

# **HANSARD**

**NOVA SCOTIA HOUSE OF ASSEMBLY**

**COMMITTEE**

**ON**

**COMMUNITY SERVICES**

**Tuesday, November 3, 2009**

**Committee Room 1**

**Brain Injury Association of Nova Scotia**

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## **COMMUNITY SERVICES COMMITTEE**

Mr. Jim Morton (Chairman)  
Mr. Gary Ramey (Vice-Chairman)  
Mr. Leonard Preyra  
Mr. Trevor Zinck  
Ms. Michele Raymond  
Mr. Leo Glavine  
Ms. Kelly Regan  
Hon. Chris d'Entremont  
Mr. Alfie MacLeod

[Mr. Alfie MacLeod was replaced by Mr. Keith Bain.]

In Attendance:

Ms. Kim Leadley  
Legislative Committee Clerk

## **WITNESSES**

Brain Injury Association of Nova Scotia

Mr. Don Sullivan, President

Ms. Margo Dauphinee, Executive Director

Ms. Jane Warren, Past President

**HALIFAX, TUESDAY, NOVEMBER 3, 2009**

**STANDING COMMITTEE ON COMMUNITY SERVICES**

**9:00 A.M.**

**CHAIRMAN**  
Mr. Jim Morton

MR. CHAIRMAN: Good morning everyone. I call this meeting of the Standing Committee on Community Services to order. My name is Jim Morton and I'm the chairman of the committee. Just to get started, I want to mention we have several guests in the room, some of whom will get to introduce themselves. We may have a few photographs taken this morning, so don't be surprised should that happen - of course you can see there's a camera taking some shots as well.

To begin, we do have a little less than an hour this morning, so I will start by asking members of the committee to introduce themselves.

[The committee members and the clerk introduced themselves.]

MR. CHAIRMAN: We have guests today from the Brain Injury Association of Nova Scotia, and perhaps I could first ask you to introduce yourselves.

[The witnesses introduced themselves.]

MR. DON SULLIVAN: If I could, I'd like to take a moment to point out the presence of a couple of other people as well?

MR. CHAIRMAN: Yes, please do.

MR. SULLIVAN: Sitting behind us is Jane Warren who is the current past president of the association and we also have a woman on the other side of the room, Amy Moonshadow, who has been a long time member of the Halifax Chapter of BIANs.

MR. CHAIRMAN: Okay, to begin with, I know that you plan to make a short presentation and I just want to emphasize it, because time is precious, I know you plan to be succinct, but if you can do that, that would probably help us and then I know we'll have questions for you.

MR. SULLIVAN: I don't think I've ever been accused of being succinct. (Laughter)

MR. CHAIRMAN: That's why I brought it up.

MR. SULLIVAN: I'll promise this, I'll try not to make many gaffes. I've been known to do that.

First of all, we originally were to be three people presenting; I just wanted to point that out. Dr. Richard Braha is the Program Manager for Acquired Brain Injury services for Capital Health and he was planning on being here. He also serves on our advisory board, so there's a connection with BIANs. He's unable to be here on fairly short notice, as he informed us that H1N1 requires him to be on duty, on-site, in one of the hospital buildings in Halifax. We'll do our best to handle what he probably would have handled. He has extreme knowledge of the topic and not just locally within Capital Health - it's his job - but what's going on here, there and what's going on in other places. What should be going on here, what is and what isn't and so on. So we may miss him a little bit.

We have provided a package of information, included in that is a newsletter, the latest one, I believe, from BIANs. There is a brochure from BIANs included in the package as well.

In addition, we have an outline of some information some of you may have seen before. We have spoken with caucuses in the past, on this topic. That information, we'll be taking a walk through with you, and in addition to that, there is a bundle of reference material. This yellow guy here with the title on it, Reference Material, includes mainly documents that have been done in the past and studies and reports that it referred to.

BIANs considers itself the voice for ABI survivors and their families. You'll often notice when we use that term, we don't just stop at survivors - we say "and their families". That's an important part of this. The letters ABI stands for Acquired Brain Injury, meaning injuries to the brain, to the head or to the body that result in injuries to the brain that are acquired during one's lifetime, not something that you were born with, et cetera.

You'll also see some other initials kicking around by times on this topic. TBI will oftentimes sort of jump out at there instead of ABI. It gets a little complex in some ways,

but ABI injuries are basically two categories: you have traumatic and non-traumatic, and then you start getting into medical stuff. That's why you see somewhat different terms.

Most ABI survivors and their families have not been well served by government in Nova Scotia. This goes across departments. You can look at it through the eyes of Health, Health Promotion and Protection, Justice, Labour and Workforce Development, Education, Community Services and probably most of the others. In a nutshell, this is the succinct part - after excellent acute care, ABI care in Nova Scotia has little to offer.

This was officially recognized when the Continuing Care Strategy for Nova Scotia put together a 10-year plan - this was done about five or six years ago, because we're now in year four - it was deemed that in year four, brain injury care would be addressed. We have a document which is included in the reference material, and you look down through year four, the way that document is set up, each of the ten years has a list of actions that should take place at that time, or at least start to take place. For brain injury care, this is what's written there - the heading says, "Respond To Acquired Brain Injury Care Needs" and underneath the heading the descriptor says this: "Incorporate the needs of persons with acquired brain injuries in continuing care services."

The wording of that, to us, is significant. Incorporate the needs of persons with acquired brain injuries is, to me and our organization, a recognition that until now hasn't been done. So in year four of the 10-year plan, this is going to start to be done and the start is a significant concept to us as well.

If you look through most of the other entries in the 10-year plan - if you look at tweaking, fixing, adding, adjusting, and so on and so forth, this might not be the only one that comes from that angle, but it certainly does. There's an analogy that I always try to fit into presentations I'm making wherever I can. I'll see Margo's eyes rolling there in a moment when she hears the phrase "picket fences." (Laughter)

MS. MARGO DAUPHINEE: No, no.

MR. SULLIVAN: I don't know where I came up with this or how it actually evolved. I've been using it for a while, so I don't remember, but if you think of health care in total as a long picket fence with little rails and pickets on it, a nice big, long white fence, and if you think of - I know some of you have heard this before - the various components of health care as a section of that and then stop to examine them, probably in every case you'll find that every one of those sections needs a little care. There will be some paint needed over there, a couple nails replaced there, there's a crack over in that one, and so on and so forth.

[9:15 a.m.]

When you come to the section in our estimation for brain injury survivor care, what you find is a couple of rails, one picket at one end holding the rails apart at that end. At the other end, they aren't really apart - they're kind of lying on top of each other. It all needs a coat of paint and certainly it could use a few more pickets along the way. I use that as just kind of a visual analogy.

Being year four in continuing care strategy, back in the Spring we asked for a meeting with the Health Minister at the time, and we ended up meeting with the continuing care people in lieu of that. Our purpose for going to that meeting was to say, well, okay, this is year four, it started in the Spring, and this is a little bit into the Spring, so where do things stand? At that meeting we were basically told that nothing had been started at that point pursuant to that. So that's kind of getting us up to now.

In our opinion, the way to start this process of addressing the needs of ABI survivors and their families is to develop an ABI strategy for the province. We also feel that this strategy has to be multi-dimensional; it crosses through all aspects of living in our society. It's not just a health alone sort of thing. Margo, myself, and Dr. Braha recently met with Health Minister MacDonald to share our perspective on this. After the meeting, in our opinion we feel, and still do, that Minister MacDonald has a good understanding of the issues and of tremendous gaps that have to be addressed sooner rather than later. We feel it was a very positive and hopeful meeting.

In closing my part, the introductory part of the presentation, we've asked to present today basically because we want to solicit this committee's support to support our idea of having an ABI strategy developed in the Province of Nova Scotia as the first step to starting to deal with the broader, more complex issues. At this point, Margo would like to start to run through the information package that's with you, particularly to highlight some of the things; not simply just to read it to you. You can do that, but there are some things that might need a little bit of extra comment by us or questions by you, or whatever. Over to you.

MS. DAUPHINEE: Thank you, and thank you, Don. Just for a point of clarification, I was not eye-rolling about the picket fence. (Laughter) It was a smile, because I think that nothing describes what is lacking in the gaps than Don's picket fence example.

As Don said, it's my pleasure to run through the information that you have in your kit, which are slides that are basically a PowerPoint presentation, but due to time we just wanted to basically run through some of the points.

I can give you a little bit of a background in the gaps in the continuum of life. I know we sometimes use the term continuum of care, but it's a continuum of life for survivors and their families. So as Don did give you the definition of acquired brain injuries, I'm not going to spend any time going over that.

On page four, you see some statistics. We estimate that 30,000- to 40,000-plus Nova Scotia families are dealing with the issue of brain injury and it's close to 9,000 new cases every year. That's roughly five people a day, and we know that these numbers are probably low. The reason? The way these injuries are coded, the way that people may not go to the emergency room - they may not even go to their doctor when they sustain an injury. When we talk about injuries we talk about things like concussion, whiplash - which may not show until after the incident, months after - and also that ABI is an umbrella term.

Now the cost. In 1997, Kreutzer estimated the cost to be about \$4 million. He spoke at a conference last year in Toronto and that estimate, in his opinion, has gone up to about maybe \$8 million to \$16 million for a survivor. That's in lost revenue and costs to the family.

Moving on to the fifth page of the handout, there have been many studies done. One of the studies that's included is our study back in August 2007 and, as Don mentioned, has been presented to the three caucuses as well as the Continuing Care Strategy, which John also mentioned and is also included in your package.

What are the gaps? Well, there are many and these are just some: the need for specialized in-patient and outpatient rehabilitation; services are few and wait lists are long; there is a need for navigators in each of the district health authorities; no day treatment programs or clubhouses; no behaviour management unit; supports for employment are lacking. Some services and programs have the criteria of "must be motivated," and for some brain injury survivors motivation has been an issue that has been impacted by their injury. Survivors are in hospital, which are costly to support because of the fact that there is a lack of community supports.

Education - not only within the health professions, but other professions about ABI and how to work with survivors and their families. No adequate homecare support or staff trained in ABI and, as mentioned, identification and data tracking are issues - how do you get the stats when it's hard to track them? Not enough long-term residential care, and for me, one of the things that impacted me most was when I went to nursing homes and saw the number of survivors in their 20s and 30s. That's where they are - in nursing homes with residents that are older than they are, and I'm thinking, wow, what an option, but it's the best that's available. Services are limited.

Those are just some of the gaps that are there. There are probably others, but I just wanted to highlight some of them and, as Don mentioned, it is not just an issue for the health care sector. It's an issue that runs the whole gamut of society.

I want to focus a little bit on page 11, which sort of says what's currently in place, and this is where we would have turned things over to Dr. Braha, because these two slides on page 11 and 12 are his. I'm a very poor substitute for Dr. Braha, but I'm going to give it my best shot.

This diagram is what is currently in place, and it appears to be a partial diagram. It's demonstrated by the blank boxes and the lines that seem to be going nowhere. This diagram is designed to be superimposed to show what should be in place, and we know, as Don said, that acute care in Nova Scotia is second to none. People are surviving brain injuries who normally wouldn't have survived 20, 30 years ago. We have excellent paramedic services and emergency neurosurgery - the infrastructure is in place. We realize that is excellent, but what's currently in place after the acute care? There is some in-patient rehab, there is some outpatient rehab, there's some community living and some facility care - not very much if you're looking even visually at the diagram. That's not a lot.

What should be in place is the focus of page 12: outpatient rehab therapy, outreach team, a rapid response team - which are those three little blocks in the centre - and from them flows into the circle of a clubhouse that has day programming, pre-vocational, sheltered workshop, and avocational services. Within this is also a day centre which can provide socialization, respite for family, and rehabilitative learning for survivors. Outside of those parameters are things such as navigators, community living, network community-based resources - these are just some of the pickets that Don is referring to that need to be on the picket fence.

Also, our feeling is that what is needed, as Don alluded to, is a provincial ABI strategy that crosses all departments, all levels, all stakeholders. A strategy that is consultative, integrated, and coordinated. There needs to be a plan, there needs to be a thought process in order to ensure that these programs and services that are developed, and those that are currently existing, benefit survivors and their families.

On the last page you have our contact information and the contact information for Dr. Braha, who said to say that if anyone on the committee has any further questions to please contact him directly. In that regard, hopefully, it gives you a little bit of an understanding of what are some of the gaps and why there is a need for a strategy.

So back over to you, Don, or you, Mr. Chairman, for any questions.

MR. CHAIRMAN: Thank you, Ms. Dauphinee, and thank you Mr. Sullivan. I think that probably the place we could move now is to an opportunity for some questions and a chance to interact, which will probably give you a further opportunity to describe your thinking. We probably have - just because we need to probably end shortly before 10:00 a.m. - that gives us 35 minutes or so for questions. We haven't worked out a pattern of questioning but, if there is someone who would like to begin with the first question, please start. I think I saw Kelly's hand first.

Before that, we've had Mr. Preyra and Mr. MacLeod enter the room - I wonder if you could introduce yourselves.

MR. LEONARD PREYRA: Yes, I'm Leonard Preyra, the MLA for Halifax Citadel-Sable Island and I'm sorry I was late.



MR. KEITH BAIN: Hi, I'm Keith Bain. I'm representing Alfie MacLeod this morning on the committee and I apologize for being late as well.

MR. CHAIRMAN: Okay, Kelly.

MS. KELLY REGAN: I have a couple of points - two weeks ago I had a community clinic where people could make appointments and come in and meet with me. I met with a father of a young man who has ABI and we talked about the lack of financial supports for survivors of brain injuries. Particularly in their case, they're starting to get worried because he and his wife are in their 80s and they have a son in his 50s, and they're concerned about what is going to happen to him in the future because, right now, they are providing for his living accommodations and things like that, but of course like many of us they've taken a beating in the stock market and all of that, so they don't have as much money, and they are concerned about what is going to happen to him when they are gone. I wonder if you could speak to that - just sort of what are the positives about what is in place and what is lacking.

MS. DAUPHINEE: I think probably . . .

MR. SULLIVAN: Gee, it's a biggie - go ahead.

MS. DAUPHINEE: I was just going to say I get those calls as well. I get those concerns from family members who are very concerned about what is going to happen to them, but I think maybe I'm going to bounce it over to Don, because Don is the father of a survivor and I'm sure that's an issue that you can probably speak to probably better than I could. Over to you, Don.

MR. SULLIVAN: I'm just thinking, where do you start? When you're around this topic, you come in contact with people - survivors and the families - in all ranges of financial circumstances. So if there's a big insurance settlement related to an accident, for example, and barrels of money out there, then you can buy the care, whatever aspect it needs to be - either here or away or whatever.

The other end of it is, you don't have a pot to pee in and you can't afford any of that. Then you have to take what is available in the public system as it is - and it isn't much. So I don't know what I'd tell the father in those circumstances.

If our system evolves, the system of care related to brain injury evolves, then financial constraints obviously are not going to be of the issue that they are now. So that's why we're here, I guess, and that's what our thrust has been in the last number of years particularly. I could paint you a scenario of what may happen to that person and it isn't pretty - likely a nursing home somewhere with people who are paid to work there looking after him.

MS. DAUPHINEE: Or worse.

MR. SULLIVAN: Or worse - not looking after him, until that person dies. The aspects of brain injury survivor care and so on, it's complex in the sense that there are so many strands coming together. It's a physical injury, but it's not like a broken leg. Basically, if you have a brain injury, you have it the rest of your life, and the rest of your life could be 30, 40, 50, 60 years - you could be five years old when this happens and you could live to be 85, it doesn't go away. Within the system that makes it cumulative, so brain injury survivors that are new at it this year are added to the ones from last year and so on.

[9:30 a.m.]

I know I'm wandering a little bit, but there is a point to this - I always say that, even if I don't have a point. (Laughter) But when you go back and look at the gaps that Margot was running through, the word that came to me when we were doing it - it's not the first time - it's overwhelming. But it's overwhelming primarily because there isn't anything out; it's never been started. I think myself, and this is just a personal reflection, one of the reasons why in recent years it hasn't really gotten off the ground is, where the hell do you start? What do you do? What do you do first? Blah, blah, blah, blah, blah.

Hence, it makes sense that the first thing you do is plan what's going to have to be - that has to be there. It's too complex to start throwing money at this, that, and the other, and so on - it has to be planned. That's why we're not here asking you guys to give us some money, but we're asking you to support the idea that there has to be a comprehensive strategy so that this can get started - started is the word. So back to buddy - I don't know.

I wanted to ask - I introduced Jane a little while ago and she's chomping on the bit to answer a question or whatever and I don't know if that's okay.

MR. CHAIRMAN: That's acceptable, but she needs to come to the mike.

MR. SULLIVAN: I just want to warn you ahead of time, you might need a hook - you think I'm bad.

MS. DAUPHINEE: Before Jane starts, I think the comment, to build on what Don is saying - imagine if there's a strategy in place. There are certain things that don't need to wait until a fully developed strategy. There are certain things that can be implemented sooner rather than later within a strategy, but we're also talking about the family and the stress, and we know that if you look at anything with the determinants of health, when a family is under stress there are health implications as well.

So imagine if there were things in place - not just for financial, but for places that the son could go and that offer respite for the family - what kind of impact that would have. The stress would be relieved.

That's why we're here, because we really believe that a strategy is a place to start. Over to Jane.

MS. JANE WARREN: I leaped into this. The possibility that the son could get provincial disability assistance, the problem is . . .

MS. REGAN: He's on social assistance, but we're concerned that does not provide enough for him to have a decent life.

MS. WARREN: Any sort of quality of life, or even to eat the last two weeks of the month. Beyond social assistance, if you have a brain injury, you have to be classified as mentally ill or mentally challenged. There's no such disability as brain injury in the disability assistance criteria. I'm 100 per cent mentally disabled according to the Department of Community Services, so I was on social assistance - but I could not have gotten on it if they just said oh, she's brain injured.

The fact that I couldn't talk, walk, cook, go out and buy groceries, or anything made no difference. So they said, okay, she's mentally challenged, she can't do this, and this and this so she's obviously not able. It's like fitting a square peg into a round hole, you have to be . . .

MR. CHAIRMAN: I'm concerned that we probably have a lot of questions in the room and Kelly said she had - could you limit yourself to one more question, because I know we have Mr. Glavine and Mr. Ramey on the list as well.

MS. REGAN: Actually, I think I could sum it up very quickly - just wanted to point out to you that there is a really interesting article in the New Yorker from October by Malcolm Gladwell, who did the books *Blink* and *Outliers*, on the brain injuries of football players. He actually links up football players and dog fighting and asks how we treat football players, but he talks about the cumulative effect of brain injuries. You can get a concussion one day which doesn't appear to be that bad, but if you get hit on the head a week later, it's cumulative. So I just wanted to draw your attention to that.

The other thing is, one bright spot that I wanted to point out to you, our middle daughter received a very bad sports related concussion in April and did not, for example, write her final exams at university. I just wanted to point out that St. F.X. University has been terrific in their response to this. They're testing her, they're doing a number of things with her. She has had to drop one course, so she's taking a slightly lighter course load and she decided not to go into business as she was going to do, because she couldn't make change.

MS. WARREN: The Atlantic Centre for students here at St. Mary's is another place where they have quiet rooms that you don't get distracted by lights or people.

MS. REGAN: Yes, I mean they give her extra time to write her exams and things like that.

MS. WARREN: Yes.

MS. REGAN: So I just wanted to say that we have a lot of lack here but I was really impressed by St. F.X.'s response.

MR. CHAIRMAN: Mr. Sullivan.

MR. SULLIVAN: Just sort of a response in a general sense, not to that specifically. We could tell you some bright stories, as well, from different directions, but the stack of them and the other kind are, you know - I'm just making that point because you gave me the opportunity to make it, that's all.

MS. REGAN: I would like to point out that before she returned to St. F.X., we were pretty frustrated by the long lineups here to get her looked at. I could do a whole another rant on the particular sport that she was involved in, and there are no controls on that, but I'm not going to do that now.

MR. CHAIRMAN: Maybe there will be a later chance but I'm not sure; I wouldn't be confident about that. Leo, I think you're next in line.

MR. LEO GLAVINE: Thank you, Mr. Chairman. Picking up on Kelly's personal story there, how does Nova Scotia rank in terms of brain injury on a per capita basis which, again, can often highlight that we have a greater need should that be the case. How do we rank on a per capita basis? I know we have around 2,200 a year, but how do we compare to other provinces? I know Dr. Braha would probably be able to tell us that.

MS. DAUPHINEE: I would say that would probably be in Dr. Braha's realm.

MR. SULLIVAN: Probably at his fingertips, he might not have a specific number, but he might be able to give you an opinion on that. I don't recall anything off the top myself that would lead to sort of a ranking or anything like that.

MR. GLAVINE: Okay, what about services across Nova Scotia? I mean I've come to Community Service meetings here for the past six years and - not to create any divide of urban and rural, but there are areas of rural Nova Scotia that truly have immense challenges. I'm just wondering, what about the differentiation of services across Nova Scotia?

MR. SULLIVAN: Metro, basically the preponderance of hospitals and the centres that are here - Dr. Braha's position, for example, even in metro, that's fairly new. He's a neuropsychologist and did a lot of clinical work at the rehab centre for years. It's only a couple of years, approximately, that this particular job position that he's doing came up

and he applied for it. So even in metro, there are hospitals here, the rehab centre is here, but if you go back to the chart, there's not a lot happening overall, whether it's here or there. People from the rural areas, outlying areas, will come into Halifax for whatever. There's very little out in the rural areas that they can access themselves, but that might be similar to a lot of other aspects as well.

MS. WARREN: There are eight or nine neuropsychologists in Nova Scotia and those are all based in Halifax.

MR. GLAVINE: Okay, I'll let it move on for now.

MR. CHAIRMAN: I think Trevor may be next.

MR. TREVOR ZINCK: I thought Gary was next.

MR. CHAIRMAN: He just signaled to me that he would rather wait for you to go first.

MR. ZINCK: All right, that's fine. I had three questions but your presentation answered two. I'm interested in what other jurisdictions across the country are doing, what other provinces. Have there been successes? Have there been models, such as in the end of the presentation, being done in other provinces in Canada?

MS. DAUPHINEE: I know that in different provinces the services vary. One of the things that we're working on is looking at developing an ABI day centre, so one of the things that we've done is made calls across the country. Some provinces and towns have some good day centres, others don't, and so when we talk a little bit more they say, oh, we'd love to have that, so it does vary.

I know that one of the issues within the Afghanistan conflict, one of the signature wounds coming out of that is ABI. That's an issue that the military is looking at as well, and gearing up for and addressing, so it differs and varies. Dr. Braha certainly has his pulse on what is happening with other jurisdictions across the country, but it varies. Changes mentioned - Alberta does have some programs and services, B.C. as well. Within Nova Scotia, I know our valley chapter has been running what's called the Inroads Program, which Mr. Morton may be familiar with and Mr. Glavine from being up in that area. They've been able to fundraise to operate that program for about eight or nine years and that is definitely one of the successes that Don mentioned that we do have. We don't have enough successes in that, I guess, is our message. We want to have more successes.

MR. ZINCK: So there is no other province with a particular strategy or method of addressing the overall concerns that we could perhaps look at in comparison to what we might want to do?

MS. DAUPHINEE: I think that when we were meeting with the minister, we know that there are bits and pieces out there that, quote, unquote, the wheel does not have to be reinvented. With research there are bits and pieces, and I know that Jane has done a lot of research and knows things like in B.C., Australia, I think is really key, which is a federal jurisdiction. I know that that's one of our messages that we've given the Brain Injury Association of Canada - as our national association, maybe that's something that they need to be working at the federal level as well. So there are these things that we have been kind of working towards. We also realize that within Nova Scotia, we need to have something started now.

MR. SULLIVAN: If I could, just to add a little bit to that. Again, for some of this it sounds like we defer to Dr. Braha. We're kind of used to doing that, for starters. We had short notice late yesterday that he wasn't going to be here, so he could be a little more specific to your follow-up questions. Within Canada, yes, there are different things happening, the two provinces that were mentioned, but also in Saskatchewan and also in Ontario as well. I don't know the history of any of those so whether they started out with a strategy and whatever. There may be some of that. It sounds fairly involved in Alberta so maybe they did it that way. I suspect in some cases they were addressing specific needs and it has evolved, I suspect, I'm not sure.

Another analogy, the wheel. We don't really need to reinvent the wheel here and I just want to slide this in - there's probably not a wheel out there that fits Nova Scotia. I'm not that naive, but there are a lot of spokes out there, and there are a lot of spokes in other countries. We could probably assemble appropriate ABI strategy- with the talent that is in the Province of Nova Scotia, and the knowledge - pulling some of those spokes together and making our own wheel as we do it. Somebody, I think Margot or Jane, mentioned Australia - fairly involved Acquired Brain Injury services and things there, too, so it's there.

MS. DAUPHINEE: If I could also add, too, part of our research, when we were making these calls across the country, was how different programs are funded. Some are charity, some do receive some provincial funding for programs and services, some are United Way-funded, those types of things. That can make a difference as well.

MS. WARREN: In B.C., the brain injury funding programs seem to come and go as the economy goes up and down. I mean, sometimes it's funded, sometimes it's not, but I was told a couple weeks ago that the best brain injury rehabilitation was at - it's in Panoka, Alberta. They have an apartment building with brain injured living there and they sort of learn how to live again, learn how to do activities of daily living.

MR. CHAIRMAN: I think that takes us to Mr. Ramey.

MR. GARY RAMEY: Thank you, Mr. Chairman. I have two questions, but after I ask the first one I'll ask you if I have time to ask the second one. My question relates to what my honourable colleague from Kings West was, I think, getting at as well. I was

looking at Page 11 and Page 12, and I listened to what you said about facilities. I know some of these folks end up in homes for special care, I think he said.

I was trying to find out how many actual residential facilities do exist, if any, specifically for people who have this type of injury. I know there's a place in my riding called Peter's Place, which I'm pretty sure you are familiar with. Are there any other places like Peter's Place scattered across the province?

[9:45 a.m.]

MR. SULLIVAN: Scattered is a good word. There's one in metro, the residence is called Aiseirigh House - the Gaelic word for, I believe, rising from the ashes. It started a number of years ago as a pilot project from BIANs, long before - well, Jane was involved at that time, before Margo and I were around. It has since become accepted as part of the rehab care in the province. The house was purchased by Community Services, its operating budget is from Health and it has room for three residents.

In talking a little while ago - write stories and personal stories and things of that sort - the MLA from Bedford-Birch Cove was making some references to circumstances, financial and so on, and my son happens to be one of the three residents there currently, so I know the place quite well.

In addition, there is Peter's Place. A little bit of history on it: it started as a private operation, specifically for brain injury - Tom Donnellan's operation, his son Peter, hence the name. Not that long ago, I believe, and I'm not quite sure of the exact circumstances of how all of that works - I think his operation is incorporated into long-term care now but I don't know if there's a designation on it still as brain-injury specific. I think maybe not; I think it's open, it's part of the long-term care system.

Certainly if you went there right now, most of the people, if not all, who are residents there will be there as a result of brain injury, but I don't know if it's specific.

MR. RAMEY: So if I've heard you correctly, there are two places that we are aware of - one with three people in it in Halifax and Peter's Place. Is that correct?

MR. SULLIVAN: Yes, six beds.

MR. RAMEY: But I mean there are two locations that we're aware of.

MR. SULLIVAN: Two locations.

MR. RAMEY: Do I have time for a second question?

MR. CHAIRMAN: I think you do.

MR. RAMEY: We've heard BIANs members speak on their desire to initiate an educational program on brain injury awareness to government employees and interested community members. Do you have any ideas on how you would roll that out if you were to do it?

MR. SULLIVAN: We have, as an organization - one of our strengths, I guess, is the networking that is taking place within it; hence people like Dr. Braha compared to people like me. Our funding comes from whatever we can raise - that's it, special events. We just finished two golf or two ball-a-thons - one in the Valley, one in Halifax - and in the summer a golf tournament. Both of which have taken a little hit, I suppose, in the economic times. So our funds are very limited, and we probably spend as much time and energy trying to figure out how we spend a few bucks and how we raise a few bucks as we do things of this sort, which sometimes wears you out.

We don't actually have a lot of resources to do. What we do have is people. We have volunteers, we have a lot of survivors in our organization who speak and talk and will go and present and so on and so forth - bicycle safety, helmet safety, we've done those issues. Largely, it would be people who are knowledgeable on the topic coming to speak - not high end on the resource part of it, but more on the human resource to be able to go and talk, explain, teach and educate as best we can.

MS. DAUPHINEE: And, if I may add, one of the things we do is get requests. For instance, in a couple of weeks I'm doing a presentation for employment counsellors and so part of the presentation - because I do have that window of time, a three-hour window of time - will be talking a little bit about brain injuries and some tips on how to work with somebody who is a survivor. I'm bringing along three survivors with me; Jane is one of them, actually. It's that personal contact of seeing a survivor. I remember an instance with a couple of survivors, we went to a nursing home facility and they were surprised that they were survivors because they didn't look like survivors, like the individuals they were looking dealing with within the facility. So even that is an educational component.

So how would it look, well, obviously, as Don alluded to, to have proper funding you set up a proper education component and presentations with professionals because we do have, as Don said, access to some very knowledgeable people, professionals as well as family members and survivors who certainly can speak to it.

Also, too, in regard to employment, we are also part of the development of the Labour Market Strategy for Persons with Disabilities through Labour and Workforce Development because, obviously, employment is an important component in the continuation of life for survivors. Survivors can become educated, they can get employment through an interview, but those supports are needed and employees to be knowledgeable on how to work with survivors. For instance, some survivors may walk into this room and not find it a good room for them because it's too bright.

MR. RAMEY: So education is, obviously, very important.



MS. DAUPHINEE: Education is extremely important and so when we talk about education, it is not just health professionals, but also the general public. One of the things in the needs assessment is the talk of the public stigma, the lack of knowledge that the general public has about brain injury because some of the behaviours can be hard to deal with, with Joe Q. Public.

MR. SULLIVAN: Just a little add-on, if I could, really quick. I think that it would be fair to add a comment, not so much to the question but to the circumstances. BIANs is not just about chasing the government around, and the departments and so on and so forth; there are other aspects to it. I think probably in recent years there was the frustration of what was available and what was there in the form letters from bureaucracies saying, yes, we know there are problems and when we get some money, and so on and so forth.

So, currently, our thrust, if you will, is to get some things happening. It doesn't mean that we've forsaken other things. But that has been our focus in the last little while and will be for a bit. I just wanted to explain that a little bit.

MS. DAUPHINEE: Just to add onto that - education would be part of an ABI strategy.

MR. CHAIRMAN: I'm highly conscious of time and we have Leonard on my questioner list as well as Michele, and maybe if those questions and responses can be kept brief, there would be a moment for a closing statement.

MR. PREYRA: Thank you for a very helpful presentation. I really just have a comment and maybe a request for more data, and maybe table a question.

Just following up on your comment about people looking like survivors. I teach at St. Mary's and the Atlantic Centre is a great resource. You can't really tell who is on campus and whether they need support or what kind of support they need, and it points more to navigation rather than any additional support, you know, they provide classroom support for different teaching and learning.

Also, at the nursing homes and senior homes in my constituency, there are a number of people who are there who are living independently and are a part of that community. So, I'm just wondering if we have any more data than the macro data that you presented - you know, 30,000 to 20,000 people affected and maybe 9,000 every year - and whether we have a breakdown of where those people fit in the continuum and where the more specific gaps are. Is it within independent living, is it with navigation or what number will be affected if we adopted programs for that? I don't expect an answer now. (Laughter) But I would like to see some data, a breakdown of that 30,000 to 40,000 figure, or the 9,000 figure, just to let us know where the traumatic or non-traumatic injuries are coming from. Thank you.

MR. SULLIVAN: If I could make a comment; it certainly won't be an answer. I'm glad you weren't expecting one - it's extremely difficult collecting data in this area.

I remember once when I was chairing the advocacy committee for BIANs, we had Dr. Braha come in as a guest speaker and he spent half an hour explaining why - in his circumstances - he couldn't collect appropriate data that he needed, and so on and so forth. A lot of it has to do with record-keeping in the health care system and how it's in different areas in coding; there was a reference that Margo made to that earlier. It's a very real problem in terms of, you continually see numbers that are rounded off with lots of zeros in it and things because nobody wants to say it's 39,342 because they can't back it up, but it's extremely hard to do that.

MS. DAUPHINEE: And if I may, too - I get calls from people, one just recently from a lady who had a slip and fall and hit her head. This was 18 months ago. She's calling me now because of the fact that something is kind of off - headaches, memory, fatigue. Would she even be coded anywhere? No.

I know at a presentation recently up in the Valley, Noggin Knowledge. Dr. Clarke spoke and he is a neurosurgeon, he sees only the tip of the iceberg. Then what about the ones who show up at the emergency room? They may or may not be primary coded. Then what about the lady I just mentioned, where would she fall? Well, she wouldn't. So it's really hard to get those statistics. We are looking at estimates and that's part of the problem and the issue.

So I will take your request back to Dr. Braha and see if he can dig up, for want of a better word, numbers and also within the IWK, as well, and see if they have any statistics and things like that. Then I will try to get back to you on that.

The thing with brain injury is that the results are so varied. You have those who are severely impaired by their injury and you find them in the nursing homes. Then you have those who can function on their own, then you have those who are high-functioning but have some little supports that need to be in place. So it's such a wide gamut and those numbers are hard to capture as well, but we'll do our best to get something back to you.

MR. CHAIRMAN: I think we'll take time for one more question. Michele, you're on the list and so is Leo, but I think we're going to have to make this the last question.

MS. MICHELE RAYMOND: I'll be very quick about this. I was going to ask you about the highest risk groups and it sounds as though that's probably not something that you can easily get hold of.

MS. WARREN: Males between the ages of 14 and 21, or thereabouts, the new drivers . . .

MS. RAYMOND: For traumatic.

MS. WARREN: Yes, 16.

MS. RAYMOND: Okay. One of the things that's interesting, though, you made it - I mean obviously there's a huge continuum of injuries and they range from very subtle to utterly devastating, but you referred to a couple of things that sound as though there are some common elements in adaptation. You talked about the Atlantic Centre for Disabled Students having a quiet room and you made reference to the bright lights and so on. Are there some fairly standard environmental modifications that actually work for people all the way along this continuum? Are there some common factors, or no?

MS. DAUPHINEE: I think it really all depends on the individual.

MS. RAYMOND: It does, okay.

MS. DAUPHINEE: Really and truly, like a customization. There's no cookie-cutter solution.

MS. WARREN: With repetition, consistency and patience of the teacher or whatever.

MR. SULLIVAN: But even in a broader sense, there are commonalities that you tend to find. Cognitive areas, concentration, focus, things in that area tend to be dominant characteristics that you will find - not in all brain injury survivors but in a large number.

MS. DAUPHINEE: And also, too, frustration will be key.

MR. SULLIVAN: Especially in the survivors - I mean in the family, sorry.

MS. DAUPHINEE: Just building on my comment to Mr. Ramey, when we talk about and make presentations to employers and people we are working with and we talk about, well, why is it all of a sudden - because that's one of the reasons we get a call - why is it all of a sudden I'm dealing with this survivor and I get this inappropriate response? One of the things I say to them is, well, maybe it's because it's the frustration building up and building up and building up, and then all of a sudden it just erupts like that, because of everything else that may have gone before. So you get that inappropriate - what they term as "inappropriate" - response to something very simple. So that's another commonality as well. So it's building on Jane's CPR analogy as well.

MS. RAYMOND: So concentration, cognition and frustration, okay.

MR. CHAIRMAN: We've used the time that we've allotted but if you want to take a minute to make any final comments, we'll certainly offer you that opportunity.

MR. SULLIVAN: Sure, thank you. I didn't prepare a written closing statement. I kind of was seeing how it went, I guess partly. I think to try to pull all that stuff together is, you know, Brain Injury 101, that's a brutal course. So I'm going to use one more analogy

and I can't take credit for it, it's Dr. Braha's, but I've heard him tell it and I tell it better. (Laughter)

Three of us were driving down to the Department of Health. Back in the winter, we were meeting with community care or whatever, and it was the Halifax streets in the Spring - potholes, unbelievable. By the time we got to the office and had the meeting, in the middle of it he came out with this little analogy that came to him as he was driving down. He was trying to actually put a perspective out there for the Department of Health - not for BIANs but for the Department of Health - and he said it's almost like the Department of Health was looking out over a road and in the road there are a lot of potholes.

[10:00 a.m.]

You'll find quite a variety of potholes. You'll find big wide potholes, meaning potholes that affect maybe larger numbers of people, and you'll find smaller potholes in diameter and so on, but he said the depth of the potholes are not all the same either. For example, some of the large potholes are only about that deep. Would it affect a lot of people? It doesn't take that much to kind of - whatever. While the brain injury survivor pothole is a bit smaller in diameter, maybe not as many people are affected as some of the other things, it's really deep and when you hit it, you know you're in it. Thank you very much.

MR. CHAIRMAN: Well, I want to thank the three of you for being here to share information with us on the important issues that you're concerned with every day and for helping us to become better educated. I know there was some discussion of some additional information that you might be trying to gather and should you be able to find that, or if there are other things that you think you should be bringing to our attention, they should be directed to Kim and Kim will be in touch with you with a follow-up letter to make sure you have her contact information.

I want to thank everybody and to thank you particularly for bringing the information today.

[10:01 a.m. The committee recessed.]