

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

OTTAWA, Thursday, November 9, 2006

The Standing Senate Committee on Social Affairs, Science and Technology met this day at 10:45 a.m. to consider the inquiry on the issue of funding for the treatment of autism.

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

The Chairman: Welcome to this meeting of the Standing Senate Committee on Social Affairs, Science and Technology. We are continuing this morning with our inquiry on the issues of funding for the treatment of autism and discussions centred around a national autism strategy.

We have six organizations in the health professional category to hear this morning. We will hear from them three at a time. I would reiterate what I think you have been asked by our staff, and that is to try to give your presentations in about five minutes each. At the end of the three, we could then enter into some questions and dialogue with the members of the committee.

Let me introduce the three that we are starting with. From the Canadian Psychiatric Association, Dr. Blake Woodside is the chairman of the board, a practising psychiatrist specializing in treating eating disorders in adults, and director of Toronto General Hospital's inpatient eating disorders program and a professor at the University of Toronto's Department of Psychiatry.

Dr. Pippa Moss is representing the Canadian Academy of Child and Adolescent Psychiatry. She is from Nova Scotia. Welcome, Dr. Moss.

Wendy Roberts, from the Hospital for Sick Children in Toronto, is representing the Canadian Paediatric Society and is a development pediatricians at the Toronto Hospital for Sick Children and the Bloorview Kids Rehab centre. Ms. Roberts is also a professor of paediatrics at the University of Toronto.

Dr. Blake Woodside, Chairman of the Board, Canadian Psychiatric Association: Thank you very much, Mr. Chairman.

I thought that the last time I was here, it would be the last time, but it is a good opportunity to look at some of the holes in the report or possible holes in the report. We were very pleased with the committee's report when it came out earlier.

We have our annual general meeting in Toronto right now, the annual meeting of the Canadian Psychiatric Association, and we are asking our members to write their members of Parliament to urge that the government act on the recommendations in the report.

I will make a few brief points about autism treatment from the perspective of clinical general psychiatry; my colleagues will be a little more specific.

I mentioned that we are in the middle of our annual general meeting. I am the chairman of our board of directors and we have a meeting this afternoon. I may have to slip out a little early to catch my plane. I apologize for that.

I have four basic messages to leave with you.

Autism is a neurodevelopmental condition which may manifest with wide spectrum disabilities, different in each individual, and with a wide range of clinical implications. Right now it is a DSM disorder, so it is included in the list of things that psychiatrists make diagnoses about and psychologists and others who are allowed to diagnose. Within the spectrum of conditions, psychiatrists have some expertise to assist in the treatment of

autism, not exclusively, but as part of a multidisciplinary team who can address individuals requiring interventions.

As you are already aware, there are different opinions about where this condition sits with regard to mental health disorders and disabilities. Knowledge about the conditions, its causes, interventions and outcomes is gradually increasing but there is much more work to do. Because the science is young, there are also divergent views on what clinical interventions work and what clinical interventions are needed.

The Chairman: We go through translation and we you need to be a little slower for that purpose. We are also broadcasting this as well, I might point out.

Dr. Woodside: My apologies.

My first message to you is that none of these differences actually matter all that much to clinical psychiatry, given the young state of the science. As clinicians, we can only work with what we know. We are bound by our medical training and medical code to help with whatever tools and science is available to us at a given point in time. What does matter, and this is perhaps the most important point to make, is that there are significant number of parents in enormous distress trying to secure care and support for that your affected relatives, that adults affected need services and that there is a certain degree of chaos in the way that our society is trying to deal with this right now.

From a medical perspective, that is only one perspective we will hear today, and not the dominant one, there are people bleeding. These people are bleeding and they need help. We do not have the absolute answers on this, but from a physician's perspective, it is critical to try and offer these people something to alleviate their suffering.

My second message for you from the association that represents all psychiatrists is because autism spectrum disorders affect individuals so differently it is unlikely that there is one recipe or intervention that will be one solution. As with the case as most clinical care, we need a flexible approach because different people need different services.

The third message that I would like to leave you with is to urge you not to get caught up in trying to find a tidy policy package that will be easy to sell because this is not a nice tidy situation. An approach will probably consist of a series of steps that are not tidy. One will be some steps that can help people improve their quality of life now. Some will be medium-term steps that will hopefully improve outcomes through initiatives like guidelines, sharing of knowledge and the training of cross-disciplines. A third is a significant investment in research over the longer term to try to generate new knowledge about these conditions.

What that means to us is that a federal response to the crisis that this condition represents from many parents and adults will likely have to be less tidy than we would like. It means accepting that the evidence is not optimal, but that people need help now and we have an obligation to find reasonable solutions to help people who are suffering, people who cannot wait any longer.

Dr. Moss has lived through this and she will speak to this in more detail from a personal perspective as well as a professional perspective.

The fourth point is that this is not a condition that is likely to attract research investment by industry, particularly the pharmaceutical industry, at least not right now. It will have to be governments that invest in the long-term search for effective interventions.

Last week you heard from Dr. Quirion, who described the key research projects under way. These researchers want to talk to you. We asked two of them to come today and they wanted to but their schedules did not permit

it. I urge the committee to spend some time hearing from them directly about their research and help define the scope of what more is needed.

Finally, as psychiatrists, we are concerned about a wide range of psychiatric and neurodevelopmental conditions. We are not too preoccupied with where the boundaries are with this; that is a distraction. We understand interventions in this area require the co-operation of many disciplines and that the boundaries are blurry. We do not want to get stuck in a discussion whether this is a psychiatric disorder or a neurodevelopmental one. There are people suffering that need all of our help.

We would prefer, because we are involved, that the issue was dealt with as part of the mental health strategy. We think that would provide a comprehensive approach and would mean that the spectrum of people living with mental health challenges would get the care and support they need.

Finally, we have some experience of silos of care for different conditions and we are not entirely certain that a siloed approach is the best approach for any condition that has a mental health component to it. We hope that your work will assist the government of the country in moving forward to create the mental health commission and that one of the priorities of that commission would be to work with the provinces to develop strategies to deal with autism just as like we would like strategies to deal with postpartum depression, schizophrenia and other mental health conditions. This national strategy would be ideal and would put us a few steps ahead of other nations.

Mr. Chairman, members of the committee, I will stop my remarks there.

Dr. Pippa Moss, Clinical Psychiatrist in Nova Scotia, Canadian Academy of Child and Adolescent Psychiatry: I have been practicing psychiatry for over 20 years, mostly in Nova Scotia. My originally training was in the subspecialty of mental handicap in Great Britain, where I studied under experts in the field. There I cared for autism patients from early childhood to late adulthood. At that time we thought there was incidence of about 2 to 4 in 10,000 people and had come to realize that it was a neurodevelopmental disorder rather than the result of emotional trauma or poor mothering.

When I first began to care for autism patients there was little we could do. Children were cared for at home for as long as possible then eventually institutionalized. It was extremely challenging for all involved and heart breaking for their parents. The children's needs led to high fiscal costs in terms of medical care, schooling and institutionalization; high societal costs in terms of the parents' lost work hours and productivity; and additional indirect costs due to parents and siblings increased mental and physical health problems. The stress within the family often led to marital breakdown.

Since coming to Canada, I have practiced as a child psychiatrist in rural areas, and I have continued to see autistic children and adolescents. Since their inception I have worked within the treatment and diagnostic teams for preschoolers, now established in Nova Scotia.

I have also become a mother and through this received the equivalent of autism immersion. My son is autistic.

Reading the literature, it would appear there has been a huge increase in the incidence of autism in many countries, including Canada, the United States and Great Britain. Current research indicates that the rate of autism is around 10 in 10,000 children or even as high as 1 in 250. However, some countries, such as Denmark and China, do not see an increase. Evidence, and my own clinical experience, would suggest that much of this increase in diagnosis reflects an increase in our sensitivity to the diagnosis.

Previously, children who were mentally handicapped and autistic were not given a second diagnosis, even when it was present.

There was no treatment, and it only served to further distress their parents.

High functioning autists, that is children and adults with autism and a normal, not necessarily high, IQ, were often missed or diagnosed as experiencing behaviour disorders, or ADHD.

The criteria for autism have changed subtly over the years, reflecting our increasing understanding of the disorder, and it is possible that they may have become more inclusive. It is also possible that the incidence of autism is actually increasing. It seems likely that both genetic and environmental factors play a part in the development of this disorder and both can show differences in rates over time. Indeed, it would be more surprising if the rates remain static in the long term.

By the time my son was born, there were some treatment options available using behaviour modification, and there was some indication that some children responded very well to this. Certainly, in my practice I had encouraged parents to put as much structure in place within their home as they could, to use the limited early intervention services, and to learn the specialist parenting skills required. However, there was really very little to offer children in my care, including my son.

As a parent, this is one of the most terrifying challenges to face. Facing such an awful prognosis, knowing that treatment exists but is not available, is worse than being told there is nothing anyone can do.

If there was some way that I could possibly avert the distress that my child is experiencing and the challenges that we faced trying to deal with his behaviours and reach out to him, we felt we had no choice but to do whatever we could to obtain treatment for him. Otherwise, it was not exaggerating to say that our physical and our mental health would have been at risk, and I would probably not have been able to continue with my work. As there is a shortage of child psychiatrists, many children would have been affected.

Like many parents, we toyed with the idea of moving to a larger centre, as we live in a small village, but there was little more to offer elsewhere.

In the end, we poured resources into Thomas. We chose not to have further children if they would have been physically at risk. Our home became a 24-hour behaviour modification program with paid staff. We refused to let him stop speaking. We taught him how to use his words to communicate, how to look at people, how to be gentle, to play, and many other skills that most parents take for granted.

It was emotionally and financially draining. I will never forget the first time he looked at me as I entered the room and smiled. He was four and a half.

Current research indicates that the treatments that we offered him, based on my knowledge as a child psychiatrist and my instincts as a mother, were probably as close to current treatment approaches to evidence-based that one could provide with the resources available. It cost us tens of thousands of dollars a year and it was worth every cent. We are so lucky that we could use my earnings to do this. My patients do not have this option.

Our son started school one hour a day, three days a week for the last two months of his first school year, and stayed in grade primary for a further complete year. He gradually transitioned into school full-time by grade 4. By grade 6 he was in the regular classroom for most of the day, only leaving when overwhelmed or too distracted. We always had and still have someone paid to be at our home in case he needed to leave the school, and he has had a full-time teacher's aide in school for support until recently.

Grades 8 and 9 were done at his own pace, both in one calendar year. Grades 10 and 11 were completed in a similar fashion, and he is now about to graduate, two years early, and excels in math and science. He plans to become a math professor, and there is no reason this should not be possible. Our investment has paid off and saved society a fortune in the long run.

So what does Thomas think of our earlier struggles and our insistence that he learn to act and behave like a more typical child? He says he hated it but is now glad that we did not give up.

Over time he has explained the differences that he now sees between himself and other children and is proud of being who he is, including the fact that he is autistic. He is still autistic. He still has problems with communication and organization. He is a great kid. We still run a household that is geared to his needs and his helper is now called "my assistant," because he is 16.

Working with several district's programs for preschoolers, I have seen other children make significant gains as a result of early and intensive behavioural interventions. Not only have parents expressed their delight but the schools are commenting that the children are better prepared and able to learn, and the difference between this picture and the situation only a decade ago is profound.

Obviously, not all children will excel as my son has, but it would not surprise me if a higher proportion went on to live independent lives as contributing citizens of this country. As adults, the autists that do require later care will probably be more independent. In other words, the cost savings, let alone the alleviation of distress, are likely to be significant in the long run.

Not all autistic children receive services. There are simply not enough resources available to provide them. We need to ensure that all autistic children have access to evidence-based treatments. I would suggest that this is a moral obligation, apart from the societal benefits that result from such programs.

Clearly, no one model will serve all autistic children well. Autists are not all same. They vary as much as typical children vary, and their families vary in their ability to carry out certain programs, and the acceptability of approaches in terms of their own culture.

We need to fund research to further develop the treatment models that we have and to establish new approaches. We also need to determine which treatment approach is suitable for which child and at which stage. Intensive behavioural treatments are expensive in terms of investment of times and money, and we need to ensure that the children who receive them will benefit. Also, these treatments are hard work for the child, as well as the parents and the treatment team.

It seems likely that the major benefits of such intensive interventions will be at the times of most rapid brain development and growth: In other words, as preschoolers, in the early school years, and then again in early adolescence. The most vital time is during these early years. The sad reality is that the parents who fought to have services in place are children who were too old to receive them when they were first introduced in Nova Scotia, and yet they supported the preschool program. As one parent said, we will not put anyone through what their child and us have experienced if it can be avoided. As a parent myself, I would echo that sentiment.

I know that early intensive and long-term interventions can make the difference between a child who was expelled from daycare and a danger to himself and others and a child who is able to come to a regular classroom and who will go on to university.

I would like to see this opportunity for all my patients and their families who could potentially benefit from it. I will ask you to consider, can we afford not to?

The Chairman: Dr. Moss, thank you very much for that presentation. You not only bring a professional perspective but your personal experience with your son. It is a very compelling story.

Dr. S.G. Wendy Roberts, The Hospital for Sick Children of Toronto, Canadian Paediatric Society: It is a pleasure to be here and to represent the Canadian Paediatric Society.

I thought I would let you know how I come to my perspective, which has developed as a pediatrician over the last more than 20 years now working with children and families, but also working very closely with pediatricians, because my job as a developmental pediatrician at the Hospital for Sick Children is to disseminate the information that is coming from research and to teach it to practising pediatricians in the community. There is not a day where I do not have several phone calls or emails from colleagues all over Ontario and other places asking for help with families that they absolutely do not know what to do with.

The next two days we are having 150 people in to Bloorview Kids Rehab to intensively look at the literature around child development. We do this every two years. We get constant questions from the clinicians that come to those meetings, which include psychologists and psychiatrists as well as pediatricians, about autism because they say the kids and families that we are struggling with most in our practices are the kids with autism.

One thing that has really held back early diagnosis has been a criticism of pediatricians not being aware of the signs and saying, "Oh, he is just slow to talk. He will catch up. He is okay." One of the problems is that autism looks different in every child and it looks different at every age. There are some signs that you can certainly identify at age one and age two, but those are very different signs from age 5 and age 6. Many people were trained about the signs that you would see between ages 4-6 because that was when we thought we could make a definitive diagnosis of autism. We now know that if a child is not pointing to share interest with you at age 1, they are at very very high risk. If children do not respond to their name at the same time, there are several different articles that clearly show when children do not respond to their name at age 1 and are not deaf, then they are likely to have autism. You would not pick that up if that one-year old walked in here and started running around and looking at things. They would not be looking at your faces or your eyes and backing off as a typical child would do. Rather, they would be looking at the interesting fan or the pattern on the walls. We see that shift take place somewhere between 9-15 months. My biggest learning about autism has really happened in the last five years when, thanks to CIHR, we have been able to intensively study children as they develop autism, working with Ms. Lonny Zwigembaum and Ms. Susan Brison from Nova Scotia. Lonny was one of our graduates from our developmental _____ fellowships and with Mr. Peter Zatmari, we have been studying over 300 children starting at six months. We have been doing the five-year assessments to see when were we right and wrong at recognizing the early signs. We have also had the benefit of seeing what interventions those incredibly skilled parents have utilized. They have been through it already with an older child at home with autism. With these best possibly trained parents, what do we see with the babies born into those families? One thing we have learned, and it has been heartbreaking, is that the rate of recurrence is higher than we thought. We are getting somewhere between 11 per cent and 15 per cent from our early information in terms of recurrence risk. There is always the possibility of the bias, such that people that are more worried if they see something at 3 or 4 months might be more likely to call us and enrol at six months. However, the majority of the children that we have seen that go on to be autistic, we think look okay at six months. We cannot tell the difference. Somewhere between 6-12 months, they become less interested in people and more interested in certain physical aspects of the environment.

It is absolutely heartbreaking to live with those families through that realization. I sat with a family a couple of weeks ago and their 2-year old child. We had been working with him between the ages of 1 and 2 because we saw signs that we were worried about. I sat there as both parents sat with tears running down their faces saying, "We both do extra jobs. We do 10 hours of fundraising for the private school in order to keep our first child in school. We have stretched our financial resources and our parents' financial resources to the limit. We are working 60-70 hours per week. We have trained staff coming into our home. You are telling us that we have a second one and we have to do it again? We absolutely cannot do it."

Their older child missed out on getting the provincial intervention. This second boy is doing better and, if we refer him to the provincial intervention scheme now, he will not qualify. He will be too high-functioning. There is basically no other consistent service that they can get, other than some parent education, which they have had up to their eyes with their first child, for that child in our province currently.

They were sitting there wondering whether they should move to Alberta. They asked me what I thought they should do. They have all their contacts, relatives and jobs here. That is the dilemma that paediatricians are faced with day after day.

Another blow to the parents for the second children is that they thought if they did not immunize their second child, they would not be affected. We have just as high an incidence and exactly the same kind of course of becoming autistic in the second child without the immunizations. That has broken hearts. They truly thought they would be safe this time.

We are celebrating the children that are turning out beautifully. We are celebrating the kids where the parents have done an enormously wonderful job. I agree with Dr. Moss that many of the parents instinctively know how to capture their child, get the social engagement, force those brain pathways to go in different directions. Social engagement is absolutely the key and is the basis of the new grant that we submitted to Autism Speaks that we hope will spread to NIH. It is all thanks to CIHR money that we are able to do this. We are doing it at the same time that we are involved with the Genome Canada project and desperately doing research to find the genes and new agents. We do not have any helpful medication for the severely affected kids. We have no Ritalin for ADHD comparison in terms of autism. We have to develop new agents far more effective for the aggression.

We hear so much about the early years and getting the early intervention. I absolutely agree that is true. I do not think it needs to be the 40 expensive hours a week for every child. We need a continuum of resources and we need research to figure out which kids need that very intensive and expensive intervention and which children could cope with less and with more focused intervention from a speech and language point of view or other.

We also need to look at how to help families because we cannot keep putting the brunt of this on families. I do not think I have any family where one parent has not had to give up a job and stay home unless they have a grandparent who can step in. You just cannot do it and hold down two jobs if you have not got someone else to help.

We also need to support the siblings. We just did a project with adolescent teenagers who have a brother or sister with autism. The big thing that came across in looking at their interviews was fear that their parents would burn out, fear that they would be physically hurt because of the aggression that their sibling was displaying and fear that they could not go to sleep at night unless they had checked that all the knives were locked up in the house. Yet, they displayed tremendous love and affection for the child with autism. You could go for weeks with nothing and then a horrific outburst where someone would be held against the wall with hands around the neck. This is no exaggeration; it happens to me every Monday in our medication clinic. Parents come in, particularly moms, for whatever reason with bruises and bites but we do not have the resources to help them. We need the services and we need them across the lifespan. Autism does not go away. Many parents are just thrilled with how good the kids look at age 6 or age 7 when they go to school but they come back at age 8 when normal anxiety goes up and the autism goes up and the aggression has started and the school is crying for help or kicks the kid out. It comes back in that period and it comes back in adolescence. I used to think there were fear mongers who warned people about adolescence for autism children but it was not fear mongering. I have had so many children who seemed to be doing really well who completely fell apart in adolescence. It is across the lifespan.

We are learning from adults with autism and we are learning from talking to teenagers. We are doing some wonderful focused research at a basic science level and also looking at families, but it is not nearly enough to really understand who responds to what, what truly cost-effective services we can put into place for the child, for the parents and for the siblings so that they feel supported in their communities. With that, it is hoped that they do not get into the kind of situation that one of our parents faced last month. She had a well-worked-out suicide plan for her and her boy at age 10 because after losing the services at age 6, it had been a steady downhill course for her. Her father had died and her postpartum depression had come back as a serious depression. She had thought that her boy would get better but he only got worse. She decided that life was not

worth it. It was only an older son who finally brought her to Emergency and got services back into place and tried to find some respite.

We are dealing with a huge need for service delivery and a huge need for education. If you put a child into a class where the teacher and the educational assistants do not know autism, it is a recipe for disaster. We need extended research both at the basic science level and at the level we have been talking about — finding the right intervention for the individual child because we do not have that information at this time.

The Chairman: Dr. Roberts, thank you for sharing your wealth of experience. I would mention that if you have anything in writing with respect to your presentations this morning, we would appreciate copies.

(1120 follows in French — **Le sénateur Pépin:** Ce que vous dites est très émouvant...)

(après anglais)

Le sénateur Pépin: Ce que vous dites est très émouvant. Je peux vous dire que j'ai un peu lu sur le sujet parce qu'on a tous dans notre famille des gens qui souffrent de certaines maladies. Lorsqu'on vous écoute, on a l'impression qu'il n'y a pas d'argent disponible, que ce soit pour la recherche, pour ceux qui s'occupent des malades, ou même pour ceux qui subissent les traitements. On se demande donc par où on doit commencer. Vous avez dit qu'il y a certains médecins, certains pédiatres qui n'arrivent pas à détecter l'autisme chez un enfant. Cela veut peut-être dire que dans la formation en pédiatrie, il faudrait prévoir une partie qui concerne cette maladie. Vous avez également dit qu'il y a de plus en plus de gens qui souffrent d'autisme.

Peut-être qu'on pourrait informer les futurs parents à l'occasion de cours prénataux, les informer au sujet des caractéristiques d'un comportement autiste chez un enfant, de telle sorte qu'ils soient plus en mesure de détecter la maladie.

Lequel d'entre vous voudrait répondre à ces questions?

(Dr Moss: I suggest we need to consider...)

(anglais suit)

(Following French)

Dr. Moss: I suggest we need to consider two things. One is screening. It would be possible for general practitioners or nurses that see children at around 18 months to screen children. We just need to pull together a better method of screening. We do not have a very good one at the moment. The methods we do have tend to pick up slightly too many children. After the screening, the kids picked up could possibly go on to have more thorough testing done.

The other thing is, we need general practitioners and teachers to be trained in surveillance, to keep their eyes open for the kinds of difficulties these children run into. If they see that within their office or their school classroom, they can then again refer the children on for more intensive testing to find out who does need services and help.

Dr. Roberts: I want to add that in Ontario, we have had an expert panel over the past two years looking at exactly what you have been talking about. The Ontario College of Family Practice and the Canadian Pediatric Society have worked together to modify the Rourke Baby Record, which is a form family physicians and nurse practitioners use to follow baby care throughout the first five years. We focused on the 18-month visit.

Leslie Rourke has worked very closely with us. There is now a new 18-month checklist that looks very specifically at communication, social skills and parent-child interaction. It is a surveillance tool, not a formal screening tool.

The expert panel has moved into an implementation stage in Ontario, which we are very excited about. Our goal is to have every child in Ontario screened at 18 months. Of course, that means a huge amount of training for family physicians and nurse practitioners. I think maybe at this point some of our nurse practitioners will do the fastest job in getting up to speed in using it.

We are very happy that is available. It goes along with the parent questionnaire, the Nipissing questionnaire, which again is a surveillance tool. I think the change in the Rourke Baby Record, the free access to it on the Internet for practitioners and their office will make a difference.

We now need to ensure there are community resources that do not keep the children waiting two years once the family physician has identified them in order to say yes, this child is autistic and you must start the intervention right away. There should be no more than a three-month lag in that process of recognizing it and then getting something started. That is not the case at the moment.

(French follows) Senator Pépin... Si les listes d'attente sont si longues...

(après anglais)

Le sénateur Pépin: Si les listes d'attente sont si longues, est-ce c'est à cause du diagnostic? Est-ce que les médecins, lorsqu'ils posent un diagnostic, transfèrent les cas d'autisme sur une autre liste afin de traiter d'abord des enfants qui n'en souffrent pas?

On entend beaucoup parler des enfants autistes qui ont besoin de traitements, mais j'aimerais savoir ce qu'il en est des adultes. Ont-ils accès à des traitements? Dr Moss nous a parlé de son fils, de tout le support qu'elle lui donnait. Mais que fait-on avec tous ceux qui ne reçoivent pas un tel appui?

(Dr Woodside: What I was thinking about while...)

(anglais suit)

(Following French)

Dr. Woodside: What I was thinking about while you were speaking and while Dr. Roberts was speaking about the screening program is that a huge problem is access to treatment once diagnosis is made. If we screen every child in Ontario at 18 months, that will overwhelm the already hopelessly inadequate resources for treatment.

It is a great thing to screen children — and everyone thinks it is a good idea — but what will we do with them? Without some concerted action on the part of government decision-makers, we will have this enormous pool of kids identified at risk with nothing.

Dr. Moss: When I first started practising in Nova Scotia, I was concerned to be told that autism was not a mental health problem, it was a social problem. The same holds true with mental handicap. Many of the mental health centres at that time would not even take a referral of a child who was diagnosed as autistic, even if the referral was for help with behavioural problems.

We have come a long way. Not all of the clinics, but some of them have. Presently what happens in Nova Scotia is that any child suspected of being autistic is fast-tracked into a service specifically for autistic children where they will receive diagnosis and, if necessary, treatment. If they are found not to be autistic, they will then be sent back to wait the normal amount of time with the local mental health centre.

With regard to adults, there is very little available. Even though I am involved in the child and adolescent society, I have seen people into their 40s who have neurodevelopmental disorders, including autism. My colleagues that deal with adult mental health problems really do not know what to do. I am talking about not only my psychiatric colleagues, but also the psychologists, the social work therapists and the nurses with whom I work within multidisciplinary teams.

I tend to step in to try to help out as best I can, again, trying not to distract the very little time I have available to get distracted from helping with the children.

That being said, I do also know of some adults who are living in society and who have found their niche and are doing extremely well. The only reason we have come to know them is that they are the parents of some of the children we are caring for.

The Chairman: I have a supplementary on that. Would many of the adults be institutionalized? Do you know what percentage that might be?

Dr. Moss: The majority of the adults I see are institutionalized. I suspect that is because most of the adults functioning well probably do not need help. If they do, they tend to not come my way because I only work in a very small area. The population I cover is quite small. The geographical area is what is large.

Dr. Woodside: My personal involvement in this does not have anything to do with autism, but my oldest daughter has Down's syndrome, another neurodevelopmental disorder. That was about 20 years ago. It is not the same as autism. I do not want to confuse the committee.

However, there is excellent evidence that early intervention in Down's syndrome produces much better outcomes for the children. My daughter died as an infant and only had a few months of intervention, but the intervention started at birth. As soon as the diagnosis was made, which was at birth, we were immediately connected with an agency primarily run by volunteers. It was focused on early intervention.

There is good research that that has excellent outcomes or much better outcomes than not intervening. Autism is the same sort of situation. We do not have hard and fast research like you might in some other areas of medicine, but we know that some interventions are helpful for at least some of these kids. It is a crime not to offer them to the children.

Dr. Roberts: I agree that many of the things I have learned about adult autism have come from parents, after we have made a diagnosis, coming in to talk at an extra session about the fact they think they, in reviewing their history and in looking at themselves, have been somewhere on the spectrum as well. They recognize that many of the behaviours they are seeing in their child now they have heard about in terms of their own delay in language, sticky behaviour and obsessing on certain topics. Yet some of them have gone on to be very successful adults, holding a job, getting married, having children, but what seems to have led them to a crisis sometimes with an anxiety disorder or a depression, for example, there was one mother who said, "I started hitting my head because the anxiety has gone up so high," as the level of difficulty of parenting has increased with their autistic child. We have few resources that we can send those parents to where our psychiatric colleagues really want to see them.

It is usually begging for a favour or sending them from Toronto, often to Hamilton because one of our colleagues there is interested in seeing adults with autism. Therefore, that is a big problem.

The other thing relates to the comment about the Down's syndrome. It is very frustrating. I have and many of my colleagues have found if a diagnosis of Down's syndrome is made there is an early intervention program you can call, and — you are right — you can get somebody into the nursery. If you make a diagnosis of CP, you can get a therapist within a month. They will have a paediatric assessment within three months, and they are into a course of intervention that will carry them through into adulthood.

If you make a diagnosis of autism, you are saying, "You have autism. Do you know what it is? Do you have any money because that is the only way we will be able to start intervention right away? Who can help to support you?" Then you look at this maze of services that you will have to select from if you do have money in order to try to get something that we do not have clear evidence will work or not.

(French follows, Senator Champagne: *Dois-je comprendre...*)

(après anglais)

Le sénateur Champagne: *Dois-je comprendre que jusqu'à un certain point que l'autisme est héréditaire? Est-ce que vous pouvez diagnostiquer un enfant autiste et vous rendre compte par la suite qu'un des parents était peut-être atteint mais à un degré moindre?*

Dr. Roberts: We are finding that the most recent research suggests that between 30 and 50 per cent of one parent or the other may have had some traits such as anxiety, social anxiety, extreme shyness or delayed language and then caught up and may have done very well. When you study pedigrees you will see an increased incidence, not in every case, of uncles, aunts, grandparents and cousins who may have full-blown autism, may have Asperger Syndrome, may have just not have talking until four as the history and then picking up, which is

almost a dangerous history to have because it may lull you into thinking your current child is okay. They will start talking about the time they get to be four.

The language and the anxiety are the commonest things you will see in extended pedigrees, as well as pure autism.

Dr. Moss: In many of the children there does seem to be a genetic component, but there is also a substantial area of children we cannot identify the same component. We do know these children are more likely to have had difficulty before birth, around birth or may have had infections when they were infants. Clearly, as in everything, we have interplay between what you inherit, your genetics and the environment and what happens to you as you are growing up and when you are very young.

Some form of genetic screening is interesting and something I do to quite an extent within the families we work with because it is a field I am interested in personally. You do not always pick something up, so the environment will also throw a spanner into the works with some of these kids.

Senator Champagne: You cannot know really which way. Sometimes it is hereditary and other times you do not know where it comes from or what made had happen.

Dr. Moss: Most of the time you have a combination of factors. For instance, we know many autistic children have grandparents who are scientists and engineers, so we think there may be some sort of genetic link with that. If you have an autistic child who has both grandparents that are engineers and the mom who maybe had some difficulties during the pregnancy, that will increase the chance of that child being autistic. Is it genetic? Is it environmental? It has to be both.

Senator Munson: It has been very moving and compelling testimony today. Just to share with Dr. Woodside, we lost a Down's syndrome son as an infant many years ago, and maybe that is one of the reasons why we are all here and very concerned with another condition called autism.

You talked about these are people who are bleeding and need help, and in your opening testimony you did mention that research investment by industry has been practically nil. Yet the testimony we have heard from so many people and from you about new research money and the national public awareness campaign. Why do you think these pharmaceutical companies and these big companies are so reticent get into the game and the partnership which is going on now, between provinces and the federal government?

Dr. Woodside: The first reason is that there are no pharmaceutical agents that are particularly effective. If there were an effective drug treatment for this, then pharmaceuticals or industry would be involved. My colleagues will talk more about the role of pharmaceutical treatments in these conditions, but it is not a huge component of the treatment, so the industry has no interest in it.

Most of the treatments are psychosocial treatments, that is, psychological and behavioural treatments, which the pharmaceuticals and industry are uninterested in. Those have to be funded by government.

Dr. Roberts: I think that where we are moving with the genetic research is the only answer, with the Genomic research. We have to learn more about receptors that are different. Then if we come up with some of those receptors, the pharmaceutical companies are more likely to step in and come on board. I think they are watching carefully, and with the Genome project we have moved far faster in the last year than we ever dreamt we would in identifying both the susceptibility genes. A big paper will be coming out in the next couple of weeks online. Once people see, for example, serotonin receptor, and we know serotonin is one of the neurochemicals involved in autism, then we are more likely to see one of the companies get involved.

Senator Munson: We heard from the minister from Ontario, and Dr. Woodside, you said today that we should not get caught up in a nice tidy policy project. Those of us who are politicians have been advocating the idea of

a national strategy, and it is still a generic term. We do not know what that will take — as we heard from her yesterday, a public awareness campaign to write grants to families, tax deductions for families, ease the burdens for expensive IBI treatment or child psychologists, certification of service providers, establishment of a regulatory body. At the end of the day, it seems it come down to money. Money is the bottom line. When you say do not get caught up in a nice tidy policy, what are you saying to us?

Dr. Woodside: What you just described about the testimony you heard yesterday was not tidy. You heard the minister from Ontario describe a wide ranging collection of initiatives that might be helpful, so there will not be a simple, easy solution to this problem, because it involves training providers, funding providers, funding support for families, dealing with new children who are diagnosed and dealing with existing individuals with autism who need supports. The complexity in developing a system to help these people is huge. That is what I meant by "not tidy." It is not something you can write in one paragraph that would describe what you need to do.

Senator Munson: What troubles me the most are these waiting lists. What is the impact on the child if there is a lengthy delay?

Dr. Roberts: I will certainly talk to that. I absolutely believe that we pass a critical period with a number of the kids who do not come in to the treatment program until they are five. They are definitely children whose parents have been concerned at 18 months. They have waited maybe 18 months, two years for a full assessment and then they wait another two years for intervention. They are often in their fifth year.

The difference in the neurobiology between one and five years is enormous. We can still help some behaviour problems, but we would not be able to influence the development of those social communication pathways in the way that we can if we start at 15 or 18 months.

Dr. Moss: One of the things we know about children is that the early years are a time of very rapid brain growth and development. The potential for making positive and negative change during those times far outweighs any changes you can make at a later stage. For some things, if you miss that window of opportunity when a child is younger, you might never be able to do it or never do it to the same extent if you give the same intensity of treatment and support when they are a bit older.

It is not only seen in autism, but in other children's disorders and problems as well. We must get in with these children at an early stage. That is exactly why if you have a child with Down's syndrome or CP, these intervention services are in there from a few months after birth.

Senator Munson: If there is time, I would like to go on the second round.

The Chairman: I will excuse Dr. Woodside — I do not want her to miss her flight — but we will carry on with doctors Moss and Roberts.

Senator Cordy: It has been moving testimony. During our study on mental health and mental illness, we spoke with a number of parents who had autistic children; and I have met with parents in Nova Scotia who are going through some troubling and stressful times.

One of my concerns in talking to parents is supports that we have for parents. When you are dealing with an autistic child, do you deal with the whole family? I have had parents speaking to me who have suffered stress breakdowns. In that case, one parent is left dealing with not only their autistic child or children, but also with a spouse who is depressed.

Dr. Moss: As a child psychiatrist, although the child is my primary patient, I am there for the whole family and we do provide support for the family. We do see a high incidence of parental distress and mental health problems. If it becomes something that is over and beyond what I can offer within the context of the family, we

make arrangements for parents to be seen by adult therapists and psychiatrists. We work closely with them. At times, if we were working with the family, we might have the adult therapist working with the therapist from the child adolescent team.

As a child psychiatrist, I see my role as not working with the child, but working with the child within the context of the family and the whole community. I will be working not only to support the family, but also trying to support the school and any other bits of the community that the child is integrated in. I might be meeting with people in 4H and helping integrate a child into that environment or with the local Guides or Brownies or the local church — wherever we can get the child out into the community, behaving more like a typical child and having the same opportunities that a typical child would have. However, yes, it is a significant project.

Dr. Roberts: It is also a problem in terms of limited resources and making a very difficult decision. Do you spend 10 more hours with this family where the parents are in huge distress and we do not have enough social work support to take over and work with us on the team, or do we use the 10 hours to see two new children off the wait list? We are put in this impossible dilemma of making those decisions, with huge pressure from our administrative people who are dealing with numbers and wait lists, to move on and get involved with new families. I understand that totally; yet it is morally and ethically wrong to move on if you have not found enough support for the families, because you know they are going to go in a negative direction.

Senator Cordy: True, because the parents are suffering as well. If one of our recommendations were to be that we have a national strategy for autism, how should we go about doing it?

I know when we did our study on mental health and mental illness, one of our recommendations was a Canadian commission on mental health. Our chair and vice-chair went to every province and spoke with health ministers and deputy ministers to get them onside before we went nationally.

What would you suggest that we do? How would we go about developing a national strategy, first of all, for getting everybody onside? Should it come from the top down or should we have everybody at a provincial-federal-territorial meeting, probably under health, but it certainly does not just fall under the health banner? What should a national strategy be; what should it say?

Dr. Moss: Health is a provincial responsibility. Any national strategy has to be a way in which the various provinces come together and learn from each other and with each other so that they can develop services that are specific and appropriate to their province. What works in one province might not work quite so well in another.

For example, in Nova Scotia, we do not have any really isolated northern areas. Other provinces do. Nunavut will be a completely different challenge than we face. However, a national strategy is very important so that we are not constantly reinventing the wheel in every single province.

Dr. Roberts: One of the pieces that would be tremendously helpful would be to have different ministries that are involved encouraged to sit down and talk together. Some of the most productive discussions that I have had have been in Alberta, where we have had representatives from the ministry of education working with health and with child and youth services. Over and over again, when it really comes down to moving a plan forward, it has been a territorial piece of well, it is really that ministry's job; what part of it is that ministry's job?

One of our behaviour management services that was doing a wonderful job with autism had 13 different funding sources they had to go to to pull together a budget. There is a huge waste when there is interaction between ministries that could not really be described as cooperative.

Senator Cordy: Breaking down the silos is what you need.

Dr. Roberts: Absolutely, just to have everybody at the table. I think that people often speak more of the same language than they realize, but it is not real, interactive teamwork. I would love to see some really productive think tanks with the different ministries from the 10 provinces, because I think there are some really creative things being done in each province. However, they could be shared a lot more, and we could be far more cost effective if we work together.

If you put intervention into place, but you make it contingent on assessment and you do not put any extra money into the health ministry's assessment process, that is how we doubled our wait list a few years ago. Our education system said you have to have assessment before you will get certain kinds of education intervention. The same thing then happened with children and youth in terms of autism, and there was not the infusion from a health point of view. It has to be collaborative, and I think you could save money in doing that.

The Chairman: What would you see as the federal role in this? We understand the health and social responsibilities — that the program deliveries are at the provincial level and there are transfers for that from the federal level. What would be the federal role in all of this?

Dr. Moss: One of the joys of the fact that we do have a federation is the provinces can work together and learn from each other. This was one of the things I meant in terms of how you perhaps get different departments within a province to work together.

Federally, a leadership role is really needed to encourage the provinces to begin to move in this direction — to encourage them to begin to learn from each other and to work together to have some sort of national strategy.

Dr. Roberts: I also think it is a little bit like autism intervention; it is a process of gradual pressure, encouragement, trying to build momentum to get the ministries to work together and get things to change. One of the things that will really encourage that, and one of the things that has been encouraging for us in the last couple of years, is far more interaction between government committees and our research endeavours — and the infusion of money at a research level.

A good example, which I do not know if you heard about last night, is with the CIHR trajectories money that Peter Szatmari has been leading us in — looking at 600 children across Canada in terms of how they respond to various interventions — coming in at the first time of diagnosis and following until the end of Grade 1.

Hearing about that research project got the Ontario government in and saying we should be feeding in all of our kids, those that get into the program and those that do not - that took some courage - and let us follow them with your protocol. That was a beautiful example of real cost savings and real efficiency, I think, for the research project itself.

Senator Keon: I want to ask both of you what you think of the instrument for federal-provincial initiatives of sunset programs? In other words, the federal government has the money and authority to institute a program with sunset clauses so there are exits, say 10 years down the road, and does not blackmail the provinces into something they cannot handle, so there is time to work this out. They can carry the program up front with resources to bring in new initiatives for a problem area like this. What do you think of the possibility of that?

Dr. Moss: Anything that we can do to begin to provide more support and treatment and research into this area would be very welcome by parents and by clinicians working with these children. I would see that potentially as a way of getting the provinces on board and working together.

Dr. Roberts: I agree, and that infusion of money in that kind of a clause could allow us to really combine research and evaluation of what is actually going on with increased service provision. I believe that there is a huge amount of money being poured into certain intervention programs. There is no evaluation really, in true scientific terms, going on with what is happening with that money, even in terms of the thousands being paid to supervisors of intervention programs brought in from another province or from the States with enormous dollars

attached. If we could really evaluate, find out what really works for whom, we could save money that would then allow the sort of the budget correction down the road.

That, as long as it was carefully linked, could really work. It would allow some of the basic education at every level of the team; parents, teachers, educational assistants, psychologists, physicians, speech and language pathologists, OT, social work, recreation providers, everybody you need to know about autism, to really get on board.

(French follows — Sen. Champagne, J'imagine que l'idéal...)
(après anglais Dr. Roberts, to really get on board.)

Le sénateur Champagne: J'imagine que l'idéal serait d'en arriver à un amendement à la Loi canadienne sur la santé prévoyant que tout ce qui concerne l'autisme est pris en charge par la Régie de l'assurance-maladie. Par contre, on ne nomme pas d'autres maladies comme telles et peut-être que cela créerait un précédent. Actuellement, le gouvernement fédéral transfère des fonds pour le financement de programmes sociaux et des sommes particulières sont consacrées à l'achat de médicaments particulièrement dispendieux. Vu sous cet angle, est-ce qu'on peut envisager la possibilité que le gouvernement fédéral transfère des fonds aux provinces, fonds qui seraient consacrés au dépistage et au traitement de l'autisme? D'après vous est-ce que ce serait un élément de solution?

(Dr Roberts: That would make an enormous ...)
(anglais suit)

(Following French — Sen. Champagne, un élément de solution?).

Dr. Roberts: That would make an enormous difference. There is a problem between different people coming from different territorial perspectives saying, "why autism?" If there were an infusion that really demonstrated to people how life could be so much better if children were identified early and if comprehensive services were put into place, that would then allow people to really understand what we are not doing now and what we are creating in terms of many stressors at an educational level and at a family level because we are not getting involved early. That would be wonderful.

Senator Champagne: One thing that the province of Quebec has added to its spectrum of insurance, although admittedly small at \$1,500 a year, but it is to help parents to give them a respite; to get somebody else to look after the child for an hour or two once in a while. This is also a good initiative, and it should be renewed in every province and territory.

Dr. Moss: Yes, respite is essential; otherwise parents do not survive. My other comment is I really wonder whether we should be looking at a program that is for children with autism, but also takes in children with other neurodevelopmental disorders. We have some children who have neurodevelopmental disorders that are not specifically autism but would also benefit from the kind of services that autistic children need. In the past it was heartbreak because I could do nothing for children that I saw diagnosed as autistic. My current heartbreak is the children I see with neurodevelopmental disabilities who need more intensive speech intervention but do not meet the autism cut-off. They do not meet the diagnostic criteria but are not little ones who will have an easy path.

I know it is maybe making things a bit broader, but this could be something that might be more acceptable to the general public because there is a little bit of a back-lash locally in terms of the children that get the services and those who do not. If you have a child that has a neurodevelopmental disorder that is not autistic, now that we have the autism program the services available to them are much less. Things have flipped and we have things the other way around. Not that the autistic kids are getting that much, and it stops when they go to school when it needs to continue, because the parents become distressed when children are six or five instead of at two and three. We would need to look at something that is primarily for autism, but also take into account children with other similar needs.

My other comment as regard to treatment and research is, yes, if you have a patient bleeding to death, you have to race in there and do what you can. You have to learn from what you are doing because you might modify what you do with the next patient you see bleeding to death. Anything we put in place we have to make sure that there is a strong research component so that we learn from what we are doing and are constantly able to improve things. Without that we would not have had the information that we now can use to treat the children, insofar as we have the ability to treat them right now.

Dr. Roberts: The legislation in Alberta that allowed the same amount of money to be given, if you found two areas of development significantly delayed, really gave a lot of leeway in the process when trying to sort out what is really going on in a specific developmental disorder. That legislation was wonderful. I think it was early last year that it came out. My time estimates are getting worse as I get older.

That is an example of legislation that certainly helps children with autism tremendously, but also allows some of those with severe neurodevelopmental disorders to also benefit.

The Chairman: Unfortunately we have run out of time, because I think we could still have a further dialogue for quite a number of minutes with you. We appreciate the time you have taken to come in and discuss this with us, as well as Dr. Woodside who did have to leave early but made a solid contribution as well.

We have three new faces at the other end of the table. I welcome each of you. These people represent three more associations that are involved in these issues of autism. First, from the Canadian Association of Speech-Language Pathologists and Audiologists, Tracie L. Lindblad, Director and Speech-Language Pathologist. Next we have, representing the Canadian Psychological Association, Dr. Karen Cohen, Associate Executive Director. Then we have Mary Law, who is Associate Dean and Director, School of Rehabilitation Science, McMaster University, and representing the Canadian Association of Occupational Therapists.

Tracie L. Lindblad, Director and Speech-Language Pathologist, Canadian Association of Speech-Language Pathologists and Audiologists: You will hear again some reiteration of your previous panel. That just means that the information is obviously at the fore in all of our minds and a consistent message, which may help as well.

Thank you for this invitation to present on the important need and issue of funding for autism treatment and the treatment of all autistic spectrum disorders. I am a speech and language pathologist and I currently serve as a director on our board for the Canadian Association of Speech-Language Pathologists and Audiologists of Ontario.

I am also in private practice as a speech and language pathologist, and only work in the field of autism and have for almost my entire career, after leaving our public system of education where we went to a consultation model in the 1980s and it was no longer direct treatment.

With some of your questions I can also address some of the private issues as well.

Canadian Association of Speech-Language Pathologists and Audiologists is the national voice of more than 5,000 professionals, including over 3700 speech language pathologists in Canada. Over 30 per cent of our members have a direct interest in autism spectrum disorder. Parents want their children to look at them, and we heard that very poignantly reiterated this morning. They want their children and their family members to communicate with them. Children and adults and adolescents need friends. Speech language pathologists play a critical role on the teams for early assessment, intervention and evaluation of programs and treatment for persons with ASD.

The core deficit in ASD is communication — speaking, listening, language skills, and conversational communication, such as looking at the speaker, staying on topic, and taking turns in conversations. Key

considerations in the funding plan to support autism spectrum disorder are early intervention, intensity of intervention and a collaborative team-based approach to intervention.

It is important to note with the communication problems that they lie not only with the individual diagnosed with the ASD, but affects the whole family, all the family members, peers, caregivers, teachers and other members of the community who may encounter barriers in communication with the individual with ASD.

The speech-language pathologist's role is critical in supporting the individual, the environmental and all of the communication partners to maximize opportunities for interaction and to overcome barriers throughout the lifespan.

Although speech-language pathologists do not have the legislative authority in Canada to diagnose ASD, it is critical that they be involved on the diagnosis team. As part of an interdisciplinary and collaborative team, speech-language pathologists prioritize assessment and plan and provide interventions that are critical to the achievement of communication competence. It has been well-documented that effective intervention programs have family involvement. Speech language pathologists play a key role in counselling, education and training, coordination of the delivery of services, and assisting in advocacy for the client and their family.

There is a crisis on the front lines that we have heard earlier. Grieving and often angry and exhausted parents are delayed in helping their child with special needs. They often have to wait months for the initial diagnosis, and then even years later for assessment and treatment by a speech-language pathologist, often.

A recent study of members was conducted by the pan-Canadian alliance of speech-language pathology and audiology associations on wait times in 25 different diagnostic areas for speech, language and hearing services. The survey found that some individuals with ASD and their families are waiting more than a year for the initial SLP assessment and then subsequently waiting another period of more than a year to receive services just from speech-language pathologists.

From the data collected in 2006, current wait times for SLP services for patients with autism are significantly higher than recommended by SLP experts working in the field. There are shortages. Clinicians are feeling burned out.

I would like now to focus on the recommendations that Canadian Association of Speech-Language Pathologists and Audiologists is making to the Senate committee.

We are recommending and supporting the creation of a national autism strategy that involves an interdisciplinary team approach for assessment, diagnosis, treatment, training, education and research of autism spectrum disorders.

Currently there is no provincial or federal mechanism for consolidating the areas of educational, clinical expertise, research endeavours, and clinical practice, thereby enhancing and facilitating more collaborative efforts. Through supporting and sharing national tools, such as training and education programs, best practices, awareness initiatives, and evaluation and monitoring systems, each province will then be able to develop or further enhance its own services with respect to diagnosis, assessment, treatment, training, education, and research within the field of ASD.

Funding for appropriate speech and language pathology intervention over the lifespan of the individual must be part of any national autism program. The key items we would like to stress are the importance of speech language pathologists as part of the diagnostic process, and funding for intensity in delivering appropriate treatments.

Funding must again be available over the lifespan of an individual with ASD, as most provincial funding currently has focused mainly on the preschool population, leaving school-aged and adult populations with very little resources available to help them achieve their potential and contribute as a productive member of society.

Funding for coordinated evidence-based research must be supported to determine the communication interface for individuals with ASD and to evaluate treatment outcomes with respect to speech, language and communication skills. This research will drive future practice guidelines with respect to assisting in understanding what forms of treatment are most effective, for what type of child, at what developmental stage and for what outcomes or goals.

However, we caution as well not to wait for research to deliver funding and programs. Children and families are now waiting for treatment. While waiting for peer-reviewed research evidence to develop, expert clinical judgment of highly trained speech pathologists should be considered as one level of evidence. This can help guide public policy until higher levels of research are available.

We need to stress that there is no one treatment option for ASD, as this is a very complex disorder. All approaches recognize that intensity is required. Government funding of treatment for children and adults with autism spectrum disorders should be inclusive of all methods or models that are evidence-based treatment.

The final recommendation is to ensure that assessment and treatment plans are intensive, interdisciplinary, flexible and interactive to best match the diverse characteristics of this heterogeneous population and the various outcomes desired.

Integration of services is of critical importance, not only for treatment efficacy and efficiency but also for the sake of the parents who already have tremendous challenges. Parents often experience conflicting information and promises, conflicting approaches, goals and therapists. Conflict and duelling evidence not only takes its toll on families but also on the therapists.

Interventions should be based on an integrated understanding of an individual's needs and strengths across all members of that individual's team of parents, educators and service providers. A single set of prioritized goals across all domains and an agreed upon approach or approaches should be developed to achieve the best possible outcomes for individuals with ASD across the lifespan.

Thank you again for this opportunity to present from the Canadian Association of Speech-Language Pathologists and Audiologists.

The Chairman: Thank you for your presentation. I might add I appreciate the fact have you put this in a brief. I would draw committee members' attention to the fact this is all nicely outlined, including the five recommendations, starting on page 10. Thank you for providing that.

The next speaker is Dr. Karen Cohen, of the Canadian Psychological Association.

Dr. Karen Cohen, Associate Executive Director, Canadian Psychological Association: I am pleased to be here to discuss this important topic of autism.

Thank you on behalf of the CPA for your important work in mental health, particularly for your report, *Out of the Shadows at Last*. We also submitted a brief which summarizes the CPA's position on the state of knowledge, treatment and research in autism. I will go over some highlights of that here.

We have heard what autism is, its prevalence and ideology. I will not repeat that for you now. I would like to highlight some challenges and opportunities in terms of research and treatment.

We have heard quite a bit about how important it is to fund research into to causes and etiology of ASD. We have heard as well about the importance of the early and reliable identification and diagnosis of ASD.

As is the case for many genetically or biochemically determined brain disorders, once the causes are known we are still left with people who have conditions to manage. For that reason, I compel you to understand there is as much a need to fund and support the research and the development refinement of the interventions for ASD as there is into its genetic or etiological basis. Right now, those treatments, as you have heard this morning, are often psychological, psychosocial, psychoeducational and communicative treatments. Research into those treatments need funding.

When you look at the lay as well as scientific literature on autism what is clear is that there is no one treatment, medical or psychological, which promises to cure ASD. There is no drug or single treatment that will make it go away. There is none that is the single best treatment for everyone with ASD.

There are many single and comprehensive treatments that have an evidence base of effectiveness. The comprehensive treatments with the most demonstrated effectiveness are those that are primarily based on the science and practice of psychological principles. Our colleagues who spoke before us made some reference to treatments like intensive behavioural intervention which are applications of applied behavioural analysis.

These interventions typically target educational and skill development. They aim to improve the quality of the person's social interactions, their language and communication, their sensory and motor function, as well as some of the problematic behaviours.

I would like to underscore as well something we heard from Dr. Roberts about the importance of interventions —

The Chairman: Excuse me, could you slow down, please, for the interpreters?

Dr. Cohen: To underscore the importance of counselling and support for families, the parents, in particular the mothers of children with autism, experience significant mental health problems when you compare them with parents of children with other kinds of disabilities. It is particularly around the stigma and the fact that when you see in public a child with autism who has very problematic behaviours, the kinds of responses they get from people who do not understand it is, "It is poor parenting." This is a huge pressure and stress on parents.

Another stress is also access to service which you have already heard about and I will touch on a bit as well.

Wait lists for intervention, when they are publicly funded, are very long. When they are privately funded they are at tremendous cost. There is also a shortage of trained professionals to provide that service.

CPA's particular concern about Canada's health care system has long been that our jurisdictions fund providers rather than service. In the current instance the system does not cover the best available treatment for ASD because this treatment, although clearly a health treatment, is not a medical treatment. That is something I would like to leave you with to consider.

Our colleagues on the panel before us were three physicians, representing one professional group. Although we work collaboratively and certainly respect the input and contributions they make, you have each of one of us, to put that in perspective for you.

In CPA's view, the barriers to accessibility of treatments for ASD are a severe and expensive incidence of the many mental health treatments that are not funded by our country's health system. Psychologists are the single largest regulated group of specialized mental health service providers in this country. The science and practice of the profession of psychology forms the basis for many of the best treatments for many mental health conditions and disorders and the services of psychologists are not accessible to many Canadians.

Canada needs an action plan for mental health, including diseases and disorders of mental functions. The CPA supports the establishment of a mental health commission that can be charged with this plan.

I wanted to stand by answering some of the questions that I am imagining the committee was hoping to get from the experts they invited to present. Are there effective treatments for ASD? Yes, there are. There are treatments with demonstrated effectiveness. They are based primarily upon psychological principles and practices chief among those.

Should Canada fund this treatment? Yes. We have a responsibility to provide people with the health care they need. We need a health care system that covers indicated treatments rather than only treatments covered by designated providers.

Are there barriers to accessing treatment? Yes. The barriers are related to cost, the availability of needed and indicated treatment, delivered by or under the supervision of trained and regulated health care providers.

Should funding be based on the demonstration of treatment effectiveness? CPA's position is that we should leave the obligation of monitoring best practice to the health care providers and their regulatory bodies. Treatments for any disorder should have clear and consistent guidelines. They should be delivered by or under the supervision of regulated health care professionals.

The Chairman: Please slow down.

Dr. Cohen: There needs to be national standards for the training of specialists providing treatment for ASD. Again, these need to be delivered by regulated providers.

In terms of who should provide the screening assessment and treatment, we have heard before from Dr. Woodside and Dr. Roberts that it needs to be a multidisciplinary collaboration undertaking. It is true the active diagnosis is limited to some groups, psychologists and physicians in the area of autism, but the assessment and intervention really has to be a multidisciplinary collaborative effort.

We have heard about some of the standardized measures from Dr. Roberts, as well as the behavioural interventions that have shown most effective are principally psychological ones. In CPA's view, these need to be provided by practitioners who are trained in the area of autism and who either are or work under the supervision of psychologists.

There are techniques that are part of other comprehensive programs which are delivered by other health professionals, some of whom are here today. Those, similarly, need to be delivered by regulated health care providers.

Finally, I want to address where treatment should be provided. The fact is that kids live in schools, they live in homes and they live in communities. We must have coordinated care and flexible access to the services that children need.

In closing, the CPA commends the committee for the attention it is turning to disorders of mental function, in particular to autism. We hope you will receive all input with earnest consideration, and we are available to provide you with further information or assistance.

The Chairman: Thank you for your submission as well.

We have two representatives from the Canadian Association of Occupational Therapists. They are the executive director, Dr. Claudia von Zwech; and Dr. Mary Law from McMaster University.

Dr. Mary Law, Associate Dean and Director, School of Rehabilitation Science, McMaster University, Canadian Association of Occupational Therapists: I am pleased to be here on behalf of the Canadian Association of Occupational Therapists. We also have a brief for you in printed form.

The Canadian Association of Occupational Therapists is a national organization committed to improving the health and well-being of Canadians. We help and enable people to lead productive and independent lives by helping them participate fully in self care, paid and unpaid work, and leisure.

As noted already this morning, the prevalence of autism is increasing. I will not speak about that in detail but rather focus on the potential contribution of occupational therapy intervention.

The goal of occupational therapy is to enable children with autism to participate in everyday occupations. These include taking care of themselves through dressing, bathing and feeding, for example; contributing to society through paid and unpaid work or participation in school; and enjoying life through hobbies and sports, for example.

Occupational therapy addresses barriers to participation that may occur due to illness or disability and obstacles in the social, institutional or physical environment.

How do occupational therapists help children with autism? There are two primary methods through which we do this. The contribution of occupational therapists can be most meaningful in the context of sensory and motor issues. There is evidence that children with autism process sensory information differently from other developing children.

The focus in occupational therapy has shifted recently to understanding how and when a child is reacting poorly to a sensory experience and structuring the environment to accommodate or minimize such reactions.

Occupational therapists can use a mediator, consultative or direct intervention approach to work with parents and teachers to provide strategies to prevent reactions to sensory experiences from limiting daily activities.

For example, if a child with autism is upset by excess noise at school, particularly at the end of the day, an environmental adaptation is for them to get ready to go home before everyone else. If a child is bothered by specific clothing, for example, wool, this type of material could be avoided.

By adapting tasks and environments as well as working with families and teachers on how to teach new skills and build calming or alerting activities into everyday routines we can make a difference in a family's daily life.

In particular, occupational therapy for children with autism focuses on self-care issues — feeding, bathing, hygiene and sleep, all significant issues for children and enormous stressors for families.

In the areas of activity of daily living, the focus of an occupational therapist is on task analysis — breaking down a task into manageable steps, teaching these steps to key people within the child's environment, and structuring the task or environment to support successful task completion.

Recommendations and issues around access that the Canadian Association of Occupational Therapists has identified include the following: There is a shortage of occupational therapists with advanced education across Canada to work with children with autism in their homes and schools. We believe that children and families should have access to the right professionals at the right time and interdisciplinary teams in their communities throughout their lifetimes.

The provinces and territories are not required to fund occupational therapy services. As a result, funding levels vary across Canada and services for children with autism vary as well.

Wait lists for services for assessment and treatment are at an unacceptable level for families and their children. Families are waiting up to a year for diagnosis and then a further two to three years for therapy services. For example, within Ontario there are currently 6,000 to 8,000 children waiting for school health therapy services.

Most treatment services are behaviourally based and available mainly for preschoolers. There is little treatment available for adolescents. There is a need for continued services throughout the lifespan.

The Canadian Association of Occupational Therapists supports the development of a national strategy. In fact, we would like to broaden that to be a national strategy for children with disabilities, including a national vision and action plan for children with autism.

Such an action plan should address the following areas: System issues, including access and funding; integrated health human resource planning; wait list management; research to develop evidence for evaluation and intervention; and coordination and integration of services provided by the health, education and social sectors.

Within the strategy we believe it is important to address family interventions and supports for families; participation of families and children in shared positive occupations; the establishment of guidelines for integrated collaborative services among health, education and social services; education for consumers, health professionals; and funding agencies and government to ensure a comprehensive approach to treatment that addresses functional skills rather than fringe skills that may be targeted in singular approaches. There is a need to ensure opportunities for inter-professional collaboration and to create mechanisms to develop treatment pathways based on evidence.

The key treatment issue, as has been said already this morning, is how much treatment, at what age, and when is it appropriate to discharge, to decrease treatment intensity or to increase it?

Thank you for your attention. I would be pleased to answer any questions.

The Chairman: Thank you very much, Dr. Law.

Thank you again to all three of you.

Senator Nancy Ruth: Dr. Cohen, someone who needs psychological services cannot get that through their provincial health services. Is that universal across Canada?

Dr. Cohen: There is no simple answer. If the psychologist is salaried by a hospital, a school or a correctional facility, there is no charge to the consumer. However, we anticipate that by 2010, up to 70 per cent of psychologists who are licensed will be practising in the community, and those services are not covered.

Senator Nancy Ruth: You also said something to the effect of that you wished that other groups dealing with autistic children would be under the supervision of a psychologist, and my mind went to classroom assistants.

Dr. Cohen: I was not saying that all the partners of a multidisciplinary team be under the supervision of psychologists. I was saying that those that are implementing the behavioural aspects of these intensive behavioural programs, which really comes from the domain in science of psychology, be under the supervision of a psychologist, but there are many other components to a program.

Senator Nancy Ruth: Does that include these two professions?

Dr. Cohen: No.

Senator Nancy Ruth: Who are you talking about, then?

Dr. Cohen: The title that is given to many of the therapists who work implementing many of the IBI programs is "behavioural specialist." They are not a regulated health profession, and the training and credentialing in this area is not systematic or standard.

The members of the CPA who work in the area of they are encouraging psychologists who do this kind of treatment and work in autism to have this specialized training in applied behavioural analysis, which is the domain of psychology.

We understand that it may not be the psychologists themselves. There may be some opportunity and need for people at the bachelors or masters level to do this kind of work, but there needs to be some public accountability for how it is delivered.

The Chairman: Perhaps we can spread that question across to the other two in terms of the professionals that you represent and what is or is not covered under health care plans.

Dr. Law: What is covered under health care plans for occupational therapy are services that are delivered from publicly funded institutions such as hospitals, children's rehabilitation centres and school health services. Within that, there are many areas across the country where autism services by occupational therapists are not covered. We are in a situation where many parents have to spend a lot of money for those services.

Ms. Lindblad: In speech-language pathology, it is similar to occupational therapy. Our services are covered under the health plans when they are delivered in a public setting such as a school or pre-school program or a hospital. Again, they all have wait times and some of the models are more consultation — parent training or group therapy, instead of direct therapy. It really does vary, depending on where you are and the number of speech pathologists available as well.

(French follows, Sen. Pepin: Justement, lorsqu'on parle)

(après anglais)

Le sénateur Pépin: Justement, lorsqu'on parle des différentes disciplines, on sait qu'un des problèmes importants, c'est les frais excessifs, et l'une de vous a dit que d'ici l'an 2010, probablement que tous les professionnels seront dans l'entreprise privée et non dans le public, comme les hôpitaux. Mis à part les frais excessifs, croyez-vous qu'il y aura assez de professionnels disponibles pour accueillir ce genre de clientèle, que ce soit les enfants ou les adultes souffrant d'autisme ou d'autres maladies semblables?

(Dr. Law:: I am sorry, my translation is not working...)

(anglais suit)

(Following French, Sen. Pepin — maladies semblables)

Dr. Law: I am sorry, my translation is not working; that is why I was signalling.

Senator Pépin: I was just saying that it was said in the year 2010, most experts working with autism and other mental issues will be in the private sector. Do we have the money to look after the people who need it; and on top on that, do you believe there will be enough professionals to look after those patients?

Dr. Law: There is a need to invest money for children with autism and at the same time, to evaluate those services so that over that period of time we can begin to develop some more effective and cost-effective strategies. There are children with autism who will benefit from very intensive treatment in their early years, and need less intensive treatment later on, in consultation approaches.

Many of the approaches by occupational therapists are best delivered through consultative or mediator model, through providing strategies to parents and teachers to adapt the environment to support the participation of the children in their everyday activities.

Ms. Lindblad: I would like it add to that. Some of the migration from public-funded services to private services has had to do with a shift in funding for some of those services. Speech pathology is not a mandate of service

within the education act. Schools do not have to hire speech-language pathologists, so often when budgets are cut, we are cut.

The increasing caseload sizes that we have to deal with in hospitals, pre-school publicly funded settings and school board settings are often 10 times, if not higher, than what our American counterparts have in terms of caseload sizes. It is not unusual across Canada for a speech-language pathologist to have an active caseload of 150 to 200 children in a year. In the U.S, a caseload of one autism class is a full-time position. We do not have those types of same benchmarks or limits in Canada.

The shift to consultation for some of us, rather than direct treatment and direct therapy, was also a big one. I know when I left public life and went to the private sector, it was because I was not allowed to do direct therapy anymore; and it was the direct, intensive treatment for children with autism that is beneficial. I felt, professionally, that I needed to do that.

Unfortunately, privately we still have waiting lists, because there are not enough professionals graduating. The field of autism is one of the most difficult fields to deal with in our profession. The lack of communication, the difficulty in behaviour, the intensity in approach and the supervision of the program all take a toll on the therapist as well. It is difficult to attract speech pathologists into the field of autism.

Dr. Cohen: If I could add to that, it was me who made the comment that up to 70 per cent of our members will be in private practice. Again, to underscore, that was not profession-driven necessarily; it is the investment in the salaried resource in our various public institutions that has eroded and driven people into private practice.

The other challenge in autism and other disorders is that many of the professions are realizing that much requires collaboration and a multidisciplinary approach. That is not something that can be easily accomplished by any private practitioner solo in a community. There must be an investment for that. The physicians will say to you, who will pay me while I talk to the psychologist and the OT and the speech-language pathologist; and the psychologist will say who will pay me at all to see this client who needs a lot of service? There must be an investment in the structure to support this kind of work.

Senator Munson: I am curious to know, how serious are the shortages for speech-language pathologists? You talk about burnout; are these shortages all across the country?

Ms. Lindblad: All across the country. The field of speech-language pathology is experiencing shortages. There are currently positions open everywhere, so it is a graduate market; they get to name their price if you want them to come and work for you.

In 2007, the estimate is that there will be 262 graduates across the country. There are nine programs only; three are francophone programs delivered totally in French. We have to increase that, as well, to meet the demand of services.

Senator Munson: Do you deal with young people with Asperger syndrome?

Ms. Lindblad: Yes, I do; I have actually published in that area.

Senator Munson: I will just preface that. In our committee, we talk about autism a great deal, but we have not mentioned it in our hearings thus far. Could you bring us up to date on what Asperger syndrome is, and perhaps tell us what type of speech pathology you do in this regard?

Ms. Lindblad: I do not do diagnosis, so I will let Dr. Cohen go through the actual diagnosis of Asperger so you get a technically correct diagnosis.

Dr. Cohen: Both autism and Asperger are on the autism spectrum of disorders, autism generally being considered the more severe end of the continuum. About 80 per cent of people diagnosed with autism have below average intellectual functioning; those with Asperger syndrome are either average or above.

There are some features in common, and some that are distinct. Visual-spatial skills are a relative strength for people with autism and a relative weakness for people with Asperger. General motor skills tend to be consistent with developmental level for people with autism; for those with Asperger, there tend to be some more issues around motor skills difficulties. When I say developmental level, I mean depending where you are at generally in terms of all the milestones that you reach.

Verbal skills are a weakness for those with autism, but a strength generally for those with Asperger. The more social functions of language — and my colleague in speech-language pathology can speak to that better than I — tend to be a weakness and a problem for people with both disorders.

There are issues around repetitive behaviours and interests. You will often find someone with ASD who becomes fixated on repetitive behaviours and interests — kids who may be fascinated with trucks or trains or the names of cars; it tends to be much more behavioural in autism, with repeated movements. For Asperger, it is the opposite; it might be more of an idea — a verbal or activity repetition that they have difficulty shifting set from. Finally, both disorders are characterized by what has been called a lack of theory of mind. I think this is what creates a lot of the social difficulties.

You have to understand that somebody exists separate from yourself in order to be able to develop social skills. So you know your friend has a different mind and thinks differently about a problem. That really is the foundation for empathy and getting along with others. If you cannot do that, that is really going to impact the social aspect. Maybe that was a longer answer than needed.

Senator Munson: No, we have to broaden it out. It is important for the committee, myself and others to understand because we are focusing on the big word, autism. In my brief look at this over the last few years, we have had, in fact, before a House of Commons committee, a gentleman from Montreal who had Asperger's Disorder. I was fascinated by this person who could take a watch apart and put it back together again. Because he has these kinds of skills he now works in a computer centre in a university in Montreal. Of course, the other social issues are something to be dealt with. I would assume you would believe this should all be part of a national strategy.

Ms. Lindblad: Absolutely and I commend you actually for including the entire spectrum. There is a myth out there that children with higher functioning autism or Asperger's require less services because they have better abilities. I deal a lot with children and adolescents with Asperger's and they are difficult individuals to deal with.

The social deficits are at the core of their disorder but they still can have communication disorders as well. They can have specific language impairments which often go unnoticed and untreated because it is masked by their good verbal skills. Sometimes their verbal skills are hyper-verbal; they are above what they are understanding. Again, people are misinterpreting often what is happening.

The biggest area for Asperger's is that the mental health issues begin to compound in the disorders. There is increased anxiety, there is increased depression often. There are different categories when you are looking at IQ and language skills and where it impacts the differently.

When you have typical teenagers, those of us who do, you know it is a difficult time for any teenager. When you compound it with social communication problems and perceptive behaviours and then a mental health issue such as anxiety or depression, then it becomes too great to handle. There are many individuals with Asperger's who become school-phobic because they cannot handle any amount of social interaction.

As speech-language pathologists, we have to work intensively. The limited research we have at this point is that intensity is the key. That is where we have really focused on preschools and a lot of the IBI programs available, and adolescents, have really got left out because we know there are things we can do and the parents are struggling with those individuals just as much as parents with children with autism.

Dr. Law: Children with Asperger's have difficulties which cause problems in terms of everyday activities. As Dr. Cohen mentioned they may have motor difficulties. Social difficulties may really cause them immense problems in terms of fitting into environments, school and work. You mentioned the person who could take apart a watch. With the transition into adulthood, trying to find the best fit, the proper environment and the best occupation for them in terms of paid work is tremendously difficult for youth with Asperger's as well as anyone with autism.

Senator Munson: We heard earlier this morning from three others and they talked about federal leadership that has to come from the centre. There is provincial delivery, but somebody has to sit down and say let us all get together and do something about this. Do you believe perhaps the health minister should sit down with his provincial counterparts and have a brain storm like researchers do, like you do, and to bring the provinces together to develop some sort of national autism spectrum disorder strategy?

Ms. Lindblad: I absolutely believe that a national strategy is imperative, if not for any other reason than to encourage collaboration across the nation. Our associations or our provincial associations only get together when there is a national body that facilitates that dialogue. It really is important that there be a national vision, a national strategy, and that we do not reinvent the wheel and continue to reinvent the wheel for every province and every service. There are a number of services and difficulties in strategies that run across all of our disciplines, so it would be a real cost savings strategy to come up with a national plan.

Dr. Law: I absolutely agree. Nationally, the federal government can lead in terms of bringing people together to develop guidelines and strategies to share information. The national government can lead in terms of funding, desperately needed research about the cost effectiveness of different interventions. It can also lead in terms of health and human resource strategy for a multi-disciplinary team to address these issues.

Dr. Cohen: I wanted to add, that can be the role of the mental health commission to provide that kind of leadership and oversight and commitment.

Senator Keon: Dr. Cohen, you just raised an interesting question. You said that can be the role of a mental health commission, which I am completely confident will get up and running this spring, but the problem when we were doing the hearings, is the many people who were representing the autistic community felt that autism should not be dealt within that structural framework. I did not intend to ask you this question, but since you wandered in there, you had better clarify whether you should be in that tent or in a tent of your own.

Dr. Cohen: I understand and respect the position of the autism community. It is a complex one, because autism is not alone among the other mental health disorders that have a biochemical or genetic basis. The commonalities are that it is a disorder of mental function. My concern is we do not want to deal with stigma by not using words like "mental functioning" or "mental health." It should be included within the working mandate of the mental health commission.

Senator Keon: Let me bring you back to your two last recommendations in your document and I would like the full panel to comment on where and who should provide treatment. Who is number four, and where is number five. It is tremendously interesting because indeed in all the hearings in health going back to our original 2002 report and up through the mental health report and so forth, the universal problem is that a tremendous number of people are falling outside the safety net, right? Mental health is very bad and autism is worse.

If we are ever going to find an alternate way of dealing with this, we felt, and recommended in the mental health report, that we put a heavy emphasis on community; that we make a major investment in community

resources and multidisciplinary teams, which all three of you have referred to, but try to convince people that these problems cannot be dealt with completely at the institutional level. Institutions are too big, they are too user unfriendly, people cannot find their way or cannot even park in most of them. They just cannot get access there.

On the other hand, if we drill down to community, for a very reasonable cost compared to our institutional sector in health care, we could build networks of community clinics that would have all the teams; we could eliminate the problem of funding because everybody who works there would be paid. It could be economically positive. They could be integrated in with the schools and the police, for that matter, who unfortunately sometimes pick some of these people up in the night and take them to jail rather than bring them to the community.

I have pontificated enough now. The question is for the three of you. Tell us how you think this could be organized.

Dr. Cohen: I think locating it in the community and creating an infrastructure to support collaboration would be absolutely outstanding. One of the things that the research into treatment for autism tells us is that it needs to be flexible and accommodate the individual needs of a child. Can you find a venue where it always has to be delivered with a particular team and treatment? I do not think so.

As my colleagues pointed out, some children need intensive behavioural intervention and others do not. Others may need more speech-language pathology or occupational therapy. That is the advantage of a team that co-locates and has an infrastructure to support collaboration. You can have that flexibility because there is some sort of central place where that can be coordinated.

The link with schools, though, will be key. Hearing back from some of our colleagues working in education, they will say we are worried about the resource, providing this kind of support to children in schools. There would really need to be some way of not just locating it in the community, but somehow creating an infrastructure so that schools can support the interventions as well.

Dr. Law: I agree that it should be community based and multidisciplinary in nature. The research indicates that working within the natural environment of the child who lives within families is much better. Some work has been done looking at schools as hubs, as the basis for co-location of services. Certainly, the research indicates that the fewer places that families have to go to for services, the less stressful it is and the better for the child. If we had one place within a community where multidisciplinary teams were available — have one assessment and one set of goals for which the appropriate treatments could be provided — it would be much more effective and cost-effective.

Ms. Lindblad: I agree that a community based intervention plan is probably the best suited for this diverse field, and these diverse individuals. Again, the dilemma will be cooperation. In Ontario right now we have an intervention program — the autism intervention program — and in some of the areas in the province, we are working in schools in that IBI program. However, it has become very problematic because there are turfs. We need to do a lot of research, education and training; it would have to be a team and education would have to be a major part of that team.

Health-regulated professionals are very good about working on teams. We are trained to work on multidisciplinary teams. Education has not been so much that way. It is not a health model. We would need to do a lot of work to bring them on board into this collaborative model.

The only caution would be the consistent service across the country. We already have families that are moving province to province and rural to urban. Again, it would be the national approach, having the one strategy or a nice flow of evidence-based practice to the application level. If that consistently happened across the country, that would be the best for all the clinicians and families as well.

If you have a community service and, at the community level, have clinics, you have regulated health professionals on site. Then we could better use other services that we are used to using — like instructor therapists in the IBI program. We have CDAs, communications disorders assistants, which is more like a technician level to deliver the therapy or the direct service. You have your regulated health professionals overseeing the quality of this service, and that way it is a more cost-effective service.

Senator Cordy: You have given us a great reason to promote the multidisciplinary team. It seems like autism is one of those things that just fits so well into it. Without everybody working together, it will not work for the people who most need the help, which are those who have autism.

Dr. Cohen, you raised the issue of stigma and the importance of public awareness so the public is aware of what autism is — that it is not poor parenting, that it is something that needs attention.

I will never forget a scene I witnessed at an airport. A father was trying to get his autistic child through security. The child would not walk through; it was just screaming all over the airport for everybody to hear. The father was trying to say my child has autism, trying to apologize to everybody because, as you can imagine, there were a number of looks and stares. My heart just went out to the parents.

That is something I think we could do nationally and from the federal level. Could you expand on that a little bit?

Dr. Cohen: The issue of stigma is one we can talk about not just with autism, but all mental function disorders. CPA was fortunate to sit on the technical advisory committee to the disability tax credit. One of the things we were charged with was looking at how you devise eligibility criteria for people with disabilities related to mental function, which are not so obvious. It is easy to decide if someone is a paraplegic — they cannot walk and they meet the eligibility criteria. However, how do you convey what a mental impairment looks like?

That is part of the challenge for people with autistic children at times. All the body parts seem to be there, and people are very concrete. The inclination is to say it must be something that is being done to this child or not done to this child.

We need to destigmatize mental illness. It is not a crime or a shame to have a problem in the way in which you think and feel, in the same way it is not if your legs do not work.

Senator Cordy: Do you think that this could be something that we could help with? We have promoted national education in terms of mental health, mental illness and addiction. Do you think this could fit in with that package?

Dr. Cohen: Yes, I do. One of the recommendations we made to the commission was for a Canadian mental health guide, much like there is a Canadian food guide. What is mental health? What do you need to do to take care of it, and what happens when it is not working so well?

Ms. Lindblad: I would like to add to that a cautionary note that there is an increased awareness already in the field of autism. I agree there is a stigma if it is under mental health. More education on that, before having treatments available and that whole treatment package there, is not going to help. People will be more aware; it will increase assessment and diagnosis and then nothing.

You really almost have to do it the other way around; get our treatment programs in place and funded, get our community clinics there and then do some more work on the awareness campaign and public education. I know from my own children, who are in elementary school, that they are really comfortable with all of these diagnoses now. That was something that integration did very well.

They can probably diagnose better than some of our counterparts in the community. They know that these individuals will be with them in society. They worry about it, though; typical kids worry about their peers. The stigma still is for the adult population, the parents; our children growing up today will not have that same view.

Dr. Law: Providing information is vitally important as part of a multi-pronged strategy. I would urge the committee to look at some of the research that has been done around how to transfer knowledge and information — using simple language, focusing on specific strategies, using person-first languages, respectful. There is a lot of information about how to transfer knowledge in a way that is effective and will be taken up and used by people.

Senator Cordy: One of the things that I think is important to convey to the public is that the public hears the cost of IBI, as an example, and they immediately think — and I have heard people say — that is a lot of money for one child. Part of the program could be saying this can be the end result. I think that would be very worthwhile.

Dr. Cohen: Dr. Moss mentioned it, but I will say it a little differently: Pay now or pay later. There are huge personal costs and costs to society if we do not intervene early. We would not probably be having this meeting if we were talking about a very expensive medical treatment because that would fall under the Canada Health Act.

The Chairman: I would like to ask you about the prevalence of ASD in the population. The Statistics Canada numbers are 69,000 now. They are saying that is persons with autism and any other developmental disorder. Autism Society of Canada suggests it is around 200,000. What do you think it is? How many people are in this population that we are talking about going through these challenges?

Dr. Cohen: The figures we have for autism spectrum disorder ranges from 3 to 7 people in a thousand and for autism in particular, one to two in a thousand. We heard a bit about rising incidence and I have heard figures around one in 166 and so on, but generally — please feel free to disagree — that is being attributed to the much broader definition of autism spectrum disorder rather than just autism, more systematic assessments in the community rather than an actual rise in new cases.

Dr. Law: We have done policy work with ministry and children and youth services in Ontario. As part of that work we have done a systematic review looking at prevalence rates of various childhood disabilities. I agree that it has risen but it seems to be that the systematic review indicates that the rates are about 6.5 per thousand. There is increasing worldwide agreement around those rates now, although there are some studies that tend to show vastly increased prevalence rates but they have a lot of methodological problems with them.

Ms. Lindblad: Would I agree with what my colleagues have said and also add that with the increased incidence is a tendency to over diagnose at times because some provinces have well-developed and intensive IBI programs. Consequently physicians have often said, I am not entirely sure if this child has autism but they can get service, because the corollary is no diagnosis and then no treatment.

That is happening both in preschool and in our education system. Just last week I was supervising some children in Northern Ontario, and out of some of the children in our IBI program I really feel quite strongly, and with the clinical psychologist I was with, that they were just speech and language disordered children; they really were not on the spectrum, even though they are in our intensive service and doing very well in the intensive service we are remediating. They will have best outcomes but then that is clouding the research. We actually have children in those research studies that do not belong in those research studies and in those outcome groups.

The Chairman: Thank you very much to all three of you for your contribution and your written submissions which we can study, and also to your answering of the various questions. The committee adjourned.