, which was a little complex for my family. A lot of families have that. When you're on the ground and you're dealing with a mom who is not coping, I mean they're not coping, they're getting a little respite care - Mom's home, maybe she's functioning at the level of a 13- or 14-year old and Dad's off working two jobs just to keep the family eating - that little bit of respite care goes an awful long way. To add to that, it helps with the transitioning.

We need social workers on the ground. Our social workers, from what I'm hearing and what parents are telling me, your social workers from Community Services are administering a program. They are not doing social work. We need people who can help these families cope. I speak to you particularly from the families who are low income. Unfortunately, in Cape Breton that's the story.

MR. GOSSE: Michelle, let me just ask you one other thing before I, and I know it's taken a lot of time . . .

MS. GARDNER: I'm sorry for taking too much time.

MR. GOSSE: I just want to know how the members of the Autism Society of Cape Breton feel about the applied behavioural analysis that will help families deal with autism in their daily life.

MS. GARDNER: This is the issue, this needs to come forward. We need to do something in this province and we need to do it now, because these rates, unfortunately, are increasing. They're not increasing primarily because we're getting better diagnoses, there's something else going on out there and we have no idea what it is. There are lots of pointers but we don't know.

Parents in Cape Breton need ABA. When you have a low-income family, they can't afford ABA. I tell parents, try to use your respite to get a little ABA so I have someone who takes my son three days a week and teaches him how to buy something at the store, or there are professionals out there. We need professionals who are recognized. As a society, we can make sure they have the child abuse things done and the like but we need more of that. But when it comes to ABA in particular, EIIS is so grossly underfunded and we're not getting

diagnoses early. We need early diagnoses and then we need to have that window opened for these families. I missed the window. I can't tell you how many nights I've lost sleep over missing the window.

You learn to have a lot of faith. That's the gist of it and if ABA had been in my life, I may not be here talking to you guys today and I wish I weren't - not that you're not all fine people. (Laughter)

MADAM CHAIRMAN: Bill.

MR. LANGILLE: Madam Chairman, this is a bit of a learning curve for me this morning, also. One of the things that I'm surprised at is that diagnosis is not done early. I'm hearing today that sometimes you get into the school system and are not diagnosed properly. I'm concerned about that aspect of it. I'm one of the government caucus people by the way. So, one of the things that you said was about coming under one umbrella, the Department of Health. I guess what I'm looking at is when you amalgamate them into the school program, into the educational system, how would the Department of Health be in charge of them while they're in school? Where are we looking at the monies coming from for that through the Department of Health or coming from the Department of Education, have you researched that prior to looking at that?

MR. DONOVAN: My feeling, my opinion here is that the Department of Health provides the money, it creates the treatment plan for that child. Within that treatment plan is the education plan. So, basically, the Department of Health funds it and informs the Department of Education what must be done for that child.

MR. LANGILLE: I would like to believe that it could be that simple, but I think there would be some roadblocks in the way of that. But I'm not saying you're wrong on that aspect, in fact, I think it's a good idea, it is just that I'm wondering how we could amalgamate it with the Department of Education in a seamless manner.

MR. DONOVAN: Would this not be up to the task force to come to grips with, the implementation plan, how they do it?

MR. LANGILLE: We haven't got a task force yet. So we'll have to look at that aspect and as Madam Chairman said, we'll have to see where we can go with that this morning whether we make a recommendation to the three ministers, the Minister of Health, the Minister of Education and the Minister of Community Services. We also have a budget coming out in the Spring, and we could make a recommendation for inclusion of this program into the budget. I believe that's within our realm. So I'm not going to keep you too long asking you questions. I appreciate you coming in today and I know it was very short notice. But the member for Annapolis, I guess I can use your name here . . .

MR. MCNEIL: As long as you say nice things, you can use it anywhere.

MR. LANGILLE: I'll save that for later. (Laughter) Yes, I know it was short notice and you have to thank Stephen for bringing you people in this morning. Thank you.

MADAM CHAIRMAN: Does anybody else want to speak for the first time? Gary.

MR. GARY HINES: I thank you for coming in. I don't know when we have had a presenting group in front of this committee that has brought forth so much information that has been helpful to me in particular. I can remember that I think the first and only thing I knew about autism was the movie Rain Man. I'm sure that's the public's perception and is what they see as autism. There was some intrigue that came out of that movie with, particularly the actor in the part that he played.

When I first got into politics four years ago, I had an opportunity to deal with two of my constituents who had children with autism. Again, for lack of a better word, I was intrigued by the children. I think what you have brought to me this morning is that the need for early intervention is so important. But in your presentation, sir, you indicated that we don't need to invent the wheel. We have models in other provinces that seemingly are working. I'm not sure that a task force is the approach that we need to take with this. I think that the information is there. Your group has given me enough information to realize that early intervention and your program with ABA is probably the route to go. But I'm hearing also that the medical fraternity really doesn't know a whole lot about autism either, to the point where they can do the diagnoses. That really concerns me.

Basically, I wanted to make those comments because it is from people like you that I have been able to learn so much just this morning. Also, I think it was on 20/20 just recently, there was an individual who through his own growth determined that he was an autistic and he actually married and he and his wife have both devoted their life to a book on it. I've actually written to get that book, because I was intrigued with his case.

MS. HARVEY: You can borrow it from our library.

MR. HINES: Is that right?

MS. HARVEY: We have it here.

MR. HINES: Basically I just wanted to make some comments that I think early intervention and a better understanding, and the fact that you people know so much about this, that maybe a task force is the slow way around this. I would be prepared, as a member of the caucus, to support a motion that we look at funding this in our budget and come forward, because I'm so totally taken with your presentation and your ability to relay your message to us.

[10:15 a.m.]

MADAM CHAIRMAN: Now, I just want to discuss with the members, I think I have three people who want to do a short snapper, Maureen, Mark and Leo, but we also need to leave time to discuss how we're going to handle a recommendation and what that recommendation is going to be. We do want to give our presenters just a couple of minutes, if they have any closing statements.

MS. MAUREEN MACDONALD: I'm okay, you can drop me from the list.

MADAM CHAIRMAN: Mark or Leo, do you still want to ask a quick question, or do you want to get directly into what kind of recommendation and support this committee . . .

MR. PARENT: I was going to talk about a motion. Do you want me to wait on that?

MADAM CHAIRMAN: Leo, are you comfortable with going right into that part of the meeting?

MR. GLAVINE: Sure. Absolutely.

MADAM CHAIRMAN: So we'll drop the second round. Stephen.

MR. MCNEIL: Before you get into that, I want to just put on the record my appreciation to all caucuses for supporting the motion to bring the Autism Society before this committee. I know it was on short notice and, as many of you know, this is our second meeting this month, and normally we only meet once a month. It's because of this being Autism Month. I just want to put that on the record, to thank all caucuses for their support.

MADAM CHAIRMAN: That you for bringing it to our attention, again. Certainly, a lot of us have been working on these issues over the past few years, and we recognize its significance and have some empathy and understanding of what families are going through, and we realize that there's quite a bit of urgency to this particular issue.

Let's just talk generally. What I would like to do instead of getting into motions and amendments is if we could agree on what approach we'd like to take as a committee, then we can phrase it into a motion and go through the formal part of it. I'll go back to Maureen, Mark and Leo, because I think they have some input they want to offer on where we might go next. Maureen, I had you down first.

MS. MAUREEN MACDONALD: I would like to see us stay very focused on getting the resources to implement the plan that has been developed over the last four years, across departments. I'm concerned that a task force would take us into more study, more quantifying, more debate, that kind of stuff. That would be my concern. I think that what we really need,

and I'm very encouraged by the government members on the committee saying let's, unanimously, here, pass a resolution or motion that directs the government to provide the resources for the plan that has been developed. If that's what you're looking at, let's really unite around that. That will send, I think, the strongest message that we could ever possibly hope for, coming out of this committee. That's the first thing I would say.

The other thing is, the task force that was proposed didn't have parent representatives on it, I would be concerned about that, in that form, if we were to go in that direction. Also, I have some concerns that we only focus on the Department of Health. I think the Department of Health is a key player, in terms of early diagnosis and early treatment, but there's a danger, if we medicalize this problem, this issue, and not have those other support services that families really need, the respite, the in-house supports, and then what happens in the school system. That would be a concern I would have, as well.

I would be very happy to support a motion directing the government to fund the plan that has already been worked on and that has ABA as its core.

MADAM CHAIRMAN: Let's hear from Mark and Leo before we actually put a motion on the table.

MR. PARENT: I was going to do a similar - I agree with what my colleague has to say. I was looking particularly at the work, and I'd need more information on this, of the autism research facility. Maybe they could be the lead on it. I think we need to not reinvent the wheel, we need to have a unified approach that does not medicalize the problem. I agree that's a worry. Early diagnosis, we've heard, is absolutely key. So I say let's get on with it, let's make some sort of motion.

I was going to make a motion that we support their work, and ask the minister to provide them with the necessary resources and funding. Now maybe they're not the ones we should ask. Maybe it should be more general than that, support the broad plan and provide it with the necessary funding. But I'm in agreement with what my colleague is saying, it's just a question of what's the best mechanism to get this done quickest, fastest and most effectively.

MADAM CHAIRMAN: Leo.

MR. GLAVINE: I guess I'm still a little bit of a proponent of the task force idea here, or some type of committee to work hand in hand with government. This is a cradle-to-grave issue, and it is not just the diagnosis and the preschool, and it is not just the school component, but it is the adult and lifelong, as well. I don't like the separation and the little categories that we can put autism neatly into, to be looked after, knowing, however, that certainly ABA is the most critical component, of course, that families need and need in place as soon as possible.

I'd like a more holistic approach to dealing with this. So I guess I have a little bit of reservation when I hear that the medical community, certainly, is not at the top of the information chart, that they need to be using. We, also, of course, around the province, have some very strong pockets of very professional work being done. For example, the Annapolis East Elementary School is an example where now we have military families who select Greenwood because of the program in the school there. So taking that expertise and getting it disseminated around the province, I think, is really important to the process. I'd like some kind of committee, at least, to work with government in rolling out the plan.

MADAM CHAIRMAN: I'm just wondering if I could make a suggestion. I think all of us are aware that sometimes committees and task forces can be used to delay decisions, especially around funding. I think with the extra federal money coming down for health, and the fact that the budgets for next year, provincially, have started that process, I wonder if there's some way a motion could cover an immediate recommendation to the relevant departments to start the plan that has already been presented to them but hasn't been funded. At the same time, we could either investigate the idea of a task force to look at those broader issues that cover the lifelong needs, or we could actually invite representatives from the Department of Health and CAYAC and Education in, and just find out what they're prepared to do to answer some of those broader questions. I just would be concerned about giving them any reason to delay action.

MR. MACKINNON: Madam Chairman, on that point, I would still like to go back and find out what in the heck was brought before the Cabinet Table during the budgetary process, because having sat in Cabinet, I know it would not be brought before the table unless the detail is provided to substantiate the application for funding. I would respectfully submit we could still proceed with the task force that this organization is recommending, but at the same time I believe this committee could probably either invite the Department of Health officials, the deputy minister or the minister or somebody, to come and answer for that particular issue, or at least this committee should write a letter to the Minister of Health, asking for the detail of that submission, because it affects the lives of many, many children.

MADAM CHAIRMAN: Well, we now have several strategies on the table. I'm just wondering, who feels prepared to . . .

MR. MCNEIL: I think we need to make a motion that we encourage or recommend to the government today that considering the new funding that's coming down from the federal government, that in part of this coming budget the ABA therapy program that is before them now be implemented. They can fund it with that, I think this should be added to it, in my own view, and I'll make this as part of the motion, that the task force should be put in place, whether it be over the next six months or eight months, to look at the long-term view of how we treat autism and the impact it has on the families, whether it be respite care and all those things. So, I'll put that out there.

MADAM CHAIRMAN: I wonder if we could separate those motions. Bill.

MR. LANGILLE: Thank you, Mr. McNeil, and I know where you're going with this on a task force, but I think the chairman was right in what she's saying. Sometimes these take a long time and I think in April we're looking at a budget and we know we have increased health care dollars, I think both provincial and federal. I believe at this time that we ought to lobby, by way of letter, the three ministers - namely the Minister of Health, the Minister of Education and the Minister of Community Services - for more money, more infusion into this program. I think sitting around here and looking at the MLAs, that this would be the route to go at this time.

MADAM CHAIRMAN: Mark, Maureen and then Leo.

MR. PARENT: I'm willing to make a motion to that effect that we go on record as supporting the initiatives in the three departments that Bill mentioned regarding autism support and treatment, as well as the autism research facility, and that we ask the government to provide the necessary resources and funding that are needed to implement the plans that are already in place.

MADAM CHAIRMAN: Are you putting that on the table now? Is there a seconder?

MR. HINES: I'll second it.

MS. MAUREEN MACDONALD: On a point of order. I think Mr. McNeil has a motion on the floor already and I don't think you can move a second motion. (Interruptions)

MR. PARENT: Well, it wasn't seconded.

MADAM CHAIRMAN: That was my fault. I didn't ask for a seconder before we started . . .

MS. MORA STEVENS (Legislative Committee Coordinator): You don't need a seconder.

MADAM CHAIRMAN: We don't need a seconder?

MS. STEVENS: You don't need a seconder. (Interruption)

MR. LANGILLE: Could you repeat the motion?

MR. MCNEIL: Sure. My motion was that we recommend or encourage the government, from this committee, that considering the new federal money that is coming down for health, that they implement in this coming budget the ABA therapy that has been before them and I believe a task force should be put in place to look at how we deal with this on an

ongoing basis. But the key part of that motion is to immediately implement it in this coming budget.

MADAM CHAIRMAN: You want to combine them in the same motion do you, Stephen?

MR. MCNEIL: Yes.

MADAM CHAIRMAN: I'm sorry, Mark, that is the motion on the floor because he did present that. I understand we don't need a seconder. So is there discussion on Stephen's motion? Yes, Bill.

MR. LANGILLE: I guess I have a hard time putting the two into the one motion. Personally, I would rather see it separated, your first motion and we could vote on that, which I'm definitely in favour of, but to lump that in it's pretty hard for us to do that in one motion.

MR. MCNEIL: I'm okay with that, Madam Chairman, if you wanted to separate them.

MADAM CHAIRMAN: Okay, let's separate the motion. So the first one is asking the government to take immediate action in terms of funding the ABA plans that have already been presented to Cabinet. Is there any further discussion on that motion?

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

The motion has been adopted unanimously.

Now, the second one is to handle all the other aspects of this huge issue. Stephen's motion is to call for a task force. Is there any discussion on that motion? (Interruptions) I'll get back to you, Bill. Maureen, then Mark and Bill.

MS. MAUREEN MACDONALD: I wonder if what could be done before a motion striking a task force, I'm not sure, I don't know, because I'm not normally on this committee, but I don't know whether or not we have the power to strike a task force (Interruptions) To recommend a task force.

One of the things that I'm wondering is whether or not we shouldn't bring in the early identification and intervention subcommittee from CAYAC first. Because as I understand it, they are Education, Community Services, Health and people from the field of psychology and what have you. So they, on some level, might be the task force; they are the working group that has developed a plan, so perhaps we should hear from them first about their work, where they are now and what have you, and then maybe it would be appropriate to look at striking a task force if we don't see them as meeting the needs. But my concern is that we not duplicate,

that we not have two groups working at cross purposes, particularly if one group is resourced and the other group isn't resourced.

MADAM CHAIRMAN: Let's hear the others and I've added you to the list. Is that okay, Stephen? Mark.

MR. PARENT: I agree wholeheartedly. Let's hear from the people who are already doing this work and then we can make further decisions if it needs to be augmented in some way or something, but let's hear from them first.

MADAM CHAIRMAN: Bill.

MR. LANGILLE: We just passed one motion here and I believe we ought to look at that motion and give it a chance to work. We are looking at a six-month window here before the budget comes down, rather than jumping in and looking for a task force at this particular time. Maybe we ought to take a step backwards right now rather than trying to go too forward.

MR. MACKINNON: That's the problem, Bill, we've been going backwards . . .

MR. LANGILLE: Yes, but I believe that if we give this a chance to work that in six months there probably will be extra funding here. After, if there isn't, then we can look at a task force.

MADAM CHAIRMAN: Jo-Lynn has asked just to make a comment. Are you willing, Stephen, to let her come in here?

MS. FENTON: It was more just around the EIIS project. That was a pilot project put in place for three years. The core money has been moved to base budget funding. So EIIS in it's, I guess, original style doesn't exist anymore, so I'm not sure whether or not the provincial committee is still tasked to do any jobs. So whether or not it's appropriate to call them, I'm unsure. Also, their focus is more on age zero to six. I do believe that Stephen's motion was more for lifespan issues around respite care and adult care and for people who need it, because although ABA therapy works extremely well with young children, it doesn't stop when you become six. It's a very effective therapy right into adulthood, for teaching any skill or technique that you need.

MADAM CHAIRMAN: Okay, thank you. Stephen.

MR. MCNEIL: I think I should leave it at that but being a politician I won't. (Laughter) One of the things around the committee is, and again I'll go back and express my appreciation to everybody for doing another one, is the committee is pretty booked ahead, as has just been talked about. The other thing that I envision for the task force is being able to bring all these groups together, giving them an opportunity to have a public forum - CAYAC, VAST and all

the other organizations - to bring the information that they have together so that we can, somehow, come out of that with some kind of a direction on a long-term approach.

I don't see the task force as opposing the motion that we made earlier or in any way duplicating anything. I think in many ways it's a culmination of bringing stuff that has already been done and handing them the chance to present that in a public forum and, quite frankly, to educate not only us but a good number of Nova Scotians. If this task force does nothing else but begins educating people on autism, it would be a good step in the right direction.

So I still submit that we should be holding a task force to deal with the long-term effects of autism and I hope that the committee would approve that and we move forward on that in the new year.

MADAM CHAIRMAN: I know that this is dangerous to state my position from the Chair but I just want to save time. I guess my concern with the task force is once we send that recommendation in, it's out of our hands, right? As a committee, we have nothing more to do with it. But if we did something like put in a special meeting or moved up those representatives for a second meeting on this topic or perhaps had another forum on autism and invited all those groups to the Red Room, the way we've done with family violence, that still is within our control and it gives us more information so we know what to act upon. So I'll just leave that as sort of factual information.

The motion on the floor, then, is to recommend to the provincial government that they appoint a task force to look at the lifelong issues affecting people with autism. Is that basically the essence of your motion? Okay.

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

The motion is carried.

Would you like to perhaps just take a minute or two to make a summary statement or whatever?

MS. HARVEY: Yes, something very brief. First of all, again, thank you so much for this opportunity to share this information with you, and to have your responses. You've been tremendous, and we appreciate that. Living in a family that's affected by ASD, autism spectrum disorder, is a very difficult experience. It's one that's filled with multitudes of emotions. Parents can feel great sorrow and despair at the loss of the children they thought they had, and immense joy at the thrill of seeing a goal achieved and a child moving forward, the potential that's there might be recognized. All individuals in Nova Scotia who have ASD are knocking at the government's door, and we're hoping you're going to answer. Thank you.

MADAM CHAIRMAN: I just want to say, on behalf of the committee, we really appreciate all of you coming here today. It's one thing to talk about that as sort of an academic issue, but when your family has been personally touched by this, we understand the special strain that puts on you, and we thank you so much for being so articulate and really giving us so much more information, so that hopefully we're going to be able to work with you in the future to move forward on many of these challenges facing families in Nova Scotia. Thank you very much for coming today. You did an excellent job.

[10:37 a.m. The committee recessed.]

[10:42 a.m. The committee reconvened.]

MADAM CHAIRMAN: I will call the committee members back to the table. This is a little unusual, and I want to explain to you what happened. The YWCA has been trying to get some funding answers from the Department of Community Services. They're really down to a crunch, to the point where if something doesn't happen soon, they're going to have to close a very important part of their operation next week. So, there's a lot of urgency to this particular issue.

We've actually asked a representative from the YWCA here today, and you can choose either to just use this time to schedule the YWCA on our continuing agenda, or we could actually take a few minutes to just discuss the essential aspects of this issue. Mark.

MR. PARENT: I would just throw into the pot, because I didn't do an e-mail, I used the old snail-mail approach, I don't know if you've gotten my letter yet, but we have a funding crunch with alternative transportation societies, and I think it's not just in the Annapolis Valley, I think it affects other societies as well. So I should have done an e-mail, I did it the old-fashioned way and you probably haven't gotten it, but I've asked for that to be an agenda item.

MADAM CHAIRMAN: In terms of placing them on our agenda?

MR. PARENT: Yes, and there is urgency in that one, as well, I guess, particularly with, I think we are going to be able to keep the Annapolis Valley by doing some bridge financing - it's municipal services that fund these programs - getting them to do advance funding on their yearly allotment.

MADAM CHAIRMAN: Okay, but I'm just wondering, let's add it under the YWCA, okay, and finish with the YWCA and then perhaps we can see how the committee wants to deal with that one. But yes, there are a lot of funding crises happening this time of the year.

MR. PARENT: So you are asking if we want to listen to the YWCA rep today for five minutes?

[10:45 a.m.]

MADAM CHAIRMAN: Yes, I can summarize in one sentence what the issue is and then that might help you. Basically, about half of the clients using the YWCA's shelter and support services for women in transition are clients of the Department of Community Services but the department is only paying for about half of the actual costs of providing this program and this service. One woman in particular, I think, has lived in that shelter situation for 20 years. I mean, this is not necessarily just a short-term, temporary support program. The department has sent in their own auditors and has found that actually the department owes the YWCA more money than the YWCA even thought it did. So basically it is ending up that the YWCA is subsidizing a program for some of the department's clients. The YWCA has a meeting on Friday with the minister but the department is not giving any indication of whether they are going to come through and this program will have to shut down next week.

MR. PARENT: Could I just speak to that because we have a similar thing with the item I'm bringing forward. They actually found out that the department owed them \$3,500. I think if Community Services has underpaid and they have determined that at their own audit, then I don't see any real problem in getting that money. Who is the MLA for the area?

MADAM CHAIRMAN: Danny Graham is it? Well, Sue Wolstenholme who is the Co-Executive Director of the YWCA is here just in case there are (Interruption) Pardon?

MS. MAUREEN MACDONALD: What is it that they want this committee to do?

MADAM CHAIRMAN: Sue, do you want to speak to that rather than me perhaps misinterpreting your views? Maureen is asking what, specifically, would you like the committee to do?

MR. PARENT: Are we going to have time to discuss these other items? (Interruptions)

MR. MACKINNON: Madam Chairman, on a point of order, I think we have to be careful of establishing precedents here. I have no problem listening to our witness, if that's the will of the committee, but we seem to be going a little bit off the mandate of our committee and I'm concerned that we are starting to lose our focus a little and become - I hate to use the word but - oversensitized to individual cases. That is in no way to diminish the importance of this issue and I believe anyone who knows me knows that but I am a bit concerned that if we are going to kind of jump into the middle of ongoing budgetary matters, then we are going to lose our focus.

There is a budget coming out in the Spring, there are ongoing things. The issue has been indicated or spoken to about the fact there has been an audit and it has been determined. We are assuming a lot of things here and if we start fragmenting the mandate of the committee and start going on an ad hoc basis every time something comes up - and I am fully supportive

of listening to this issue and so on but I have absolutely no detail and to start coming to conclusions without representations from the appropriate authorities, all the stakeholders, the MLA for the area, everything.

MADAM CHAIRMAN: I appreciate your point, Russell, but I think the situation, we were just trying to get enough information on the table to know whether it is something you wanted to deal with here today or whether you wanted to move up on the agenda, the long list.

MR. MACKINNON: But propping the mandate of this committee with individual witnesses coming in on an ad hoc basis sets a very dangerous precedent and I think, in all fairness, it is very concerning. I am at the will of the committee. I am fully supportive. You know I support social causes to the nth power.

MADAM CHAIRMAN: But we have had a number of groups ask to appear before us in the last year and quite frankly, part of the reason they've had to do that is because they're not getting timely responses from the various departments that they deal with. I'm just thinking of transition houses, women's centres, even this autism, that's basically a budget decision.

MR. MACKINNON: Madam Chairman, with all due respect, those individuals in those organizations have presented written briefs for this committee to be able to review, to make a determination.

MADAM CHAIRMAN: Yes, and this organization can do the same thing.

MR. MACKINNON: So do we have a copy of the audit here today?

MADAM CHAIRMAN: No, but Maureen just asked a question that I couldn't answer, and that's why I was going to get Sue to answer it. What are they requesting the committee to do? That's why we've asked her to answer that.

MR. LANGILLE: Madam Chairman, if I may, I realize you have a meeting with the Minister of Community Services on Friday to discuss this budgetary shortfall.

MS. SUE WOLSTENHOLME: Yes.

MR. LANGILLE: You say that Community Services owes you money now; how much money do they owe you, what are we talking about?

MS. WOLSTENHOLME: It's about \$60,000.

MR. LANGILLE: But you are meeting with the minister.

MS. WOLSTENHOLME: We are meeting with him, yes.

MR. LANGILLE: This is Thursday, that's tomorrow.

MS. WOLSTENHOLME: This has been an ongoing issue, attempting to get this issue resolved. I guess that's why we've asked the committee to consider it, because we don't seem to be getting anywhere. We do have a meeting tomorrow. We've had other meetings. This will be the second meeting we've had with the minister. We've had many meetings with his officials. We haven't gotten a resolution. We can't continue to lose money.

MADAM CHAIRMAN: Are you asking us, then, basically, to fast-track your appearance before this committee? That's what you're asking?

MS. WOLSTENHOLME: Yes.

MS. MAUREEN MACDONALD: I'm not normally on this committee, so I don't really know . . .

MR. MACKINNON: There are so many important issues. We've done this with the autism issue. If we're going to start doing this - and I'd dearly love to be able to read that audit, I'd dearly love to be able to know what the details . . .

MS. WOLSTENHOLME: I have to tell you that we haven't been able to read it yet.

MR. MACKINNON: Then, I think it's irresponsible for this committee at this point to start jumping into the middle of something, when we don't have sufficient detail. I'm pretty fair-minded and I'll go to bat for this organization or any organization at any time, but we have to be careful about what we're doing here.

MADAM CHAIRMAN: Will you allow them then to request to be on our agenda?

MR. MACKINNON: We can certainly, as a committee, send a letter of support for this organization, and the fact that the concern has been raised and we, as a committee, are concerned about the long-term implications of that. Then just leave it at that for an add-in and perhaps we can put it on the agenda for a future day.

MR. PARENT: I wouldn't even know how to phrase that letter without being so general, without proper background.

MR. MCNEIL: Madam Chairman, if we could maybe have the YWCA contact you following their meeting on Friday, because their meeting Friday, tomorrow, with the minister may solve some of those problems for them. If they still require or request to come before us, then, by all means, I think we should be entertaining that request, no question. Once we get the information from their meeting tomorrow with the minister . . .

MR. MACKINNON: I know it's very concerning for this witness, and I appreciate the sincerity of it, and it's a very large issue. (Interruptions)

MS. MAUREEN MACDONALD: Could I make a suggestion? I'm not normally on this committee, but I'm wondering if, following the meeting it looks like programs will be lost, then the committee would hear what the issues are in an effort to be able to be helpful around preserving a program, if that's what the implication is. We don't know that at this moment, is that fair to say?

MADAM CHAIRMAN: What time is your meeting tomorrow?

MS. WOLSTENHOLME: At 9:00 a.m.

MADAM CHAIRMAN: How about, tomorrow, we find out what's happening, and an e-mail will go out to your office, through Mora, just giving you an update. Perhaps, depending on what the news is, we could list some options, and then you could respond, and we can decide as a committee how to deal with it.

Is it agreed?

It is agreed.

Thanks very much.

So, Mark, how do you want to . . .

MR. PARENT: I just wanted to alert you that I had that letter. That's an issue for me, too, for Annapolis. I don't know if Leo has been talking with them but I know it affects the one in Yarmouth and Annapolis so I just wrote a letter. Apparently the funding that was there last year was about \$0.5 million. It has been cut back and fuel costs have gone up, insurance costs have gone up and I assume if I'm trying to beg for money from them that others are having to as well. So I wrote a letter just asking they be put on the agenda in as timely a fashion as possible and that was all I wanted to mention. I should have done it by e-mail but I did it by snail mail.

MS. STEVENS: If you e-mail that to me, I can send it out with the response from the YWCA and then it would be out there.

MR. PARENT: I thought you might have gotten it by now. I wrote it a couple of days ago.

MADAM CHAIRMAN: Then we can put it on the next agenda.

Okay, if you will turn to the second page of your agenda, these are mostly just for your information. Mora has been trying to get the home care issue on the agenda. I know we talked originally about it happening in January. Now it looks as though there is a possibility of dealing with that issue either November 18th or November 25th. So we need to know whether you want to go ahead with that and we still don't have a date for the deputy ministers to have that second part of the Forum on Family Violence. It looks as though that might be moved into early December.

MR. LANGILLE: What's that?

MADAM CHAIRMAN: The forum with the deputy ministers, but hopefully we could piggyback it on something that people were coming to town for that time of year. Did you have any more information on those, Mora?

MS. STEVENS: I'm just waiting for home care to get back to me for the best November date. The other one that was going to be in November was the small options homes. That didn't quite work so it was faster to get the home care in and then the other one would be in January. So that's why the switch.

MADAM CHAIRMAN: Mark, I just want to give you a heads-up. If they come on November 25th, I'm not going to be able to be here so I would ask you to chair that meeting.

MR. PARENT: When will we find that out, Madam Chairman?

MADAM CHAIRMAN: I'm not sure.

MS. STEVENS: I should know by the end of this week. I was hoping to even know by this morning but it just didn't work.

MR. PARENT: Okay.

MADAM CHAIRMAN: Okay, is there anything else that needs to be discussed as committee business? A motion to adjourn.

MR. MACKINNON: So moved.

MADAM CHAIRMAN: The meeting is adjourned.

[The committee adjourned at 10:58 a.m.]