

## **Traumatic Brain Injury/Brain Injury Association of America**

### **2006 TBI Grantee Orientation Webcast**

June 29, 2006

JANIE MARTIN HEPPEL: Good afternoon, everyone. Welcome to today's webcast. We're broadcasting live from Maternal and Child Health Bureau conference room in sunny downtown Rockville, Maryland, where from Sunday through Tuesday of this week we got close to 14 inches of rain, sometimes coming down two inches in an hour and even though some of us have soggy basements, we're at least out of our prior drought status. I hope it's getting drier where you are, too, if you've been through some of this weather with us.

I'm glad the rain subsided enough to allow Carolyn Cass and Anne McDonnell to get her to be with us today to talk about the recent very important work that our evaluation workgroup has been doing. We also have Eugene Tom to talk us to about reporting the Ken and Sandy from the technical assistance center will be talking about what is available from the center. Later on I'll take a few minutes to talk with you about our program priorities. Before we get into that, however, I need to review with you some basic information about today's webcast that you'll need in order to get the most out of it.

First of all, slides will appear in the central window and they should advance automatically. The slide changes are synchronized with the speaker's presentation. You do not need to do anything to advance the slides. You may need to adjust the timing of the slide changes

to match the audio by using the slide delay control at the top of the messaging window. 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 the speaker from the dropdown menu and then 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 periodically throughout the broadcast. If we don't have the opportunity to respond to your particular questions during the broadcast today, we will email you afterwards. Again, we encourage you to submit questions at any time during the broadcast. We think what we're going to attempt to do is after each speaker or group of speakers, take some time for them to answer questions that have come in pertaining to what they've said. However, if you think of something later on, go ahead and send in a question and we'll try to allow time at the end for more questions.

At the left of the interface is the video window. You can adjust the volume of the audio using the volume control slider which you can access by clicking on the loudspeaker icon. Those of you who selected accessibility features when you registered will see text captioning underneath the video window. At the end of the broadcast, the interface will close automatically and you'll have the opportunity to fill out an online evaluation. Please take a couple of minutes to do this. Your responses will help us plan future webcasts and improve our technical support. Now at this point I'm going to ask Eugene Tom to tell us the finer points of reporting which I hope some of you have begun to get into.

EUGENE TOM: Thank you. Good afternoon. My name is E.J. Tom and I'll go over with you the post award process and the electronic handbook system. My understanding is most of you are first year grantees where you haven't been in the system before so I'll go over that with a series of screen shots of showing you how to register and go through the process itself. Keep in mind that a lot of the screen shots may be small on your screen and you may not be able to read a lot of things. Just keep in mind it's to give you an idea of what the interface looks like as you're going through it. Next slide, please. All individuals require access to the post-award report will need to register in the system. The registration process is a two-part process where you need to create a user account and associate your account with your organization by using your grant number. The web address for the electronic handbook system is grants.-- as you can see below there is a screen shot of the login screen. If you haven't registered before click on the left-hand side click on registration by the red arrow.

If you've registered before click on the login link and type in your username and password to log into the system. The registration process itself is two steps. The first step is where you would enter in your name, username and password, address, phone number, email address and so forth. On the bottom of the page is the screen shot that you see here where you would select your role in the electronic handbook system. The three roles are authorizing official, business official and other employees. The authorizing official is the individual who would sign off on grants on behalf of your organization and also with that role the authorizing official has the ability to edit the address for your organization in the system as well. The business official is the individual that would handle financial matters

for your organization such as the financial status report. Any other individuals or other employee who include individuals such as project director or any other data entry staff. On the bottom is where it will ask you to enter your grant number. It's very important that you put your grant number into this field. It will help the system pull up your organization in the system so you can associate your account correctly.

This is a screen shot of step two of the registration process. As I mentioned before when you enter in your grant number the system will automatically pull up your organization for you. You would simply click on the add me to this organization button as shown by the red arrow in which case it will post your organization correctly. Do not use the registered new organization on the right. Click on the add me to this organization button. Upon successful registration in the system you would log into the system. The first step as the project director would be to add your grant to the portfolio in which case you would click on the add to portfolio link as indicated by the red arrow. As I mentioned the project director must add the grant to the portfolio in order to access post-award activity. By adding themselves they would have the ability to approve privileges for any other users that need to access the post-award report. Project directors will need their notice of grant award as they're completing this notice of grant process. Once they've done that they'll see this screen in which case they'll be asked to enter in their grant number and there are two roles within the grant portfolio. One of them is the project director which I'll be going over with you in the next series of slides. The other role is other, in which case those are other individuals such as data entry people or business officials that need to enter in any data for the budget. Keep in mind that the other role is not as in depth of adding it to the portfolio as

what I'm about to show you for the project director. As I'm going through, this is solely for the project director.

This slide here shows you the next step after the previous slide that we were on in which case it is validating the identity of the project director in which case it matches the name that you registered under with the name that appears on your notice of grant award. As final verification this system will ask you for the issue date and the CRS-EIN number located on your notice of grant award which is why the project director will need it going through the process. The issue date can be found on box one of the grant award and the CRS-EIN number can be found on box 18. Upon successful validation for the project director you'll see the screen that you've added it as a project director. After this step you can go into the grant award portfolio to access your award activity. Simply click on the portfolio. You only have to add the grant to the portfolio one time for the life of your grant. After you click on view portfolio it will pull up a list of grants. All grants that have been added to the portfolio under your account. In this case project director. It gives you information about the project period, budget period, who the project director is, grant contacts and so forth. To go within the grant portfolio you would click on the view/manage on the right-hand side.

On the next slide that you have here it takes you within the grant portfolio in which case as the project director you would have the ability to access the previous Notice of Grant Awards for your grant back as far as five years. Also within here the project director has the ability to have privileges for any other people involved in the grant portfolio and they

would click on new users. Once they've approved a user once, if they need to add, edit or remove privileges for other users they would click on existing users. To access the post award report they'd click on performance reports on the left-hand side as shown by the red arrow. The next slide is just basically an overview of what I just covered for the grant portfolio in which case you would access to Notice of Grant Awards from the past as well as having access to any other post award reports that are required. And to access that you'd click on performance report. After you click on performance report, it will pull up for you the next screen which will give you information such as when the post award report was originally available in the system as well as the due date and the period in which you are reporting.

To begin the report on the bottom of the rectangle or box you'll see a link that says start report. If you click on start report, it will take you to the program specific form main menu where it lists for you all the forms required of you for your post award report and shows you what forms are complete or not complete. It is broken down into two parts. Financial forms and program forms. The financial forms are form one, four and form. To access these forms simply click on the update link on the right-hand side under the action column. You click update on these particular forms this is just an outline of what I just mentioned about how it was broken down.

The next slide here shows you form one. Form one allows you to enter in budget information, line one is the grant award amount from your notice of grant award. Line two would be for an obligated balance. As first year grantees you would not have an

unobligated balance so you could leave it at zero. Line three allows you to enter in matching funds. Line four other project funds are not relevant to your grants. Those are not data entry sections. Line five is basically a total of lines one through four which is read-only. You wouldn't be able to edit that. Line six is where you may enter in other federal collaborative funds. I would like to mention on the top of every form there is an instruction link and a notes icon. If you were to click on the notes icon it would open up a pop-up window to enter any comments to explain any data you entered on any particular form. Also the instruction link allows you -- gives you information about particular fields on a form so if you have any questions about a particular field or how to complete the form in general I would advice you to click on that link. On the bottom of every page there is a cancel button and a save button. If you click on the save button the way you'll know the system saved your entry, it will take you back to the main menu. That's how you'll know it stayed correctly.

There is a time-out timer in the system which is about 30 minutes. I would highly advise saving it otherwise any data you don't save within the time-out timer will be lost. This slide shows form two. Again as I mentioned every form has an instructions link and notes icon on the top of every page. In this particular case this would be for FY 2006 as your application year in which case form one was for FY 2006. Read-only. Since it is read-only if you need to edit any of the budget for 2006 you need to go back to form one and make modification. For future years, FY07 and 08 you can edit the budget for lines two, three and six and you have the save and continue button on the bottom. Form four again as you notice there is an instructions icon. When you click on the note icon for a form those notes

are specific only to that form. Form four allows you to do a breakdown of your budget based on services. Also on the forms you won't be able to save if you leave a particular field blank even if it's zero. You must enter into a zero or it will give you an error message. This shows you as you're going along the main menu will automatically update showing you what section you have completed and whenever you save it will take you back here and how you know it saved successfully.

Form six also considered your project abstract. This form itself is rather lengthy because it asks a lot of information such as goals and objective. Project description and so forth. Due to this fact as I mentioned earlier about the time-out timer. What we normally advise you to do is in advance you can open up a word document and enter text for each of those corresponding fields ahead of time and log in and copy and paste in the appropriate fields and hit save so you don't have to worry about the time-out timer. Form seven is another field where you would enter in project summary data. Also on all these forms anything that's required of you is marked in a red asterisk.

This slide shows you the form status checker. The form status checker shows you progress on each of the forms and whenever if you are having problems saving a form, you can always click on the form status checker link on the left-hand side on the main menu and it will give you a detailed description of what is missing off that form that you can save as shown in there by the errors column. Then you can always use on the right-hand side the update link to go to that form and take the modification. Upon successful completion of every section you can see the screen where you'll see click on the go to

button to proceed with submitting your post-award report. If you were to click on that button, it would take you to the following screen which look similar to what you saw before when you initially started the report. This time you'll see a submit report link on the bottom of the rectangular box with all of your summarize grant information. If you click it on you'll see prompts to confirm you want to submit and you'll screen this here. In which case you can print this page for your records. Also on the left you see there is a view/print version link where you click on the link and print out a hard copy of the report. A couple of key things to know is that you must associate your user account with your organization by using your grant number. If you don't use your grant number you will have difficulty finding your organization in the system to access your post award form. When the project director is adding the grant to their portfolio the name on the notice of grant award must match what you register at. That would include any spaces, commas, periods, degrees, etc., after the last name and as a reminder every form as an instructions link in which I would advise using that if you have questions about a particular field or how to complete the form in general. For any assistance with the system itself you may call the HRSA call center. They're open Monday through Friday, 9:00 a.m. to 5:30 p.m. eastern standard time and their phone number and email address are provided on this. Thank you. Back to Janie.

JANIE MARTIN HEPPEL: Thank you, E.J. and remember if you've got questions, send them in. I don't think we've actually gotten any yet but throughout the broadcast you can send in your questions. Next we're going to hear from Carolyn Cass and Anne McDonnell about our evaluation workgroup. Before I turn it over to them, I just wanted to say a few words about this group. The group as a whole has been working since last August 2005.

Unfortunately, the Institute of Medicine evaluation didn't notice that we had begun to meet as a group but we have and that is part of the response to the IOM recommendation that we develop more of an evaluation culture in HRSA with regards to the TBI program. We had actually already begun that a little bit. The workgroup was waiting until the release of the IOM report to convene again. They wanted to see what IOM had had to say about the program and then continue their work. And they did that. They met again in May and what Ken sent out to you, I think yesterday, are some of the results of what they've come up with and we have been getting your responses and I think that Carolyn and Anne will probably try to respond to some of your questions.

We had two goals ahead of us when we first met in Chicago. One was to try to find a more PART measure. PART is another one of our government acronyms that stands for program assessment rating tool. Two years ago the program was evaluated by the Office of management and budget. We received a PART evaluation and they said results were not demonstrated for the effectiveness of this program and one of the things that they counted against the program was its failure to have a measure with a defined personal health outcome. I think we know how difficult it is. Carolyn will be talking specifically about that. And Anne is going to be talking more about our second goal, which was to find program measures that would be really useful to you in running your program that would show you how well you were doing. That would not just be useful to the government for the purpose of counting numbers and seeing quantitatively what you had done but actually would be of some use to you. I think they've done a good job in coming up with those. Without further adieu I'm going to turn it over to Carolyn.

CAROLYN CASS: Thank you. I want to thank Janie for this very special opportunity that I've been given and I think Anne and I are very pleased to be here to work with you on this. I'm going to give you a little bit of background because I think perhaps when you first review the material that Ken sent out you had a reaction very similar to that of the workgroup. I think it took us quite a little while to sort of get over it and get on with it. And so I think we struggled with the same kinds of issues that many of you that have written in with comments and questions struggled with and primarily that relates to personal health outcome was not what we were asked to really work on with our grant. I think from our perspective the TBI grant really focused on systems issues, coordination issues, infrastructure building issues, and yet OMB was asking us to come up with a measure -- an outcome measure to really look at personal health outcomes or significant changes in health status. So I think it really did take us quite a bit of time to work through all of those issues and I think we tried stubbornly to tell Janie, go back and tell them we can't do this and she did that and then she came back and said I'm here to bring you news. We need to come up with a PART measure. So we set about our task. I think where we really ended up in trying to identify a measure was to come up with something that would be useful for us as grantees. Not just something we could report to HRSA and say we had done it and then go back to our regular routine. Really, our goal as grantees is to demonstrate we've made a good faith effort to produce results that are acceptable and ultimately to be able to demonstrate that our programs are effective and that we should continue to be funded.

Our charge was to develop a way to measure a change in a personal health outcome. And I will tell you that the folks that were on the workgroup were extremely bright. People that have had a lot of experience in looking at these kinds of issues. And so we wanted to try to identify a measure we could actually use. One of our struggles was also to identify a measure or a way to demonstrate the results that all states and all grantees could come up with. So we kicked around a lot of ideas. We had actually a lot of great ideas that are in the wastebasket now because Janie would say well those are nice and good but I don't think that's what is being looked for of us. So I think Anne gets to talk about some other ways that we can measure some of the things that our grants are actually doing. What we finally came up with as an agreement and a consensus was to look at the measure of improving the functional health status of individuals with traumatic brain injury and looking at whether it's remained stable or improved.

Next slide. So what you're looking at now is functional health status of individuals with TBI and what we came up with were a series of four proxy questions, if you will, to try to get at a general understanding of how we could assess the health status of individuals. We were really looking at the health and well-being. Not just physical health. Obviously there is a lot more we want to look at and try to understand in terms of someone's health status and we see it as being made of social, emotional, physical, many components. We tried to come up with four questions to get at the issue. The first one was asking individuals to respond to questions about how they would rate their physical health. And what we decided to do as a way to make scoring easy was to come up with a five-point scale. On the first question how would you rate your physical health our scale would go from poor to

excellent with markers in between of fair, good and very good. Our second question tries to get at the issue of an individual's emotional well-being. And again we use the same rating scale for that beginning with poor, ending up with excellent and again markers of fair, good and very good as the in between markers. Then the third question again all trying to feed into this issue of functional health status, we came to some consensus around a question that would get at an individual's ability – next slide, please.

To get at an individual's ability to meet his or her daily needs. This would include any assistance that the individual is actually receiving. Again, here the rating scale would go from poor to excellent. We had quite a bit of discussion about what we were actually trying to measure with this question. But in terms of, you know, how well an individual is able to do the things that they want to do in his or her life is important in terms of health status, in terms of emotional well-being. And the last question, the how satisfied are you with your social life, we used a somewhat different rating scale beginning with never satisfied to rarely satisfied, sometimes satisfied, usually satisfied and always satisfied. So as you can see each of the four questions has a five-point scale and I think after some discussion the workgroup felt that if someone rated -- gave a rating of a three or above, that would count as, I think, stable or improve when we do the clustering of scores. So those are the questions that we came up with. The idea of this is that we would come up with a baseline that would be reported to HRSA in 2007 and then in each year we would report data and then HRSA would take that data and assess sort of holistically how the program is doing in terms of improvement in functional health status. We had a lot of questions that we wrestled with, just to let you know. They're very similar to the ones that you've sent in. I'll

sort of go through things that popped up when we were meeting. The big one is okay, who is paying for this? How are we going to do this? Who are we going to survey? Will there be technical assistance? And again, we kept going back to the, but you know, Janie, that we can maybe do this but this isn't really tied into what the goal and the purpose is of our grant and she continued to say yes, I know. But it is important for us to take a look at what we can do to demonstrate results.

In terms of the who is responsible for the data collection, each grantee will be responsible for reporting the data that we've collected to HRSA. How each state may go about that will vary. In terms of how we can pay for this, we are able to use our grant funds to do this. I think as we sort of talked about this, part of our job thus far has been to develop partnerships, look at where we can leverage existing resources and so I think for some states who have done some of that work, you will find that there are partners from whom you can draw to help with this survey project. It is not intended to be something that perhaps we will publish in the "New England Journal of Medicine", although I think it would be a good end goal. We do know this is our first attempt at coming up with a survey that will yield results and measure that is acceptable to the Office of management and budget. So I think we understand that there are going to be some limitations in terms of the scientific value and perhaps validity and reliability issues. Our first effort needs to be around showing a good faith effort to come up with a measure. So I think there will be a lot of questions about what do the results actually mean. I think that will be some ongoing dialogue that we'll continue to have. We've been assured that technical assistance will be

available to us as we sort of move forward with this project. And I think we can all put our heads together to think about states that have already done surveys of this sort.

Looking at the other questions, some of us may ask gee, is this the real measure that we're going to have to use? Is this the final measure? I think we want to have it be as close to final as we can be because Janie has to take it back to the PART people. We all wanted to see what the PART people looked like to get a handle on these folks. So Janie will have to go back and get final approval for this measure. So our goal is to come as close as possible to get Janie something strong she can take to get approved for us to move forward.

JANIE MARTIN HEPPEL: Thank you, Carolyn. While you've been talking we've had a couple of questions come in and I'll just read them so you can all be aware of them. This question on the PART evaluation we received by email I wondered if you had considered including information on satisfaction with employment status.

CAROLYN CASS: We. I can tell you that is not one we specifically talked about but certainly in terms of looking at health and well-being, that's one that we might want to go back and take a look at.

JANIE MARTIN HEPPEL: Okay. Another one came in, who do you anticipate would be responding to these four questions? What size sample would be acceptable?

CAROLYN CASS: I don't think we've come up with that answer yet. We did talk a lot about how do you even draw your sample, how do you know if you've sampled enough. What we did come up with is that we might use your partners with brain injury association, we might use our providers as partners to help us identify groups that we could survey or places we could put the survey where individuals could access and respond to the survey

>> Thank you. As questions come in we'll get them to Carolyn and then to Anne. And we'll find time at the end to go back and ask. I think we'll go on to Anne now to talk a little bit about the overall performance goal that we have for evaluating your program.

ANNE MCDONNELL: Good afternoon, everybody. Thank you. When Janie asked us to do this, Carolyn volunteered to do the piece. She took one for the team and I want to thank her for that. I got the easy part. From the questions we've been receiving most everyone can get behind the piece I'll talk about today which is the program performance measures. We looked at what all the states were doing. We had asked Ken to prepare for us before we came to the last evaluation workers meeting a grid that showed grantee goals. So we looked at what some of the states were doing. What all the states were doing and what the P & As were doing separately. What we decided, everybody had some kind of collaboration and coalition goal in their grant. It seemed to us that was a natural piece to include in an across the board and consistent measure of program performance. One of the things I'll say about the partnership grant. All the grantees are reporting this stuff in narrative reports but until this point HRSA hasn't -- the technical assistance center hasn't

really been able to wrap their brain around how to get everybody's information together into one cohesive report.

Each state will be able to decide the agencies that they want to work with. Each state will be able to decide which specific goals they want to write and the states will report, along with the narrative, a percentage of the partnership goals they were able to attain during the period of the grant award. Another one that we looked at and felt like every state had some activity around was the issue of public awareness. We picked public awareness not only because every state had some kind of activity that could be reported for that, but because public awareness is such a huge issue relative to brain injury anyway. We felt like that as we see more attention and awareness of autism come to the fore, we've become to see real policy shifts and funding changes for those persons in the autism community and we would like to see that for persons with brain injury as well. If you look at the next slide, the second measure does concern awareness. It's one of those things the grantees have been reporting in a narrative fashion but we're looking to see how we can consolidate this information so each state can look at what some of the other states are doing as a benchmark and we can report numbers and demonstrate the effectiveness of this brand. Each state will be able to decide for themselves how they want to document awareness activities.

We looked at four different audiences, individuals with brain injuries and their families. Decision makers at the state and federal levels. Service providers and the general public. Those tend to be the audiences we look to when we're discussing public awareness. And

the activities that we tend to use for those types of things tend to center around training and education, outreach and information and referral, advocacy and public information. So every state will provide some kind of yes, no, we're doing this, we aren't doing this with some kind of numbers if you can provide them as to how many activities you're doing. How many people you're able to reach. You can use any agency and organization within your sphere of influence. So while the state advisory board may be one of the agencies and organizations you use to create a little bit of movement around these goals, you can also use other state agencies, service providers, it can be a very cyclic kind of thing. And you can also -- there will also be a way that a narrative will accompany that, too. We're looking at some kind of grid thing and a narrative that explains the public awareness activities that you're engaged in.

If you look at the next slide we also decided that we needed to have a little flexibility built into this system as well. We know that the P & As do some advocacy but a lot of it is not -- it tends to fall more in the legal realm, not necessarily legislative and policy advocacy. The P & As while they may be able to report on some partnership and awareness they have some very different activities. Clarice how much from the P & A in West Virginia is working with some other organizations to try to figure out some kind of measure that would be appropriate for them to use. Then we looked at creating a fourth measure and decided probably the best thing for us to do was create a measure that had a little flexibility for the states. So what we're looking at doing is creating something that has different components to it that states may be able to report on and may not be. There may be some states, for

example, that have some goals specifically centered around cultural competence so they could report on that if they wanted to while other states may not have that kind of goal.

We talked about other areas such as the ability to leverage some funding. Data enhancements, being able to document increased number of services. We had just begun to come up with a menu of other types of measures that states report on and this is where, I think, your input is critical at this point because we'd like to know the things in your grants that you feel would be the best areas for you to report on as well. We created a list that had 25 things on it but we haven't decided exactly what those measures will be. I think this is an opportunity for you guys to have a little bit of input into this process. I think one of the most frustrating things, had you not been involved in the workgroup, our frustrations were different, trust me. One of the most frustrating things if you had not been able to be part of the workgroup is feeling like you had not been able to contribute or have any say in what it was you were going to be required to do. I think this is an excellent opportunity for everybody who has an interest to submit an idea for some part of -- for some kind of program performance measure that could be placed on a menu that would be available for states to choose another one or two items to report on. Thank you, Janie.

JANIE MARTIN HEPPEL: Thank you, Anne. I just want to say that the work of the evaluation workgroup will continue. So as Anne just said, please do let us have your thoughts. This is a dynamic process. We've only just begun and we'll be continuing for some time. So with that I'm going to talk to you a little bit about the program priorities for

this year, which are returning veterans with TBI and identifying and assisting children and youth with TBI. As if you didn't have enough to do already, I've asked you to take on some more work and this is effort above and beyond what you're doing with your implementation partnership grants in a lot of cases. Still I'm happy to report that many of you have reported activities in one of these areas. Some of you in more than one. For example, South Dakota's protection and advocacy organization has made presentations on traumatic brain injury at Department of veterans affairs meetings and established contact with three V.A. medical centers and outpatient clinics to provide information about available resources.

Minnesota is home to one of the services five trauma centers for returning veterans. It's not permitting any contact with the soldiers in rehabilitation on active duty, the protection and advocacy organization has been building relationships with the hospital staff in order to get information to the soldiers and their families upon release from rehab. Illinois has established a training initiative focusing on veterans with TBI and so far has conducted two employments rights trainings especially for veterans. Iowa will be reaching out to county veterans' affairs workers by giving them packets of brain injury information on reports available in the State of Iowa. Michigan's outreach efforts include establishing contact at Veterans Administration hospitals, veterans' clinics and rehabilitation centers throughout the state in order to distribute materials and offer training. In New York, returning veterans with acquired brain injury will be a focus as an underserved population for protection and advocacy and veterans are the major focus. They have a history of involvement with homeless veterans and they're building on that and some other

relationships to expand, to assist returning Middle East veterans. Among several activities with veterans in the Pennsylvania protection and advocacy has undertaken is unique one is setting up a roundtable discussion of veterans issues on cable television. There are many more activities in addition to these and other states are doing more things that are right now just in the planning stages.

Similarly, you have been able to do a lot with the children and youth priorities. Tennessee is one state that has a long history of reaching children and youth in hospital and in post acute care to transition to the classroom through its well-known project brain. Their latest edition is a training module called partners in communication, supporting student transitions, hospital to home to school. This is the training piece that can be used by different hospitals in different ways to train current and new staff and can be used not just in emergency departments but by anyone in the hospital who might come in contact with patients with TBI. There is more to the Tennessee project than I have time to tell you here but I will encourage you to check out the product that they've developed and they are all available. Moving away from the individual state activities for just a moment, we also have a children and youth workgroup that has been ably guided by Heather at the center. Ken has said she's under house arrest until her delivery date for her new baby. She and the baby get plenty of rest but Heather is continuing to work from home I see by the many emails I get from her. Children and youth workgroup is developing a portfolio of resources and information for serving children, assisting schools that can be distributed to all other state programs as you work with schools and the school population and also communications have been underway with the state directors of special education to

introduce them to the training materials developed for use by educators around traumatic brain injury.

Most of you are aware of the webcast we had last month that focused on handling students with challenging behaviors. Some of which -- many of which are students with TBI. There is a lot more to tell you about. I don't have time to do it today but I hope to keep you informed of both priority activities through periodic emails and I would like to put some of your accomplishments in these priority areas in future director's spotlights. We have -- I want to say we've been getting questions coming in, more questions for Anne and -- to answer, but I think maybe what we'll do now is go ahead with Ken and Sandy about what is available from the technical assistance center, get a few more questions in and go back and take questions at the very end. Okay. Ken Currier you all know, Sandy Knutson.

KEN CURRIER: Welcome, everyone. I'm used to seeing faces in front of me and just not a camera. If I look for a joke I expect the folks in the room to laugh for me. Because I like it better when you're all here. It is nice to speak to you all out in cyber space. The purpose of this presentation is really for us to go over what the services are of the technical assistance center. Many of you were probably saying we know this already and we can turn off our computers and I hope you don't do that. This will be a refresher. One of the things I tend to like to say is three times for the normal mind and not that you're abnormal but I think we do have new ways of doing things and actually we want everyone to be aware of what we're doing and to use the services that we have. I think we have a lot of good staff and a lot of great ideas and we're trying to reach out to get the ideas from you

folks so that we can mix them and come up with the best sort of solutions to be able to help you to improve systems for individuals with traumatic brain injury. Do tell us what you need and I'll try to get through the nasty part of the mechanics of who we are as fast as I can. So what we're going to do is I'll do an overview of what the contract is with the technical assistance center and Sandy Knutson, the senior technical assistant field specialist will talk about some of the trends that we have seen over the past six years at the technical center.

First of all the contract is from Janie Martin Heppel, no, we're not employees of HRSA. We aren't federal employees. We work for the National Association of state helped injury administrators. It's the third year of our contract and it ends in 2008. We have specific activities we're asked to do. We're asked to provide technical assistance to the states in the protection and advocacy systems. That's led by Sandy, the senior technical assistant field specialist and Amy Horn. They're assigned to each of the states. If you don't know who that is we have that on our website as [WWW.NASHIA.org](http://WWW.NASHIA.org) and posting to [mchcom.com](http://mchcom.com) the assignment of states and field specialists. Also in our second task that we have is information resources and Internet activities that is led by our director of knowledge exchange Rebecca and assisted by John Schuster. I forgot to mention our other team members. Heather Crown who we've heard about an Anna King both working part-time to help craft messages for us. We also in addition to the information resource Internet activities we support the program. Grantee meetings, special meetings. Supporting the evaluation workgroup so that they don't get shot by you folks and also -- that's actually handled by all of us at the technical assistance center. The outreach to

federal agencies and national organizations is our last task and that's handled by Susan Vaughn who most of you know from her Missouri days. She's also the director of public policy for NASHIA. We have an administrative assistant and if you need to pay a bill it will be Jeff Henderson.

Next slide, please. The whole approach to the contract on the technical assistance center is really the reason the program has it is to help you do your work. We're not really here to make up ideas or make a path for you. It may seem like it when we're asking for you the fill out another form or asking you to do the benchmarks or whatever. But really the notion is that there is so little resources as we all know in traumatic brain injury. Everyone is out there working on their own to do their contribution. And that many have really walked in these steps or some steps or in some angle before and that what is best to do is to use the technical assistance center to identify what some of you have done or what your colleagues are doing so that we can then sort of put that all together into various sorts of ideas, collect those ideas, turn them into technical assistance center resources that we can then maybe even formulate and identify document promising practices. Really what we're doing is helping you. The notion is to help you. I really did mean what I said before is please do communicate to us if you think the things we're doing are not on target. And we do them at the request of Janie so when we support the sorts of activities that -- and priorities she has for the program.

One of the things that we worked with historically and with the grantees and many of you were part of that, is trying to figure out what is it we're trying to do? So we got a group of

grantees together and tried to figure out how do we know if we're improving our systems? How do we know if we're there? We created benchmarks to be able to say how do we know we're being successful and moving our TBI systems of services and supports forward? The next slide is the slide that gives all the benchmarks that we have. There is 12 of them and they are -- you can get the actual report. It is in our information management system traumatic brain injury collaboration space and get it from your technical assistant field specialist but they have rankings -- that's not the right word. It's sort of an ability for you to see basic developments, intermediate developments and comprehensive developments. What I want to say is these are just guide posts for you to look at what you're doing and how you're moving along. It is not to mean that when everyone is comprehensive that you're there and can sit back and relax. We know everyone has moving an changes there and we also can succeed and there is some slippage. You have to fit the work you do. There isn't enough resources and such great need into what you're able to do and what the opportunities are within your state. That's what the benchmarks are trying to help you do so you can have some sense of where you're going as you're being pulled in a multitude of directions.

Next slide. We break our technical assistance services into different categories of ongoing and specialized technical assistance. The first category is our formal technical assistance center services. What they are and how you can use them. The first is through our field specialist Sandy, Amy and myself you get some individualized problem solving and strategic planning as you're working through activities of your grant or thinking through some of the activities with your advisory board or in your action plans and activities within

your state. We're also available to perform site visits. In the past the site visits usually are when a state needs some national perspective or assists with setting goals and objectives when there has been a turnover in the staff at the project or also identifying promising practices and we may -- if we are knocking on your door we may be telling you you're doing something really great and we would like to write it up so we can get it around to everyone else. We do try to help you with your grant application when it's time to do that. We don't guarantee you that our help will get you fruitful but we do our best and have a history of working with the grants and do have some sense of what the review panels are looking for and maybe even what that guidance meant when it asked for something three or four times.

Some of the knowledge exchange activities that are done you can -- John Schuster works on the resource alerts and grant alerts. Idea spotlights that come out over the listserv which he also does. They come from any of the assistant center staff in terms of great notions that you let us know and we heard you tell us. And we write those up so you know what those are so we can build them into a practice or you can duplicate them.

Educational packets are one of these ideas that sort of has grown into something that's more than just an idea. We have sort of an idea for a resource. We have two coming up, one is on screening tools that are being used in the states and then another is on trust funds. All the different trust funds and specific activities around that. So those are written up by the technical center staff and then presented and marched through the Office of communications process that Janie has to deal with at HRSA and we do as a contractor to approval and that's why it can take sometimes months before you receive them in your

hands and that's not the mail. We also have draft product review service. We are -- you are to give -- wherever you create a product you are to give that to the technical assistance center. As you're developing those products we offer -- we have a committee of grantees and technical assistant center staff and Janie to look at your products to give you recommendations to sharpen it, make sure it's on target or suggest to you that maybe this is something we like that we would like to broaden into a national perspective.

We have also tutorials that can be done, traumatic brain injury collaboration space and that tutorial can be done to help you. We'll keep telling you it's the most important thing. And that if you're having trouble going in and that nasty password is bothering you please email Rebecca and she will get you in and she will schedule you or someone from the staff will be able to help you to sort of understand what is that thing that you have? That's where we're putting our stuff. The next slide we'll go over some of the things I've given you teasers on and that is let's just do the self-service TBI collaboration space since I keep talking about it. In there is all the grantee goals and objectives for each of your projects. And that you can also get the contact information for who you all are. We have your ideas that you've submitted to us or we've added in and we have all the product. I want to make -- this was quite a masterpiece that Rebecca led the effort to put together. It really -- when you use it, it is great. If you're looking for an idea, sometimes we pick up the phone but sometimes it's the middle of the night and maybe you can go in and look into that and there will be something there. So use it and let us know how it works. But we also have other sorts of ways we try to gather your information and experience and disseminate that. We have an evaluation workgroup and we have also the benchmarks I mentioned before

that we got together grantees, we just completed -- Sandy completed a process with the grantees to revamp the needs and resource assessment tool and these are really sort of defined by the activities that we see.

So one of the things we're also doing is trying to formalize -- not really formalize but sort of create more opportunities to hear what are the activities that you're up to and so now you'll see a new thing coming over we're inviting you into technical assistance calls around activities that we see a fair number of grantees doing. Activities and what they could blossom into is work groups also like the benchmarks and the needs and resources to develop tools around a particular issue. We have learning communities which are opportunities for you folks to talk together amongst yourselves. We facilitate them in terms of keeping notes and having the phone number for you. But really it is for you folks to talk amongst yourselves. We have four of those.

Project directors onto the next slide. Thank you. And we have state project directors. Protection advocacy directors. Advisory board chairs and members of individuals of TBI and family members. If you're interested in participating in those they're open to everyone to be able to participate in those and just let us know. Most of you know our listserv, please if you aren't on it, email John Schuster and he'll be able to get you on and if that is -- there is about 700 folks that are on that talking of grantees, also others in the field that are federal agencies, federal grants programs and then individuals and those that are interested in TBI that can benefit from the information. There is quite a bit of dialogue. We

think there can be even more. Put your questions out there. Think of it as a resource. I did hurry along with the slides.

Now we have more -- I finally got to where you are and that's what we have is some focus areas and initiatives in the technical assistance center. The ones that Janie was just mentioning, the new initiatives are around veterans and children and youth. We have a children and youth workgroup that we're using to support the children and youth initiative. Veterans is being -- we're in the process now of just finding out what is going on out there and we'll be coming up with some notions around that. We aren't really at the workgroup stage. We'll probably have one soon. If you have ideas on that I'm the contact person. Please do send them along. Our focus areas are really the priorities of the program and that's full participation of individuals with TBI and family members in the development of systems and the administration of systems of care and support services. And then also we have one on cultural competence and first and directed services. If you're interested in those, also contact me and I'll get you hooked up with that. Our other major activity that many of you probably are aware of is supporting the annual grantee meeting that you do have to come to and you are to bring three people to. One of them being an individual with TBI and family member. And that will be held in March of next year. We don't have a date yet. So stay tuned for that. We also have a webcast like this that we help Janie with and we also write some products.

Next slide. Some of the other things that you can find that we support the program in is actually the government website for TBI and we also monitor through our outreach task

what is going on in terms of state and federal legislation. Susan Vaughn puts together a comprehensive list of all the state legislation that's happening and the federal legislation and that's available on the website.

Next slide. That got us through the things that we do and that we have available for you. I do encourage you to let me know if there are some things you would like for us to focus on, some particular issues that would be really helpful for you. We may of some other state working on it or we may be able to start up one of those work groups to be able to get some answers for you. One of the things that we sort of notice and we've -- the grants have been sort of recast as we're meeting you where you are. And we're going to be able to do whatever the state is prepared and where the opportunities are, and so even though these things all probably sound familiar to you in terms of the challenges you face when you're doing this, I guess I think that maybe it's misery likes company or that you're not alone in doing this and that when you're sitting there saying god, this is hard work and I think some of the folks have come back for recent meetings and they're saying it sounds like what happened 20 years ago when I was in this field and I say that because I've only been here for six years. But it seems repetitive and it can seem hard and seems like there isn't progress and you are not alone in that.

This is really just part of the systems change effort and how hard it is to do this work when we have so little resource and so great need. Some of the things that we have seen that have challenged grantees as they've looked forward are changeovers in staff. We have sort of got either your boss, you or the people that work for you or the people that help you

do the work you're doing, all of a sudden change and you have to reeducate them or there is changes in priorities and we know that certainly the big changes in terms of politics that can change and wipe out the ability to be able to move forward with TBI. We've also seen that grantees can have issues around sharp subcontract administration that you really need to be aware of and the sorts of activities that are needed and making sure that deliverables are being done and reliant on deliverables from a subcontract you'll see the process of the subcontract and it has been a struggle an not as sharp as it could have been. Clearly I think there is a four-core component to the program. Having a designated lead agency, having an advisory board, a needs and resources assessment and a strategic plan of a state action plan.

I think those continue to be reiterated that those are the important things in terms of moving the system change forward. If you're going to take a little bit of money and try to capture everyone together to be able to move forward and to do that what we see is those that are more successful than others are those that have those opportunities and are able to capitalize. It really takes the next two bullets. The lead agency that has the vision to be able to do this and sort of the commitment to do this and then also the advisory board have the commitments. One of the things that is so important is that the advisory board really is representative. I think often when we're doing the application guides there is a long list in there about 30 people and agencies that could be in there and people say do we have to have one of each? No, but really almost one of each is really necessary to be able to effectuate change over time.

State budget climates, as everyone knows, talking for the choir can really change the advance of TBI systems change and time. It just never seems like there is enough of it. So we're there to probably tell you the next webcast that these are the same things that you're struggling with and -- but really, I think what we try to do is try to help you come up with not only that others are doing this but maybe what are other strategies that states have been able to do to work their way through some of these difficulties. What I want to do next is introduce Sandy Knutson so she can go over some of the trends that we've seen over the past years with the working.

SANDRA KNUTSON: Thank you. I get the fun part. Looking at where we are with recent trends over the last several years and then now where we are and what we're finding with the current trends. I think you have the slide up there. The first one we'll look at is advisory boards and council and going through the benchmarks as we look at those. We have them organized along the lines of the benchmarks and I think that it's interesting to see how Ken is right, some things have stayed the same but I think we're seeing changes and there are some, I think, pretty remarkable progress. The recent trends have been assessing advisory board wellness and moving from project to policy board. That was recent. We are starting to see now the advisory boards and councils are beginning to take ownership and leadership responsibilities which I think will help move things along even more. A policy board is having to reassess their membership and member roles and responsibilities and becoming a little bit more formal. We're seeing that it really is becoming a sign of maturity and sustainability in the states.

The next one is on lead agencies. The recent trends are the states were assessing is this where we belong? Is this a good fit for our agency? There was a lot of that discussion. I think at one point we've had something like, what, 11 -- how many different agencies historically? It's hard to remember. We're blanking on that. I know we've had a lot of different lead agencies. Every state basically works through the decision of what is best for this particular -- for the functioning in this state. Working at building the collaboration with the advisory board and now currently lead agencies are getting much clearer on defining their roles and asserting their leadership. We're seeing leadership in two key areas in the benchmarks. I like to think of them as the cornerstones of the program when you're looking at strong, committed lead agencies, very strong, committed advisory boards and where they're really working together.

Next slide, please. The needs and resources assessment. Ken mentioned that we just updated the needs and resources assessment tool and this will be coming out in a resource alert and it will be there for you very soon. The recent trend was the move from a single assessment to a systematic assessment process. We have really been trying to encourage states to look at this not as a one time situation but to really look at it as an ongoing needs and resources process. The current trend, then, is conducting a policy analysis. Sitting down and looking at what are the eligibility issues. Where are the services so states can really start seeing what do we really need to be doing to fill these gaps? Currently there are about 33 states in their current grant applications that are utilizing some function or feature of a needs and resources assessment process over the next three years. And there will be some looking at assessing discrete areas, looking at

underserved and unserved populations. We're finding many of the states went through the general process of assessing basically the needs of individuals with brain injury and their families and then a large overview of what the state services were. Now states are going back and looking at older populations. People in the criminal justice system. Domestic violence. Starting to get into more discrete populations where we know people are underserved and looking to find out what their needs are and how best to meet these needs. Also the current trend is assigning this responsibility more and more to the advisory board that they really take it on and make it their process.

Next slide, please. Then the last of the four core components the TBI action plans. The recent trend was to create a measurable plan and address the multiplicity of plans with congruent and incongruent goals. There was a not of congruency to the action plan. Looking at the current trend it's designed based on a systematic needs and assessment process. States are realizing the value of what the needs and resources assessment process provides in building and activating those things needed for the state action plan. Again, this responsibility is being assigned more and more to advisory boards. We've encouraged you all along to make this a living, breathing document so it's not something that's done on a one-time basis and sits on a shelf and that's where it sits. And it's very interesting. I learned just recently that in Iowa as a result of the fact that the state has had an ongoing needs and resources assessment process and had an updated state action plan, these two documents along with the advocacy work being done in the states, when the legislature came to them and say do you have the necessary information and data for this piece of legislation they were able to produce this in a heartbeat and subsequently

that legislation passed and something I learned about recently. So that's one of the values of having this in place.

Next slide, please. Policy development. So now we're going into an area that is not one of the four core components but one of the rest of the eight benchmarks that are important to make all these things come together. Recent trends had be to address policy development in a broad sense. We're finding that the current trends, again, the advisory board is taking a greater ownership and responsibility for policy development. To the point where many of the advisory boards are creating work groups or subcommittees to work specifically on policy issues. And as well as they're learning how to ral date the current gaps, working with the protection and advocacy system. They're out there in the field and finding where the gaps in services and supports are. Several states have hired a person with their current grant to work in the policy areas. We'll be watching this closely to see how it works as we may be able to then bring the suggestions, ideas and tools to all the states as a result of the work that is happening in several states with their new grants. Coordinated state services and support system.

The next slide, please. This one has two slides. So I've split it up with the recent trends and basically if you look at this particular benchmark, coordinated states systems and services and supports is the outcome of all the work we're doing. This is really what it's all about. Improving access for people with brain injuries and their families. Getting the necessary services and supports in place. The recent trends have been really focusing on service coordination. There is quite a bit of peer mentoring going on in the field. We've

built some educational team models. Growing public awareness. Continuously working on this area. I'll talk a little more about that in a minute. Data collection and the issues of cultural competence. The next slide, please. The current trends again we're starting to get into more discrete areas of screening and identification and many of the states are looking at veterans and active duty military. Children and youth. I mentioned these earlier. Criminal justice system and domestic violence. States have been able to do relatively broad-based work on looking at the general needs of the population and now are moving into more discrete ones.

The information and referral system which is one of the again basic premises of any coordinated state system is getting the information to people and providing referrals. We've had several states looking at web-based information and referral systems although we had a technical assistance call for five states that talked about this in their current grant applications yesterday and I think maybe we're looking at more information and resources than we are information and referral. So this is going to be something that is going to be developing. It's a work in process and we'll be looking more and more at this. We also have a total of about 14 states in the current grant applications that are working on information and as we're calling it right now referral in their grants. I think we'll be looking at how you're doing it, what the commonalities are, what the basic elements are and what kind of tools can be developed to assist in the process.

Next slide, please. Program evaluation, I think that we've had quite a bit of discussion. We have two people smiling over here. The process measures and we were busy comparing

apples, oranges and grapes. I remember the very first report that came out about the needs and resources assessment process after the first 14 grants. It was very difficult for John to put that report together because there was really no commonality and baseline other than states had conducted in these resource assessments. I think he did a masterful job in pulling it all together. The current trends, Anne and Carolyn talked to that today. Developing an evaluation culture. I think you're seeing that more and more in your states. Looking at outcomes and looking at evaluation and of course demonstrating the outcomes including the individual health outcome.

Next slide, please. This is collaboration and coalition building. The glue that holds it all together where you're building those relationships. We're really starting to see a greater sense of maturity particularly on the advisory boards and with the lead agencies looking at how they're building maybe a more formal relationship such as through a memorandum of understanding or a memorandum of agreement. Minnesota has done this for years in the work. Arizona there, the collaboration readiness determines what area to address now. Arizona has worked over the years developing a chart basically on levels of collaboration. The tool to how to really assess the readiness for collaboration and who your potential collaborators might be. This is very important. This is the glue. These are the relationships where things really come alive. The next one, please. Sustainability. The current trend is assigning a lead for shared responsibility to the advisory board and again you'll notice the advisory board comes up over and over again taking on a stronger and stronger role within the life. TBI work being done in the state. It's critical. This has been an issue, this has been a problem. It's limited funding. It's been a problem. A lot of the states have

learned now maybe we can look at sustaining this system one piece at a time. Let's work toward a trust fund or a waiver or let's work toward one certain piece of activity or funding stream and get that in place and then work on the next one. So they are really looking, instead of trying to do an overarching big picture let's sustain the ball of wax at one time. They're looking for the opportunities to do that. And again a lot of that comes through the collaboration.

Next slide, please. Data and data processes. You'll notice there is a five-legged stool over there. We started out a couple of years ago with a three-legged stool, we added the fourth leg and now we're at five legs. What the stool symbolizes is the available data sources that everybody has been tapping into and what has been the recent trend. What we're starting to see is that people are determining what data are needed. They're sitting down and looking at what kind of data do we need for what we want to be happening, what we're doing. They're working to capture the information on the underserved using the whole idea of sound bytes and personalized or localized information. I think Ken pointed it out several years ago we're looking at hard data with a D and heart data, the story. Using the faces and the stories for the hard data. It completes the circle. The data that you're presenting.

The next slide, please. Product development. Adapting existing products. People are -- there is a lot of material out there now and we're stopping at having to think we have to develop something brand new but learning to adapt existing products. Then working with work groups which is helpful to get a cheap buy-in. When you involve people with brain

injury and their family members, to get buy-in for the products. As new media comes out applying new strategy with the new media that are becoming available. Ken mentioned earlier using the TBI product review service. I would encourage you to do that. A new product, send it into the technical assistant center and ask for a product review. The last of the benchmarks, next slide, please, is public participation and training. The current trends are, again, back to assigning ownership to the board. This whole area of how do we get education out there? It is continual. Don't turn to the next slide yet but you'll see when we get to it the idea of public awareness, education and training. This is where Ken mentioned. We're back where we started. In some respects we are back where we started but we have more products, more information. We I think have a larger group of people that are moving this process forward in the states.

I think we'll go to the next slide simply because we're running out of time. Critical indicators are basically what is needed? Again, more and more education and training, public awareness. It is a continual process. People come and go and as you know, from many of the surveys that we have done, that we think that we have educated the public out there but we need to keep going back and bringing this before people on a continuous basis. The issues of system entry and access, what the grants have been about, is developing system entry and access. Advocacy. This is where your bright lights and champions come into play and developing them. There is a very good definition in the benchmarks of what is bright lights and champions are. I would encourage you to look at those and then building those partnerships and collaborations. As Ken mentioned it takes time. We all want these things to happen quickly but it does take time. I think those of us

that have been in the field a long time are really starting to see some progress. That's very exciting. Maybe when we say that we're seeing the same old things we are because these are the basic elements that are needed to move things forward. How do we do it, what are the means we do it?

The last slide, please, lead agency, TBI and statewide advisory board. Needs and resources processes and a TBI action plan. Those are the four components are the means by coordinated states systems of services and support will be made available for people with brain injuries in their families. I lied, the last slide is really contact information. And what we will be doing as Ken mentioned afterwards is also posting the rest of the TBI technical assistant center staff and all the states these different assignments that Amy, Ken and I have so you know who your technical assistant specialist is. Back to Janie.

JANIE MARTIN HEPPEL: Thank you Sandy and Ken for the great overview of things available and the recent trends. Also like to thank Carolyn and Anne. A couple more questions for you. You may not have time to answer them now but we'll get back to you in a question. I think it's a good sign that we have not gotten any questions for E.J. and thank him for that clear presentation. I would also like to thank our behind the screens professionals, Amy horn from the technical assistance center. Our technical moderator Stephanie Colter. They've done a fine job. Congratulations to each of you for applying for and receiving an implementation partnership grant. We are just about out of time. If you think of questions later on, please don't hesitate to contact me or anyone in the

organization and we'll look forward to hearing from you as you go about implementing your new grants. Thank you.