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Thursday, December 9, 2010

Chair

Mrs. Joy Smith

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● (0900)

[*English*]

The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)): [*Inaudible—Editor*]...we are going through the study of autism, something that's been of paramount importance to our committee.

I welcome Mike Lake here today as part of our committee.

We have a number of witnesses today.

We have Laurie Mawlam, who is executive director of Autism Canada Foundation and also with the leadership committee of the Canadian Autism Spectrum Disorders Alliance.

That's a long title, Laurie. Good morning, it's nice to see you.

From Autism Society Canada we have Kathleen Provost, executive director, also with the leadership committee of Canadian Autism Spectrum Disorders Alliance.

Kathleen, welcome.

Suzanne Lanthier is executive director of Autism Speaks Canada, and from the Canadian Paediatric Society we have Dr. Wendy Roberts.

Welcome to you both.

We're going to start with ten-minute presentations from each, and I think I'll start with Laurie....

Yes, Mr. Lake.

Mr. Mike Lake (Edmonton—Mill Woods—Beaumont): Madam Chair, on a point of order, I know it would be very unusual, but I wouldn't mind having my son Jaden sit at the table with me.

I would just ask the other members of the committee if that would be okay.

The Chair: Oh, absolutely.

Mr. Mike Lake: Jaden, come over and sit here.

The Chair: Hi, Jaden. Welcome to our committee. I'm so glad you're here today. This is wonderful.

I was a teacher for 23 years. When I was a resource teacher, I taught for three years a class of children who had autism, and they're just very wonderful children.

So welcome, Jaden.

Laurie, please go ahead.

Ms. Laurie Mawlam (Executive Director, Autism Canada Foundation, and Member, Leadership Committee, Canadian Autism Spectrum Disorders Alliance): While I'm the executive director for Autism Canada Foundation, Autism Canada is also a proud member of the Canadian Autism Spectrum Disorders Alliance. I'd like to make a very short presentation from Autism Canada Foundation, and then, together with Kathleen Provost, who is also on the leadership committee of CASDA, we'll do a presentation on behalf of 38 autism organizations from coast to coast.

When I got the invitation last Thursday to be here, one of the first things I did was pull the report we had submitted to the standing Senate committee and read it. I could have easily just changed the information on our board of directors and submitted the same report.

That said, I'm really optimistic that we're ready to do something.

There are three things I'd like to point out from Autism Canada Foundation's perspective that I don't think you will hear from the other organizations—or maybe you will, but just so there's not so much duplication.

Number one is what brought Autism Canada Foundation together: we believe autism is a whole-body disorder, and all of our board members, including me, have a child who's been diagnosed with autism.

I'd like to reference a paper that was published in clinical neuropsychology in 2005 called “Autism: a brain disorder or a disorder that affects the brain?” It was written by Dr. Martha Herbert. While autism is defined behaviorally, and historically has been thought to be a brain-based, strongly genetic disorder, emerging evidence and hypotheses support a broader-based model, viewing it as a systemic disease, likely due to the interplay between genetics and the environment.

I also did a PubMed search of oxidative stress and autism, and found 82 documented papers from multiple countries. I then did a PubMed search on immune system dysfunction and autism, and found 253 papers published.

In January 2010 the journal *Pediatrics* published a paper entitled “Evaluation, Diagnosis, and Treatment of Gastrointestinal Disorders in Individuals With ASDs: A Consensus Report”. The report made 23 consensus statements and went on to conclude:

> Recognition that problem behaviours might indicate an underlying medical condition will facilitate diagnosis and treatment and ultimately improve the quality of life for many persons with ASDs.

I ask you, isn't this what we all want—to improve the quality of life for individuals with ASDs?

There's also strong clinical evidence that treating medical problems that present with autism, or perhaps are part of the autism, have a profound effect on that person's ability to function and learn, accompanied by improvements in autistic symptoms.

To summarize, I'd just like to say that if you're not feeling well, how well do you function?

I'd also like to talk about coming off the spectrum: recovery. The word “cure” even comes up at times. I just want to say that people are writing books about it. Researchers, neurologists, doctors, service providers, and autism organizations are talking about it and acknowledging it.

Dr. Martha Herbert wrote a paper for the *Autism Advocate*. I've pulled a quote out that I'd like to share with you:

> We are hearing a growing number of reports of children recovering substantially or completely from their autism.

It goes on to say:

> Some of these recoveries are attributed to intense behavioural therapy; some to intense biomedical intervention; and many to a combination of both. Although autism has traditionally been considered incurable, the “incurability” is merely an assumption—it has never been scientifically proven.

That's food for thought for everyone here.

I'll also say that in May 2009, researchers from the University of Connecticut presented at the International Society for Autism Research that they didn't know for certain what percentage of children were capable of moving off the spectrum, but it was probably in the neighbourhood of 10% to 20%.

This was based on children recovering through ABA treatment only. How many more would there be if we combined ABA with medical treatments?

● (0905)

Autism Canada Foundation believes in a multidisciplinary approach to treatment. We must look beyond the behavioural diagnosis and treat the individual. All the behavioural interventions in the world can't correct things like a prolapsed rectum, colitis, strep infection, PANDAS, GERD, viral infections, clostridium infections, or immune system dysfunctions. Persons with autisms need to find their place to receive these medical treatments.

The last point I want to make is about some interesting research that's going on in Canada at the University of Western Ontario at the Kilee Patchell-Evans Autism Research Group. Dr. MacFabe has put together probably the best animal model of autism I'm aware of. But interestingly enough, he's pulled together not only social, fixation on objects, and inflammation in the brain; he's pulled it all together in this model, and it's one piece of research that deserves more attention. It could be one of many smoking guns, because we know that this is a complex disorder.

This is my message from Autism Canada. I look forward to presenting with Kathleen Provost on behalf of CASDA.

Thank you.

The Chair: Thank you so much. You gave some really good new information that I hadn't known. Thank you for presenting that.

Kathleen, would you like to present as well?

[*Translation*]

Mrs. Kathleen Provost (Executive Director, Leadership Committee, Canadian Autism Spectrum Disorder Alliance, Autism Society Canada): Good morning and thank you for inviting us here today to provide you with more information on the autism spectrum.

[*English*]

Autism Society Canada, for almost 35 years, has been speaking as a collective voice for hundreds and thousands of families through our provincial societies, which are located in each province and territory, and we still feel we have a challenge. It is the same challenge. There is inconsistency and inequality across the country in terms of access to a health solution. Every Canadian does not yet have access to health solutions based on where they live and what happens.

The committee asked to meet with us on the subject of diagnosis. The first challenge we have is a waiting list. Everybody faces a number of time impediments and conditions that affect what happens when there is a diagnosis and then what comes after. Every province has a different solution.

Today in Canada we actually have a two-tiered health system for Canadians living with an ASD. There is a health system that is inconsistent because of where you are, what province you live in. There's also a health system that's not equally accessible. I have a bunch of quotes here, and I did a bit of research. In terms of private access, just to get a diagnosis in B.C., it could be up to $1,500. That is just to sit down and understand what's happening. We seem to have a public health system versus a private health system.

There are solutions, however, and we can establish national standards and try to establish best practices in the field of autism.

You wanted to know about treatment. There is some evidence that early intervention for children will have a positive effect in altering the impact of autism in the life of individuals. Autism treatment plans are unique for each individual. We have heard they require collaboration among many different health care professionals: medical doctors, occupational therapists, behavioural therapists, speech and language pathologists. Today in Canada, a multi-disciplinary approach could cost up to $50,000 per year. This is not funded by medicare or other programs, so the accessibility might vary, depending on where you are, what you have access to, and what your needs are.

But we have solutions. A lot of resources are needed, and a lot of collaboration among government departments that can be dressed up, or designed, or invented. There exist some mechanisms for direct funding. We can do CRA adjustment regulations. There are a lot of formulas that can be found to make sure that in the end we have a zero sum for the families.

You also seek information regarding the health and economic burden associated with Canadians living with ASD as well as their caregivers. The children living with an ASD today will grow up and become adults living with an ASD. They are not a burden. They are Canadians living with a lifelong need for a continuum of support that will evolve. It will continue to evolve, just as it will for you and me; as we age, our needs will evolve.

So now what? What do we do? These individuals need access to tailored services, resources and adult treatments to enable them to become contributing members of Canadian society, just like you and me. Today in Canada, owing to a lack of appropriate supports, we continue to marginalize this group of individuals and their families. However, we are experiencing a new wave of families, those transitioning into the next phase. Parents of school-age children who are now transitioning into adulthood will still be challenged with enormous impacts if we have no implementation of changes.

You asked what the impacts on caregivers are. A family will have to use all available resources to provide treatment, even if it exceeds their ability to pay. Wouldn't you do that if it was your child? Families lose their homes, parents divorce. There is a lot of stress. Families sometimes run out of options.

The impact on siblings is enormous—emotionally, socially, and economically. They must anticipate being the support of last resort when those parents age and go away. This is our legacy for the future. The next generation will bear the impact of non-implementation.

● (0910)

There are solutions. The federal government has many employment programs, with support and training. We can offer tax incentives to employment, employers, and different formulas. We can extend some of our training programs that exist already.

Then there's housing. I know of adults living in a halfway house. That's not where they should be. We have federal low-income housing. Those can be extended. We can find formulas to find solutions.

Education grants can be given to support secondary education.

In conclusion, we need to address the oversight. We cannot have non-implementation. We have formulas. We have things active in our system that we just need to review, maybe be creative about.

Across the country our member societies are actively working with the provincial governments and territorial representatives for services and support. But this is not a provincial issue. There are examples of national health strategies by the federal government, so we do need to reinvent.

We turn to the federal government to provide a creative solution. Australia, the United Kingdom, the United States are doing it. They have strategies. Autism Society Canada would like to think it's time we have one in Canada.

Thank you very much.

● (0915)

The Chair: Thank you very much, Kathleen, for your insightful presentation this morning.

And now, from Autism Speaks Canada, Suzanne....

I'm sorry?

Ms. Laurie Mawlam: Madam Chair, we made it short so that we could present on behalf of the Canadian ASD Alliance.

The Chair: Absolutely.

Ms. Laurie Mawlam: Is that okay? Or do you want us to go at the end?

The Chair: No, no, just go right ahead now.

So you want to do that right now on behalf of the Canadian Autism Spectrum Disorders Alliance.

Ms. Laurie Mawlam: Yes. It's a group of 38 organizations—and growing—across Canada. We have a website and we have a position paper, and we'd just like to run through it.

Mrs. Kathleen Provost: We're just going to highlight a few points that we think are important from our position paper.

CASDA came about as a result of the “Pay Now or Pay Later” report. In 2007 there were challenges amongst the community, so we did come together in a collaborative effort. As Laurie said, we are 38. We think that together we can improve our collective understanding of autism spectrum disorders and share best practices and treatment, raise awareness, and respond to the immense challenges that are faced by individuals living with an ASD, as well as their families.

[*Translation*]

We are ready to partner with the federal government. We want to work together and help to develop a national strategy. We have given a lot of thought to a few items on which we consulted our community, and we would like to share them with you.

Laurie.

[*English*]

Ms. Laurie Mawlam: I just want to recap the situation.

It's our opinion that we have a real health problem surrounding ASDs in Canada. To date, we are not doing national surveillance, but there is at least one region in Quebec and in other countries that are. I just want to share two examples.

In the region of Montérégie, Quebec, data taken from 2000 to 2007 shows the prevalence. And "prevalence" is the total number of cases of autism divided by the population, the total number in the population. So from 2000 to 2007, it went from 12 in 10,000 to 60 in 10,000. I called the public health department this week and asked if they had a more recent number, and they did. In 2009 the number went to 106 per 10,000. So that's from 12 to 60 to 106 per 10,000.

The Centers for Disease Control and Prevention released their last set of surveillance summaries on December 18, 2009. This resulted in a figure of 1%—or 1 in 110—of children in the United States classified as having an ASD. This is a 57% increase from 2002 to 2006.

In that same CDC paper, they went on to say, and I'll quote, "These results...underscore the need to regard ASDs as an urgent public health concern".

Autism is now more common than childhood cancer, juvenile diabetes, and pediatric AIDs combined.

You may hear that this increase is a result of changing the diagnostic criteria or broadening the definition of autism; however, note that the criteria we use to diagnose autism—which we refer to as the DSM-IV, the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition—has not changed since 1994.

You may also hear that we just called ASD something else before, what we refer to as "diagnostic substitution". This certainly cannot be true for the CDC data. In the Montérégie data, it does not seem apparent either.

So based on that, we'd like to discuss some points that we believe the federal government can be looking at and things that they can do.

Mrs. Kathleen Provost: Surveillance, as we said, is a mandate of the Public Health Agency of Canada. In November 2006 the Honourable Tony Clement, then Minister of Health, announced a package of initiatives that included a consultation process to inform the development of an autism surveillance program.

Consultation to inform this development was undertaken between 2007 and 2008, and in December 2008 the minister approved a contribution of $147,000 to Queen's University to expand their existing ASD surveillance system. To date there have been no announcements from the Minister of Health or PHAC on the status of the work, but we're trying to link and stay connected.

The federal government has the key responsibility for public health issues. Currently there are over 300,000 full-time employees at PHAC working for surveillance and public health assessment, which includes some of Canada's best epidemiologists. Some of this wealth we hope could be turned towards autism. PHAC has proven its commitment to being accountable for the methodology and results and making these results accessible to the public. For this essential data to be comprehensive and credible, it should be more than outsourced. It should reside in our Canadian system under public health.

● (0920)

Ms. Laurie Mawlam: The next point we'd like to make is about best practices. The governing health bodies, including federal departments, have historically set the pace in identifying and monitoring best practices and disseminating this information across the country. We have seen this in the recommendation for waiting times in hospital emergency rooms, infection prevention and control practices, and recommended vaccine schedules. The same is needed to be done with ASDs, specifically in the areas of early screening, treatment options, the use of seclusion and restraints, educational communication interventions, transition planning, and successful independent living for adults.

As an example, in 2009 the National Autism Center in the United States released a 68-page document entitled "Findings and Conclusions of the National Standards Project", in which well over 100 qualified individuals were involved in a report that addressed the need for evidence-based practice guidelines for ASDs.

They use an evidence classification system to rate each treatment. They rated them and gave them four categories: an established treatment, an emerging treatment, unestablished treatment, and ineffective and harmful treatment. An established treatment was one where there were well-controlled studies that showed the intervention produced beneficial effects. They also noted that it wasn't going to be effective for everyone. Then they had emerging treatments, which were ones that had some studies to support them and they were effective but not enough to say they were established. They went on to note that they weren't in a position to rule them out as not effective. Then unestablished was there was little or no evidence in the scientific literature to draw a conclusion. Again they noted there was no reason to assume this treatment was either effective or ineffective. Then, interestingly, they found no treatment had sufficient evidence to be classified as ineffective or harmful.

So it's critical that we work together to facilitate broad and accurate communication of the best practices for autism. A good starting point is to acknowledge what is established and encourage research into the investigation of emerging and unestablished treatments so we can put ourselves in the position to help more people to ensure they can make significant and meaningful progress.

Mrs. Kathleen Provost: We think the federal government is in a unique position as a national facilitator engaging provinces and territories. The federal government can stage and maintain a national agenda for autism. Precedents exist in introducing agenda items at health ministers conferences or first ministers conferences. At present, families migrate across the country to provinces that can provide or are perceived to provide better care for their family. That has many implications for Canadians. The challenge before us is to find effective ways to leverage the strength of our federal-provincial system to advance the autism agenda in Canada so we can provide universal access to treatment and services.

Additionally, the federal government has the lead role as a health care provider for aboriginal communities. These Canadians must have access to autism spectrum disorder specific care for all individuals diagnosed. These include treatment options, supports, and services across each person's lifespan.

Ms. Laurie Mawlam: Another federal government mandate is research. A significant increase in ASD-specific research funding is urgently needed, with a focus on prevention and treatment.

The Canadian Autism Intervention Research Network, which we know as CAIRN, released a report this year entitled *CAIRN: A guide through difficult terrain*, which shared the results of an online survey asking participants what they felt research priorities should be. The number one response from 839 of the 1,003 survey participants was treatments. We need research to investigate emerging and unestablished behavioural and medical treatments, especially ones that have strong anecdotal and clinical evidence.

CASDA would like to see priority funding towards studies in the area of environmental triggers, for example. In October 2007, the Institute of Medicine released an online pre-publication of a workshop that took place April 18 to 19, 2007, called “Autism and the Environment”. The participants identified a broad range of research priorities, and they summarized it in eight pages in this document. The summary lists numerous items for further research, which we feel our federal government needs to be examining.

Dr. Landrigan told the interagency autism committee that:

> It has been known for years that environmental toxicants are especially harmful to the developing brains of fetuses and infants. A 1993 report by the National Academies Press, “Pesticides in the Diets of Infants and Children,” stated that young children are not “little adults,” and they detoxify and excrete chemicals very differently than adults. It has also long been suspected that children with autism are more susceptible to environmental toxicants than other children.

It is time to make environmental triggers a priority.

The last point I'll make is on financial assistance to families. We need the office of the Minister of Finance to review the Income Tax Act so that expenditures for treatments and services can be used as medical expenses on families' federal tax returns.

We hear repeatedly from families that they are being audited for items that are being recommended by licensed professionals, such as pediatricians, psychologists, occupational therapists, speech pathologists, and nutritionists. Lately families have been audited with regard to the qualifications of the service providers they've hired to provide behavioural interventions.

Families with members with ASD perceive they're being audited with greater than average frequency. Their lives are fraught with the continued need to fight for their family member's needs. They should not be left to fight the government too.

● (0925)

Mrs. Kathleen Provost: Autism spectrum disorder has received considerable attention in the media recently, and some public funding.

The Chair: Kathleen, can I ask you how much longer? I've given you a lot of time.

Mrs. Kathleen Provost: This is my last point.

The Chair: Okay. We can't miss that last point.

Mrs. Kathleen Provost: We just want to say that despite the perceived lack of reliable information, we think there's a great need and value to ensuring that we continue to inform communities about ASD.

[*Translation*]

To conclude, we would like the Canadian Autism Spectrum Disorders Alliance to work together with the federal government and all its organizations in order to develop a national strategy, all while representing Canadians living with ASDs across the country.

[*English*]

It is CASDA's request that the Minister of Health seize this opportunity to champion a national ASD strategy in collaboration with all provinces.

Canadians expect national public health to be addressed by the federal government, with options and solutions tailored for all Canadians.

The Chair: Thank you.

Now we will go to Autism Speaks Canada, with Suzanne.

Ms. Suzanne Lanthier (Executive Director, Autism Speaks Canada): Thank you, Madam Chair.

I want to thank you and all of the members of the subcommittee for including autism on your agenda today. To have autism formally and finally recognized as a health issue, and one that needs to be included in the neuroscience agenda, is indeed a significant step in the right direction.

Autism spectrum disorders are now being diagnosed at a rate of one in every one hundred and ten children. One in seventy boys is being diagnosed with an ASD. I should note that these statistics are quoted from prevalence studies generated, as Laurie has mentioned, by the CDC in the United States. Dr. Eric Fombonne, who is the director of psychiatry at Montreal Children's Hospital and a world-renowned autism researcher with particular expertise in the field of epidemiology, confirms that the statistics are not significantly different here in Canada.

We don't know with any certainty how many individuals live with autism in Canada. We do know that the federal government, through the Public Health Agency of Canada, is embarking on a surveillance initiative that will ultimately provide us with a clearer picture. This is another step in the right direction, and we, again, applaud this necessary investment.

We do know that autism is a lifelong condition, and when you factor in immediate and extended families, employers, teachers, therapists, neighbours, and friends, it's very difficult to find someone who is not directly or indirectly impacted by autism. It is an epidemic and one that is not going away.

Autism is an incredibly heterogeneous disorder that impacts every individual in a unique way. This makes it very difficult to describe and even more difficult to study in a research lab.

Despite its heterogeneity, there are commonalities that are faced by Canadian families with a loved one who is on the autism spectrum. There are lengthy wait lists to receive a diagnosis, sometimes up to two years, depending on where you live in Canada—two years, just to get a piece of paper that says your child has autism so that you then have the privilege of sitting on a wait list for even longer for treatment. If you have personal wealth, you could access a privately funded diagnosis, which will cost you between $2,000 and $4,000, depending on where you live in Canada.

Then the real fun begins. Then the torture begins as you sit on a wait list for treatment. And that's if you're lucky enough to live in an area of Canada that provides the type of treatment that is required by your child, and then lucky enough again if you qualify to receive those treatments.

As an example, if you live in Nova Scotia as a family, your name is put into a lottery and you wait to see if your name comes up in the lottery to receive medically necessary treatment for your child's autism. If you live in Ontario, you are judged upon how severe your child's autism is to see if you qualify for services.

If you'll allow me, I have this comparison. You have two families, one with a child with cancer and another with a child with cancer. For this family with the child with cancer, the cancer is not maybe as grave an issue as it is for this other child's family. Who makes that determination? I don't know. But this is the case with autism, that the families who have a higher-functioning child are denied access to treatment. They're not even given the opportunity to sit on a waiting list.

We know that the sooner we recognize the early warning signs and the sooner we get a diagnosis and begin intensive treatments, the better opportunity we provide for a productive, meaningful life that will be less of an economic burden to society in the future. “Pay now or pay later” actually should be reworded to be “pay now or pay much more later”. It's just that simple. The costs of providing timely diagnosis and effective intervention may be high when viewed through the overall lens of increasing health costs, but the cost of doing nothing or doing not enough is even higher. There have been some cost-benefit analyses conducted in the U.S. that suggest early intervention could save one million dollars per individual per lifetime.

Too many children arrive on the steps of their local public school to start kindergarten not having received any form of treatment or one minute of therapy. We are setting our children up for failure. We are setting our teachers up for failure, and we are undermining the quality of education of all students. And ultimately, our families are failing as well.

There is extreme financial and emotional hardship placed on families who receive this devastating diagnosis, significant stress placed on the siblings of affected children, and, of course, the drain on Canada's workforce when parents must leave work temporarily or permanently to stay at home to care for their child who can no longer be accommodated in a typical preschool, daycare, or school-based environment.

● (0930)

Then our kids grow up. There are thousands of adults living with an ASD with virtually no access to any meaningful employment or community services. That's not to say that our kids don't have the potential; they do. They are just not given the opportunity.

In a recent supplement of Autism Speaks Canada published in *The Globe and Mail* last April in recognition of World Autism Awareness Day, Dr. Fombonne called the autism situation in Canada a disaster. He is not alone in his assessment.

So that's the bad news. There is good news.

Where we excel in this country is in the global research agenda. Canadian researchers from coast to coast continue to play a critical role in global consortiums that are making significant headway in all key areas of autism research: causes, diagnosis, and treatment. A pillar of our mission at Autism Speaks is to accelerate the pace of autism research, and this remains our key focus. In the last five years, over $142.5 million has been committed by Autism Speaks to global research initiatives through 2014, and that includes a significant investment right here in Canada.

So what do we know? What has been the return on our investment? We have made significant progress over the last five years in the area of early diagnosis. Through research led by Canadians in the baby sibling studies, we now see some of the earliest warning signs in children as young as eight months, and we've used this research to empower parents who suspect their child may be showing some early warning signs to not take no for an answer.

The heightened awareness of autism through awareness campaigns generated by Autism Speaks, coupled with resources now available to families, means that when family doctors tell parents to wait and see, parents know not to wait, because waiting could mean years on a waiting list for diagnosis and for treatment. We've seen remarkable results in early interventions through grant funding provided by Autism Speaks Canada and its Toddler Treatment Network, which is led by Canadians Dr. Wendy Roberts and Dr. Susan Bryson. We know that with timely, appropriate, innovative, flexible, and child-focused treatments we can change the trajectory of the development of some children who show early warning signs of autism.

We have identified some ASD-causing genes and copy number variations that could account for about 15% of individuals with autism. We know that autism is likely not caused by one gene, but by hundreds of genes. If you ask Dr. Stephen Scherer and Dr. Peter Szatmari, two Canadians who lead the global autism genome project, what is holding us back from even more discoveries in the area of genetics, the answer is simple—money.

I've included a recent summary of a special two-day conference on autism held prior to the annual meeting of the Society for Neuroscience in San Diego, giving scientists an opportunity to focus on ASD and share ideas. The conference was called “The Emerging Neuroscience of Autism Spectrum Disorders: Etiologic Insights; Treatment Opportunities”, and offered an overview of current autism research from many of the world's leading autism researchers. One of the keynote speakers was Dr. Stephen Scherer, a Canadian.

Individuals with autism invariably suffer from a host of co-morbid medical issues, seizure disorders, GI issues, sleep disorders, gross- and fine-motor development problems, and nutritional deficits. Until recently these medical issues were often treated in isolation from autism. ATN, the Autism Treatment Network, is funded by Autism Speaks and is developing best practices for treatment of medical issues associated with autism.

Without sounding too much like a broken record and a very un-Canadian way of giving ourselves another pat on the back, it has to be noted that one of the key sites of the global ATN is right here in Canada, jointly led by Sick Kids, Bloorview, and Surrey Place Centre in Toronto. And one of the principal investigators is sitting right here beside me, Dr. Wendy Roberts.

We hope to expand the Canadian presence of the ATN to other sites in this country and continue to grow this important field of study that gives families access to a range of specialty practitioners in each of these medical areas and also informs the global research agenda.

Each year, Autism Speaks publishes the top 10 research innovations in autism. I've included the 2009 version in the folders I've provided to the clerk, and 2010 will certainly be another extraordinary year.

Autism Speaks holds its many research funding partnerships with CIHR in the highest esteem and showcases its public-private partnership all over the world. At Autism Speaks we know that partnership and collaboration will ultimately lead us to the answers faster and more efficiently.

To conclude my introductory remarks, there are clearly some ways that the federal government can have an impact on the autism community.

● (0935)

First, it can continue and grow its support of research in all areas of the study—causes, diagnoses, treatment, biology, and knowledge transfer of the research results—thereby attracting and supporting emerging scientists to work in this very exciting and fast-paced field.

It can continue its efforts through the Public Health Agency to initiate a national surveillance program.

Moreover, it can make the development of a national autism strategy a priority, using willing and respected partners, like my colleagues and I, to garner stakeholder input to ensure that identified priorities are addressed and put into action.

At Autism Speaks Canada, our goals are very simple. We will continue to raise funds to support autism research in Canada and to partner with CIHR to leverage the support needed to find the answers to the autism puzzle.

We will continue to raise awareness of autism, in particular the early warning signs. Awareness will also heighten the consciousness of the unaffected population to enhance its acceptance of the incredible autism community and the value that each individual with autism brings to society.

We will continue to raise money to fund community grants and other family services initiatives, such as our *First 100 Days Kit*.

We will work with current partners across the country to further enhance our autism resource database to provide quick, easy, and reliable access to information on all things about autism in Canada—anything from where to get a diagnosis, where to access funding, where to find a speech pathologist or an occupational therapist, all the way through to where to find a dentist who specializes in special needs populations.

It's our goal to make the path, which is a very windy path right now for families, as straight as we possibly can. We need to do this for our families. We need to do this for our teachers, for our researchers, and for our service providers.

We will continue to advocate and be a willing partner with all levels of government in developing strategies and system changes to reduce wait times for diagnosis, to ensure immediate access to intensive evidence-based treatments that are flexible and meet the needs of each individual child, and to ensure that these treatments and supports continue across someone's lifespan, and are not cut off by their age.

We will continue to advocate and be a willing partner with all levels of government in the discussions of how we service the needs of our adult and our caregiver communities. This is a huge, huge void in Canada.

This is a very large and very daunting task—

● (0940)

The Chair: Suzanne, excuse me, I've given you way over our normal time—

Ms. Suzanne Lanthier: Okay.

The Chair: We do need time for questions, so do you mind wrapping up?

Ms. Suzanne Lanthier: Sure. I'm pretty much done anyway, so I will stop right here.

The Chair: Thank you.

This is a very important topic that the committee has undertaken simply because we've been made aware of it. I knew about it long before I came to Parliament because I taught children with autism. My colleague Mike Lake has also done a lot in this area to educate all of us.

There's just one sensitive area that I wish perhaps we might be aware of. I'm just going to ask that we not compare autism with a disease like cancer. This is a very, very important topic, and I know it hasn't been up at the forefront the way cancer has, but many children have lost their lives because they've been on waiting lists. I saw it first-hand this past year.

So this disease is something that has never been recognized, but I would ask that we keep the discussion to autism, and not compare and contrast it with another disease, if we can.

Thank you.

Ms. Roberts.

Dr. Wendy Roberts (Pediatrician, Canadian Paediatric Society): Thank you, Madam Chair.

I am delighted to be able to represent the Canadian Paediatric Society. I'm a developmental pediatrician, and the Canadian Paediatric Society has an increasing corps of developmental pediatrics, as in new developmental pediatricians, a new subspecialty in Canada in the last few years. It's a subspecialty that has emerged because the demands on general pediatricians for information about developmental disorders has been so great.

Many children, particularly children with autism, fall between mental health services on the one hand and general medical services on the other. Nobody has really been a champion for those developmental issues, which of course are associated with lots of other medical issues.

Really only in the last 10 to 15 years has autism honestly been believed to be a disorder that has major effects on the brain, and right from the time of earliest brain development has been making a difference.

I remember the first rounds that I organized on autism at SickKids. I think it was about 1993 or 1994, and we had Dr. Margaret Bauman, a very well-known neurologist in Boston, who has really, I think, changed the world in terms of understanding the neuroanatomy of autism. It was the first time I had evidence that I felt my pediatric colleagues would accept that was hard-core enough to show that the brain was developing differently. She had pictures of slices of the brain that she had sat for thousands of hours analyzing, one microscope compared to another—typical autism, typical autism—and she showed the very specific parts in the central parts of the brain and the hind brain that were clearly different and consistently different in individuals with autism, and changed in a consistent way across the life span.

That was, for me, a big step, and I think since then the research has gradually ramped up. Canada has been a real leader in terms of funding research. Autism Speaks often gives it a push first, and then we've got CIHR funding to really lead the understanding of the etiology, particularly in the genetics.

The genetics is one big piece. The complementary part of the CIHR autism research training grant program is really growing young scientists, in a wonderful way, to establish careers in autism.

Our baby siblings research is now across Canada, from Edmonton out to Halifax, and we have the pathways to better outcomes trajectories project, with Peter Szatmari leading our group. We're now almost at eight, so we'll know how children diagnosed between two and four in different provinces actually look in terms of their outcomes: school, social, family, and all the different effects. We're just starting to collect the A-tier data now.

That's going to give us a chance to see across provinces and across treatment interventions, across severity of autism, and across intelligence, all the medical factors. We're going to understand outcomes in a much better way. It's the first really big natural history study, and I think Canada has been a leader in funding that, which is great, thanks to CIHR and to Autism Speaks.

I think that the heterogeneity that Suzanne was talking about is a big thing. Kids all look different. That has made training of our front-line pediatricians and family doctors a really hard job to do. We're trying to get away from the old situation where parents were saying, “If only our family doctor had listened to us two years ago, we would have been so much further ahead.” In fact, I had a parent recently who said to the doctor, “If you had just read the sign on the back of your door, we wouldn't have been sitting around for an extra year waiting for our child to get a diagnosis.”

So we're trying. We know that there are many medical concerns. We were so happy to become the Autism Treatment Network site. We've got 2,400 kids in that registry now across North America. We have constant phone calls with colleagues across North America, looking at how to establish guidelines to deal with the epilepsy in up to 40% of kids, to deal with the esophageal problems, the reflux, things that stop kids from eating, the most severe constipation we've ever seen in our lives.

We're finding techniques. We're finding ways to help with the sleep problems. We know that parents, when they go to work and have been up most of the night with kids screaming and different kinds of sleep problems, aren't productive citizens. They're also the parents who are waiting for the phone to ring at any minute saying, “Come and take your kid home from school. He's too aggressive. He's having a bad day. We can't cope with him anymore.”

We know that there's a huge loss in the workforce from parents with autism struggling with their kids.

● (0945)

I must say that in the majority of cases where I see severe autism, one or the other parent has had to stop working. At a time when they need the most money—because they have to buy treatment if they're going to get it, in the majority of cases, unfortunately—they have the least money coming in. I see many grandparents with big mortgages now on their houses because of trying to get in on that early intervention piece.

Pediatricians are working on it. I think our Autism Treatment Network is pulling in a lot more pediatricians to see how they can help. But they very much recognize that parents don't have a single number to call to access service. They also don't have a single number to call to say that this is definitely a kid with autism; now can we have a service system that will pick him or her up?

In fact, in the system, we are funded to do assessments. A father said to me recently—I actually had underestimated how much he was going to contribute to our feedback session—“So you're telling me that you're putting my kid into a different boat, and you're now about to cut the rope and put me out into a different ocean with no GPS?” I couldn't give him a single number that would....

You asked us not to refer to other disorders, so I won't talk about the father who runs a big clinic for another childhood disorder, who said to me, “Wendy, I wouldn't do this in my part of medicine. How can you live with yourself doing it this way?” That's just a little anecdote.

What do we need? We desperately need an integrated service system that anybody with any degree of autism can get some guidance from. The children who do well would often do a lot better and need nothing if we could give them help. If we could get in there early and work with the so-called higher functioning kids, it would probably cost the system nothing in the future. That's probably somewhere between 10% and 20%, but that's still a significant number of dollars.

An integrated service system will only work if we do the knowledge translation work to have everybody educated at every level of the community.

Actually, coming from our earliest-signs research, we're picking up kids somewhere between nine and 18 months, often, as they become silent, as their sounds change to a higher-pitched sound, as they stop using words, and as they don't respond to their names. There are all those early signs we're picking up.

I think the way to really improve outcomes and to improve the standard of child development in Canada—we're down lower on the list, among developed countries, in terms of the standards for early child development—is to have every daycare provider and early interventionist across Canada knowledgeable about the early signs of autism and ready to teach parents right off the bat, the minute a red flag appears, well before you would put them on any kind of a wait-list, which may actually delay things two or three years.

There are many services mandated across Canada and funded across Canada. If that early interventionist and infant development person could get involved pre-diagnosis and turn things around, as we've shown in our 12 to 15 month early-intervention study, we would actually, in doing that training of infant development and daycare people and in supplementing that daycare system for the 20% of parents who won't recognize the signs and won't be able to do it themselves, improve early child development for all Canadians. There would be a huge ripple effect in terms of understanding what really constitutes good development of social communication skills. I think there's a huge win-win there in terms of so-called treatment before diagnosis.

Although I totally understand that we're working hard to try to get wait-lists down, the discouraging thing is that now a parent can recognize those early signs between 15 and 18 months, wait at least a year, in the Toronto area, anyway, and then wait another two or three years. So they've gotten the early signs at 18 months, but at five and in school, as Suzanne has said, they have had nothing.

Integrated services across the ministries is the other thing I see people struggling with in the different provinces. That is where we need kind of a lead. You get assessment through health. You have to get intervention through child and youth services. And then you really need the service within the education system. We have a huge amount of work to do there. Then you get out of school at 18 to 21 and fall off the cliff. That's when many parents say that they now have to stay at home, because there is no workplace, no vocational setting, to go to.

It's access all across the system.

● (0950)

From a health point of view, the other piece where I think we need leadership is in mental health. Up to 40% of individuals with autism will end up with mental health disorders, diagnosable anxiety, depression; a much smaller number may go on to have some signs of psychosis. Many mental health systems will say, sorry, we don't accept autism because our staff doesn't know how to deal with it.

We hear that from almost every mental health institution across the country. There has to be huge knowledge translation in the mental health world. And I take responsibility; we need to work more with our psychiatric colleagues to kind of "accept" autism. There's an uneasy issue around accepting autism. I think because it's so poorly understood, that really impacts access to care. So that's another area where we need research.

Our research has grown phenomenally. The public-private partnership with agencies such as Autism Speaks has made a huge difference, but we need to increase it to become more specific. Just as another anecdote, in terms of our genetic research, when we tell parents we have found a mutation that we believe links to their child's autism, every single parent, particularly mothers, will sit back and say, "Oh, I am so glad to hear it's biological, because inside I really was still blaming myself."

So I think that's where we need answers. We don't have specific medications to treat many of the symptoms of autism. We borrow from all the other disorders. We need answers that are going to change treatment and outcomes and have a huge impact on all the lives that are affected across the country.

The Chair: Thank you, Dr. Roberts.

It's been really compelling to listen to your presentations this morning. For anybody who has been touched with autism, whether it's a family or a teacher or whatever, these frustrations are certainly there. Some of the solutions are very compelling and really common sense.

Now we'll go into our first round of seven minutes, questions and answers.

We'll begin with Dr. Duncan.

Ms. Kirsty Duncan (Etobicoke North, Lib.): Thank you, Madam Chair.

Thank you to all the witnesses.

I'm really glad our colleague Mike Lake has joined us, and particularly Jaden Lake.

Thank you for your science, your fighting so hard for families, and your courage—your courage to say that this is an epidemic and this is a disaster.

I have a number of requests so that we get some real recommendations for our report, then I'll ask some broad, open-ended questions.

The first thing I would ask Dr. Roberts and Ms. Lanthier is if you believe a national strategy is needed in Canada. I would ask that you table with the committee your key components of what that strategy would be, including how much money is needed for treatment as well as for research. That would be my first request.

Then I'll ask you all if you're willing to table with the committee all examples you're aware of, of national strategies around the world. What is working? Some of the strategies will have stuff that's working. What is not working? Let's get to what we need to know, please.

I think the wait times are so important. You've highlighted them, but if we have a report, what are the wait times for diagnosis across the country? I have real difficulty in my riding. I've worked for 30 years with children who live with ASDs, and I love my kids. We just can't get the diagnosis. We have a real challenge, because I have one of the most diverse ridings in the country. We have a large newcomer population. We now have a Somali population in which this can only be described as an epidemic. They've now started an organization. They had a picnic for the children this summer. We talk here about arriving at kindergarten with no treatment. But I have 18-year-olds who have never had any treatment. That is the reality.

Perhaps we could table with the committee a status report on the wait times for diagnosis.

The last thing I'll ask that you table with the committee is what the average yearly costs are and whether it's for ABA, IBI, or other treatments. As you say, if you want that early treatment, you're often going to be forced to pay. What is that across the country? There is a fairness piece here.

To begin with the open-ended questions—I don't know where to start—I'll ask you, Dr. Roberts, what are the key gaps for services to children, and what recommendations would you make?

● (0955)

Dr. Wendy Roberts: I can start.

I think one of the big gaps is access to the appropriate kind of intervention. We have this discrepancy in models across the country where some provinces give a set amount of money to a family. For autism, $20,000 will buy some services.

I would say a lot of parents who have moderate incomes are spending over $50,000, and many with lots of money are spending over $100,000. So there are huge differences in what families are able to get. Families in, say, Ontario, who don't qualify for the severe category get nothing unless there's some respite special services money, but even that was frozen this last year. They would be thrilled to get $20,000. We know that some families have moved to, say, Alberta, because they're more likely—or were in the past, at least—to get some of those solid dollars that they could count on.

I think a huge gap is access for everybody to some form of intervention. I think another gap is a consistent approach across the education system. We could put a lot more of the treatment dollars, IBI, ABA dollars, the behavioural intervention dollars, into preschool years and after-school programs, if parents had confidence that the education system was trained to provide the specialized kind of behaviourally delivered programs the children need to varying degrees.

Until we have confidence that the education system can do that, parents will continue to feel that they have to buy a lot of services or try to access services outside of the educational system.

If we had integration of the ministries to provide those services, that would be a key part, I think, of what the national strategy needs to be, but it's a long, slow process to get every teacher and every teacher's assistant trained in the behavioural techniques needed.

I'd like to see educational assistants who specialized in autism and had training so that parents could say “Okay, I know the class my child is going in has a teacher and an assistant and a support team that all really know autism, and the treatment will go on at school. I can just be a parent at home.”

The other big gap, and it's an enormous vacuum, is when children leave school. We have more and more young people...some going on to college and university, but even then still having nowhere that they can fit into in terms of the workplace and the community. I believe it is possible to develop services that would meet the needs of children and young adults at all different levels of capability so that they could feel like worthwhile citizens.

● (1000)

The Chair: Thank you very much.

Dr. Duncan, your time is up.

Mr. Dufour.

[*Translation*]

Mr. Nicolas Dufour (Repentigny, BQ): Thank you very much, Madam Chair.

Thank you very much to all the witnesses for being here.

You provided us with a lot of information and we really appreciate it. I have a question about tax incentives. I noticed that one of the solutions proposed by the Canadian Autism Spectrum Disorders Alliance to the federal government deals with tax credit incentives.

Do the provinces have tax incentives like that? Have you seen something similar elsewhere?

[*English*]

Ms. Laurie Mawlam: One thing that I am familiar with, having had a child diagnosed on the autism spectrum, is that there is a federal deduction for a child with severe disabilities. I believe it's to the tune of about $9,000, $10,000. I haven't done it for about six or seven years because my child is now off the spectrum and doesn't qualify.

There is a deduction on the federal return. I'm not familiar with one on the Ontario provincial tax return. I had mentioned about the Income Tax Act being looked at.

A pediatrician could suggest carnitine or eating yoghurt or a probiotic after being on antibiotics. We look at curriculums that maybe a behavioural specialist has recommended. We can look at sensory items that an occupational therapist can recommend.

Parents are going out and buying services because they're on a waiting list and then they're being audited on whom they've chosen to purchase the services from.

Clearly, there's work that we can do here. If they're spending their after-tax dollars, surely they must feel it's important.

[*Translation*]

Mrs. Kathleen Provost: I just wanted to add that it is difficult to assess, because every province has a different program. A little earlier, we talked about gaps or...How can we understand it? I think we need to review what every province does across the country. There are success stories, whether in education or in social programs, like in some provinces.

To answer your question about taxation, I believe that each province will implement it according to their conditions. Some will receive funding and others will get tax breaks. There is a whole system to go through and there are many obstacles. I feel that if we stopped to look at what is happening, we could take the best practices and greatest success stories and try to share them and put them into practice.

Mr. Nicolas Dufour: Do you have examples of best practices in the provinces? Could you give us some ideas to—

Mrs. Kathleen Provost: We often encounter challenges. As we said, in Ontario, there's a limit. It stops.

[*English*]

Ms. Suzanne Lanthier: It's almost as if the grass is always greener on the other side. You have families in Alberta, for instance, and Alberta is often held as the shining star in terms of services and the level that's provided, but then you have families in Alberta saying, “You know what? It's not that great.” And then you have families in Ontario that, as Wendy said, get nothing. But then if you just have the diagnosis and you live in B.C., you at least get $20,000 up to the time your child is the age of six. It varies so much. And then if you live in Nova Scotia, again, you get into a lottery. So it just does vary so much.

I would say, as someone who has seen and heard about experiences from across the country, Alberta really does lead in a number of ways. They've invested a lot more money in terms of treatments and interventions. As Wendy described, they give a more comprehensive range of services, not just one type of therapy or treatment. There's more of a comprehensive range.

Again, I'm generalizing, because there are families that are still waiting. What happens is that everyone hears, they move to Alberta, and then all of a sudden the wait lists start to go up and up and up.

So you have to be very careful not to say you're from Ontario if you move to Alberta.

Voices: Oh, oh!

● (1005)

[*Translation*]

Mr. Nicolas Dufour: I know that Ms. Duncan—and I thank her—asked that you submit to the committee what is being done internationally. Could you give us an idea of the initiatives that work and that are going on in other countries?

[*English*]

Ms. Suzanne Lanthier: Well, the situation in Canada is very similar to other countries. We often look to the States. We get a lot of information from the United States, and the U.S. has done some great work. As an example, they've lobbied their insurance industry very successfully in certain states to provide access to medically necessary treatment—to ABA therapy, for all intents and purpose. They're going state by state and lobbying for this, and that's seen as successful, but again, it's the grassroots people who are spending their time doing this activity when they really should be spending their time with their families.

So it's been successful and we've seen some great results, and as a result more and more families are receiving access to treatment and to therapy.

I have a lot of colleagues down in the States who have access to a lot of families, and it's quite remarkable. Families down there say, “Well, geez, I had to wait for three months to get access to therapy.” I kind of laugh at them and say, “Three months? That's crazy....”

I've had Canadian families who live down in the States call me and tell me that they're thinking about moving back to either Quebec or to Ontario; these are two instances. I get them to describe to me what they have in place.

One family in Pittsburgh had to fight for what they got, but they had access to an incredible range of services: the school was on board, and everything was going well for the child. She wanted to move back to Ontario, and I told her not to come.

There was another family in New York City who wanted to move back to Montreal and be closer to family. But in New York they'd had immediate access to speech, to OT, to behavioural interventions, and I said, “Don't come.”

So as a Canadian, I'm like, “Don't come back to Canada. Stay in the U.S.”

There are good examples out there, and there are some parts of the U.S. that are not so great, but what we can do is we can—

The Chair: I think Laurie wanted to make a comment as well before we run out of time.

Ms. Laurie Mawlam: I just wanted to make you aware that there is a global autism alliance that has been initiated from the Autism Research Institute out in California. Autism Canada is a member of that, and I would guess that there are about 20 countries around the world.

One of the mandates they have is to take documents like the journal article I referred to that was published in *Pediatrics* about gastrointestinal disorders in individuals with ASD and translate them into other languages. Most of the information that's coming out, of course, is in English, so we're trying to get that into other countries.

As things come out, we're getting them out to as many countries in different languages as possible.

The Chair: Thank you, Laurie.

Now we'll go to Ms. Hughes, please.

Mrs. Carol Hughes (Algoma—Manitoulin—Kapuskasing, NDP): Thank you.

I want to thank you for being here.

Ms. Lanthier, I want to say that I certainly didn't take it out of context; I didn't think you were trying to compare children with cancer to children with autism. I understood very clearly that if someone has a cancer that's more advanced than the other person, they have to be provided with a different type of service or wait time. I understood that. I also understand it's the same thing with respect to autism.

I have a friend who was trying to get her son diagnosed and to get him treatment. When they did finally diagnose him, they basically wrote him off and said that he wouldn't fare well. Fortunately for her she did have the dollars, and she believed in her child. That child is now a very functioning part of society; albeit, she still has a lot of struggles.

So I did understand what you were trying to say and I think we do have to look at the differences, when it comes to that.

I think there is so much with this specific condition. One out of every 110 children, and the fact that it is going up from year to year, is something we should consider to be a crisis.

I have some questions with respect to funding. Has the research funding decreased? If not, has it increased? If so, how much?

There used to be a time when hearing tests weren't being done, and now hearing tests are done regularly. Is it your opinion, especially you, Dr. Roberts, that a specific test should be done regularly with every child, to make sure they're not part of an ASD?

The other thing is how this is impacting people in rural and aboriginal communities with respect to access? My friend was in Elliot Lake, and I know the services were very limited. How many of these children are being placed with Children's Aid or in foster care because the parents can't continue to care for them? How many of them are being abused? Are there any statistics on that?

I know the NDP has certainly been pushing for a national strategy for quite some time. I don't think the baby steps we're doing are enough for where we need to go.

I'm going to leave you with that, and if we have more time I'll go through some more.

● (1010)

Ms. Laurie Mawlam: [*Inaudible—Editor*]...Autism Canada Foundation has three full-time equivalents.

I don't know how big your group is now, Suzanne.

I know you'd like information from us, but it's very difficult. We are answering the phones, and we have our mandate. Can we put some of this back on the federal government to collect this information, whether it be the wait times or the costs?

Mrs. Kathleen Provost: I have the same concern. We're a virtual organization with no staff, so we can't do this kind of scanning. We have anecdotal information, and I could make you a list of anecdotal....

What you're asking for here is very sound and professional, but....

Ms. Laurie Mawlam: It's labour-intensive.

Mrs. Carol Hughes: Maybe we could get that from the analysts. I'm just trying to get some sense of this.

I guess that's something we'd maybe have to get from the provinces, with respect to how many children with autism are actually—

The Chair: Ms. Hughes, in answer to your question, the analysts tell me that information is not collected.

Mrs. Carol Hughes: So maybe that should be part of the national strategy.

Dr. Wendy Roberts: I do think we need better data. I think the issue of whether every child should be screened and at what age is an interesting one that evidence needs to be collected on.

The American Academy of Paediatrics suggested that all children should be screened at 18 months and 24 months. We've had a lot of talk about that, but it's not practical within our current health system. We have adopted a principle in Ontario called "developmental surveillance", which means that physicians and nurse practitioners are being trained to screen for all developmental disorders during well-child or well-baby visits.

The key items for identifying autism at 18 months are now built into the Nipissing questionnaire, which the Ontario government has bought the licence for, so practitioners can just download it off the net. There is also the Rourke well-baby record, which was developed by Leslie Rourke, working with the Canadian Paediatric Society. We inserted the key questions for autism into it, and it's a point-of-care tool. It has been shown to improve the quality of care if the primary care physician or practitioner has to tick off the things they've asked about.

I think our 18-month surveillance visit, the enhanced visit that we got funding for this year, will pick up a lot of children at 18 months that would have been missed otherwise. But now we're trying to work with the services to see what we can do with all these kids who have red flags at 18 months. We're talking about a sea of red and where we go now.

That's a critical point, but we have to get the intervention ready to start. We can't just put them all on a waiting list. We're working hard on wait-list strategies, but the intervention has to be there once you do the identification.

Mrs. Kathleen Provost: And that's just Ontario.

Dr. Wendy Roberts: That's just Ontario.

Mrs. Kathleen Provost: So we'd like to mirror that times 12. Ideally, a national strategy would do that. Take best practice or what's working and multiply by 10 provinces and 3 territories.

Dr. Wendy Roberts: Absolutely.

From the research point of view, I think it's wonderful; the Nova Scotia government has been working with our colleagues in Halifax on the early intervention project that Suzanne was referring to. An ethicist gave them advice that a lottery system was the most equitable way to provide the service, because people know that the more advantaged families somehow manage to move their way up the wait list.

Wait lists actually disadvantage the disadvantaged even more. So the lottery system was fairest. However, they've developed a system that they're evaluating and that has been rolled out effectively in all parts of the province. I think it's a program that should be available across the country. It's a fabulous model that Susan Bryson and Isabel Smith have worked together on, and it contains the same strategies we're using in our early intervention studies across the country. So there is a pattern there; it just needs to be available to everybody.

● (1015)

The Chair: I'd like to ask a question. I wonder if some of these data might be found at the provincial level. In the school divisions, when we dealt with autistic children, we kept close track of their progress, starting at kindergarten. That might be available through the provinces. A lot of what you talk about is under provincial jurisdiction, so there needs to be that collaboration.

Have you done anything to see if the provinces have those data?

Mrs. Kathleen Provost: Dr. Jeanette Holden at Queen's is doing a pilot process in that direction, and this is one of the challenges they have identified. They work with Manitoba and Ontario. In Manitoba, it's kept under social services. In Ontario, it's under the education system. They're not tracked the same way.

So it's a challenge to gather it. But I agree with you that a collaborative effort might help us find a way to build a consensus.

The Chair: I taught in Manitoba, and they also kept that information in the school divisions. So I don't know what information you have, but I think it's under both social services and school divisions. I think you might get some interesting data if you look provincially.

Mrs. Kathleen Provost: That's what we're doing.

The Chair: We'll go on to Mr. Lake.

Mr. Mike Lake: Thank you.

It's very interesting to listen to the conversation today. I'm going to start by making kind of a statement in regard to what Dr. Roberts was saying. I'm just going to share a little bit about our experience in Alberta.

Jaden is 15 now. He was two and a half when he was first diagnosed. It's very interesting to hear you talk about what people could find out at 18 months. In our case, there's no reason Jaden couldn't have been diagnosed at 18 months.

As parents, we were sent to speech therapy training types of things and workshops with other parents because Jaden wasn't talking, and they figured that was just because he was a boy. Sometimes boys don't talk as early. So we were sent to speech language training.

What keyed in for us that Jaden had autism—we actually diagnosed it ourselves—was reading *Let Me Hear Your Voice*. As we read that book and read how Catherine Maurice described her son, we said, “That's Jaden.”

Jaden was quiet until I started talking. Now I think he wants to try to get in here too.

At any rate, when we read that book, the description of Catherine Maurice's son was Jaden. Had the doctor had that same background, there's no reason they couldn't have seen exactly the same signs.

Thankfully, more and more pediatricians and GPs are more aware of autism, I think, thanks to the work that all of your organizations are doing.

In Alberta, I know the challenge at the time—it was right around the time when they were coming up with the strategy that has morphed into what is there today—was the big battle among the health, education, and social services jurisdictions within the province, and who would handle it. The ball would be passed from one to the other, and no one would actually do anything. I think those battles still exist today, maybe in other provinces more than in Alberta.

Eventually, to Alberta's credit, they decided it was all three. I think Iris Evans, who was the children's services minister at the time, deserves a lot of the credit for saying, “Let's get this together.” They put together an act. I think it was called the Family Support for Children with Disabilities Act. They didn't treat it as autism-specific but said it was for children with disabilities, to help them and their families to deal with those.

So you have this entity that bridges all of these different jurisdictions and actually brings them together. That's why it works in Alberta. Obviously there's funding that goes along with that, and that's an important part of it. There's also an accountability that goes along with it. We had to go before a panel—I think it was every year—to get reassessed. They'd ask a lot of questions to make sure that we still needed the funding that was being given, because it was a lot of money, a lot of taxpayer dollars that were being used to fund Jaden's program.

As you can see, Jaden is not cured of autism, but life is a lot better for us because of the treatment that Jaden's had all his life. There's a much higher likelihood that Jaden can stay with us instead of being institutionalized as an adult, which of course does save the taxpayers dollars in the long run.

In terms of my questions, first of all, I will say one thing about health, education, and social services. It's interesting; the federal government funds health and education and social services, more today than at any time in Canadian history. There's more money going to the provinces in those three areas than there has been at any time in Canadian history. The escalators in those areas, moving forward, are still pretty high, higher than the rate of inflation.

The money is there, but it's fair to say that autism funding isn't being made a priority in many provinces. Is it also fair to say that it's better today than it was five years ago, in almost every province across the country, in terms of funding?

Suzanne looks skeptical.

● (1020)

Ms. Suzanne Lanthier: It's not very different. When my son was diagnosed about seven or eight years ago, I faced the same challenges that other families are facing today. I said the same things that other families are saying.

I think the explosion of prevalence—and the enhanced awareness—has just meant significant stress. In some ways we've created a situation, which I think is necessary, where families are more aware, so they're demanding more services, and they not taking no for an answer. So there's more and more stress on the systems.

We're not set up to deal with it the right way. I think we need to really look at how the money is being used. Are we using the money in the most effective way to really effect the changes at the end of the day that we need to see? I don't think so.

Mr. Mike Lake: To that end, maybe I'll go to Dr. Roberts on the evidence basis for treatment.

If you had only five minutes to talk to a provincial official and explain what they should be doing for individuals with autism—I don't want to say children with autism, but individuals with autism, across their lifespan—what would you say to them their priorities should be with limited taxpayer dollars?

Dr. Wendy Roberts: I think it's really about making sure that every individual gets the kind of support—it's usually behaviourally mediated support—and medical care they need at their specific stage of development. So for one- to three-year olds, or zero- to three-year-olds, it's very intensive infant development services that are really focused on social communication.

Once you get into school, it's behaviourally delivered academic skills and skill development that are needed. And with adolescents, as you see their trajectories, it's more a case of looking increasingly at either academic or life skills, or both. I say this because we're behind in building the life skills of the very high academic achievers, who come out and then aren't ready to do anything.

For the over-18 age group, it's about finding some kind of a workplace where the behavioural environment, the staff, and their level of understanding are able to cope with everybody, so that Jaden, for example, can have a successful place to go to every day where he feels like a competent human being who's worth being able to do something.

Mr. Mike Lake: When we talk about “contribution”, defining contribution—“making a contribution”—can be difficult sometimes. I always think that if Jaden and one other person are able to contribute more than that one other person would be able to contribute on their own, then Jaden's making a contribution.

● (1025)

Dr. Wendy Roberts: That's right.

Mr. Mike Lake: It's kind of a neat way of thinking about it.

In Jaden's case, now he's 15. His school has done a good job—which I imagine can happen across the country—because they've embraced him. He works in the library there. He's in a grade nine class, but he's not learning what the grade nines are learning. Instead he's learning the social skills. The kids learn as much from him as he learns from them, but he also works in the library and the school cafeteria and does things that he's good at. He's fantastic at putting books in order. He does it better than any other grade nine student would, and he runs around laughing as he does it because he loves it so much. And that's contribution, right? So we kind of see a future for him as he gets older, as an adult.

I think about my previous life with the Edmonton Oilers, who still have someone—now he's a man, who's older than me, I think—Joey Moss, who has Down's syndrome but has spent his entire life working in the dressing room at the Edmonton Oilers. He does a phenomenal job there, contributing by cleaning up, vacuuming, and washing the equipment for the guys. He has this great relationship with them because somebody took the time to include him in what they were doing. And there are so many opportunities for adults with autism, I think, in these areas.

I don't want to get cut off by the chair here—

The Chair: No.

Some hon. members: Oh, oh!

Mr. Mike Lake: —but I could talk for a long time.

The Chair: To tell you the truth, all of you have gone way over time. I'm trying to be so balanced and fair here, but it's been blown into the wind. I haven't cut anybody off, but I am going to ask for something highly unusual today, as I notice that Senator Munson has joined us.

I'm very much aware of your work, Senator Munson, and we have, as you know, brought autism to the health committee for a very important reason, to bring it up on the public radar screen and to do other things.

So I was wondering, with the committee's permission, if I could give the senator five minutes to make a comment or to contribute to the discussion.

Hon. Jim Munson (Senator, Lib., Senate): I wasn't prepared to do that, but as unaccustomed as I am to public speaking....

I don't have to be elected to sit here. That's an interesting concept.

The Chair: Actually, let's not get into that.

Voices: Oh, oh!

The Chair: I think I actually bent some rules.

Hon. Jim Munson: Well, thank you. I didn't expect to speak. I came to listen, because I think it's very important that senators and members of Parliament listen.

I was listening to what Mike was talking about. Of course, Mike and I are working together to try to help those in the autistic community, and I mean everyone in the autistic community. I just think that's extremely important.

You're aware of the report that we had in the Senate, “Pay Now or Pay Later”. I still feel strongly about a national autism spectrum disorder strategy, and more so, I believe, in national autism spectrum disorder standards, in the sense of a level paying field where we have national standards across the country dealing with this issue so that we don't have to go with the many arguments that we've heard about, with breakups, family breakups. We've heard those stories, and personal stories of friends of mine who are going to British Columbia or to Alberta to get continuing treatment. I spent a wonderful afternoon recently in the Geneva Centre in Toronto and saw the good work going on there.

At the end of the day, I think we have to try our best to work on the same team from coast to coast. I recognize that there are different groups, but we all have the same message. We're trying to make a better life for Jaden and others.

I recently have been travelling across the country and speaking to any autistic group that wants to hear what I have to say. I was in P.E.I. recently. It's amazing how you can have a prepared speech about what you're looking for...and when I talk, I itemize everything that I believe in. But I just sort of looked out at the crowd and said, “Wouldn't it be a wonderful idea if Holland College in P.E.I. worked together with the University of P.E.I. in terms of training and so on and so forth?” I just did this as an off-the-cuff remark: “You're such a small island. You know your neighbour, and you feel for your neighbour because it's a very neighbourly province. Wouldn't it be wonderful if the autistic community came to P.E.I. and had a centre here?”

I had this speech that I had prepared for a month, and this just came from the heart. Of course, the headline in *The Guardian* the next day was that the senator recommended P.E.I. But what it started there was another public discussion. I had really no intention of starting that public discussion, but once again, there were people at Holland College and UPEI, and I think they're having a chat and discussing this kind of issue now.

It wouldn't hurt to have an autism summit. That just came to me, an autism summit, in the sense of—

The Chair: Senator, you are pushing it.

Hon. Jim Munson: I know, but it wouldn't hurt to have that. We do have meetings with all of these groups here. We've had meetings and Mike's had meetings, and Mike's been a leader. We worked at this and we worked hard together, but I still believe we're working in silos. We've got to step out of that. We have to have a public meeting.

I mean, there's one thing about research and science: that's something. When I get into that room, after five minutes I don't quite understand a lot of it. I think if everybody got together and there was a summit, and the federal government and the minister were involved, it would be extremely important.

I thank you for the time. I'm honoured. I appreciate that.

● (1030)

The Chair: Senator, I'll certainly take that suggestion back to the minister. There are many wonderful things that come out of this committee because of the people who present. There's one or two that are political, but for the most part, this whole committee is not the health committee, and so what they do basically is try to work together to come up with solutions, and that is why you're sitting where you are right now, Senator.

Hon. Jim Munson: Very briefly, Mike was talking about Down's syndrome and the gentleman who works for the Edmonton Oilers. In the Senate, we have a program called Friends of the Senate, and we also walk the walk when it comes to hiring. I just recently, three months ago, hired a Down's syndrome young man, age of 22. Mike is in the office and he just does everything. He's wonderful, and of course there's always humour in everything. It was his birthday the other day and he just wanted to sing *Hark! The Herald Angels Sing*. He wanted to do that. Everybody stopped and listened to him. He gave us a moment.

He was chatting with me and he looked behind me and he saw the picture of me and Jean Chrétien and Bill Clinton. He looked up and said, “Bill Clinton”, and I said, “My goodness, Michael, that's wonderful that you know who this is in politics. Would you know anybody else besides me and Bill Clinton in politics?” He looked and he said, “Yes, of course: Bob Dole.”

Voices: Oh, oh!

Hon. Jim Munson: And I went, “My goodness, this is a wonderful thing....”

I just want to finish quickly. There's a story.

Mrs. Carol Hughes: Madam Chair, we've already lost a lot of time today—

The Chair: Just a minute, Ms. Hughes, I think he's trying to make a point.

Senator Jim Munson: Just one small thing.

I said, “Bob Dole? How would you know Bob Dole?” He said, “From *The Simpsons*”, because he was a character.

Just to end it—I'm sorry, Ms. Hughes—as you can see, I'm passionate about it like everybody else is around this table.

Thank you very much.

The Chair: Thank you, Senator.

We'll go to our second round, starting with Dr. Duncan.

Ms. Kirsty Duncan: Thank you, Madam Chair.

Again, I'll just highlight, before we go on, the issue of what poverty means in getting help for these children. To come back to the Somali community, it's two and three children per family. It's not one. There is such a huge need here.

I also invite all of you, if you want, to make recommendations regarding respite care, key gaps in transition from childhood to adulthood, and of course, the needs of adults living with this. We'd like to have your recommendations.

I will ask you about schooling and I will ask about families in crisis. It would be unusual not to have a weekly call from a parent in the riding who is fighting with the school yet again. The child's been sent home; the child's been suspended; now the child has been hospitalized.

How can we make it better for the school issue? How do we make it better for families in crisis? When I get a call Christmas Eve and the father is sobbing on the other end, this is in absolute crisis.

Ms. Suzanne Lanthier: I'll start off by saying that a lot needs to happen before we reach that point, obviously. It doesn't solve the problem of the family in crisis on Christmas Eve, and we all know that happens and it's going to happen. We're going to get the same calls you get, and I'd be interested to know what you say, what the constituency office actually says to them.

Ultimately, what needs to happen is we need to do what we're talking about doing. When I said we're setting our families up for failure, I mean that quite literally. We're setting them up for failure by not giving them access to the treatments and interventions that they need at the time they need them and at the level they need them, and across the range that they need them. We are setting them up. We are sending them on a path for failure.

There are families in crisis who, as we know, get called because they are told that they need to pick up Billy from school because he's thrown a desk across the room or the police have been involved because there has been an assault. As we know, this is not intended behaviour. It's behaviour as a result of frustration. It's behaviour as a result of not being able to communicate, as a result of being overloaded from a sensory perspective, and not having the folks adequately trained specifically in autism to identify when those triggers are going to happen and prevent them from happening in the first place.

Wendy mentioned the training of EAs in the school setting. There are great EAs out there; and I'm generalizing, I hate to say this, but EAs for the most part are glorified babysitters. They are there to keep the kid safe and the other kids safe ultimately, but they really don't know how to identify a situation that could be a problem.

I'll leave it at that and let my colleagues answer a little bit more as well.

● (1035)

The Chair: Who would like to comment? Laurie and then Dr. Roberts.

Ms. Laurie Mawlam: We just all have to look and say, “What can I do?” At the federal level, CASDA has a position paper in French and English here. I'd like to suggest that these are things that the federal government can do. I guess everybody just has to do their part, right? I take about 20 calls a week and e-mails from families in crisis.

So I hear you. That's my only point. We all just have to do what we can do.

Dr. Wendy Roberts: Our psychopharmacology medication clinic has become almost like the crisis triage point in Toronto because when everybody throws up their hands, they say maybe medication is the answer.

As we try to move ahead in our genetic research and clinical trials to look at some medications that may be more helpful, the majority of the time we don't have a medication that can make a huge difference in a crisis. It's usually the hyperactive children with autism who have had negative results with many of the medications that we use. They end up in crisis and many of them are the ones that end up in some kind of residential care. It's almost impossible to get residential care let alone short-term hospitalization in most areas.

The Chair: Thank you, Dr. Roberts.

Mr. Lake.

Mr. Mike Lake: I didn't expect it to be coming back to me so quickly—

The Chair: I'm actually giving the proper time now.

Mr. Mike Lake: —but this is perfect.

I really appreciate the work that Senator Munson has done. The story about Michael, I've heard that once before, and that's fantastic.

I want to focus, if I could, in this round just on this concept of a national strategy. Now at the table we have three groups that are probably the three most national groups in terms of autism in the country. I think that would be fair to say.

One of the things that is difficult when we talk about national strategies, and can sometimes get in the way of national strategies, is that all the groups aren't necessarily pulling in the same direction on whatever issue it is that you're talking about having a national strategy on.

With this question I'd like to focus on areas where you are pulling in the same direction. Maybe give us an idea of what kind of common agreement there might be in terms of what should be the priorities in dealing with autism across Canada.

If Laurie wants to start, then maybe we'll just hear from all three of you.

Ms. Laurie Mawlam: On behalf of the 38 organizations that CASDA represents, we've pointed them out to be surveillance; best practices; the facilitator role, which would be having ministerial conferences, etc.; looking after the health of the aboriginal community, because you are a health care provider at the federal level; research specific to autism, increase it; financial assistance to families was the next point we made about the Income Tax Act; and lastly a national awareness campaign.

Mr. Mike Lake: Kathleen, did you have anything to add to that?

Mrs. Kathleen Provost: I would echo that. In terms of surveillance, a lot of you are putting this question to the table: can we understand what's out there? We cannot. They have told us that there is no data.

You can't build a strategy on speculation. I think we have to sit down, assess, take the pulse. There are things out there.

Mr. Mike Lake: Suzanne.

Ms. Suzanne Lanthier: I really don't have much to add. From our perspective, really it all comes down to research. Without knowing what causes autism we don't have an understanding of treatments and preventions that are unique to every child in every situation.

We'll continue to focus on our need for research and for the equality of services, access to services and diagnosis. There's no reason, as Canadians, that we should have to look at where to live in this country in order to access services.

On the rest, I think we're all pretty much on common ground. We know that things can be a lot better.

● (1040)

Mr. Mike Lake: Right. One of the things I've been encouraged about over my five years as an MP is that there seems to be a lot better understanding of the jurisdictional component. When I say jurisdictional, I'm not talking about health, social services and that stuff, but provincial-federal jurisdiction. There's a lot more recognition that the provinces are really responsible for funding the treatment of autism, they have the money to do it, and they need to make it a priority. I think at the federal level we need to equip them with the tools to make those decisions, and the research and surveillance, for example, is a big part of that equation.

Madam Chair, I don't know if there are other meetings scheduled for this particular topic at some point.

The Chair: Mr. Lake, I'll stop the clock for a minute.

Next week we are doing the research component on autism. We're very excited about some researchers who are coming in. That's going to be on our subcommittee.

Mr. Mike Lake: One thing that may be helpful to the committee, too, is to have an official from the government. I know that we've had some meetings, and the people at the table have had some meetings, with some really capable officials who might be able to shed some light on what's actually happening out there as well.

The Chair: Yes, we do. We have some really good information. You kind of precluded what I was going to announce. Thank you, Mr. Lake.

I was going to invite you back on Tuesday to listen, and you might get some extra documentation. And everything that's said here is recorded. You can find it in Hansard. That might be useful to you.

Mr. Mike Lake: Do I have a couple more seconds?

The Chair: You actually have a minute and a half.

Mr. Mike Lake: Okay. I'll use that minute and a half.

There are three organizations; Kathleen and Laurie, you have the individual organizations of Autism Society Canada and Autism Canada Foundation. A lot of people who might be listening to this or following the transcript might wonder, “Okay, so we have three national organizations. Why do we have three organizations?”

So I guess I would ask you, what is the focus of your particular organization that makes your organization unique?

Ms. Laurie Mawlam: I'd just like to say that when it comes to addressing the federal government, Kathleen and I do it under CASDA. The other member of the leadership committee is Margaret Whelan, who is the executive director for the Geneva Centre for Autism.

Outside of being here today, which I do under the umbrella of CASDA, the one thing that makes us maybe a little different is that we talk about autism as a whole-body disorder. That would be one thing that would stand out, in that recovery is possible, which is what I put in my opening comments.

The Chair: Thank you.

I'm sorry, but I have to stop there. I gave you a little extra time, Mr. Lake.

Monsieur Dufour, you're last but not least. You're the best.

Mr. Nicolas Dufour: I have no questions. I will give my time to Mike Lake.

The Chair: You want to continue, Mr. Lake? Okay.

Mr. Mike Lake: Thank you, Nicolas.

I'll just use the time to ask Kathleen to continue on that topic

Mrs. Kathleen Provost: Autism Society Canada has been around for 35 years. We have a provincial-territorial representative. We take the pulse out there regularly. We're virtual, with no resources. It's all done by volunteers and based from the ground up.

I'll also add that there are strategies out there. The U.K. and New Zealand have some. I'll forward all that after the meeting.

Ms. Suzanne Lanthier: Autism Speaks Canada, very simply, raises money and gives out money. We raise money and we give out money to research communities through family services grants. It's our goal, through the resources we provide, our website, and the information we provide, to make the path a little straighter.

I also want to comment briefly on this idea of a summit and what Autism Speaks in the U.S. did very effectively for the adult community. If they can do it across the U.S., we can certainly do it across Canada. They had virtual sites set up where they hooked up stakeholders, policy makers, and members of service provider groups in centres across the U.S. Everyone voted on issues that were important to the adult community. They developed a strategy as a result of that.

The technology is there to do it virtually across centres. I think that's a really exciting concept. When the senator mentioned that, it struck me. I attended the central hub in Chicago to see how the technology worked. I think it's a fantastic concept, and we would be happy to lend our expertise in that.

● (1045)

The Chair: I'm sorry, I have to end our conversation there.

This has been a really good meeting with a lot of very insightful comments. I let the time fall away because you had some very insightful things to say and I didn't want you cut off.

I would invite you to join us next Tuesday in the audience at the next meeting, because I think the witnesses we have there will be extremely good and may be very helpful for you.

Ladies and gentlemen, our next meeting is in Room C-120 at 11 o'clock.

This meeting is adjourned.

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