Traumatic Brain Injury/Brain Injury Association of America

Ready, Set Go:

Including Children and Youth in TBI Programs

June 17, 2008

HEATHER CROWN: Hello and welcome to today's Federal TBI Program webcast, "Ready, Set, Go: Including Children and Youth in TBI Programs". I'm Heather Crown with the federal TBI programs technical assistance center. With me today are Paula Denslow from Tennessee and Brenda Eagan Brown from Pennsylvania. The purpose of today's webcast is to discuss Tennessee's and Pennsylvania's children and youth activities to allow other states to replicate.

Before I introduce the speakers I need to go over a few housekeeping details. First I will mention this will be a discussion format followed by questions and answered from the audience and we won't be using Power Point slides. We encourage you to ask the speakers questions at any time during the presentation. 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. Please include your state or organization in your message so that we know where you're participating from. The questions will be relayed onto the speakers at the end of the broadcast. If we don't have the opportunity to respond to your questions during the broadcast, we will email you afterwards. We encourage you to submit questions at any time during the broadcast.

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will see text captioning underneath the video window. At the end of the broadcast, the interface will close automatically and you will have the opportunity to fill out an online evaluation. Please take a couple of minutes to do so. Your response will help us plan future broadcasts and improve our technical support.

First I will introduce Paula Denslow. Paula embraced responsibilities at the project coordinator for Tennessee's Project B.R.A.I.N. Before that she worked within a Pennsylvania school system for 12 years and for two years in middle Tennessee as a substitute teacher. Two of Paula's three children sustained a traumatic brain injury. Understanding that each TBI is unique and misunderstood propelled her to advocate on behalf of students and their families improving successful educational outcomes of students affected by TBI. Paula is actively involved with Tennessee's Department of Health traumatic brain injury and the federal TBI assistance center and serves on the committee on pediatric emergency care responsible fought Tennessee Department of Health for implementation of the Tennessee emergency medical services for children program. She participates in ongoing staff development training regarding the Americans with Disabilities Act and diversity and sensitivity issues via the Tennessee disability coalition.

In addition to speaking with audiences in both the brain injury and education field, Paula has presented to diverse community organizations with focuses ranging from national conferences addressing federal decisions to community coalitions working to improve local services for those with TBI. Paula is a certified brain injury specialist for the American Academy of certified brain injury specialists.

Brenda Eagan Brown works for brain steps. She specializes in the educational aspect of traumatic brain injury. She holds three Pennsylvania teaching certificates in elementary, mentally and physically handicapped and reading and a special education teacher in Fairfax, Virginia and actively consulting with schools and parents regarding brain injury since 1997. When Paula was 14 her 13-year-old brother sustained a traumatic brain injury after he was hit by a car while riding a bicycle. This experience created the passion in Brenda to pursue a career in improving educational outcomes for students with TBI. Tennessee's Project B.R.A.I.N., bra*in resource and information network, was developed in 2000 with funding from the Federal TBI Program. The project began with a goal to improved indicational outcomes for children with traumatic brain injuries in Tennessee. Pennsylvania's child and adolescent brain injury school reentry school was developed in the fall of 2007 with funding from Pennsylvania's Department of Health Maternal and Child Health Block Grant. Paula, please describe Project B.R.A.I.N. for us.

PAULA DENSLOW: Hello and let me begin by saying thank you for inviting us to participate in this broadcast today. The Tennessee disability coalition and the Department of Health statewide traumatic brain injury program established a partnership in July of 2000. With a shared goal of improving educational outcomes for Tennessee students with TBI. Project funding has come from the health resources and services administration, Maternal and Child Health, the Tennessee traumatic brain injury program, the Tennessee Department of education Division of special education and the Tennessee disability coalition. Our original focus was the provision of education and training for educators, families and healthcare professionals who support students with TBI. Based on success -- on a successful TBI resource team model implemented in other states, we established 18 statewide brain resource teams. Utilizing the data collected from the Tennessee TBI registry, the selected school systems were chosen based on their incidence rates of

school age children and youth who had been identified as having TBI. Our teams are comprised of professionals varying disciplines in selective school system. Team members act as consultants and may also provide basic training and educational resources to colleagues and families as needed. Team members' participation in our program is voluntary and our project continues to offer supports and trainings -- training opportunities as they come available.

Expanding on our project's historical foundation, recognizing the need to improve our efforts with communicating with the healthcare professionals, we strengthened our relationships throughout selected Tennessee hospitals by developing effective communications links from hospitals to homes to schools promoting successful transitions for our students. Again, accessing the data from the Tennessee traumatic brain injury registry we identified hospitals due to their incidence rate of treating and releasing students who have been identified as having brain injuries. Currently we are -- we have formed relationships and partnerships with seven hospitals across the state. In 2006 we launched a train the trainer manual for hospital emergency departments. This is known as an ongoing -- was developed as an ongoing staff development tool. We've been very busy sharing the many resources within and throughout the healthcare community but especially with our designated hospitals and we continue to build on our relationships while learning more of the infrastructure of these hospitals.

>> The brain injury association of Pennsylvania, through a grant from the Pennsylvania Department of Health, has partnered with the Pennsylvania Department of education to create the child and adolescent brain injury reentry program that we have named brain steps. An act co NIMH for steps stands for strategies teaching educators and students. Our program in Pennsylvania works to make sure that those who provide educational

support to children with brain injuries in the schools have a good and thorough understanding that will help them achieve optimal educational success. Brain steps consulting teams are comprised of professionals from varying disciplines across the state who have received an extensive training on educating students with traumatic brain injuries. Team members act as consultants for the school regions where they work and provide basic training and resources to families. The brain steps program provides coordinated training and consultation regarding identification, ongoing educational strategies, IEP development and planning, school reentry planning and long term monitoring of students through graduation. Brain steps also provides consistent and familiar contacts for hospitals and rehabilitation facilities working to successfully transition students with brain injuries back to school. And last, a unique aspect of Pennsylvania's school reentry model is that we have funding available to pay for individualized one-on-one from rehabilitation specialist such as rehabilitation therapists and life care planners. When the teams need extra help for a student they're working with from outside the typical educational realm of services.

The Pennsylvania Department of education has organized the state into 29 distinct regional service agencies called intermediate units. The brain steps program decided to establish brain steps consulting teams beginning in these intermediate unit regions that were already established across Pennsylvania. Our teams consist of school psychologists, school nurses, school therapists, assistive technology consultants, administrators, teachers, school nurses, family members and also medical rehabilitation professionals from the community. This year we have trained 14 regional teams consisting of 103 committed team members.

HEATHER CROWN: Our next question why did your state choose this activity? And mainly, what was the need that was being addressed and discuss any barriers that your projects hope to overcome.

>> We have several reasons for addressing and choosing this topic. Over time we became aware of the communication breakdown among families and schools. Educators were not always in the loop after a student had sustained an injury. We asked why and what could be the cause of this breakdown of communication and we learned that if we backed up a little bit, it was because the gap in communication and available resources from the hospitals, between hospitals and families. Families understanding the importance of informing the school with a concern and it was something -- these are things we had heard over time repeatedly heard over time. The lack of healthcare's understanding of how TBI may impact a student after leaving the medical facility. Another reason was due to the lack of available tools and resources shared with the family at the hospital level to increase awareness of what TBI may look like down the road. Especially when the injury is hidden in nature. There were no direct links that we could find that -- from the hospital to the school system to assist families in the continuum of care to help with the coordination of services.

Another area that was brought to our attention from one of our resource team members was the fact that the miscommunication in language. Healthcare professionals use terms such as concussion versus mild TBI. School systems need to have the correct diagnosis for the student to be able to receive special education services if they are appropriate. Under the IDEA one of the other realms of this, when we opened -- when we addressed one question, it -- as it does all the time, it asked at least 15 more. One of those was, because it's time sensitive in nature in bringing about the resources for this student, was

that in Tennessee if a person with a TBI is treated and released at the hospital within 24 hours, no further follow-up is provided. If the person is admitted to the hospital and stays over 24 hours, that data is then sent to the TBI registry where a follow-up letter is then distributed and forwarded on to the family. The TBI registry the hospitals are mandated to send this data to the registry and the gap in time between the date of injury and receiving and the family receiving this letter would have been cut in half had there been available resources in place, whether it's a staff person or a physical handout or a simple conversation in expressing this information. That would have cut down the time for that individual and family to receive support and a level of understanding and awareness of TBI. Families clearly indicated that after receiving the letter, they had no idea that there could be long term effects as a result of this injury. Another -- we have always seen the barrier as being a need, which is another reason why we chose this activity. Healthcare professionals welcomed learning about the impact an injury may have to a student and that long-term effect down the road. They wanted to learn all they could about the available resources and from our understanding from our first initial conversations they did not realize that there were resources in the community and they didn't realize the need for those resources. Schools were not on the healthcare radar as a resource or as a piece of the puzzle, a piece of the student's puzzle. We had many light bulb moments when we were able to share the -- these are things that people realized but didn't put it in perspective with serving students with brain injury. The light bulb moments were -- I just lost my train. The light bulb moments were the fact that there are supports and services that are available to support the needs of a student but we just needed to communicate and bridge that infrastructure, that gap, if you will. One of the main barriers for us in implementing our goals was to actually get in the front door.

Each hospital is administered uniquely very similar to all of the experiences we had with school systems. They are administered differently and uniquely and you need to find out who you need to connect with. Who was the best person to implement the system's change. How do you want that system change to be implemented and what is going to be the greatest effect as a result of the implementation? Hospital staff changes. We would build a relationship with a person who is able to implement certain changes and then their roles and responsibilities within that healthcare facility changed. There again we needed to build on those relationships. Costs and times of materials. Who was able to do what and after collaborating and many conversations within the healthcare community, who was going to be -- who and what would be the best method of delivering this information?

Another area where you see what would be a wonderful relationship or a position is to have someone in the role at the healthcare facility that would serve as a community link or liaison to the TBI services that are outside of that healthcare facility. The ultimate goal we all came down to bottom line is we all want to be able to get the information as fast as we can into the hands of the families and the students who have TBI. And in Pennsylvania, the child and adolescent brain injury school reentry program was created because over the years Pennsylvania's statewide traumatic brain injury advisory board began to highlight the problem. There was an extremely high number of children and youth sustaining brain injuries in Pennsylvania when compared to the numbers of adults who were sustaining traumatic brain injuries. The Pennsylvania Department of Health, which is our lead TBI agency, focused on children and youth as a top priority. The statewide traumatic brain injury advisory board looked at current statistics for traumatic brain injury and began to apply the statistics to Pennsylvania's population and found that over 25,000 children every year sustain mild, moderate and severe brain injuries in Pennsylvania. That does include mild brain injuries which are also concussions. Further, a closer look at some

statistics from the Pennsylvania Department of Health in 2004 there were 3,374 children in the State of Pennsylvania in one year who were hospitalized with a medical diagnosis of traumatic brain injury. So these brain injuries, the 3,374, were moderate to severe brain injuries. Now that's in one year. In the year 2005-2006 the following school year, according to the Pennsylvania special education data roster numbers for the number of children who were categorized under the special education law IDEA and receiving special education services as TBI, traumatic brain injury, there are 912 children cumulatively K-12. We have 3,374 children in 2004 who in one year received these brain injuries, but our numbers were not syncing up with the students receiving services in special education. Now, we do realize that not all children, not all of those 3,374 children will need special education services. But we do know that there will be, you know, a large amount. If we're getting that number on average every year, the numbers are not syncing up. The closer that the Pennsylvania Department of Health looked at the TBI problem in children, the more that they realized there was a huge gap between medical rehabilitation services and the schools for addressing the needs of these students once they returned to school. Pennsylvania realized that educational professionals did not have a firm understanding of brain injury and the impact it can have on school performance even over time. Pennsylvania also realized that the medical rehabilitation field did not have a smooth avenue for the coordination of school reentry following brain injury. It was very cut and dry for the most part. Now again we consider barriers that we wanted to overcome as needs that Pennsylvania wanted to overcome. One need in Pennsylvania, as well as the entire nation, is the under identification of traumatic brain injury in the schools. This is a huge problem. Our program goal is to educate the public schools where we have created teams on the need for correct identification of brain injury and the need for implementing a functional educational plan that's appropriate.

Another need in Pennsylvania was the lack of brain injury education among professionals who were already involved in the school reentry. We realized that we had to first address a professional's understanding of what exactly brain injury is and what the future effects of a brain injury can have on a child's education before we could make an impact in the life -- lives of students. And the final identified need was the lack of consistent communication flow from the rehabilitation to the school. We plan to bridge that gap with our teams by creating our teams to include not just educational professionals, but family members and medical rehab staff.

>> I would like to underscore the importance when Brenda mentioned Pennsylvania's numbers, that as we all know, data drives funding and it is imperative that if states work on children and youth activities that they find these numbers and compare that number of students classified under the individuals with Disabilities Education Act with the numbers of children that are hospitalized. And anyone watching, if you're not sure how to locate these numbers you can feel free to contact me at the TBI Technical Assistance Center and I'd be more than happy to help you locate these numbers. Our next question, my next question to you both, what is the overall goal of your project and what is the method logical approach for getting the work accomplished and also in this discussion please include any existing resources that you use to accomplish these goals. Paula.

>> Okay. Our goal is in two parts. One is to expand Project B.R.A.I.N.'s capacity to improve the linkage between hospitals and schools in support with students and youth the TBI to help the student outcomes. Project B.R.A.I.N. and the resource teams provide ongoing training presentations, developed a training module in a train the trainer format with research libraries. It's called supporting students in the classroom which targets educators and families. The primary objective of brain injury 101 is to help people who

support students with TBI understand the nature of brain injury and the unique needs of this group of children and young adults. In the years -- from the years 2000 to 2007, over 4,000 people in Tennessee have participated in brain injury 101 presentations. We have participated in booths or exhibit-type events between the years 2003 to 2007 and the calculation is that we have been an available resource within the community to over 16,000 people who participated at the events. The second part of our overall goal is to establish the communication links there again between the hospitals, families and school systems. We developed a train the trainer module as an ongoing staff development tool, again but this one is targeted toward the hospital emergency department staff. Our training is titled partners in communication, supporting student transition, hospital to home to school. One of the resources that we use to accomplish our goal was while developing our partners programs we utilized the TBI Technical Assistance Center, the knowledge exchange committee, which was a wonderful resource for us to present in draft form where we are in the developing process. They would, again, critique us, make suggestions where we were able to incorporate. Some of their suggestions and it is -- such as an example would be to use people first language. That was part of the guidelines we had already taken care of that concern. But another area was to make sure that we were -- we had diverse -- that we were able to present this information to diverse populations. So there -- their collaboration with us in developing this resource tool was very well worthwhile and I would recommend it to everybody. And I will say both of these training modules are available at the TBI technical assistance training center website and Heather said having resources available after the broadcast. Another piece of our overall goal was to share our project's existing resources such as the interactive virtual school which is now accessible on the Internet and present the information for all healthcare staff of emergency departments. Such as the discharge planners, the social workers, the trauma staff, the nurses, the physicians and the rehabilitation, in patient and outpatient

staff as well. Another piece of our puzzle is to be consistent with all of our materials and resources. We use consisting colors. Our logo has stayed the same. We have colored -- continued on our color scheme, our logo and all the formats so the people would recognize this resource as one that has longevity and sustainability.

>> Now the goal of Pennsylvania's program, brain steps to to ensure any child who sustains a brain injury receives an appropriate education by professionals who understand the educational impact of a brain injury and how to best create a learning environment for optimal student success. Our goal is to have a trained brain steps team in each of Pennsylvania's 29 intermediate unit regions within the next two years. Another goal is to ensure that there are educational professionals who are sensitive to a family's unique needs following a traumatic brain injury happening to their child. These parents have been through a nightmare and they've lived through a nightmare and we don't want them to have to struggle to get their child an appropriate education. We began to develop our statewide program by utilizing the TBI Technical Assistance Center's article building capacity as educators to serve students with TBI, a regional team approach. We also utilized the IDEA section from the TBI technical assistant centers tools for developing relationships with educational agency prior to meeting with our state Department of special education's director to gain their partnership. We were able to use the Power Point presentation that was provided in this resource as a guide when creating our own Power Point presentation that we tailored specifically for Pennsylvania's needs using statistics, language, etc. We also consulted with other states who have implemented their own models of brain injury school reentry teams. Dr. Janet Tyler of Kansas, Dr. Anne and others in Oregon. Paula Denslow in Tennessee and a person from Hawaii shared their resources such as forms, brochure, application packets, etc. for ideas so that we as a state didn't have to recreate the wheel and spend time and energy recreating things that were already created. They were generous in sharing their resources with us so that

Pennsylvania could focus on developing our program and figuring out what would work for our program. And that is a key, key thing that Pennsylvania -- we learned doing this program. I participated as the program coordinator in site visits to Kansas and Oregon's school reentry program for children who have brain injuries to see exactly how their teams and trainings were developed. This is another key piece to setting up a program like this in your state. And to do site visits. Kansas has been doing their program now for 21 years and Oregon for 18. So they have been here for a long time. They helped us see what works, what doesn't work, so we didn't have to learn what doesn't work ourselves. Now, Pennsylvania again they're broken down into 29 educational intermediate unit regions. We identified 12 intermediate units and two large school districts who were interested off the bat in our program for the first year. We then formed teams by contacting the special education directors of each intermediate unit region that was interested and they compiled teams of varying disciplines from within their regions and area school districts. Also what helped was, we took the Pennsylvania Department of Health statistics showing how many children had received moderate to severe brain injuries and I broke it down into counties. I compared for each intermediate unit region that was creating a team, I compared the data from children in their counties who had received moderate to severe brain injuries in one year and how many children in their region were being served as TBIs. Educational professionals, family members and rehabilitation professionals comprise all of our teams. The teams are intensely trained utilizing local experts in the field of pediatric brain injury. The teams have update trainings a few months later with two national experts who we brought in. This time we brought in Dr. Janet Tyler and Linda will kerson from Kansas focusing on educational and behavioral strategies regarding brain injury. These expert presenters incorporated team building exercises as part of their presentation. The teams are now expected to reenter all students with both traumatic and non-traumatic brain injuries from hospitals or rehabilitation centers back to school with continued monitoring

through graduation. And the educational packet that Brenda just mentioned as well as training presentations that Paula mentioned are available for download in a document webcast resources with this webcast. So you should see that and my contact information is on there as well. Our next question, discuss challenges in terms of both opportunities and barriers that are likely to be encountered in designing and implementing the goals and objectives and approaches that were used to resolve such challenges. Brenda, you start this one.

BRENDA EAGAN BROWN: Okay. Now again we consider these challenges, not barriers. We stay positive. We have found that identifying the children with traumatic brain injury in our state is a huge challenge for our program. The feedback we've gotten from our trained school reentry teams so far is okay, we're trained, how do we find the children? How do we find them? They are not all coming from rehabilitation centers. Our approach to resolve this challenge is to have each team form partnerships -- forge partnerships within their local hospitals and rehabilitation centers where they live. Let the medical community know we're here to help the children, send them to us. Teams have presented to therapist groups, emergency room discharge staff, Grand Rounds, pediatrician groups and they provide hospitals and their hospitals and anyone they present to their contact information on how to refer children to them, to the brain steps team, flyers, team brochures to give parents. Another challenge that we found is finding family members to serve on each team for at least a two-year commitment. We ask that all team members serve for at least two years. We found it was initially difficult to find family members that were willing to serve on a team. We began to utilize the brain injury support groups, the brain injury association of Pennsylvania that's created throughout the state to network to try to find some parents and that worked and we also net worked with pediatric rehabilitation facilities in areas to gain parents. While forming next year's teams, we decided to start with the schools and

also ask the schools and the intermediate units for names of parents who had children who re-entered the school following brain injury and that has actually really been working very well. The third challenge is that this program to keep together the teams for the school reentry program. It takes work on an ongoing basis, to keep these team members melded as a team. There has to be ongoing communication and facilitation of the team. There has to be ongoing training. It can't be a one shot deal. They need to have continued training so that the teams can go out into the field and feel confident knowing that they have background knowledge, they may not be experts, none of us are experts, but they can feel comfortable knowing that they probably have a lot more knowledge about brain injury in the schools than the person who didn't go through our training. So we just need to make sure that the teams stay together could heesively. Without the teams we won't have the school reentry program. That's a challenge we're working on to keep facilitated.

>> The distribution of our educational materials on brain injury in the emergency departments has proven to be problematic. As we have been talking about as building relationships and partnerships throughout our broadcast, it starts and continues throughout that process. The problems that we are faced with is how to best find that complete method to distribute this. Everyone agrees the ideal is to link the injury with the ICD9 code of hospital discharge planning. That always brings about questions, how is it done, who is responsible to do this and what codes are linked with what resources? When we were able to meet with some of the hospitals and they pulled up upon discharge what an individual would receive as far as resources when they left the hospital, a lot of the information we found to be antiquated, out of date for that family to then access whether it was phone numbers or whether it was your general awareness of what TBI is. Those resources and things of that nature were not available. The discussions regarding data collection methods of students who are treated and released has not -- there isn't a data

collection method in place at this moment for folks treated and released less than 24 hours in our hospital emergency departments in Tennessee. Who and how does the hospital help the family contact the schools? Should there be release forms? Where would those release forms come into the process of the discharge planning? How would they be introduced to the family? Should they be introduced to the family as a resource? And what is the best mechanism we need to put in place or develop to make that a smooth transition all the while respecting the nature of trauma and we are in a hospital emergency department setting. So everything has to be streamlined and cohesive with links for the hospital and school system to serve our students. We also wanted to know -- we thought it would be wonderful in addition to all of this that an opportunity would be to have a direct link with the Tennessee traumatic brain injury service coordination program. Does that mean to have a position or a role within the hospital emergency department that would directly link to the Tennessee traumatic brain injury program? That's the question we're addressing and continue to address about there again providing the fastest, most appropriate means of communication for our family and school system. The project participation at the healthcare events, one of our challenges that we have to address financially is to be able to participate in the healthcare events. We need as a project of this nature, we need to immerse ourselves within that healthcare community. The best way we've seen to do this and the most successful way we've done this based on our history educating school systems we were then participating within our educational forums and conferences. The same thing holds true with our hospital and healthcare events. Problematicly is that those events cost anywhere from $500 to $1,000 to participate. That's participating as an exhibitor. That was not in our budget early on. We didn't realize we would incur those types of expenses and Tennessee is designated by three grand regions. So our hospitals are selected. We have hospitals in each of those grand regions across the state. That's another area where we need to be able to financially support

participating in events such as healthcare, trauma nurses, trauma conferences that are being held for nurses and the other emergency department staff and we want to be able to be there. With all of that is that we have gone and we have been able to introduce the project and present the partners programs. Many times in abbreviated fashion due to the availability of our healthcare community but we've been able to across the board train our speech and language teams within certain hospitals, the inpatient, out patient rehabilitation. The hospital emergency department staff have ongoing nurse staff development whether it's Grand Rounds at 6:30 in the morning or an early evening presentation at the end of a shift. We try to make ourselves available for all of these presentations to bring this information to them. What we said before is we haven't changed our message. We've twisted and turned around the focus a little bit, expanded it so that we can encompass the healthcare community and present a continuum of care from the point of injury getting the resource in the hands of the family and then ultimately into our school systems. By doing this our approach is to be a known resource within our community both locally, statewide and then accessing all of our friends and collaborators and partners across the -- our country and beyond.

>> Next question for each. What interorganizational collaborations are required for your project, and if you could specifically speak to any involvement that your states have with Maternal and Child Health program and your departments of education.

>> Okay. Well, I'll get this one right off the top. I will say that we need -- we know we need to do better with our statewide Maternal and Child Health collaboration and that's part of our goals. We always say our project is a work in progress. We've been carrying the torch since the year 2000 proudly and there are areas that we know we need to do better and we're working towards that. But what our collaborations and what we are doing effectively

is we work closely with the Department of education, the Division of special education, as I have stated earlier. They are part of our funding source for this project. And it is ongoing. Our local school systems allow teachers to attend the trainings and to participate as resource team members and there again across the state we've been able to secure this wide range of participation. And I will say we had the pleasure of having one of our educators who was a resource team member from one of the counties attend the leadership conference this past March -- or April, I should say, the end of the month, along with me to actually see how our program is doing, where we are now and how we can all integrate and support the needs of students. But it was that participation on behalf of the local school systems is really valued and appreciated. The traumatic brain injury program, is our grant recipient and we collaborate with all of their programs in particular the brain injury service coordination program. Our children grow up to being adults with brain injuries and we collaborate on a daily basis, sometimes many times a day within our traumatic brain injury service coordination program. The TBI program in Tennessee has eight service coordinators that blanket the state covering all 95 counties within the state. The Tennessee disability coalition provides a home and administrative oversight of our grant and the Tennessee hospital association has a representative on the traumatic brain injury council and have agreed to assist in developing linkages between the hospitals and school systems. The Tennessee association of school nurses, they are very familiar with our project and they've incorporated some of our resources into daily happenings within the school environment itself. We collaborate with the brain injury association of Tennessee, with the families and with the brain injury association of America. We also collaborate with the Centers for Disease Control and prevention and another unique collaboration we have is with the Tennessee family voices, which is an advocacy organization within the Tennessee disability coalition who advocates on behalf of children with special healthcare needs. We also collaborate with a steps program in Tennessee,

the support and training for exceptional parents program. One of the relationships that came about as a result of my interactions with the family voices team is my relationship -- my introduction to and now how I serve on the committee of pediatric emergency care known as COPEC. This organization is responsible to the Tennessee Department of Health for coordination and implementation of the Tennessee emergency medical services for children programs.

>> Primary to getting brain steps up and running, it was -- it's being run by the brain injury association of Pennsylvania, who I'm employed by. And also we needed to get the Pennsylvania Department of education partnership right in the beginning because again our funding comes from the Pennsylvania Department of Health Maternal and Child Health Block Grant but without the Department of education's partnership in this program, it would be very, very difficult to help students in schools. So luckily we were extremely lucky and we set up a meeting right off the bat with the director of special education for the State of Pennsylvania and three of us went and met with him, presented a presentation and he said, you know, this is something that the needed in Pennsylvania. Let's do it. So he was very instrumental in helping us begin our program. Now, some secondary collaborations to get the program brain steps up and running were we needed to make all of our connections and partnerships now with the individual educational intermediate unit regions. So we did that. We also needed to make connections with all of the pediatric rehabilitation centers or any rehabilitation facilities in the state who saw children. We partnered with hospitals and one of the most beneficial referral programs thus far has been with the sports medicine programs throughout the State of Pennsylvania who utilized the impact percussion program. We found that creating a partnership with these doctors and neuropsychologists seeing students with concussions on a daily basis who return to school and have problems at school for, you know, several months, sometimes longer in

5% of the cases it can be a lifetime. There was a lot of education that needed to be done in the schools on the fact that a concussion is a brain injury and a concussion does cause changes in altered -- altered memory. So it was -- we had to overcome that challenge and we are overcoming that by having teams present to sports trainers and PTO associations, simply on what concussions are and signs of concussions. But the referrals that we're getting from the clinics who use the impact concussion program have just been great because these are doctors who didn't have time to go to the schools to fight for accommodations for children who really needed them because of their concussion. They have another venue. We are there and can help do this for the children and their families.

>> What is and what has been the role of your statewide TBI advisory boards with these projects?

>> Well, our Pennsylvania statewide traumatic brain injury advisory board was very integral in identifying -- (No audio for captioner)

>> The Pennsylvania Department of education Division of special education for their partnership to move forward. The advisory board in Pennsylvania is always a wonderful resource that I turn to when looking for presenters and family members to be part of our team.

>> One particular traumatic brain injury advisory council member at that time is and has been credited with conceptionalizing the idea of project brain. This council member has an educational background and this was something that came up in discussion between she and the council -- other council members at one of the meetings which eight years later I think it's really remarkable to have that input. But the statewide advisory council certainly

has a vested interest in this project and the success of serving our students. The advisory council members constantly have been asked to serve on planning committees for a variety of reasons within our grant for our grant applications and for other activities within our grants. Project B.R.A.I.N. staff is Jennifer Raymond and myself that cover the state. We make regular progress reports and updates for the Tennessee disability organization as well as the Tennessee traumatic brain injury program and the advisory council members. The council members are encouraged to make suggestions and provide guidance in our program development. I don't want to say we use such an evaluation but because they're so integrated into our daily activities, we welcome their feedback and vice versa. It is a very good longstanding relationship.

>> Our next question we'll start with Paula. What is your evaluation plan and what information and data is being collected and how will this be used?

>> Our evaluations are done through session evaluations. The review of the evaluations after we presented a session, we sit there and we revise and edit and take their input, participant's input and we listen to it. By that I mean one of the things that has been brought to our attention was many times educators felt like they didn't necessarily need to have training on educating students with brain injury and we found that the presentation style, the information was great, but being presented on the basis of in a format where the school system has now identified this student as having special needs, that of having sustained a traumatic brain injury we're all called in as resources, I want to say on the fly, whereas we've been able to take that information from our session evaluations and turn it around and now we present many times as an invited presenter for their back to school training sessions. It's more of a staff development tool as a proactive measure instead of in the immediate and that's one way we've been able to address from our session

evaluations. A lot of this information is difficult to actually -- the concept is difficult to measure. We do know that we're measuring the improvement in knowledge in the education by the evaluations of training sessions. And we know this because of the word of mouth of how the project resources and availability of these resources is getting out. And we're experiencing more invitations within the healthcare community and school systems and community organizations to bring us in to present, to be part of their next event, to be part of their staff development. The distribution of our materials is being implemented as handouts. Sometimes as I mentioned the word of mouth when we present our partner's program to our healthcare community, it's oftentimes the nurse that is preparing just in simple conversation with a family while they're in that -- in the exam room allows an opportunity to begin educating the family on the resources that are available and things like that we have really seen the healthcare community embrace and the families are relieved to know that things like this are in its place because of the lack of communication that they have received from early on. So we're compiling all of it but that type of measurements, if you will, have been very hard to document. But we just -- we take great notes.

>> The brain steps program, there are two main things that we want to evaluate. That is we're hoping to measure an increase in knowledge about brain injury and how to help children in the schools so we want the people attending our trainings to increase their knowledge about brain injury and its impact on the school. We also hope to demonstrate an increase in the number of children with traumatic brain injury correctly identified in the Pennsylvania public schools and ensure that their educational success is ongoing. To do that we use many different data collectors to demonstrate these outcomes. First, prior to attending any of our training sessions, each team member must take an online pre-test. And then after they attend the training they have to take an online post-test and that data

is all tabulated. At the training session each team member must fill out a three to four page detailed session evaluation. From that, we monitor and go back and we revise our program, we revise our next training based on the immediate feedback that we're getting from the evaluations. I also monitor the team through ongoing program evaluations with the team leaders. Each of our teams has one team leader designated. The team leader essentially is someone who ensures that when referrals come in with students someone from the team, whoever can, one, two, people, is taking on that case. So they kind of keep things together when I can't be there. And the team leaders, they meet with me monthly during conference calls and during these conference calls they are set up for brainstorming sessions. Also needs assessments are conducted to ensure that update training focuses on areas the team feels are important on their needs, what they need to know. The brain steps trainings and program are continually adjusted based on these evaluation methods. We'll also be looking at the Pennsylvania Department of education's special education TBI data roster numbers. Now again, like I said earlier, our program ensures that children with all brain injuries, all acquired brain injuries, traumatic and non-traumatic brain injuries are serviced by our team. Brain tumors, strokes, car accidents, we include everything but what we need to do is in Pennsylvania, the special education definition, they have adopted the federal definition which does not include acquired brain injuries, just traumatic brain injuries. That's the easiest thing right now for us to tabulate is the TBI numbers. Children who have things such as brain tumors and aneurisms, non-traumatic brain injuries if they need special education services those would fall under OHI under the individuals with Disabilities Education Act classification. Each team member is also required to fill out and turn in to me on a quarterly basis student consultation forms and presentation logs detailing their brain injury workload. We got this idea from Kansas. They do that there. And it has been working very well so far. So we know how many students each team member has seen that quarter and also how many presentations

they've given out in their region whether it's the PTO, school districts, administrators and how many people attended those sessions. Now each team member is provided with a thumb drive that has a Power Point presentation geared specifically for Pennsylvania students and they are expected to go out each team member and give this presentation at least twice in the coming year. The overall data for each area that I just discussed will be used to demonstrate the absolute need for this type of brain injury school reentry program. The Department of education in Pennsylvania and our goal is for their continued partnership and support as the years go on.

>> For each of your programs what are the plans for long-term sustainability? Paula.

>> I just want to touch on something that Brenda just said. I was reminded of technology, which is part of our long-term sustainability plan and I think it's amazing when Project B.R.A.I.N. started our training modules were in a format with a VHS tape. We had the overhead slides, transparencies, thank you, and now we are DVD, we're doing webcasts, we have a lot of resources available on -- that are accessible from websites so I think that's a huge component in program sustainability and information dissemination as well. The traumatic brain injury program financially could support the project at approximately $100,000 per year depending on the availability of the traumatic brain injury fund. We will request continuing funds from the Department of education, Division of special education. Currently we have been for several years now receiving $50,000 per year and $100,000 of our grant is from HRSA. So we have a cumulative, $150,000 budget that we have set. We have sustained it the last few years but we would anticipate to present a proposal to the Department of education, Division of special ed. in Tennessee to increase those funds to perhaps $75,000 per year to $100,000 per year and our goal, we would love to then again have a third resource specialist in the west Tennessee region. Other ways of sustainability

will be through various products and materials as I mentioned a few minutes ago and their accessibility to folks in different formats as well. Early on and still to this day the development of our resource teams was seen as a component of sustainability. We have not only a financial need but we have recognized the need for infrastructure both financially and programmatically, if you will. We need to educate society. People need to know and to understand and be able to identify that there is a need and then I feel for sustainability it will be one of those, we'll close the loop. We'll be able to educate society by having our resources and materials accessible and presented in a fashion where they are out there and people openly communicate about and discuss traumatic brain injury. I feel this is a huge component to long term sustainability as an independent child within brain injury and then the programs and systems change components will complement that as well.

>> Brain steps is funded by again the Title V Block Grant through the Department of Health. We hope to sustain that through the Department of Health to continue our program indefinitely. We envision the first two years as building the infrastructure phase to build all connections, to sustain our program moving forward. With continued ongoing direct consultation from myself and continued update training, each of our teams are really being set up within the Department of education's special education unit so they can self-sustain over time with our continued support. As a regular part of the team members' workload. Year three and beyond will focus on consultation and update training for teams, replenishing team members due to attrition and continually offering update training. On brain injury. There will also be a gap analysis to see where besides the public school sector, which is what we focused on the first initial two years of our grant, to see where else teams may be needed such as private schools, lab schools, homeschool groups or cyber schools, Internet schools.

>> Paula, as you've mentioned, Tennessee's TBI lead agency is the grant recipient. What staff is actually needed to implement the project?

>> Okay. The Project B.R.A.I.N. has currently two full-time staff positions, one is the project coordinator, that would be me and I'm responsible for overseeing and implementing the project and supervising one regional specialist. The TBI program oversees and monitors the overall program and the director commits 5%, I'm sure it's a little more if we're calculating, approximately 5% of their time for the project. The service coordinator is a component of our management plan serving as coordinators and links to our students throughout the hospitals, the families and the school systems ultimately.

>> Brenda, you told us the brain injury association of Pennsylvania implements this project through funding from Pennsylvania's Maternal and Child Health Block Grant. What staff is needed for you to implement this project?

>> The brain injury association of Pennsylvania hired me as the full-time employee as the program coordinator to develop the program and train the teams, find the teams and establish everything. We also have one part-time program manager who oversees the brain steps program and we have a steering committee with board members who are voluntary, all volunteer, they meet with us every week to determine next goals and problem solve.

>> Okay. Now before we go to the questions and answer segment we'll first discuss challenges and lessons learned. Paula, what are challenges and lessons learned for other states looking to replicate your project?

>> Challenges and lessons learned. Lessons learned is that we truly drew upon the expertise and the strengths of the TBI community. Not only in Tennessee, but across our borders. So that we weren't spending time reinventing the wheel, as Brenda alluded to earlier. That's valuable time. We also recognized the foundation of our actual project from earlier on in the development and we expanded on those. That was a huge lesson. We learned that when our -- we got to the point where our reputation preceded us, that was a valuable tool in opening doors. We had approached the Division of special education specifically for funding and when we arrived dressed in our business suits with all of our papers and information and ready to go, we were warmly received and the opening comment was they would be proud to be partners with us and to support in part our funding for our resources due to our reputation that the assistant commissioner had heard about us from the folks in the educational field. So that in itself was an unbelievable lesson learned that it's really important to go back there and nurture these relationships. We have been consistent with being out there in the community. We learned and we continue to learn the importance of the working infrastructure within our healthcare community. It's similar to the school system but it's quite unique where we're not able to yet have a real chunk that we can do systems change across the board of how to implement this in all of our hospitals. But we wouldn't have known that had we not gone through all of the process and relationship building that we have been doing. The -- we have realized that partnerships and relationships are the key factors in successful implementation of all of this. We graciously acknowledge and value the input from all of our professionals, however the specialty lies within the families and the students themselves that are living with the aftermath of brain injury. And I guess my last comment is that we need to be patient and flexible in our thinking. Systems change does not happen by 5:00 in the afternoon. It takes time to develop these resources and collaborations and to maintain that

and it also takes money. But we need to be flexible and patient when the phone calls and we are interacting with an individual who is distraught and emotional. There are factors that sometimes you can't put down on paper but are a huge component of what this is all about and what we're here doing. My final note is that I had recently been at a presentation and the speaker made a comment about collaborations and partnerships and as I was preparing for this webcast it really hit home as I was doing my research for this and that collaborations mean we work really nice together. But partnerships, establishing effective partnerships mean we work towards outcomes with shared responsibility. It is all of our parts. We all need to partner in providing all that we can to support the needs of students with TBI.

>> Some lessons learned. We learned a lot of lessons. Our program just started this past September. We've accomplished a lot this year through our brain injury association of Pennsylvania, but we have learned some lessons and first of all I would say begin recruitment -- if you're going to do the program begin recruitment of your term in the spring prior to fall training. Follow the school time lines since that's a easiest thing to follow with educators and it's very important if you pull up the article that Heather will have linked to, the building capacity of educators, a regional team approach. There is a time line in that. Follow that time line. It is there for a reason and it will make things go very smooth. The second thing is to hire a full-time -- at least one full-time dedicated coordinator with a passion for the educational aspect of brain injury. You cannot hire someone for this position who wants to work 40 hours a week and be done with their job. It is so important. If I had -- who would have known 20 years ago after my brother's accident this was my purpose in life. It is and I'm so thankful to be doing this job and making a difference in Pennsylvania and I hope there are people out there in every state, I'm sure there are, who have just as much passion for this type of work that can do this program in your state.

Also it's important to consult with other states who currently have brain injury school reentry models in place and conduct site visits. Advertise your teams. Establish your partnerships with rehabilitation centers and hospitals, let them know who you are and that you are available and how they can contact you and you have to do that more than once because there is such a turnover in hospital staff sometimes that you always have to be continually updating that. Making the initial case in the beginning of your program to medical rehabilitation centers. It's sometimes difficult because they do not understand their roles really within the educational system. So getting their facility buy-in is key from the very beginning. Each state is challenged to figure out their state's own structure beginning from the top down, I suggest starting with your Department of education, your Department of Health, start high to get their buy-in and once you have that it opens doors, so many doors. It just really works. And one likely challenge is you will need to gain a thorough understanding of your own state's Department of education's infrastructure and framework to understand how to best create the teams in your own state. Now, we were lucky in Pennsylvania because it was already easily divided up into 29 regions for us. So that was an easily accessible resource for us to tap into. So it's important to figure out your own state, do the homework, get the statistics before you set up your meetings with any departments and then go from there.

>> Thank you. Just to reiterate the resources that we keep alluding to are available at mchcom.com. Click on the link for this webcast and navigate to the download handouts to those links. My phone number is on that if anyone has any needs in the future. Now we will look at some questions. Everyone feel free to ask questions now. The first question since traumatic brain injury can possibly be caused by brain tumors and they're removable are those children factored in as children who may need a diagnosis to receive education at school in the revised education plan?

>> The first thing that came to mind as I mentioned before is to use -- to find out the definition that your state is going by. But with the IDEA, the individual Disabilities Education Act it clearly defines an external physical force. We need to take to educate our doctors so that we can use the word traumatic brain injury from the point of injury. And maybe they have to write a paragraph in that diagnosis but maybe they'll have to do something like that to incorporate all of the appropriate language so that that child is then able to receive the special education services that they're trying to access faster, get those services moving earlier on.

>> This is a huge problem. These children who have non-traumatic brain injuries such as tumors, strokes, aneurysms, they're experiencing the same effects as children who have traumatic brain injury from external forces. The effects are the same. It's easier if we could include them under one definition for special education purposes rather than confusing the teachers and everybody and lumping them in the non-traumatic brain injuries with other health impaired. Depending on what state you're from it is important to check your special education definitions and see exactly what that says. Each state is different. Some adopt the federal definition which does not include non-traumatic brain injuries and other states have adopted their own.

>> We just want to be cohesive with the language to get the services necessary for our students.

>> Our next question, from a physical therapist from Kent intermediate school district in Michigan serves as the coordinator for the traumatic brain injury transition team that

provides the services you've spoken of in your presentation. The question is how do you find having people receive all the training that you talk about?

>> Special Ed. students needing physical therapy in addition to the job as the coordinator it would be very difficult to find time to provide all of the educational opportunities.

>> Well, I can answer that from our standpoint. In Pennsylvania, we -- I guess we've been really lucky. We have had -- each of our teams have between one to three medical rehabilitation therapists serving as the team member on each team. And the medical rehabilitation centers have agreed to let them come to our trainings. We try to hold our trainings regionally so they don't have far to travel. But I think they might have had to travel two hours at the most. But the rehabilitation centers have paid for travel, have paid for hotel expenses. That has not had to come out of our budget. Now, for team members, for instance, if we utilize the expertise of a physical therapist from a rehabilitation center who serves on a team, we have funds available to pay for that staff person's time to serve as a team member. Now on the other hand, they have donated a lot of their time also. It has just been right now we haven't had an issue with -- with funding. Knock on wood.

>> What we've experienced is we try to present all educational opportunities and sometimes I call it advertising. We have to market and get that information available to them. We send out emails, we encourage folks to sign up and to be part of Tennessee's traumatic brain injury listserv program which we post all of this information. We do distance learning training so when anything like that comes up, that allows for an educational setting, a school teacher where I'm always reminding everybody that is doing or coordinating an upcoming training event is to appreciate the fact that teachers, you either have -- they have to take out a whole half day, get a substitute oftentimes for a

whole half day of training or a whole day. So you want to make sure that your window of opportunity for learning also recognizes their travel time. Which is why distance learning is really great. That will be able to keep them in their classroom within their school system and be able to log onto events such as this. The other piece that we try to do is bring our project and our training to their type of educational forums. Whether it's a healthcare forum or conference. We present as presenters and the same thing with our educational conferences across the state and we really target statewide conferences. Your school nurse association conference, your special education conference, this year in Tennessee I believe there were over 1400 that attended that conference that we were actively a part of.

>> Those are all the questions that we have this afternoon. I would again like to thank Brenda and Paula for participating today. It was fabulous information. Please fill out your evaluations. Feel free to contact me, Heather Crown at the TBI Technical Assistance Center. I can leave you with Brenda and Paula if you have any further questions for them and for any more help and resources. Thank you very much. Have a good day.

>> Thank you.