

THE STANDING SENATE COMMITTEE ON SOCIAL AFFAIRS, SCIENCE AND TECHNOLOGY
EVIDENCE

OTTAWA, Wednesday, November 8, 2006

The Standing Senate Committee on Social Affairs, Science and Technology met this day at 4 p.m. to consider the inquiry on the issue of funding for the treatment of autism.

Senator Art Eggleton (*Chairman*) in the chair.

The Chairman: The Standing Senate Committee on Social Affairs, Science and Technology continues its examination of issues involving autism, particularly with respect to the funding aspects.

We are pleased to have Mary Anne Chambers with us this afternoon. She is the Minister of Children and Youth Services for the Province of Ontario. Just by way of introduction, although some of us around the table know her quite well, the minister is the provincial MLA for the Toronto riding of Scarborough East and has been since October 2003. She served as Minister of Training, Colleges and Universities before coming into this position in 2005. She has had a long career in the private sector as well, most notably a lot of volunteer work in organizations such as the United Way, where she served on the board as the past chair of the United Way of Canada, in fact. She is the past president of the Canadian Club of Toronto, former Governor of the University of Toronto, and was vice-chair of the governing council for three years. She came into the position of Minister of Children and Youth Services with support for youth services in her area, and so comes quite naturally to something that she is now involved with as minister.

Minister, I will let you take it from there for some introductory remarks, and then we will come around the table for some dialogue.

Mary Anne Chambers, Minister, Department of Children and Youth Services of Ontario: Thank you, Senator Eggleton. It is a pleasure to be here. Interestingly enough, at my first FBT minister's meeting, I actually suggested to my provincial and territorial counterparts that we get together and talk about autism on a national scale. I did that because I felt I needed help in Ontario, because this has been a little bit of a challenge for us. However, we are turning the page, and I am very happy to speak about it.

The first time I had any significant insight into autism and what it means to kids and their families was about 14 or 15 years ago when one of my sons got a job as a youth worker while he was at McMaster University. The job was to work with a 14 year old autistic boy, more as a companion than anything else. When he had his interview with Michael's mother, she said, "I look forward and pray for the day, just one day, when Michael will not hit me." My son decided that that was the behaviour he would focus on. One day, he arrived at their home, and she was in tears. He thought, "Oh, dear, what has happened?" She said, "Today, Michael said, 'You know, mom, I really do not like when you do that,'" and he did not hit her.

Autism spectrum disorders range in severity, starting from quite mild, almost indistinguishable. There are lawyers practising in this province who have ASD at the milder end. It goes to the very severe, where kids tear their homes apart and beat up their parents when they are asleep. I have photographs showing where they injure themselves very badly. There are also parents who speak about autism from the perspective of these kids simply learn differently. We concluded that no two kids with autism spectrum disorder are alike.

Until July of last year, Ontario provided intensive behavioural intervention, or IBI, therapy for kids until they reached the age of six. Very shortly after I was appointed to this ministry, in keeping with a commitment that the premier had made in 2003 during our campaign, a commitment not to discontinue IBI therapy at age six, that changed. I read some of the notes from Hansard and some of the debates that you have been having on this subject. I wanted to put that on record that Ontario no longer discharges kids on the basis of age. That is the good news.

The other news is that our waiting lists for IBI therapy have grown substantially. Right now, we are providing IBI therapy to just about 900 children. Of that number, approximately 60 per cent are age six or older. We have waiting for intensive behavioural intervention therapy approximately 1,000 kids, and about 45 per cent of that number are age six or over.

This was actually a program that was designed as a preschool program, hence the age. What I have learned from what we are seeing is that parents are not satisfied with the supports that their children get in the school system. Otherwise, they would move them out of school because they really do want their kids in as normal a setting as possible. An integrated educational system is where they want their kids to be. In 2004, there were an estimated 7,000 kids with autism in the publicly funded school system in Ontario.

What we are working on is, first, greater support for kids whose families would like them to receive intensive behavioural intervention therapy, which can be anything from 14 to 24 hours a week of intensive behaviour intervention. At the same time, we are working to provide more supports beyond that -- that is, a continuum of services -- so that regardless of age or stage of development there will be services available for these kids. We must also ensure that we have the capacity, the service providers, to support these kids. Much has been said about families moving to Alberta, but you may or may not have heard that they are not necessarily getting the service. They are getting the money for the services but they actually have a very severe shortage of service providers. We have read about Ontario families who have gone to Alberta and then said this is not what we expected.

I will come back to the financial aspect of it in a minute but in terms of building capacity in Ontario, last year we started a college graduate level program that is delivered out of nine colleges in Ontario. We are training behaviour analysts who can work as instructive therapists providing IBI for kids. We had the first cohort of 92 graduates this spring. By 2008-09, we should have 200 therapists graduating each year. We are also training childcare workers. We have a target of 1600 childcare workers to be trained so that if children are in child-care facilities, the people who work with them will understand what their needs are and how to help them learn. We are also training 5,000 education teaching assistants in the school system, again because we know that these children will benefit from some one-on-one types of supports. We also have a school support program where we have had 180 consultants working with educators to help them understand the principles of applied behaviour analysis so they can support their students in school.

As far as the financial side is concerned, we have more than doubled spending on autism over the past couple of years. Ontario's budget for autism is \$112 million per year, and that is the autism-focused budget. In addition to that, we also provide speech and language therapy and other kinds of therapies for children with complex special needs, including autism, through our children's treatment centres where we have a budget similar in size to the one that is focused on autism.

Yes, it is expensive. One of the reasons why it is expensive is because of the amount of hours of therapy involved. As I mentioned, IBI would be anywhere between 25 to 40 hours per week. We average somewhere between \$35,000 and \$50,000 per year per child receiving IBI therapy. You have heard from parents who are aware that parents are financially strapped. Even some of the children who are on our waiting list are actually receiving services, but at their parents' expense. We hear about parents remortgaging their homes and moving into their in-laws' basement. It is a very difficult situation.

We also hear about people not being able to stay in the workforce. A mother said to me other day, "Two weeks into my new job my employer said I need someone I can rely on. I cannot keep you," because she had to miss a few days to take care of her son. Her husband had had a nervous breakdown over these challenges. The day before she spoke with me she said, "I cannot handle this any more. I love our son but I cannot handle this any more." He then left.

We see cases of family break down, and we see people not being able to work, which adds to the financial hardships. This is not a condition for which there is a cure so far. We started a research chair at the University of Western Ontario towards the end of last year or early this year. The research is actually very thin on ASD, autism spectrum disorder.

I am happy to be here to provide input to the work you are doing. I am happy you are working on it. I also have some ideas as to what a national strategy could entail. Maybe I should stop now and allow you to ask me questions. Somewhere through the discussion, perhaps I can talk about some of the thoughts I have.

The Chairman: We would like to hear those. That would have been one of my questions. There are a number of members of the committee that are not here because the Senate is still sitting. Normally, we try not to have a conflicting arrangement but the Senate is still in session dealing with Bill C-2, the accountability bill. At least there are five of us here.

We will start with Senator Munson.

Senator Munson: Welcome, minister. I can hear in your voice that you are passionate about this. That is extremely important. It has reached the point where the autism situation has gone to the courts. I understand today that 35 families in Ontario are taking the Ontario government to the Supreme Court. They have appealed. They are saying that the Ontario Court of Appeal made several errors in its judgment this summer. Would you care to comment on that?

Ms. Chambers: It was 27 families, with 33 kids, who had launched the case a few years ago. It was with regard to the age cut-off. When our government came into office, the court hearing continued. It was continued on the basis of jurisdiction -- that is, who has jurisdiction over the determination of how public resources should be allocated? The Court of Appeal determined that it is the government that has that responsibility. The Court of Appeal for Ontario ruling indicated that the government was not obliged to provide services for children beyond age six and older.

In fact that was an exercise about jurisdiction. As a matter of fact, we are providing services. As of July last year we have been providing services for kids, IBI for kids, including services for those families, age six and over.

I will continue to go along that route. That is our commitment and that is what we think is the right thing to do. The court case has been one of jurisdiction and it has not changed our delivery of support to these kids beyond the age of six.

Senator Munson: Since this case is now before a court again I will not go any further there, but you did talk at the very beginning of our discussion about your own ideas at the beginning of a national strategy and dealing with this. You said you actually suggested that there maybe should be a ministerial conference. Do you still believe that should be done and would you call for one?

Ms. Chambers: I actually spoke about it with my provincial and territorial counterparts. I did not get a lot of interest in it. Alberta said they were doing fine, thank you very much. I do not know if I was the only one but I was the one who expressed an interest and a need. I do not know if you have heard otherwise from speaking with ministers in any of the other provinces or territories but the interesting thing is that what Alberta does is quite different. Alberta does not have an IBI-focused program per se, or an autism-focused program. Autism presents a number of characteristics in terms of behaviours, et cetera, so they have a multidisciplinary team that assesses kids and will say, okay, we will fund X number of hours of speech therapy or Y number of hours of behaviour therapy or whatever. They do not track numbers of kids with autism.

As I mentioned before, they actually have a resource problem in terms of service providers. However, for the family that is mortgaged and re-mortgaged and re-mortgaged, the financial aspect is very severe and very significant for them.

My understanding is that there is not much in the way of federal-provincial-territorial coordination on autism, because at the federal level it comes under health and at the provincial level it comes under social services and never the twain shall meet.

Senator Munson: You talked about the whole idea of resources. I think Ontario has the same problem despite the new monies that have been poured into this. You talked about the problem of growing waiting lists and those young people between the ages of three and six who are waiting, when the key time of getting this intensive behavioural therapy or something along that line is not happening and you may say they will get treatment beyond the age of six now, but we are still losing the opportunity, from my perspective, in Ontario the opportunity to do something for these young people when they are diagnosed at the age of two or three.

Ms. Chambers: I will define "resources" more clearly. Alberta has money. They do not have sufficient service providers. We have been building service provider capacity. At this point in time we have no clear indication that we have a service provider shortage but we have been training service providers in an aggressive way. What we obviously need more of is money, even though we have more than doubled spending on this file. Remember, our population is about 39 per cent of the population of Canada, so Alberta is actually dealing with a population smaller than Ontario's. They have the money. They need the service providers. I am very nervous about losing service providers from Ontario who might be interested in going to Alberta, where they would not only get jobs readily but they would be paid handsomely. I am nervous about that because I am training them and I want them to be in Ontario.

Senator Munson: Do you feel there is a crisis yourself at this time, because of the numbers that we keep hearing? The way I look at it is that if you live in New Brunswick you get some form of treatment; if you live in Ontario you get some form of treatment. It is just a hodgepodge scattered approach and sometimes it is very good and sometimes, as you say, there is not enough money. I guess there never is enough money, but there seem to be 10 different approaches to this in 10 different provinces and territories and from my perspective I fully believe in a national strategy of some sort where you can sit down with your federal counterpart here and

other ministers and work something out so there are envelopes that money goes directly into an autism portfolio.

Ms. Chambers: In Ontario we have money that goes directly into the autism portfolio. We have \$112 million that is only spent on autism. In addition to that we spend several more millions on services that are delivered by children's treatment centres which also benefit children with autism.

If we are talking about a national strategy, one thing we can discuss today is what that could look like because until we talk about what that could look like it would be presumptuous for me to say that all the provinces and territories should do the same thing or have the same programs.

The Ontario program, for example, is autism focused. It is IBI, which all the research suggests provides good results and the earlier the intervention the better. We are finding that most kids with autism spectrum disorder are diagnosed around a year and a half to two years old. In terms of crisis, I would not call it a crisis with the lack of a national strategy. It is a little bit of a leap in my mind to crisis because we do not have a national strategy.

I would say that certainly the numbers on our wait lists would be smaller if we were not including six year olds or older kids on the wait list, obviously, because 61 per cent of the kids who are receiving IBI right now are six years old. If we were discharging them on the basis of age, our wait list situation would look quite different. Our wait list also is comprised 45 per cent of kids who are six or older. Again, if those kids were not there our wait lists would be shorter.

My objective is not to simply have kids go away so we do not have to do the right thing for them. My objective is to do the right thing for the kids and to provide the supports that will benefit them.

Senator Cordy: You certainly do sound passionate about the issue of autism and in my other life I was an elementally schoolteacher so I know some of the stories of which you speak, of parents coming in extremely frustrated and parents who were quite delighted when their children started school because for them it was the first period since the child had been born that they actually had some quote-unquote free time, Some respite from care giving of the child. In many cases there were two children because, as you said, it is diagnosed at the age of one and a half or two and in many cases another child had been born or the mother was pregnant with a second child too who had exhibited autistic tendencies.

To follow up on Senator Munson's questions, I am wondering about a national strategy and how we develop one. Do we do it through federal-provincial-territorial discussions? You have already said they have not been too successful. Do we look at top down looking at it from a federal perspective and have federal legislation? What would you suggest would be the most successful way of doing it?

Ms. Chambers: When I think of what could be done nationally, I think of things that could benefit all families wherever they happen to be in this country. I have not gone as far as to say we should all do the same things for these kids, but when I think of a national strategy I think of something that originates at the federal level and would benefit all kids and families.

Would this be a good time for me to touch on some of them?

Senator Cordy: It would be a good time.

Ms. Chambers: One thing parents tell me, and you will find this, is that many people do not know what autism is. Many people think the children just misbehave; they are out of control; they have tantrums. School bus drivers say they cannot take these kids because when they use a different route the kids get upset because anything destabilizing or unfamiliar can cause a child with autism to have an episode, a severe reaction.

One mother told me that she tried to explain at length to some people at an event she was at that the reason why her child would not get up off the floor and kept doing things that other children were not doing was because he was autistic, and she felt as if she was making excuses. One thing that could be done across this country is to launch a public awareness campaign, to help people understand autism.

Some parents say, "My kids have special talents. They learn differently. External triggers cause reactions." In fact, some of these behaviours can be tempered by available treatments.

There is correlation also between ADHD -- attention deficit hyperactivity disorder -- and autism and other conditions that tend to be seen as mental illnesses. There could be greater public awareness of what autism looks like and how people could work with kids with autism -- not work with intensively but socialize with or live with them. "Tolerate" sounds terrible; we want understanding of what is happening there. It would go a long way to helping parents cope, and helping kids to avoid the triggers to which they react so badly.

I mentioned that many parents with children with autism have had to leave or have not been able to enter the workforce. We have support at the taxation level for caregivers, for babysitting, for people who look after their senior relatives, for example. There is no such consideration for families with children with autism. Even with the 900 children who are receiving intensive behavioural intervention in Ontario, their families still have financial challenges for expenses that are associated with the condition that their child has or children have. Incidentally, I have met many families with more than one child with autism. One is challenging enough, but two or three?

Direct grants or tax deductions to help reduce the financial burden could happen at the national level. There could be tax deductions for services. One father was very emotional when he spoke with me the other day. His child was diagnosed three or four months ago. He said, "I cannot continue. I just do not have this kind of money. I have other kids and other responsibilities. Is there not even tax relief for my expenses?"

There is tax relief for medical expenses over a certain amount, medical expenses that are not covered by OHIP or other kinds of health insurance plans. It has just not hit that radar, if you like.

Senator Munson showed me an article from today's *Ottawa Citizen* newspaper, in which research suggests possible causes of autism. As I said, we created a research chair the last year at the University of Western Ontario, simply because there is so little research being done on autism.

I do not know if there is an increasing number of kids with autism. I do know that diagnoses that would not have occurred ten or 15 years ago are now occurring. Parents have told me there was a time when physicians would not diagnose their children because it was like a death sentence; they just could not tell them. They just could not bring themselves to tell parents that this was happening to their child.

We also have a severe shortage, in the thousands, of child psychologists. I have heard very little about that issue. In fact, I only heard about it when I came into this ministry, in the context of my youth justice portfolio. It is more often than not psychologists who are involved as case managers, doing the diagnoses and the ongoing assessments of these children because, as I have indicated, there are a variety of services that can benefit these children and their families.

Those are some of the ideas I have. Money is always something that provinces and territories would love to have more of from the federal government. I assume that is a given on everyone's wish list. When we talk about a national strategy, I equate that with national recognition, appreciation and support for the challenges that families with autistic children face.

It is important to know that autism, so far, is not curable. What happens with these kinds of behavioural interventions where medication is brought to bear is a tempering of the behaviours, a tempering of the symptoms, but autism does not go away. As some of you have recognized from the notes I have read, as these children get older and as their parents get older, we are looking at the fact that the parents will not be able to take care of their children any more. There are different stages of residential opportunities or options for people with a range of disabilities. We have assisted living, supportive housing, semi-independent living, and finally, fully dependent living.

In Ontario we have adults who became adults in children's facilities. Residential supports are not sufficient, and these come at great cost. The more that we can do with our children to enable them to get to the point where their potential actually includes some ability to take care of themselves, the better it will be for the country as a whole and certainly a huge relief to their parents.

The Chairman: I will piggyback on this and ask you a supplementary with respect to this development of a national autistic strategy. In terms of delivery of health care services and social services, those are provincial jurisdictions, but we have developed strategies here before.

We have a national diabetes strategy; there are numerous other ones – for example, cancer – that have been developed. However, we have never gone to the extent, for example, of one proposed private member's bill in the House of Commons that suggests that we say that IBI should be indicated as a health requirement in terms of the Canada Health Act. That kind of thing has never happened before.

How far should the federal government get into this? Tax deductions and those things you have mentioned, yes, certainly, and public awareness campaigns could be federally led or it could be by organizations such as the Autistic Society.

Since we need to work this out as a Senate committee, in terms of the federal government involvement in all of this and particularly the funding aspect of it, what would you see as the appropriate federal role in that development?

Ms. Chambers: Just about all of what I have mentioned in terms of role involves fiscal contributions, because that is very significant. As it is right now, all of money that we are spending is going to services for the kids or to training for workers in the field.

In terms of who should actually deliver, it is not necessarily the same as who should fund. For Autism Society Ontario, we have funded the development and maintenance of a new website called Abacus List. We have two options – a direct service option where we do not give parents any money; we provide them with services, which they receive through our service providers, and we pay the service providers. We also have a direct funding option, where we give the parents the money to buy the services from service providers that they choose.

One thing that parents were telling us was that they could not determine whether or not the service provider was appropriately qualified to help their kids. We created, with Autism Society Ontario, a list of questions that they could ask to determine the qualifications of the prospective service provider.

We also are funding a registry, and this has been very popular. This was implemented in July of this year and they have had thousands of hits against this website. This registry includes service provider names, locations where they provide their services, the kinds of services they provide and their qualifications, so that parents have something to go on when seeking service providers.

The other thing that we are working on, and parents have said would be very useful to them, is certification of the service providers. In Ontario, we are working with an organization called the Association of Behavior Analysis. They have taken this idea to their membership and we expect to hear from them in January, where we could have at least a standard certification. That is an example of something that could be standard across the country.

We could also go a step further, which would be to establish a regulatory body for behaviour analysts or therapists.

From a standards perspective, these kids have unique characteristics, so to say that every child needs the same thing would not apply to kids with ASD, autism spectrum disorder. However, in terms of helping to ensure that the service providers meet certain standards, that is fair.

I have worked with regulatory colleges before and that tends to reside at the provincial and territorial level; I am not sure that that has to be nationally directed. On the subject of health coverage, the Canada Health Act speaks to medically necessary, right? The jury is out on whether or not autism would fall into that medical category, except for kids who are actually being treated with the kinds of psychotropic medications, for example, that kids with attention deficit are receiving or other mental health type conditions. There is some of that but for the most part, this is therapy.

You have a similar challenge with psychologists and psychiatrists being covered differently. The whole concept of medically necessary is not particularly welcoming to situations or conditions that do not have a medical base in the treatment.

The Chairman: Members of the committee, normally we would go to six o'clock. We do not have to be out of here at six, so we can go later than that, depending whether the minister can do that.

Ms. Chambers: That is fine with me.

The Chairman: I wanted to draw to members' attention the fact that there are other committees going on, including one I am supposed to attend down the hall after six o'clock, so we do have that kind of problem. With that in mind, if we can keep the questions short and tight, we can get done within a reasonable period of time.

Senator Cordy: Thank you for talking about the national strategy. Certainly, the items that you gave us are things that could be done at a national level and under federal leadership. That was very helpful for me.

I was going to ask you about research, but in your comments you said research is sadly lacking in this field, so I will move on to my next question. What about advocates for parents? I, too, met with a family where the father had a nervous breakdown because it was difficult dealing with two autistic children. There was no respite care for the parents because the grandparents were unable to handle the two children, so the parents were struggling financially; they had many stresses. In addition to that, and you made mention of it earlier, there are so many

silos within our governmental systems. You are dealing with the school system, the health system and community services, and sometimes parents who are absolutely stressed out find it difficult to wend their way through this governmental maze. Have you looked at any type of advocacy for parents who are going through the stresses of working with their autistic children?

Ms. Chambers: In the spring of this year, we announced an additional \$13.1 million in funding for a number of things, which included parent support networks through Autism Society Ontario, consultation-type opportunities with service providers. Our services also include parent training.

Incidentally, the new college has a course that we started in September of last year. I know it has also been taken by parents because parents find that when they understand how to cope with their kids, it makes a huge difference. All parents should have some kind of training in that. I knew that is what was going through your head, senator.

We fund summer camps. I visited a summer camp in the Ottawa area this year that was working with kids with autism from 3 to 19 years of age. It was fantastic. I thought about the fact that these parents did not have to worry about those kids this summer. I also thought about the fact that this was a break for those kids. I asked the people who run the program what sort of reaction they were getting from parents, and they said the parents love two things. The kids come home exhausted, ready to go to bed, and, as they are going to bed, they say, "We just cannot wait until tomorrow morning to go back to camp." It works.

We are funding a variety of programs and services, but there is no question that there are parents who are finding it very difficult. There have been cases of parents with complex special needs who have actually gone to the children's aid societies and said, "We cannot take care of our kids any more."

Senator Nancy Ruth: I have three questions, minister. You frequently used the phrase "six years or older" but not given a context for what that means. Is that a behavioural change or an age change?

I heard from Mary Eberts last week that, in the Toronto school board, school assistants can be promoted. This is a union issue. They could have been on the janitorial staff or something else, and if they there is a job opening, they can go to school assistant. In some cases, they may go into a class with special needs students. The union contract gives the person the option not to take the special training that is available to them, and therefore you can get unskilled people dealing with kids that need skills. What do you know about it, and how do you fix it? You were talking about standardized training nationally, not necessarily provincially, and then you went on to all these associations being provincially regulated. Is there a place to stop this and recommend a national training standard that could be bought into by all provinces?

Ms. Chambers: Thank you. On the six or older issue, the significance of that is that in Ontario, until last year, kids age six or older were discharged from IBI services or did not receive IBI services. That was for two reasons. It was defined as a preschool program, so six was Grade 1, and the other is that IBI is well documented as being most effective in the earlier years, as is the case with so many things that kids encounter, or even adults. The earlier you get to it the better. Certainly intensive behavioural analysis was seen to be more effective when the kids are younger.

Having said that, we have also seen it as having positive effects with older kids. With the cut-off at age 6, parents had advocated very strongly for the removal of that cut-off, and that is what went to the courts. That is what has created a lot of noise in Ontario. Dalton McGuinty made a commitment before being elected that he would provide services beyond age 6 for kids. It has gotten a lot of confusing visibility because of the court case, et cetera. That is why we talk about six or older.

Senator Nancy Ruth: How much is older? How long does this go on?

Ms. Chambers: Through the school years.

Senator Nancy Ruth: To 18, or older if they did not get through high school, maybe?

Ms. Chambers: In the school system, yes. The way IBI is delivered is really quite intensive. A therapist works with that child, for the most part, one on one. They may have some small group sessions as well as the child is benefiting and improving, but it is really very intensive.

The version of IBI that is provided in the school setting I would like to compare to reading recovery. Reading recovery involves a teacher taking a child out of a classroom and providing a little extra help, more attention, more tips on how to read and comprehend what is being read. That child returns to the classroom and is able to put that learning to work with the other kids in class. ABA would be the same type of situation, because applied

behavioural analysis is placing emphasis on appropriate behaviours and also reinforcing learning styles and helping kids.

I heard a physician interviewed, an American woman. She is autistic. She said that until she got to university, she thought everyone thought in pictures. That is how she learns. People thought she was strange because she would visualize. She would picture things and draw pictures. Again, it is different learning styles.

As to the unions and the schools and what is mandatory or not, you have hit a sensitive point there. There are a number of issues. One is that some parents have said they should be able to take their children's therapist into the classrooms with them, to school with them. That has not been received well by unions. However, we have found a significant range of response from school to school, less so at the school board level. It seems to be at the level of the principal as to how receptive that school will be and how supportive that school will be to the needs of an autistic child. That is definitely an area of challenge.

I mentioned our school support program where we have these consultants who are training educators. Nobody can be forced to take that training. It is not mandatory. We have heard of cases where educators have not taken advantage of the opportunity.

On the matter of regulation of the service providers, I had a situation in working with internationally trained professionals in my previous portfolio with the dental surgeons. Each province has their own college for dental surgeons, and I was working with each regulatory body to find out what their practice was for accrediting people with international credentials to practise in Ontario. The dental surgeons came and said, "We have typically put internationally trained dental surgeons through two years of university, at \$40,000 per year, automatically, but we have discovered they did not always need all of that retraining or training." A light bulb went on, and they said, "Why do we not assess them first before we insist that they go through these two years?" I thought how wonderful, because 80 per cent of them were not needing the training. Think about the two years they were not able to work because they were in school full-time, not being able to support their family adequately and spending all of this money to pay for their training. I said that sounded wonderful to me and was very progressive. They said, "The only problem is that we cannot make this decision on our own because we are one of several colleges that make up the Royal College of Surgeons, the national body. As it turned out, everything worked out well. All the provinces adopted this new approach, which had to be approved at the national level. Not all the regulatory bodies work that way. Certainly, to set up a new one we could start from scratch. We could do it at the national level. It is certainly something that could be pursued.

Given the cost of this kind of therapy, you really want to ensure that children are indeed benefiting because they are in fact getting the right kind of support. It makes sense to have some standards in that regard.

Senator Fairbairn: Many of the things that you were responding to in response to Senator Nancy Ruth were things that were going through my mind. However, when I walked through the door you were in full tilt going on about the province of Alberta, which is where I am from. You noted it had money, which it does.

Ms. Chambers: I am jealous.

Senator Fairbairn: One of the good things about this committee is that it does look into these things. Over the last year, I have been reading through newspapers in my province. I have noted again and again that in reporting about the kinds of events and meetings that are going on they often involve some kind of medical difficulty within a community. You have been talking about the lack of child psychologists and service providers. To your knowledge, why would that not be taken on by the province of Alberta? It is a province which takes pride, and so it should, in places like Edmonton and Calgary in terms of the innovative work that their hospital and medical communities do. I gather from you that autism is pretty low on the list.

Ms. Chambers: No, that is not right. What I have said about Alberta and how Alberta supports families and children with autism is that there is a multidisciplinary team that assesses the condition and needs of the child. It determines what they will do to fund that child in terms of services.

It is not an autism program. It is a program for kids with special needs. They do not track the number of autistic kids. They do not track the time it takes to assess them. They do not track anything like that specific to autism. I am not sure what they do in terms of the total number of kids who receive services; but they do not have numbers specific to autism.

However, families have no difficulty getting money. I talked about the two options in Ontario. The direct service option involves the province paying service providers to deliver the services. The direct funding option involves the province handing parents money for the services that they will purchase.

From what I have read, Alberta's challenge is insufficient service providers. Families are receiving money and then having difficulty spending that money.

When I spoke at the federal-provincial-territorial ministers meeting, everyone was crying out for help. I wanted to know what the others were doing and how they were doing it. Alberta's minister actually said, "We really do not have a problem." Many families would say the same thing. However, some families will also say they are unable to find the service providers. They do receive the money.

Senator Fairbairn: But there is no one to help.

Ms. Chambers: I would not say "no one". They do not have as many service providers as there is demand.

Senator Fairbairn: The more I am listening this afternoon the more I think there ought to be some kind of national attention on this issue.

Ms. Chambers: My concern is that as I am building capacity I do not want to lose them. I define capacity as service providers, trained child care workers, education assistants, educators and behaviour analysts who can actually provide therapy. The risk I have is that I need more money to pay for these services. Many of my families are paying for the services themselves, but it is really hard on them.

Senator Champagne: Anyone who hears you talking about autism would be really concerned. I knew very little about it until we talked about it in the last two or three meetings that we have had. I knew of it because I had seen things on television. I think you could sell anyone on the necessity of doing something.

You were talking about doing something that is medically necessary. Before you said it, I had just written down: Why is it not considered a sickness? Is it because there is no cure? Is it because they do not grow out of the problem? If they cannot get cured, is it not a sickness?

If there is an accident, if there is a problem with bones when a child is born, there will be operations and rehabilitation for physical problems. Working with a psychologist is really rehabilitation for the mind.

How can we convince our governments at the federal or provincial level that whatever is needed for those children should somehow come under the Canada Health Act? If you need a nurse at home because you are sick, it can be paid for, either by an insurance company or the government. For the parent who needs the help, who needs a psychologist for that child, there is no money to be had. I cannot understand this. We have to reach someone at our level and at the provincial level to get together so that these parents can get help. That to me is very important. I am very happy to see that in my province of Quebec there is a little bit of help for the families. It is nothing; it is \$1,500 a year. At least it may allow someone to take a week or two of holiday or something like that, but it is not enough. We need to look after the parents and the children. I am talking where you should be talking.

I cannot help telling you how much you have convinced me of the need to do something. I am delighted, Senator Munson, that you raised this subject for us to study. Hopefully, with what you are telling us, we will be able to convince people that we do need a strategy, that we cannot leave those kids alone, and that we cannot leave those parents without the help they need and they deserve.

Ms. Chambers: Thank you, senator. I have made a point of listening to parents and hearing from as many parents as possible. I have also heard from parents. There is also a movement that does not believe in IBI. That is fine, too. There are a range of services that will benefit these children. As I said, there are many kids that are receiving support through children's treatment centres that is not IBI but that is what their parents have determined to be best for them.

Senator Champagne: More research is needed, I would imagine.

Ms. Chambers: Very much so.

Senator Champagne: We need to put money into research as well.

Ms. Chambers: I think so.

Senator Champagne: One thing I have seen on television recently is three different programs from three different countries: One from the United States, one from France and one from Canada. They were suggesting totally different types of treatment. You say where do you go? If I had a grandchild that would be diagnosed as autistic, where do we go and what do we do?

Ms. Chambers: The easy answer to that is the families I have met will do anything that they can to help their children deal with the presenting characteristics.

I want to go back to the Canada Health Act. One thing I have experienced, having only been in government for a little over three years, is how much of a snowball effect some change in legislation can have. Remember when

we were talking about the psychologists versus psychiatrists? It is my understanding that psychologists are not covered by the Canada health Act. That is correct, right? That is because they are not medical practitioners. For the most part, the people who work with kids with ASD are not medical practitioners. You know where I am going with this. If you open the Canada Health Act to define ASD as something that is equivalent to "medically necessary care," then you must look at what other kinds of practitioners should be covered under the Canada Health Act. If that autistic child receives Ritalin, which quite often kids with ADHD are prescribed, then that is covered because it is medication. However, the therapy, the respite care and the summer camps are not deemed medically necessary. The question is: How do you still provide supports? I tried the Canada Health Act thing. I bounced that off my deputy. As every good deputy will do, she helped me to understand the implications of my big crimes. Is that a fair assessment? I then say, "How can we still achieve at least a significant amount of what I think we need to be able to achieve for these kids?"

Ms. Chambers: Even in the autism world, families who do not believe in IBI are seen as a problem for families who believe in IBI.

There was a conference recently called the Joy of Autism. They were saying that these kids are not these monsters that they are made out to be by some people. They just learn differently. They have different talents. They are artistic; some of them are very high IQs, et cetera.

Senator Champagne: They see *Rain Man* all over.

Ms. Chambers: Yes. That works for those families and the families who want IBI. They have heard how other kids have benefited from IBI say, "If you go that route, I will not get the support I need. Are you with me?" Our approach has been to look at a range of supports and services so that parents can choose what would work best for their kids.

The Chairman: I wish to close this off with several questions about the financial challenges. There are emotional and financial challenges that families face with autistic children. You said several things that I wanted to get clarification on.

First, you talked about waiting lists. How long do people wait on these lists? Second, you mentioned that with those who are getting IBI therapy, they could be spending \$35,000 or \$50,000 a year. Is that \$35,000 or \$50,000 that the province is covering or is that their expenses? If it is, how much is the province covering at this point?

Ms. Chambers: I will answer your second question first. The average cost of the IBI program, that is the 25 to 40 hours per week of intensive therapy, is between \$35,000 and \$50,000 per year. For those kids who are not on the waiting list – that is, for those who are actually receiving the intensive behavioural intervention, as far as we are concerned, our government pays for that.

If they need respite or other kinds of services, that is an additional expense. Some of the kids who are on the wait lists are receiving therapy that the parents are paying for themselves. Those parents are desperately trying to get the support to their kids. They do not want to simply watch them go day after day without supports so they pay for those supports themselves. It is a huge hardship for those parents.

The Chairman: How long?

Ms. Chambers: The wait times right now are approximately two years. We are dealing here with a need for additional financial resources so we can provide more kids with funded services. As I have indicated, if we simply wanted to say, "We have X amount of money and that can only serve Y amount of kids, so those who are above whatever age, you should really be in school, you should not be in this program," then our wait lists could be shorter. However, the question is: Would we be doing the best thing for the kids?

The Premier of Ontario says that we would like to do the right thing for the kids.

The Chairman: Good. Well, I know we could keep going longer. I am in your hands, but some of us do have another committee to attend. With that, let me thank Minister Chambers for coming here today. I think she has impressed us all with her first-hand knowledge of this subject matter. All the information that she has given us is most valuable.

You are the first provincial minister to come here. We hope some others will do the same.

Ms. Chambers: Maybe you received the reaction I got when I raised it at FPT. There was not a lot of enthusiasm.

The Chairman: Thank you so much for being here. We might want to contact you in future about this. We are just starting into this. We will have an expert's round table and we will have various organizations coming in. By the end of the year, we hope to have some recommendations that might lead to a national strategy.

Ms. Chambers: I want to thank you for doing this. I want to thank you for getting the ball rolling on this, Senator Munson. I want to thank you for inviting me here. These parents rally; they protest. They say things that are not necessarily positive about government, but have I never seen them as enemies because if I had their challenges I would be doing the same thing.

The Chairman: Yes.

Ms. Chambers: When they rally outside my office, I make sure I am there to speak with them. I get beaten up, but I listen to them.

The Chairman: I think we have a rally on the Hill next week.

Ms. Chambers: I think they are interested in national attention to this challenge. I know that they know that I am working on their behalf because I do listen to them and I think they have very valid challenges. Thank you for doing this. Thank you for having me.

The Chairman: Our meeting is adjourned till 10:45 tomorrow morning.
The committee adjourned.