

# PRINCE EDWARD ISLAND LEGISLATIVE ASSEMBLY



Speaker: Hon. Francis (Buck) Watts

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## Standing Committee on Education and Economic Development

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LOCATION: LEGISLATIVE CHAMBER, HON. GEORGE COLES BUILDING, CHARLOTTETOWN

SUBJECT: BRIEFING ON CONDITIONS FOR PEOPLE WITH AUTISM IN PEI

### COMMITTEE:

Alan McIsaac, MLA Vernon River-Stratford [Chair]  
Hannah Bell, MLA Charlottetown-Parkdale  
Hon. Richard Brown, Minister of Communities, Land and Environment (replaces Hon. Paula Biggar)  
Kathleen Casey, MLA Charlottetown-Lewis Point (replaces Hon. Robert Henderson)  
Jamie Fox, MLA Borden-Kinkora (replaces Matthew MacKay)  
Sidney MacEwen, MLA Morell-Mermaid  
Hon. Robert Mitchell, Minister of Health and Wellness  
Hon. Pat Murphy, Minister of Rural and Regional Development

### COMMITTEE MEMBERS ABSENT:

Hon. Paula Biggar, Minister of Transportation, Infrastructure and Energy  
Hon. Robert Henderson, Minister of Agriculture and Fisheries  
Matthew MacKay, MLA Kensington-Malpeque

### MEMBERS IN ATTENDANCE:

None

### GUESTS:

Stars for Life Foundation for Autism (Carolyn Bateman, Peter Rukavina)

### STAFF:

Ryan Reddin, Clerk Assistant (Research and Committees)

Edited by Hansard

The Committee met at 10:00 a.m.

**Chair (McIsaac):** Call the meeting of Standing Committee Education and Economic Development to order.

To begin with, we have a few replacements this morning. Richard Brown is sitting in for Robert Henderson and Kathleen Casey sitting in for Paula Biggar, and Jamie Fox sitting in for Matt MacKay. I'd like to welcome all the committee members here.

As well, our two presenters: Carolyn Bateman and Peter Rukavina. We will go right into your presentation. I take it you have a presentation for – how long is your presentation for, do you feel?

**Carolyn Bateman:** It's not that long. I have like three pages of notes.

**Chair:** Okay, that's great.

**Carolyn Bateman:** That's it.

**Chair:** We'll try and hold our questions until the end of the presentation.

**Carolyn Bateman:** Yeah.

**Chair:** Send your questions through the Chair and I'll keep a list and we'll go down in an order.

Do we have a motion to adopt the agenda?

**Ms. Casey:** So moved.

**Chair:** Thank you, Kathleen.

Carolyn, are you going to start?

**Carolyn Bateman:** Thanks.

Thanks for the opportunity. Peter and I are both on the board for the Stars for Life Foundation for Autism. I'm sure you're aware of that.

We asked for this opportunity to address this committee due to our concerns after reading one of the transcripts, report from one of your last meetings. We were kind of left with the impression that maybe you felt everything was fine in the way of autism services once kids transition from the school

system. Our understanding is that you do – you're looking at cradle-to-grave type services. We thought that you may not have had the entire picture of services that are available for those with autism once they leave the school system, and what their needs are, what their services look like today and where they need to be.

As you're well aware, there's one in 68 Island children who are receiving an ASD diagnosis from severe autism right on up through to the high-functioning ones with Asperger's. That means one in 42 boys are receiving the diagnosis. We have over 100 children, easily, now, who have left the school system with an ASD diagnosis, and hundreds more to come. There's no end in sight.

Parents are really terrified of what's going to become of their children when they leave the security of the school system, and how they're going to cope when their supports that they've had up to now dry up. They wonder if they're going to have to quit their jobs to take care of their adult child. And where will their child live when they can no longer care for them? How will the child ever get a job and who's going to teach them all the new skills that they need to make their way in an adult world?

They've come from a system which is scheduled and supervised into an adult world where these regiments no longer exist. Without supports, many of our high-functioning kids are failing at university and college.

Adults with autism have an ability, with the proper supports, to be contributing members of the Island community. They can have jobs, which will help to give them the benefit of their self-esteem, mental health and making them more independent. It will decrease the needs for supports from social services; the knowledge that their families will also have that their adult child will have a life when they're no longer able to care for them.

Having services means that they can improve their communication skills, which is going to assist in their frustration levels, assist in their ability to get a job, and we find marked improvement in their behaviour with those skills increasing.

They also require extensive life-skills training for the adult world, which they now find themselves in; however, graduating into an adult world is very difficult for them, and for their families. Autism supports basically dry up when they leave the school system outside of the funds that they receive from the DSP program, whose funding levels haven't changed in, I would say, over 10 years.

The only autism-specific supports available are what the stars for life foundation provides. We're very limited, as we do not receive adequate funding. We have 30 in our programs today; five living in the home, and a few more living in their independent apartments and over 40 on our waitlist and growing. Their needs did not disappear the day they left the school system. They need emotional and mental health counselling, life skills development, communication skills improvement, employment skills development.

Young people with Asperger's are getting into trouble with the law. They've been taken advantage of because they don't have the ability to discern who's a good friend and who is not. Drugs are becoming an issue, and unemployment becoming an issue as well.

These are skills that are often not – they're not ready to learn when they're in the school system and need to be taught once they leave, once they get more maturity.

We're getting young people now, who have mental health issues and depression due to their bullying in the past in schools where they just really didn't fit in. Many of them didn't even receive a diagnosis until they left the school system. They were just different and they didn't – no one knew really what was wrong.

They have a feeling that they have no future and no friends. Within the school system there needs to be an improvement. One of the ways that I think I find really needs to be a huge improvement is in psychology support for these clients. We feel that there may be a lack of understanding that these young people with Asperger's, which are considered high-functioning. That they don't get the need – the attention that they're needed, and that their disability is more

invisible so they don't fit in with their classmates. They sit quietly in school. They may be able to complete their school work under those, sort of, supervised settings, but when they come out they really are having depression.

I've gone to a lot of conferences over the years and looked at school services. In this particular case, I'm going to give you an example; it is in the States where the school has a psychologist attached to the school. A teacher, if a student with Asperger's had an issue she just never addressed it in the classroom, she'd just wrote a note of what the issues were. The psychologist came in once a week, or once every other week, and gave a little work session, I guess, separately with two or three students with Asperger's and helped them through and deal with their issues, and taught them how to deal with them.

Those sorts of things really need to be happening for those kids at a young age in the school system, so that when they come out of the school system we're finding some pretty broken young people who never really fit. It's difficult for us because we are not psychologists and we do need access even within the stars for life foundation to psychology for these young people.

These high-needs individuals need to have continued supports to learn life, communication, social skills and support families in their daily care. Those are the ones with the high needs. I mean, it's such a continuum of services, even those high-needs individuals have mental health issues because their disability is quite different from other disabilities.

There is no other NGO that really provides supports specific to autism. They're offered – we looked at them. We had somebody come in before we started the stars for life foundation, a professional in the autism field in Ontario come in and look at our services in PEI, and assess, you know, how they're operating. Is it autism friendly? The outcome was it wasn't great for them. I know that they're servicing some young people with autism. I'm sure that some are doing well there.

There are some, you know, very basic differences. The high-functioning do not fit

there at all. The Asperger group has no place to go outside of us. The higher functioning ones, there's some policies such as, changing over staff every six months so that a young person doesn't become attached to their staff member. That's exactly what you need for autism, not the opposite. The types of activities they may do and the ways that you handle behaviour are very different. They may end up being punished in a way for their behaviour, which is to do with their autism and not just straight behaviour.

Those types of things, I think are really important that, for the same reasons that we needed a different autism services within the school system, we need the same outside the school system.

We – do you have any – before I go on –

**Peter Rukavina:** No.

**Carolyn Bateman:** I've been yabbering away here –

**Peter Rukavina:** Keep going. You're doing very well.

**Carolyn Bateman:** We have a need for stable, sufficient, long-term funding for the stars for life. The foundation has need – so we need sufficient, long-term funding to address the needs of those with autism on PEI once they leave the school system. We need well-compensated staff equivalent to other NGOs, which is something we do not have right now; enough qualified staff so that we can increase the number of young people we serve.

We mainly exist on our fundraising efforts and from the funds that are assigned to an individual so that they can provide direct programs for these young people. But these funds have had virtually like, as I said, no change in over 10 years.

We have transition planners within the school system. Doctors and other community support leaders suggesting that the stars for life foundation is the place for their son or daughter, but we cannot, in our current way that we are funded, help them. We are at full capacity and overflowing. We really do need a stable, sufficient, long-term funding.

We really need to look at an integrative provincial autism strategy. That in part seeks a continuity of support from childhood to adulthood. We cannot continue to send all of these young people out into the world once school is finished and think that the parents can – sorry, can continue around-the-clock care without the supports and only receiving a small monetary support from the DSP, and no way to access their services that their jobs needs.

There needs to be more housing opportunities; more support for families. Some are not – some of them, as I mentioned before, some of the adults with Asperger's are not getting their diagnosis until after they leave the school system. If we don't start addressing these issues now, they're only increasing and it's going to become more expensive for government and not cheaper.

Peter.

**Peter Rukavina:** Maybe I'll jump off from what Carolyn was talking about: the need for an integrated provincial autism strategy.

There was tremendous work, I should start off by mentioning, done about a decade ago in the autism action plan that never actually went forward. Parts of it were adopted and we benefit from those, but as an integrated strategy, I think, we were left wanting.

To give you some example of that from my personal experience, I have a son, Oliver, who is 17 years old, who was diagnosed as being on the autism spectrum when he was 11, which is relatively late. Although he was screened when he was three and five, that was not conclusive; so we sort of came in to whatever autism supports do exist when he was 11 years old, although he was supported by preschool special needs and the education system up until that point.

When you look at the number of touch points Oliver has, he's certainly not without services, but the services that he receives and that we receive as his supporters are by no means integrated at all. For example, we receive funding from the school-age autism program, which is administered by the department of education. He's eligible for the Disability Support Program, from the Department of the Family and Human

Services. He's been overseen since the minute he was born by a pediatrician from the pediatric clinic at the Queen Elizabeth Hospital. He receives mental health support systems from the mental health, Community Mental Health at Richmond Centre. But none of these – and then, of course, he receives school supports, you know, educational assistance and resource support in the school.

None of these are done in any, by any means in a coordinated fashion. For example, every month I have to fill out claim forms for the Disability Support Program. I have to pay an employee. I have to remit payroll remittances. I have to register to CRA as an employer. I have to do that for school-age autism funding. I also have to do that for the Disability Support Program. Over the course of the year, one will run out and the School-age Autism Funding program funds us to support Oliver in a different way than the Disability Support Program. We have to make sure that we're doing the right things with Oliver at different times of year when funding is available. It really ends up being a patchwork quilt of things.

That's up until the point that Carolyn was talking about, where stars for life can take over and offer supports to Oliver and people like Oliver. Then, a lot of those things that I'm talking about, like school-age autism, like the support he receives from the pediatric clinic, those drop away. I think that cradle of support becomes more like a cliff, I think, as Carolyn was alluding to.

I think it's not a matter of there being no supports, especially for preschool children and school-age children, but the supports are not offered in a coordinated fashion. Certainly, then we are now faced with a 17-year-old, who is coming up to his last year of school. There is a sort of a great question mark there. Some of those questions that Carolyn was referring to: Where will he live? How will he live?

Oliver has a broad intellectual life that needs support, but he also can't cross the street by himself. The Chair was making reference to the fact that he had never seen me by myself before. That's because we see each other at the Farmers Market every Saturday and I'm always with Oliver. In fact, Oliver is always with an adult. Often that is me or my partner

Catherine, but just as often that is a support person who needs to be paid for. That's something that we're now faced with, you know, needing to figure out a way of happening, after he leaves the school system. Then, of course, we won't be here forever, and that the stress, that when you talk to parents of adults with autism, the what-happens-when-I'm-gone is a question that we really haven't addressed sufficiently.

I know stars for life is residentially supporting four, five, six people. There are, as Carolyn said, hundreds of people on the autism spectrum, who are going to need that support and we don't have a plan for that yet. That's why I'm sitting here beside Carolyn.

**Carolyn Bateman:** The thing (Indistinct) issues sort of apply as they leave the school system that Peter was talking about; becoming an employer, having to submit your EI, CPP for your workers, all out of that meager fund from the DSP program. I know everybody is doing their best, but we are so far behind the eight ball now. It's just, it's disheartening.

I can understand where you just can't give carte blanche money out under the DSP program. The cost would be astronomical; but you can target the services and give them appropriate levels of core funding so they can operate within those parameters.

This is one of the things that the stars for life foundation does, is take that stress off families of hiring people; training people to become their son or daughter's workers. Having, creating a program for them, supervising a program. Those are things that are one of the reasons why we started the stars for life foundation to begin with.

I don't know if you remember Joan TeRaa, years ago, who was with ACL then became with us, started the autism society, and then the stars for life. We got together and said: Okay, we have this pot of money for our kids now that they've got a school. We're going to hire and train our workers. Then, they leave. Then you had to rehire and train your workers and then your son and your daughters were upset because of the changeover. You said staffing issues, that they didn't show up, or they weren't doing a good job.

In one of my son's case, his worker was taking him to his labs at university, and she was doing her own work, not helping him and yet I was paying her. There was no supervision. There really has to be an accountability.

Although it's wonderful to have the DSP and have that, those options and choices to make on behalf of your son or daughter yourself, which is phenomenal, but it also requires a lot of assistance, as well, to make sure that families get the help that they need, and it comes in the right way.

**Peter Rukavina:** I would add, as well, that, I think we have demonstrated through other programs that we can actually confront challenges in an integrated way. The example that I would bring up, and Carolyn and I both have personal experience with this, is the integrated palliative home care program. Which, when you stand back and look at it is a miracle of bureaucratic excellence. You can only imagine, if you have any experience in the bureaucracy, how challenging it is to get disparate parts from different departments and from third-party agencies to work together. Yet, that has been achieved. It is an amazing program that is offered in an integrated fashion that puts the patient, the person receiving care, at the heart of the issue, which is really what we're talking about, trying to move towards with autism.

I guess, I would finish off with one comment, which is that my son, Oliver and I go walking at the Holland College walking track every night. We've been doing that to try and get some exercise in the winter. The hallways at the Centre for Community Engagement at Holland College are not wide enough for Oliver, Oliver's service dog and I to walk down. This precipitated a conversation between Oliver and I about whether architects, when they're designing a building should design buildings so they work just for some people or whether they should work for everybody. Of course, his answer was that they should design buildings so they work for everybody.

Really, I think that the approach that, on a bird's eye level, we want to be taking when we're talking about supporting people with autism, is designing all of our systems so that they work for everybody, not just for

some people. I think, maybe, what gets missed here sometimes is that Carolyn and I have both spent a lot of time raising young adults or full-fledged adults with autism and they're our children and we love them. They are not patients. They are not broken. They're full-fledged contributing members of society and we want to be there to support them and we want them to be supported by the community when we're not there to do that ourselves.

**Chair:** Thank you very much for your presentation.

I was going to ask you, Carolyn, to give us a little history on where stars of life came from. I don't know how long it has been going now. I know it's been there for a while.

**Carolyn Bateman:** Way too long.

**Chair:** I wanted to know the make up of your board, too. How many are on your board? Is that turning over or is it hard to get members to sit on that?

**Carolyn Bateman:** It can be. We have – do have need there for our board. We do have some really committed community members. Some have been there since we started. They're so committed to us I think they – I'm hoping they'll never leave. But we have lawyers and accountants and business people. We have about nine of us right now. We could always use a couple more.

I think one of the things we worked on over the past year was to come up with a brochure to try and address long-term funding. We've been waiting for 17 years for government and it's not coming. I guess it was the same reason why we started the foundation to begin with because the plans for services weren't coming. We decided we needed to start something ourselves to make it work and hopefully that government, over time, would see the value of what we're doing and the need for it and start to fund us.

**Peter Rukavina:** Part of the challenge of involving people in the life of an organization of stars for life, and this is not unique to us or non-profit organizations, but raising a child with autism is a 24-7 all consuming challenge. Being able to

contribute to organizations like stars for life is often a challenge just being able to get to meetings and to have the energy to do that. We're lucky to have parents and caregivers of adults and young adults with autism on our board, but it is a struggle to just allow those people to participate.

**Chair:** Right. It goes back to about the time that Jeremy (Indistinct) –

**Carolyn Bateman:** It started when Adam and Jeremy – well, Jeremy had left school. I think we really got into it in 2000, I guess. When we started stars for life we incorporated in 2001. We're working virtually under the same funding level that we were then. That is a big challenge for us because our staff are – they have teaching degrees some of them. Why we're lucky enough to have them is because they couldn't get a job teaching so they're teaching with us. But we're paying them less than other NGOs by about \$5 an hour less, on average because we don't get the funding. We have to only use the DSP money for that staffing.

**Chair:** In your opening comments you talked about the previous presentation that we had here. You thought it left some, it was lacking to some degree. Did you mean in the supports after the kids left school or even through the whole process?

**Carolyn Bateman:** No, I think there were just some comments about autism and where, and I can't remember how it started out exactly, but comments about where the kids are going. There was a comment about Tremploy is working with kids with autism. I really believe in a lot of work that Tremploy is doing, but I don't believe it's the best venue for people with autism, in particular those on the higher-functioning end that they don't fit.

**Peter Rukavina:** Carolyn made reference earlier in her remarks to the fact that other professionals in, whether they be bureaucrats or private practitioners, are making reference increasingly to stars for life as a: Well, you know, your young adult child will be able to receive supports from stars for life when they graduate out of the public school system. And if all the people who have referenced us; referred to us to stars for life actually knew that Oliver is

actually number 43 on the waiting list and for the foreseeable future will not actually be able to enter the day program. I think if we're able to live up to the number of referrals we'd be a much better-funded, healthy organization.

**Chair:** Thank you. Jamie Fox.

**Mr. Fox:** Thank you, Chair.

I would like to have some, just some – I don't know a lot about autism. I'll be honest with you. At the very first you said that there's 100 right now.

**Carolyn Bateman:** I don't have the specific numbers, but I guarantee you that there's at least 100.

**Mr. Fox:** Okay –

**Carolyn Bateman:** Or more.

**Mr. Fox:** After that, you said: there's 100 more, hundreds more to come.

**Carolyn Bateman:** Yeah.

**Mr. Fox:** Could you clarify that?

**Carolyn Bateman:** I believe the number I was told, there's 385 kids in the school system. That doesn't count preschoolers. They're not stopping diagnosing people. It's not like we're done diagnosing. They just keep coming. Those kids are all going to graduate out of the school system. A vast majority of them are going to need continued supports.

**Mr. Fox:** Also, can you touch – can you expand on, you mentioned touch points. What do you mean by that?

**Peter Rukavina:** It's the different parts of government that provide services to us –

**Mr. Fox:** Okay.

**Peter Rukavina:** – in a way that is very valuable to us, but is done in a fashion that is not coordinated with the other parts of government that are offering services to us.

As I suggested we get support from the Pediatric Clinic. We get support from Community Mental Health; from the

department of education, from Public Schools Branch, from family and human services. We're lucky when we can get all of those people in a room with one another. We very rarely pull it off and when we can that's of tremendous benefit to people to understand all of the things that are happening.

The fact, for example, that Oliver's supports are funded by family and human services and by the department of education, from two different pots of money that come from the same government, but they require separate administration, separate claim forms, separate case workers. I think taking an integrated approach that focused on the individual as opposed to focused on the bureaucracy would change that.

**Mr. Fox:** With that, do you find that there's cooperation between the two departments? Are they working together or are they sort of working alone without knowledge of each other?

**Peter Rukavina:** I think more of the latter than the former. They have knowledge of each other. I think they aspire to work together.

If you go back, again, to that draft autism action plan, one of the things that the people who made that action plan referred to specifically in the action plan is the fact that the professionals around that table often didn't have the latitude in their own department to cooperate with one another.

I think that's something – if only that happened, I think we would achieve great things. If there was more coordination of the type you're talking about.

**Mr. Fox:** Are you aware – is there any programs in any other school systems in North America or in the world where maybe there's like a buddy system set-up where, if you have a child with autism in a classroom that maybe we have a buddy system where a child or a mentor or another child in that classroom would buddy with him on a daily basis?

**Peter Rukavina:** I mean, that kind of thing, I know that that was part of Carolyn's and Adam's life and it certainly is a part, to some extent, of my son's life. Through the

resource department at Colonel Gray High School where he attends school there are variations on that theme of various kinds and it can be quite powerful.

**Mr. Fox:** Final point for now: You say Oliver has a service dog?

**Peter Rukavina:** Yeah.

**Mr. Fox:** Can you expand on that? What's –

**Peter Rukavina:** He has an autism assistance dog. It's funded by Lions Club. Lions Club nationally has a Lions Club foundation that funds service animals for K-9 vision and diabetes and epileptic seizures. They have an autism assistance dog program. It's provided at no charge to clients. There are more than one on PEI right now.

You'll recognize them from a red service dog vest when they're walking along the street. They're there for a variety of supports and services to the client. It can provide emotional support. It can provide an icebreaker, and so we're walking along the street with someone and we encounter someone then they have a, sort of a way of talking to Oliver. It provides a constant source of friendship to Oliver.

When the service dog came into our life in 2014 Oliver hadn't slept through the night in two or three years. The first night the dog jumped up on his bed and he was asleep like that and slept through the night ever since.

**Mr. Fox:** Impressive.

**Peter Rukavina:** It's a tremendous support to us. I mean that – we owe a great debt of gratitude to Lions Clubs for supporting that.

**Carolyn Bateman:** My son, Adam, had a service dog, too, when he was at – going to Colonel Gray. The dog has since passed away, but it was a tremendous support to him for breaking the ice between the other kids and him. Kids wouldn't come up to him, but they'll come up to that dog, so therefore you get the benefit for the child.

**Mr. Fox:** Impressive.

**Chair:** Kathleen Casey.

**Ms. Casey:** Great, thank you. Thank you, Mr. Chair. Thanks, Carolyn, thanks, Peter for your thoughtful presentation.

This is not the first time, Carolyn. I know you have been here a dozen times over the years that I have been here. Your presentation is always thoughtful and informative. It's still hard to believe it has been 17 years and you're waiting for long-term funding. Could you explain the link between the autism society and stars for life? When people say they're funding the autism society, does it mean they're funding stars for life?

I just want you to clarify that for the record.

Thanks.

**Carolyn Bateman:** I guess, I'll just go back to the history of it. Joan and I started the autism society. We did for a number of years, and there were just a few of us on the Island who had a diagnosis of autism then.

But as things grew and as all these kids started to come out of the woodwork with autism, and we were getting older and our kids were leaving, starting to look at leaving the school system and all the young parents were coming in with young children and ABA therapy came along at that time, the needs of those children were vastly different from the needs of our children.

We were treading water, basically, and these young parents had all sorts of energy and wanted to beat down the doors of education and get these programs into the school system. Basically, we said: Go to it, that's great. Joan and I would work on what services should look like for the kids when they leave the school system. That's basically how the stars for life foundation started out. It's grown tremendously; could grow tremendously more.

The autism society kept their focus on the younger people, where we kept our focus on the older kids. We do meet once a year, casually, to catch up on what each other is doing so that we're not – we have sort of a – we're not duplicating presentations to government or within the community, so that we're all sort of working in conjunction with each other.

**Ms. Casey:** Thank you.

**Chair:** Kathleen.

**Ms. Casey:** Thank you, Mr. Chair.

Just so everybody is really clear, stars for life is for kids who age out of the school system and so when you talk about buddy systems and stuff, that's within the school system. It's the concern that we have for those who are aging out of the school system and where do they go?

The \$6,600 that students receive when they're in the school system for supports, that doesn't follow them as an adult, does it?

**Carolyn Bateman:** No.

**Peter Rukavina:** In fact it follows them until they are 18; and because my son Oliver was later entering school, he actually turns 18 in October but doesn't graduate from school until the next year. So, under the strict letter of the law, it actually ends when he turns 18 in October, although we've been assured that it will actually continue until he graduates from high school.

**Ms. Casey:** Thank you. I think at the end of the day we all realize that the number one thing is long-term core funding; 43 people – Oliver is 43<sup>rd</sup> on the waiting list. There are more students coming through that will eventually age out.

Long-term core funding, I know you've expanded on it, but could you for the record again say what the long-term core funding will allow you to do?

**Carolyn Bateman:** It's going to allow us, number one, to pay the existing staff we have adequate wages, at least wages to the same level that the other NGOs are paying so that we don't have the huge turnover in staff.

It will allow us – right now the people that we have, I guess you could call them managerial or operational positions where they supervise the programs; they hire the workers. They train the workers. Our executive director that ends up at the business end of things, or our administrative assistant that's doing payroll and accounting and all of those things; it's like running a

business. So, those positions are not paid for.

The only funding we get is the direct funding that's attached to the individual under the DSP program. That hires their one-on-one workers, and that allows us to provide them with programs. Like I said, that staff now is not being paid; probably about \$5 an hour less than others on average. But we have to fundraise for our executive director, our administrative assistant, our program manager, our house manager – all of those things that have to happen, we have to fundraise for, which means that we're not focusing on the programs that we need to develop and how do we expand?

If we had core funding, then we get to start to look at: Okay, we're going to have 60-70 people in a day program. We need a new centre. What is that going to look like? How are we going to raise the funds to build that? We're going to need more housing. What sort of variety of housing do we need? All those things need to take place and it's a huge project, but it can't take place until we get stable. Then we can start looking ahead. We can't look ahead right now.

**Peter Rukavina:** I've been on the board of stars for life two years as of April, and when I look at the amount of time that the organization has to spend just raising money to keep the lights on – when I look at Carolyn, one of the smartest minds about autism on PEI with a tremendous depth of experience who has spent endless hours on the phone selling car-draw tickets, which is not a valuable use of her time; it's not a valuable use of anybody's time.

We had the opportunity to meet with the new deputy minister of family and human services and I think he said it best when he said: Nobody is served by keeping NGO support organizations like stars for life on the brink of bankruptcy at all times. Because we truly are one fundraising dinner or one car draw away from not being able to provide the supports we provide.

I think Carolyn made the point very validly that if you look at the fact that we are funded by the disability support payments that are attached to our clients, but that doesn't pay for the light or the heat or the snow plowing

or the person who is providing the curriculum for the day programs, and so there really is a need for an umbrella of funding above and beyond the disability support program, to allow the car draws to not have to happen.

**Carolyn Bateman:** I must add, too, that we do get a small bit of funding to operate the three people that have 24-hour care in the house above the DSP. We get \$150,000 a year for that overnight and weekend staffing, which is a very bare bones amount.

We just this past week received an amount for one of our young men that is staying there who is having some serious health issues that's going to require virtually one-on-one 24/7. We are getting that, but that really doesn't address our needs within the day programs.

The thing is that I find that government sort of goes back; over a number of years, housing might be their issue or over another number of years, day programming may be their issue depending on what the drive is at the given time, but I don't think the two can be separated. If you have proper day programming for families, that decreases their need for long-term housing for their son or daughter for a number of years before they go into panic mode and say: I need a place for them to live. They will go into panic mode day one if they're leaving the school system, have no day programs; both parents are working: What do I do with my son or daughter that needs 24-hour care?

It's a huge issue, and they can't be separated, really. If we build a new resource centre, then we put more housing involved in that and just so much can be done. We haven't even tipped the iceberg yet until we get stable. There's no way we can.

**Peter Rukavina:** Carolyn made reference to panic mode, and I think it's worthy of mention that there is a cradle of supporters whether they are parents or grandparents, or guardians or people in the community who are supporting young adults and children and adults with autism. The mental health of those people, and Carolyn and I would be included in that group, is something to be concerned about as well because if we're freaked out all the time, then we're not effective contributors to the economy and

we're not effective caregivers, we're not effective members of relationships.

I think the follow-on effect of supporting people with autism is to support their families, and to improve the mental health in everyone.

**Ms. Casey:** My final question, Mr. Chair. Thanks.

Peter, thanks for recognizing, on the record, Carolyn's valuable contribution. I followed it for many years.

Carolyn, the school system and the teachers in the school system also recognize the value of stars for life because the teachers in the school system are now calling stars for life, consulting with them, and asking them questions of what's going on. Stars for life doesn't charge them for that kind of unofficial consult, but I think government really needs to step up.

We've heard this presentation many, many times and building a new resource centre, core funding; we keep continuing to push on your behalf. Hopefully soon you'll get some good news on that and I thank you, again, for your presentation and the work you do for those with autism.

Thank you.

**Carolyn Bateman:** Thank you.

**Chair:** Thanks, Kathleen.

A question from Robert Mitchell.

**Mr. Mitchell:** Thank you, Chair.

First of all, Carolyn and Peter, thank you very much for being here today and your presentation.

Carolyn, as you know, I've been at the stars for life house on several occasions. It's a wonderful facility. There's no question about that. The service that's provided there is so instrumental to the lives of anybody that is dealing with autism or Asperger's, so I continue to applaud you for doing the work you do on limited dollars and financing.

As Kathleen said, continue to advocate for your needs and it's something that we as

government hear your message, and hopefully at some point in time we'll be able to act, I guess, with you supportively. I just want to thank you for that part.

Peter, in regards to some of your comments on, I'll say, breakdowns within departments for needs for those, I'll say school-age children specific. Since coming into my chair as minister of health there just a number, I think nine weeks ago, I learned, and I didn't know until that time that there's a social deputies hub, which would be deputies from health, family and human services, justice, I believe, education, I think, as well.

To your points, I would like to kind of like to make a suggestion. I'm sure they have lots of work on their plate that they're working on, and not to suggest that there can be overnight solution to some of the comments you made, but I wouldn't mind asking them to take a peek at some of that stuff that you mentioned, form some linkages where they need to. Obviously, it's not a very streamlined process and it could be. Maybe there's areas that could work together to kind of, I'll say build some bridges that maybe are falling apart there now. They may have it on their radar, but if I can add it to the radar I certainly would like to do that. They're a good group that get a lot of work done together. If there are things that's streamlined for the family that's obviously better help for your family overall, better outcomes for your son and others that need that, I'm going to suggest they take a look at that.

**Peter Rukavina:** Thank you.

**Chair:** Thanks, Robert.

Sid MacEwen.

**Mr. MacEwen:** Thank you, Chair.

Thank you, Carolyn. Thank you, Peter. I much appreciate you coming in.

I haven't been around for 10 or 12 years to hear all the presentations. It's frustrating to hear that those presentations have been going on for that long, for sure.

One of the big things that, when I met with constituents back during the election and

since then was just – and when I met with both of you last fall, one of the big issues was about, and you mentioned it, Peter, you touched on it, you're so busy in your own family life and your own, whether it's filing remittance or doing that stuff, it's hard to lobby on behalf on what's going on. I don't think people know enough about the good job that you're doing.

Kathleen, you started touching on it, but Carolyn, can you talk about just briefly the efficiency of stars of life with the services you provide, as well. When I met with you guys I was impressed with what you do for those dollars, kind of thing. Can you speak to that efficiency?

**Carolyn Bateman:** That's a loaded question.

Basically, we have an autism manager who will deal with, on behalf of families, they deal with the family services. They have to apply – if a family comes in and wants services, for instances, they have to, on behalf of that family, write a report to government to say what we're going to do, how many hours we think that they need, and get the funding for them. All of that preamble, we're not funded for.

Then we have to get to know that child and hire a one-on-one worker for them. Some of the work will be done one-on-one, some of it will be done in a group setting depending on what the skill we're trying to learn. We're teaching life skills. We're teaching communication skills. We're teaching employment skills, employment readiness skills. We've just developed a workshop series for some of the guys with Asperger's who don't like so much one-on-one intervention where we give them the information in a more classroom-type setting where they're just like a workshop and teaching it that way.

We have support workers who go out and help them find jobs, help talk to employers, find a job, help supervise their jobs, help them keep their jobs.

We have – some of the people with Asperger's who get into trouble in the community and have mental health issues, our staff is being called in the middle of the night on a weekend when they – because

that becomes their go-to person. Even the parents don't know what to do, so they're referring it to one of our staff people that their child or is – or their adult son, I guess, is having a mental health issue, and we're not psychologists. But we help and try to direct them the best way we can to get them into emergency rooms or get them to see a doctor.

It goes right down to for people with high-needs with teaching their self-help skills. Helping them learn to cook; helping them to become more independent. Spend a lot of time working on their communication because it reduces their stress levels and their anxiety. Whether it may be flash cards they learn to communicate with or a variety of methods.

We also have created a group of products that we sell to the tourist industry that gives those higher-needs people opportunities to have some sort of a little job that they may not have – be able to get outside the community. We market those to the tourist industry. It gives them a job and we pay them over the summer.

We have one-on-one assistants that take some of the students to their university classes or to Holland College, help them through their work. We've had a number of young people who were failing, when they came to us and the following year, with the proper supports they're now passing their classes.

We have a couple of young people that, basically, have graduated out of our program. They have fulltime jobs now that are – the families are quite happy. They have jobs. They're becoming independent on their own. What else can I tell you that we do?

**Peter Rukavina:** But –

**Carolyn Bateman:** We have the housing –

**Peter Rukavina:** I think it's important to, you know, we talk about the autism spectrum. Mr. Fox, you mentioned the notion of not being very familiar with autism and you're not unique in that. I think the broad community, unless you have a family member with autism, or you have a

friend with autism, it is sort of a mystery to most.

I think when we talk about an autism spectrum that simply means that the way autism manifests in any individual is unique to that individual. In some cases it's communication challenges, transitions challenges, making choices can be an issue. Sometimes you'll meet someone on the autism spectrum and you won't know that they're on the autism spectrum. Sometimes it's very clear because it's difficult to have verbal communication with them.

To the efficiencies of stars for life, you know, if we were in the business of supporting people with broken legs, there's a pretty standard way that you break you leg and we would have two or three things that we would do and we would support you. If you look at the different ways unique to every individual that autism can manifest, we have to be ready to meet each of our clients where they are. With the same staff and the same support network that's a challenge in and of itself. That's one of the things that impresses me constantly is just the ability of the organization to do that.

**Mr. MacEwen:** Exactly what you're saying, Peter, is what I want to stress. Just from our first meeting, I know, Carolyn, I know you won't come out and scream how efficient you are probably compared to some of our other government-funded institutions, who are all doing a really good job, but it was the directors that were there that day that were like, I just, you know, as you say, they're accountants or they're lawyers or whatever that they're doing, they can't believe the efficiency that what you guys are pulling off at stars for life. The funding dollars that you do get are being spent quite wisely.

The big takeaway from our meeting that I got was what Peter, what you talked about, and part of your presentation was about is adult autism falling through the cracks of government departments?

The first question and the question that I asked last fall was: Who do I ask my question on autism to? I knew the Speaker might say: you can't ask that. The government ministers will decide who answers that question, so I asked about it. When I looked across and you can't see it

out of the camera, the health minister, the education minister, the justice minister, they all started looking at each other. I did it to make a point that there isn't a minister for autism. You talked about – it is, I don't want to say it's falling through the cracks because I know people are caring, but when you go to lobby for something like that there isn't a set person to talk to. Can you speak more, a little bit more to that? You talked about all the different services that Oliver has in all the different departments.

Even going back to that report from 2009, do we need someone dedicated to this file to take it on to make it more coordinated?

**Peter Rukavina:** I think, whether it's an individual-specific responsibility for autism at a Cabinet level, or whether it's the kind of coordination that Minister Mitchell talked about on a deputy level.

Before we even begin to talk about additional funding, I think taking advantage of what's there already, but doing it in a more coordinated fashion, especially when you're talking about adults with autism, you know. Oliver, for example, benefits from an excellent head of the resource department at Colonel Gray. That person is basically our liaison to anything to do with the school system, but also to transitions and, in some cases, to the mental health system.

When I look at, you know, what we could benefit from, and I made allusions earlier to the palliative home care program where my partner has a palliative home care nurse that she can phone 24-7 who can provide her with anything from ambulance service to any of the range of support services that she needs.

One of the things in the autism, draft autism action plan was a need for a single point of contact for families where it's not necessarily that person offering all the services, but they are basically your caseworker, and we're starting see – we had participation in the focus group for the, sort of, the reimagining of the Disability Support Program. There are some encouraging signs there.

One of the things that was mentioned is, often people with autism who are receiving Disability Support Payments also receive

food, clothing and shelter allowance from family and human services. Right now, they have two caseworkers in family and human services, which, again, just makes it all the more complicated. They're talking about, at the very least, having one caseworker so that you have one person that you can deal with.

Being able to have someone in that position who knows something about autism, because, in many cases, family and human services, even disability support workers are not specially trained in autism and don't have the breadth of skills and experience that would benefit them in that position. Then, having that person, not only the person who is the bank teller, so to speak, between the client and the disability support payment, but really a gateway to the breadth of services, whether they be in, you know, department X, Y or Z, being able to be that liaison. Really, their supporter, or their ombudsperson, in terms of managing their relationship with government and government support.

**Mr. MacEwen:** A good segue into my next question when you talk about that: You talked about the support that's in the school system and I remember you and I had spoken about it, too. You didn't know about all the different services that were available to you. One of the questions I asked to the minister of education was about the, what was the name of the program? Trying to find it here in my notes. I'll get it here for you in a second. The Be Aware and Get Your Share Program that's available for vulnerable Islanders to get federal benefits.

I asked the minister, you know, do we have something like this for autism on PEI so that people are aware in what they're getting? The minister said: I think that's a great idea, honourable member, and I wouldn't be too quick to overlook the work that's being done by the stars for life group.

We've got the minister of education recommending your group to find out what supports are available for autism. That was the first thing he said –

**Ms. Casey:** Exactly my point.

**Mr. MacEwen:** – he went right to you.

**Some Hon. Members:** (Indistinct)

**Mr. MacEwen:** That's not right when we've got the minister of education.

Another example is I asked about an increase about for the core funding. Kathleen, I know you asked about this before, an increase in core funding for stars for life. Asked it to any minister, the minister of education stands up and starts talking about all the great programs that are available for school students, right? You, Jamie, you asked the question about school supports for stars for life. Kathleen, you pointed out that this is for after school. I didn't know that until I met with you, as well; but here we have the minister of education also talking about all the supports in school even though stars for life technically doesn't – isn't supposed to. I know you deal with it a lot because of questions you get.

It's frustrating. Chair, I hope you excuse me, but we've got Cabinet ministers here. After we asked those questions, is it discussed at Cabinet? Like, what's the plan going forward? We've got one, two, three, almost four, former minister right here. Is it discussed? Do we talk about this stuff? When we asked those questions last fall, when Kathleen asked these questions before. Do we – is it – you have a great idea minister, today, about bringing those deputies in. Do we bring that up? Rural development is a perfect example, out in rural PEI, having to travel in to get these services. Are we talking about it? I don't want to talk about it in 10 more years' time. I know you guys won't – you're very respectful in the way you're lobbying –

**Carolyn Bateman:** I'll be in the old age home.

**Mr. MacEwen:** – but –

**Peter Rukavina:** I think, if I can respond, not as a Cabinet minister, but part of the reason that I am sitting here is because I talk about how it takes me five or six hours a month to do all the paperwork for disability support and school-age autism and I'm happy to do that. I've got that set up in a spreadsheet and I press a couple of keys and things spit out.

When you talk to Natalie at the autism society about the uptake of the school-age

autism program, which can provide tremendous support to a family, that program is not fully subscribed.

**Mr. MacEwen:** Nope.

**Peter Rukavina:** She says, give or take, there are half of the families raising young children with autism are not taking advantage of that. In many cases it's because of the bureaucratic overhead.

I think, when I think about how privileged I am – I have a fulltime job. I have a two-parent family. I have some technical abilities that allow us to do a lot of the things that need to be done. There are far more vulnerable families in the community than us who are raising children with autism. I think it is those families here that I am trying to speak for as well.

To your earlier point, often – and I think almost any family who has raised a child with autism and gone through that diagnostic process will talk about – we went over to the IWK when Oliver was 11 and he went through two days of grueling neuropsychological tests. Then, we had 45 minutes to an hour with the psychologist at the end of which she said: essentially your son is on the autism spectrum. Good luck. And we came back here.

We haven't been living in isolation and we have received supports; but you made reference to, in some cases, not knowing about programs. Nobody, in any of the myriad of departments I was talking about offering us touch points, ever thought to mention to us that there was a thing called the Disability Support Program.

**Mr. MacEwen:** Yeah.

**Peter Rukavina:** Oliver was diagnosed at 11. We didn't actually start to take advantage of disability support until he was 16. Not because we weren't eligible, just because we didn't actually know that such a thing existed. If we didn't know about that, then I think there are probably a lot of other people who don't know about that.

Again, there is an existing, admittedly, imperfect funding program, but, at the very least, we need to connect people with it. The notion that you were talking about in terms

of what the federal government is doing to connect people with the disability tax credit information, I think we do need to do a better job at just spreading the word.

That's where the autism society comes in. They do tremendous work, especially for younger families. They have a binder that they can hand you. We just need to make sure that everybody gets that binder, and knows what's in it.

**Mr. MacEwen:** One more, and our committee will – we quite appreciate you coming in and we'll make a recommendation in our report that we get the stars for life gets core funding and a whole bunch of more good recommendations.

Minister of health, you made a great idea today to go back to the deputies and look. We've got two more ministers here today. Can we just verbally agree that this comes up – I know Cabinet has confidence, but this can come up at the next Cabinet meeting?

**Chair:** We can do a little bit of discussion on that afterwards when we come back to our recommendations, Sid.

**Mr. MacEwen:** But seriously.

**Chair:** Right now, we're dealing with the group that is in here (Indistinct) –

**Mr. MacEwen:** But, I know the recommendations to the committee. Just for Peter and Carolyn's sake. Let's say, let's put it on the table. Maybe there's something coming in the budget.

I know, Chair, we go through this thing. And we can go back through 12 reports that say, yeah, we should increase the funding, or we should coordinate things. We've got an autism strategy. We've got ministers here right now. Could we just say, yes, we'll bring it up at the next Cabinet meeting?

**Chair:** We're going to (Indistinct) –

**Mr. R. Brown:** Yes.

**Chair:** Okay. It'll come through in the recommendations anyway, Sid.

**Mr. MacEwen:** I know, but that's the problem. They've been coming through for 10 years. Cabinet is where things happen.

**Chair:** We're – I know. We're going to make recommendations to Cabinet so that's when we'll do it.

**Mr. MacEwen:** Thank you.

**Chair:** Good. Okay, Hannah Bell.

**Ms. Bell:** Thank you, Chair. Thanks very much. It's great to see you here today.

I'm always struck by the amount of labour that we download to NGOs. The NGOs keep stepping up and doing it because they know that if they don't, it won't get done. To be able to hear it publicly and have it, even if it is the tenth time that you've been here, that in itself is another level labour; but I appreciate, from having been outside the fence, how much of that is downloaded into NGOs and how much we expect.

I'm also struck by being reminded again about the navigation and the secret handshake kind of thing that's needed to be able to find, like you said: If you don't ask exactly the right question to exactly the right person you don't get to find out about the supports that should be available because they are about what is best for the client.

Saying that, my first notes I have on here are around the provincial autism strategy and the autism action plan, which obviously sounds again like a significant piece of work and one that, is something that you have talked about a lot and has not moved forward. Could you speak to sort of the key recommendations from that action plan? I'm thinking we probably heard some of them already, but is there like a here's our top five things?

**Peter Rukavina:** I don't think I can give you the top five things. I think the important thing to realize as well is that that plan is now eight –

**Ms. Bell:** Eight years.

**Peter Rukavina:** – 10, 12 years out of date.

**Ms. Bell:** Right.

**Peter Rukavina:** The bones of that plan, so to speak, and the constituency of people who are brought together to help formulate it, I think, was very solid. I think to get to the point where we have an adopted autism action plan is going to require another similar exercise, perhaps even with a broader group of people. We have not only, you know, the very definition of autism has changed since that original autism action plan came up.

I would return again to the notion that the key recommendation, as far as I'm concerned, is that level of coordination.

**Ms. Bell:** Yeah.

**Peter Rukavina:** It's not only the kind of deputy-level coordination, but it's the bureaucratic coordination. It's getting people in the same room as one another to look in a person-centred approach to support.

**Ms. Bell:** Yeah.

**Peter Rukavina:** I mean, I think if you read, and it's, unfortunately hard to find copies of the autism action plan –

**Ms. Bell:** Yeah –

**Peter Rukavina:** – now because it was never formally adopted, so it was –

**Ms. Bell:** Right.

**Peter Rukavina:** – never a formal publication. I would refer anyone in the room to go and find a copy of it because I think it has some very – the methodology behind it was very solid.

**Carolyn Bateman:** If I remember back to that plan – which was a long time ago, I (Indistinct) read it – but, if I could remember a feeling I had after reading it, it was that we talk a lot about the school-aged kids and when they leave school, it's all over and you're done of your job.

In some ways, that's when your job is really beginning. They're 18, 19 when they leave the school system. Most of their life is when they leave the school system and that's when the most difficult job starts and when we really need the help of more

professionals to look at the needs and the mental health of these kids, which is not doing well from what I can see with a lot of them. We've had some great success, but we've had some great setbacks too, and a lot of concern about what's going to happen in the future for these kids.

We can only do so much on our own, and I think we've done it in spades, but it really gets disheartening when you think of what needs to be done; what could be done. We could be so proud of ourselves as a province on what we could be doing because we are smaller. I know it's expensive, but the alternatives are even more expensive. I think we just need to decide that this is something we need to do. If we're a society that takes care of our weakest citizens, it's time we start.

**Peter Rukavina:** I think one of the things that I remember very strongly, and sort of one of the seminal moments of my life as a parent is a meeting; it was actually when we were talking about introducing Oliver's service dog into the school system. We were meeting with people from the English Language School Board at the time, and we were talking about educational assistants because educational assistants have to be comfortable with having a dog under charge. They are the handler of the dog when the dog goes to school.

One of the people from the English Language School Board, one of the administrators there, said that the role of educational assistants in the school is to allow their charges, the students that they're working with, to survive, not to thrive. While I appreciated their honesty in that case, I think that's a depressing statement to make; but I think it also reflects our societal approach to not only people with autism, specifically with autism, but people with all manner of atypical conditions.

I think when Carolyn is talking about what could we do with more coordination and more funding, we're talking about let's not treat survive as what we're going to live up to. Let's allow adults with autism to be full, contributing members of society with the full supports that they need and not treat this – I mean, we fall into the trap of talking about autism as though it's a burden or as though these clients are somehow weighing

us down, or as though they are broken individuals and they are not. They are you and I. I think to allow them to participate fully in society is an economic issue, it's a human rights issue, and it's a social justice issue.

**Chair:** Hannah.

**Ms. Bell:** Thank you.

There's a ton of stuff in there, but one of the pieces in there is to follow up on my colleague Sid's point there, this is more than funding. Though funding is a piece of this story, and it's about why, and what do we want to achieve? Which is this broader picture of recognizing and valuing that all residents of PEI, whatever their experience, deserve to have the same opportunities.

I would certainly like, for the record, to comment that we're talking about core funding for an organization that provides a support that no one else does; about a plan or a strategy that looks at the continuum of care through the school system and beyond including long-term care-based housing options; day programming, and programming supports independent of core funding for the organization which are integrated across departments, and supports for caregivers and families in that integrated approach.

The other piece I would also like to make sure we have in the record is that government is the enablers of this process, but are not the experts of the process. The experts reside in the community with the great work and background and experience that sits there. Any development of plan; any associated allocations of resources to it should be done being led by the organizations that have already demonstrated that they are the leaders in doing so.

I'd also like to state that, on a personal basis, I am on the Asperger's – I am on the autism spectrum. I'm a high-functioning Asperger's – late diagnosed, very late in life, with no supports or any of those interventions and my daughter is currently going through the assessments for the same. On a personal basis, this is something that is, as you said, something that I am hugely worried about. I would also like to feel that we can be

hopeful that we would be able to sort of demonstrate a different model of care and approach that says that the value of our citizens is not measured by how they look, like everybody else, but that those individuals themselves are rich.

Really, it is about money in terms of the bottom line when we look at budgets and things, but in this case we do have to think about consequences for what that says about us as a province and what it says about us in terms of how we reflect ourselves out into the world.

I'm really encouraged to hear from Minister Mitchell to speak about social deputy's hub. It's something that's come up a lot with other programs. It also will require this piece and I would also ask that perhaps that work of the social deputy's hub would consider consulting with NGOs as a key piece of that activity whenever they're developing any strategies or plans.

Thank you very much for the time, Chair. I appreciate it.

**Chair:** Thank you.

Jamie Fox.

**Mr. Fox:** Thank you.

We've touched on different departments that you have to deal with. How many different departments would you as a parent have to deal with to get autism services of some sort or another?

**Peter Rukavina:** I would say, certainly, health, family and human services, and education at a bare minimum; but I think for some families, justice enters into it at some point as well, and any kind of plan or autism action strategy would have to involve justice as well. Those three departments would be the three that we would deal with on a most regular basis.

**Mr. Fox:** With that then, there should be at the least one person somewhere in government that should deal with all autism that could navigate through that bureaucratic system.

**Peter Rukavina:** Yes.

**Mr. Fox:** Makes sense.

How much of an issue are transportation services for a parent with a child with autism on the school side or up into the employment side, or to after he leaves the household? How much does transportation – is there a lack there or what's going on in that area?

**Peter Rukavina:** Yeah, I mean I think, again, it depends on the individual; but I think some adults with autism have a driver's license and are independent in that regard. Many adults with autism are not.

My son, Oliver, can't ride the school bus to Colonel Gray just because it's too bright. It's too noisy. I drive him to school every day and, again I'm able to do that. Some families are not and that presents them with challenges. We live in the city and can walk to many of the services, but in rural areas that would not be the case and certainly a family raising children with autism or adults with autism in the rural areas, I think would face some transportation struggles as well.

When we talk about coordination, we've talked, I think, to this point a lot about coordination of services and I think that's an important thing; but I think what you're really introducing is an important new page in this book which is – when you think, for example, about going to the emergency room as a young person or as an adult with autism and the fact that there are bright fluorescent lights in the emergency room; stressful situation for everybody. But, many people with autism, many other people as well, are particularly susceptible to fluorescent lights and find that to be a very stressful environment to be in.

We need to get to the point, I think, where when we're building a new emergency room we think about: What should the lighting be? When we think about that, we should think about all individuals, not just typical individuals. I think when we're talking about transportation planning and we're talking about how wide should the hallways in a school be, and we're talking about how do you get to the beach; we're talking about should there be rock and roll music playing at the swimming pool or is that too overwhelming for people – I think just having people with autism or their

supporters, and/or their supporters, involved in the discussion at every level in a coordinated fashion would make life so much more livable for so many people.

**Carolyn Bateman:** For stars for life, on a daily operating basis, transportation is an issue. Our staff members are all required to transport their clients to their work, to their school, to whatever activity they're doing. They get a small amount under the welfare for transportation for a month; but it is limited, so you're always deeply concerned. You want to take them to the beach in the summertime. Well, that's going to cost you half their monthly amount for transportation. So those activities they don't get to do because there's a limited amount that's in their pot for transportation, and you have to compensate all the staff for their per-mile per diems.

**Chair:** Jamie.

**Mr. Fox:** Has there ever been an education system educating bureaucrats within the government of the different departments to educate them on the whole thing around autism or that, so that they're more aware of – like, I'm thinking of Access PEI. If somebody with autism goes into Access PEI and that frontline worker, is he or she prepared to deal with what this person is trying to convey to them to get services?

**Peter Rukavina:** That's an excellent point.

Personal story: I took my son to Access PEI in Charlottetown last year to get his voluntary ID photo. The person behind the desk, the lovely clerk, asked him to take his glasses off. He was having a bad day. Being asked to take his glasses off just – it pushed him over the edge. He had a full-blown meltdown, caused everybody distress, caused me distress. Other people didn't know what was going on.

If you're right, if that person – now, would they have known perhaps to not ask Oliver to take his glasses off? Probably not; but I think in terms of increasing the awareness of everyone, ourselves included, to the way that autism manifests, I think is something that stars for life is not particularly well-equipped to do, but we do it anyway, and I think just raising the profile of people with autism and ways in which we can change the

daily lives of all the systems. Access PEI is a good example because it's the (Indistinct) –

**Carolyn Bateman:** One of the positions that we would like to fund is a position whereby it really is a community access person who will go out to speak to employers. We're doing it on a really piecemeal basis where we go to talk to professors at the university about teaching people with Asperger's or autism in their classrooms and the differences that they may need to take into consideration. We do that without pay.

But one person that if we had hired, that would go out and talk to employers, that would help us break down those doors to get employment for people, and it would have that additional benefit to what you're referring.

**Mr. Fox:** I hate labeling people and I hate singling people out, but I think that the more we can make the public aware or the workers aware, the bureaucrats aware, the frontline workers aware, I think it's a major move forward.

Final question I have is: Back a while back, you said about when you have to submit an application for funding for a program for a child or for someone with autism, that's not covered. That comes out of basically your own pocket to –

**Carolyn Bateman:** Yes.

**Mr. Fox:** – do that?

**Carolyn Bateman:** Yeah.

**Mr. Fox:** So that core funding that's provided, that doesn't cover that off?

**Carolyn Bateman:** Okay. The Disability Support Program, let's say takes, provides somebody with maybe a high-functioning individual five hours a week. That five hours a week, the amount of time it takes us to write reports to government, apply for their funding, design their program, hire and train, is not covered; because that DSP money only covers the hours of their program, period. So anything that happens outside to support that person is not covered.

I need to qualify that, because there is an amount that we're allowed, a small amount that we're allowed to take for each individual that we take in for the DSP program that helps us with some of the overhead costs. It doesn't really cover what we need it to cover. So there are small little bits that are people trying to help us out, but it's not sufficient.

**Mr. Fox:** Okay, thank you.

**Peter Rukavina:** If I could just respond to your comment about labelling, which I think is a valid point to make. I think one of the things that we would say, I think, and certainly I would say personally, is that it's not so much singling out individuals with autism and making accommodations for them. It's looking, I think, at a bird's-eye view at how do we design our systems and how do they work for everyone.

An example I'll give of this is the one-hour delay, when you have the one-hour delay at school. You might think: Well, that creates some inconvenience for families and you have to delay your job. If you're a parent raising someone with autism in the public school system, then a one-hour delay is tantamount to a nuclear bomb dropping into the middle of your family. Because it's not only is there a change in routine, but there's this one hour where you don't know whether you're going to school and I mean, it's just – it's an incredibly stressful situation.

You would see that on the surface as: Well, it's just a simple transportation issue. But no, it's not actually. It's a mental health issue, it's an economic issue, it's a design issue, it's going to affect in many cases that individual's day or perhaps their week or their month at school. So when we're making a decision about, well, should we have a one-hour delay or should we just cancel school or not cancel school, maybe we should design the system so that it accommodates and takes into account that stress on individuals with autism –

**Mr. Fox:** Which goes back to my education point.

**Peter Rukavina:** Yeah; but also, the other thing is that probably – and this is why I think people with autism are actually of tremendous benefit as – you know, if you're

an individual that has trouble with transitions and choices, a lot of people, autism or not, have trouble with transitions and choices. You can sort of in some ways consider people with autism to be an extra sense of sort of canary in the coalmine, so to speak. If people with autism have trouble with a one-hour delay, there's probably a whole raft of other people having trouble with a one-hour delay. It just doesn't affect them to the same extent. So if you design for people with autism, I think you design for everyone and it improves the lot of everyone.

**Chair:** Thanks so much.

Okay, Richard Brown and then Kathleen.

**Mr. R. Brown:** Thank you, Mr. Chairman.

Carolyn and Peter; I've crossed paths quite a bit with Peter over the years. I've seen Oliver grow up: Prince Street, Birchwood, and Colonel Gray. I'm walking to your work, you're walking to school, or walking back and forth, it's great.

One question I have is: You say at the age of 18 they're basically cut off. If they go to Holland College or UPEI does that support continue, the 6,600?

**Carolyn Bateman:** No.

**Peter Rukavina:** No.

**Mr. R. Brown:** Well, that's (Indistinct)

**Mr. MacEwen:** There's your (Indistinct) –

**Mr. R. Brown:** No, thank you. I want to say, too, that stars for life has done a tremendous job and I was around when you built the new building and it was a fantastic improvement to the lives of many kids on Prince Edward Island, or young adults.

Thank you.

**Chair:** Kathleen.

**Ms. Casey:** Thank you. Thank you, Mr. Chair.

Carolyn, you and I have had these conversations for as long as I've been elected. Sometimes I feel like you think I'm

not doing anything, but my colleagues around the table know that I've been pushing this file –

**An Hon. Member:** Yep.

**Ms. Casey:** – for a very long time. Even after one of our conversations, and we talked about all the silos of all the departments as to who's dealing with what and Sid said about his question in the last sitting about who's going to answer this question, I said to you I'm going to get the ministers together. When we were talking about long-term core funding, my thought was: Okay, if we can get Family and Human Services, health, education and justice all in the same room, I can convince them to take just a little bit out of each of their budgets and voilà, we would have long-term core funding. So they're very aware. That meeting did take place, and they're very – they're aware of silos and everybody talking to each other.

I like the suggestion from the minister of health, and I probably have another one that I will undertake is – with the Minister of Workforce and Advanced Learning, you talked about employment skills and how you're training people for employment. There has to be funding. I know there's funding for all kinds of streams of skill development and everything. Hopefully, there might be something, and I know you've probably –

**Carolyn Bateman:** We've tried.

**Ms. Casey:** – tapped into that, but we can go back again and see if we can find that. The other thing is: What does core operational funding look like for you? What is the ideal number?

**Some Hon. Members:** [Laughter]

**Carolyn Bateman:** The million-dollar question.

**Ms. Casey:** The million-dollar question.

**Carolyn Bateman:** I put to government a couple of years ago a very – and I'm probably really naïve – the most barebones budget again, thinking that the little bit that we're allowed to keep out of the DSP program for our operations, that coupled

with a couple of hundred thousand dollars a year we can sustain what we have right now with one fundraiser type of thing a year and we might be okay; but that's only just still treading water to where – the size we are right now.

It's going to look a lot different if we're going to look at building a new resource centre that's – and more housing and needing more staff, and if you bring in another 40 people we're going to have to double the amount of operational staff that we have to supervise and train and work with all these young people. Basically, you'd be doubling that number again.

**Ms. Casey:** Perfect. Just one more, to follow up on her question: Carolyn, with the National Housing Strategy, the big announcement of the National Housing Strategy and the provincial housing strategy, is there any way that stars for life can tap into this new funding for housing? Would that fit your organization? Did you look into that?

**Carolyn Bateman:** It kind of goes back, I believe, to the way that we were funded for the first home. It required that any funding that we required, you have to be able to sustain and operate the house, basically on your own, for a minimum of five years. We can't fundraise anymore.

The fundraising we're doing is helping us to sustain the house we have. We can't fundraise more to sustain another home. That's the issue. We're sort of tapped out. Any of those federal programs or provincial programs, yes, there are wonderful grants and silos of money that we can access. It came up to about half the cost of the first home. We raised \$500,000 on our own outside of that; but if we're using all of – and that took 10 years to do. Like I say, I'm going to be in the old age home by the time this is going to happen again.

We have to look at different ways. Really, there has to be a partnership and a willingness to go forward beyond, yes, we can tap into all those sorts of money, but then you get into the operational costs of such a thing that we need help with.

**Ms. Casey:** Okay.

**Peter Rukavina:** I think there are also different models. All of the supported housing that supports adults with autism doesn't need to look like the existing apartments at stars for life.

**Carolyn Bateman:** Right.

**Peter Rukavina:** In some cases, all that might be needed is someone to go and make breakfast with someone every morning. In many cases, it's more – it's not that we don't have the housing stock in the community; it's that, you know, Carolyn was making reference to the fact that adults with autism are more – they're a vulnerable population. So, we need to have human supports as opposed to infrastructure building there.

I think the picture of housing is going to be as varied as the needs of the adults that we're supporting.

**Carolyn Bateman:** We've come up against some issues such as, when it came to housing, we had two people that we thought would make – be able to share an apartment together, but it required that they needed two bathrooms; but under the family services and the welfare program, they couldn't get enough money for the rent for that level of apartment and it wasn't approved.

We, you know, we're stumbling blocks because of rules and regulations that are set out for people who are in different situations. They're able-bodied people, maybe, but just on hard times. So, they need a leg-up with the welfare program, but our population is different and their needs are different and their levels of care or support are going to be different, but we're still in that big pot and there's no opportunity to step outside it.

**Peter Rukavina:** I think that point bears repeating, which is that: Autism is not something you catch or something you're afflicted with, it's who you are; and it's how you will be. That's the way that we have to approach things. It's not as though the needs of the population that we're working to support are going to go away. When we're thinking of 43 people on a waiting list, that's 43 people who are uncertain, and 43 sets of parents or caregivers who are uncertain about what comes next in their life.

When you're talking about what level of funding would be suitable for stars for life, certainly taking that waiting list from 43 down to zero would be a good start.

**Ms. Casey:** Okay, thank you.

**Mr. MacEwen:** And there's other waiting lists. (Indistinct) There's a lot more waiting lists than that one for sure.

**Chair:** I've exhausted the list, but this has been an absolutely fantastic session. Thank you so much for the work you do and are doing. Hopefully, we can help out in some way with that. Thanks for the presentation and sitting through almost an hour, a little more, of question period and doing an excellent job there.

We are going to take about a two minute break. Then, we will come back and do some follow-up and make some recommendations that we will take to the House, which will go directly to the ministers.

Again, thanks so much to both of you for presentation and –

**Carolyn Bateman:** Thank you for –

**Chair:** – spending –

**Carolyn Bateman:** – for the opportunity.

**Chair:** – that time with us.

**Peter Rukavina:** Yes, thank you.

**Carolyn Bateman:** It's awesome. Thank you.

[recess]

**Chair:** We'll call it back to order.

Just as a follow-up, my understanding now is that recommendations and discussion of that are usually done in camera. The clerk has said he has captured a lot of that. It will come forward in a report early in the session that we will agree upon or whatever.

If some member wants to make a recommendation formally, or whatever, you can forward that to the clerk, as well, and we'll deal with that report early in House

session before we – and get agreement on it before we take it to the presentation of a committee report.

We're going to move now to item number four, which is a review of requests received. The first one on that list is a request from Peter Bevan-Baker regarding Bill No. 100 *An Act to Amend the Employment Standards Act*.

Does anyone have any comments on that? Or should we move to have some people come in? Or what's your direction you want to handle them at on that topic? Or do we want to deal with that one as our next topic?

**Ms. Bell:** Chair?

**Chair:** Hannah Bell.

**Ms. Bell:** It was – this is on the list as it was referred to committee during the last sitting by Minister Gallant. And so, further to that recommendation during the sitting, that is the appearance of it on the list here for the work plan.

**Chair:** Who would we like to have in to discuss that?

**Mr. Murphy:** I think maybe the chambers of commerce. Some of the chambers, would be good to have them in.

**Chair:** One, two? Or how many would you like to have in? All of them?

**Mr. Murphy:** Four. There's four of them, representatives from each one, or –

**Chair:** Shall we put a request in –

**Mr. Murphy:** – as a group.

**Chair:** – into the chambers?

**Ms. Bell:** I'm just (Indistinct)

**Chair:** Hannah Bell.

**Ms. Bell:** – the context for this bill is the *Act to Amend the Employment Standards Act* would reflect the whistleblower protection for private employees, just for context.

**Chair:** Okay.

**Mr. R. Brown:** And to the unions, too.

**Chair:** Okay.

**Mr. R. Brown:** You know the Federation of Labour.

**Mr. Murphy:** Who is it going to impact? Right, then that's who we want to hear from.

**Chair:** The chambers, the Federation of Labour –

**Mr. R. Brown:** (Indistinct) Federation of Labour.

**Chair:** Federation of Labour is what I said. You know what –

**Ms. Bell:** Sounds like (Indistinct)

**Mr. R. Brown:** Yeah, I know (Indistinct)

**Chair:** – under that, the (Indistinct) agriculture –

**Mr. R. Brown:** He's a good FA man.

**Chair:** – have a lot of employees, that's for sure –

**Mr. R. Brown:** (Indistinct) good point (Indistinct)

**Chair:** That's right.

**Mr. R. Brown:** Yeah.

**Chair:** So we may want to hear from –

**Ms. Bell:** Absolutely.

**Chair:** – that side, as well so –

**Mr. R. Brown:** (Indistinct) Cornwall.

**Chair:** – thanks for bringing that up.

Any other questions or comments on that? So, we'll set that as the next agenda item for our next meeting –

**Mr. R. Brown:** Great.

**Chair:** – we'll continue on with the – and I think we'll just go with the one that time for – that might take one or two meetings, really, if we have a bunch of the – several of

the chambers come in. Then, we'll continue to work down the list after that. Okay?

**Clerk Assistant:** I just have a point about the next meeting.

**Chair:** Ryan.

**Clerk Assistant:** For clarification, you also have the workplan summary in front of you. The second priority of the committee beyond today's presentation was to hear about the district advisory and Learning Partners Advisory Councils in education. You're wanting to put the Bill No. 100 ahead of that?

**Mr. R. Brown:** I think so. The House is coming up. I've got no problem.

**Chair:** Okay. Sid MacEwen.

**Mr. MacEwen:** I think this has been the priority for – I'm new to the committee, but this has been the priority for a little while, hasn't it?

**Clerk Assistant:** Yes.

**Mr. MacEwen:** Yeah. Do you –

**Mr. Mitchell:** Advisory councils?

**Mr. MacEwen:** Yeah. I think that was on the priority list from before the last House session, wasn't it?

**Chair:** I'm new to the committee, too, so –

**Mr. MacEwen:** Yeah.

**Mr. Mitchell:** (Indistinct) I think (Indistinct) –

**Mr. MacEwen:** I would –

**Mr. Mitchell:** – (Indistinct) myself that brought it up after they were struck. It's some –

**Mr. MacEwen:** (Indistinct) yesterday.

**Mr. Mitchell:** No, that wasn't yesterday.

**Mr. MacEwen:** I think we should probably deal with that one, first, personally.

**Chair:** Okay. Can we have a motion? We've got two items that we have a –

**Mr. MacEwen:** I see it's already a priority after the one today so –

**Chair:** Yeah.

**Mr. MacEwen:** – I think it was already voted on.

**Chair:** I'm just going by the list.

**Mr. MacEwen:** Yeah.

**Chair:** (Indistinct)

**Ms. Bell:** (Indistinct)

**Chair:** Okay.

**Mr. MacEwen:** Yeah.

**Chair:** A motion to that effect then? Sid?

**Some Hon. Members:** (Indistinct)

**Mr. MacEwen:** I move that we go with the priorities already determined.

**Mr. R. Brown:** Sure.

**Chair:** All those in favour signify by saying 'aye.'

**Some Hon. Members:** Aye.

**Chair:** Contrary minded, 'nay.'

Great. That's what we'll do. We'll have the clerk line up those items as in order.

**Ms. Bell:** And then, Chair, we'll follow then with the bill as the next priority?

**Mr. R. Brown:** (Indistinct) Tell Peter I tried.

**Chair:** Good.

**Some Hon. Members:** (Indistinct)

**Chair:** Okay, any other new business or –

**Mr. MacEwen:** Chair.

**Chair:** Yes, Sid.

**Mr. MacEwen:** Can we not book another meeting for the Bill No. 100 *An Act to Amend the Employment Standards Act*? Do we just –

**Chair:** Yeah –

**Mr. MacEwen:** – book (Indistinct)

**Chair:** – that'll be the next one come up.

**Mr. MacEwen:** Okay.

**Chair:** Okay, great. Other questions or comments? New business? Motion to adjourn?

**Ms. Casey:** So moved.

**Chair:** Thank you, Kathleen. Good. Okay. Thanks, folks.

The Committee adjourned