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Study on Funding for Treatment of Autism

Motion to Adopt Report of Social Affairs, Science and Technology Committee and Request for Government Response—Debate Adjourned

Hon. Art Eggleton, pursuant to notice of April 26, 2007, moved:

That the twelfth report of the Standing Senate Committee on Social Affairs, Science and Technology, entitled *Pay Now or Pay Later, Autism Families in Crisis*, tabled in the Senate on March 29, 2007, be adopted; and

That, pursuant to rule 131(2), the Senate request a complete and detailed response from the government, with the Ministers of National Revenue, of Intergovernmental Affairs, of Health and of Finance being identified as Ministers responsible for responding to the report.

He said: Honourable senators, I rise today to speak about the twelfth report from the Standing Senate Committee on Social Affairs, Science and Technology, entitled "Pay Now or Pay Later, Autism Families in Crisis."

I wish to start by thanking the members of the committee who demonstrated great compassion and care toward Canadians with difficulties. This is the first study report that the committee has released since I became its chair, succeeding Senator Kirby, and I was impressed with the contributions of all members. This is once again a unanimous report, which puts forth sensible and attainable solutions to a serious problem.

As well, I wish to highlight the contribution of Senator Munson. On May 11, he began an inquiry, which turned into the order of reference that launched the study. Families across Canada owe him a debt of gratitude as he brought an important issue to the floor of the Senate.

Like most senators, I know the issues of autism from what I have seen in the media. Many stories have appeared regarding court cases, perhaps some of them highlighting protests by parents or announcements by governments — which do not seem to satisfy anyone. However, I did not really understand the depth of the issue.

Those stories do not fully portray the frustration and fear that parents of autistic children have. After hearing from researchers, interest groups, parents and autistic individuals, I can say that I better understand. Hearing the stories pulled at my heartstrings, but they showed the reality of the situation and proved that it needs our immediate attention.

We heard from parents and what they see in their children in crisis, with very little help forthcoming. The reaction of each of us when something threatens our children is to protect them.

Laurel Gibbons, a mother with a nine-year-old autistic son, testified that instead of using her son's health care card to access treatment, she relied on two other cards: her library card to research autism, and her Visa card to pay for treatment.

She added:

We were going to have to pay for any interventions, including ABA, as well as the recommended speech and occupational therapy that ran into thousands of dollars.

After re-financing our mortgage three times in the last four years, the money has run out. The speech therapy has stopped, as did the occupational therapy for his sensory issues. . . . We are still doing what we can piecemeal. I worry every day that I may have to relinquish my custody of him and hand him over to social services because he becomes unmanageable.

Honourable senators, after hearing that, how can we not act? How can governments not support these parents and how can we not expect parents to be frustrated or angry?

Treatment, honourable senators, can cost \$60,000 a year, the committee was told time and time again. There is varied support from the provincial and territorial governments. Certainly, it is not equitable across the country. The majority of that \$60,000 is coming from the pockets of parents.

The committee was pleased to hear from a number of adult witnesses who have autism. Their testimony was inspirational and touching, and it showed what the results of detection and treatment can mean. Their testimony leads to some of the recommendations contained in the report.

Mr. Kristian Hooker, from Selkirk, Manitoba, spoke to the issues that persons with autistic spectrum disorder face. He said:

A big problem with people facing ASD in society is that others often have a stereotype of how a person with ASD is supposed to look or behave. Many people with ASD could eliminate that stereotype but rarely get that opportunity, especially with a large group of people.

That is why one of our recommendations is for the inclusion of autistic individuals in both national public awareness campaign and the proposed symposium announced by the Minister of Health last year. It is essential that this group be represented at any table that discusses what to do to help people with autism.

Mr. Jason Oldford is 36 years old and was diagnosed in 1974. He supported the views expressed by Ms. Laurel Gibbons in her testimony when he said:

ABA is an expensive treatment. You have probably heard the figure \$60,000 per year per child. . . . Parents put themselves on the verge of bankruptcy when they have to pay for that treatment out of pocket. I certainly understand the situation they are in.

The testimony of people like Jason Oldford and Laurel Gibbons is the reason that the committee recommended that the federal government convene a federal-provincial-territorial ministerial conference to examine innovative funding arrangements for the purpose of financing autism therapy and that the federal government establish an appropriate level of funding — its appropriate share — in all of this. Parents are facing extraordinary costs to help their children, and what they need and ask for is help. They are asking their federal, provincial and territorial governments to help to alleviate this stress. The proposed meeting is not just needed, it must happen and must happen now.

Honourable senators, beyond these two significant recommendations of inclusion and a federal-provincial-territorial meeting, the committee further recommends: the creation of a public awareness campaign to enhance knowledge and understanding of ASD and the difficulties, the challenges and some of the great qualities and abilities that many ASD people exhibit; the creation of an autism knowledge and exchange centre and an internet-based web portal for reliable data for those seeking information on autism. The committee heard from many witnesses that there is too much confusing information.

The committee also recommends the creation of an autism research network and the provision of money for research through the Canadian Institutes of Health Research, because there remains much to learn about ASD disorders. The committee recommends that the federal government work with the provinces and territories to address the human resources issues, including training standards. The Province of Alberta provides funding, but they do not have the human resources; Ontario does not provide as much funding but has lots of human resources. There are problems right across the country of that sort, including training standards, which are so varied. As well, we ask that the Department of Finance study the implications of income splitting and other tax measures to help the families.

Pulling it altogether, the committee recommends that the federal government, in collaboration with the provinces and territories, establish a comprehensive national autism strategy, which is needed now.

The committee also noted that in Budget 2007 the government has taken steps toward helping parents — and I congratulate those who sit on the government side in this place on announcing the creation of a registered disability savings plan. However, this plan will help only some people tomorrow, not today, and today is the issue. Parents are going broke now and there is no money for tomorrow.

In the words of Jason Oldford — and I quote:

. . . if you pay for it now, look at the return you get on your investment. The people with autism will get out into the real world and get jobs, and that will stimulate the economy. Or you can pay later, which means they will go into group homes and it will cost the taxpayers a lot of money in the long run to keep them there.

Pay now, or pay later. Honourable senators, that is why we need to act today.

In conclusion, I thought I would use the words of my esteemed colleague and deputy chair of the Social Affairs Committee, Senator Keon: At committee, when asking one of his questions of witnesses, he said.

Our job is to come up with a plan that is good enough that government cannot say no to it.

Senator Keon said that, in his experience, plans are turned down if they are not good enough but that if they are good enough, they are never turned down.

The report of the committee contains good recommendations that will help families across the country to deal with this growing problem. I know we could have gone further, and many people wanted us to, but we had to make recommendations that could be and should be implemented — ones that are reasonable. These recommendations help to move us in the right direction on this issue, to show parents and autistic adults that they are not alone and that they have not been abandoned.

Honourable senators, I look forward to hearing from the government in respect of this motion on the twelfth report of the Social Affairs Committee and, more important, I look forward to the implementation of this report.

Hon. Gerry St. Germain: Would the honourable senator take a question?

Senator Eggleton: Yes.

Senator St. Germain: Autism has emerged in my life. As well, I have been approached by people in British Columbia on the issue. Does the honourable senator know, through his studies with the able assistance of Senator Keon, why has this illness has been neglected in the process of treatment? Why has autism not been recognized by provincial health authorities?

Is there an increase in the number of births of children with autism? Are there any scientific projects under way to determine whether diagnoses of this illness are on the increase?

I speak with sincerity, honourable senators, because I have a niece who has two autistic children. I have seen a beautiful young woman virtually deteriorate before the family's eyes.

The information given to me by some who are active in British Columbia on this issue has clearly stated that there appears to be an increase in the number of births of autistic children. Could the honourable senator clarify that point? Did the committee's study reveal why the issue has not been addressed by provincial health authorities and Health Canada?

Senator Eggleton: I thank the honourable senator for the excellent questions. It is not clear whether there has been an increase in the number of births of children with autism. However, it is clear that there is an increase in awareness of autism, with earlier diagnosis and earlier treatment for some, but not for everyone because not everyone can afford it or access it readily. Certainly, there is an increase in awareness but an increase in the numbers is not clear from the studies to date.

With respect to health, one of the difficulties with autism spectrum disorder is that it covers more than one field. It is not only a question of health. They go to doctors and clinics, but many things would come under the social service umbrella or even the education umbrella. Also, many costs relate to the fact that many of these young people require one parent to stay at home. It is extremely difficult for both parents to work.

The Hon. the Speaker: Honourable senators, it being six o'clock, I am obliged to leave the chair unless there is consent not to see the clock.

Hon. Gerald J. Comeau (Deputy Leader of the Government): I propose that we give the senator a few moments to conclude.

Hon. Senators: Agreed.

Senator Eggleton: This is why we think we need a national autism strategy. We need to pull together the governments at different levels to work out how we can cross the lines of health care, education and social support services, and what to do about the loss of income for parents. All these things create enormous financial and emotional pressures for these people.

This is why we have suggested that we need a strategy. We need the symposium that Minister Clement recommended, which would include people in the autism field. We also need the federal and provincial governments to come together to work on this national strategy.

On motion of Senator Cowan, for Senator Munson, debate adjourned.