

NAPAS/TBI

Management Approaches for New Drugs

August 4,2004

ELIZABETH PRIAULX: Hi, everyone. Welcome to the webcast on "Working with Medical Professionals to Enhance and Support PATBI Advocacy and Education Efforts." This is Elizabeth Priaulx with NAPAS and I'll give a quick overview of the agenda. Go through some quick procedural stuff here, introduce our speakers and they'll take it away.

Basically is slides will appear in the central window and they'll advance automatically. The slide changes are synchronized with the speaker's presentation. You don't need to do anything to advance the slides. You may need to adjust the slide delay control at the top of the messaging window. The most important thing is we encourage you to ask the speakers questions at any time during the presentation. They will -- we'll be saving questions to the end but you should type your questions as they occur to you. You simply type your question in the white message window on the right of the interface. Select question for speaker from the dropdown menu and hit send. Include your state or organization in your message so we know where you are participating from. The questions will be relayed onto the speakers at the end of the broadcast.

If you don't have the opportunity to respond to your question during the broadcast, we'll email you afterwards with a question since we'll have a queue of all of them. Submit your questions at any time. On the left of the interface is the audio window. Adjust the volume of the audio using the volume control slider by accessing the loudspeaker icon. Those of

you who wanted accessibility features will see text captioning. The interface will close automatically at the end of the broadcast and you'll have an opportunity to fill out an online evaluation. Please do so. Your responses will help us out as we plan for future training. And thanks again to all of you for being on. Now a quick review of the agenda. We are going to start out with Dr. Warren Lux. He's medical director with the defense and veterans brain injury center and he'll be talking about improving PATBI advocacy by understanding medical characteristics and other things. It's a very brief summary. Then we're going to have Mr. Brian Hartman the director of the Delaware community legal aid society which is the Delaware PNA. He's done all sorts of policy work and is going to be talking about some of the exciting initiatives there and then we'll have two representatives from the disability rights center, Ms. Julia Freeman Walport and Miss Amy Messer.

They'll be talking about many collaboration initiatives they've done, initiatives in the school system, great work there. And then Amy will talk about some of the work that she's done in her what they call ABD waiver litigation. Then the last speaker will be Mr. Kenneth Currier, the director of the TBI technical assistance center unrelated to our topic but it's so valuable I had to squeeze him in talking about the different funding sources for TBI so you can make sure you're aware of them and insisting that your state tap into them. At the end is when I will look through the queue of questions that you'll have been typing in all along and we'll direct them to the presenters. So at this point I would like to ask Dr. Warren Lux to begin.

WARREN LUX: Thank you. My purpose this afternoon is to go over with you some of the more important neuromedical aspects of brain injury and how that plays out in the lives of people who have suffered brain injuries. So that you are better prepared to understand the kinds of things that they will bring to your attention or that will be brought to your attention by others. Now, Elizabeth has kindly put some slides up while I'm talking that she derived from a couple of other sources. The whole problem of medical aspects of brain injury is huge. I couldn't possibly cover it in 15 minutes, of course. Nor could I even cover all of the different things on the slides. But they are there for you to look at. I'm happy to answer questions at the end about any of them or elaborate further on that. But for now I want to focus a bit on really the core parts of the problem of brain injury and so in the end I hope give you a sense of where the real difficulties lie. In order to -- in order to do that, let me -- well, let me say first that indeed, every brain injury is different. In focusing on the core facts I don't want to get away from the understanding that indeed every brain injury is different. That's true for a number of reasons, most prominently because every person is different.

The brain is the organ of the personality to a great extent and, of course, we're all different. So how the injury affects each of us depends upon who we are to some degree. But in addition to that the injury itself can involve lots of different things and different patterns. So the whole picture can get quite complex. Yet through all of that, through all of that complexity, there are certain common cores that are likely to be present in most persons who have sustained brain injuries, even if these differences are also there. Now, in order to focus on that I would like to spend a little bit of time with you talking about a

classification of basic mental functions, basic brain functions. In the classification that I'll use, we'll start off with the first and most basic one, is power function. That is the raw power in the system and power function has a couple of aspects. One is arousal and two is channel capacity. And I'm going to go into those a little bit more as I go on. But the basic power. Then if you have the power turned on, if there is adequate power in the system, the next thing that you have are all of your various specific cognitive and sensory motor abilities. Your ability to calculate, use language and recognize shapes and texture and all sorts of other kinds of specific abilities.

And then the third part of this classification is what has been called executive function. Executive function is the ability to take all -- if you have enough power in the system, executive function is the ability to take all of those specific cognitive abilities and apply them in a coherent, organized way to real world situations. To carry out and execute tasks in the real world that are goal directed over time using your various cognitive and sensory motor abilities. A more organizational function. Now brain injury first and foremost affects power function. That is sort of obvious. Because even the mildest brain injury your arousal is at least momentarily altered. You're at least stunned and often you lose consciousness. But even as one begins to regain consciousness, the other part of power function is very frequently disturbed. And that is channel capacity. Let me go in -- this is something that, once you're back on your feet with reasonable arousal, this is something, this channel capacity disturbance, is something that is likely to still be there, whatever else happens. I'm going to go a little more into what a channel capacity disturbance is all about. As the injury gets more severe, however, one begins to pick up

disturbances in those other areas and in particular it turns out that executive function is more sensitive than any of the specific abilities. So that if you are going to have something more than a power function disturbance or channel capacity disturbance what you're likely to have is an executive function disturbance and not a major problem with any of your specific abilities.

Now, it's beyond the scope of this to go into a lot of detail about how that happens, but it has to do with a number of things with regard to the anatomy of the injury. But it's -- it's also true that executive function, that is this broader organizational type of ability, is more sensitive, will break down more quickly in the face of a channel capacity disturbance than will other kinds of more specific, more localized functions. Back to the channel capacity disturbance. Channel capacity, the number of effective, efficient channels in the system, if it's disturbed, it gives rise to problems in two domains. The first problem is the problem with multi-tasking. Doing multiple cognitive tasks at the same time and the second problem is a problem with cognitive endurance. That is, sustaining your cognitive tasks over a period of time. Let me give you a very schematic, not a real, a schematic example of how this plays out. Let's assume that you have an eight-channel brain. And there are the tasks out there for you to do require four channels. If you injure your brain, the first thing that happens with -- when your arousal is disturbed that a lot of your channels aren't working. As you recover, let's say you recover well but now you only have seven of those eight functioning channels.

Well, the first thing that is obvious, of course, if you have a four-channel task to do is that you can't do two tasks at the same time. You can only do one. Note, however, that the individual four-channel task that you're going to be doing you can do just as well as you ever did before. It is just that you can't do two of them at the same time. So if you do them sequentially you'll be already. If you try to do them at the same time you can't do it. But then let's say you are chugging along doing this -- this four-channel task and on channels one, two, three and four and channels one and two get fatigued and start to drop out so you continue along using three, four and you pick up five and six so you're doing the task on channels three, four, five and six and you continue along and channels three and four get fatigued and drop out and one isn't ready to come back online and you look for seven and eight. You only find seven so your task performance breaks down at a time earlier than it would have if you had had that eighth channel where you could have chugged along for a period of time. After brain injury the limits are greater. People with mild injuries will have these kinds of disturbances.

People with more severe injuries, as they recover, will be left with fewer channels and therefore will also have these kinds of disturbances. Over and above the channel capacity, that is the power function disturbance, the next area that tends to be more involved after a traumatic brain injury is executive function. Executive function being the ability to anticipate, plan, initiate, carry out in the proper sequence a goal-directed activity with appropriate self-monitoring and self-correction as you go along. That sort of thing is what is -- is the next most sensitive thing to damage in traumatic brain injury. So what tends to happen, then, after brain injury, is that your specific abilities may look very good.

You may appear entirely normal in lots and lots of situations. Where you tend to break down is when you go out into the world and have to do creative, novel execution using your abilities. And then that problem is complicated by the fact that the real world is a more difficult stimulating place. So there is more multi-tasking that has to go on out there. So the -- after traumatic brain injury, the kinds of things that you tend to see are real world performance failures.

Out of proportion to loss of abilities that are obvious on exam or casual conversation or even, perhaps, in a neuropsychology laboratory. The test situation tends to look more sensitively at the specific cognitive abilities which tend to be least affected. I'm not saying that they're not ever going to be affected. You'll see plenty of people who have problems in various domains of specific cognitive abilities but even when that is present, that is -- the disturbances in channel capacity and in executive function exist out of proportion to the loss of the specific ability. The problem that the person with brain injury has is that whatever abilities he or she has, he or she has difficulty using those abilities effectively in an environment that is a real world environment where the requirement there is for execution. And you have to do it in a circumstance in which channel capacity is something that is important for you to be able to execute successfully. So that's kind of the overriding concept that I wanted to get across for you today.

Now, let me in the remaining few minutes just talk about a couple of other aspects of mental function that you are probably thinking about and wondering about because you've heard about them. Attention and memory. Where do these things fit in? These --

attention and memory are kind of multi-factorial mental functions. Attention and memory are functions that require all three of those basic mental functions that I talked to you about before. They require power in the system, they require specific cognitive abilities. For example, you know, to remember things you have to have a specific ability in the domain in which you're going to remember, that is, whether it's a visual memory or verbal memory. Then you have to have executive function because, well, just to take memory as an example, for memory to be effective, you have to be able to search through your memory bank in a real world situation and have an effective search strategy where you can pull out the things that are relevant to the problem at hand and inhibit the things that are irrelevant to the problem at hand. So you have to be able to use your memory effectively depending upon the task demands that you're facing in the real world. Consequently -- the same kind of thing is true of attention. Consequently both memory and attention are going to be very sensitive to the effects of brain injury.

And even someone with a pure power function disturbance with a pure channel capacity disturbance is going to have some trouble with attention and memory, particularly as the environment gets more stimulating and as there is a greater demand for sustaining the task over time. That is for cognitive. Those kinds of things will be there. But again, back to the basic point. It is the real world performance failure in the person who looks pretty good in an examination situation that you need to be thinking about and dealing with. Whenever you see that, that's a thing to think about even if there has not been a history of head injury, it's something that you may want to get some further evaluation on if you see that kind of thing. Someone who everybody thinks should be doing well but isn't doing

well in the real world. It is also kind of a red flag because a lot of people -- this is counterintuitive to a lot of people. A lot of people, when they see that, they think that somehow this person is shirking. That there is more behaviorally psychiatric basis for it. That they're faking or crazy. You'll hear these kinds of things over and over again. Exactly the opposite tends to be true in this situation. People who are malingering look terrible on tests. These folks in a test situation can use their abilities pretty well and look pretty good. They can't then turn around and use them quite so well out in the real world where the conditions under which they're trying to use them are somewhat different. I think that gives the kind of overview that I wanted of what the broad problem is.

Obviously there are many, many, many aspects of this that I haven't even begun to touch upon. And many, many circumstances that are different and unusual. But again, these are some of the really core ideas that you need to keep in mind when you're dealing with persons who sustain traumatic brain injury. I'll stop there, Elizabeth. And you can move on.

ELIZABETH PRIAULX: You have two more minutes on the schedule. I would like to ask when we were talking earlier, we had mentioned a little bit about accreditation and the issues around accreditation. I know that's of interest when advocacy agencies go to challenge assessments or to determine whether a person has seen the appropriate professional. Could you talk a little bit about assessments and accreditation?

WARREN LUX: Sure, I can, yes. In dealing with traumatic brain injury there are a broad range of professionals that deal with different aspects of it. Physical therapists, occupational therapists, speech/language pathologists and many others. Each group has their own professional certifications and clearly you should be dealing with people who are certified by their primary organization. However, certification by your primary organization doesn't necessarily mean that you have special expertise in the special kinds of problems that occur after traumatic brain injury. In terms of that there is no really set way. There is a fledgling attempt being made to certify therapists in brain injury expertise in a project that evolved out of the brain injury association of America but now is somewhat separate from it. It's not a uniformly used or accepted certification. There are -- another way you can look at this, though, is to look for professionals to help you evaluate a patient or to give you input on the basis of their experience with brain injury and their participation in brain injury specific centers that themselves are accredited. There is an organization that credits rehabilitation facilities and it does have subspecialty rehabilitation accreditation for fast nilts -- facilities in a couple of areas, spinal injury and brain injury. So professionals that are experienced on the basis of working in those accredited brain injury centers would be the kinds of people who would have the sorts of credentials that you're looking for.

ELIZABETH PRIAULX: Thank you very much, Dr. Lux. Now I would like for Mr. Brian Hartman from the Delaware PNA to begin his presentation.

BRIAN HARTMAN: Good afternoon. I will be addressing my PNA's involvement with healthcare professionals with emphasis on systemic work. First, establishment of the

state council for persons with disabilities brain injury committee. Unlike many other states, Delaware had no viable interagency group or committee to engage in systemic planning on behalf of persons with traumatic brain injury. Delaware did have an existing super council, the state council for persons with disabilities, which serves as a hub for other disability-related councils and organizations. Last year, I convinced the council to establish a brain injury committee. It is chaired by a board member of the Delaware chapter of the brain injury association, and I serve as vice chair. The brain injury committee includes several members representing public and private healthcare agencies including three private hospitals, a neurohealth provider, Easter seal and multiple state divisions, including public health, child mental health, adult mental health, developmental disabilities, aging and physical disabilities, and vocational rehabilitation.

The committee benefits from this set of healthcare representatives when analyzing state legislation, regulations, policies, and initiatives and promoting training events. Anyone interested in further details can access the committee's minutes at www2.state.de.us/scpd. Turning to legislation and first prevention legislation, healthcare providers are naturally interested in prevention of traumatic brain injury. One of the committee's legislative priorities was prompted by a "New York Times" article which described a national problem with unscrupulous repair shops installing fake or non-functioning replacement airbags in vehicles. Less than 15 states had legislation regulating installation and replacements. I drafted a bill which, number one, added installation of fake or non-functioning bags to Delaware's auto repair fraud prevention law and two, clarified that laws requiring owners to maintain occupant safety systems in vehicles cover

not only seat belts, but airbags as well. The bill was enacted and signed by the governor on June 29, 2004. Turning to DUI, in order to qualify for full federal highway construction funds,

Delaware, like other states, was required to lower its DUI blood alcohol level to .08. The committee supported state legislation to effect this change since it was viewed as reducing accidents and resulting traumatic brain injury. After languishing for many months it was finally signed by the governor on July 12 of 2004. Turning to the learners permit driving restrictions. Based on safety concerns, some states limit distractions to persons driving with learner's permits. The committee supported a bill to prohibit cell phone use and also limit the number of passengers in vehicles operated by drivers with learner's permits. The bill passed the Senate but not the house. Turning to dram shop liability. Delaware is one of only seven states which do not authorize suits against taverns and restaurants which sell liquor to drunk patrons who injure others through vehicular accidents. The committee supported a bill to sue by victims but the bill was not enacted. Childcare seats. Delaware law authorizes prosecution of drivers who fail to place children under age seven or 60 pounds in a child safety seat. However, the court was authorized to dismiss all charges if the driver documented the purchase or procurement of a safety seat subsequent to the violation.

The committee supported a bill to delete this 20-year-old authorization which had originally been adopted as a transition measure while drivers became aware was the law. The bill was signed by the governor on July 6, 2004. Turning to electric scooters and bicycles.

Sales of electric scooters, electric bicycles and hybrids have been skyrocketing nationwide. Ads target children as primary users. Multiple bills were proposed to regulate driver qualifications, restrict use on public roadways, address helmet use, and require that sellers provide buyers with notice of restrictions prior to sale. The committee provided articles, ads and bill critiques to the legislature and the Delaware Department of Transportation. A comprehensive bill reflecting the committee's views was enacted and signed by the governor on June 29, 2004.

Next slide. Turning to services legislation, we'll begin with special ed. identification. Delaware lacks adequate statistics on children with traumatic brain injury which undermines health and social services planning. In 2003, our public school system identified zero students with an I.D.E.A. classification of TBI. I drafted a bill to eliminate financial disincentives which was actively supported by the committee. It was enacted and signed by the governor July 1, 2004. Turning to the nurse practice act exemption context. TBI survivors often need healthcare assistance to remain in the community. Delaware's nurse practice act restricted such support. I drafted a bill to authorize competent individuals to delegate healthcare acts to lay persons which they could normally perform themselves but for functional limitations. The bill, which was actively supported by the committee, was enacted and signed by the governor on June 18, 2004. Domestic violence is a common cause of traumatic brain injury. The committee supported a bill to extend eligibility for violent crime compensation to include victims of domestic violence.

The bill was enacted and signed by the governor on June 29, 2004. The final bill I would like to highlight is money follows the person legislation. TBI survivors often have difficulty transitioning from residential healthcare settings to the community given the unavailability of support services. I assisted with the drafting of a bill to facilitate the transfer of institutional funds to cover community support costs. The committee supported bill was not enacted but a Senate resolution to study the feasibility of this initiative was adopted on June 30, 2004. If you would like a copy of any of those bills, you can go to the state website and access them. And that is at www.legis.state.de.us.

Next slide. Let's turn to regulations. Child abuse is a common cause of TBI. The committee prompted several amendments to propose child abuse regulations. However, despite submitting contrary medical information on shaken baby syndrome, the state declined to remove a provision requiring an actual impact injury to qualify as shaken baby syndrome in the child abuse context. Daycare helmets. The committee promoted several amendments to propose daycare regulations. The proposed standards allowed children to ride bikes smaller than 20 inches without a helmet. The regulations also prohibited children from wearing helmets when using playground equipment. Final regulations have not yet been adopted.

Next slide. Let's talk a little bit about training. As a follow-up to my bill promoting special education identification of students with TBI the committee supported a seminar by a prominent neuropsychologist on screening, identification and profiles of juveniles with TBI. They set up a subcommittee to review handbooks on TBI which I obtained from a private

publisher. The committee plans to choose one to two sets of materials, seek funding for a bulk purchase, and supply them without charge to the 98 public school psychologists in the state.

Next slide. Turning to our service delivery system. And first is the Division of developmental disability eligibility regulations. The healthcare experts on the committee assisted with my critique of state agency regulations revising eligibility standards for TBI survival. Assessment tools used to evaluate TBI may be different from those with mental retardation. The state adopted some of these recommendations prior to placing this initiative on hold earlier this year. The state incorporated many committee recommendations into its ABI Medicaid waiver application which was finalized last fall. Similarly the state has filed an anticipated services waiver in June after incorporating many committee-endorsed recommendations and finally the state has promised to provide an advance draft of a family support waiver for review prior to submission to SMS.

Next slide. Turning to the think first plan. Think first is a national injury prevention foundation supported by the American Association of neurological surgeons. The committee prompted several amendments to a Delaware chapter think first plan earlier this year. Finally I would like to give you a few examples of our involvement with psychological and medical experts in some individual cases. The first one is a Medicaid matter. We represented a 3-year-old TBI survivor with cerebral palsy who had very brittle bones resulting in high risk of fractures. The state Medicaid agency denied an IV infusion of a medication to strengthen the bones regarding the treatment as experimental. They

obtained a supporting letter and journal article from the Al DuPont hospital for children which prompted the state to settle an administrative hearing by approving the treatment. We're also representing a 16-year-old TBI survivor with complex needs. The state has agreed to fund a private placement since the local district cannot provide an appropriate program. The PNA is working with the neuropsychologist in assessing the viability of alternative programs for the teenager. I believe we'll now be turning to Julia Freeman.

JULIA FREEMAN: Should I just launch in here? OK. I'm planning on discussing some of the ways that in New Hampshire we collaborate with other agencies, including medical professionals and also ways that we do outreach to the various TBI-involved con -- constituency.

I should start off by saying after working at the PNA for 15 years I left and went to the New Hampshire's TBI state grant program. It was an implementation grant at that time. And I was the project coordinator of what we call project response. This was an effort to increase the knowledge of medical professionals, medical and other professionals in New Hampshire about the neurobehavioral consequences of brain injury. Some of the things that Dr. Lux was mentioning. Because in the needs assessment phase of the TBI grant it was very, very clear that a lot of professionals were lacking in knowledge about brain injury. For instance, psychiatrists tended to see them at neurological and nobody seemed to be thinking that it was something that they could deal with. So the project response was set up to specifically train medical and other professionals about neuropsychiatric aspects of brain injury. And you'll see the collaborators on slide 18 that were involved in this project. Two state departments, developmental services and behavioral health and

the state brain injury association of New Hampshire as well as Dartmouth medical school. There was a team of professionals, including neuropsychiatrists and neuropsychologists that were the core of project response.

One of the main things that this group did was to work with six different regions of the state. The developmental agencies and the Mental Health Centers, to essentially improve their skills in identifying brain injury and in working with brain injury. We also did some training for other providers. We did a conference -- we trained the Mental Health Centers and area agencies and when they were trained they put on a conference for all the other providers in their region. Home healthcare people, vocational rehabilitation, even the prison came, school districts and so forth. And the whole purpose was to increase the basic knowledge base in the state about the NBC of TBI as we called it. On slide 19 you can see I've listed some of the kinds of ways that we coordinated. After I left project response, I came back to the PNA here and I can serve as a resource about TBI issues. We -- the state project and the PNA have kept in fairly close collaboration being on each other's advisory groups and collaborating on some grants.

And one thing, for instance, that I did still back when I was with project response was when New Hampshire got the PNA grant and they were one of the first round of grantees, I came over, along with our consultant, who is a woman who has a brain injury, and we did two or three hours of training with the staff of the PNA to help them to be able to recognize and identify issues that people with brain injury -- injuries might have. The things that happen in educational settings such as the lack of identification, as Mr. Hartman

mentioned. Delaware had no kids identified in 2003. New Hampshire didn't do much better. We managed to identify about 50. And by the brain injury association's estimates there were probably a couple thousand kids. Helping the PNA to spot the issues, whether it be identification or IEP's or programs not providing the kinds of services that people with these kinds of executive functioning impairments and other kinds of cognitive impairments were experiencing. We also worked together when -- well, when the PNA developed their grant, we gave them some advice and then vice versa when we were developing some post demonstration grants.

One of the things that with the first post demonstration grant we decided to do was to reach out to family members and survivors in a number of ways. One of them was to develop a course to train folks on -- to train people who have had brain injuries and their families in what the issues are, what the services are, and the PNA was -- is planning on doing a unit on advocacy and self-advocacy skills so that the people that have taken the course are going to be better able to not just find the resources that they need, but to do a better job of advocating to get those resources. In New Hampshire, as in probably the rest of the country, budgets are quite tight now and getting access to services is a major problem for people. So anyway, some of the other ways that we collaborate on slide 20, our legal director is on the board of the brain injury association and so he's able to keep up to date on what the issues are. We happen to have a very good brain injury association. Very active. Several programs, an excellent legislative network. And generally well run and a good resource for people. So that's a good resource for the PNA to know about and in addition for them and others to know about PNA services. So, for

instance, we -- that's later on. We do some outreach with them and with their newsletter and some other things. They've recently started a program called resource facilitation that was done with some new legislation which had originally was going to be through a trust fund and later was switched to a line item in the budget. But it did fund resource facilitation for people with brain injuries. And they're aware of PNA services. So if they're looking for help for somebody and are having trouble getting it they may call on the PNA and if we're doing the same thing and we're looking for some assistance with -- we go back and forth.

The BIA also has a legislative committee and a lobbyist as well on an annual basis in a fairly organized way they create an agenda of legislation that they would like to support or propose. And we keep in touch with those things through the committee and also there is an email list that lets everybody know what is happening. We also report to this legislative committee about legislative issues and rule issues that we think are important for them to know about. For instance, the ABD waiver case, the letting folks know what the status of that is. Also, we are currently having an issue about mental health rules and the rules are being redrafted and there are some issues with the way those rules are being redrafted. They're essentially narrowing eligibility and narrowing the service planning process that involves the consumers right now. And since a lot of folks with brain injuries end up in the mental health system, we thought it would be important for them to know about this as well so that they could advocate and also let their people know.

On slide 21 I've talked a little bit about the individual casework that we do here. We've taken, since January 1, 54 individual calls in the PATBI program. When folks call us pretty much all special education calls, they are surveyed for a couple of things that sort of as a special aside to intake. One of those is we're looking for kids who have been suspended or expelled from school, or otherwise excluded. And the other thing is students that may have an unidentified TBI that are miscoded and therefore not receiving appropriate services. So -- and part of the impetus for that was collaborating with the BIA and the other agencies and identifying the miscoding and lack of proper services in special education as a key issue. On slide 22, I've listed some of the issues from our database that people are calling about. People with brain injuries. And the significant thing, I think, is that they are the same kinds of issues that all the other folks call about. They are housing problems. Employment discrimination, special education and so forth. And so it's important, I think, for the brain injury community to realize that while there are significant differences and issues in the things that people with traumatic brain injury experience, there is also a lot of common ground with other people with disabilities.

Employment discrimination, for instance, landlord/tenant issues, special education and so forth. And I think a lot of times the folks in the brain injury community feel like they're latecomers to the table and fighting to get a spot at the table. One thing that we hope to encourage is to develop some collaboration between the different disability groups so that these special education issues, for instance, so that they can work together on these issues. Slide 23, I am -- I want to talk about some of the outreach that we do to the TBI community. First of all, the brain injury association has a newsletter that goes out

quarterly. It reaches about 7,000 people, which in New Hampshire is fairly significant number. It goes to people with brain injuries, it goes to medical professionals. It goes to the legislature. And lots of other different groups. So the disabilities rights center has an article in every issue dealing with something related to legal rights. The last one had to do with your housing rights.

The one before that I believe was employment. The one coming up is on self-advocacy. And we hope with this to provide a little education to the community and also, of course, to identify that if there are problems in these legal issues relating to employment or whatever, that the disabilities rights center is the place that they can turn for some advice and assistance. And we also have a website with a TBI page. Another thing, the brain injury association in New Hampshire as an annual conference and we have participated with information about protection and advocacy services as a way to reach out to the TBI community. It's a very good conference. It has a lot of information about a lot of things. So we can also learn from, you know, from attending that conference.

ELIZABETH PRIAULX: Next slide, please.

Julia Freeman I'm sorry. And let's see, also there is a professional provider council. A lot of the providers in the state get together every couple of months and talk about their agencies, what is happening, what the problems are, anything new, any new services, any new problems. And it's an opportunity for the DRC to hear about those issues and also to

let them know if there are developments that they need to know about or other kinds of things. So slide 24, we also did a priority setting process which turned out to be a good deal more than priority setting. This was in 2003. In addition to helping us figure out what to focus on, it served as a major way to reach out to different groups to get their input and also to tell them about PNA services. So for instance we contacted all of the brain injury support groups in the state. There is about 12. And offered to come and meet with them with the group to find out what their concerns were, what they thought the PNA should be working on specifically and also to tell them about PNA services and encourage them to call us if they needed help. And that was an excellent way to sort of get the word out and to start working with some of these groups as well. There was also an input survey.

There were two public forums open to everyone. As part of our process we looked at the needs assessment that had been done with the original TBI state grant program. The assessment phase. On slide 25, please. One of the things that we found was that when we collated what folks thought were the most important priorities for people with brain injuries, they were -- the population of folks with brain injuries that responded and the general population identified the same three top priorities. Those were the quality of education and special education, access to healthcare services, and also access to Medicaid and Medicare services. That would include the home and community based care waiver services. So they were -- the TBI group had them in a slightly different order but they were the same three priorities. That's an important piece of information for the TBI community in order to do some broader coalition building. It also, I think, points up to

the fact that a lot of the things that the PNA is doing are going to benefit a broad group, including folks with brain injuries.

I slides 26 and 27 there were some smaller things in these support groups that people emphasized again and again that were problems for them. One was that the criteria for the ABD waiver were too narrow and needed to be expanded. In our state the level of care that is required is quite high. So only a little over 100 folks actually are currently on the waiver. So that was one of the priorities. Also special education, TBI coding. It was suggested that there needed to be some work to broaden that coding so that folks with other acquired brain disorders had access to those kinds of services in special education. And in general better accommodations across all environments for people with brain injuries both cognitive and physical impairments. On to slide 27, please. Another thing that people consistently told us was that medical personnel just don't have enough knowledge about brain injuries, be it in the emergency room or vocational rehabilitation or wherever. Particularly in post-acute care settings. You know, the rehab facilities right after the hospitalization. People tend to have some knowledge. After that, the knowledge base drops off quite a bit and that was identified one of the major factors hindering people from accessing appropriate services and the lack of reentry transition was mentioned. Then in general just the systems at lots of different places were for people with cognitive, memory, cognitive slowing impairments. Those kinds of services were inaccessible. They were too confusing and too difficult. And then finally, the whole process of applying for benefits like Social Security really threw people with brain injuries for a loop. And getting help with that process was also a problem. So as we are -- have designed our priorities

for TBI we've kept those things in mind. That's pretty much the end of my presentation here and I would like to turn it over now to Amy Messer.

AMY MESSER: Hi, everyone. I'm a senior staff attorney at the disabilities rights center. I work with Julia, although I tend to do more of my work on the litigation side. So I'm going to talk a little bit about New Hampshire's home and community based care waiver and how I've worked with medical professionals both in terms of eligibility issues as well as advocating on behalf of the individuals who are found eligible but are awaiting services through an ABD waiver wait list case we have in federal court. Let me start by talking about what our waiver is. And who is eligible and then I'll talk a little bit about what kinds of services people get and my work with the medical professionals. So our ABD waiver is available to anybody in New Hampshire who is a resident here and is already Medicaid eligible. The individuals have to go through the regular Medicaid eligibility requirements. And they have to be determined to have an acquired brain disorder or traumatic brain injury. Let me just stop a minute there to talk a little bit about what that means for folks and one of the reasons I think it's important if you have in your state regulations regarding who qualifies as an individual with an acquired brain disorder or traumatic brain injury that you really take a look at how that is defined is because I think that a lot of folks really don't know who might qualify for services.

In New Hampshire it's an individual with an acquired brain disorder is someone who has a disruption in brain functioning that is not congenital or caused by birth trauma. But rather one amongst a number of different causes which I'll get into in a second. It needs to

present a severe and lifelong disabling condition that significantly impairs a person's ability to function in society. In New Hampshire, it must be a brain injury that occurred prior to the age of 60. And it has to be attributable due to external trauma. Accident, fall, assault or some other hypoxic injury such as cardiopulmonary arrest or carbon monoxide poisoning. Airway obstruction or hemorrhage. Those kinds of injuries. It can be the result of disease or toxics exposure. In New Hampshire this would also include a neurological disorder such as multiple sclerosis or Huntington's disease. I think that's important. I recently received a phone call from someone in the National MS Society that an individual with multiple sclerosis might be able to receive significant home and community based services through the acquired brain disorders waiver. That call prompted me to talk a little bit about who is eligible because I think it's important for folks in your states to know if they might be eligible for a waiver service, the home and community based services that they are eligible.

In addition, the brain disorder has to be manifested by some significant decline in cognitive functioning or ability and a deterioration in personality, impulse control, judgment issues. Those kinds of deficits. So the ABD waiver also requires, as Julia mentioned, it is a relatively high level of care you have to meet in order to be able to be found eligible for home and community based care waiver here. It would require a skilled nursing or rehabilitative level of care. And it's really that level of care issue that has led to much of my work with medical professionals. In the community to determine who really meets that skilled nursing or skilled rehabilitative level of care. The services that are available under our ABD waiver include case management, personal care services, respite care,

supported employment. Environmental accessibility. Adaptations and crisis services. It's interesting you don't see residential services when you look at what is available under a waiver. However, those residential services are often supplied to individuals under a waiver through -- in the group home setting, or by having 24 hour care in their home. But much of the cost of that is paid for through personal care services, Medicaid reimbursement for personal care services in an individual's Social Security that goes to room and board. But people deal with required brain disorders who have a high level of care and can't live independently and some of them may require 24/7 care. That can be paid for through the ABD waiver. So there is really two kinds of advocating for ABD services. One involves who is eligible and another is litigation to advance enhanced services. Let me talk for a minute about the issue of advocating for eligibility. Oftentimes people are denied eligibility for ABD waiver services.

Additionally, in New Hampshire you can be found eligible for ABD services but not ABD waiver services. The distinction there is important. You may be an individual with acquired brain disorder not meeting these skilled nursing facility or rehabilitative level of care. However, you would still be entitled to case management services. So if you have an acquired brain disorder and meet the eligibility or simply having an acquired brain disorder, traumatic brain injury, you would be eligible to receive case management services although that really doesn't give you any direct care services. It simply connects you with the resources. It's done through our area agency, our developmental services delivery system and they might assist you, for example, with applying for Medicaid, connecting you with the brain injury association, maybe some individualized checking in

on how you're doing but it would not give you any direct services. Which, of course, leads to a huge gap because many, many people with acquired brain disorders or traumatic brain injuries do not reach a skilled nursing facility level of care. Therefore, you know, it ends up kind of being an all or nothing thing whereby if you have a very high level of care, and you're lucky enough not to be waiting for services, you have quite an array under our waiver program to assist you in living within the community. However, if you don't reach that level of care, all you get is case management services and there is really not anything in between.

Focusing on the advocating for eligibility for a minute, it's important to focus very specifically on the eligibility criteria and precisely what the regulations say. Doctors are often quite willing to advocate on behalf of their patients who have acquired brain disorders to ensure that they get the level of care they need. But really don't have oftentimes a good understanding and may very well have never seen a regulation that defines what makes a person eligible. In New Hampshire where you have to meet a rehabilitative level of care it's important to get a doctor focused on what does that mean. In New Hampshire in the regulations themselves there is no definition. It's very, very broad. And the state does not have specific criteria. However, they do use criteria that is similar to that used by skilled nursing or rehabilitative professionals. And I would also direct your attention, if you are in a state that uses these skilled nursing facility level of care, to go to the CMS website which has a manual that Scibs describes what it means for a rehabilitative level of care because it really does give you kind of broad areas to look at in terms of what are the needs of the individual. And it's very helpful in looking at your

client with your doctor and saying, does this individual require the kinds of services that are available in a skilled nursing facility or rehabilitative facility? So working with a doctor, focusing on the kinds of services that are provided in those settings is very, very important. I think it's also really important to work with the doctors to get beyond specific test data.

As Dr. Lux indicated earlier, sometimes individuals with acquired brain disorders or traumatic brain injuries do quite well on certain adaptive living tests. But when they're in the real world they are really unable to meet the kinds of -- the kinds of standards that are -- that the test would lead one to think that they would be able to do or the kinds of activities that the test would seem to indicate that the individual would be able to do. So really talk to not just the doctors but also family members, friends, others in the community that your client has everyday contact with to talk to them about what does the individual's daily living skills, what do they look like? What does their -- even though their intellectual functioning might show to be quite high on a test, how does that really work in the real world? Are they able to go into a store and purchase things on a list, or manage their money with a shopkeeper? Talk about behaviors. Disinhibition is very often an issue with people with traumatic brain disorders and acquired brain injuries.

Hygiene is often an issue. What is their ability to manage money or to monitor their own medications? What are their physical limitations? So, for example, I had a client who performed extremely well on an adaptive living skills -- daily living skills test, but in reality, when I spoke to the physicians and when I spoke to the people that knew him best I

learned that despite those test scores, he really was unable to function independently in the community. Let me also mention, if the individual is in a rehabilitative or skilled nursing facility and you're looking at moving the person out in the community or home-based setting one of the other possibilities is to talk -- have the individual evaluated by, for example, a home and community-based care setting that would provide additional services to the individual once they're in the community so they can talk about what kinds of services would be provided to meet your client's needs. Let me move now to advocating for enhanced services, that is, my work with doctors through the ABD wait list case. Physicians can be extremely helpful in looking at ADA and OLMSTED issues. Wait list litigation is one of the ways in which many of us have looked to move people out of institutions and into home and community-based settings. It has been very helpful in my litigation to have some independent doctors evaluate an individual's ability to move from an institutional setting to a home and community-based care setting and also to talk about what kind of detrimental effects there are in having the individual remain in, you know, an institution or skilled nursing or rehabilitative facility for a long term.

In New Hampshire there have been a fair number of individuals who have stayed in such settings way beyond the time in which a less restrictive environment would have been appropriate for them. So we had some physicians go and complete a tour of the institutionalized individual's setting. They looked at records, spoke to the individual, perhaps their guardian and staff members and talk about the level of care that the individual required. And whether or not that could, in fact, be provided outside the institution to show that there are, in fact, less restrictive environments for that individual.

And also to evaluate the detrimental effects of remaining institutionalized. A number of doctors did this and reviewed many class members in our ABD suit and it was very, very clear that, in fact, all of those individuals would be more appropriate in less restrictive environments but were simply awaiting services. Of course, as many of you know, I'm sure, the discussion under the ADA and others, a significant amount of our time and work has been regarding fundamental alteration issues, which I won't talk to you about now. But I do think that it is very helpful to work with doctors who can really talk about individual's needs and the benefits of being in home and community-based care settings.

Just a quick update on our ABD wait list lawsuit. We are -- we've now been litigating this case for five years and we've been up to the first circuit and now back down to the federal court and the federal court recently denied the state's motion for summary judgment as well as our motion for summary judgment, but has determined that, in fact, the case will proceed to trial. So we've been through summary judgment twice in the lower court up to the first circuit on some Medicaid issues and now we're back down in the district court and expect to go to trial on the ADA and rehabilitation act claims probably sometime around February. So I'm going to now turn the presentation over to Mr. Currier and thank you all for listening.

ELIZABETH PRIAULX: Ken, before you start, we are tremendously on schedule so I am not afraid of you losing your time here. And I was thinking that it might -- we just have a few questions and we might just spend the next five or six minutes where we're kind of

ahead of time to answer some of the questions before we get into your presentation which is somewhat unrelated. Is that OK with you, Ken?

ELIZABETH PRIAULX: I want to thank all of you who have spoken to far. Dr. Lux, are you still on the call?

DR. LUX: Yes, I am.

ELIZABETH PRIAULX: I believe the first question was to you. And now I scold up -- scrolled up so much I can't find it. OK. It was from Alice Stevens and she I think was commenting -- you were mentioning how it is sometimes difficult to diagnose or recognize traumatic brain injury because it can be so different in individuals. They can test well on tests but not in the individual world and her question was how do you diagnose these types of injuries? Do you want to take a stab at it?

DR. LUX: Sure. There is a lot of things that go into it but the most important thing. Our last speaker touched upon some aspects of this. You have to be in touch with history of the individual both from the individual but as well from other sources. You will get a lot of input from employers, from family members, from friends. Now, obviously there are limitations that may be placed on who you can talk to and under what circumstances based on privacy issues and things like that but to the extent that those issues can be resolved, it's getting that kind of history that really gets ahold of what you want to know about how the person really is functioning. It's important to get a variety of sources, in part

because you will find great variation in the amount of insight that an individual with a brain injury has. Into their various deficits and problems. Some individuals have good insight and can tell you themselves, others have very poor insight and you need to get the information from others. That's the most effective way of doing it. Now, you can under certain circumstances, however, do other more functional evaluations. Some community reentry, rehabilitation programs, in addition to doing rehabilitation, will actually take a client for a period of a week or two and put them through their paces, if you will, in a variety of community settings under the direct observation of sophisticated brain injury therapists and from that you can get some rather more objective feedback about their performance in the real world. That's not readily available often but it is a potential resource. The amount of value and information you can get in formal testing. You can get reasonable information, it's just that formal, structured test situation compensates for the deficits so you can miss things there.

ELIZABETH PRIAULX: Thank you very much. In order to stay on schedule we'll go to Ken now. There are lots of other questions waiting for us for our question and answer period. Thanks, Ken.

KEN CURRIER: OK. Good afternoon I'm Ken Currier, I'm the deputy director of the National Association of state helped injury association and the director of the TBI association at national. The National Association of state helped injury administrators is the first and only national organization created by and for state agency employees working in brain injury. Our members including 185 government employees from 46 states and

territories who work in health, human services, developmental disabilities, Medicaid, special education, voc rehab and other state agencies. The mission is to assist state government in promoting partnerships and building systems to meet the needs of individuals with brain injury in their families. My purpose today is to speak generally on the various funding options used to finance services and support for individual with individuals with traumatic brain injuries. The variations are many and I'm not an expert on all the details. I will provide you with some of the options and issues we see as we support state TBI programs and developing state systems of services and support. A good resource that speaks to funding issues and TBI in the states is the the state guide to funding services, a compilation of a 2002 survey of the states including some information from all states but South Dakota.

That was funded by the federal TBI program. You can seek copies of the guide are available at www.nashia.org. You can go in there and pull down any of the various funding sources and you can see specific information about your state that you have there. Just as no two brain injuries are alike no two states have funded systems in precisely the same way. As has been well documented individuals with brain injury in their family seek supports from multiple state agencies. I think you could see some of the broad areas that touch in terms of policy when Brian was talking earlier about what was going on in Delaware and how brain injury affects so many different agencies. An individual with brain injury there are short-term and lifelong but will change over time. States use a variety and combination of funding streams to plan and provide services for individuals with brain injury and their families who have no other access to needed care

and/or supports. There may not always be brain injury specific services but individuals may be served with programs available for other qualifying criteria. Therefore, services and supports vary to to eligibility including injury severity, age, asset income limitations and state programs have parameters in terms of scope and frequency.

When you were talking about the waiver you got an excellent example about New Hampshire's approach and the limitations that happen as you select the different types of eligibility issues. We're not able to identify and count individuals with brain injury in every program. However, the states reported throughout the NASHIA survey an aware of supports available for individuals with TBI. 46 states report they have assessment and evaluation. 46 states report case management and services coordination, transportation services are funded through 45 states. Respite services in 45 states. Behavioral programs and services in 41 states. Supported employment in 37 states. Long term residential services in 35 states. Pre-vocational services in 35 states and community education in 33 states. Certain funding is provided by the federal government and is available in all states. Individuals with brain injury may be eligible for services from these Block Grants which are administered by state health, social services, mental health or substance abuse agencies or serving people with disabilities or the elderly. Services defined by the state within parameters defined by the administering agency.

The Block Grants include the Maternal and Child Health Bureau which includes health and welfare services for mothers and children administered by the health resources and Health Resources and Services Administration. Maternal and Child Health Bureau. There

is also a preventive health and health services Block Grant that supports clinical services, preventive screening. Laboratory research, work first training, public education, data surveillance and program evaluation for targeted health issues and that is also administered by the Maternal and Child Health Bureau, Division of state and community mental health. The substance abuse prevention Block Grant provides substance abuse and community mental health services administered by the substance abuse and mental health services administration, Center for substance abuse and treatment. The community mental health services treatment helps with support services for people with mental illness, their families and communities administered by the Center for mental health services. The social services Block Grant provides critical services such as meals on wheels, daycare, home-based services to children, elderly and individuals with disabilities.

Individuals with TBI may be eligible based on their disability and most often will receive in-home services and transportation assistance through this Block Grant. This is administered by the children and families association. The temporary assistance to needy families grant that assists needy families so children can be cared for in their homes.

Promote job preparation, work and marriage. Preventing out of wedlock pregnancies and encouraging the formation of two parent families administered by the administration for children and families. The Block Grants as we're saying have the flexibility within the states to be able to determine. No one state will always have the same rules or coverages and so you really need to look and see and contact the individual state agent see that administers your program to be able to see what would be the services covered.

Another source of federal funding is authorized by the rehabilitation act which provides formula grant programs for vocational rehabilitation, supported employment and independent living. Your state VR agency provides comprehensive rehabilitation services that go beyond those found in job training programs to including work evaluation services, assessment for and provision of assistive technology, job counseling services and medical and therapeutic services.

The supported employment program is to assist states in developing collaborative programs with appropriate public and private non-profit organization to provide supportive employment services and these services augment time, limited services and VR services. Independent living grants supply financial assistance to supply, expand and improve independent living services. The services are information and refer all. Independent living skills training. Peer counseling and individual and systems advocates. The vocational rehabilitation is administered by the Department of education rehabilitation services administration and the final type of federal funding is provided through the individuals with disability education act, idea. It ensures due process rights, educational programs and mandates special education related services be provided in a least restrictive environment. It includes traumatic brain injury eligible, though not often or always counted.

Services are transportation, developmental corrective and other support services required to assist a child with a disability to benefit from traditional education. These funds are distributed by a formula grant by the Department of education Office of special education

and rehabilitative services. Again these -- each of these are federal programs and awarded to a state agency. It's a source of collaboration and funding for brain injury services in your state. Moving on to federal and state funds, the title 19 of the Social Security act of 1965 paved the way for the federal state health insurance program known as Medicaid supported through a mix of federal and state funds. Medicaid provides three types of healthcare coverage. Health insurance for low income families with children and people with disabilities, long-term care for older Americans and individuals with disabilities, and supplemental coverage for low income Medicare beneficiaries for services not covered by Medicare and Medicare cost sharing. Every state has a Medicaid plan that details mandatory and optional services cover and they vary considerably from state to state as well as within each state over time.

Nevertheless every state provides basic medical and related services to individuals with brain injury and their families who qualify given their income and other resources.

Medicare allows for the services to overcome statewide requirements by the use of waivers. Waivers have to be budget neutral to be approved. There are several types of waivers. The one that New Hampshire was talking about is the 1915C or home and community based services waiver is the -- it's the type of waiver most often accessed by people with brain injury. These waivers may provide case management, homemaker services, home health aid services, personal services, respite care and others. Other optional services may be approved. Supported employment. Assistive devices and transportation. States are given flexibility. That best meet the needs of the individual. They must show the waiver services will cost no more to provide than the cost of

institutional care. That's how some of the turning down gets. NASHIA study 47 states had Medicaid waivers that served individual with brain injuries. 1915C waivers. 31 states had developmental disability waivers. 12 states had disability waivers and 10 states had elderly waivers.

There are also brain injury specific home and community based Medicaid waivers. A NASHIA study in 25 states having such programs in place in 2001. The range of services available under TBI Medicaid waiver vary by state but may include assessment.

Transportation and some will pay for residential services. According to immediate stat, a contractor to the centers for Medicare and Medicaid services the funding levels for TBI waivers ranges from \$580,000 innd more than \$17 million in Minnesota with the total exceeding \$80 million nationwide. There is not an average per person cost of Medicaid waiver services nationwide because the type and duration of services varies widely depending on the criteria in each state. Moving on to state funding. Some services and supports for individuals with TBI are supported through state only funding. Funds collected from income, sales and property taxes or types of general revenue. In the study we found 22 states allocate general revenue ranging from \$70,000 in Iowa to more than \$6.1 million in Massachusetts for brain injury specific initiatives. Four states allocated special revenues, usually tobacco settlement funds for brain injury specific initiatives.

States used general and special revenue to provide services such as case management. Personal assistance. Rehabilitation, transportation and supported living. They pay for policy planning, central registries and data collection and research. There is considerable

variation of variability in eligibility criteria for these programs and some programs are targeted to adult populations, others to children and youth and sometimes there are income requirements as well. There is also on the state level trust funds established through legislation to receive funding from fees and fines typically assessed on speeding, reckless driving, driving while under the influence and other civil convictions. Surcharges have been added to driver's license or firearm registration. It appears to be a promising practice as it provides a steady if not increasing flow of funds not subject to court enforcement. Today there are 18 states that have trust funds and a NASHIA study report that trust funds annually yield between \$750,000 in Tennessee and \$15 million in Florida. Trust funds pay for everything from assistive technology and speech therapy to personal care and vehicle modifications. Employment, housing and long term supports are less likely to be funded by trust funds because it's usually other agencies. Trust funds often have annual and lifetime caps and therefore don't accommodate long term support. If we just look at the different types of waivers, Medicaid waivers,

TBI specific Medicaid waivers and trust funds, four different types of sources of funding. We look across the states seven of them have a single source of funding. 21 have two sources of funding. 18 have three sources of funding and 3 have four sources. That's a fairly impressive array of services and funding sources that we have but if you look at the numbers there is a certain -- in terms of eligibility and definitions on some of these issues that we mentioned before, we estimated using the guide and we have to remember that there is issues around data collection, but 47,492 individuals were served through the various types of funding sources. 4200 in voc rehab. 13,811 special education, 5,440 in

TBI Medicaid waivers and 23,000 in state only resources. We've agreed we need to be looking at for further study and investigation to sort of -- there is a big difference between the 5.3 million people living with the disability and what we're showing in terms of state and federal funding sources.

Considerations you should be thinking about advocating for individuals with TBI is to know the definition of TBI in your state. All states don't use the same definition. You need to know the TBI lead agency in your state. The lead agency is designated entity with primary authority and responsibility for coordinating brain injury services. 17 states the lead agencies in the public health department. 15 states in the human or social services department and 4 states for lead agency is in the rehabilitation department. You also need to really get to know your advisory board in the state. 47 states have created an advisory board or council to facilitate collaboration and citizen participation in policy form lags and program implementation. It's council is unique in its relationship to governmental bodies. 20 states have designated theirs through state statutes. Three created it through an order by the governor and others have created it by department leadership. I think you need to continually use your knowledge of the needs of individuals with TBI to increase the awareness of the lead agency and state agencies in providing services and support as well as encourage collaborations among state agencies to address the barriers to receive services and supports. That's it.

ELIZABETH PRIAULX: Thank you very much, Ken. Thank you to all the speakers. I'm going to go in order that the questions were received and if you have follow-up questions

once there is a response, feel free to type them in because we have a good 20 minutes. OK. The first couple of questions were for Brian and they all relate to the brain injury special committee. I can summarize them as how is the committee funded, how did the members get identified, and one says you're doing great work. And Wisconsin would like to know if there is a link to the bylaws and membership guidelines for the special committee because they're reorganizing their brain injury advisory committee and they could use the information as they make decisions. Can you answer those, Brian?

BRIAN HARTMAN: I'll try. The state council for persons with disabilities is funded by the state and it's under our Department of administrative services. And it is really solely funded with state dollars. I don't think they have any federal dollars. It is established in state law. Let me see if I have the code section. Actually if you go to the website for the state council. I gave you the citation in your material in the -- on the webcast presentation, there is a section there on the Delaware code and it gives you the code citation and description of the council itself. And I actually had to do some convincing in order to get them to set up a brain injury committee because they didn't want to have a proliferation of committees that were dedicated to each disability. Otherwise you would end up with a committee on mental retardation, brain injury, autism. But because we are not one of the 47 states that Ken Currier mentioned as having an advisory board, we needed to do something. I was able to convince them to set this up. There is no separate funding for it but one advantage of tacking this committee onto this existing council was that it gave us automatic staff support and infrastructure. We chose members in consultation with our Division of aging and adults with physical disabilities which has generally been the lead

agency for TBI and ABI in the state and they're the ones that administer our ABI waiver. So we really, in consultation with the council and if consultation with that agency, came up with a good mix of representatives and again if you go to the website, the minutes are there and you can see who the representatives are for each meeting. Attendance has been somewhat spotty at times. But because we have so many members, we've generally got a good crew for each meeting. And was there one other question? The bylaws. I can probably submit the bylaws to Liz who could then forward them to other folks on request. I don't have them immediately available to me but I have a copy of them someplace around here. So I'll do that. I'll send you the bylaws.

ELIZABETH PRIAULX: Great. I hope you heard the comment that you're doing a great job.

BRIAN HARTMAN: We're having fun.

ELIZABETH PRIAULX: A question which, I think, similar to the one I asked of Dr. Lux for Julia in the context of your work with identifying students, Lynn asks, what questions do you ask to find an unidentified TBI student?

JULIA FREEMAN: OK. It's a fairly -- I'm looking it up right here. It's a fairly broad screening. We don't get into many details although there are some instruments developed, I think, by Mt. Sinai and about -- with more specific questions to identify students actually by Wayne Gordon, I think. The one that we do here at the PNA is very

quick. It asks if the child has ever received a head injury. And what the child's special education coding is. Is the child getting special ed. services due to the head injury and whether the services are appropriate or not. That sort of follows a question about suspensions and expulsions. Sort of some broad questions about that. That's another of our concerns.

ELIZABETH PRIAULX: Somebody asked, what are the problems with the TBI coding that you mentioned?

JULIA FREEMAN: In New Hampshire? Well, a lot of times the -- first of all, the TBI got added to the IDEA later than some of the other categories and so a lot of school districts just don't really have it on their wavelengths. In addition, in our state there was some confusion with some of the guidance given by the state Department of Education about what criteria had to be met in order to qualify for a TBI coding. Essentially it had to do with how many functional limitations there were. So a lot of school districts were avoiding the TBI coding and instead -- actually this is true around the country. Instead coding kids as having a learning disability or an emotional handicap. Those are the most common or sometimes other health impaired. And that -- theoretically the child should still be able to get the kinds of services, the same kinds of services no matter what the coding, but often what happens is the child is not -- if the brain injury is not identified, the proper services are not provided. For instance, a child with an emotional handicap sometimes needs other -- different kinds of interventions than a child, say, who is disinhibited due to a brain injury. And if the school is dealing with those problems inappropriately then the student is

not going to get any better and is not ultimately going to learn very much. So it's sort of a mix of not being able to identify the brain injury and then also being somewhat reluctant to use the TBI coding because of some misunderstandings about who qualified and who didn't.

ELIZABETH PRIAULX: OK. Thank you. Just going down to another question. Debbie would like to know is there a website where we can get additional information about the ABD waiver in New Hampshire and eligibility requirements for other states to consider about developing their own TBI waiver? I guess that would be to Amy.

AMY MESSER: Let's see. Sorry, I needed to think about that for a second. The state's website in New Hampshire does have the eligibility requirements for the ABD waiver. But you have to kind of find your way through the regulations in New Hampshire. Let me just see if I have -- I should have that website here. Ask another question. I don't have the answer to whether or not there is some comparisons regarding other states ABD waiver eligibility requirement. If you go on to another question I'll look around on my desk and see if I can find -- I've got it. If you go to www.dhhs.nh.gov that gets you to our state's website and you have to follow the prompts through the -- there is a prompt for administrative rules and then you'll want to click on administrative rules and look for HEM522, which is our rules regarding acquired brain disorders. And I think that that will lead you to the regulations. The other option, of course, is the disabilities rights center has a website and you could contact us and we could get you that information if you needed it.

ELIZABETH PRIAULX: Thank you so much. OK. The next question is from Marsha Cooper and she -- you were talking earlier, Amy, about how you found that people with MS and some less -- immediately recognizable disabilities can be covered under the ABD waiver. Are individuals with Alzheimer's eligible under the New Hampshire waiver?

AMY MESSER: You know, I know there has been some discussion around that issue internally in the state. It is not specifically mentioned in the state regulations with regard to who is eligible, you know, who meets the requirements of an acquired brain disorder. I think one of the big issues is that your brain disorder or brain injury has to occur before the age of 60. You have to have onset before the age of 60 which is, I think, less usual for Alzheimer's. The regulations, as I say, are not specific with regard to that. But there are some open ended provisions such as the provision with regard to other neurological disorders. I think that's an open question in New Hampshire.

ELIZABETH PRIAULX: How did you identify professionals and entice them to do the tours of the facilities?

AMY MESSER: That's a good question. New Hampshire is a relatively small state and we really did a lot of talking to both our local brain injury association as well as some physicians around the state and members of our board and, you know, just learning who really are the professionals in New Hampshire as well as some outside New Hampshire who really have extensive knowledge regarding traumatic brain injuries and acquired brain

disorders and didn't have difficulty in this instance in finding medical professionals and that's information that again we would be happy to share with individuals if they contact us directly.

ELIZABETH PRIAULX: This is for anyone on the panel. Are any of your states using pass R screening tools to identify folks with TBI in nursing homes

BRIAN HARTMAN: In Delaware I'm not aware of any. They should be reviewing people with developmental disabilities. I don't know -- and mental illness. I don't know how -- if they're also screening for TBI.

ELIZABETH PRIAULX: They're not required to but a number of folks have asked whether or not the states have broadened it.

AMY MESSER: Not in New Hampshire that I'm aware of.

ELIZABETH PRIAULX: OK. We actually do not have any other questions. So this is the last chance for people to type in their questions. And if you found this valuable and you want to encourage other people to listen in on the webcast, they can go up on the same site. I don't know how long it stays up but I think it stays up for a long while. I just wanted to thank HRSA for funding this webcast for the PATBI programs. This was actually not funded at all by NAPIS but just an opportunity as part of HRSA and maybe TBI tack. I'm

not sure how the funding worked. I want to say thank you to them for making this happen. Seeing no other questions.

BRIAN HARTMAN: This is Brian. Let me add a follow up to an earlier question. There was an inquiry about the bylaws for the state council for persons with disabilities brain injury committee. And the council bylaws I'm looking at are right on the website so they can just go right on the website and get the council bylaws. There are no separate committee bylaws, just the council itself.

ELIZABETH PRIAULX: OK. I hope you all have been stimulated to work on prevention and work with the veteran's community and no of the resources of the veteran's brain injury center and of your other PNA programs that are working around the country. If you ever want to continue to get ideas for how to spend your PATBI funds call Elizabeth Priaulx at NAPIS. Submit your forms and put in comments for future webcasts that should be hosted.