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# Subcommittee on Neurological Disease of the Standing Committee on Health

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## Tuesday, December 14, 2010

## Chair

**Mrs. Joy Smith**

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● (0855)

[*English*]

**The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)):** Good morning, everybody. Welcome to the committee.

I'm Joy Smith, the chair. This is the subcommittee on Neurological Disease of the Standing Committee on Health. We are going to be continuing our study of autism today.

There are some witnesses who have been held up by the storm, and they will be coming in a moment. I think it's advisable to start now with the presentations.

We have with us Dennis Lendrum from Coffee Chat. That's an interesting acronym or title. I'm happy to have you here, Mr. Lendrum.

From the CanChild Centre for Childhood Disability Research, we have Dr. Peter Rosenbaum. Welcome back.

We have a couple of other people coming from the Centre d'Intervention et de Formation.... I'm not sure how to pronounce that in French.

**Mr. Warren Jason (Contributor, Programme socio-dynamique d'intégration par l'art, Pervasive Developmental Disorders, Autism Spectrum Disorders, Centre d'Intervention et de Formation Socioculturel International):** I can help you. I would say it's a centre for—

**The Chair:** Formation of—

**Mr. Warren Jason:** It's a training centre.

**The Chair:** Yes, it's an international centre. We have Mr. Warren Jason with us, and we have Mohamed Ghoul. Welcome. I'm happy to have you here.

From QuickStart, we have Suzanne Jacobson, who is the founder—it's Early Intervention for Autism. Welcome, Suzanne.

From the Public Health Agency, we have Kim Elmslie, who is the director general, and Anne-Marie Ugnat, the associate director.

We also have Dr. Laurent Mottron, who will be joining us shortly.

They have all been introduced, so we'll just go into their presentations when they come.

I would like to begin with Mr. Lendrum for a five-minute presentation.

**Mr. Dennis Lendrum (Coffee Chat, As an Individual):** Hi. I'm honoured to be here.

My name is Dennis Lendrum and I come from Espanola, Ontario. I'm the grandfather of a seven-year-old autistic child.

First of all, I'd like to thank the honourable Carol Hughes, the MP for Algoma—Manitoulin, for inviting me to speak today in the House of Commons. It's truly an honour.

I am a grandfather of five grandchildren, one of whom is seven years old. His name is Alex Bertrand. He was diagnosed five years ago as severely autistic and non-verbal. At that time, I didn't even know what the word “autism” meant.

I've worked in a pulp and paper mill in Espanola since 1981. I had two back surgeries and had to resign from that job in 1998. During that time, I've been a volunteer firefighter for 15 years. I'm also the volunteer president for the snowmobile club of the area.

I sit on a committee with the greater Sudbury Regional Police. I was part of a team that is working on creating a registry for wandering persons—that's not only for autistic wandering persons, but for anybody who may wander away from home. We have the attention of the provincial police. We're hoping this will soon become provincial and maybe even national.

Now all I ever speak about is autism. Social functions, meetings, media, all candidates meetings—wherever I can get in a word about autism, I'm going to do it. I've spoken to Carol Hughes many times, and I'm sure when she sees me coming she knows what I'm going to be talking about. We've met—

**The Chair:** Mr. Lendrum, you really have to be concise in your presentation, because we have a lot of presenters. I just want to make sure that you get in all the points that you think this committee needs to know. At the end of the time, I give latitude. But we need to get through all the witnesses and have all the questions.

**Mr. Dennis Lendrum:** My main part was the beginning; the latter part is just information for the committee.

**The Chair:** Good.

**Mr. Dennis Lendrum:** Five minutes and I'm ready to stop. Then we can chit-chat.

**The Chair:** Thank you.

**Mr. Dennis Lendrum:** Alex was first diagnosed a week before his second birthday, in October 2005. We were told to get him ready for 30 hours of IBI treatment, as he was priority number one. So our daughter and her husband worked on changing his sleeping habits and everything else in their life and their world to get him ready.

Then, in 2006, the list changed, and Alex went to the back of the list. Apparently, it went to a “first come, first served” basis.

We got a lot of information from the medical field on what direction we should be going, and everything pointed to the idea that we should get Alex into IBI treatment as soon as possible. So we started looking for instructor therapists and found a couple. We had a home program put together in Sudbury. The cost was nearly $70,000 to my daughter and her husband. It blew them away.

In September, I drove my daughter and my grandson to Toronto, and we met with Frank Klees and John Tory. We explained our story. We ended up meeting the Minister of Children and Youth Services, the Honourable Deb Matthews. Then, all of a sudden, my grandson got into the program.

**The Chair:** She actually appeared before our committee, Mr. Lendrum. Thank you.

**Mr. Dennis Lendrum:** Okay.

We got Alex into the 30-hour program. He went through this program. In January of last year he was taken out of the IBI program and dropped into regular school, which hasn't helped him at all.

Other parents couldn't have gotten their children to go to this program. Other parents haven't gotten their children to. I have a letter here from a reverend who was in my home community at the same time, and he got so frustrated with the system that he moved his entire practice to Manitoba. He sent me a letter for you to read. It's attached. It's the last two pages.

When Carol called me in November asking me if I'd speak, I was quite shocked. I spoke to a lot of my friends in Nova Scotia, Manitoba, and all over the place about autism and about what I was asked to do, and they all encouraged me to come here. That's why I'm here.

At the end of the day, most people I speak with want the Canada Health Act to adopt autism. That's the bottom line that we can see helping. Provincially, there are programs all over—in Nova Scotia or Manitoba—that are different. That shouldn't happen. All these children are Canadian.

I've met with Senator Jim Munson. He came to Espanola and spoke with me and several other parents. His statement was, “Pay now or pay later.” Is paying later an option? I am going to pass on. My daughter is going to pass on. What's going to happen to my grandson then? Those are the realities out there. So many parents are afraid of that happening.

I co-created a social group called Coffee Chat. I've created one in Espanola, and that's where parents just go to sit down once a month for an hour or an hour and a half and chit-chat with each other. Everybody is just so afraid of what's going to happen in the future.

As you can see, there's other information in the package I've passed out to the committee, but the big thing we want to see is a change in the Health Act.

● (0900)

**The Chair:** Thank you, Mr. Lendrum.

We're so grateful that Ms. Hughes called to have you on our committee. There will be a chance for questions and answers later, and you'll have lots of time then. I've given you a couple of extra minutes this morning.

Also, the committee actually doesn't have your presentation, because we have it in translation. We will make sure that everybody gets a copy. I've just gone through it here in front, and it's just excellent, very detailed.

So your presence here is very much appreciated.

And thank you, Ms. Hughes, for doing that.

We will now go to our next witness, Dr. Peter Rosenbaum, please.

**Dr. Peter Rosenbaum (Professor, Paediatrics and Canada Research Chair in Childhood Disability, Mentoring and Dissemination, McMaster University, CanChild Centre for Childhood Disability Research):** Thank you. It's a pleasure and an honour to be able to talk with you. My remarks will be rather broader than being just about autism, because I'm addressing the issue of neurological diseases as they affect children. Most of what I'll talk to you about is research-based.

I want to present five themes.

The first is that collectively, children's disabilities and neurological disabilities are many and varied. There are a lot of names and terms used, and these terms are often, if not always, descriptors rather than names of specific diseases. We know that there are about eight children in a hundred in Canada who have a neurodevelopmental disorder of some sort, including, obviously, autism, cerebral palsy, epilepsy, and so on. While it's important to make distinctions between conditions for a host of reasons, which I've outlined in the notes that are available, it's also very important to think collectively, in what is called a non-categorical way, about these conditions and what they have in common. The idea that has been argued for many years, with evidence to support it, is that these conditions have a lot in common. And the way we think about them and deal with them should recognize that reality.

The second theme that's really important is to recognize that children are developing beings. They're not small adults. Children are constantly in a state of becoming, and this is true whether or not they are neurologically intact. That's a very important issue when it comes to children with neurodisabilities, because we tend to think of them as people who need treatment and fixing. At the same time, whatever fixing we can do, we have to recognize that they are developing beings. And neurological impairments affect children's development, which is why we often refer to them as neurodevelopmental conditions.

Rehabilitation services of the sort offered to adults are not particularly relevant or applicable to children because of these differences. The way we think about children, the way we frame their disorders, is very important in conditioning what we do and how we do it. It's important to remember that children with neurodisabilities grow up to be adults with those conditions. We don't fix very much. We don't cure very much. The adult world—the world of adult services—does not serve children with developmental disabilities effectively. A major issue, to which Mr. Lendrum alluded, is what happens to children with neurodevelopmental disabilities as they grow up.

The third self-evident comment—in a way it's self-evident—is that children grow up in a context and an environment called “family”. Developmental and chronic health conditions affect families. It's estimated that one Canadian family in five is raising a child who has either a neurodevelopmental or a behavioural disability. There's very good Canadian research evidence of the negative physical and mental health toll these conditions take on parents. That's both clinical and epidemiological data. We know also that when services are developed and delivered to the family as the unit of interest, there is a big impact on the satisfaction parents experience, on their mental health, and on the amount of stress they experience, which is lower when services are family-centred.

The fourth theme is that we have new ways of thinking about childhood disability, moving beyond the biomedical concern of the diagnosis. Ten years ago, the World Health Organization published the International Classification of Functioning, Disability and Health, what's called the ICF. This is a framework for health that applies to everybody. It is a useful way to think about childhood disability. The idea is that whatever the impairment or condition, it may affect body structure and function, but it also has an impact on activity. It also has an impact on people's participation or their engagement in life. And contextual factors, of which family is the most important, environmental factors, and personal factors are hugely important in the way in which that condition affects people.

● (0905)

Therefore, it is terribly important that we recognize that interventions for children with neurodisabilities need to be directed at promoting function and activity in ways that are safe and effective, in order to enhance participation. It's also sadly the case that more therapy isn't necessarily better. At the end of the day, development and participation should always be the goals of services, to help parents help their children become adults who are as capable, confident, and independent as they can be.

Briefly, my fifth theme is that we need to continue to study these questions. I can tell you immodestly that Canadian research on childhood disability is the envy of the world. I'm very proud to be a Canadian who goes to other countries and hears about the work we do and how much regard there is for it.

We need to continue to study how best to help families, and of course their children. We need to assess the effectiveness of our interventions to adopt and promote those that work, and to stop doing those we know don't work based on good evidence. We need to support collaborative national research programs built on modern thinking about children, families, development, and a life course approach.

**The Chair:** Mr. Rosenbaum, I've given you a lot of time. Do you mind wrapping up, please?

**Dr. Peter Rosenbaum:** That's fine. I was finished at that point.

**The Chair:** Thank you so much.

We'll now go to Mr. Jason Warren, please.

**Mr. Warren Jason:** Hi.

This program is a socio-dynamic integration program through art. This new approach uses the rhythm of the African djembe as a medium for communication. From that building block, we communicate with those along the autistic spectrum.

What we're doing right now is to put in place different structures, starting from ordinary schools to psychiatric regional hospitals, implementing the program accompanied by research.

This new approach lowers aggression levels and lowers all the integration difficulties of the clientele we're touching. It's applicable to all types of handicaps among children or adults. What it does is to lower anxiety.

During the formation of trainees in these organizations or institutions, it brings a better atmosphere. This brings the participants into a context of creation. So when a participant is in the context of creation, this is always associated with emotion. With these two together, there's a “dynamic neuron” that's created, as I call it, which stores this information. This emotion and creation together stores this information in what we call memory. When we come back to that memory, it often becomes a permanent building block from which we can use the rhythm and every other tool to interact with that person.

From that first building block, the experience of creation brings a person to knowing that he or she can now communicate with the outside world. From that building block, we can put in different music, different words, and different rhythm. It's always within the rhythm basis: the communication is based on rhythm.

During the formation stages in institutions and hospitals, the cost of that formation is lowered because the results are, in the short term, very important. So the cost of the formation is very low compared with the fantastic results.

We're looking at getting government acceptance of this so that schools and different institutions can have this program available on demand.

That's about it for me.

● (0910)

**The Chair:** Thank you very much, Mr. Jason.

We'll now go on to QuickStart, with Suzanne Jacobson, please.

**Ms. Suzanne Jacobson (Founder, QuickStart - Early Intervention for Autism):** Thank you, Madam Chair. I welcome the opportunity to speak today before your subcommittee.

I am the grandmother of two young boys, Alex and Nathan, ages six and three. Both have been diagnosed with autism spectrum order, ASD. They are brothers.

My husband and I were privileged to be able to pay for private therapy for Alex while he waited the 10 months for the publicly funded assessment and diagnosis. As I learned the importance of early identification and intervention, I wanted to do something that could help all children, not just those children whose families could pay.

That led to the founding of QuickStart-Early Intervention for Autism in 2008. QuickStart is a non-profit Canadian charity.

QuickStart's goal is to find the most effective way to get immediate help to the children who are showing signs of autism. To this end, QuickStart has helped to establish the first Canadian pre-diagnosis clinic.

QuickStart also advocates for children with autism and their families. That is why I have asked to appear in front of your subcommittee today; first, to underline the health and economic burdens to the family; second, to emphasize the importance of early identification and intervention; and third, to highlight the encouraging results of an intensive early therapy for toddlers.

First is health and the economic burden. Our own personal family experience is that it is an enormous stress, on not only the family but the extended family. We have watched our daughter and son-in-law fight every step of the way for their children. We have seen the schedules they keep, with the numerous appointments, therapies, etc. It never ends. They are exhausted. My daughter has had to stop work, so there is the loss of her income.

On top of that, we have to come up with the funding for private therapy, which is easily $50,000-plus. We're talking after-tax dollars, and it's often the extended family who helps with this. Personally, I have cashed in all of my RRSPs to pay for my grandsons' therapies, and my husband and I are cashing in our other retirement investments so that our grandsons will have the best opportunity to develop.

I also hear from other parents. They call me. They're desperate. They are re-mortgaging. They are selling their homes. They're moving to other provinces to get better care.

One grandmother called me to tell me she continues to work, so she can pay for her grandson's therapy.

I'm here to tell you that we're the lucky ones. What if you don't have a home or investments to sell, or an extended family willing to help? Your child waits while you can do nothing, and valuable time is lost.

Second is the importance of early identification and early intervention, knowing what to do. I have a perfect example with my two grandsons.

Alexander was not identified right away. His GP wanted to take a wait and see approach, which is very common. We didn't know where else to take him to get help. Once he was flagged at 20 months of age, Alex waited a further 10 months for the assessment and diagnosis. Alex did not come to the top of the intensive behavioural intervention therapy, the publicly funded therapy here in Ontario, until he was 54 months of age. That's 34 months, almost three years from when he was first identified.

Nathan, his brother, is a different story. He took part and is still in a siblings research study with Dr. Lonnie Zweigenbaum in Toronto. At 15 months there were concerns raised. At 18 months he was showing some red flags for autism. He was diagnosed at 21 months.

Here I feel there is something that is very critical as well. Alex had regressed significantly by the time he started private therapy. Nathan started to receive private treatment as soon as he began to regress because we knew what to do with Nathan.

Alexander currently attends grade 1 with the help of a full-time aid. While Alex has many strengths, we are not sure at this time if he will be able to live independently.

Nathan, after 21 months of intensive therapy, has improved so much—and that's private intensive therapy—that he no longer qualifies for the IBI therapy. We are optimistic that he will live a full and independent life.

The third thing I'd like to talk about is an intensive therapy for toddlers. I would like to briefly highlight the encouraging results of an innovative new early intervention therapy for toddlers that's based on behaviour analysis, called the Early Start Denver model. This intensive early intervention approach by specialists and with the child's parents is suited to children under two and a half years of age. It has shown significant improvements in outcomes and cost effectiveness. Nathan's rapid progress has confirmed these results.

● (0915)

I believe his progress is due to a combination of these key factors: early identification and intervention, weekly speech therapy, and his intensive therapy with the Early Start Denver model. We're very fortunate to have someone trained in that here in Ottawa—the only person in Canada.

Madam Chair, I thank you for this opportunity to appear today. I thank your colleagues for bringing their attention and hope to this matter.

Thank you.

**The Chair:** I thank you, Ms. Jacobson. This committee has been very concerned about this issue. We find it very helpful to listen to all the input from all the members, and especially from people who have autism in their families, because it's a very real thing that needs to be addressed.

Thank you.

We'll now go to Ms. Elmslie.

Welcome.

● (0920)

**Ms. Kim Elmslie (Director General, Centre for Chronic Disease Prevention and Control, Health Promotion and Chronic Disease Prevention Branch, Public Health Agency of Canada):** Thank you very much, Madam Chair. My apologies for being a little late in arriving this morning. I was battling the traffic on the Queensway.

I'm very pleased to be here this morning from the Public Health Agency of Canada to provide you and the subcommittee members with an overview of the agency's work on surveillance of autism spectrum disorders.

I will start by briefly giving you an overview of health surveillance generally. Then I will focus on the development of the autism surveillance program.

As many of you will know, health surveillance is a core public health function, and it is a critical part of the work we do at the Public Health Agency of Canada. What is surveillance? Surveillance is the ongoing, systematic process of data collection; expert analysis and interpretation; and, most importantly, communication of the resulting information for public health action.

The information we use may include rates of a health condition; emerging trends over time; variations in the occurrence of a health condition according to specific populations or geography—where those populations live; information about risk and protective factors, and so on. There are many ways we do surveillance and many types of data that we collect.

With our surveillance information, governments, health care providers, public health practitioners, researchers, and Canadians can take action to prevent disease and promote health. The responses may be in the form of policy and program development, changes in clinical or public health practices, provision of advice and education to the public, or research. As you can see, there's a broad range of uses for the surveillance information we provide, and we are very careful to collect that information to meet the needs.

I will now focus on the development of a national autism spectrum disorder surveillance program. Autism spectrum disorder, as you know, is a group of neurodevelopmental conditions that typically occur before three years of age. These conditions are characterized by impaired verbal and non-verbal communication, impaired social interaction, and repetitive behaviours. Rates of autism spectrum disorders in Canada have been estimated at 6.5 per 1,000, based on studies by researchers such as Fombonne, and studies from the Senate Standing Committee on Social Affairs, Science and Technology, in their 2007 report.

The lack of complete and reliable epidemiologic data on autism spectrum disorders in Canada resulted in the identification of the need for a national surveillance system that would be equipped to fill information gaps and provide reliable information in three areas. First is the prevalence of autism spectrum disorders: how common are these disorders, and how do they differ in prevalence across the country? Second is to describe the population of children with autism spectrum disorders. Third is to understand changes in prevalence of these disorders over time.

We have a strong foundation in the agency and with our partners, on which we are building. The national epidemiologic database for the study of autism in Canada was established in 2001 and is coordinated by Queen's University. Researchers, clinicians, and government agencies in six regions of Canada are collaborating to better understand and estimate the prevalence of autism spectrum disorders.

A prerequisite for successful surveillance is standardization of case definitions and data collection. We want all of the people participating in surveillance to be collecting the same thing, according to the same definition, in the same way, so those data are reliable. We are working with Queen's University to develop and test surveillance methodologies for ASD based on their experience with the national epidemiologic database.

We have consulted with key stakeholders, including parents, caregivers, individuals with autism spectrum disorders, health and service providers, researchers and clinicians, and other persons affected by these conditions.

In brief, the priorities for a surveillance system of developmental disorders should include a valid case definition based upon scientific evidence, and a comprehensive selection of indicators that accurately describe the spectrum of disorders and enable an accurate estimation of the burden of illness in Canada.

In November, we attended the Geneva Centre for Autism's international symposium in Toronto, Autism 2010, and had an opportunity to hear first hand the needs of patients and families and from organizations working to provide services to children with developmental disorders such as autism. Through meeting with international counterparts and national experts, we learned first hand of the need for a coordinated national approach towards assessing the burden of disease related to the spectrum of autistic disorders in Canada.

● (0925)

At this point we're in the process of establishing our scientific advisory committee for the autism surveillance program. We will work with this committee to identify and confirm the measures or indicators we should be monitoring. This will be building on work we're already doing with Queen's University.

This process will define the specific data needs and our approach to data collection. We will benefit from the considerable depth of expertise on autism spectrum disorders that exists in Canada in research, clinical care, social services, and through organizations representing the needs of children and families.

This includes the work of the Canadian Autism Spectrum Disorders Alliance and Autism Speaks Canada. As you know, members of these organizations are committed to the establishment of a national autism surveillance program. We are working with these organizations to ensure the information from the surveillance program is communicated to stakeholders, that we receive their feedback, and that opportunities for ongoing dialogue are established.

To accelerate our efforts in establishing our surveillance program, we have dedicated a senior epidemiologist to manage the development of the program. The most important next step is the establishment of our scientific advisory or steering committee. This committee will begin its work early next year to identify and confirm the measures and indicators that will form the basis of our program. It will help us determine the best ways to collect these data. Our plan is to build upon the considerable depth of expertise that already exists in order to build a surveillance program that will accurately assess the burden of illness in Canada.

Thank you, Madam Chair. I would be happy to answer any questions from the committee.

**The Chair:** Thank you very much.

We've been waiting for Mr. Mottron, but we haven't heard from him. Perhaps he's having challenges with the weather today, as we've all had.

We'll now go into our first round of questions and answers.

We have Dr. Duncan first, but she may be doing this in sign language this morning, so I hope you all know sign language. She has a very sore throat.

Dr. Duncan.

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

Good morning, everybody, and thank you for coming.

**The Chair:** You have to feel sorry for her.

**Ms. Kirsty Duncan:** Thank you to all the witnesses for your time, and to the families who fight so hard for their children and grandchildren. It is a fight, and as you say, if you're lucky enough to have the means to continue that fight.... So thank you all.

Dr. Rosenbaum, I really appreciated your five themes. I was wondering if you could table your wish list for each of those themes with this committee. I would appreciate that.

I'm also wondering if someone could take this on. I think the Senate report was a very good report, and it was comprehensive. I'd like to know our progress on that report. There were a number of recommendations. What has been completed, what's in progress, and what needs to be addressed?

**The Chair:** Dr. Rosenbaum.

**Dr. Peter Rosenbaum:** In three minutes?

**Ms. Kirsty Duncan:** If you could table it, that would be great.

**Dr. Peter Rosenbaum:** I think the main theme I would underscore is the one the other witnesses have commented on, particularly parents and grandparents. It is that we recognize that childhood disability affects families, and that services and policies reflect that reality.

I think a number of things can be done at the service level, including early intervention along the lines that Suzanne Jacobson described. I think we are too stuck. We doctors in particular are too stuck on making a diagnosis, as if that is necessary, when clearly children with disabilities present functional challenges that can be addressed in ways that are rarely specific to that condition. We need to change the paradigm enormously. So that's one comment about services and the way professionals think about them.

The second, as I mentioned a minute ago, is the importance of recognizing the context of children, which is family, and that services be provided to families rather than just to children.

The third is that I suspect there are ways in which national and provincial fiscal or tax policies and other financial policies can recognize the financial impacts on families, not just of having to pay for services that aren't easily available, but things like tax benefits and employment support for families who have either to change what they're doing, stop what they're doing, or miss opportunities for advancement because they are preoccupied with the well-being of their children.

With respect to research, clearly the wish list would include identification of childhood disability as a major issue in this country, to recognize the prevalence of these conditions, the impact of these conditions on children and on families, and on the reality that these children will become adults who become orphans in the adult world for a host of reasons.

The final comment I would make is that there is an enormous imperative for knowledge translation, which is to say to get the best available research to the people who need to know it. That includes families, service providers, policy-makers. We need to stop doing the things we know don't work in favour of the things we know do work.

● (0930)

**Ms. Kirsty Duncan:** Thank you.

Could you comment on the CanChild model, its value and scaleability versus lack of funding?

**Dr. Peter Rosenbaum:** CanChild was developed in 1989 as one of the Ontario government's health-system-linked research units. A small group of people were empowered to develop a five-year research plan in childhood disability, and we received infrastructure funding, which allowed us to hire and retain very skilled staff.

We still had to go out, and still do go out, to compete for research funds for specific studies, but this kind of platform, if you will, has allowed us to develop and maintain a very skilled group of people across a host of disciplines, across a number of centres in this country, in America, and in the Netherlands. Collaboratively, we're able to do things, including longitudinal studies, that simply are not possible to do when one has a two- or three-year grant and has to stop at that point.

**Ms. Kirsty Duncan:** Thank you.

I think there are two issues that we've yet to address, and I'll open this up to everyone. We know how hard families fight for child care. We know it becomes much more difficult for transition to adult care and then how few supports are available for adults. If someone wants to address that, and also the issue of respite care....

**The Chair:** Ms. Jacobson.

**Ms. Suzanne Jacobson:** Yes, I am more familiar with Ontario, but I'd like to say that the special services at home that provide funding for respite care for families who have children with autism has had no funding available for the last three years, so there is no funding there at all.

I should have taken notes on what you asked me.

**Ms. Kirsty Duncan:** Respite care was one issue, and the availability of it, the funding of it. The other issue was on supports. Once children becomes adults, if they finish school, what is available to adults?

**Ms. Suzanne Jacobson:** I just had a parent tell me that her son is transitioning from child to adult, and she said to me something to the effect that if you think the supports are sparse right now for you with your young grandchildren, wait until they become adults. There is nothing.

● (0935)

**The Chair:** I'm sorry. Our time is just about up, but Mr. Ghoul, you wanted to mention something.

[*Translation*]

**Mr. Mohamed Ghoul (Intervenor, Trainer, Programme socio-dynamique d'intégration par l'art, Pervasive Developmental Disorders, Autism Spectrum Disorders, Centre d'Intervention et de Formation Socioculturel International):** I would like to say something about services for adults. Our program was created in Rouyn-Noranda, in Abitibi-Témiscamingue, with the mission of developing services for adults. In Quebec, no programs are available for people over the age of 21. There isn't really a place that works on their readjustment or social integration. Our program was designed to offer these kinds of services. The program is set up in various environments, including schools, hospitals and other institutions. Our program helps the participants develop their concentration and increase their social participation.

I also have here a few videos of adult special education classes. I added these videos to the documents that I sent to you.

There is also the training program and the formalization of the method of intervention. The documents I gave to you today contain various letters sent by the heads of a number of institutions, including Dr. Lemay from the St. Justine hospital and the people from the Malartic psychiatric hospital.

We are having a lot of difficulty in introducing this program because the work we do touches on health, art, communication and education. Provincially, it's difficult for us to position ourselves so that a ministry will say that it will take responsibility for this recognized program. We've done some 5,000 hours of work that we can make available to committee members and guests.

[*English*]

**The Chair:** Thank you very much. I'm sorry. I'll have to go to Mr. Malo now.

[*Translation*]

**Mr. Luc Malo (Verchères—Les Patriotes, BQ):** I would like to continue this discussion. You are telling us that it is difficult to classify the type of program or work that you are proposing. Is it clear to you that this is a treatment to find a cure for a disease?

**Mr. Mohamed Ghoul:** We are trying to find a solution to the integration difficulties any person living with this type of problem has. It involves incorporating all the possible models into society, schools and community associations so that society becomes a stakeholder in this development.

But our teams on the ground have observed that the communication interfaces between the various school, community and institutional environments are practically non-existent. Each environment is trying to develop and maintain its own things. Our program became an answer to this lack of communication between these environments. In particular, the program made it possible to develop interactions and life plans. We will soon be leaving to go and work at an artists' residence for autistic adults in Paris and Orléans. We are going to Tunisia. We will document this experience, and we hope to open a training centre next fall to train caseworkers in autism and autism spectrum disorders and, more broadly, in mental health.

So we have various training modules. We are managing to get into the environments so that these people can integrate into society. Art and culture become a great way to encourage social development in both children and adults. Our intervention model makes it possible to connect with people who do not have any access to communication. The videos that I am leaving for you show this and are verifiable.

**Mr. Luc Malo:** Do you consider it a medical treatment?

**Mr. Mohamed Ghoul:** No, I'm not a doctor; I don't take care of people like that. Instead, the treatment has an interpersonal and social integration focus. I think that this goes back to what the professor said earlier, that we need to change the way we think and live.

Social status is not important in our workshops. People come with their baggage and their backgrounds. It's the same thing for an autistic person, a person with autism spectrum disorder, or anything else. It's filmed and analyzed.

Here are the graphs that I left for you and that show the participation and concentration curve for each individual. Each colour represents an individual. From this graph, we can make pairings to put together groups that we would not think to put together. The idea is not to force the relationship, but to let it come together.

We work with participants who have some level of anxiety. We are managing to control that level.

We have also developed terms. An SO is a social opportunity, an SP is a social photo. An SS is a social stagnation. We are observing these three models, which help us create a profile for the person. One thing that is very important is working with the families. The families have access to the videos. Parents see me working with their child. Sometimes they aren't at all happy with what I'm doing, but they can see it.

It's a process of artistic creation. As a result, we don't put the authority of parents or doctors in jeopardy. It's a cultural process, a neutral place that allows freedom of expression. Thanks to that, so far the work we've done has been very good. We will also give the training in Paris and Tunisia. People already want this program. We would like to establish it in Abitibi-Témiscamingue. Our partners are well-established. We need support to be able to take care of the research and development side of things. We have five or six possible training locations for various clients, for various participants, school settings, institutional settings and community organizations.

● (0940)

**Mr. Luc Malo:** Dr. Rosenbaum, what do you think about what Mr. Ghoul and Mr. Warren have said?

[*English*]

**Dr. Peter Rosenbaum:** I'll answer in English, because my French is not as fluent as my English.

I think what we're hearing about is very much a model of social integration, which presumably, if I understood correctly, is not diagnosis specific. It fits very much with some of the things I said earlier about the fact that most of our interventions are not specific to a diagnosis but are about functional well-being. I think this is extremely powerful. It addresses the social dimensions of the lives of people whose lives are complicated by virtue of a medical, in this case neurological, impairment.

It's also important to emphasize, once again, that people with childhood disabilities grow up with a different kind of experience of life—not better or worse, but different—than adults who acquire a disability, for whom our efforts are to rehabilitate them back to the state they were before. Really, the culture of the person with a developmental disability is a different life experience, and I think this is a very powerful and positive approach.

[*Translation*]

**Mr. Luc Malo:** Mr. Ghoul, you said that there is still research that needs to be done. Can you go into more detail?

**Mr. Mohamed Ghoul:** Research needs to be done on training because it draws on everything related to interpersonal emotion. Not just anyone can necessarily take part in an artistic, cultural and creative workshop, be filmed and want to enter into a relationship simply for the sake of it. This approach is not part of current training, not at the college level or at the university level.

Right now, we are learning how to carry out an intervention and put a program in place. We don't necessarily use everything related to the interpersonal and the emotional as a tool. I would like to continue research on this so that we can be even better equipped and better informed on possible content and profiles so that we can be more specific. In our jargon, we would say that we are doing social surgery. It's really image by image. We can really see the growth and creative process. We are talking about a wave and, at the end of the workshop, after five or six weeks, there has already been an increase in the concentration of participants and amount of time they can look at each other. We start one-on-one with what we call the serious cases, the cases having difficulty, institutionalized individuals.

[*English*]

**The Chair:** Excuse me, Mr. Ghoul. I hate to interrupt you, but perhaps you could keep your eye on the chair a little bit. I've given you quite a bit of extra time. Could you just wrap up your thought quickly, please?

[*Translation*]

**Mr. Mohamed Ghoul:** I'll wrap up quickly.

We want to do research so that our program is better equipped and so that our interventions are more specific. Thank you.

[*English*]

**The Chair:** Thank you. It's nice to hear your passion, and it's nice to hear your interest.

We have with us Dr. Mottron. Doctor, I understand that you drove in from Montreal this morning. I just came back from Montreal. I did some work there on human trafficking this weekend. The driving is absolutely interesting.

With the indulgence of the committee, I would like to just pause for five moments and give Dr. Mottron a chance to make a five-minute presentation. We will then continue with the questions and answers with Ms. Hughes, if that's okay with the committee. Is that fine with you?

Dr. Mottron, welcome. I'm glad you got here safely this morning.

I'm very interested in hearing your presentation.

● (0945)

[*Translation*]

**Dr. Laurent Mottron (Full professor, Department of Psychiatry, Research Chair in Cognitive Neurosciences, Centre d'excellence en troubles envahissants du développement, Université de Montréal):** Should I speak in French or English?

[*English*]

**The Chair:** You can use any language you want.

[*Translation*]

**Dr. Laurent Mottron:** As a doctor-scientist and head of the Centre d'excellence en troubles envahissants du développement at the Université de Montréal, I would like to take five minutes to defend the idea that, in Canada, we are making a mistake right now by offering services based on diagnosis rather than on the level of suffering and on the level of adaptive deficiency.

There is such a range in the autism spectrum in the DSM-V, which finds that there is a single category, but that there are so many modifiers in the table that providing a single service, specifically the ABA method, based on the diagnosis, makes absolutely no sense.

Furthermore, scientists are quite divided on this matter. But, it seems to me that the way things are currently, it is entirely irresponsible for the Government of Quebec—

[*English*]

**The Chair:** Dr. Mottron, I know you were in a hurry getting here this morning, but you're going to have to slow down for our translators.

**Dr. Laurent Mottron:** Sorry.

**The Chair:** They can't keep up with you. You're too fast.

Okay, continue on.

[*Translation*]

**Dr. Laurent Mottron:** The Government of Quebec and the governments of the other provinces, I think, decided to impose a specific type of treatment for autism based on knowledge that I feel is entirely insufficient. In fact, the effect sizes for the studies that report positive effects are also insufficient.

It is unique, both in the field of the professions and in the field of disease, that a government would give an opinion on one specific technique. Can you imagine oncologists being required to put in their flasks one product over another? It makes absolutely no sense. It's the result of excessive and unfair lobbying, in my mind.

Some things are not challenged when it comes to assisting autistic individuals, particularly what should be done for adults in terms of employment and housing. There is currently a funding imbalance in favour of early intervention. Actually, almost all funding is set aside for children from birth to age six, so there is almost a complete lack or a very large dearth of resources for adults, including in housing and employment. This seems to me to be a mistake.

There is currently another argument going on in Quebec. We think that we need to fill up the waiting lists so that everyone can have the famous 12 hours of the ABA method. But this technique is too lengthy, not very effective and time-consuming.

I strongly suggest that we rebalance this budgetary choice and that the relative amount set aside for adults compared to what is set aside for children be redistributed on this basis.

Do I still have a few more minutes? Or are the interpreters out of breath?

[*English*]

**The Chair:** Well, you do. I think you have a full two minutes left, actually. You may speak slower if you want to.

Go ahead.

[*Translation*]

**Dr. Laurent Mottron:** Lastly, a little idea in the world of autism treatment. Actually, we're saying that the ABA method is scientifically established. I would like this phrase carefully examined by the policy-makers. What's been proven? The effect sizes are very small. There has been no long-term demonstration; there is no predictor of the percentage of children who are going to respond well to it or of the percentage of children who are not going to respond well to it.

For all these reasons, as well as those I just mentioned, I think that this statement is demagogic. In fact, we are giving in to a pressure group. We aren't basing our argument on best practices when we favour a technique under these conditions. It's unjustified.

[*English*]

**The Chair:** Thank you very much, and thank you for making it to our committee this morning.

Now we will go to Ms. Hughes. You have seven minutes.

[*Translation*]

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

This subject is very interesting. I think the message here is that the treatment shouldn't be the same for everyone. Patients should be treated on a case-by-case basis. Right now, the treatments and the services available are not...

● (0950)

[*English*]

It's not really good for everybody. I'm just trying to get some sense here—I'm quite interested in finding out—with respect to your centre...is that a private centre or is it paid by the province? What is the percentage...? I'm just trying to figure out, is this apart from the IBI treatment, or are people accessing both of those?

[*Translation*]

**Mr. Mohamed Ghoul:** No, it's a treatment that was designed as part of a concept project 10 years ago. We provide services and, at this time, all the support comes from autistic children's friends and parents, and from collaborators. We're not funded by the provincial or the federal governments. Five years ago, we succeeded in obtaining research funding from the Office des personnes handicapées du Québec, which assessed the program and ruled it eligible for funding.

**Mrs. Carol Hughes:** Do those children not go to school?

**Mr. Mohamed Ghoul:** They go to school and participate in the program.

[*English*]

**Mrs. Carol Hughes:** I just want to continue. We heard from Health Canada that you're dealing with the surveillance. I think that's extremely important, but the other aspect is that what we're seeing, from province to province, is that it varies on the level of service and then on the type of service

We just heard from Mrs. Jacobson and Mr. Lendrum with respect to the fact that it's quite expensive in order to.... They know, they can see, what their children and grandchildren need. Yet the province chooses to ignore that by saying they have only so much money. If a child or someone has cancer, they go for treatment and they're provided with that treatment because they have the cancer.

A child with autism is being told that the only treatment we have in Ontario is for, what, five or six years?

**Ms. Suzanne Jacobson:** Two years is the average course of treatment.

**The Chair:** I think Dr. Rosenbaum wants to comment.

**Mrs. Carol Hughes:** I'll just finish my train of thought on that one.

My question—because we're seeing people go into debt—is if it would not be better to have a national strategy where everybody gets the same level of service or treatment according to their individual needs, as opposed to saying, “This is the service we're providing and that's all that is available for two years.” What do you do after those two years? What do you do after they grow up? How do we actually best support them?

I have another question, and I'll leave it with answers for all of you. It's with respect to the surveillance, and it's a question that I actually brought up at the last meeting. Is the surveillance being done with respect to how many children are ending up in Children's Aid? How many of them who have autism are abused? How many families are finding themselves in the mental health field because they can't cope with the stress?

I'm going to leave it at that. I know Mr. Lendrum wanted to speak with respect to the cost and the availability of service, and what happens when they don't get IBI, and then maybe—

**The Chair:** So that we get some answers, we're going to start with Dr. Rosenbaum and then go to Mr. Lendrum, and then to whoever else would like to make comments on this.

By then, the time will be up. Be mindful of each other's time, because we'll go on to the next question.

**Dr. Peter Rosenbaum:** A quick comment that follows on Dr. Mottron's remarks about autism spectrum disorder is that what we do not have in autism is a way of classifying levels of function, as we do in cancer or in cerebral palsy. We don't know who might benefit from what treatment, because we lump everything into one category. We don't do that with other conditions. That's a fundamental gap in our understanding of autism, and it's a resolvable gap.

I could say more about it, but I won't.

**The Chair:** No, but that was very well put.

Go ahead, Mr. Lendrum.

**Mr. Dennis Lendrum:** What I want to hit on is the social aspect of the entire family. As I said earlier, Coffee Chat is a group of parents who get together and sit down and chat with each other. They understand that respite care is needed. There's nobody really out there. I come from a rural area, Manitoulin Island. There are no services over there, and it really gets tough for these people. As Carol has said, if my grandson had cancer, we'd take him to the hospital and they'd give him whatever care he could get.

The cost is just outrageous. Families are just struggling. I'm fortunate in that my daughter works, her husband works, and I have an income. We've been fortunate. I hear from other parents who just can't afford the price.

● (0955)

**The Chair:** Thank you.

Go ahead, Ms. Jacobson.

**Ms. Suzanne Jacobson:** First, I'd like to say that the IBI treatment is very good in what it does, but it's narrow, and it has a 52% success rate. We have children being discharged from the program with no alternate option to take. We need to broaden the services. For instance, my grandson responded to music. That is how we got his attention.

I would like to see a very broad variety of things offered. You find out then what the child reacts to. You go with that, and that opens the door, and you can carry on from there.

**The Chair:** Thank you.

Ms. Elmslie.

**Ms. Kim Elmslie:** Thank you very much.

I just want to follow up on the comments you made about the surveillance program. I think they're excellent comments and are very helpful.

One of the things that's important to us, of course, is that provinces and territories have jurisdiction over the services delivered in their provinces and territories. Our role, at a national level, at the Public Health Agency of Canada, is to ensure that we're working with provinces and territories and the stakeholders in general to collect the most reliable information so that we can inform their decisions. Where are the points of service delivery they need to be focusing on? How are patterns changing across the country? Those will shine a light on geographic areas and issues that require more focus by other stakeholders and more development.

**The Chair:** Thank you.

Dr. Mottron.

[*Translation*]

**Mr. Laurent Mottron:** I think we should also distinguish between being better adjusted and being less autistic. The comparison being made between autism and cancer can be very misleading in some respects, since someone can be very autistic and, at the same time, be marginally adjusted or emotionally damaged.

I think that autistic adults, in particular, must be involved in selecting therapy or adaptation options, which is currently not the case for them, but it is for most other minorities.

[*English*]

**The Chair:** Thank you very much.

We'll now go on to Mr. Lake.

**Mr. Mike Lake (Edmonton—Mill Woods—Beaumont):** That last point is kind of interesting.

I have a 15-year-old son with autism, and one of the first questions people always ask is how serious it is. In his case, I would say, based on some factors, that it's pretty serious. He doesn't talk, and he's 15. He can't think in the abstract at all, virtually. He thinks almost entirely in concrete terms. Dr. Mottron, you talked about, sort of, the ability to adapt or how significant the impact is, I guess, in a sense. He's a very, very happy kid. He is able to find areas where he can excel—I was talking about this last time—such as working in a library and things like that. Sometimes I see more difficulty for people who might be “less” autistic, because there's more anxiety, because in many cases they actually realize that there's something different about them and they have a very difficult time dealing with that. I think that's an important point you made.

I just want to get a couple of clarifications.

Ms. Jacobson, did you say there's no support at all for respite care in Ontario?

**Ms. Suzanne Jacobson:** There has been no funding available for three years from the special services at home program.

**Mr. Mike Lake:** A family dealing with autism gets zero funding for respite care right now in Ontario.

**Ms. Suzanne Jacobson:** That is correct.

**Mr. Mike Lake:** Okay.

I can't imagine that. That's something we rely on significantly, obviously, as a family, to get some level of a break, I guess, in a sense. And we have since Jaden was born.

You said there is a 52% success rate for IBI. Where does that number come from? I've never heard that number before. That sounds like a pretty specific number for something that, to me, sounds pretty immeasurable, to an extent.

**Ms. Suzanne Jacobson:** I would have to get more information to give you that answer.

**Mr. Mike Lake:** Okay.

**The Chair:** Can I ask you to get that information, Ms. Jacobson, and submit it to me or to my clerk so that we can get that and share it with all the members?

● (1000)

**Ms. Suzanne Jacobson:** Sure.

**The Chair:** It is a very specific number, and if indeed that is true, we need to know that.

Thank you.

**Mr. Mike Lake:** Dr. Mottron, I can't remember the exact wording you used, but you seemed to say that we should move away from “evidence based”.

You didn't use the words “evidence based”? Okay. You said “scientifically proven”. You had a problem with the wording “scientifically proven”. It struck me that you were suggesting that almost too much emphasis was put on “evidence based”. Am I correct in understanding it that way?

**Dr. Laurent Mottron:** Can I answer on the term “scientifically proven”?

[*Translation*]

This is a cliché used in all the arguments for defending certain methods, especially the Lovaas technique. As I pointed out, the term “scientifically proven” is used in a misleading way. We're not talking about 52% but about 47%. That's the magic number the 1987 Lovaas study reported. These are figures that, as you said, are much more exact than they can be for studies with low effect sizes that are related to methodological problems pointed out over the 30 years following that study. Therefore, it hasn't been scientifically proven that the ABA method is that effective.

There have been at least three meta-analyses, including those conducted by Patricia Howlin, by Ospina, and the Australian study conducted by Spreckley. Those meta-analyses are different from one another. Spreckley's analysis is about the absence of effect. Patricia Howlin discusses an unpredictable effect on some people. The third study talks about a low effect.

We should also point out that there are now a few randomized controlled trials for studies on communication. We're talking about studies that are conducted for two hours a week instead of for eight to ten hours, and their effect sizes are similar.

The cost-benefit ratio of the ABA method is currently lower than that of the other communication techniques. We must admit, however, that effects are low in all cases.

[*English*]

**Mr. Mike Lake:** Mr. Lendrum, I can relate to so much of what both you and Ms. Jacobson said about the ages of the kids, what they went through, and the challenges with doctors actually understanding what it was. Although it seems to be getting better, there are still significant challenges in understanding.

You mentioned that you thought autism should be in the Canada Health Act, which is something I hear a lot. Sometimes there's a misunderstanding of how the Canada Health Act works. Maybe I'll turn to Ms. Elmslie, because there's nothing named in the Canada Health Act.

How long is the Canada Health Act in the first place? It's not a thick document, is it?

**Ms. Kim Elmslie:** It isn't, but I must defer that to Health Canada. Health Canada is responsible for administration of the Canada Health Act, and I'm from the Public Health Agency of Canada.

**Mr. Mike Lake:** Okay.

I'm pretty confident that nothing is named in the Canada Health Act. From time to time we get a private member's bill in this place demanding that autism be named in the Canada Health Act. If autism were named in the Canada Health Act, it would be the only thing named there, because nothing else is named there.

When I talk to families, I often try to develop a bit of understanding of who's responsible for what in Canada. Funding for the treatment of autism is clearly a provincial responsibility. I was encouraged to hear that you met with Deb Matthews and John Tory. It was probably around the same time I took Jaden in and we met with both of those individuals on the same day.

I have to say that both meetings were fantastic. I found John Tory to be fantastic in terms of his understanding. For someone who doesn't live with it every day, the understanding he had was pretty remarkable.

Did you take your grandson into those meetings when you visited them?

**Mr. Dennis Lendrum:** Yes, we did.

**Mr. Mike Lake:** Good.

**Mr. Dennis Lendrum:** John Tory stood up in front of the House and had my grandson beside him as he spoke about autism. I was quite impressed by that.

**Mr. Mike Lake:** A good starting point to get across to parents all over the country is that every parent with a child with autism should take their child to meet their provincial elected official in their given province and take the time to have a conversation. If you can't describe it because your kid is displaying too many autistic tendencies, you will probably make your case better than you could have in the first place.

I'll let the chair move on.

● (1005)

**The Chair:** Thank you, Mr. Lake.

Now we're going into the second round, and as you know, it's a five-minute Q and A round. Our first person up would have been Dr. Duncan, but I'll put her in when she arrives back.

The next one up is you, Mr. Lake, so you have five more minutes.

**Mr. Mike Lake:** Okay.

I'm going to go to Ms. Elmslie again, and I should thank you for the work you have done. I know we've met on several occasions now, and I've seen you interact with stakeholders on the issues, and your level of understanding is fantastic. I know those meetings have been very, very helpful, so thank you for that.

You talked about something being a Health Canada area. You're with the Public Health Agency of Canada. We also have the CIHR. Could you describe the interaction between those three federal agencies, what each is responsible for, maybe specifically as it might relate to autism?

**Ms. Kim Elmslie:** Sure, I'd be glad to.

As you would imagine, the Canadian Institutes of Health Research holds the federal mandate for ensuring that health research across the country is occurring and is supported in an effective way so that it is meeting the needs of Canadians. In particular, in the context of autism, CIHR is engaged in both basic scientific research as well as applied scientific research. So their research agenda is to elaborate on autism spectrum disorders, better understand how the health care system is responding, and also, of course, to support basic science to understand causes and treatments for autism. You'll find that at CIHR.

In the context of the Public Health Agency of Canada, our role is in the area of surveillance. So we are very focused on working with stakeholders to develop a world-class surveillance program for autism spectrum disorders.

From the perspective of Health Canada, Health Canada is concerned about the overall health policy and health care policy in the country and working with provinces and territories in that regard.

I'll just come back to the Public Health Agency of Canada for a moment, picking up on what Mr. Lake has just indicated with stakeholders—and by stakeholders, I put first and foremost the families and organizations that are representing families with children who have autism spectrum disorders. That interaction is of extreme importance to us. We will judge the value of our surveillance program on the feedback we receive from those who use that information in designing programs, in accessing programs, and in determining what the needs are going forward for families with autism spectrum disorders.

**Mr. Mike Lake:** Dr. Rosenbaum.

**Dr. Peter Rosenbaum:** Let me make a very brief comment. Arguing by analogy with cerebral palsy, there is a surveillance system in Europe called SCPE, the Surveillance of Cerebral Palsy in Europe, which has been operating for more than 10 years and which involves several countries, and it involves some of the elements that Dr. Elmslie talked about. It is an excellent model for how this can be done.

**Mr. Mike Lake:** All right.

In terms of the surveillance, when we did meet with stakeholders, there were two things that I took away from that. One was that generally I think the stakeholders realized there was more happening than they thought was happening. And then I thought the other officials in the room took away that there's still a lot more that needs to be done—

**Ms. Kim Elmslie:** Very well said.

**Mr. Mike Lake:** —so there was a good balance there.

If you were to describe in terms that families can understand, how far away are we from a surveillance system that is actually tracking and working, as opposed to being explored? Second, what does that mean to families across this country?

**Ms. Kim Elmslie:** In terms of the timeframe for the development of the surveillance system, there are a couple of things that need to happen and that will happen very shortly in order for us to be more clear on how close we are, and that is the meeting of our scientific advisory committee, which is currently in the process of being finalized.

That committee will help us determine whether we have the case definition for surveillance correct. In order to do surveillance, you need to have a definition of what you're measuring, and that definition needs to be accepted by those who you will rely on to collect the data. So that will be our first real milestone in terms of moving on to the data collection in this system.

Early in the new year we expect to have our scientific committee in place. The first thing we'll bring to them is a discussion: Do we have the definition right? What are the gaps in this? With that definition, we will also then be talking to our stakeholders in the organizations such as Autism Speaks and the Canadian Autism Spectrum Disorders Alliance to ensure that with that definition we are actually going to be measuring what those stakeholders need.

● (1010)

**The Chair:** Thank you, Ms. Elmslie.

Dr. Duncan isn't here yet, so you're up earlier than expected, Monsieur Malo.

[*Translation*]

**Mr. Luc Malo:** I would like to continue the conversation with you, Mr. Ghoul. You told us earlier that you wanted to conduct additional research to study the service you provide more in depth. You said that you had received, at some point, assistance from the Office des personnes handicapées du Québec to conduct a first study, but that further studies needed to be done.

Have you looked into different possibilities for obtaining additional funds in order to be able to carry out these studies?

**Mr. Mohamed Ghoul:** We would like to have a study with much more data. We conducted a study with a 10-person group. Although the study is documented, there is supporting video footage and it is done under supervision, we would really like to have a study with 100, 200 or 300 people.

As for the budgets, we have submitted an application to the Department of Education and the Department of Health. Unfortunately, as I was saying earlier, our application was rejected each time, ostensibly because we did not meet the criteria, since our study is based on too many different parameters.

Lately, through the Conférence régionale des élus, we have been working with MDEIE, which should—thought this is not yet final—fund the training program that is to begin next September. However, we're currently still unsure of what will happen.

Parents are asking for the study, the federation is behind us, as is Dr. Lemay of Hôpital Sainte-Justine. The Malartic regional psychiatric hospital wants to implement the project. The letters we received from them are attached to the document we've presented. Therefore, we have a group of present and future partners. There is also the neurological centre and Professor Catherine Barthélémy, who is very interested in expanding the method. This is a program that can easily be integrated into schools. I think that it's something that could be done in Canadian schools.

**Mr. Luc Malo:** Thank you, Madam Chair.

[*English*]

**The Chair:** Thank you, Monsieur Malo.

We'll now go back to Mr. Lake.

**Mr. Mike Lake:** Thank you, Madam Chair.

**The Chair:** You're really having your day here today, aren't you?

**Mr. Mike Lake:** If I were in a different committee, I'd be panicking right now, because I'd be thinking about what I could ask. But I don't have a shortage of things to ask here.

I have a quick point, and then I'll do something a bit different.

Further to what I was saying about jurisdiction, I think one thing that's important to make clear when I say that treatment funding is provincial in nature is that families across the country are not getting the help they need. There's no question. There are some places where families are going into lotteries to determine whether they should get treatment or not, and that can't happen. That said, provinces need to individually be held to account to make better decisions and make autism funding more of a priority. The federal government today is transferring more money to the provinces for health care, social services, and education than at any time in Canadian history. So as a parent of a child with autism, I'll just say that the provinces need to make autism more of a priority.

I'm going to do something a bit unusual. I went over and gave Mr. Lendrum a heads up that I was going to do this.

**The Chair:** Yes, that was highly unusual, actually, Mr. Lake. I was going to interrupt you, but you looked too engaged.

**Mr. Mike Lake:** Yes, I thought you might have thought that.

What I wanted to do was give him an opportunity to ask a question. There are some experts at the table, and as parents, there are so many questions we have. I wanted to give Mr. Lendrum an opportunity if he has any questions to ask them.

**Mr. Dennis Lendrum:** Yes. Right now my grandson is seven years old and he's just been put into school. He's been with CCR, Child Care Resources, since he was about two years old, in their program. Now he's out at the IBI program, and on Friday we were notified that he no longer has any ties with Child Care Resources.

He's seven years old. He's autistic. What am I supposed to do? Just let him go? Where are the services? He's Canadian. I have documentation from a reverend—

● (1015)

**The Chair:** Dr. Mottron, I think you want to answer that.

[*Translation*]

**Dr. Laurent Mottron:** Yes.

[*English*]

**Mr. Dennis Lendrum:** I have information from a reverend who lived in my community who couldn't get services in Ontario. He picked his family up—his church, the whole works—and moved out to Manitoba. He's really happy with the program out there.

**The Chair:** Being from Manitoba, I can understand that, Mr. Lendrum.

**Mr. Dennis Lendrum:** That's just what it is.

Right now, on Friday, we were notified that Child Care Resources is done. Now what do I do?

**The Chair:** Dr. Mottron.

[*Translation*]

**Dr. Laurent Mottron:** The program varies from one province to the next, but most of the Canadian provinces are using the model that is based on the belief that intensive intervention, if applied extensively, can eliminate a child's need for services in the future.

So, the model that you feel is inadequate was actually chosen by people. The timeline varies depending on the province, but, in all cases, an extreme amount of care is provided, followed by a total lack of care. However, adolescents and adults need crisis management cells that are extremely flexible, versatile and available as needed. They need this all their lives.

Regardless of whether they are doing very well or very poorly, autistic people need assistance on and off throughout their lives, especially when it comes to work, housing, social duties, such as filling out paperwork, and so on. No type of intensive treatment will help those people dispense with the services as adults.

[*English*]

**Mr. Mike Lake:** In my experience, no one advocates like parents or grandparents of kids with autism. You've already established that you have the ability to meet with some key decision-makers. Your local MPP would be where you would start. Carol is your MP, but you would want to meet with your local provincial official as well. The Minister of Children and Youth Services, the Minister of Education, the Minister of Health—it's important to connect with all three ministries. That's one of the challenges. The ball gets tossed from one to another and there seems to be a lack of understanding that this is a bigger picture. You can't compartmentalize it in one place or another.

Mr. Rosenbaum, if you were to have five minutes to talk to a provincial official, a decision-maker, and you were able to tell this person what works for kids with autism, what would you say? Mr. Mottron might want to jump in on this too.

**Dr. Peter Rosenbaum:** I'm not an expert in autism, but part of what I would say is what Dr. Mottron has said: the one-size-fits-all approach is not sensible and doesn't work. What we don't know is what works for whom. We haven't looked at this question in the way we have looked at cerebral palsy, and that's the kind of information we need. What I know works for sure is support for families, in addition to whatever interventions are being offered for children. That unequivocally matters.

**The Chair:** Thank you. I'm going to break a few rules here. I want to make sure Mrs. Hughes gets a chance.

Mrs. Hughes, would you like to take the floor now?

**Mrs. Carol Hughes:** I'm glad that my colleague Mr. Lake asked that question. It was what I asked a while ago—what happens once they're out of IBI treatment? I agree that one size doesn't fit all. If a person who is handicapped needs a specific device, and if at the end of two years we take that device away, what happens to that person? This is basically what's happening with children with autism. Mr. Lendrum, you've worked over the years with politicians Shelley Martel and France Gelinas, and they've been tireless advocates on this issue.

I'm sure there is some respite care for children with autism. I know I've had to deal with that in Elliot Lake. Most of my riding is rural and the services are almost nil in some of those areas. It's unfortunate that we see people move from province to province. We heard that last week as well.

Ms. Elmslie, is there a specific amount of money that's given to the province for autism?

● (1020)

**Ms. Kim Elmslie:** No, there is not.

**Mrs. Carol Hughes:** So it's just part of the funding envelope and they do as they please.

On that note, I know that Dr. Mottron was actually shaking his head a little while ago when you were talking about surveillance, and I think he had something to say on that.

[*Translation*]

**Dr. Laurent Mottron:** Perhaps we shouldn't harbour too many illusions about the success rate of the monitoring. One of the best therapeutic studies, which was published in The Lancet, said that small variations in case definition methods doubled the prevalence.

Those involved in epidemiological studies on autism know that the current definition of phenotype is only slightly more specific than the definition of intellectual disability.

The fact that this category is terribly expansive, as a result of the criteria being insufficiently specific, creates something a false public health problem, since the figures quoted are misleading.

[*English*]

**Mrs. Carol Hughes:** Did you want to say something?

**Ms. Kim Elmslie:** I just wanted to say that that's precisely why we are taking care, as we develop the case definition for the autism surveillance program, to ensure that it's scientifically sound and reliable and that we can in fact replicate and use those measures to get a better sense of the true prevalence of autism in the country. What we've heard loud and clear from stakeholders is that there's a huge information gap in Canada around autism prevalence and that this needs to be filled, but it needs to be done in a very scientific manner.

**The Chair:** Dr. Rosenbaum.

**Dr. Peter Rosenbaum:** I would just add that the same can be said for virtually all the other neurodevelopmental disabilities that affect children. We do not have precise numbers for anything in Canada. There are some numbers we could get, like how many children were born with Down's syndrome last year, because all children with Down's Syndrome have a chromosome anomaly and that is assessed in genetics laboratories. But we don't know the prevalence of epilepsy, or the prevalence of cerebral palsy, or the prevalence of autism, or the prevalence of Tourette's syndrome because we don't have systems to collect that and we don't have clear definitions, as has been said repeatedly.

**The Chair:** Ms. Jacobson, did you want to say something?

**Ms. Suzanne Jacobson:** Yes, please.

Ms. Hughes, I'd like to address the respite issue. My younger grandson has not received one cent for respite care at all. His older brother got in as one of the last children; he was diagnosed four years ago. Respite services that you can pay for are available in Ottawa. Some of them are at no cost, but they're typically for medically fragile children or children with multiple medical diagnoses, not just autism. As QuickStart, we are actually, in January, implementing a respite program where local hotels are donating weekends. Autism Ontario is donating gift certificates for meals and entertainment, and QuickStart will be providing some funding towards the cost of child care while the parent is away.

**Mrs. Carol Hughes:** As I've mentioned, I needed to check into it because I remember that our office had to look into that for a family.

Do I still have a little bit of time?

**The Chair:** You don't, but really quickly if you want to, and then I'm going to go to Mr. Brown.

**Mrs. Carol Hughes:** I was just going to ask Mr. Lendrum if he had anything else he wanted to add with respect to what he's heard here today, and to talk about, again, the frustration level with respect to being able to get some care.

**The Chair:** Mr. Lendrum.

**Mr. Dennis Lendrum:** Again, when we talk about the Canada Health Act, I don't know what we're going to call it, but I just want, as a Canadian citizen, my grandson to get the same treatment anywhere in Canada, period. What we've got to call it or what program it's going to come out of, I don't know. But I've got representatives sitting here representing Canada, and I'm saying, let's do it. Call it what you like. Get it done.

Alex is seven years old; he's going to be eight next year.

● (1025)

**The Chair:** Thank you very much, Mr. Lendrum. Is there anything else?

**Mr. Dennis Lendrum:** No.

**The Chair:** Mr. Brown.

**Mr. Patrick Brown (Barrie, CPC):** Thank you, Madam Chair.

One thing I wanted to ask about that we've gone over in some of the previous hearings with neurological disorders, and I don't think we've paid significant focus to today, is that which is certainly in the federal domain, and that is research. One thing we talked about with previous groups was how difficult the application process was to apply for a CIHR grant, about the number of projects that are being left off the table. That was a common thread we heard, whether it was ALS, Alzheimer's, Parkinson's, or a variety of other groups that we've heard from.

I wanted to get your impressions on what you've heard about the CIHR process. And do you know if there is a fair amount of research that is being left off the table in terms of autism?

That's a general question for whoever may be best equipped to answer that.

**The Chair:** Who would like to start?

Dr. Rosenbaum.

**Dr. Peter Rosenbaum:** I'll start with a brief comment. I'm aware that CIHR is concerned that among the four pillars of research—basic biological studies, clinical studies, health services research, and population health—health services research is the least funded, but that's partly a function of who's doing what kind of research.

A good grant, well written, has a good chance of being funded. There is still much more emphasis put on basic biological research than there is on health services research. Health services research is complicated and messy, and it's very hard to do experimentally.

We need a great deal more of it to look at issues like the preventability of the physical and mental health toll that parents and grandparents experience when they raise children with complicated lives. Those kinds of studies are possible, but they're messy.

**Mr. Patrick Brown:** Laurent, you had a comment?

**The Chair:** Dr. Mottron.

[*Translation*]

**Dr. Laurent Mottron:** Legislators should be informed about certain risks involved in autism research. For instance, pressure is being applied by lobby groups to bypass peer committees in cases involving false miracles. In Quebec, the Fonds de la recherche en santé du Québec—the equivalent of our CIHR—was being unduly pressured to have secretin tests conducted under conditions bypassing peer committees. It turned into quite a spectacle. The situation is the same in the case of hyperbaric oxygen therapy and all the other so-called miracles that crop up in autism research every other year. I think it's very important for scientific criteria—even though the apparent result is that many requests do not get approved by CIHR—not to be relaxed only because autism is involved and is being pushed to the fore unduly, in my opinion.

I find the fact that a committee like this one exists very worrisome, although I am taking part in one of its meetings. Will there some day be a committee on Tourette's syndrome? I doubt it. Will there be a committee on intellectual disability? I doubt that as well.

Currently, in Quebec, an autistic child automatically qualifies for about 10 hours of help with schoolwork, on the mere basis of a diagnosis, even if the child has an IQ of 120 and is fairly well adjusted. As the father of a child with Tourette's syndrome, which has worsened, I have come to realize that having another neurodevelopmental condition doesn't make people eligible for any services.

We should also think about equality. The popularity of autism, which we benefit from when we are, like myself, autism researchers, or, like yourself, parents of autistic children, is also something of an injustice. So it should be kept in mind.

[*English*]

**Mr. Patrick Brown:** What Dr. Rosenbaum said was interesting. You said that a good application, well written, will likely be funded. That's not what we've heard from the other neurological disorder groups.

That's certainly encouraging, but I wonder if it's because we're not looking for research enough; the criteria are not appropriate enough. One thing we heard again and again was that about 20% of applications got funded, but 80% didn't. They said it wasn't because they weren't good applications. They said there were excellent applications for excellent research projects that weren't being funded. That was told to us by all the other neurological groups.

What do you think makes autism research different?

● (1030)

**Dr. Peter Rosenbaum:** I don't know that autism research is different, so I can't respond to that comment. I will tell you that every one of the grants that I've had funded was an excellent grant, and all the ones that weren't funded were excellent, and how the hell did somebody not recognize that?

The reality is that there is a huge amount of competition for grant funding. CIHR at 20% or 22% is far more generous than NIH, with which I've had experience, which is about 8%. It's a very competitive world.

There are opportunities when a grant that one thinks is excellent is not funded. There are opportunities to go back to refine it using the feedback. I can't argue that there's unfairness. I could tell you that if we had twice as much money, there would be twice as much research.

That may be a point that this committee could let the government know to continue to support and enhance the funding of CIHR, because if there were more money, there would be more grants funded. The most recent grant that we submitted was ranked 16th out of 69. They funded 13. We've gone back. If there were more money, we would have been funded.

**The Chair:** Thank you very much.

We are running out of time. We've exhausted a lot of the questions, but I was wondering whether, with the committee's approval, I could allow each of the members to just say what they haven't been able to say, or would you like to go into a few more questions? It's entirely up to the committee.

Monsieur Malo.

[*Translation*]

**Mr. Luc Malo:** I just have a follow-up question for Dr. Mottron about a comment he made. You can do whatever you like with the remaining time.

[*English*]

**The Chair:** Well, you're not next on the list, but I think I will do that, Monsieur Malo.

Go ahead.

[*Translation*]

**Mr. Luc Malo:** Thank you very much.

Dr. Mottron, I would just like some clarifications on one of your comments.

Do you think that the decision of the Subcommittee on Neurological Disease to study only five particular disorders is creating an imbalance or unfairness toward other diseases that also need to be examined?

**Dr. Laurent Mottron:** You're not creating the imbalance, but you are exacerbating it.

**Mr. Luc Malo:** Could you tell us more about this? Throughout the meeting, you have been able to communicate your message well.

**Dr. Laurent Mottron:** In France, a category called orphan diseases was created to group together, with the same lobbying capacity, diseases that were not sufficiently represented to come under scrutiny.

Autism has something of a special status, as if it were something more tragic or dramatic than other diseases. I don't think that's the case. I have spent my life conducting research on autism and fighting for the rights of autistic people. However, I don't think they should be treated any differently than other human beings.

In Quebec—I'm not familiar with the legislation of other provinces—there is an imbalance between the number of services people are automatically entitled to when diagnosed with autism, and the number of services people are entitled to when living with conditions that, in some cases, may be far more debilitating than autism.

For instance, there is Tourette's syndrome, which I bring up for personal reasons. People with Tourette's can be doing very well, but they can also be doing very poorly, much worse than autistic people who are doing well. The same is true of intellectual disability and post-surgery epileptic patients, or those suffering from various neurological syndromes.

I would like to repeat my initial suggestion. If we were to provide services based on the level of disability, sector by sector, and not based on the diagnosis, we would be less likely to create orphan categories.

**Mr. Luc Malo:** Thank you.

Thank you, Madam Chair.

[*English*]

**The Chair:** Dr. Duncan does not have a question.

I'm going to briefly let the witnesses speak for one or two minutes. I will have to cut you off if there's one witness who takes too much time—my apologies.

I would like to start with Mr. Lendrum. Do you have any comment you would like the committee to hear before we adjourn?

● (1035)

**Mr. Dennis Lendrum:** Again, I go back to my grandson. If he had cancer, if he had some other disease or problem, he would get treatment. Now that he's seven years old, he's getting zero treatment. That has to change. How we change it, I don't know, but it has to change. When he turns 18 and he's out of control or whatever, or his parents pass on, where is he going to be then?

**The Chair:** Dr. Rosenbaum, would you like to say a couple of words?

**Dr. Peter Rosenbaum:** I would just underscore points that I tried to make and that Dr. Mottron has made as well. I believe it's very important that we think about neurological conditions of children very broadly, of which autism is an important group but by no means the only group. That's number one.

Number two is that we think about function and development and family well-being, and not about specific treatments, because by and large we do not have specific treatments. The notion that IBI for autism or botulinum toxin for cerebral palsy is the treatment is I think misguided and distracting.

**The Chair:** Ms. Elmslie.

**Ms. Kim Elmslie:** Again, from the point of view of the work that we're involved in, in surveillance, I wanted to stress the point that while we are beginning with autism as a priority for the development of our surveillance program, we are also looking at developmental disabilities more generally.

As we grow this program, we will include other and more developmental disabilities over time. Our priority at this time is to ensure that we have a comprehensive national autism surveillance program that is meeting the needs of families.

**The Chair:** Thank you.

Ms. Jacobson.

**Ms. Suzanne Jacobson:** Thank you.

What I saw in the case of my grandson was that no services were available until we had that diagnosis. So the system is set up to work for you only if you get the diagnosis.

QuickStart has altered that somewhat through a partnership with the Children's Treatment Centre. Services are now being provided to children pre-diagnosis.

Why can't we just treat the child? In the end, does it matter what the diagnosis is? If a child is not speaking, should we not provide speech therapy? If a child has a self-injurious behaviour, should we not be doing behaviour therapy? I don't see the need to have the ultimate diagnosis to provide the care to the child and the family.

**The Chair:** Mr. Ghoul.

[*Translation*]

**Mr. Mohamed Ghoul:** I would like to add that our program helps establish a before, a during and an after. It makes it possible to build a life plan. Our program is not intended exclusively for autism or ASDs. We're working with the general population. Therefore, we deal with intellectual disability, trisomy, Tourette's syndrome and mental health. Our program can be integrated into society and plays the role of a social integration moderator through artistic creations that enable everyone to remain neutral.

Thank you.

[*English*]

**The Chair:** Thank you.

Mr. Jason, do you have any closing remarks?

**Mr. Warren Jason:** All I ask is that you have a look at the site, cifsci.org. There are a lot of videos, documentaries, and all the research. Everything that's being translated into English will be put on the site. It gives you a picture of what we're doing. In terms of the video, there are no words to replace a video. So good viewing to all of you.

**The Chair:** I want to thank all the witnesses for appearing today, especially with the inclement weather out there.

Dr. Mottron, your perseverance in getting here, from Montreal to Ottawa, I can relate to that this weekend. Your input was very insightful and will be very useful to the committee.

I will adjourn the committee until we go into another committee at 11 o'clock.

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