

# **HANSARD**

**NOVA SCOTIA HOUSE OF ASSEMBLY**

**COMMITTEE**

**ON**

**COMMUNITY SERVICES**

**Tuesday, December 2, 2008**

**Committee Room 1**

**Provincial Autism Centre**

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## **COMMUNITY SERVICES COMMITTEE**

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Hon. Leonard Goucher  
Mr. Patrick Dunn  
Mr. Gordon Gosse  
Mr. Trevor Zinck  
Mr. Keith Colwell  
Mr. Leo Glavine  
Mr. Manning MacDonald

In Attendance:

Ms. Kim Leadley  
Legislative Committee Clerk

## **WITNESSES**

Provincial Autism Centre  
Ms. Cynthia Carroll - Executive Director  
Mr. Michael Price - Program Director  
Ms. Kristie McAllister - Board Member and Parent

**HALIFAX, TUESDAY, DECEMBER 2, 2008**

**STANDING COMMITTEE ON COMMUNITY SERVICES**

1:00 P.M.

CHAIRMAN

Ms. Marilyn More

MADAM CHAIRMAN: I'm going to call the Standing Committee on Community Services to order. Sorry for the delay but we needed to have a quorum and it's a very busy time of year for all MLAs, so we have a quorum now and we'll get underway.

We're very pleased to have with us representatives from the Provincial Autism Centre. What we'll do is, we'll introduce ourselves and then perhaps you could introduce yourselves and your other guests and we'll go into the presentations. I just want to mention that they've asked to have a little extra time to do presentations and I have agreed. They want to do a short video and I think it would be very appropriate for us to have as much information before we start our first round of questions and comments.

So Pat, would you like to start.

[The committee members and the witnesses introduced themselves.]

Welcome to you both and thank you for coming this afternoon. So we'll go right into your presentation.

MS. CYNTHIA CARROLL: Wonderful. Madam Chair, and honoured members of the standing committee, I'd like to thank you for having us here today. We have prepared a Power Point presentation, as well as a short video that we'd like to wrap up with today. All three of us will be presenting. We would like to start with Mike Price, our program director, followed by myself, and Kris McAllister will be the third person to speak, before the video. So we'll begin with Mike.

MR. MICHAEL PRICE: Thank you for having me. I'll start off by pointing out our vision statement there, which is "A World Where People With Autism Can Live Their Lives Fully", and I'll take the opportunity to go over some of our history and let you know about our programs and services and how we fulfill that vision.

First of all, some program history. We did a needs assessment across the province as we first formed - we were established in 2002 - called Navigating the System. Through that we were identifying service gaps for the autism community, and out of that came clear evidence that there was a big gap in services for adolescents and adults with autism, so we began to offer programs and services to the autism community.

First, we started an autism lending library, and we can say we offered the largest autism resource library east of Montreal. We have over 1,000 resources and a lot of current resources. We run eight different teen and adult social groups for people with autism themselves - historically, parents of children with autism have come together to support one another, but there has maybe not been the same approach to having people with autism come together, and we have people in our group ranging in age from 13 to 57 years of age.

Then we have Autism Arts, which is our first program for younger children on the spectrum - and it supports kids from 5 to 15 years of age - it's a partnership with the community, with the Art Gallery of Nova Scotia, and the Craig Foundation; we are piloting a Preschool Autism Arts program for children 3 to 5 years of age and that's sponsored by the Halifax Infant Foundation; we have a program called Autism Online which offers moderated chat groups for people with autism - this is a great way to connect with small-town and rural Nova Scotia and it's sponsored by the Mental Health Foundation.

We have a summer volunteer program we've been running for three summers now - this is an opportunity for teens with autism to enter the workforce and get some work experience from a younger age, so they can make better-informed career choices later on; we have a weekly drop-in centre for adults with autism; we have ASAN NS which is a self-advocacy network for adults with autism; the Autistics Aloud Newsletter - which I believe is in your package - that's a newsletter written entirely by people with autism, including the editor is autistic as well.

We provide to the community Autism 101 information sessions - we did over 50 last year, and as we've offered those our reputation has grown and we're invited to present at provincial and national conferences now. We provide public information sessions, helping people who offer autism services connect with the autism communities around a wide array of different disciplines.

With NSCC, we worked on what's called the Autism Tool Kit, which is a guide for students with autism themselves as they enter post-secondary education. It's meant to inspire and help them develop strategies to navigate university life. It's important to note, too, that we receive regular, daily support calls and e-mails from the autism community,

from parents, from people with autism themselves, and from employers who are trying to troubleshoot issues with employees as well.

And just quickly I will note that we do have a number of recognition awards - the Sheelagh Nolan Award, we have certificates of appreciation for outstanding work in autism, and both those awards will be given at our open house this Thursday. Then we have our Sobeyes Green Jacket Award, and there have been a number of notable Nova Scotians who have won that over the years - this year's past winner was Kym Hume.

Now I'll turn things over to Cynthia.

MS. CYNTHIA CARROLL: We want to begin by giving you an overview of our programs and services at the centre to give the standing committee an understanding of the demographic that we reach across Nova Scotia, but also within the autism community. We now want to move the presentation to discuss a little bit about our operating budget and a few more statistics that we feel are beneficial from an information-sharing point of view.

The Provincial Autism Centre currently has an annual operating budget of \$340,000. It's supported by the generosity of the community. Currently our administrative-related costs are approximately \$60,700, and our direct program and service costs, individuals and families, is \$279,300.

So what that number of the \$279,000 figure mark entails is direct costs related to the programs and services that we offer, and they include - Mike is going to go back one screen, and Mike spoke a little bit about these programs and services - the teen adult social groups, Autism Online, the costs of running our library and mailing out library resources across Nova Scotia, individual and family support calls, our Autism Arts program, our drop-in centre, education sessions in the community, the training and managing of volunteers, Autistics Aloud, supporting ASAN - our Autistics Self-Advocacy Network - and outreach support.

As I mentioned, we currently operate on the generosity of the community, through funding support and through major events such as our Autism Golf Ball event, which takes place every October during Autism Awareness Month. We also do a lot of grant writing at the centre; we have an annual holiday appeal; we have third-party fundraising initiatives; and in memoriams, endowments, and planned-giving donations coming to the centre.

A few statistics that we've been collecting and finding extremely helpful to us and also valuable to share with the standing committee is, on average, we currently have about 41 monthly walk-ins off the street - we're located on Brenton Street, which is right off Spring Garden Road, which is a high-traffic location. We also have 589 hits to our Web site, on average, every month with the exception of September, which always seems to be around 755. September is sometimes a challenging month for families, when they go back to school after summer break and the needs that are arising there.

[1:15 p.m.]

Out of those hits to our Web site, we have unique users that range from 189 to 326 per month, so there are unique users who are going to our Web site to learn more information about autism and find out about our services.

Mike mentioned this as well, but I think it's worthy of a second mention. We get over 100 support calls and requests monthly - that's not just from families and individuals with autism, but also educators, teachers, professionals and the community at large.

We currently have 85 children, teens, and adults who participate in our monthly programs, and all of those children, teens, and adults are linked to families and extended families and community members within the Nova Scotia community. And, as I mentioned, we fundraise on a regular basis, but we're also very aware that as much as we are striving to build long-term sustainability for the Provincial Autism Centre we have a 12- to- 15-month burn rate, which means that if we stop fundraising today we would have to close our doors between 12 and 15 months, and the impact to the autism community and all of Nova Scotia would be tremendous.

MADAM CHAIRMAN: Cynthia, before we leave that, could you just explain again about unique users, because I don't . . .

MS. CARROLL: A Web site without regular, repetitive hits. Unique users are people who have never been to our Web site before. Most of our hits - I think 90 per cent of our hits are from across Canada, specifically in Nova Scotia, but we do get hits from the U.S.A., and as far away as Australia, Africa, Guatemala, Kuwait, and India, but the 189 to 326 unique users are users who have never been to our Web site before, so it is the first time that they've arrived at our Web site.

I'd like to now move into talking about a few upcoming projects that our board of directors and the centre is committed to as we launch into 2009. One is an employment support program that is due to launch in January. This is a three-tiered program that actually will see the expansion of our summer volunteer program for teens between the ages of 15 to 19, to help them explore career options, but also to help them build life skills, opportunities, and social skills in the community.

The second tier of this program will include autism in the workplace educational sessions, which will support employers who are hiring individuals with autism but also help the employee with autism have success in the workplace. As well, a supported employment program which will actually be similar in the form of job coaching, but also going into the workplace for the first little while and helping those adults with autism and individuals to kind of navigate through some challenges, but also work with co-workers as well and ensure that there's success.

We also, as Mike mentioned, have the expansion of Autism Arts to preschoolers in Yarmouth, Cape Breton, and New Glasgow and that will begin in January, 2009, and throughout the year. Another project that we were partnering with the Momentum Group on is an innovative autism Web site. This Web site will include web technology that will enable on-line communication between support groups across all of Nova Scotia. It will be a shared platform of information that will include blogs, networking tools, live question and answer utilities, and direct ways for individuals, communities, and businesses to get involved.

Our vision for this Web site is that no matter where you are in the world, specifically in Nova Scotia, that when you go on to this new Web site, you'll be able to click anywhere in Nova Scotia. So if you are in Yarmouth, you could click on Yarmouth and you'll be able to find the autism resources in your area - or lack of - but you would also be able to go across Nova Scotia and find out how to connect with professionals, medical professionals, community and non-profits. There will be links to the Autism Society of Cape Breton, to VAST, the Valley Autism Support Team, anywhere where families can get support. We're also hoping with the live question and answer utility that we can continue to engage the community, as we have over the last six years, and get them participating and supporting the autism community throughout Nova Scotia.

What we are here to propose today is we're hoping that - the Provincial Autism Centre is proposing a partnership with the provincial government. We certainly are collecting numerous statistics that we feel are valuable, but also helpful, in sharing with the provincial government, and also being able to reach more families and individuals with autism throughout Nova Scotia. What we're asking for, or what we're proposing, is support of \$500,000 over five years, which works out to be \$100,000 a year for five years.

The benefits of a partnership with the provincial government would show long-term cost savings with respect to adults with autism, families living with autism, and community service programs that currently have a tendency to miss the mark with respect to the needs of individuals and families with autism. It's a partial solution to the skill shortage. Certainly there are many adults with autism who are wanting to participate and give back to their community and they certainly have the strengths to do that, they just lack the support to be able to have success in the workplace.

Less strain on the health care system - adults with autism are at high risk of depression and other mental health concerns. Ideally, we are looking for a partnership with the provincial government so Nova Scotia is seen as a leader in autism by addressing and investing in the lifespan issues of those with autism. We don't want people leaving Nova Scotia and going across the country - we believe in Nova Scotia and we want to be the leader, we want to be the leader together for autism in Nova Scotia.

I'd like to now turn the floor over to Kristie.

MS. KRISTIE MCALLISTER: I truly want to thank you for the opportunity to speak with you today, I know how busy your schedules are, so I really appreciate the time.

My name is Kris McAllister and I'm the mother of two wonderful, beautiful sons, Alexander and Dylan Knox, who are 20 and 19 years of age. Both of my sons have autism. I'm now a member of the board of the Provincial Autism Centre, and my husband and I will do whatever we can do to support this vital organization.

As parents we are deeply disappointed that provincial health care has still not established a system to respond to this silent and growing emergency. We live each day, week in and week out, building ongoing supports and trying to survive in a province that does not acknowledge critical lifespan needs.

There are none of the traditional supports that most people dealing with a disability can rely upon. For instance, the vast majority of physicians have never received training in developmental disorders, and autism is the most complex. Another source of support increasingly used by governments for social intervention is the non-profit sector; in our case this would be organizations established to assist people with disabilities. We sought help from local, provincial, national, and non-profit organizations as parents, and not one of them was equipped to assist our children or understood the particular needs of our family. Even worse, some well-intentioned organizations and individuals, trying to be all-inclusive, offer inappropriate assistance. Ill-informed support can be unintentionally destructive to people with autism. Autism in Nova Scotia is the special needs group of the special needs community.

Frustration, humiliation and despair over lack of services have been made worse by the media attention that autism has received in recent years. The public assumes this immense coverage has created positive results - it has not. I compare this phenomenon to the 2005 hurricane disaster in New Orleans. The coverage was massive, but the attempts to help were feeble. The country assumed that the cavalry was on the way - it wasn't.

Most individuals with autism and their families have felt as abandoned by the system as the victims of Hurricane Katrina. The divorce rate for parents of children and adults with autism is higher than families struggling with cancer - it is over 85 per cent. Many of us lose hope, and hope is huge when you deal with a challenge that gets so very little public, non-profit, and government support.

The lesson we have learned in being a surviving couple of this community is that it is not the kids that create the stress, it is dealing with the system. Over 40 per cent of people diagnosed with autism will also be diagnosed with a mood disorder - this is a fact that even the Kirby report did not acknowledge. Many individuals with autism fight despair and loneliness, trying to survive in a world that can more easily grasp concrete, physical and intellectual disabilities but can't grasp the complexity of this disorder and the needs that accompany it.



Like the majority of families who deal with the battle for services for autism - the financial and emotional stress is huge - we have fought exhaustion, bankruptcy, despair and hopelessness. The lack of credible services and supports is mind-boggling. It has almost cost us our home and our health. Two years ago I almost lost my husband. He had lost hope in his ability to provide for our children and their future. One year ago I almost lost my oldest son; he had lost hope for his future as a person with autism, trying to live in the community.

My husband has built a company which now employs 40 people. The Provincial Autism Centre is one of the reasons we stay in this province, and we want our business to be successful so that we can support the centre and also to ensure our sons do not end up in long-term care which, in Nova Scotia, is horribly inappropriate for individuals with autism. Hopefully, the Registered Disabilities Savings Plan will be adopted in Nova Scotia as income and asset exempt, as a majority of other provinces have agreed to.

It was very emotional for me when I entered the Provincial Autism Centre for the first time. We saw hundreds of books on autism that I could take home and read. For years we either could not afford the literature or we literally didn't have the energy or time to search for it. Here was a place that could separate the snake oil from the truth for us. I was speechless the first time I spoke with a support worker at the centre who actually understood autism and the needs of our sons and our family. I know the wonderful people at the centre deal with many families in crisis. I was so happy when I found out that the centre offered social groups for teens and adults with autism. They knew how to set up the environment so these groups would work. The centre has even established support for adults with autism who are trying to break into the workforce. This support is absolutely vital.

Soon our sons will leave high school and the support of the IWK Autism Team and Maritime Psychiatry, and without the Provincial Autism Centre there would be absolutely no supports for them. People with developmental disabilities once had a shorter lifespan, now they will outlive us.

The disorder is not rare, the services and supports are. The centre is the only organization that supports adults with autism. Please know that the Provincial Autism Centre is literally a lifeline for parents and for people like my sons. It is the Provincial Autism Centre that gives my husband and I hope for the future of our sons and other adults like them. Our sons will be in the adult world for much longer than they were children. Thank you.

MR. PRICE: Thank you, Kristie.

I'm going to queue up this video to show you now. This explains our employment initiative that we'll be launching next year.

[A video presentation was played.]

MS. CARROLL: In conclusion, I just wanted to again thank the Standing Committee for giving us this opportunity to present. I just want to close with - the Provincial Autism Centre was founded in 2002 and started out as an information resource centre and began program developments based on the needs assessments that Mike spoke about, by going throughout Nova Scotia. So our programs have been around for four years and the growth has been unbelievable, based on the need of the autism community. I can honestly say - we currently have three full-time employees and two part-timers. One is a part-time occupational therapist who facilitates our autism arts program and our social groups and another part-timer we're fortunate to have now on a grant that's linked to the Adult Self-Advocacy Network.

We're really operating at maximum capacity. I guess what we're kind of presenting today is the hope that the provincial government will plant the seeds - we will continue on the path of progress because we believe in supporting the families and individuals with autism, but also educating the community at large regarding this issue. We'll get there, it might take six years but we're hoping that with a partnership, we can get there in three and be seen as real leaders in Nova Scotia, so thank you for your time.

MADAM CHAIRMAN: Thank you very much. That was an excellent presentation. Yes, Len, would you like to start.

HON. LEN GOUCHER: Thanks very much. That was quite a moving video, actually. It was great to see Ruth Goldbloom and Pier 21, who I have some connection with and Stewart McKelvey and their involvement.

Looking at the whole issue - I was looking at, in doing your presentation you talked about Yarmouth, Sydney and New Glasgow with opening, I believe, a preschool? How important, and you're going to have to forgive me on this, I've got a friend, actually, who has two autistic children as well and I should know more but a lot of us don't and I'm not scared to admit that. How important is early intervention with children who are autistic? Does it help? Does it improve their chances for success as they get older? Or is the early intervention just - I guess it's just a question with regard to success when you look at them as they grow up and go through life.

MR. PRICE: I'll speak to that, sure. I think if you look at the program in Nova Scotia, for instance, the big principle of it is to bring communication skills out of a child. I think it's safe to assume that that will prevent the need to access all sorts of other special services over the course of their life, if they have that functional communication from a younger age those other services won't be needed. That's why I think, for instance, our employment program I look at somewhat of a similar way, that by supporting someone upfront, they won't need to keep accessing expensive services overall, over time.

MS. CARROLL: Well, I also feel that if you talk to any child development specialist, whether a child has autism or doesn't have autism, they're neuro-typical, they certainly would be able to explain the importance of the first five years of life from birth

to age five, and I don't think early intervention for autism - certainly there's an argument to be made there as well. I don't know that at the Provincial Autism Centre we would want to comment too intensely on early intervention because we like to leave that to the experts like Dr. Susan Bryson, Dr. Isabel Smith and the early intervention specialists we have in Nova Scotia. Certainly the program that we have is an excellent program and it appears to be getting very positive results. Us being here today is, if anything, evidence that autism is a life span issue that starts at birth.

Although we're talking a lot about teen and adults because of significant service gaps there and there is currently no funding for teen and adults at all, we know that there's a long way to go in all areas of lifespan issues for autism and I think early intervention is no . . .

MR. GOUCHER: The only reason I ask is when you look at our own lives, a normal life, and I look at my grandson who went to pre-school from 3 years on and the socialization aspect which probably is very difficult, learning, I think is for the average child, is very beneficial to them - I was just wondering, from the standpoint of an autistic child, does the early intervention help them?

And I know for the - and I'm sorry to use the word, average - but for the average child it appears to, in a lot of cases and I was just wondering for an autistic child, would it be the same benefit to an autistic child?

MS. MCALLISTER: Can I comment? Just from a mom's perspective, I always liken the early intervention for people with autism to the window of opportunity that people have after they've had a stroke or a brain injury. We know about the neuroplasticity of the brain that - actually when I asked Dr. Sarah Shea, the director of the clinic at the IWK, why she was so passionate about autism, she said because you can do so much.

As a family, we tried our best to pull together early intervention services for our sons, but I'd like to say the early intervention is crucial, but it only focuses on the first six years. That's the first decade of someone's life. Now, as a parent - and my sons have to think about the next seven decades and my sons personally made the most progress since they were six years old. I'm a firm believer in the early intervention.

MR. GOUCHER: Thank you very much.

MADAM CHAIRMAN: I should mention also that we've been joined by Minister Ron Chisholm from Guysborough-Sheet Harbour and Leo Glavine from Kings West. Next I have Pat, then Keith, then Leo.

MR. PATRICK DUNN: Thank you for being here today and also for being the voice for autism, or for the awareness that you bring into all sectors of society, not only in our province, but right across the country through the Internet.

Of course, the most important of all this is the support system that you are putting in place which, no doubt, is very beneficial to people who have autism and families that have the emotional stress and so on. I'm wondering if my friend - the MLA for Kings West - will have similar experiences; we're both in the educational field. I can remember over 30 years, and I remember back in the mid-1970s, the awareness certainly didn't appear to be there. Compared to now, it's like night and day. As my teaching career continued to go on, I can remember back where as far as resource material, strategies for the classroom teachers and so on, the educational part of it was lacking, as far as the inclusion of everyone within the classroom setting and so on.

Having an interest in sports too, I notice a lot of people involved in sports having children with autism - Doug Flutie would be one, Scott Mellanby, an NHL hockey player and you can go on and on. Apparently boys are three to four times more likely to have autism as opposed to girls. Any particular reason why that happens? Is it something to do with genes?

MR. PRICE: That's what I was going to say, something to do with genes. Of course, there's so much research going on into autism right now and our understanding evolves and changes all the time. All I think I can do and anyone can do is sort of guess at that sort of thing. Some people have guessed at it and I could share some of their points of view, but I guess I don't have a point of view myself.

For instance, one of the leading ones is that the brain in autism systemizes and is the classic male brain, in a sense. Simon Baron-Cohen at Cambridge University, that's their main focus of research. So it is a genetic component, what that genetic component is, there are lots of different theories out there.

MS. CARROLL: The Hospital for Sick Children in Toronto is doing a 15 year-long gene study on autism and they've been making some considerable progress and discoveries around the genetic components of autism. I think there are genes they're linking to autism. As complex as autism is and everyone is unique, what they're finding out, even from a DNA perspective, is that it could be any one combination of genes, which makes it really difficult to try to pin it down as well.

[1:45 p.m.]

MR. PRICE: There's not just one gene associated with autism - there's up to six and maybe more.

MS. CARROLL: Down's Syndrome might have one, but autism has a variety and it could be any one of those combinations. The possibilities could be endless and how do you narrow that down? The mysteries in some ways are unlocking, but still continue on different research levels.

MS. MCALLISTER: I was just going to say, our family is part of that study. I'm proud to say that Canada has led in the forefront with that and so I get information about the study that I often don't share. I think they've discovered over 13 genes and ever since the CDC announced in the States that they consider this a crisis health situation, more money has gone into the research. This study is one of the first times that such a complex study has been collaborated around the world by so many scientists. Scientists used to just guard their information, but for this people are breaking down a lot of barriers. There's some hope there about some answers.

MR. PRICE: That's the Autism Genome Project, right?

MS. MCALLISTER: Yes.

MR. DUNN: Going back to the classroom, again this is just my experience in my area in my former career, the inclusion certainly created a lot of challenges for teachers, but I believe the challenges were heightened because of lack of support systems and resources and so on. One thing I found to happen, practically all the time in my experience, was the acceptance of other students with students that had autism. That seemed to always be there, in my limited experience which I always appreciated at the time.

Just one last, quick question, any comments on the interaction of the educational system from your centre?

MR. PRICE: Quite a bit actually. We serve on the Autism Advisory team with the Department of Education and we have for a couple of years now. That's led by the autism consultant for the province and supports each of the different autism lead teams in the different school boards. We've worked with them.

We've had a relationship with the Department of Education around - of course they access our resources and we had a post-high school transition committee that members served on, the provincial guidance counsellor person and the provincial autism consultants, so we've partnered on that level. Maybe even more importantly is all the support to different education assistants who come into the centre when they have a chance after school just to get some good information for that kid they're going to support the next day, teachers or resource teachers who come in and are able to try on different resources and try things out, so I think in both ways we've worked well with the Department of Education.

MS. CARROLL: We've also done quite a few presentations to bus drivers around the HRM, for the Halifax Regional School Board. These children are on bus routes - how do you manage those social situations? I mean, the playground is a battlefield and the bus ride home is no exception. Recently Mike did a presentation to HRM bus drivers, we've been around the province to Membertou.

MR. PRICE: We've done a lot of support actually to the Mi'kmaq community around education. We presented at the Atlantic conference this year and have worked with MK, the office in Membertou that supports the Mi'kmaq school system.

MR. DUNN: Thank you.

MADAM CHAIRMAN: Thank you. Keith.

MR. KEITH COLWELL: I'm very interested in the employment program you are kicking off in 2009. I realize it's probably not for everybody with autism but hopefully for a large number of people, as you go forward. What's your biggest obstacle from actually working with somebody until they can get a job? What is the biggest obstacle that you have, is it training or is it support for the training?

MR. PRICE: Honestly, if I can jump in there, what I find is one of the biggest obstacles is - in early childhood, autism is so challenging, there's no question. It's really hard to be a parent for a child of autism, so much of their early childhood is spent accessing services and making sure we help them learn to communicate and they are able to get through school and get that education. Maybe there's very little room for dreaming for yourself and saying, again, that video showed kids talking about - I want to be a paleontologist when I grow up. I think so many times people are discouraged over the years, by the time he hits his teenage years, I hope he's still saying that. Part of me thinks at that point, he'll maybe be doubting that he'll be able to be anything in the world so I think having people's self-esteem stay intact so that they continue to dream for themselves into adulthood - I think that's the biggest challenge.

MS. CARROLL: From an operational perspective, Mr. Colwell, you're absolutely right - there's the funding and the training that is associated with bringing in a program like this so it is successful. One of the things that we really looked at was the Division TEACCH model, which the Department of Education has spent a lot of time in North Carolina learning about it. I know Kym Hume is very familiar with the Division TEACCH model and you mentioned it would cover as wide a range from the spectrum as possible and that's in some ways the beauty of the Division TEACCH model because it can be adapted for very high-functioning individuals who have autism, but also can be modified to individuals who may need a little bit more support in the workplace. You could have a dentist who is on the spectrum, but you also might have somebody who really enjoys data entry, or architecture, or mechanical engineering. It's also creating the awareness piece - this isn't just about creating job coaches. It's about forming those community linkages with existing organizations, sharing and getting trained in the Division TEACCH model.

Just as autism is a lifespan issue, this employment program has to be a holistic approach. It's not just about supporting the individual, it's supporting the workplace to have success as well because it really is a mind shift. Autism is a social communication disorder - it's not an intellectual disability - so those who are employment-ready have the capabilities and the strengths to get the job done. In some ways, it's like being on the

playground in the school system when you're at school, sometimes the social battlefield has moved to the workplace.

How do you help colleagues and employers understand that you just need to make a few social accommodations and understand autism, so that if an individual with autism walks by you and doesn't say hello, it's not because they don't like you; don't personalize their actions. It's because they're very focused, they have an acute attention to detail and they want to do a good job and be conscientious, but they sometimes miss all the social cues. So it's about educating employers, supporting the individual and trying to reach that teen group, that pre-teen group, which we've done through our summer volunteer program. That has had huge success - some of our members have been in the program two years, and some have actually gone back and been employed by those employers the following summer. That really speaks volumes, as we're getting out there, just like autism awareness is getting out there when individuals with autism are in the workplace. Employers - as you saw in the video - are saying wow, this really is the undiscovered workforce. We know it's not going to be a fit for everybody but it is a fit for many. I think we're underestimating how many.

MR. PRICE: I'll give you a for instance along those lines. There's a company in Belgium called Specialisterne - 40 employees, all are autistic. What they realized was that they would have a competitive advantage if they employed only autistic people - only people who weren't concerned about the social dynamics at work and would just focus in on developing software - and they've won several awards. They're a regular Microsoft client and they do quite well. I think it's because they recognized the strengths of autism, they didn't just decide to try to include people in the workforce. It wasn't a charitable act, they actually are successful because of autism.

MS. CARROLL: We believe in the program that we are in the process of developing and, to be completely honest, we don't have the money in the bank to launch it full out of the gates in January, but we're going to chip away. We know, at the end of the day, whether it takes us a year or two years to get there, we know that we are going to have a solid program that is going to be well researched, supportive and holistic, so that when it is operating at maximum capacity, full capacity, that it will be a program that will be not only innovative in Nova Scotia, but possibly in Canada. So we're very excited to be embarking on this journey and our board is extremely committed, as are we, as a team, at the centre.

MR. COLWELL: It's very exciting, actually. As a former employer, it's always hard to get really dedicated employees. There are a lot of excellent workers in Nova Scotia, needless to say, but it's another avenue. I would think that probably your biggest problem is - you go through the training, you can sort of have an institutional system to do that with a person and adjust for that person. I think your biggest problem is going to be with the employers.

I know that one time in my business, there was a young man who approached us in a wheelchair to work; just a mobility issue and nothing else. Unfortunately, for other reasons, he didn't come to work with us, but it created all kinds of problems for us, initially, but once those were - and we looked at how we could make everything accessible, really is what the issue was at that point. It was a really big issue for us to change how we did business. But, when you looked at the credentials of the young gentleman who was coming, it was worth it. Unfortunately, he did find something else that he liked better and that was fantastic.

I think we missed an excellent employee out of the whole thing, just the idea of having someone there who really was dedicated to what they're doing. A lot of people aren't very sociable anyway in the workplace, in a very competitive work force.

How do you envision that working? How do you envision going to companies and selling them on the idea? Here are individuals who may be very, very helpful to your business, because that's the way you're got to sell it.

MS. CARROLL: Absolutely. We also have a Program Advisory Council that we've struck at the centre which includes affluent members of the business community, we believe, as well as medical professionals and community members who were talking about some of those issues.

With respect to our employment program directly, we launched this video at our autism golf ball event very strategically because we had a room full of potential employers. I had three conversations that night with large organizations that are all interested in the employment program for the exact reasons that you talked about.

One of the reasons why we're so keen on having this educational piece - it may be at the centre that Mike and I begin to go out, and other volunteers begin to go out into the workplace and educate, but the model that we want to work from is we want business professionals to educate business professionals, very similar to the Junior Achievement model. I don't know if you're familiar with that model - they have 1500 volunteers across Nova Scotia. What better way for us to lead in autism, from an awareness and education piece, than to get other colleagues sharing information about autism with other colleagues? So that's part of the model that we're looking at.

We're going to use the community linkages that we've built within the business community, and hopefully I have a few ideas around how we can do that to start to open those doors. Once the doors open, I think they'll come quickly. I mean, if you look at the growth of the Provincial Autism Centre in the last four years, I say it's like a dam - it's overflowing and it's kind of cracking and we certainly are at maximum capacity in many ways at the centre, but it's hard to say no.

The needs are out there, but we know we can't be everything to everyone. But we know the programs that we focus on, if we invest the time and build a strong foundation,



there will be quality, innovative programs that will really have a strong impact, and that's what we're going for.

MR. COLWELL: I think that's a really good approach and I'm really excited about this because so many times you see people with difficulties, whatever the difficulty may be - they don't quite fit socially, or whatever it is - and usually somebody wants to put them away somewhere or just ignore their abilities, and it's really good to see that you're working toward employment, as one of the things you do of course. That really will help everybody - number one, it will help people understand more about the problem that individuals have; plus, I think it will add to our economy dramatically.

MS. CARROLL: Absolutely.

MR. COLWELL: I mean if you can take someone and make them feel, number one, that they really belong and are helping themselves and their employer and the province as they move forward, it's pretty exciting what you're doing.

[2:00 p.m.]

MS. CARROLL: We're very excited.

MR. COLWELL: On the side of potential employees, say I was still running my business - which I don't anymore - and I come to you and I say, I have this particular job I think may fit somebody you have. How do you go about training that person so that when I get them, I have the least amount of difficulty integrating them into the job they're going to do, number one, and into the business? How do you approach that? How do you plan to approach it?

MR. PRICE: We would spend a lot more time up front with that employee to make sure they understood not just the rules of work, but the whole dynamic in that workplace. It would be things like what sensory considerations do you need to have - is it a noisy workplace, are there fluorescent lights and different things like that? - so they can prepare strategies ahead of time for dealing with those things, that there's not something that sort of throws them off. So helping them come up with strategies to talk about autism amongst co-workers, that it's a different type of conversation you're going to have with your employer or with a customer, or something like that, so to at least help people troubleshoot the sort of issues that will come up around talking about autism.

For instance, if I'm someone who needs to spend lunchtime alone in order to recharge my batteries and stay focused for the afternoon, I need some sort of strategy to explain that to my co-workers because if I just get up and leave right at twelve o'clock, then they might all think, gee, he doesn't like us very much, or he's rude, or all sorts of assumptions. So we'll really work with them to make sure people aren't making false assumptions about them.

Also, some people will need visual strategies. For instance, our summer program, the tasks involved in a job, we'll sort of lay out a checklist with some visual cues for each one. So for instance, if someone is working at a museum and there's a certain process they have to follow to close, we would sort of lay that process out for someone on a checklist so they can follow it, and then the job coach's role would be to sort of fade that tool out so they wouldn't need it anymore.

So they might come in the door using something like that or all sorts of different types of accommodation approaches. Then, as they get more competent and comfortable with the job, and as co-workers get to know them and as natural supports, as we say, sort of come into place - because the reality is that none of us do our jobs in isolation. We all get support from co-workers, and different people have strengths and weaknesses and we work together as a team. I think our approach is to help people with autism fit into that team and recognize that they bring strengths to the workplace, and how we help those strengths come through rather than being left having people make assumptions about them.

MS. MCALLISTER: I just wanted to say that I got a lot of good advice from the Autism Centre, which I took back to the learning centre, because both of my sons still go to high school. Of course, they were born in 1988 and 1990, and that's sort of the beginning of the tidal wave of people with autism who are heading into the system, so we keep having to break new ground in the education system. So I got a lot of great advice.

One of the pieces of advice I gleaned from the centre is that I did raise the benchmark a bit for my son. I really wasn't quite sure how we were going to get him work experience, but we shared the information with the learning centre and now my oldest son started out with support at Jumbo Video - we live out in the St. Margaret's Bay area - and he had support at the beginning, but it has faded back and now nobody is there, so he fits in actually wonderfully. Then he did volunteer work at Feed Nova Scotia and actually was just on the front page of the Masthead News, saying: Student with autism sets example for a community, because he raised a lot of food for Feed Nova Scotia.

I don't think I would have pushed the benchmark if I hadn't had the support from the centre, and the learning centre passed that on to the high school as well. I think it has had a ripple effect with the other students at the high school, of which there are probably eight or nine who want to get out and get some experience in the workforce while they still have some support in high school.

MS. CARROLL: The other piece of this program that we're talking about too, it has huge implications - think of co-op programs in schools, to be able to expand and reach a younger generation that Kris just talked about. How many teens with autism have the option to participate in a co-op program at their high school, but to have a program with a model like the Autism Centre that's transferrable to actually be able to then have those students have an opportunity to participate in a co-op program and have the same career exploration opportunities as any child would have in the school system.

MR. PRICE: I just wanted to say, sometimes because supports aren't there parents don't feel safe to challenge their kids to do more and more. I've been in situations, for instance, where the whole support team decided if someone was going to go to NSCC to fix elevators, when we explored it with the faculty at NSCC they were saying look, he knows more about theoretical engineering than we do - we can't teach this guy, we're learning way too much from him. He should be at Ryerson, he should be taking theoretical engineering. But the answer back was no, no, we know a guy and he fixes elevators and he'll be safe with him and that's what he's going to do, so it goes both ways.

I think having an agency like ours so that employers know they can check in with us - this happened, is it something autism-related or is that just him - or a person with autism can check in with us. Parents, as well, know that they can let their kids go a little bit and there is a safety net for them.

MS. CARROLL: And that's tough. We see a lot of families come in that have really - for all kinds of reasons - protected and done a wonderful job of keeping their child with autism safe and sheltered. They want them to be happy but they're really struggling with that transition phase of the exact example that Mike just gave, where someone with autism would have this amazing knowledge and ability but the parents are kind of struggling with wanting them to gain their independence but that letting-go period as well. So we spend a lot of time talking about some of that, as well, at the centre and it really is that fine balance we struggle with - I mean, I'm a mother of two children, but now I think I'll struggle with that - I can imagine having a child with autism and the intensity that comes with that. So that's something else that we regularly do.

MR. PRICE: And, of course, historically there has been no understanding.

MS. CARROLL: Rightfully so, parents don't want to kind of put their child out there because - do they understand my child, are they aware of autism?

MR. PRICE: I have an autistic sister and she has really just found her niche in the workplace in her early 30s and people say, oh, that's so young for someone with autism to find their niche in the workplace, because sometimes it's not until their 40s even that they can find that fit.

MADAM CHAIRMAN: Thank you. Leo.

MR. LEO GLAVINE: Thank you, Madam Chairman. Thank you, Cynthia, Michael and Kristie, for being here today, it was a wonderful presentation. I'm sorry I was a little late but there was a little delay on the highway today. Kristie, is this your second time appearing before the standing committee - were you ever here before?

MS. MCALLISTER: No.

MR. GLAVINE: Okay, it must have been another mom of autistic children that I'm getting mixed up with.

Anyway, there's certainly a number of comments I could make. I've been associated now with autism in my area of the western part of Kings County and Annapolis for about 10 years and much longer, of course, like Pat, as an educator. Although we had the general label of behavioural, slow, developmental issues around children who we now have firmly diagnosed as being autistic. However, there are still adults out there who were in the school system for a period of time.

One further little comment - I want to commend you for acknowledging the work of Kym Hume with the Sobey's Green Jacket. She has been a real pioneer in our area and perhaps in the province, actually, with the work that she has done.

Also, I am pleased that you have a provincial perspective. You know you've got all kinds of demands right here in metro but I think having this provincial mission is really important for the province. Are you going to embrace the lifespan or do you see yourself perhaps a bit - will the workplace become your central focus? Or are you going to see the lifespan issues associated with autism and Asperger as being key? A little bit about your mission, I guess, I'd like to have you expand on it.

MS. CARROLL: I know you mentioned that you came in a few minutes late, so I know Mike did present that for the last two years, our autism arts program - in partnership with the Art Gallery of Nova Scotia and the generosity of the Craig Foundation - has really been the first program that we've offered to children with autism. So historically, up until two years ago, our focus has really been on the service gaps of teens and adults, and also at that time the province. A few years ago, early intervention had come in as well.

With respect to where do we go, when we developed the programs, we did do a needs assessment throughout Nova Scotia and we met with families and individuals with autism and that was the greatest need at the time, that we were doing the navigating the system survey throughout the province. So what we like to say is that our programs and services at the centre have really been - we've been really listening closely to the autism community and that really has been guiding what we've been developing and where we've been going to date.

So to answer your question, I guess there's no kind of simple answer right now. With preschool autism arts launching in some rural areas of Nova Scotia, we, I guess, can effectively say that we're touching from preschool right to, I think 55 is kind of the span that we are offering programs and services to now.

We do feel that the employment component is a significant component, that there are significant teen adult service gaps and, as Kristie mentioned, we live most of our life in adulthood so that certainly is an area that we are committed to continuing to focus on. Mike, I know that you want to say something.

MR. PRICE: There have been a few major surveys of adults with autism as well. Most notably is that one called Think Differently About Autism, in the U.K. and through those it has become clear, and it's clear anecdotally - we hear it from the adults we know at the centre - that they key issue for adults is employment. Finding suitable employment would improve lives more than anything else. So I think that's certainly a top priority but not going to be the only one.

MR. GLAVINE: I do thank you for that because my own observation here, being associated with two sheltered workshops - the Flower Cart and the Bee Hive, and in particular, the Bee Hive in Aylesford. When I go there, I take a look at the fact that most of these men and women also live in small options homes. When you take a look at the cost to the province for a lifetime, I mean it is absolutely incredible.

Do you hold out real hope and possibilities for some of those people? Like this one young man, Michael, is about 39 and I think he speaks less than 10 words. So his employability, to me, seems very, very limited, but isn't there hope for moving some of these people from sheltered workshops to an expanded job possibility?

MR. PRICE: Absolutely. For instance, we've referred to Division TEACCH and their program a few times - there are different models you would use for different support levels. For instance, someone who required maybe more support on the job, you would look at maybe a work team of maybe three or four people with a job coach. Maybe that job coach wouldn't ever fade their support, but they're still doing sort of dignified work in their communities and contributing.

Sometimes they get pleasant surprises when someone is in that model for a long time, but they are able to break out of it because they develop some work skills. I think the lack of opportunities - we will never see people's full potential until they have the opportunities.

When I used to work in Vancouver, we had a very different approach to supportive employment and I had a lot of clients there who were very successfully employed and ironically sometimes people say about people with the same functioning level here, oh, no, they'll never be employed in the community. Well, I saw it first-hand many times.

MR. GLAVINE: In terms of the EIBI program and the provincial initiative which is bringing about very strong results - I know you want to be very collaborative. I take a look at pre-school, school, post-high school, employment areas - you want that pan involvement, but would you get into the EIBI program if your funding and resources were to permit that?

[2:15 p.m.]

MS. CARROLL: I think it's hard to give a definitive answer to that because we would have to see what does that mean, what does that look like for us. What does it look

for the movement that's kind of happening in Nova Scotia with EIBI. I think I mentioned before, our programs and services and our board of directors has always listened to the needs of the autism community and if the need was there and it was a fit, we would consider any opportunities to support initiatives that were happening in the province if we were able to do so with the proper funding support and the credentials on our team.

I know that Nova Scotia really is, in many ways - some of the autism research that's happening in Nova Scotia, we need to be very proud of. There's a lot of innovation happening in Nova Scotia and I think I mentioned in my presentation, we want people to come to Nova Scotia for that autism innovation and not leave Nova Scotia. We're very interested in the development of a strategy, whatever that might be, to make that happen. I certainly wouldn't rule it out, but certainly our focus at this point is teens and adults.

With our infrastructure because we see the dam as overflowing, but we also know we can't be everything to everyone.

MR. GLAVINE: I asked you that question because it was a little bit of a set-up in many ways. We lost a medical team, two doctors, because they decided to go to Manitoba where there was a stronger program. Not to be too aggressive politically here, there's enough going on in Ottawa, but one of the most striking headlines for me personally, as an educator, was in the ChronicleHerald: EIBI successful, Tories will not support.

How do you react to that? The Provincial Autism Centre? With the work that's being done and the pioneering work. Are we missing out here on something?

MS. CARROLL: You know, how do we react at the Provincial Autism Centre? We want, to be completely honest, there's a lot of wonderful work happening in addition to EIBI across Nova Scotia that hasn't been hitting the headlines. So, I guess, for us in some ways, that saddens us because there's a lot - not just the Provincial Autism Centre, there are a lot of other grass roots organizations doing that, but EIBI - if we could wave the magic wand, would we at the Provincial Autism Centre want early intervention to reach every family that needed it? Absolutely, we would want that.

They say an ounce of prevention goes a long way, so certainly we are supportive of those initiatives. We also are aware, as Kris mentioned, that her sons really started to begin to develop from six and up - they had considerable progress during those chronological ages and now that they're getting ready to go into adulthood they're going to spend potentially seven decades in adulthood. I think that there needs to be balance, I guess that's what we feel.

MR. PRICE: I just wanted to say too, we were talking about the EIBI Program and the province, again, it's not part of our mandate or whatever to speak about that, but I did want to point out that you can't really compare apples to oranges which I think some people do in the media right now. For instance when we talk about other provinces having a wait list for a very different type, older program - in Nova Scotia, we have a very innovative

program. It's not as labour-intensive, so it's more productive than other provinces' programs. Should it be made accessible to all the kids? Probably, those that need it, but I think the goals are a lot more focused. They're focused on communication rather than maybe other provinces where they cover everything.

MS. CARROLL: I just wanted to say one thing. I think what we need to be doing in Nova Scotia is we need to be looking at a continuum of care here. I guess early intervention is critical, absolutely up to age six, then these children with autism are hitting the school system and you mentioned Kym Hume, who has done fabulous things within the school system and she's in the Annapolis Valley, but there is even a difference in what all the schools in the Halifax Regional School Board are doing, so there isn't consistency and a consistent continuum of care. Then, you know, these children are moving through to adolescence and we all know that adolescence is a time where you want to become more independent, you want to kind of fit into your social network and start to explore your community.

These adolescents with autism, there are zero options for them - where do they go? That's one of the reasons why we started the Teen and Adult Program so they could find that very sense of belonging that many of them were looking for. Then when you turn 19 and you lose the support of the autism team and mental health, then you're even more isolated but not just the adult now with autism is isolated, but the family who was able to access limited support and now has no support. There really is a fragmentation in the whole continuum of care piece.

We're talking about employment which is a significant service gap and you're right, there are huge financial savings and implications there. But I guess when we see government won't fund early intervention, I wish someone would say, where's the commitment to the full continuum of care? It is about early intervention, but they're one piece of the puzzle of the large picture that spans from birth to potentially 90 and there are big issues here. I guess at the Provincial Autism Centre, we value all of those areas on the lifespan so we're not going to say, we value employment more than we value early intervention because every stage is critical. We also know that these individuals are spending the majority of their life in adulthood and there hasn't been any focus on that.

MR. PRICE: There is no one approach that will be meaningful to everyone with autism, it's far too complex.

MS. CARROLL: Yes, it's unique, it's individualized based on that person's needs and I think that's the other thing, and that's the tough thing, that's what's so hard sometimes with autism because it does have to be somewhat individualized. When you're talking about continuum of care, it's not that one brush stroke that's going to apply to everyone on the spectrum because there has to be programs that recognize that it's about individualized needs and family needs. Those are the programs that are going to be successful. Those are the programs that are going to have the most impact.

MADAM CHAIRMAN: Thank you. Just to remind members, we probably have until about 2:50 p.m., we have some business items to deal with at the end of our agenda, so we'll continue with round one of questions and comments. Trevor, you're next.

MR. TREVOR ZINCK: Thank you, Madam Chairman. Thank you for coming in today. I've got a couple of quick questions actually. The employment program - have you partnered up with any companies now that are ready for the launch in January where you can automatically take some people and plug them into those companies?

MS. CARROLL: What we plan to do in January is expand our summer volunteer program which we already have longstanding relationships with many corporations and companies that have opened their doors to a lot of our volunteers, kind of formalizing that and getting that component going year-round.

Also, we're going to start with the Autism in the Workplace education piece. As I mentioned, we don't have the funding in the bank unless something happens in the next four months because we need to do the training, we need to start building those relationships and we do have, well, a list of quite a few corporations that we know we can go to and say we're now ready, this is what we need from you. But also, when we go to them, we want to be organized. We want to say this is kind of our rollout plan. We know you've been on board for the summer volunteer program but we also want to go beyond those corporations and businesses that we've been working with over the last few years for that program. We have to start opening other doors of larger corporations and within the community. So did that answer your question? Mike, did you want to add anything?

MR. PRICE: I was just going to say, another thing we're doing to sort of prepare and get ready is that the self-advocacy network has a career group that has just been formed, a sort of self-help group specifically for those people who have post-secondary education and haven't been able to get their careers off the ground. It's a pretty impressive repertoire there - there's dentists and physicians and journalists and people who have professional degrees and haven't been able to get their - so I think that group will also help inform the whole business community about the strengths of people with autism.

MR. ZINCK: Labour and Workforce Development - have you approached the new department with potential of a proposal, or promoting what you're trying to do?

MS. CARROLL: Not yet. If that's your recommendation, that's what we'll do.

MR. ZINCK: It would be a good one. With the new federal monies coming down and whatnot, a lot of organizations are wondering how it's going to be rolled out and that's going to be rolled out in 2009, so it would be worthwhile. I mean we talked today about plugging some of the labour shortages, but also for the post-secondary educated individuals, we can find something for them.

Kristie, your two boys, they live at home?



MS. MCALLISTER: Yes, they do.

MR. ZINCK: How long do you see that happening? Do you ever see them being out on their own? Do you see them being part of the workforce, living in the community, being supported in a smaller capacity, compared to what they're getting now with yourselves - you and your husband?

MS. MCALLISTER: Right now there's no place for my sons to go. I know that there's 400 people on the waiting lists for living options around just the metro area, but the special needs of people with autism have never been taken into consideration. I would actually feel that I was being very negligent if I were to think that a small options home would be a good place for my sons, run by people who don't understand the needs of autism. I've heard too many horror stories and I've visited small options homes myself but there's just not the understanding that's out there. We don't know what to do.

I know that there are places that have established - like in New Maryland, there's cradle to death services for people with autism. There's a group that supports 800 individuals with autism, from early intervention right up to employment. But here there's nothing.

One of my sons, I think, will be able to live fairly independently but he will require support throughout his life because often when people with autism get into stressful situations, they can regress. My other son, if he was here, he's sort of an interesting, complex kind of guy - he would be pacing and arm-flapping. He has memorized every video he has ever seen and can repeat that to you. He's going to require a lot of support, even though he leads the Grade 12 math class. These are complex kids, right.

So I don't see it as appropriate if something were to happen to my husband and I, for my sons to be placed in the next opening in a small options home with a six-year-old with one problem and a 40-year old with something. I would see that as being very negligent on our part. The future - there has to be appropriate living places for my sons.

MR. ZINCK: The reason I bring it up is, I've been working with a number of parents who are at the point where you're at where their children are 19, 20, a lifetime of struggles trying to keep the family together. You know the financial burdens, you had gone into some detail that this committee had heard before and recognizing that, absolutely, there are many different behavioural problems in the option settings. But what I've been approached by a number of parents on is a program that would be designed specifically for autistic children, not that there's any one solution.

We are working on a current model with the Department of Community Services with these families as kind of a pilot. It may take some time but we do have a similar model that we're going by. So just to let you know that government (Interruption) Well, myself and Percy Paris, the member for Waverley-Fall River-Beaver Bank, have been working with a group of parents and the department on trying to come up with a model for that,

recognizing that there will be a point when families can no longer take care of the kids, but the kids deserve to have that place to go.

I want to talk quickly on - it is a full continuum of care. EIBI is a wonderful program, it's a lottery - we've heard that - and we know that one of the reasons for no expansion has been the lack of professionals to come in and take on more students. That being said, it is up to the age of six and whatever happens after then, the parents go into the education system, they're battling the education system to have the same sort of structure in place.

[2:30 p.m.]

You made mention in your presentation that you do 50 or more presentations both provincially and nationally. What is your hope? I mean, we talked today about cost as well, and it's not just with autistic children, it's with any person with a disability. What is your hope as far as having a national program that would allow funding to come to the provinces to deal with what we know now is becoming an epidemic, coming out of some of the presentations that you've done nationally?

MR. PRICE: I should qualify that. We've done presentations for national conferences, but here in Halifax. It wasn't that we travelled nationally to do those.

What I hear you asking is, what sort of national strategy would we like to see in autism? I think it's one that maybe could embody our values at the centre which is, again, looking at that continuum of care. I think one of our strengths at the centre has really been that we've included the voice of people with autism in our decision making and our planning, we've really been informed by people with autism. So any national strategy, I hope, would really be - as long as it was strongly informed by people with autism, we could be pretty sure that it would hit the mark. If it's parents and professionals making the decisions and excluding the voice of adults with autism, then I can't imagine we'll have a very comprehensive strategy.

MADAM CHAIRMAN: Thank you. Gordie.

MR. GORDON GOSSE: Thank you for coming in today, it was a very nice video and I listened well. I looked at your Web site last night, and everything else, and there was something on the Web site that said the Autism Centre doesn't endorse any particular therapy. EIBI is not something you endorse as an association, there are many different therapies that you work on, but do you work with other autism organizations in the Province of Nova Scotia? The Autism Society of Cape Breton, Valley Autism, the Halifax metro area - do you meet up on a regular basis with those organizations?

MS. CARROLL: Actually, I can probably say that, yes, we do. I've been at the Autism Centre for nine months and I'm the new executive director at the Autism Centre.

When I first arrived, I, as the new executive director coming in, I met with a lot of the other organizations and leaders of those organizations and volunteers - all very committed.

There was a theme that really developed there, which is that we really need to get together and we really need to start communicating with each other and sharing resources. We were all for that, so we got together and held our first autism community day on November 8<sup>th</sup> at the Provincial Autism Centre. I facilitated the group, although I was equal partner in bringing that group together. That group included the Autism Society of Cape Breton, the Autism Society Nova Scotia, the Provincial Autism Centre, the Valley Autism Support Team, South Shore Autism, the self advocacy network that Danny Melvin is currently leading, as well as board members and volunteers linked to those organizations. So there was a group of 18 that met at the Provincial Autism Centre to talk about what we do.

We're collaborating with the Autism Society of Cape Breton to bring Autism Arts to Cape Breton. We are working with groups in New Glasgow and Yarmouth, and although they're not formally established, they are networks of professionals and parents that have come together. They don't have society status, but certainly we're collaborating with them as well.

What we didn't mention, because we were talking about the rural areas, we're also partnering with the Autism Society of Nova Scotia to do preschool Autism Arts in Dartmouth and with the Sackville-Bedford group. Even though parents could drive to the Art Gallery of Nova Scotia, it's about bringing some services to the communities in which these families are living and for these children. So we're also doing pilots in Dartmouth and Bedford and Sackville, as well, so yes, we are collaborating and coming together, and I think our voice as a community in the future is going to continue to get stronger.

MR. GOSSE: So you'd be aware that we had a summer camp in Cape Breton the last two years, a very successful summer camp, and we also had the biggest crowd that we've had in the last five years at our autism walk this year, so we've been very active in Cape Breton.

MS. CARROLL: Absolutely. The Autism Society of Cape Breton is doing some wonderful things.

MR. PRICE: We spent a lot of time, actually, in Cape Breton with Michelle Gardiner before they started their social programs and they use our model pretty much.

MS. CARROLL: Yes, they do.

MR. GOSSE: I ran the Whitney Pier club and now that I'm an MLA, I guess I still have the same rapport with Michelle and the autism group - I pretty well know most of the children with autism in the Sydney area, in the industrial area. I know parents who have

two children with autism, I know parents who have mortgaged their homes, I know parents who have lost everything.

Kristie, when you said earlier about the children getting to the age of the teenage years and now finishing school, you talked about a waiting list of 400 for living in small options homes. Also the waiting list in your area, is there such a thing as we have in Cape Breton like the Horizon Achievement Centre, an adult day activity program, or like the Prescott centre here in Halifax? I find a lot of parents in Cape Breton now are getting worried as their teenagers are getting older, and actually some have graduated, but instead of being able to find them employment, like you're trying to do, they're actually keeping them in school until they're 21 - although they've graduated, they're keeping them in the school program because they don't have any services for them.

Is this something that you look at as a parent, that when they're 18 and they've graduated and they've got their certificate from high school, you have to keep them in that school because you don't have any services or programs that are available to them with their needs? I don't know what it's like in your area but I know that's a major problem for us in Cape Breton; that we have to keep them in there. There are 300, I think, on a waiting list for the adult day programs at the Horizon Achievement Centre, so that's something that we have to look at in the future.

Trevor had mentioned earlier about this - it's actually a very good time now that the Skills Development funding program from Ottawa is going to be coming to Nova Scotia. As of April 1, 2009, the province will be administering this program; they've just signed what they call an LMDA, a Labour Market Development Agreement, for \$80 million. So it's a good time for your organization to look - Stu Gourley, I think, is the guy who is putting that together through the province to look at what money is available. Some organizations - and my colleague, Leo, had mentioned this earlier - are worried about this agreement. Are people with disabilities going to be left out, are people with disabilities going to be included in this Labour Market Development Agreement that we've just signed?

It was actually in the Throne Speech last year - you know, instead of going forward, I think the word was "devolution" that they had used in the Throne Speech - you'll actually see it - which is to revert back, because they want you to provide the programs, the Province of Nova Scotia. So there is some concern with parents in my area about what's going to happen with this LMDA when it's rolled out in April - will people with disabilities be included in that, are minorities going to be included in that? There are all kinds of questions around that. So I wonder, are you familiar with that in your area?

MS. MCALLISTER: I'm not familiar with that. I'm terrified about what's going to happen when my sons leave high school, and they're still in high school. Part of their program is actually to have support and go out to get the work experience. I mean we built it ourselves by working with the learning centre and with the Autism Centre. For both of my sons, a place like the Prescott Group would not be appropriate for either one of them. I

find that a lot of the sheltered workshops or areas have not been designed with the needs of individuals with autism in mind. So for me it will be health care, employment - we'll be marooned, that's how I'm feeling, pretty desperate about it. What do I do with two young men at home all day costing \$15 an hour to leave the house?

My biggest concern really is not me, because I think I've proven my resilience, but my concern really is for my sons. I think everybody should have the opportunity to feel purpose in their life and to contribute somehow, and they can, there's just no place to go.

MR. GOSSE: What do you think needs to be in place in this province for them to go forward and succeed, and become productive members of society? What do you feel needs to happen?

MS. MCALLISTER: I think support means success. Every piece of intervention, 40 hours a week that my husband and I did ourselves by reading books and gleaning what information we could, we realized that we just keep making these leaps - it's very labour-intensive. Even an employment arena to have knowledgeable support that is then faded back is the model that we've used from the time the boys were diagnosed at two and a-half. It's really remarkable the progress that we have made, but now there's nothing. As parents, there was the IWK team that we could at least get information from, but when the boys leave it will be the Autism Centre for us that we'll need. So if they were able to develop a program for support for people, for adults, at least my sons would be able to socialize and find employment - that's a goal.

MR. PRICE: I just wanted to jump in quickly. You mentioned the Prescott Group, too, and there are three sort of larger service providers around HRM for people with intellectual disabilities: the Prescott Group, the Dartmouth Adult Service Centre, and Anchor Industries. I think they all have very significant waiting lists and like Kristie mentioned, to put your child on a list for three years and then they're not meeting their needs, it makes you feel defeated.

MR. GOSSE: Just one quick question. I just wanted to ask Kristie again, you talked about leaving the IWK, so at the age of 19 the services are no longer provided through the IWK? Interesting, because I have a son who's 33 and who is epileptic, who is still being treated for epilepsy by Dr. Canfield, who first came there in 1978 when my son, who will be 33 in March, first seized. But he has always kept him as a patient, now for 30 years.

MS. MCALLISTER: Sometimes it can be out of the kindness of someone's heart and I have to say when my oldest son landed in the emergency room at the QE II, I was very frightened because people didn't understand autism there - the attending psychiatrist, the emergency room physician. At the end of the day, I thanked the emergency room physician. I said, I have to say I'm totally relieved, you are just so wonderful and she said, Kristie, I have to tell you I was on the phone with Dr. Orlik all day and he's the chief of psychiatry at the IWK.

MS. CARROLL: But your point is a good one though, which is if your son has epilepsy and he's 33, those services are still accessible, but that's not the case for someone with autism.

MR. PRICE: We hear from a lot of adults. A lot of parents come in with adult children and it's very frustrating, because to access diagnostic services through to anything in the adult system seems to be much more difficult than it was at the IWK.

MADAM CHAIRMAN: Thank you. Ron.

HON. RONALD CHISHOLM: Thank you, Madam Chairman, and thank you very much for your presentation today. It was great and I do apologize for being a bit late. I guess it's not really the best time to be the Minister of Fisheries these days with the issues going on, so that kind of tied me up a bit.

Anyway, I enjoyed your presentation, especially the video - it really was an eye-opener. In your proposal, you had a partnership with the provincial government and I guess your ask is going to be, or it is - I'm not sure, have you applied anywhere, or are you in the process of applying? What is the story on that?

MS. CARROLL: Well, it's been unveiled here and certainly what we're looking for is direction from the standing committee on perhaps how we can go about applying for that support.

Our operational budget is very small and that request really over five years is very small but we also are committed. What it states is that we're committed to continue the way we've been continuing. We value those community linkages, we want to work with the Labour Market Development Agreement, and we're very committed to that as well, but we also know that we have a burn rate of 12 to 15 months and we don't have any sustainable core funding at this point.

[2:45 p.m.]

We're confident that we can grant write and get project-based funding, but we're also looking 25 years down the road and the progress that we're going to be making in those 25 years, and not wanting to be - we don't want to be a service-gap hole when that's really what we're trying to fulfill.

MR. CHISHOLM: That was my next question, is it going to be used for core funding, or will it be used for the employment support programs, or whatever?

MS. CARROLL: Yes, it would go into employment support - it would actually go into the employment support program because that funding will ensure that program is developed for the next five years. That's what we're asking for now, as well as the Web

site project that we talked about, which is kind of a road map to autism in Nova Scotia, which will be a huge benefit for the autism community, as well.

MR. CHISHOLM: Well, you know, I'd be interested in any information that you may have, as to the funding, what it will be used for and that sort of thing. If you could maybe go through the committee clerk and she can get it to me. I can assure you I'll certainly support it when it comes to my table, so I'll be watching for it.

MS. CARROLL: Thank you.

MADAM CHAIRMAN: You wanted another question?

MR. GLAVINE: If I could, I was just going to build a little bit with a motion.

MADAM CHAIRMAN: I'm the only one who hasn't had a chance to ask questions.

MR. GLAVINE: Oh sure, okay, if I can make a motion at the end of your presentation.

MADAM CHAIRMAN: Certainly.

MR. GLAVINE: Okay, thank you.

MADAM CHAIRMAN: Thank you. I wanted to actually - I was going to pursue the same line of questioning as the minister. As you may realize, we're an all-Party committee and what we can do is make a recommendation, or make a motion and if we support it, we can pass that along to the government.

I just wanted to say that I think I've learned more about autism and the needs of families in the province today than I have known in a long time, so you're very effective spokespersons for the autism community. I'm really excited to hear about the degree of co-operation and sort of collaboration within the sector now, because I think that is something that government is looking for when they look to sectors to support.

But I am curious, I don't know much about the provincial committee that's been put in place and I'm just wondering, do you have any involvement with that committee and will they be researching some of the same issues that you've identified in terms of the lifespan needs of families and individuals coping with autism spectrum?

MS. CARROLL: Thank you, Madam Chairman. Just in response to that question, I think part of the reason we're here today was actually in response to a letter that Mike Price wrote a year ago to the standing committee, which talked about the development or the rumours of the development of a working committee, the government working committee for autism, and at that time the Provincial Autism Centre was not on the radar of that group that was advocating. That group was the Autism Society of Cape Breton, the

Autism Society of Nova Scotia, and the Valley Autism Support Team, and we certainly value the advocacy that they put forth to kind of get the autism working group, and we're keeping our fingers crossed that that working group will meet the outcomes that was designed to meet.

We are certainly still learning about that working group. I know the initial letter that was written to the standing committee regarding the working group - we weren't involved in the initial approach for that working group, but certainly endorse what that group is doing and we're in regular contact with the autism community and we know that part of the agenda that we committed to when we met on November 8<sup>th</sup> was that group would continue to give updates to the whole autism community on what's been happening with that group as well.

We certainly hope, we're willing to share any information we have with this group. We want to help this group move forward in any way possible. I think any work in this area is a good work.

MR. PRICE: We have done a lot of our own research already on adult issues.

MADAM CHAIRMAN: This committee did send a recommendation to government asking that such a work task force, or whatever, actually look at the life span issues. The response back to us was that they already had an internal process going on that would meet some of those needs and they didn't see any need of setting up a parallel process.

Gordie, do you have an update on that?

MR. GOSSE: Well, it's very difficult because I think the working group has been embargoed not to say anything, but I know for a fact that they just met recently.

MS. CARROLL: Yes, they have.

MR. GOSSE: Okay. So you know that they just met recently and I think they're trying to keep - you know, they met with five different government departments, Education, Health, Community Services, I think there was a representative from five different departments, plus a representative of each of the agencies you already mentioned. I think they're just getting started and they'd rather much keep the work they're doing - how do you say? - quiet or embargoed, fly under the radar. They've gotten this far and they just want to keep going, so I think they're kind of hesitant to come out in the open. You don't want to see another headline in the ChronicleHerald or something, but they're working behind the scenes and I think that maybe we'll get them back in the new year if we can and give us an update.

But I do know for a fact that they've met just recently. They're moving forward.



MADAM CHAIRMAN: So have you officially requested to meet with them? You might want to do that and at least if you can't have an ongoing involvement, at least you can make a presentation and make sure a number of the points you're making - because what strikes me is that you mentioned 7,000 individuals have been diagnosed?

MS. CARROLL: Yes, 7,000 Nova Scotians have some form of autism spectrum disorder based on the one- in -one- hundred- fifty statistic . . .

MADAM CHAIRMAN: Right. We don't have time to get into why it's increasing, but it's certainly my impression, which I think has been borne out by the demographics, that the number is growing every year. Despite my admiration of the reasoned, best-practice approach that your centre is taking, I have to say that my impression is that your centre and the other associations are just barely able to scrape the surface of need for families in this province.

Obviously, there has to be a much larger collaboration and more effort put into this, especially, as you say, because individuals - thank heavens - are living longer and have the ability to be much more productive if they're included in communities and in the workforce.

I just want to thank you on behalf of all of us here for a very impressive presentation. We do appreciate you giving up so much time, thank you very much. Joan, thank you for joining us here today and thank you for your initiative in getting the Provincial Autism Centre started. That's a wonderful legacy. So thank you very much, would you like to make a few closing remarks? (Interruption) Oh, sorry Leo.

MR. GLAVINE: In light of the fact that all of us here, as MLAs, are well aware of the outstanding work being done by the Provincial Autism Centre - I mean, in five years, what you have done is quite remarkable. To that effect, I would like to make the motion very simple that the Standing Committee on Community Services encourage government to support your work with an annual grant of \$100,000 for a five-year period.

MADAM CHAIRMAN: Do we have a seconder?

MR. CHISHOLM: Why don't we make it \$150,000?

MR. GLAVINE: Well, that would be wonderful.

MR. CHISHOLM: I'm not so sure you should put a price tag on it, really.

MR. GLAVINE: Well, I was following their lead and their ask because they've been self-starters.

MADAM CHAIRMAN: Did I hear you say at least \$100,000?

MR. GLAVINE: \$100,000, yes.

MADAM CHAIRMAN: That's what I thought I heard.

MR. GLAVINE: For a five-year period, at least \$100,000 for five years, yes.  
(Interruption) Yes, that would be part of it, yes.

MADAM CHAIRMAN: That can be worked out in the negotiation.

MR. GLAVINE: Sure.

MADAM CHAIRMAN: So it has been duly seconded. Is there any discussion?  
Would all those in favour of the motion please say Aye. Contrary minded, Nay.

The motion is carried.

Sorry, I did mean to get back to you, Leo, on that.

MR. GLAVINE: That's okay.

MADAM CHAIRMAN: It's a good thing our vice-chair kept us in check. So thank you very much.

MS. CARROLL: Thank you, Madam Chairman. Just in closing remarks, we are very honoured to be here today to have this opportunity to share with you some of the information and issues around autism. So we're really quite excited about the future.

We also just wanted to let you know that we are having a Christmas open house and I understand that Trevor Zinck will be in attendance as well as a few other MLAs. If you haven't already received your invitation in the mail, you certainly are all welcome to attend our open house on Thursday, December 4<sup>th</sup>, from 5:30 p.m. until 7:30 p.m. at the centre. If you've never been to the centre, it would be a wonderful opportunity for you to see where we conduct a lot of our innovative programs and services.

MADAM CHAIRMAN: Thank you very much. We just have to stay behind and do a few housekeeping items but you're free to leave.

I wanted to go over the annual report from the standing committee. I believe you all had a chance to read it. I guess we'll take a 60 second recess.

[2:56 p.m. The committee recessed.]

[2:58 p.m. The committee reconvened.]

MADAM CHAIRMAN: There are two items. We have to approve the annual report and those members who are here today, I encourage you to stay behind to sign the statement of submission before you leave. I just want to confirm the meeting date and topic for our next meeting. Would someone like to move adoption of the annual report of the Standing Committee on Community Services?

MR. GOSSE: I so move.

MADAM CHAIRMAN: Seconded?

MR. GLAVINE: I'll second that.

MADAM CHAIRMAN: Any discussion? Would all those in favour of the motion please say Aye. Contrary minded, Nay.

The report is adopted

I just want to check with you that our next regularly scheduled meeting would be Tuesday, January 6<sup>th</sup>, that's a Tuesday, 1:00 p.m. to 3:00 p.m.

Is everyone in agreement?

It is agreed.

What we've done is at their request the Nova Scotia Disabled Persons Commission had requested a delay, so we've booked them for that January meeting. The Provincial Autism Centre officials were able to fill in today, so we'll go ahead with the Disabled Persons Commission on January 6<sup>th</sup>.

We still have two outstanding groups, the request from the Public Accounts Committee to do the Nova Scotia Association of Health Organizations to have them come before us in terms of, I think, its health human resources. A group that's left over from 2007, I believe, the Federation of Students is still on our list. Probably some time after that we should have an organizational meeting and get each caucus to submit new topics.

Any questions? Yes.

MR. CHISHOLM: The one on the health, what was that again?

MADAM CHAIRMAN: Nova Scotia Association of Health Organizations. I believe they had asked . . .

MR. CHISHOLM: Public Accounts, you mentioned Public Accounts.

MADAM CHAIRMAN: Yes, it has been forwarded to us from the Public Accounts Committee. I'm not sure whether the Public Accounts Committee had asked them originally to come or whether they had asked to go before the Public Accounts Committee.

MR. COLWELL: They asked.

MADAM CHAIRMAN: They asked, okay. The Subcommittee on Agenda and Procedures of the Public Accounts Committee are asking that this organization and the topic be forwarded and dealt with by this committee. So should we set them up for our February meeting then? The only reason I mention February is because often universities have a break in February and it might be problematic, so why don't we have the Federation of Students come in March and then we can regroup. Wonderful.

MR. GLAVINE: That gives us three meetings with definite stakeholders.

MADAM CHAIRMAN: Yes. We know the topics for the next three meetings.

MR. GLAVINE: Good.

MADAM CHAIRMAN: All right. Any further business?

MR. COLWELL: I move we adjourn.

MADAM CHAIRMAN: Motion accepted.

We are now adjourned.

[The committee adjourned at 3:01 p.m.]