

HANSARD

NOVA SCOTIA HOUSE OF ASSEMBLY

COMMITTEE

ON

PUBLIC ACCOUNTS

Wednesday, May 9, 2018

Legislative Chamber

**Services and Supports for Children with
Autism Spectrum Disorder/Complex Needs**

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Public Accounts Committee

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[Mr. Allan MacMaster was replaced by Ms. Barbara Adams.]

[Mr. Gordon Wilson was replaced by Mr. Bill Horne.]

In Attendance:

Ms. Kim Langille
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Mr. Gordon Hebb,
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Ms. Nicole Arsenault,
Assistant Clerk, Office of the Speaker

Mr. Andrew Atherton,
Assistant Auditor General

WITNESSES

Department of Community Services

Ms. Lynn Hartwell,
Deputy Minister

Mr. Joe Rudderham,
Executive Director - Disability Supports Program

Ms. Wendy Bungay,
Director - Placement Services

Department of Health and Wellness

Ms. Denise Perret,
Deputy Minister

Ms. Francine Vezina,
Project Executive - Risk Mitigation-Primary and Acute Care

Department of Education and Early Childhood Development

Ms. Karen Gatien,
Associate Deputy Minister

Ms. Ann Power,
Executive Director - Student Equity and Support Services

Ms. Susan Jozsa,
Autism Consultant

IWK Health Centre

Ms. Jocelyn Vine,
Vice President of Patient Care & Chief Nurse Executive

Dr. Andrew Lynk,
Chief Pediatrics - IWK Health Centre Halifax Nova Scotia
Chair of Pediatrics - Dalhousie University
Consultant Pediatrician - Cape Breton Regional Hospital Sydney Nova Scotia

Nova Scotia Health Authority

Ms. Lindsay Peach,
Vice President - Integrated Health Services Community Support and Management



House of Assembly
Nova Scotia

HALIFAX, WEDNESDAY, MAY 9, 2018

STANDING COMMITTEE ON PUBLIC ACCOUNTS

9:00 A.M.

CHAIRMAN

Mr. Allan MacMaster

VICE-CHAIRMAN

Mr. Gordon Wilson

MR. CHAIRMAN (Mr. Brendan Maguire): I ask everyone to take their seats. We're going to get the committee to come to order, please.

I'd like to remind all those in attendance that their phones be on silent or vibrate. I ask the committee members to introduce themselves.

[The committee members introduced themselves.]

MR. CHAIRMAN: On today's agenda, we have the officials from the Department of Community Services, the Department of Health and Wellness, the Department of Education and Early Childhood Development, the Nova Scotia Health Authority and the IWK with us to discuss services and supports for children with autism spectrum disorder and complex needs.

I ask that the witnesses introduce themselves, and we'll start with some opening remarks. I'm sure many of you want to give opening remarks so we ask that we be mindful of time for questioning.

[The witnesses introduced themselves.]

MR. CHAIRMAN: We'll start with opening remarks. Deputy Minister of Health and Wellness, Denise Perret.

MS. DENISE PERRET: Thank you for the opportunity to be here today to discuss services and supports for children with autism spectrum disorder. As you are likely aware, autism spectrum disorder - or shortened to ASD - is a developmental disability that causes a range of social, communication, and behavioural challenges.

There are many degrees of autism and unique circumstances. On the evidentiary front, we are still learning about the incidence and manifestation of ASD, and ongoing research in this area guides the health system policy, programs, and service. The Health and Wellness policy priority is to provide the best start in life for children with autism. In addition to the base operating grant, the Department of Health and Wellness provides funding to the health authorities for the early diagnosis and services for children with ASD and their families.

The Health and Wellness-dedicated budget for autism is over \$15 million; the majority of this budget - approximately \$13 million - funds universal EIBI, which is Early Intensive Behavioural Intervention. It is delivered to preschool-age children through our colleagues at the IWK and the NSHA, and this is done in partnership with the Nova Scotia Hearing and Speech Centres.

EIBI involves the development and delivery of an individualized treatment plan coordinated by a team consisting of parents, one-to-one interventionists, clinical specialists, and speech language pathologists. The goal is to facilitate development of the child's communication, play, and other functional skills, before the child enters Primary.

Last year, more than 150 children in Nova Scotia started the EIBI program and more than 300 were receiving intensive services at some point in the year. The demand for services has increased significantly. Over the past decade we've seen the prevalence of autism spectrum disorder almost double and in part this is due to broader diagnoses and greater awareness.

In addition to EIBI, diagnoses and other supports are provided by the IWK Autism Team and the NSHA Child and Youth Mental Health and Addiction teams across the province. These teams support families when children need to access mental health services. They are also involved when care planning is required for children with complex care needs.

Autism requires a shared approach. Health programs and services are only part of the equation. As a result, work is ongoing to build a comprehensive continuum of services that addresses the full scope of program and service needs. The shared goals of the organizations represented here today are to serve and support the interests and needs of children with ASD and their families. In this regard, the input and advocacy received from parents and organizations like Autism Nova Scotia are important. We appreciate their tireless efforts to give their children and the families they represent the best support possible. We thank them for the work they do to inform our policies and programs.

We're also grateful for the dedicated work of front-line staff who support and serve these children and families every day. Our organizations strive to coordinate and integrate our programs and services.

The representatives from Education and Early Childhood Development and from Community Services will explain more about the range of services provided. I thank you for the opportunity to be here, and I'll turn it over to my colleague Karen Gatien from Education and Early Childhood Development.

MR. CHAIRMAN: Ms. Gatien.

MS. KAREN GATIEN: Thank you for this opportunity to continue the discussion regarding supports and services for ASD. As Deputy Perret has noted, there are many challenges faced by individuals with ASD and their families. Some children and youth with ASD manage very well in our public system, and there are others who have more significant learning and behavioural needs, who require more support through education and from our government partners. We're working hard together to continue to build connections with these partners in government and community to provide an integrated multidisciplinary service model to ensure that all children, including those with ASD, receive the best education possible.

Early learning opportunities are especially important for children with ASD. EECD was an early partner in efforts to get the EIBI established here in Nova Scotia. Last year we also introduced the Pre-Primary Program to 46 school communities as an early play-based experience for children before they enter Grade Primary. This Fall, we add an additional 91 school communities for a total of 137 that will offer the Pre-Primary Program, and government has invested \$24 million to date in that program.

As of March 2018, there were 24 children in pre-Primary with a diagnosis of ASD, and children with ASD in the Pre-Primary Program can access the special supports that they need. These can include EIBI, Developmental Intervention services, paediatric psychology services at the IWK, Nova Scotia Hearing and Speech services, occupational therapy, and physical therapy.

Our school-based teams work with pre-Primary, EIBI, and other service providers to transition children with ASD into school. This is a good example of the multidisciplinary planning that takes place for children with ASD. Children need to be ready, families need to be ready, and school staff and school-based specialists need to be ready, and we're united in our commitment to make that happen.

EECD has also provided funding for provincial training and intervention strategies to help children with ASD who need it in the early grades - so from Grade Primary to Grade 2. The STAR program, or Strategies for Teaching Based on Autism Research, is one of these programs.

Through the years, EECD has also added positions and programs to address the learning needs of students with ASD. Susan Jozsa, who is here with me today, began as the single school-based ASD specialist in the province. Today we have 14.5 full-time equivalents across the seven regional centres for education and the French CSAP board. We value the special expertise they bring to the classroom and educational planning for children and youth with ASD.

In addition to the ASD specialists, we have created positions in behaviour support and program planning and have increased positions in speech language pathology and psychology to develop programs and interventions specific to the needs of students with ASD from Grade Primary through to Grade 12.

Students with ASD require skill-building in different areas, and social communication is a notable area of challenge. Since 2013, we have invested in training and implementation in the Program for the Education and Enrichment of Relational Skills, known as PEERS. This program is for older students with ASD to learn those important skills for developing relationships with peers and others in the community as they prepare to transition from school.

Our partnership with the Atlantic Provinces Special Education Authority has been particularly successful. APSEA's autism and education partnership brings together the Education Departments of from the four Atlantic Provinces to promote current research and best practices in ASD and offer training and professional learning.

This partnership developed a 40-hour ASD online course, offered in both English and French, that has been taken by over 1,700 school-based staff in Nova Scotia. In addition, APSEA AIE offers an ongoing webinar series and a two-day symposium.

Yesterday, government announced its plans to move forward with the recommendations and the report from the Commission on Inclusive Education. We will be working together under a new inclusion policy framework. Part of this first stage of our work will be to develop a provincial autism strategy for education and we will, of course, be involving our partners in its development.

We are committed to ensuring quality education for all students - including those with ASD - through our training and program development, and government is adding \$15 million to education to make that happen.

We will be increasing specialist positions across the Regional Centres for Education in the CSAP, including adding 15 new ASD specialists, 30 behaviour support teachers to support classrooms, and 25 learning centre resource teachers and program planning specialists.

We recognize that vulnerable youth and students with complex issues require additional support and we are introducing 40 child and youth care practitioners to help develop and implement specific programs and interventions.

We will also be investing in 11 parent navigators to help families understand what programs and resources are available in school and how to access the supports and services for outside of school.

We will be funding a training program for teachers to become board-certified behaviour analysts, and these individuals will take advanced training in behavioural analysis to train other staff and support program development for students with ASD who have significant learning and behavioural challenges. Together, our board-certified behaviour analysts, autism specialists, behaviour support teachers, and child and youth care practitioners will work with teachers and students to create positive, healthy, safe learning experiences.

We have listened to teachers and families tell us that their children with ASD need specialized interventions to deal with some very complicated behavioural challenges that affect learning, relationships with peers, and create family crisis. This is not a job that any one department can do alone, and I think my colleagues here today would agree with that. The investment shared today and the work we can do together will help us in the path forward.

I will now turn it over to our colleague from the Department of Community Services, Deputy Minister Lynn Hartwell, to talk about their work.

MR. CHAIRMAN: Deputy Minister Hartwell.

MS. LYNN HARTWELL: Thank you to my colleagues for their remarks. I will try to keep my remarks short so that we can get to the questions on this topic. It's a topic that is of great importance to all of our departments, and Community Services is interested in talking a little bit more about the role that we play.

What we know to be true is that children do best when they are with their families, and so we have at Community Services a role in providing respite support services that enable families to hire the respite that works for them. That respite can include individuals known to the family who can provide some much-needed hours of relief. It can provide the hiring of people who have particular specialized training and education and these families help shoulder the burden, the challenges, and the wonderful opportunities that families may face in caring for these children.

Our Direct Family Support for Children is part of our larger Disability Support Program. Overall our program - of which Mr. Rudderham is the executive director - provides children, youth, and adults with intellectual disabilities, long-term mental illness,

and physical disabilities a range of community-based residential and vocational and day programming.

Our Direct Family Support for Children is, as I've mentioned, a respite program that provides eligible families up to \$2,200 a month for respite services. We have an enhanced program for people who are experiencing greater needs, and that amount is up to \$3,800 a month.

In February, we were able to eliminate the wait-list for this program, so there is actually now no longer any cap for the program. If a family needs that support, we are able to provide it.

Many families who are purchasing or are looking to find the respite services that work for their family may struggle with that, so one of the things that we're introducing this year is a respite coordination program, so that we can help families find the respite support providers that they need. Again, that is a very personal and unique matching - because you can imagine having people come into your home and provide support to your family, you want to make sure that it's the right person.

We have heard from families consistently that often their best sources of referral are other families and others that are known to them, and so it's building on the strengths that the very strong, community-based organizations already have in this area.

We are working as well to reduce the wait-list in our adult program - our community disability support programs so that we're able to - when children age into more independence, we're able to provide them with families with a path for their children.

We have programs that include the adult version of our direct family support program for children, which is called Flex Independent. It has the same levels of funding, so children can remain, as they age, with their families even after they turn 19, if that's what works for that family.

We also have - there's Flex at Home, which was the first one, Flex Independent, where people are able to live independently with the support of their family, whether that's in an apartment or some other location that the family and the individual have chosen, and we're able to provide supports. Then we have other programs such as the Independent Living Support Program and the Alternative Family Support Program, which again offer pathways for young people as they age into adulthood. By reducing the wait-lists for those programs, we are looking to have more people given the support they need to live independent lives and be able to participate fully in their communities.

In that vein, we're also looking to create opportunities for young people to attach to the labour market. I want to mention that we are working with Autism Nova Scotia to help people better transition into the workforce through some job coaching. In our respite

program, we do have parents who have been purchasing job coaching supports through the respite funding. This is an opportunity to create even more opportunity for young people who have autism and their parents, to start to imagine what a future is going to look like as they age into adulthood.

So we can look forward to Autism Nova Scotia being able to offer employment support services to adults on the spectrum over the next three years. That's a great piece of work that I'm happy to talk about.

One of the challenges that we work on with our colleagues - and we need the strong partnerships that exist - is finding appropriate placements for children and youth who have extreme behavioral issues and who are in a place where they're no longer able to be cared for by their family. It may be that their family has other challenges going on, or it may be that particular behaviors have been exacerbated, et cetera.

We know, as I said at the beginning, that children need families. Many of the children who are on the spectrum need structure, need familiar surroundings, and they need their unique needs to be captured in their care arrangements. Sometimes their families need something different than that care being provided at home, so we do have a network of service providers around the province that we can go to, to create the one specific arrangement for that family. Again, it's always with the idea that we're providing supports that allow that child or youth to return to their family with the supports that they need.

Fortunately, those situations are fewer in number and, I would say, those are the times when our organizations pull together, and we can also share some information with you about how we have complex case protocols to make sure that we, and the colleagues that you see seated before you, are working together to make sure that we're wrapping some services around families.

For many of the people that the Department of Community Services helps - we have a broad range of programs - the services and supports are an interim solution for people as they're moving forward. We also know that there are people who will require supports from the Department of Community Services and supports from our partners for most of their lives. So, we are spending a fair bit of time working to improve our ability to plan ahead and have pro-active supports in place, so that we're not simply responding to crisis.

We need to build pathways for young people and their families that are based on their strength, that recognizes some of the challenges and opportunities that come with the neurodiversity that they bring. Part of our work is creating the places where we and our colleagues can come forward and start with a child and that family at the centre and build supports out. The transition to adulthood is a period that we were spending a fair bit of time on because we know that that can be a real source of challenge for families.

We have made good progress, and we recognize that there is still work to do. We are working with our partners, as I have said, to address the challenges. I look forward to answering your questions and being able to provide some more information about the work we're doing.

MR. CHAIRMAN: We'll start the questions with the Progressive Conservative caucus. Mr. Houston, 20 minutes.

MR. TIM HOUSTON: Thank you to the witnesses for their opening statements. I have to say this is the most witnesses I have ever seen appear before committee. There are more witnesses than committee members here today. On the one hand, I guess that is a good indication of the seriousness of it.

The thing that scares me is, how could a family possibly know where to turn if it takes this many witnesses to come before committee to answer questions? I think what we're seeing here is - you often hear people in government say, it's not my department. I just wonder, how could a family possibly navigate through the system when there are this many witnesses who are necessary to come before committee to answer questions? It is a definite concern to me.

The Department of Health and Wellness mentioned that they have invested \$15 million in ASD services. I wonder if there's a similar number for the Department of Education and Early Childhood Development. What would the Department of Education and Early Childhood Development say is the investment in ASD services?

MR. CHAIRMAN: Ms. Gatien.

MS. GATIEN: I'll ask Ann Power, the executive director, to respond.

MS. ANN POWER: We have targeted grants of \$630,000 that are specific to ASD to help with the implementation of programs that Associate Deputy Gatien mentioned before. We have a number of positions within the ranks of Education and Early Childhood Development staff who provide services to a number of children, not just specifically to children with ASD.

For instance, we would have 92 speech-language pathologists, and they will serve the students within their catchment area. We have 72 school psychologists, 1,357 education assistants, and 770 resource teachers. We have 14.5 specialists specific to ASD who are working specifically just with those students. Many of our staff - including teachers, classroom teachers, and the new staff that we have coming in - will be working with those students as well.

In addition, we have 30 new behavioural support teachers and 15 specific new specialists to add to the approximately 15 that we have now specific to ASD. I would need to get you the salaries of all of those people to add it up, but it's a significant investment.

MR. HOUSTON: The \$630,000 in grants - is that student-specific grants or school-specific?

MS. POWER: It's really more to the Regional Centres for Education. We provide them with targeted grants each year that they can use for professional learning and professional development so that the teachers stay current and new teachers coming into the system can also learn the techniques and skills of such programs as STAR, which is Strategies for Teaching Based on Autism Research, or PEERS, which is the Program for the Education and Enrichment of Relational Skills.

MR. HOUSTON: Community Services - what would you say is the investment from Community Services in ASD services?

MS. HARTWELL: Specific to children, I can say that we spend roughly \$12.5 million. Children on the autism spectrum are about 35 per cent of our caseload in our Direct Family Support program. We would spend an additional amount of money, which I can get for you with a little bit of work. If we have children who are on the autism spectrum who happen to be in the care of the minister, we would also be providing some supports there as well.

MR. HOUSTON: Thank you. The IWK conducted an internal review of its autism services. Is that report, is that review finished, and can we get a copy of that report?

MR. CHAIRMAN: Ms. Vine.

MS. JOCELYN VINE: I'll just start with a little bit of background on the purpose behind the review, and explain where we are on that process.

Recognizing the challenges that we've been speaking of here, we recognized an opportunity within our organization to really focus - as we do in all areas of our service - on quality improvement; looking for opportunities to work together across our system and also with our colleagues at Nova Scotia Health Authority to identify opportunities to streamline aspects of work and make sure that the flow of patients goes well. We also had the opportunity to hear directly from patients and families who really explained their experiences to us as well.

One of the foundational pieces of a quality review within the health care system - and this is common across health care systems - is really creating a confidential environment so that all clinicians, families, providers, et cetera, can really give us their

confidential perspective on what is happening. What the reviewers do is then synthesize that information into a list of recommendations.

The review itself is not a matter of public record. It's a tool for us to improve, and the recommendations that we have from that report are forming the foundation of ongoing quality and improvement efforts within the health care centre, and I think would not be surprising given the theme. For example, families at times find it challenging to navigate across systems - they gave us ideas and suggestions on that.

I'll just hand over to Dr. Andrew Lynk to see if he wanted to add some further comments.

MR. CHAIRMAN: Dr. Lynk.

DR. ANDREW LYNK: I think Jocelyn stated that quite well. That report served as a catalyst, and I can tell you that there's a lot of senior leadership, and a lot of our teams at the IWK have been spending a lot of hours over the last couple of months trying to make the system better for families and children, getting families involved. We've been taking half days or several days out of our clinical work to just devote to this. That work is ongoing to try to be streamlined - how to be responsive and try to identify the gaps of where we could do better.

MR. HOUSTON: Thank you. So, the review is confidential, I guess. Are the recommendations out of the review also confidential?

MS. VINE: The recommendations were shared with the providers within our health care system, and the themes from those recommendations are really helping to guide our quality improvement efforts. In general, the report itself is confidential in order to ensure that for this review - and any future reviews that we do within the health care system - people feel very open in telling us where they see the opportunities for us.

MR. HOUSTON: Thank you. Would you have discussed the report at least with Autism Nova Scotia? Is there anyone else involved that could help develop those themes?

MS. VINE: I would say that we do work with Autism Nova Scotia on a regular basis, and we have families who are members of Autism Nova Scotia who are part of our quality-improvement processes absolutely, yes.

MR. HOUSTON: Do you feel that members of the autism community would be satisfied with that response - we looked into it, we know what to do, we're going to do it, but we can't tell you what we're doing? I don't want to oversimplify it, but I'm basically hearing that you can't see the review, you can't know what changes we're making, but we did a review and we're making changes. Do you think that people would be satisfied with that?

MS. VINE: I wouldn't characterize it in that exact way. What we're doing is when we have identified an area for improvement, we then set up a working group, basically, that involves members of the autism community who are then helping to advise us ongoing. It's very much a co-design improvement journey that we tend to use.

We find that is incredibly powerful because families can give us tremendous insights on what will work for them, what works for their children, and they are also really connected to other families with autism often so they can bring broader perspectives. We tend to have families engaged who were involved in our services and maybe had graduated from them, but also those who are currently in the middle of them. We find that incredibly valuable input and really helps to move us forward.

[9:30 a.m.]

MR. HOUSTON: I'm not sure who to direct the next question to, but most members of the committee, most witnesses, would probably be familiar with the experiences of the Sutherland family which were chronicled in a number of news articles.

My question is, what services are available for those families who are at the most challenging end of the spectrum - would anything be different today? The Sutherland family kind of fell through, the services weren't available.

Okay, I see a funny expression there. I caught you by surprise, I guess, with that summary, but from my understanding of the news reports there weren't a lot of services for them. That may take you by surprise, but that's certainly my understanding from watching the news - am I wrong?

I guess I'd direct that to Mr. Rudderham there, because you had a strong reaction to that statement from me. Did that family fall through the cracks? Did they miss services there were available? Are there services available? What was the reason for your response to that?

MR. CHAIRMAN: Mr. Rudderham.

MR. JOE RUDDERHAM: Thank you, and I apologize for my facial expressions; they don't necessarily represent what I'm thinking at the time.

I'm not going to say that the Sutherland family didn't struggle and didn't have very intense needs. What I would say is that the two departments came together and actually found some really good solutions. As much as any individual family might struggle in any given moments, we have a process in place in which we actually address those concerns and we try to wraparound the services needed to ensure that the family is able to stay together, and with a priority that we actually have the family stay together within the home.

Is the system perfect? No. Do we do all we possibly can to help families? Yes, we do and we make changes and we're involved in the continuous improvement of programs, expanding the Flex Program, for example, providing more support. Now we're beginning to look as well into how we can, in those very, very, particular situations where the resource requirements are intense, how we can provide those supports to make sure the young Nova Scotian remains with their family.

So, the Sutherlands - as much as there were struggles, I think there was also great success as well.

MR. HOUSTON: Thank you for that. I guess I'd stay with Community Services because you did reference in your comments the network of service providers who can provide supports the family needs, even under complex cases - I think you have a complex case protocol that you referred to.

I guess the response is that there are services there, but we've just got to know how to access them. Is that what you would say?

MR. CHAIRMAN: Deputy Minister Hartwell.

MS. HARTWELL: Thank you very much. I'll give a little bit of a history I think that helps explain a little bit, with your indulgence. In 1997, the province made the decision that it would close what we called "children's training centres." Those were large centres where children lived who had challenging behaviours or more profound disability. I think that was the right decision because, as I said earlier, children do better when they are in a family environment.

As a result of that, though, there are no children's facilities that remain so there are no places that are appropriate, as part of our formal continuum, for a child to be placed and receive the types of support, in part recognizing that's not where children thrive. They thrive in families; the entire system has been reoriented to try to provide supports to families in home.

One of the comments you made is that it takes all of us to be here to answer questions. I actually see that as a really good thing. The partnerships we are able to create, the solutions that are unique to fit a particular family, that's where the magic is. It is actually not in creating a standardized response to every family's situation, and it does take all of us to do that . . .

MR. HOUSTON: I'll stop you there for a second, if you don't mind. Sure, I love team work and team approaches, but sometimes you have too many people involved, and nobody feels accountable.

I'm thinking of the *Choosing Now* report that was done for families living with autism; 42 recommendations were made in that. Would you feel responsible for implementing any of those 42 recommendations in the Department of Community Services, or is that somebody else's job? That's what concerns me. Who would take ownership of working with Autism Nova Scotia to say which of these 42 recommendations could be done? Would that be Community Services?

MS. HARTWELL: I was getting to that point which is that, while we share responsibility, we also have an accountability. When any report like that comes out, there is often a department that takes the lead. I know that, in the past, there have been times where it has been the Department of Education and Early Childhood Development that has taken the lead. Other times it has been the Department of Health and Wellness. We are certainly at all the tables.

In each of our systems, we are not only striving to work together at a senior level to make sure that we have policy coherence and that we're addressing any kind of challenges or gaps that may exist, but our front-line staff work together quite closely as well. In our DCS system, every family that's involved with us has a care coordinator. Part of that person's job is to do some of the liaising so that the family has a place where they can go. If they are involved heavily in the school system, I know that there are folks who would take the lead depending on the need of the family at that time.

The announcement yesterday about 11 parent navigators is really exciting because parents are, without a doubt, the most effective advocate for their child. Giving them a formalized support, other parents that they can go to, will help. It won't replace the expertise that a care coordinator might bring, but at least there is that point person.

To your point, a family shouldn't have to look at 20 different people and figure out who is the one to help. They should have one person they can go to. That one person could be located in each of our systems, again, depending on where the family is at that point.

MR. HOUSTON: So who's the lead department on the *Choosing Now* report? You said there's often a lead department on a report like this. Who would be the lead department on the *Choosing Now* report?

MS. HARTWELL: On the *Choosing Now* report, I believe it is the Department of Health and Wellness (Interruption) Sorry, no. They just whispered in my ear that it's the Department of Education and Early Childhood Development.

MR. HOUSTON: The Department of Education and Early Childhood Development is the lead. (Interruption) You don't have total agreement on who is the lead department on there. The Department of Education and Early Childhood Development is not the lead department on *Choosing Now*.

MS. HARTWELL: Okay, whoever whispered in my ear is wrong. It is the Department of Health and Wellness.

MR. HOUSTON: We can try again. Would the Department of Health and Wellness consider themselves to be the lead department on the *Choosing Now* report?

MR. CHAIRMAN: Ms. Vezina.

MS. FRANCINE VEZINA: My understanding is, I don't believe the document was commissioned per se by government. I believe that it was an independently written and submitted report. Having said that, we do have a great working relationship as well with Autism Nova Scotia. We have started implementation of some of the recommendations that are in there, such as the implementation of the eight autism resource centres as well as the . . .

MR. HOUSTON: In the interest of time, I'm going to come back to that in the second round. Just so I know, I would say there's some reluctant ownership of the *Choosing Now* report by the Department of Health and Wellness, or is the Department of Health and Wellness the lead department on that.

MS. PERRET: I think what you're getting is a response to the concept of lead department in the context of the report. I would go back to my opening comments. We really appreciate this type of input, and it's the type of input that informs our policy and programs. As Ms. Vezina has said, we have that report. We're looking at the recommendations, we're working with our partners, and we are starting to implement some of them and consider them in policy and program planning.

MR. HOUSTON: There's 42 recommendations in the *Choosing Now* report. Do you know how many . . .

MR. CHAIRMAN: That's time.

We'll go to the NDP and Lisa Roberts.

MS. LISA ROBERTS: I would like to start with that moment of crisis that the Sutherland family arrived at, having provided a lot of support in their home, where they needed help from the IWK. I think perhaps this is most appropriately directed to, I don't know, Deputy Minister Perret or to the IWK - what services are available in that moment of crisis for a family with a loved one who has ASD and needs help beyond what they have been able to resource through at-home support from your various departments?

MS. PERRET: It's an important question and it's an experience that we all learned from. In some cases, the starting point is within the health system, as you noted, and a child, say, at the IWK that is in a critical situation is going to be assessed and there is going

to be a care plan put together. In the Sutherlands' case, that child isn't falling between the cracks in the sense of once assessed at the IWK, a comprehensive care plan is developed.

Where there have been challenges - and we recognize them and we work on them - is in the transition points because the hospital isn't a long-term residential environment. As Deputy Minister Hartwell has indicated, we're then looking at how we can either support the child and the family in the home or if there has to be a more secure residential environment, we look at how to set that up.

As I said in my opening remarks, these are highly individualized treatment plans with a tremendous amount of resources that go into creating them, and so it's true that sometimes it takes us some time to respond in a customized fashion to the needs and services that that child and family need. I can assure you - and I think there would be agreement here - that we are getting better at that as we come together, to the point that we have daily conference calls when we have some of these cases, to coordinate these transition points and make it as easy for families as possible.

MS. ROBERTS: I'd like to share some of the story of Cuen Eng who is 15 years old and has ASD. According to a news report from December 2017 - and this was referring to a crisis that his family encountered in 2015 - he spent 37 days at the Garron Centre at the IWK. There were no specific services or treatments for children with autism. Eng and his mom Marni Adams say it changed nothing for their family.

Currently when families are resorting to, I guess, initially probably a call to 911 or a visit to the emergency room at the IWK - when they arrive there and given that there is no other residential facility, as Deputy Minister Hartwell spoke to, is the Garron Centre geared up and resourced with appropriate therapeutic services so that it's not just a holding space until the child is returned home? Is there capacity there to help those children and those families actually get to a better spot at the point that they're exiting those doors?

MS. VINE: While I wouldn't comment on a particular situation, as you would understand, I think the role of the Garron unit is important for us to understand. It is a highly acute care environment. When a young person with any psychiatric diagnosis is admitted to that unit, really the main focus of a high acute unit like that is a level of stabilization. Once that stabilization process is under way, then we're able to start pulling in additional resources.

It does take time often for stabilization to occur. Often when there is a particularly serious crisis for a family, even the time that it takes to do the proper medical and psychiatric workup does take time. Potentially that is part of it, but IWK does have specialized resources for autism and we are able to mobilize those resources to the Garron unit - the psychiatric in-patient unit - yes.

[9:45 a.m.]

MS. ROBERTS: Again, in Mr. Eng's case, he says he's gone to the IWK emergency department more than ten times, but has been admitted twice. If not to the Garron unit - if a person is not in such need of stabilization that admission there makes sense, is there another place within the IWK? Again, given that someone is arriving at the emergency room or calling 911 because things at home are really not working in that moment - they are dangerous for family members, they are dangerous for the individual with ASD - is there a resource at the IWK, on an in-patient basis, where those ASD services are located?

MS. VINE: Really, what I would say is that when there is a high acuity situation for a young person with autism that includes psychiatric diagnoses or medical diagnoses, those services are provided in the most appropriate location for that child.

In general, best practice would tell us that in-patient services are not ideal. The best approach to dealing with young people and their families is to make sure that the services wraparound and supports are brought to them in their normal environment. That is typically the most appropriate role and that is the goal we are always trying to get to.

In terms of in-patient admission, those should be as limited as possible. For individuals with ASD, coming out of their home environment into an unfamiliar environment is often more harmful than good.

MS. ROBERTS: I do appreciate that. I also appreciate, I guess, the level of approaching despair families are at the point that they arrive at the IWK. So, to tell them, actually you need to go home, in that moment, or even in that week when that moment has probably come at the end of a month or months of crisis and failure to access resources, I think that's a little bit difficult to just accept, frankly.

Our caucus did request the update from the working committee that is looking at the Autism Management Advisory Team Report on Lifespan Needs that came out in 2010 and was updated in 2012. This update is from April 2017, and one of the recommendations from that 2010 report was that, "Further exploration of crisis services for families and individuals with ASD should be investigated to determine if supports are appropriate, timely, and accessible."

We were able to get the full update on many of the recommendations, but the information on the actions taken related to that recommendation were fully redacted. So it does have Department of Health and Wellness here as the lead agency, and I would appreciate knowing what actions have been taken on that exploration of crisis services for families and individuals with ASD - Deputy Perret or Ms. Vine?

MR. CHAIRMAN: Ms. Vezina.

MS. VEZINA: At the time, what our immediate actions were and our focus was on was expanding the mobile crisis unit for the mental health and addictions crisis line - to expand that across the province.

We continue to explore with our partners the needs around the crisis service for families with children with autism. As everyone has already indicated, we are looking at something a little bit more complex, that is going to have to be very nimble and able to respond to a variety of needs for families.

MS. ROBERTS: Do you have a timeline on when families can expect to see something different, sort of clearly on offer?

MS. PERRET: It's an important question. As I referred to earlier, we have an increased focus on that issue. We've seen how important it is to work out more options for families when they are in that crisis point.

I would reiterate what Ms. Vine said: a hospital environment is not a good residential environment. Part of this is putting those supports in place through things like crisis units, but probably on a more long-term basis. Whether we need an alternate secure and safe residential component, that might be an interim solution or the supports that are put into the home.

I think it's fair to say that our organizations - and I made reference to conference calls because I'm quite serious about it - we're doing those regularly to say, "What are our assets, in the sense of how many secure residential placements we have? How do we get those right and skilled support workers who we can put in the home?" As my colleague said, how are we nimble and adaptable to unique situations that have some very challenging requirements?

Are we there yet? We're not. Are we aware that we're not there? Yes. Are we dealing with this daily? I can honestly say yes. It is a high priority for all of us.

MS. HARTWELL: I just wanted to add to my colleague's comments. To reiterate, we're part of those daily phone calls. Again, we are putting the needs of the child or youth and the family at the centre and trying to build the support outward. The experience in the past was, again, that children were in places where their unique needs weren't taken care of. As we learn more about the particular needs of children who are on the spectrum, we absolutely know that things like structure, familiar surroundings, and a sense of community that might look different than a community that is in other facilities, are important.

We referenced the network of service providers. We have service providers around the province, some of whom provide residential options for adults, who are able, when we have a child or youth in a particular need, to craft something that is a child-appropriate

situation. Sometimes they are longer term. Sometimes they are to stabilize and to help a family or help a child over a particular piece.

I can give you an example. We are working with a service provider right now who has hired and is training five staff to support one young man who is going to be at home with family. Those five people are going to be coming in and out of the home to provide the support. That's what worked for that. That's what we believe is going to work for that young person, far better than us creating a place that he will be away from his family and the things that he knows.

That may not be a solution for other families. They may need something a bit more remote. That's why it really is a one-off and quite situational.

MS. ROBERTS: Given that we're trying to put the needs of the individual and of the family at the centre, do we have the resources necessary to come up with those solutions if they do require a stay away from home but also out of an acute hospital environment, which I understand is not appropriate? Do we have the resources we need to be able to look at a third option that provides respite and therapy and stabilization?

MS. HARTWELL: We have a lot of resources that are currently in our system supporting children and families. They may not be where they need to be, again, to have a more nimble response. So it's finding a way to reroute some of the resources we may have in a particular bricks-and-mortar solution that may not be the one that will support this child. It's finding a way to reallocate.

I will say that a challenge we all share, and that I believe we are all looking for, is finding skilled, trained individuals who have the ability to work with children and families, sometimes in non-traditional settings - again, working in a home as opposed to working in a care facility. We're always on the lookout for that.

Often individuals need to be trained, not just generally in autism but specific to a child's particular needs. That child's own behavioral interventions may require an entire plan that people have to be trained on. Finding the people and training and supporting them is a big area of focus for us, for sure.

MS. ROBERTS: Again, in this progress update from April 2017, the progress on another recommendation was also fully redacted. That was the one about creating regional autism centres that should be located and coordinate services in key areas of the province. We have been talking about the IWK, which is in Halifax. What progress has been made on those regional autism centres that were envisioned to include a lending library, resources for families and parents, a navigator or case manager, and those wraparound services?

MS. PERRET: In this year's budget, there is \$300,000 for Autism Nova Scotia to establish eight of the autism resource centres. My understanding is that they are going to

be located in the following communities: Yarmouth, Hebbville, New Glasgow, Amherst, Truro, Kingston, Halifax, and Port Hawkesbury with outreach to Sydney.

MS. ROBERTS: Just to clarify, this is a progress report from the Autism Management Advisory Team Report on Lifespan Needs from 2010. None of the work towards the centres was done up until this budget year?

MS. PERRET: I don't have the history; I have only been here a year. I can tell you that that budget is in place this year, and the work with Autism Nova Scotia to establish them is under way.

MS. ROBERTS: There is a lot that I could ask, but just quickly - for the representatives who are here from the Department of Education and Early Childhood Development, obviously there is a lot of investment in EIBI, and now there is a significant investment in pre-Primary. It's great to hear that some children who have been diagnosed with autism are currently working within pre-Primary. There are 24 students with ASD in pre-Primary.

What happens, though, for those children who will not be diagnosed until later? Perhaps you have a diagnosis at five and a half either of a student who is not currently accessing pre-Primary or even a student who is in pre-Primary, but doesn't get the diagnosis until later. Will they be able to benefit from EIBI, perhaps by repeating pre-Primary? How is the system working with those families?

MS. GATIEN: You can't repeat pre-Primary, but it is voluntary, so they could choose to wait a year. If the diagnosis came later, say five and a half, they would certainly have access to all the supports within the education system - all the program planning and supports that would happen for all students while they're in school.

MS. VINE: If the diagnosis does come within six months of school entry, we can offer EIBI for that six months and then transition into the school system. There is a plan for the clinicians who work with children to transition them into the schools. A minimum of six months in order to be effective is what's required. Otherwise, it would be the education colleagues mentioned.

MS. ROBERTS: In the hopes that my Liberal colleagues will allow an answer to my question as I run down the clock - just to clarify, if that diagnosis comes at six instead, what happens for that child? Are they effectively too late for EIBI? In which case, what happens?

MS. VINE: I think that's when the answer is, as was said, with the education system. The window for EIBI is up until school entry, and then a plan is made to transition the child into the school system and access the resources in the school system.

MR. CHAIRMAN: That's time. We are going to head over to Ms. Lohnes-Croft. I would just ask the members of the committee, when you ask your question, to direct it toward one of the departments to simplify this.

Ms. Lohnes-Croft.

[10:00 p.m.]

MS. SUZANNE LOHNES-CROFT: I will try; there are so many. Thank you all for being here. Autism has been very important for me. It has been a large part of my career, supporting families and students with autism and I've seen great progress. I'm really happy to hear the investments that have been made in the last number of years into inclusion and the announcement yesterday, there are some parts of it, I'll get to them later.

Did Ms. Roberts have her question completely answered? Her question was completely answered. Okay. She was talking about the EIBI, which was created around 2008, I understand, but it was a lottery. It's no longer a lottery and I'm pleased to hear that. Could someone speak to me about how you go about getting into the program? I know it's a preschool program but a lot of autism is diagnosed around 18 months to two years, so, what is the timeline there?

MS. VINE: Typically, a child may come forward in multiple different ways and Dr. Lynk will be able to speak to his experience as a pediatrician because being referred to a pediatrician would be an example of a way a child, at a young age, parents might notice something that they feel is not typical and that would lead to engagement with their local pediatrician. They could be referred to a mental health service. They could come to the IWK and that would lead to a diagnostic process. If the diagnosis is ASD, then they would be eligible to receive EIBI in that preschool period and, you're right, the access to EIBI is now universal and we are able to offer spots to every child prior to that, you know, requirement to enter school at age 6.

MS. LOHNES-CROFT: Then, as we move on, we've made investments into the pre-Primary program and we're adding more classes next year. I've toured a couple of locations and I've heard some success stories of students who've come in with autism and, you know, it took a few months for the transition to go smoothly. Do you see this as a way of making that first year in school more successful for many of the students with autism?

MS. VINE: I would certainly say so. The focus of EIBI is really to build on the strengths and work very closely with both the parents, the family, and the school system at the point of transition to really build the opportunities and skills around communication. We know if a child is able to communicate their needs, their wants, that is really going to help them to be successful. They also learn the beginnings of social skills and how to relate to others which is another key area of development and so those areas of focus are really the work that is done with EIBI. Parents are also trained in order to do that work and there's

a lot of expertise within the school system. I hope that answers your question. I'm not sure whether Education colleagues would have additional comments.

MR. CHAIRMAN: Ms. Jozsa.

MS. SUSAN JOZSA: I would just say that with regard to the pre-Primary program, the focus of that program is actually on play and the development of social skills. So it really dovetails quite nicely for those youngsters with ASD who are also receiving EIBI and the program that we have that we referred to earlier, the STAR program or the Strategies for Teaching based on Autism Research has a component in it that is very much linked to the primary focus of the program in EIBI related to communication and social interaction. So, we really try to work very hard to transition our young children with autism in pre-Primary and then again into school, being very mindful of those challenges that the children face as Jocelyn really well described.

MS. LOHNES-CROFT: I was really excited to hear about the Parent Navigator Program. If that's one thing that I get even as an MLA - these parents are incredible, who live everyday with family members, some families dealing with more than one individual with autism. They are incredible, they are resilient, and some of them are getting pretty tired at times, but I must say, that's one thing I've always said to my parents, you're doing an incredible job because its 24 hours a day.

To have this parent navigator - I assume there's no job description as of yet, but I see that as a game-changer. So many parents are tired or they're working, and finding the time to find the route - I think Deputy Minister Hartwell said there's no standard approach, and I have to agree. I was very pleased to hear that it's case by case. These navigators will really help parents, because every individual case is different, and everybody's needs - some will need more of other things.

Also, the role of the nurse - I do remember back in the early years, there was a nurse on our school board that did come around to our learning centres and our schools and did work. A lot of their work was around medication, because there's a lot of medication that students are taking who have autism, and I found the role of the nurse was very important, and parents had a lot of confidence in being able to call that nurse with concerns. You know, sometimes it's not as easy to get a hold of your GP or your family doctor just to ask a question. I see that component as a bonus with the navigators, plus the other supports that are going into the inclusive education.

I guess this would go to the associate deputy. How overall do you see the additions to the inclusive education, the supports that were announced yesterday - how is this going to affect people who are in the school system and coming into the school system with autism?

MS. GATIEN: Certainly the aim - and I think it's what will be realized - is that we'll be able to respond to the needs. The way we determined the positions and what was needed was in part from the recommendations of the commission, but it was also what was ambitious and achievable for the coming year.

We worked with the regional centres and the school board to say, we want to stretch ourselves, but we also don't want to promise something we can't deliver. This is the first phase; this is just the beginning. It's really to meet the needs of students and teachers, and meet the needs that we've been hearing about for a number of years. What we're hoping is that the supports and services will be there for the students and teachers who need it the most.

MS. LOHNES-CROFT: I see this as a continuum of care with all the stakeholders. I think it's really great we see the stakeholders here today, which shows that collaboration is really essential.

When someone presents with autism in the school, especially in the complex cases - Ms. Hartwell, maybe you're the best person to direct this to - what is there for the protocol when there are complex cases?

MS. HARTWELL: I'll start and then I'll turn it over to my colleagues, on how we become aware of a complex case. So people come into the community services program through an assessment, and they often are referred by their family doctor, or referred by another family that they know. The idea is that once they're in our program, we would do an assessment to see what the needs are of the family. That's not a clinical assessment, that is really, truly an assessment on what the family might need, knowing that that will change. They're assigned a care coordinator, and then in our Direct Family Support Program for Children, then they are able to receive respite funding.

If things start to change that can be triggered by the family calling the care coordinator, indicating that behaviours are escalating or that there's perhaps a medical complication that's adding to the complexity, any of those things, then that would trigger our care coordinator to go out and do a reassessment but then also to start to make the connections with other professionals who may need to be engaged, whether they are in the health system, whether they are in the education system, to get a sense of what's going on.

Our care coordinators, on a regular basis, do regular reassessments. They stay in contact with the family, so even if the family doesn't contact them we will be reaching out and, at some point, we will be the ones maybe noticing that things have started to escalate or that families are struggling to keep up. Certainly, often families will go to their family doctor or to others, often through the school system, to indicate that things are ramping up.

Our staff on the front line do fabulous work. They have built relationships with colleagues and they try to come up with solutions in the work they are doing every day -

whether that's making sure that all of the information of what's happening in the school, for example, that they can be part of a plan to help that continue over the summer months, if we can provide some funding for that, that kind of thing.

There will be cases, though - and these are the ones that we hear about and the ones that really all of us get involved in occasionally - where the needs of the young person or the family have escalated quite significantly and the supports we are providing or the supports that they are receiving do not seem to be meeting their needs at that particular time. That's when we have to do what we're calling a wraparound - we have to have more senior level of people who are involved in problem-solving who can bring resources to bear, who can canvass service providers, canvass departments to see what is available and what can be done.

We do have what is called a complex case protocol, which really started from these cases where who can trigger that we actually bring everyone to the table. My colleague is not exaggerating when she says there are cases currently where there are daily phone calls between senior people, trying to problem-solve around supporting a particular family and young person. That isn't perfect because the complexities that some of these families are facing are significant and can be challenging. I'm using the word "families" deliberately because often there are other children involved, so they are parenting children who have all kinds of needs. Sometimes we can provide supports to support those children and not necessarily the child who is on the spectrum.

Ultimately, when a complex case reaches a point of crisis we do have our legislation in the Children and Family Support Act which does allow for parents to enter into a voluntary agreement with the minister to have a child placed temporarily in care. That is an absolute last resort and it is not one that any family would ever consider lightly and it should never be held out as a panacea, not that anyone would ever want it to be, because kids need families. If they come into the minister's care we are not always able to recreate a family setting and we don't want children to not be in families.

All of the work around the complex case protocol, all of our work is very much focused on supporting that family as much as we can and providing that wraparound that allows them to continue their parenting for the health of their whole family, including that child.

DR. LYNK: I just wanted to add one piece of the system improvement puzzle that we haven't talked about, and certainly we can get better in all sorts of areas, from crisis to intensive supports, both preschool children and older teens and young adults. There's lots of room for improvement, but I think we are making some progress for sure.

One thing we haven't mentioned is the role of the community paediatrician. I just wanted to bring that up. I was a paediatrician in Cape Breton for 25 years before coming down to Halifax. We work closely with our education colleagues and our colleagues in

Community Services. The community paediatrician who works with the families gets to know the families in concert with the family doctor, but they add a lot in terms of being that navigator person who can coordinate, who can manage medications if need be, who meets with schools, meets with DCS, who helps prevent crisis.

[10:15 a.m.]

I would just say that one goal we have in the province - and we are pretty close to it, with a few exceptions - is that every child in the province, no matter if you live in Yarmouth or Liverpool or Inverness, should have reasonable access to a community pediatrician for whatever special needs you have, including autism. Huge value in that.

We work with DHW in our HR planning, and we are going to be adding one new pediatrician that we just got funded for in HRM, for example, but all through the province, everybody should have that access. I think that will go a long way in having those local advocates for the child, working in concert with our partners.

As a community pediatrician, I think one thing that goes a long way for kids with special needs is that every school board - I know we don't have all the school boards anymore, but everywhere in the province - that we have a sufficient number of social workers attached to families of schools, which we did in Cape Breton for a long time. That might be under a little bit of reduction.

A social worker who can work with children and families is worth their weight in gold. If I had to choose between an MRI machine and a social worker, I'd take the social worker any day, in terms of the good it does.

MS. LOHNES-CROFT: I think there is usually a social worker connected - at least the teams I've worked with - with the schools. There's been the caseworker and the social worker, learning centre teachers, principals - I'm quite impressed with the teams that we have around.

I think there was a question about the resource centres. On the South Shore, we had an incredible autism resource centre that was staffed with a high-end EA - or TA, they call them now - who also went out into the field. If you were working in a learning centre and you needed some aids, this person would come in and observe and help get those aids into the learning centres and the classrooms where they are needed.

I can't speak for the whole province, but I do know that on the South Shore we have a pretty awesome centre. Parents can access it, as well as educators and other people, and it's been quite successful.

DR. LYNK: I just have one quick point - a really quick point, sorry. The social workers also help the families, and there are all sorts of families - a full spectrum of families

who have their own struggles and challenges, whether you have a child with special needs or not.

One last point I will quickly make is that we have an opportunity with the new provincial school board or advisory council that is going to be constituted in the next couple of months. I would really put strong advice - and I've written to the minister before - that there be a community pediatrician on that advisory council to give that health angle and also to advocate for kids with special needs and to work with our education partners, which we've done in the past, which really added a huge value.

MS. LOHNES-CROFT: Transitions are challenging and that is one of the biggest challenges when you are working day-to-day with autism. In particular, I am interested in the transitions, like from Grade 9 - from junior high to senior high - but also at the end of school, when they become adults and are going out of the school system. I've worked on Grade 9 to Grade 10 transition teams, but I haven't been there for the Grade 12, or when they max out at age 21, if they stay in the system.

What transitions are there?

MR. CHAIRMAN: Ms. Gatien.

MS. GATIEN: I'm going to ask Susan Jozsa, who has more in-depth information on that, to answer your question.

MS. JOZSA: You are quite right when you note that our students with ASD really can sometimes struggle with transitions. We are particularly mindful of the big life transitions that occur when our children move from wherever they were - preschool into school, as they go through school, and then the lifechanging transitions that we need to consider as our youth move from junior high into high school, and then planning for a life beyond school.

Our program-planning teams begin to look at transition for our students with autism on an individual basis, working with families.

MR. CHAIRMAN: That's time. We will revert back to Mr. Houston for 11 minutes.

MR. HOUSTON: Just two quick questions before I pass to my colleague. For the IWK, you mentioned the complex care coordinator. I think that's a position that was vacant for six or seven months. Do you know if that position is filled now?

MS. VINE: Yes, we do have clinicians who have extra expertise in complex care coordination. Actually, for any young person who is going through a transition from a health care environment particularly, whichever domain it is - medical, psychiatric - we do have quite a nice roster of people with highly skilled backgrounds in complex cases. So

those do happen. What we do from the very beginning of complex admissions - medical or otherwise - is call the partners as we have been talking about earlier, bring in the workers who might assigned either through school or through DCS, and make sure that we're doing a care plan that is understood across all of the system.

MR. HOUSTON: Is there somebody who has the title of complex care coordinator?

MS. VINE: I'm not sure that we have that position named that way. But the important role of social work was mentioned, particularly for complex care areas. The social workers in the Garron unit, for example, would be focused on that work.

MR. HOUSTON: I think in responses earlier, you mentioned that there's a transition plan after a child has been staying at the IWK. In the case of the Sutherlands, the transition plan was a four-day notice to vacate, to leave. Could that happen today? Or is there a system where the transition would be a little less abrupt than "we need you out of here in four days because we can't care for you?"

MS. VINE: I would like to say that we are able to pull resources together in a cohesive manner. That planning is done very much with parents involved, again, from the beginning. I do recognize, and I don't think any of us would underestimate, the stress and strain that families are undergoing that would lead them to come into this system in the first place. Those transitions home are very stressful.

We do make every effort to plan ahead, help people understand what the plan is while the in-patient care is going on, and also understand what the step-down resources would be. We have clinicians who transition from an in-patient environment into the home as well. I wouldn't want to underestimate that, in situations of severe complexity, it is challenging across our system and most especially for families themselves.

MR. CHAIRMAN: Ms. Adams.

MS. BARBARA ADAMS: I am really curious to know about the recommendations from the Autism Nova Scotia report from 2017, which all of the departments have embraced. The one that I'm most concerned about, because it's the one that I hear about the most, is access to a diagnosis. If you don't have a diagnosis, you can't access any of the programs, funding, or respite. The families are out in the cold until they get the diagnosis.

In particular, I have a military community where they'll wait on a wait-list to get in for a diagnosis, but then they get posted. Then they start on another list. I have people who didn't get their child diagnosed until they were 12. Most of those in military families ended up paying privately for their diagnosis.

Just for the record, because it hasn't been mentioned, my understanding from the autism report is that the prevalence of ASD was 1 in 2,500 in the 1960s, 1 in 110 in the 1990s, and 1 in 68 now. So clearly, the needs are more pressing.

I have two questions I would like to address to Dr. Lynk. How many people are waiting on a wait-list to get assessed for this now compared to five or 10 years ago? The report suggests that the wait time is between one and a half to two years, yet children are getting diagnosed between the ages of three and five. There's a really narrow window there. I just wonder if you could talk a little bit about the wait time to get diagnosed in Nova Scotia.

DR. LYNK: That's a good question, and it's a bit complicated too. If I was up in Cape Breton and I would see a child who came in the office between the ages of two and three - often because they weren't speaking which would be the first thing parents would notice - as community paediatricians who would see these children, for many of them - not all of them, but for many of them - you can make a diagnosis in the office and have a pretty strong suspicion. Then you'd go on a wait-list for an official diagnosis and depending on where you live in the province, that's usually with a psychologist and/or developmental paediatrician.

Sometimes that can be quick - it can be a couple of months or it can be up to a year and a bit for preschool children. But in the meantime, I just wanted to let you know that as a community paediatrician, if I have a child I think has autism, or I am pretty sure has autism, I can start the speech therapy part, get their hearing checked, do genetic testing, get early intervention services involved and, if the parents need any help through DCS, I can do all that. So it's not like waiting for the official diagnosis means you don't get any services at all - you certainly can get some services.

Once they get the official diagnosis, and you are right, some parents - not all parents but more parents today than maybe 10 or 15 years ago - have health care plans that for about \$150 from the parents they can have a private psychologist make the diagnosis so we can get that done earlier. That's not for everybody, obviously we have lots of people who can't afford that, but some can. Then they can get placed on the wait-list for the EIBI, the early intervention program which they get before they start Primary.

I think the bigger problem for diagnosis were people wait longer, and I take your point for the military family that would be very distressing and frustrating when people move and we do have people moving all the time, that can take a couple of years sometimes. Again, the community paediatrician may be able to make the diagnosis in concert with the school - I should say a suspected diagnosis and again, some families can go down the route to private testing if they have to, but in terms of public testing that can take a couple of years sometimes, no question. That can delay them getting disability tax credits, it can delay all the extra sort of services they can get.

Can we do better, especially in school-age and young adults? No question that's a gap. There are numbers before me, but what I see is that these fluctuate and, especially for people who are school-age, they are too long, if I can summarize it that way. I can provide you with specific numbers later on, but the wait times are too long now for school-age, for sure.

MS. ADAMS: The number you quoted was \$150 for a psychologist to get diagnosed and the parents I have in the autism support group in my community had to pay for a full assessment, which was somewhere around \$1,500 to \$1,800 and they can't afford that so they went without diagnosis.

My question now is again to Dr. Lynk. We have a lot of families who don't have a family doctor so they can't get referred to a psychologist because they need a referral in order to get any amount covered under their private health plan or to get into the IWK. What do we tell parents who don't have a family doctor and they suspect their child has this disorder?

DR. LYNK: That's a tough problem for sure. What would happen - and I can only speak in my practice in Cape Breton because I did just in-hospital work in Halifax - in that case if either a social worker or a school board teacher or somebody, they would just refer to my office, for example, and we would see that child if they were school-age. If they didn't have a family doctor it wouldn't matter, but someone would have to sort of advocate for that as well.

Preschool, that is a problem. That's a problem for kids getting vaccinations, getting all sorts of things so we are working hard, as you know, to try to recruit and have more physicians for families - we have the physicians but try to recruit to fill those spots. It's a huge issue across the spectrum.

MS. ADAMS: Thank you for that answer. One of the big questions then is, given the high incidence of this condition, is it possibly time to move towards the family doctor being able to make the diagnosis? I mean it's fairly rare for conditions to be diagnosed by somebody other than a physician, this is one of them but, given the incidence, is it possible that that's something we need to move towards? As well, all the other allied health professionals were training the teachers, but the other allied health professionals need that training perhaps at the beginning of their career as well.

[10:30 a.m.]

DR. LYNK: It's a great question. There are screening tools that are built into something called the Rourke Baby Record, and the Rourke record is what we use to do the well-child check at infancy and preschoolers. If you had the time, it would probably take about 25 minutes to do a complete Rourke record. In addition, you could do a screening tool if that came up.

To make the actual diagnosis would probably require an hour, two, or three. There are other tools, and practically speaking, for busy family physicians who we don't have enough of right at the moment, that wouldn't be a practical solution. It could be for community pediatricians to be trained. They do this in Ontario now, and we're talking about it here. Community pediatricians can actually make the diagnosis using tools without people having to go to expensive psychologists.

MR. CHAIRMAN: Time. We'll go to the NDP caucus and Ms. Roberts.

MS. ROBERTS: I want to direct my questions to the Department of Community Services, particularly around respite services through the Direct Family Support program and eligibility for that program. It appears that there is - I almost want to call it a loophole, but it's not so much a loophole as just a gap that many kids with autism and their families fall through. I understand the eligibility for that program - there are a number of different criteria that would result in eligibility. Two of them require intellectual developmental disability and the other is significant physical disability, and children with autism do not necessarily have an intellectual disability - at least if you're measuring it with IQ.

Would you agree that there is a current gap for families with children with autism, 45 per cent of which don't have what you would typically call an intellectual disability?

MS. HARTWELL: We are looking at the IQ requirement for certain. I would say that when the policy was created, that standard seemed to be a reasonable one, but as we are learning more about the complexities of autism and some of the extreme behaviours that may come that are not associated with an intellectual disability, and yet that child has an impairment and may have all sorts of behavioural challenges. We are absolutely looking at that. That has been identified as a gap.

I would say that currently while we're assessing what would be a reasonable replacement, a reasonable assessment replacement, if there are families that are in that situation then come to us and we'll be able to do some other things to try to work with that situation because we are certainly aware that the policy as it was developed several years ago is not keeping up with what we are now learning more about autism.

MS. ROBERTS: I would welcome some further comments from Mr. Rudderham who looks like he might have something to say. No? Okay, maybe it's just the face again. (Laughter) I guess I say I welcome further comment because, frankly, it's great for a deputy minister to say to an MLA, come and talk to us, but on the ground when you're a family member and you're trying to get access, and there's a policy that is on the books which says you are not eligible, you don't have the access that I as an MLA have to you, a deputy minister, in this room.

How is that practically working for people? Because frankly, we're hearing from Autism Nova Scotia that it's actually not working very well for many families.

MR. RUDDERHAM: I need some training on facial expressions. (Laughter) What I would say is that I agree with my deputy that there is definitely a gap. We've identified IQ as not necessarily an appropriate - and other provinces have identified IQ as not an appropriate measurement to gain access. What's critically important is that we provide the right supports and services to families where we've identified that there are significant behavioural issues.

The example you gave previously was around the Eng family. I know Cuen, and I know Tristan - I know the family quite well. Cuen has a very high IQ. He is incredibly intelligent, but he is also an individual who has been provided supports and services through the Department of Community Services - I think I can say that.

There are ways and means in which we will sort of bypass what we now consider to be an eligibility requirement. It's not necessarily working. It's not working because getting access to the assessment piece, and it's not working because - I'm going out on a limb here - but I think a lot of the psychologists who would have done this in the past are not comfortable with doing it on a go-forward basis. We know we need to change it.

Part of what we are doing around assessment itself is that we also recognize that we need a really good assessment methodology and associated tool, not only for adult program participants, but as well for children.

What we need to make sure is that we actually allocate very, very limited resources to families who need it the most. Just a very particular diagnosis of ASD on the spectrum - if it's an individual who has a very high IQ and limited-to-no behavioural, that doesn't necessarily mean that supports and services should be provided through the Department of Community Services program.

If there are functional limitations, behavioural issues, we all agree that those families need access to services.

MS. ROBERTS: Thank you. I will just voice aloud my concern that, while I guess this gap has actually been identified for seven years running now, my concern is that one possible reason it has not been acted on is not only the difficulty in coming up with an assessment tool, but frankly, that we are dealing with - I guess the government decided that a scarcity of resources is a way of limiting those who are eligible.

Again, Mr. Rudderham's face is wonderful. He shakes his head no.

MR. RUDDERHAM: Can I just respond to that?

MS. ROBERTS: Yes, please.

MR. RUDDERHAM: I'm not disagreeing with you. I think the positive point here is that we recognize that the IQ itself is not a good measure, and we are taking measures to fix that, but families who are in need - we are supporting them.

Again, the Eng family is a good example where the IQ wouldn't have - we wouldn't have provided supports, but we found a way to do it because the family was in crisis and we needed to provide the supports and services.

MR. CHAIRMAN: Ms. Hartwell.

MS. HARTWELL: I just wanted to add on the resourcing. The Disability Support Program is the program that has received the most funding increase over the last decade, and that's in part because of the complexities of the cases that we've seen. I don't want you to think it's just a new idea but probably starting about two years ago, we began to work to look at what would be appropriate assessment methodology for the services that we provide. Again, less about a clinical diagnosis and much more about family, instrumental activities of daily living, what is required.

We have received the funding to move forward with a new methodology this year. As part of our transformation, we have been looking at having that kind of reliable methodology, so that we can actually make sure we are getting the resources where they need to go.

MS. ROBERTS: I promised my colleague a few minutes, and I'm afraid that we'll get into a big conversation, so I will pass it over to Mr. Wilson.

MR. CHAIRMAN: Mr. Wilson.

HON. DAVID WILSON: Thank you. Quickly, I know a lot of the attention, a lot of the resources, a lot of the programs are geared towards young people with autism. One situation that stood out for me as a former Minister of Health and Wellness and doing updates on the EIBI program, is that there are a number of adults who are diagnosed with autism and they have older parents who are the caregivers.

What is being done to look at what happens when those caregivers age and when they pass on? Is there work being done currently to address that need? That demand that is just around the corner, I believe, as the population gets older, especially here in Nova Scotia.

MS. HARTWELL: Yes, you are absolutely right that there is another demographic challenge, and that is the one that comes with aging parents who are supporting family members - sons, and daughters - with a wide variety of challenges, some of which may be autism, some of which may be developmental delays, et cetera, and it is a source of worry.

That is one of the things that we are taking into account, as we are transforming our system. Because most of those folks have been caring on their own, the family member may not have their own network of supports - their own natural community, so we have been investing some support in what we call our adult day programs because where people sleep, where people live is one part of it, it's what they do during the day, their ability to have their own friendships, their own lives, their own jobs, all those things and they may have had a quite sheltered experience.

We are working closely with the DIRECTIONS Council, which is the lead for all of the day programs that we fund, to not just create more opportunities, but actually pilots looking at transitions of young people from high school into adulthood; also transitions for people who have been at home and who now need to start to form their own lives. That's the day piece which is important, and we sometimes don't talk enough about that.

We also are focused of course on the residential piece. As you know, several years ago the province committed to a road map to really change our focus on how we support people with disabilities to live more independently in community. I say "the province" because it was of course a different government that brought it in, but it was endorsed by all three Parties, a really clear statement that Nova Scotia was taking a new direction.

It is taking time, in part because of the complexities of some of the - well all of the individuals are unique and have their own needs. I would say we have a system that is focused quite heavily on larger facilities and people who have lived in those larger facilities for some time, and helping support those people to transition to community is a long process and one that has to be done safely and one that has to be done respectfully with their needs and wishes at the centre.

We are investing in more small options homes which . . .

MR. CHAIRMAN: Time. We'll now go to the Liberal caucus and Hugh MacKay.

MR. HUGH MACKAY: Actually, Mr. Chairman, with your permission I'd like for Ms. Lohnes-Croft to be able to finish her question she started and then perhaps revert back to me.

MR. CHAIRMAN: Ms. Lohnes-Croft.

MS. LOHNES-CROFT: I think we left off with Ms. Jozsa about transitioning from the school system into adulthood and probably Ms. Hartwell, you could add on because that's when respite care is really going to kick in and possibly the job coaching..

MR. CHAIRMAN: Ms. Jozsa.

MS. JOZSA: When we last were talking, we were discussing the preparation for students. Once they get into junior high we begin to work with families to talk about what their hopes are for their students, what the students' interests are. Transition is very individual so we work with families beginning at that stage to develop a plan, through program planning, for where the student is headed, what skills the student needs to acquire so they can meet their potential, and acquire those skills that will set them up for leaving and entering community.

We also work with our partners in other government departments and other associations or agencies to look ahead to what supports families may need to access and we help to prepare them to do that.

We have a post-secondary program for our students called Achieve that we have developed in partnership with NSCC that helps to prepare our students with special needs, including those with autism, for potential post-secondary study. We have seven Achieve sites in conjunction with NSCC and we'll be adding two additional sites.

We also look at if the student is able to continue post-secondary, and we try to help support them to head in that direction. If the student is going to require more training and being in a work placement setting, we try to support them in learning the skills that will allow them to be successful. Then it really does call upon us to work with our partners because they are often the ones who are developing those programs post-secondary - The respite and the job coaching that comes with all that.

MS. HARTWELL: Thank you for that question, and absolutely. I referenced the Adult Service Centres, the day programs - not only are we looking at increasing the capacity but we want to look at increasing the capacity for those organizations to work with young people who have more in-depth challenge. So, if there's a young person who has a particular need that they actually have the skill and the ability to put the required adaptations in place.

The job-coaching pilot that we are launching this year is really exciting because it is about the possibility that young people with autism bring to the table. Incredible families, incredible young people who want to be contributing, and may need some support in how they are approaching jobs, understanding what adaptations if any might be required, but also, it's about creating employers that are - we call them Disability Confident employers - employers who know how to recruit, work with, and support people who may seem different, who may have a different way of looking of the world, but that is actually a benefit.

We are working with Autism Nova Scotia on that, and couldn't be more thrilled. That's exactly the right organization. I would say that there are some incredible advocacy organizations who are trying to support overall inclusion of more people with disabilities, including people with autism, in all of the employment supports, knowing that we also

have responsibility of course for income assistance, and we know that people with disability can be overrepresented in our Income Assistance program, in part because they're not able to make that job attachment.

I did want to mention that we also have, through our employment support program, a support called a Workplace Support Program. We will actually fund - if there is a young person who needs an attendant with them to attend a job as they get used to that - we'll fund that attendant's salary to be able to go to the job with that young person and help with the adaptations. It's probably a bit undersubscribed, to be honest.

MS. LOHNES-CROFT: Would that work for day programs? Often the day programs are teaching the clients - I think they become clients at that stage - they're teaching them skills that they can use for the workforce.

MS. HARTWELL: I would say the Workplace Support Program is not necessarily in that environment. The day programs themselves often have staff who have that skill set - that is actually the staff that we're funding there. When you think about some of the programs around the province - I think of Summer Street Industries, for example, an incredible organization, a strong social enterprise. They have programming that not only supports people with a sense of community, a sense of vocation, all of those things, they are also supporting people to work in the mainstream labour market and that's really the goal for many young people, and I would say particularly young people with autism, who just need a slightly different support and orientation so that they can succeed on their own. So, we're really interested in exploring that.

MS. LOHNES-CROFT: Okay. Thank you. I'll pass it over to Mr. MacKay.

MR. CHAIRMAN: Mr. MacKay.

MR. MACKAY: Through the growing awareness of autism, I think we all recognize now that it is a spectrum, that there is a broad range, and of course, much attention has done into some of the complex cases and some of the - we've mentioned the Sutherland family and Eng case today - and of course, these are the things that will attract public awareness and attention, which is good to bring attention to the autism spectrum.

Of course, there are hundreds of other cases that you're dealing with that do not get that kind of exposure, which is a good thing, and I agree with Ms. Vine's comment earlier of the stress and strain, though, that is on families all across the spectrum. I have a great-nephew on the spectrum - my niece's son - who's been very well served, I'd say. He's not a complex case, but he's been very well served, particularly by the wraparound approach that is becoming more common. One of the best things that has supported my family has been respite care, without a doubt.

While I know you've touched on that in your response to Ms. Lohnes-Croft, I was wondering if perhaps we could go into a little bit more on respite, particularly from the Alternative Family Support Program, as to what types of respite services are available, because I need to convey that back to my constituents. I'll direct that to the Department of Community Services, perhaps Ms. Hartwell.

MR. CHAIRMAN: Mr. Rudderham.

MR. RUDDERHAM: One of the things that we've done, and we first did it in the adult program, was to increase the nature of flexibility and what parents and what families can use the respite dollars for. Traditionally, it was just to bring somebody in or to have their loved one go to another location for respite for the family. Now families can actually use the funding for a variety of opportunities. It could be going to the movies for example, it could be hiring very specific staff for example - basically, what it is, is what the family needs.

We've also looked to reduce the administrative burden on families. Keeping track of receipts and doing all those things for families who are receiving \$500 or less - we say, we don't want any receipts, we trust you; our care coordinators know who you are, know that you're using this money wisely, and using the money to provide support for your loved ones. So we've increased the flexibility of that.

We're also adapting the same flexibility in the children's program as well, so enabling families to use the resources the best way, because families know best and we want to make sure that families can continue to do that. There are no very specific limitations per se, there are some guidelines in the policy, but it is quite flexible.

MR. CHAIRMAN: Mr. MacKay, we have about a minute left.

MR. MACKAY: I would note that my niece and her husband's family are a military family and they have been in many jurisdictions and they certainly have commented to me that Nova Scotia, particularly as we're moving forward now with some of the programs announced, is a leader in the federation and that's good to hear.

In the time that's left, I'm just wondering - and perhaps, Ms. Gatién, if you could just comment - what the announcement yesterday means to your department and the services you'll be able to deliver.

MS. GATIEN: I think in a nutshell, it really means that inclusion will really be the driver of our work, first and foremost. It will be the work of the regional centres and the French school board and it will be really shifting the system to be more focused on needs: what do students need; what do teachers need? There's a lot of work ahead certainly, but we're anxious for it, we know it's needed, and it's really to respond to what we've been hearing for a number of years and it's exciting for us.

MR. CHAIRMAN: That is time, so we will open it up for closing comments. If we could keep them short and sweet, that would be great.

Deputy Perret.

MS. PERRET: Certainly, on behalf of the health side of this equation, we just appreciate the opportunity to be here and to participate in what is a very important discussion. Thank you.

MR. CHAIRMAN: Deputy Hartwell.

MS. HARTWELL: I reiterate that comment and just because I don't think I did a very good job of answering it earlier, I'm going to say it now. We have gotten to a point where we don't actually care who is the one that convenes the meetings. We are committed to working in concert, to make sure that when there's information that comes forward - whether it be a report, whether it be a new piece of research, whether it be a case that is one that we really all need to scramble on - what you see before you are partners that are ready to wrap around and forge a new way of working, and we're seeing some results. We still have more to do. We really thank you for the opportunity to talk about it.

MR. CHAIRMAN: And the last word is to Education and Early Childhood Development - Ms. Gatien.

MS. GATIEN: I want to thank you as well for the opportunity to be here and I really want to echo what Deputy Minister Hartwell just said. Whether we're the lead or we're a part of the team, we see it as we're all responsible to make a difference and meet the needs of students and teachers in our case as well. So we're really pleased and excited to work. This is a real wraparound service and we talk about a lot of that in our system. But this is what it looks like in government as well, how we all come together and work together to improve the lives for Nova Scotians. Thank you for the time.

MR. CHAIRMAN: Thank you for your time today and we'll give the committee 30 seconds for the witnesses to move out.

Okay, we'll jump right in. There is no committee business. (Interruption) The member for Pictou East.

MR. HOUSTON: Just looking ahead at the schedule, I think we have an open date on May 23rd. I would like to make a motion that we invite the Department of Internal Services to appear before committee on May 23rd to talk about protection of personal data and government's response when personal data has been compromised. Of course, people watch the news. We saw that the charges were dropped against the young man who was villainized in this House on numerous occasions by ministers and the Premier.

I would like for this committee to hear directly from the Department of Internal Services as to their plan for response when Nova Scotians' personal, private information is compromised through computer systems. I would like to make a motion that we invite Internal Services to appear on May 23rd.

MR. CHAIRMAN: Mr. Wilson.

MR. DAVID WILSON: I would support that motion. In light of the recent events and the ongoing question around the safety of information that the government has on Nova Scotians, I think it's important to bring Internal Services here. Government needs to be transparent and open, and here is a good way to do that. I would think the Department of Internal Services would welcome a chance to come to Public Accounts and discuss this issue. We would support that motion.

MR. CHAIRMAN: Ms. Lohnes-Croft

MS. LOHNES-CROFT: We voted on this twice before - very similar motions. We said before that the Auditor General and the FOIPOP officer are both investigating this. This can be brought up at an agenda-setting meeting, but we will not vote in favour of that.

MR. CHAIRMAN: This has been brought up several times before. The vote was clear the last couple of times. I will defer this to next week, when the Chairman is here, to allow a discussion around agenda-setting. I will wait for next week, for the Chairman to return. As was stated earlier, this has been voted on twice with yays and raising of hands.

With that, our next meeting date is May 16th. The Department of Seniors will be here for the Nova Scotia Action Plan for an Aging Population and age-friendly community grants.

Mr. Houston.

MR. HOUSTON: Just for clarity, there have been similar motions before. This is a motion that is placed before the committee today. Is it not necessary for the committee to vote on a motion that is put before it? Can a vote be deferred? Maybe you can check with Legislative Council. I would like to see it brought to a vote. Is that necessary, or is that at the discretion of the Chairman?

MR. CHAIRMAN: This has been brought up several times. It's essentially the same motion that has been here at the last Public Accounts. The results were no, to wait and see for the Auditor General and the Privacy Commissioner to do their work.

I don't see the purpose of voting on something again and again. This is an agenda-setting topic. If the chairman, when he returns next week, wants to have a discussion in

camera or in public around adding to the agenda, that will be up to the chairman. As of right now, I don't see the need to do that without the chairman here to help set the agenda.

With that, we will close the meeting.

[The committee adjourned at 10:59 a.m.]