HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

Standing Committee on Health

HESA • NUMBER 057 • 1st SESSION • 41st PARLIAMENT

EVIDENCE

Tuesday, October 16, 2012

Chair

Mrs. Joy Smith

Standing Committee on Health

Tuesday, October 16, 2012

● (1100)

[*English*]

The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)): Could we ask the members to please be seated. We will begin.

I would like to welcome Senator Munson. Thank you so much for being here today.

Pursuant to the order of reference of Wednesday, June 20, 2012, Bill S-206, An Act respecting World Autism Awareness Day, I want to welcome you, Senator Munson.

We will begin.

Hon. Jim Munson (Senator, Lib., Senate): Thank you, Madam Chair. It is really a pleasure to be with my parliamentary colleagues this morning. It's Tuesday, October 16. It has been a long journey, but a very positive journey for me, my team, and my office, and for senators—Conservatives and Liberals on the Senate side—in working with the autistic community.

As we know, this bill deals with An Act respecting World Autism Awareness Day. This bill has had quite a journey. We've had a number of prorogations and one general election among the events that complicated what I believe should have been a straightforward passage. But this happens in politics. Being a former journalist and covering the Hill—I can't believe it—in the 1970s and 1980s, I understand that in a democratic system elections do get in the way from time to time.

I'm here as a parliamentarian. I've been tremendously encouraged by the reception this little bill has received at various stages and from all parties throughout its circuitous journey. It would not be where it is today, attending consideration by your committee, were it not for all the individuals here on the Hill and throughout this country who recognize the implications of and the need to address the mounting autism crisis.

On October 19, 2011, almost exactly one year ago, I stood in the Senate chamber when the bill was moved to second reading. I felt it was important on that occasion to recognize some of the people who have supported the bill in efforts to help Canadians become more sensitive to the realities of autism.

In the Senate we've worked together with Conservative Senator Keon, who's been a great supporter, along with Senators Oliver, Eggleton, Mercer, and Trenholme Counsell. I have to say at this particular point that one of the good things about working in Parliament is working with politicians from all sides. It has been a pleasure working with Mike Lake, and in particular, Jaden, who has been an inspiration in all of our lives. I'm also heartened by working with my colleagues from the New Democratic Party, from Peter Stoffer to Glenn Thibeault and many more who have supported this particular bill.

Dany Morin, who brings so much to this committee, I understand, covered the key strategic issues related to autism. These include the necessity for all levels of government to support research on the real causes of ASD. Jacques Gourde reminded those present of the Canadian adolescents and adults with autism who did not have the benefit of early diagnosis and prompt treatment, illustrating just how important it is to have easy access to reliable information. Monsieur Gourde described their experiences this way: “Teenagers are all too aware of their limitations and differences, which can make them feel marginalized, vulnerable, and isolated.”

For me it's been 10 years. I walked onto the Hill. I was appointed in 2003. There was a gentleman on the Hill who was wearing a billboard. He said, “Munson, you're not going to walk by me. You used to work at CTV. You should see this as a news story.” I looked at him and saw that he had a billboard saying, “Please help my son.” I was not that familiar with autism, and I said, okay, let's sit down and chat.

So it was because of that gentleman, Andrew Kavchak, and many others that I said, “What should I do about this?” I made a statement in the Senate. We're not televised, so people don't see our statements very often. Then somebody said, “Well, why don't you launch an inquiry?” I said, “How do I do that?” Well, that's a longer statement, so I did that. Then I said, “What happens now?” They said, “Well, you haven't built up enough support yet.” I said, “Well, damn it, how far do I have to go on this?”

The social affairs committee in the Senate sat back and said they'd have a limited study, but it turned out to be a pretty darned good study, called “Pay Now or Pay Later, Autism Families in Crisis”. That was in 2007. That's a bit of the background. The words “pay now or pay later” came from a gentleman from Fredericton, New Brunswick, who was one of our witnesses with Asperger's. He said, folks, if we don't do something more in terms of recognition and paying more for science and research, you're going to pay now or you're going to pay later. And is he correct about that.

We have so many national strategies in this country dealing with heart disease, diabetes, and cancer, so why not autism?

● (1105)

With each passing day, the need for a greater federal commitment to address this health crisis becomes greater and greater. At the very minimum, I believe the federal government has a role in the lives of aboriginal children who have autism. I think there is a place for more leadership.

I have to congratulate the government for what it has done thus far in helping set up a surveillance and monitoring system, which I think is extremely important. I also believe that with one in 88 children in this country having ASD, what the Minister of Finance did is extremely important. He has been very good to some of my causes, including the Special Olympics. He introduced the registered disability savings plan a few years back. It is an excellent, sensitively crafted savings vehicle for parents who have children with disabilities.

This bill about World Autism Awareness Day is more than just an act respecting World Autism Awareness Day. It's an act respecting those families that have to deal with autism every day. Isolation is, of course, one of the principal characteristics of autism, but the disorder also isolates the families and friends of people. Constant care is often required.

As we all know, and as you folks in this committee know—you've studied it and you've talked about it in Parliament—this could mean that in a two-parent family, one person stays at home full time and looks after the child with autism. It's a heavy burden. Simple activities such as birthday parties, play groups, play dates, trips to the library, and even an afternoon in the park can be exhausting and demanding.

For me, it comes down to one simple thing. It was said when I was in Halifax last week. I was handing out a Diamond Jubilee Medal to Dr. Susan Bryson at the IWK, the children's hospital in Halifax. The minister's deputy of the government in Nova Scotia said that what's so important is that we need to have the things others have so that a son or a daughter, through whatever therapy helps, can have a sleepover, just like any other child. I think we have to think about that. Some of the natural things that we accept do not happen naturally with an autistic child.

This bill to respect World Autism Awareness Day will not change many realities, but it will send out a message that these families deserve to hear. It will say that Parliament, parliamentarians, are thinking of these children and that we have more to do to help these children, as the preamble to my bill states. It will say to these children and their families that they are not alone. It will show these families that their plight matters and that the people of Canada respect and admire them for doing the best they can in the name of their children, brothers, sisters, grandchildren, nieces, and nephews.

World Autism Awareness Day will help build awareness among Canadians about autism, its symptoms, the people who are affected by it, and the need to address the crisis it has become.

Just as this day would engage individuals and society, so too would it empower governments to do even more. It would be my wish to see the federal government increase its involvement. We have taken major steps, but we have to go further, in my view, where the need is greatest, such as in funding and programs for aboriginal children, as I said before.

My former colleague, Dr. Keon, had good advice for me. He still knows so much. He told me to keep pushing for a federal role in science and research. World Autism Awareness Day would be the ideal opportunity to get this message out. So I sit here humbly before you. And I'm grateful to all of you, Madam Chair, and vice-chair, and all the esteemed members of this health committee, for the consideration you are giving this bill and the people who represent its purpose.

I'm here to answer any questions to the best of my ability.

Thank you very much.

● (1110)

The Chair: Thank you, Senator Munson.

I would ask the rest of the witnesses to approach the table and take your seats in front of the microphone so we can hear your presentations.

Now we're going into the second part of our witness presentation.

Thank you so much, Senator Munson, for your presentation as sponsor of the bill. It was very insightful to hear your presentation. I thank you for that.

We have, from the Canadian Institutes of Health Research, Jane Aubin, and Nathalie Gendron, assistant director. Welcome.

From Autism Society Canada, we have Richard Burelle, executive director. Welcome.

From Autism Ontario, we have Margaret Spoelstra. She is the executive director. Welcome. I'm glad you could come.

On video conference, joining us soon from Autism Speaks Canada, we will have Suzanne Lanthier. She is a member of the board of directors. I assume she will be joining us very shortly.

Can we begin, please, with the Canadian Institutes of Health Research?

Will you be sharing your time with Nathalie, Ms. Aubin?

Dr. Jane Aubin (Chief Scientific Officer and Vice-President, Research and Knowledge Translation, Canadian Institutes of Health Research): I'll give the speech and Nathalie may also participate in answering questions.

The Chair: You know that you have a five-minute presentation.

Thank you.

Dr. Jane Aubin: Thank you very much, Madam Chair and honourable members, for the opportunity to address you today regarding the work of the federal health portfolio on autism spectrum disorders, or ASD.

Let me say at the outset that I am not an expert on ASD. My own research through the University of Toronto deals with musculoskeletal health and arthritis. But as the chief scientific officer for the Canadian Institutes of Health Research, or CIHR, I am pleased to bring you information about federal ASD-related projects. My colleague, Dr. Nathalie Gendron, is with me today as a subject-matter expert.

Your deliberations are about ways to raise awareness of ASD, and I submit to you that the research and surveillance activities supported by the health portfolio provide the facts on which to build this new and growing awareness. At the same time, drawing increased public attention to ASD serves to highlight the impact of research and to generate more support for it.

If we are to do justice to this issue by raising more public awareness about it, one of the most important things we can do is to continue to build our knowledge base and to apply that knowledge to ease the path of people with ASD and their families. The Government of Canada supports a number of activities aimed at doing just that. For instance, my colleagues at the Public Health Agency of Canada are developing a national surveillance mechanism to systematically collect essential data to better understand how many Canadians are living with ASD, and their circumstances.

To ensure that the surveillance system is robust and useful, the agency consulted with provincial and territorial governments to determine priorities and data availability. It has also established an expert advisory committee to review information collected from the provinces and territories and to help identify indicators and appropriate models. This committee includes representatives from government, universities, health care, and community groups.

With respect to advancing the science of ASD, the Government of Canada has made significant investments through the Canadian Institutes of Health Research. Since its inception in 2000, CIHR has invested nearly $44 million in autism-related research, with $5.8 million invested this year alone.

Our work in the area of ASD is led by our Institute of Neurosciences, Mental Health and Addiction, but several of our other institutes are also involved. This helps to bring to bear many academic disciplines and perspectives on this very complex problem.

Through CIHR, the Government of Canada has recently established a chair in ASD treatment and care research. The purpose of the chair is to support an early career investigator to bring innovative approaches to the treatment and/or care of ASD. Partners for the chair competition are CIHR; Autism Speaks Canada; the Canadian Autism Spectrum Disorders Alliance; Health Canada; NeuroDevNet, which is one of the national centres of excellence; and the Sinneave Family Foundation.

We are delighted that Dr. Jonathan Weiss of York University has accepted the chair appointment, following a rigorous selection process that was administered by CIHR. Dr. Weiss is a licensed clinical psychologist and a rising star in ASD research.

In addition to this new chair position, CIHR is supporting a range of other research projects into ASD and activities through our regular granting mechanisms. People like Dr. Adrienne Perry at York University, Dr. Susan Bryson at McMaster, and Dr. Isabel Smith at the IWK Health Centre in Halifax, among others, are all contributing to the ASD knowledge base.

Other CIHR research programs are aimed at health services. For instance, the CIHR signature initiative in community-based primary health care encourages researchers to investigate the ways in which health care services are structured, regulated, managed, financed, used, and delivered. For people living with ASD and their families, better service delivery could make all the difference.

Finally, in our convenor role, CIHR supported the international meeting for autism research and a stakeholder-focused workshop held in Toronto in May of this year.

CIHR is also pleased to reach out to stakeholders and interested members of the public regarding ASD. We'll be doing this again on October 29 in Edmonton, when the CIHR Institute of Neurosciences, Mental Health and Addiction hosts a Café Scientifique on ASD. This will be a great opportunity for raising awareness and sharing the latest in scientific research on ASD in an informal and comfortable setting.

● (1115)

Madam Chair, honourable members, I would like to close simply by emphasizing the fact that the efforts I have outlined are not solutions in themselves. Rather, they are interdependent activities that get us closer to a solution. Our approach must continue to combine work on causes, treatments, and care with surveillance and sustained efforts at raising awareness.

I thank you very much for the opportunity to speak to you today. I'll be happy to answer questions later.

Thank you.

The Chair: Thank you very much, Ms. Aubin.

We'll now go to Autism Society Canada, to Mr. Richard Burelle, please.

[*Translation*]

Mr. Richard Burelle (Executive Director, Autism Society Canada): Good morning. My name is Richard Burelle, and I am the executive director of the Autism Society of Canada.

[*English*]

Madam Chair, committee members, Senator, members of Parliament, and guests, I want to thank you for allowing me to represent Autism Society Canada as we give our wholehearted support to Bill S-206, An Act respecting World Autism Awareness Day.

Last night I sat down, pen in hand, ready to make some notes about what I wanted to speak to you about today regarding our support for Bill S-206. I gathered my notes—they're all right here beside me—including the number of committees the ASC has; the challenges and successes we have gone through; the news on advances we have made at the federal level; and the list of hurdles that are still ahead.

But I hesitated, because what I really want to talk to you about is people. I especially want to talk to you about family members and caregivers, those very people who are challenged on a daily basis to support and care for loved ones living with an ASD, an autism spectrum disorder.

Let me share with you a story. A little while ago, Autism Society Canada received a memorial donation for someone who had, I suspected, wanted to send a gift to a charity in lieu of flowers. We're always appreciative of those who think of us at a time that must be extremely difficult.

The next day we received a few more donations in memory of the same person. Her name was Susan.

A couple of days passed, and yet a few more memorial donations came in for Susan.

This is not totally uncommon. Our organization may receive quite a few gifts in memoriam during the course of a year. However, I thought to myself that Susan must have been a pretty special person to have so many friends and family members who cared about her. I felt as if Susan herself was sending us all her flowers.

As is often the case with memorial gifts to national organizations, I normally do not know the deceased personally, and I'm often unaware of their connection to Autism Society Canada. This case would be different.

A couple of weeks after that first memorial gift, I received a letter from Jan, who is Susan's mother. She wrote to me to tell me about Susan.

You see, Susan was the mother of a child living with an autism spectrum disorder. Jan told me about how Susan fought for five years with her local school board to get her child in an appropriate class. She told me how Susan's child did not have friends at school, nor in the neighbourhood. She told me how Susan felt: that she had failed as a mother and as an advocate for other children with autism. Jan told me that Susan had taken her own life.

Losing Susan should not have happened.

I have chosen to recount this tragedy, which is an extreme case, to illustrate a point. There's a misnomer out there that autism is not deadly. I would beg to differ. Autism awareness is clearly lacking.

I applaud Bill S-206, An Act respecting World Autism Awareness Day, which by definition takes on this issue. Ignorance of autism can no longer be an excuse.

For Canada, this act is essential to support the many autism organizations striving to work together on behalf of individuals living with an autism spectrum disorder and their caregivers across this great country.

Bill S-206 also gives Canada a unique opportunity to demonstrate leadership in this area to the international community.

● (1120)

In closing, I would like to reaffirm the need to raise awareness on autism spectrum disorders so that tragedies like Susan's never reoccur.

Autism Society Canada has a broad reach. Our member societies work in direct contact with families, caregivers, individuals living with an ASD, across this country. Our societies inform us that access to services from one province to another is indeed unequal. There exist glaring gaps in treatment and resources across this country. We believe it is time for this to be addressed. We believe it is time for a national autism strategy in Canada.

Madam Chair, I would like to thank you and members of this committee for your invitation to be present today. I would also like to thank you, Senator Munson, for your unwavering dedication to pursuing Canada's full support of World Autism Awareness Day.

Thank you very much.

The Chair: Thank you for your heartfelt presentation. It certainly brings to mind how real the challenges are around autism. Thank you.

We'll now speak with Autism Ontario and Margaret Spoelstra, executive director. Thank you for coming, Margaret.

Ms. Margaret Spoelstra (Executive Director, Autism Ontario): Madam Chair and committee members, thank you very much for the opportunity to speak with you and the Standing Committee on Health.

As a director at Autism Ontario, one of the largest advocacy organizations in Canada, it's my honour to be working for such an organization that is led by 300 volunteers, mostly parents, through 28 chapters throughout Ontario.

People with autism spectrum disorders and their families in Ontario have been waiting a long time for national recognition as full citizens of Canada. They have tremendous gifts to offer despite their significant challenges with social understanding, sensory sensitivities, and fitting into a neuro-typical world, a world that seeks out novelty and yet finds the novel, sometimes unusual mannerisms and unconventional social responses of people with ASD to be uncomfortable or, at worst, unacceptable.

For many years, the media has portrayed autism as a condition associated with children. In their early years, their parents are desperate to find clear, accurate diagnoses, assessment, and evidence-based intervention that will help their children to get the best possible start in life. Canadians need to know that far too many families are waiting for these services and intervention, and missing vitally important and comprehensive supports.

In school years, children and teens with ASD have unequal access to quality, individualized education that meets their unique learning needs. They are frequent targets for bullying by peers, and often fail to achieve their potential through kind, but untrained, professionals in evidence-based practices. It has been said that when you've met one person with autism, you've met one person with autism. ASDs are complex. In addition to the difficulties they face in navigating social environments and societal demands, over 50% of people with ASD will also experience mental health challenges in their lifetime, many already beginning in their youth. With quality individualized health and education supports and tailored environments, these children can grow up to have jobs, make friends, and enjoy their families and communities.

Children with autism grow up to be adults with autism. Their parents worry, “What on earth will happen to my son or daughter when we're gone?” Caregivers of children, young and adult, face enormous stress in raising their children across the lifespan. We can improve the experiences of these families through a day such as World Autism Awareness Day in Canada, so that there is greater understanding in communities across the country, and so that people with ASD might take their places as full contributing citizens of Canada.

In 2007, Senator Jim Munson sought a national strategy for supporting people with ASD and their families. The “Pay Now or Pay Later” paper identified the same points being made today. Such a strategy includes the funding of excellence in research, clinical services, education, and the creation of inclusive, welcoming communities. With one in 88 children being diagnosed in the U.S., and one in 100 children in Canada, in recent studies, the numbers are growing daily to crisis proportions. We must not fail to support people with ASD, our most vulnerable citizens. Autism Ontario strongly supports the passage of Bill S-206, An Act respecting World Autism Awareness Day as an important step in achieving acceptance and opportunities for all people with ASD.

Thank you very much.

● (1125)

The Chair: I thank you very much for your presentation, Margaret.

We are to have by video conference Suzanne Lanthier of Autism Speaks Canada, but she has not arrived yet, so we will go into our five-minute question-and-answer rounds. We want to make sure that we get through this bill, because we have committee business, as promised, and we have the clause-by-clause.

Having said that, we will begin with Ms. Davies, for five minutes, please.

Ms. Libby Davies (Vancouver East, NDP): Thank you very much, Chair.

First of all, to Senator Munson, thank you very much for coming here today to present your bill, and to the witnesses who all did an amazing job of giving us a real sense of what this issue is about.

We're only spending one short meeting on this, and it's not enough, so I'll get into it right away. Obviously, we support the bill. To raise awareness is very important; that's a given.

I want to read out an e-mail that I received from a parent who has three daughters who are on the autism spectrum. Her name is Amy. What she wrote to me was that

> 'Autism Awareness' is done and advocated for with the best of intentions. However, it is not something that is actually for autistic people and their families. They are already very aware.

She's saying that awareness is not enough:

> Awareness needs to be matched by meaningful action. It must lead to appropriate lifespan supports and services across this country that allow autistic people and their families to reach their fullest potential.

You've all spoken about that. I want to get at the issue of what more we should be doing.

Senator, your bill is about an awareness day. I know that the Senate committee you instigated in 2007 made a number of recommendations, one of which was calling for the federal government, in collaboration with the provinces and territories, to establish a comprehensive national autism spectrum disorder strategy, including treatment, supports, and so on. I believe the Conservative government, in their platform in either 2006 or 2008, also promised such a strategy.

I wonder whether you have had any response to the Senate committee report or whether any of the other organizations are aware of any further support. It seems to me that the awareness is very important, but that unless we follow through on the need for a strategy and the treatments and supports to families, we're not getting nearly as far as we must get.

Could you respond to that?

● (1130)

Hon. Jim Munson: I'll talk briefly, and perhaps the other witnesses can say a few words.

Meaningful action is what is extremely important. This is not the last step; this is the beginning of many steps, from my perspective, of what we're all trying to do in dealing with it.

As I said, the government's new surveillance and monitoring program is a good first step. Also, dealing with the issue of the disability payments, many grandparents and others have come to me and said that this is a really good step.

But those are only steps. I fully believe, and said in my statement about aboriginal youth, that, my goodness, children are slipping through the cracks every day in the aboriginal community alone. Why couldn't that be a second step for a national government's involvement?

I also believe that it's time to think outside the box. I know there are provincial governments that are delivering autism services as well as they can, but it's about time to think outside the box. We have the terminology that “it's a provincial responsibility”. It's Canada's responsibility.

I feel that whoever is in power should think outside the box and bring people together in a room like this, with scientists and researchers and other politicians from all spectra, to sit down to hammer out something that can work. I really believe that—and not only for autism, but for those with other severe intellectual disabilities.

I'm originally from Atlantic Canada—I'm from northern New Brunswick—and I'm an Ontario senator, but I'm a Canadian. As a Canadian, I'm tired of hearing about people who are getting on little airplanes in northern New Brunswick and travelling to Alberta and other provinces to get treatment, which lasts from zero to the age of 18, with a diagnosis.... You name it.

We have to get there, and I think what we're all trying to do is get there. I think we have a moral, ethical, and a loving obligation to get there.

Ms. Libby Davies: I totally agree with you, and let's hope that a federal strategy is coming, as promised.

I want to raise the issue of gender. I don't know if any of the organizations here today have further information on the issue, particularly on young girls who are diagnosed a number of years later, so that they often miss out on the early intervention. Very little research is done on this, but there is some research.

I wonder if some of the organizations have looked at the issue of gender, of girls versus boys, and how we're falling behind in intervention, support, and treatment for young girls because they're often not getting diagnosed early enough.

Could you address this briefly?

The Chair: I'm sorry, I'm trying to wind this up.

Margaret, could you quickly respond to that?

● (1135)

Ms. Margaret Spoelstra: Sure.

You're absolutely right that girls are underdiagnosed. Part of the diagnostic challenge is because girls are socialized much earlier on how they should behave, and they often go under the radar. Unless there is a particular behavioural response, they tend not to be recognized for that, but underneath a very quiet or calm exterior are often significant challenges and mental health issues that emerge later on in their lives.

Autism Ontario runs girls groups, very specifically, and brings girls together to help them deal with significant social pressures. Girls are significantly at risk at school, for date rape, and for other social challenges, in relationships as they get older, and even as they become young women making choices.

The Chair: Thank you, Margaret.

We'll now go to Dr. Carrie and Mr. Lobb. They will share their time.

Dr. Carrie, go ahead.

Mr. Colin Carrie (Oshawa, CPC): Thank you, Madam Chair.

I want to thank the witnesses for being here. I particularly want to thank Senator Munson for all the good work he has done. People around the table know our family was one of those families that had to fight the school board. My wife put her career on hold to help with our son, who was diagnosed with Asperger's. We went for the private school, and I'm happy to say he started university this year. So with a lot of hard work and sacrifice.... The success stories are out there.

With the system we have in Canada, there are challenges with provincial–federal jurisdiction. Dr. Aubin, you mentioned the steps the government has taken. Senator Munson said we have to start thinking outside the box, that we have to start working on science and research.

Could you talk about the role of the federal government and the role of the provinces and territories in delivering health services for people with autism spectrum disorder in Canada?

Dr. Jane Aubin: Thank you very much for your question.

Let me start by reiterating that CIHR, as a federal funder, funds the best research across the nation. It covers the most basic research on the genetics behind susceptibility to autism, to help with early diagnosis and early intervention. At a national level, we are funding across the country.

We play a very important convenor role as well. What I mean is that we don't just convene researchers to share their research findings and build upon them; we convene partners. We convene provincial partners. We convene the policy makers with researchers, to share and act upon the evidence we require. It's at a multiple level that CIHR and its other health portfolio partners coordinate our activities and bring together the information with partners.

I hope that speaks to some of what you're interested in knowing, and I'm happy to speak further.

Mr. Ben Lobb (Huron—Bruce, CPC): Ms. Spoelstra, grandparents in my riding have a grandchild in the Niagara region. I want to run through their scenario briefly and explain if that is in fact the situation, and how we could improve the timeframe.

They knew their grandson, at 12 months, had a problem. It took 16 months for him to be diagnosed as severely autistic. They want their grandson and their son to be in the intensive behavioural intervention program; they've been told it takes three to five years to receive that treatment. They are number 750 on the list, so if that's the present-day scenario in Ontario, obviously that's unacceptable.

What can we do to get that number down to what is realistic? What else can we do? I'm sure there are hundreds of families in Ontario in the same situation.

Ms. Margaret Spoelstra: You're absolutely right, that situation is unacceptable. We hear that story from families across the province on a daily basis, and they despair. To have a number like 700, or whatever, just says that child is not going to receive the best intervention we have to help him or her at this stage in their life, and to know that window is closing at a time when the plasticity of the brain is at a stage when it can accept lots of information and change. We know, in fact, that this treatment can have a significant influence on how that child develops for the rest of its life.

First of all, my heart goes out to those families. They should not feel that they're competing with another family whose kid did get on that list. All of those children should have access—all of them, not only the ones who are eligible for the service—to that early assessment and intervention at a time when it makes the most difference in their lives.

It is at least, in part, a funding matter, but it's also a policy matter and thinking about some ways to adjust the system, so that there is fairness for more families to have access to that. Also, it takes training, not only in those early years.... One of the biggest fears families have is exiting that system and moving into the school system—where the training for the professionals is not as it should be—so that families can feel confident that those same strong evidence-based practices are being implemented in the school years, and into adult life as well.

● (1140)

The Chair: Thank you, Ms. Spoelstra, for your insightful comments.

Now we'll go to Mr. Pacetti, please.

Mr. Massimo Pacetti (Saint-Léonard—Saint-Michel, Lib.): Thank you, Madam Chairman.

Thank you to the witnesses.

We all have stories about autism, so I don't think we need to get into that. You've got support around the table, so I'll try to focus more on educating myself on certain aspects.

Mr. Burelle, you referred to the fact that there's inequality in the services between provinces. Can you give me a couple of quick examples, if possible?

Mr. Richard Burelle: I believe there's no study currently comparing the services across the country. What the Public Health Agency of Canada is trying to do is put in a surveillance program to actually get Canadian data on the prevalence of autism across Canada, which is a first step. We'll then be able to identify if are there pockets, if there are areas of the country where perhaps we need more services.

The Autism Society of Canada has proposed a pilot project in order to create a needs assessment across Canada. If we could create this needs assessment where it would actually be a study across Canada to figure out where the services are, in what areas, and if we could superimpose that upon the surveillance program, the gaps would clearly rise to the top.

Mr. Massimo Pacetti: I don't mean to interrupt you; it's because we have limited time.

If the bill were to be passed, would this help that particular cause?

Mr. Richard Burelle: Keeping autism in the forefront is always a good thing. As Senator Munson said, the fact that we're piggybacking on World Autism Awareness Day is great. Any kinds of forward steps we can take in order to keep autism in the forefront, to create that awareness, are steps in the right direction.

Mr. Massimo Pacetti: Again, to educate me, maybe, Senator Munson, you can answer the question.

If we already have World Autism Awareness Day, wouldn't that already be officially recognized by Canada?

Hon. Jim Munson: There has been a ministerial declaration, and that's a generous act on behalf of the minister, but that's a declaration from a government. What this does is set up a legal framework where Parliament, where you, as a member of Parliament, are speaking on behalf of Canadians; all of you parliamentarians are speaking on behalf of Canadians. Putting it into a legal framework... whatever government comes into power has to respect this day; 192 countries already do.

Remember, this only began in the United Nations in 2008. What it does here is empower every MP from every party to stand up and be counted. So it's about Parliament, which I think is extremely important.

To briefly answer your question, and I talked about this in the other questions, we can provide statistics for you to show you how different it is in different provinces. For example, in Nova Scotia it's wonderful what's going on. They have nine areas now in the province where you can go and get intensive behaviour treatment. Before, you went to Halifax. As I mentioned, in Alberta and other provinces the programs last longer. But at the end of the day, it's about us as Canadians, as parliamentarians. That sets a legal framework to recognize this in a legal bill.

● (1145)

Mr. Massimo Pacetti: Let me challenge all of you. As members of Parliament we're asked almost on a daily basis to make a declaration or a statement on a certain day, and they're all valid causes. Tell me why World Autism Awareness Day has to be ranked up there?

Hon. Jim Munson: I think World Autism Awareness Day should rank with the bills that have already been passed by Parliament. You have to mean what you say, right? You can't just get up and say, I have to do this because this is a good little press release and my constituents will like it, and so on. You have to be behind it, and show some spunk behind what you do with the bills.

We've passed a national seniors day in Parliament. We have passed a day to increase awareness about epilepsy, a national flag day, a peacekeepers day, and a blood donor week. What do they do? And by the way, my wife would be very upset—*mon épouse est acadienne*. There's an act respecting a national Acadian day. That's a great thing in our family, for a Scot like me.

In essence, what we're doing with these things is we're saying to every one of these communities that we're there and we're going to do more than just stand up in one day. This is about carrying this message forward. The surveillance and monitoring you're talking about would be a unique opening for the federal government once they have enough data to say, okay, provinces, come on, let's sit in a room like this and analyze it together with those who understand the science and research. That'll be another step—and I'm not going away.

The Chair: Thank you very much.

Now we will go to Mr. Lake and Mr. Brown.

Mr. Lake has been a tremendous support to the autism initiative, and we're very familiar with his wonderful son Jaden.

Welcome to the committee, Mr. Lake.

Who would like to begin? Mr. Brown? Okay, thank you.

Mr. Patrick Brown (Barrie, CPC): Thank you, Madam Chair, and thank you, Senator Munson, for putting this proposal forward. I think anything that brings awareness to autism is a step in the right direction. Thank you for all the comments here today.

On Sunday in Barrie we had our annual autism walk, and that's why I said to those who attended that this brings awareness and attention to the issue. For the hundred families that came out, it does. It raises the flag and expresses an intention that we want to do more. We want to raise it, we want to talk about it, and we want to have it in the public dialogue.

On November 10 we're having our annual gala in Barrie for the same purpose, to fundraise and to raise awareness. I think this is something that would be appreciated by families and friends who have loved ones who have autism.

My question is actually for Jane. I know there is a patchwork, in a sense, a variety of different services, depending on where you live in Canada. I know I've had families in Barrie tell me that it's fundamentally different in Alberta, for example. Could you explain the breakdown or the division of provincial, federal, and territorial jurisdictions when it comes to services for those with autism?

Dr. Jane Aubin: Let me answer your question by really talking about CIHR's strategic research priorities, one of which is the strategy for patient-oriented research. This is a case where as a federal agency we're working in partnership with the provinces and territories to do exactly what's been commented upon, to bring together the knowledge from different parts of the country, to share collegially together, to work together, to harmonize, and to share best practices.

One of the particular initiatives under the strategy for patient-oriented research that I commented upon in my opening remarks is the community-based primary health care signature initiative. Within that initiative we're looking to roll out a national network to bring together the bits and pieces that exist in different provinces, to accelerate the sharing of what works within particular jurisdictions, and try to harmonize it at a national level. It's not only individual researchers, but working federally to convene the provincial policy-makers and health care professionals to deliver on best practices.

Mr. Patrick Brown: I know Mr. Lake has a question.

● (1150)

Hon. Mike Lake (Edmonton—Mill Woods—Beaumont, CPC): I'll be quick. I probably won't get time to ask a question, though.

I want to start by thanking our colleagues from all parties. You guys have been amazing. I have a 16-year-old son with autism, as I think just about everybody in this room knows. He's like a three- or four-year-old in a 16-year-old's body. He comes here every year and gets a chance to meet all of the MPs, and he tries to raise awareness in his own way. I have to say the response from colleagues, regardless of party affiliation, has always been amazing. I thank you for that.

Jim, thank you for your tireless work on this. You and I may not always agree on exactly what the answer is, but we agree that what we want to do is help people with autism, not just autism—people who need help in a lot of areas. On this specific issue, I thank you for the work you've done.

Stakeholders, we've had many, many conversations over the years. Kathleen, thank you for the work you've done. We've had the opportunity to bring you together with the officials. We have the officials sitting here at the table to talk about some of the issues that we've been talking about today.

I know I'm going to get a chance in a few minutes to actually ask some questions, but I'm going to use my time right now to say thank you for the work you've done, and to let you know how important this is to my family.

I think, Marg, you made the point that if you meet one person with autism, you meet one person with autism. That's what it's like with Jaden. The challenges Jaden has aren't the same challenges that everybody else has. Hopefully over time we'll get a chance to meet more and more people. We'll see them in stores when we go to the store, we'll see them working in the library when we go to the library, or, in Jaden's case, as he participates in musical theatre, and he cooks, and does things that we would never have thought he'd be able to do. Thank you all for the role you play in helping our families get to that point.

The Chair: Thank you, Mr. Lake, for your very insightful support and all the help you've been to this particular initiative.

We'll now go to Dr. Sellah.

[*Translation*]

Mrs. Djaouida Sellah (Saint-Bruno—Saint-Hubert, NDP): Thank you, Madam Chair.

I also want to thank all of our witnesses today for shedding some light on this issue.

You described the situation here, in Ontario, but I can tell you that things are worse in Montérégie, the region where I was elected. In fact, 1 in 106 children there is said to have autism or PDD. But the figure for the rest of the country is 1 in 110. I also know that the wait time for a diagnostic assessment is 18 months, and that assessment is limited to children 0 to 5 years of age. That's a pretty small window when you consider treatment. After the age of 5, children attend regular schools like others their age, even though the schools aren't properly equipped to meet the needs of autistic students. Unfortunately, once they turn 18, they are left to their parents' devices or, without a family to care for them, they end up in a residential, long-term care centre.

Do you have an idea of where things stand in the rest of the country, as compared with my region?

[*English*]

The Chair: Who would like to take that question? Nathalie, would you like to?

[*Translation*]

Dr. Nathalie Gendron (Assistant Director, Canadian Institutes of Health Research): Every province in the country has problems in terms of services. One thing is crystal clear: the level of care being provided to children and adults with autism is not as advanced as it should be.

Nevertheless, we are here on behalf of the federal government, and its role is quite clear. We can support research efforts across the country, as Dr. Aubin mentioned. We can support initiatives that target epidemiology, as well as surveillance. Bear in mind that federal government efforts fall within our mandate and are aimed at supporting what the provinces are doing. Health care services are the province's domain, at the ministerial, hospital and community level.

The role of the research or surveillance work being done by the Public Health Agency of Canada is to support the provinces. That support is in the form of information provinces need to identify the most effective services and the best diagnostic tools to ensure children are looked after quickly following an autism diagnosis. As far as surveillance goes, the incidence and prevalence of the disorder do vary from one part of the country to another, as you pointed out. Given the complex nature of the disorder, a Canada-wide study focusing on prevalence and incidence is necessary to fully understand the range of children affected and their needs. That will result in an effective surveillance system.

All federal efforts are meant to support the provinces in their decision making, be it in terms of finances or health priorities. In addition, as Dr. Aubin mentioned, we are doing a lot of research at the community level. It is clear that most people who have an autistic family member or who are autistic themselves need community-based support. So that's the type of research we are working on.

I want to stress, however, that we cannot lose sight of our role or the need for close cooperation with the provinces, so they can come up with the best possible strategies based on the information we give them.

● (1155)

Mrs. Djaouida Sellah: I am quite familiar with the problems surrounding autism. As a health care professional myself, I am especially aware of the social repercussions. The bottom line is that parents are having to turn to private institutions for help and ending up penniless as a result. I want to know whether help is on the way for these parents or caregivers.

An answer to my question would be appreciated.

[*English*]

The Chair: Thank you so much, Dr. Sellah.

Now we'll complete our round of questions with Mr. Lake.

Hon. Mike Lake: Thanks again.

The bill as presented is designed to increase awareness, and I just want to talk about that awareness. Notwithstanding the fact that we have a long way to go in terms of awareness, I think we can acknowledge that we've actually come a long way in terms of awareness. As a parent, certainly there's definitely more awareness I find in society than there was six or seven years ago—awareness of the challenges we face.

I would also say there is awareness in the sense of what we can do about it. I think an important part of this discussion is what we do in Canada to make lives better for all Canadians, because we're hearing of some significant challenges. I think one of the things we can agree on—we may not agree on it politically, and we have different ideas of how to get there—is that we want the situation for families across this country to be better tomorrow than it is today. To do that, we have to take a look at what's being done and what needs to be done.

When we take a look at what the federal government has done at this point, we've got some of the best researchers in the world—world-renowned researchers—leading the way. There's Steve Scherer, for example, in Toronto, and Lonnie Swaigenbaum. I think, Jim, you mentioned Susan Bryson. They're some of the world's best researchers. We've got the surveillance project under way. I think we can agree that was something that was overdue. But it's on track now and it's going to be an important part of understanding the puzzle that is autism in this country.

There are things like the opportunities fund, which doesn't just deal with people who have autism, but with vocational issues. We've increased funding for that opportunities fund to try to train people with different circumstances, different developmental challenges, so that they can have a better shot at getting jobs. We've introduced the RDSP, which, Jim, you mentioned. There are still significant challenges at the provincial level with treatment.

I think that's where I'm going to go with a question here, Marg. I'm going to come to you in a second to lay the context in your province.

In Ontario, there is 48% more money going to health care, plus 45% more funding going to social services, than six years ago, for example. What does the circumstance look like for families looking for treatment, looking for answers to their challenges health-wise, social services-wise, and education-wise in your province? Maybe describe some of those challenges. Have things been changing at all?

● (1200)

The Chair: Who would like to take that question?

Ms. Spoelstra, go ahead.

Ms. Margaret Spoelstra: There have been good things happening. In fact, we know what to do. I think that's the most important thing to say first off. We have access to the best information, the best research, and we have good clinicians who can help with services and supports in Ontario. The investments have been significant in the province, and we're grateful for that. Those are distributed across the nine regions. But what happens for families is they experience the system in pieces, and they have to constantly be cobbling together supports and services in a timely fashion for their kids when they need it.

I would say that the idea of seamless supports seems so elusive. The nature of autism is that it changes across the lifespan, so it's not a one-shot thing ever; it's multi-faceted. We need various ministries working together, so that the experience of families is not one where they're having to knock on 30 doors to get one answer for the situation they're facing today, as well as the situations that are going to continue to change across the lifespan. But we do need to invest more, because there are more kids.

As I was saying earlier in comments about those families in those early years, not receiving those services is so disheartening. When we say we want to support those caregivers, they need access to those services in a timely fashion, and they need a response to the nature of autism spectrum disorders as they are uniquely represented by each child, each adult. Then there's also caring for the caregiver. The parents bear an enormous burden in having to take the responsibility of being case managers, in addition to 20 other hats they wear on a given day.

I would also say they need additional supports to help them be families to their kids, to help them be effective in getting the services their children need, and in not having to pay out of pocket, which many families do. They go bankrupt in their efforts to get those services and supports and intervention strategies.

Hon. Mike Lake: Is it fair to say...?

Time is up? Okay, no worries.

The Chair: I'm sorry, our time is up. I've given you a little extra time, actually.

I'm going to thank the witnesses so much for coming today.

We are going to suspend for three minutes. Then we will go into the clause-by-clause and then to committee business.

There will be a three-minute suspension.

● (1200)

(Pause)

● (1205)

The Chair: Could I reconvene the committee now and can we get this bill examined?

We are going to postpone the preamble, pursuant to Standing Order 75(1). We will postpone clause 1, which is the short title.

Does anyone want to speak on clause 2, or can we go straight to the question?

(Clause 2 agreed to)

The Chair: Shall the title pass?

Some hon. members: Agreed.

The Chair: Shall I report the bill to the House?

Some hon. members: Agreed.

The Chair: We are now going in camera for committee business. I would ask anyone who is not a member to please leave the room so we can continue with our business. Thank you.

[*Proceedings continue in camera*]

MAIL POSTE

Canada Post Corporation / Société canadienne des postes

Postage paid
Lettermail

Port payé
Poste–lettre

1782711
Ottawa

If undelivered, return COVER ONLY to:
Publishing and Depository Services
Public Works and Government Services Canada
Ottawa, Ontario K1A 0S5

En cas de non-livraison,
retourner cette COUVERTURE SEULEMENT à :
Les Éditions et Services de dépôt
Travaux publics et Services gouvernementaux Canada
Ottawa (Ontario) K1A 0S5

Published under the authority of the Speaker of the House of Commons

SPEAKER'S PERMISSION

Reproduction of the proceedings of the House of Commons and its Committees, in whole or in part and in any medium, is hereby permitted provided that the reproduction is accurate and is not presented as official. This permission does not extend to reproduction, distribution or use for commercial purpose of financial gain. Reproduction or use outside this permission or without authorization may be treated as copyright infringement in accordance with the *Copyright Act*. Authorization may be obtained on written application to the Office of the Speaker of the House of Commons.

Reproduction in accordance with this permission does not constitute publication under the authority of the House of Commons. The absolute privilege that applies to the proceedings of the House of Commons does not extend to these permitted reproductions. Where a reproduction includes briefs to a Committee of the House of Commons, authorization for reproduction may be required from the authors in accordance with the *Copyright Act*.

Nothing in this permission abrogates or derogates from the privileges, powers, immunities and rights of the House of Commons and its Committees. For greater certainty, this permission does not affect the prohibition against impeaching or questioning the proceedings of the House of Commons in courts or otherwise. The House of Commons retains the right and privilege to find users in contempt of Parliament if a reproduction or use is not in accordance with this permission.

Additional copies may be obtained from: Publishing and Depository Services
Public Works and Government Services Canada
Ottawa, Ontario K1A 0S5
Telephone: 613-941-5995 or 1-800-635-7943
Fax: 613-954-5779 or 1-800-565-7757
publications@tpsgc-pwgsc.gc.ca
http://publications.gc.ca

Also available on the Parliament of Canada Web Site at the following address: http://www.parl.gc.ca

Publié en conformité de l'autorité du Président de la Chambre des communes

PERMISSION DU PRÉSIDENT

Il est permis de reproduire les délibérations de la Chambre et de ses comités, en tout ou en partie, sur n'importe quel support, pourvu que la reproduction soit exacte et qu'elle ne soit pas présentée comme version officielle. Il n'est toutefois pas permis de reproduire, de distribuer ou d'utiliser les délibérations à des fins commerciales visant la réalisation d'un profit financier. Toute reproduction ou utilisation non permise ou non formellement autorisée peut être considérée comme une violation du droit d'auteur aux termes de la *Loi sur le droit d'auteur*. Une autorisation formelle peut être obtenue sur présentation d'une demande écrite au Bureau du Président de la Chambre.

La reproduction conforme à la présente permission ne constitue pas une publication sous l'autorité de la Chambre. Le privilège absolu qui s'applique aux délibérations de la Chambre ne s'étend pas aux reproductions permises. Lorsqu'une reproduction comprend des mémoires présentés à un comité de la Chambre, il peut être nécessaire d'obtenir de leurs auteurs l'autorisation de les reproduire, conformément à la *Loi sur le droit d'auteur*.

La présente permission ne porte pas atteinte aux privilèges, pouvoirs, immunités et droits de la Chambre et de ses comités. Il est entendu que cette permission ne touche pas l'interdiction de contester ou de mettre en cause les délibérations de la Chambre devant les tribunaux ou autrement. La Chambre conserve le droit et le privilège de déclarer l'utilisateur coupable d'outrage au Parlement lorsque la reproduction ou l'utilisation n'est pas conforme à la présente permission.

On peut obtenir des copies supplémentaires en écrivant à : Les Éditions et Services de dépôt
Travaux publics et Services gouvernementaux Canada
Ottawa (Ontario) K1A 0S5
Téléphone : 613-941-5995 ou 1-800-635-7943
Télécopieur : 613-954-5779 ou 1-800-565-7757
publications@tpsgc-pwgsc.gc.ca
http://publications.gc.ca

Aussi disponible sur le site Web du Parlement du Canada à l'adresse suivante : http://www.parl.gc.ca