

Traumatic Brain Injury/Brain Injury Association of America

Unidentified TBI:

The Importance of Screening to Find

Those Who “Get Lost” and to Find Those “Not Found”

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JANE HEPPEL: Good afternoon, I'm Janie Heppel director of the federal traumatic brain injury program. Wayne Gordon is here with us talking about unidentified TBI and the screening of those who get lost and those who aren't found to have TBI.

Before I introduce Dr. Gordon I need to give you some instructions about how to send in questions and just how to effectively use this webcast. I want to also say that we have with us Heather Crown who will be the technical moderator for this webcast and take your questions as they come in and at the end of the presentation Dr. Gordon will answer as many of your questions as we have time for.

Okay. Slides will appear in the central window and should advance automatically. The slide changes are synchronized with the speaker 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 message window.

We encourage you to ask Dr. Gordon 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 may know from where you are participating. The questions will be relayed on to Dr. Gordon and if we don't have the

opportunity to respond to your question during the broadcast, Dr. Gordon is going to give his email address and you can send questions that aren't answered to him directly.

On 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 will have the opportunity to fill out an evaluation. Please take a couple of minutes to do this. It will help us to plan for future broadcasts and will also help us enhance the technical quality of the broadcasts.

And now it is my very great pleasure to introduce Dr. Wayne Gordon, Ph.D. who is the Jack Nash professor of rehabilitation and associate director of the Department of rehabilitation medicine at the Mt. Sinai School of Medicine. He joined the faculty of Mt. Sinai in 1986 from the Rusk Institute of the New York University Medical Center. He's the Project Director of the TBI Model System, the RE and the Mt. Sinai injury control research center. He's a diplomat in clinical neuropsychology and fellow American Congress of Rehabilitation Medicine. In 2006, he received a special recognition award from the National Association of rehabilitation research centers. He was president of this organization from 2004 to 2006. Currently he is President Elect of the American Congress of rehabilitation medicine, a member of the board of the Brain INJURY Association of America, and board member of the Ontario Neurotrauma Foundation. He has published more than 100 papers and book chapters and has presented nationally and internationally. On TBI research, stroke rehabilitation, cognitive remediation and assessment of rehabilitation outcomes. Now, Dr. Gordon, we look forward to your

presentation, which I might add, is going to be available in the next issue of "Brain Injury Professional."

WAYNE GORDON: Thank you for inviting me and I also want to thank the National Institute on disability and rehabilitation research and the Centers for Disease Control and Prevention and the generous support of the John Blair Haldeman Fund. I'm on slide four now.

Next. We have a challenge and the challenge is unidentified TBI. It is a major unrecognized cause of social, educational and vocational failure. There are barriers that prevent those with TBI and especially those with mild TBI as being a person with a brain injury, gaining access to care and having their long term TBI-related difficulties addressed so that their quality of life can be improved. Let's look at TBI statistics in terms of incidents.

Next slide. There are more than 180 to 250 per hundred thousand TBIs in this country a year. A million and a half new injuries a year, 4,000 per day or about three per minute. How does TBI happen? Let me give you some examples.

Next slide. Each year there are 400,000 people who sustain a TBI in falls, 300,000 people who sustain a TBI in crashes, and about 160,000 people who sustain a TBI as a result of an assault.

Next slide. About 80,000 people a year are discharged from acute care and rehabilitation with a significant disability secondary to a TBI and TBI results in at least 50,000 deaths a year. That number of 50,000 deaths a year is larger than all the number of all the American soldiers who were killed during the Vietnam War. So every year more than the

total number of soldiers who were killed in Vietnam are killed in this country as a result of a TBI. There are about 5.3 million individuals living in the United States with an identified TBI. TBI in the medical system on slide nine, TBI accounts for about a million visits to emergency rooms a year and in New York City it accounts to 10% of all the calls to EMS. In children, TBI is the leading cause of death and disability and more than half of all the TBIs that occur, occur before the age of 25.

I'm on slide 11. These are the numbers that we count. These are the counted individuals with TBI. Who remains uncounted? The unidentified.

Next slide. The data I just cited don't include the 425,000 people each year who are treated in physician offices secondary to a concussion. It doesn't count the 90,000 people treated in other types of out patient settings. It doesn't include the 320,000 soldiers returning from Iraq and Afghanistan who report having a probable TBI. This accounts for more than 20% of all those who have served in the war. There are others, too, and I'll get back to this later. In some, there are those who are identified as having a TBI are only the tip of the iceberg. We don't -- failure to identify results in many getting lost and those who are not found and there are those who are not found in the first place. So getting lost after TBI, what do I mean? Many people with a TBI are sent home from an emergency room without any follow-up. Many people are sent home from an acute care hospital without any follow-up. Many are sent home from rehabilitation without any follow-up. And many of our soldiers come home from war often with other injuries but with an unidentified brain injury. What do I mean by not being found after a TBI? Many individuals who sustain a mild TBI do not seek medical help. They are people who have been assaulted, soldiers who have been exposed to blasts or explosions, women and children who are victims of domestic abuse or domestic violence. People who spend the night on the floor of a bar after being

in a brawl. Elderly people who fall downstairs and don't know they may have sustained a brain injury. Children injured during sports or at the playground. Those who get lost and are not found -- these are the ways that these individuals are not identified. Failure to identify, how does this happen? Individuals may have no immediate symptoms. These are people who may be in accidents, who fall or who are abused. When you go to an emergency room following a crash, or a fall, you don't know if you have organizational difficulties. You don't know if you can't remember things the way you used to. You don't know if you have difficulty functioning at work. These symptoms are not readily apparent immediately after a brain injury. Soldiers who are dazed in a war may not have any physical overt injuries and may not have any cognitive or behavioral challenges until they return home and life is different and the structures under which they function are different. Children who are injured in parks or playgrounds or playing in the street may not be observed following their injury by a responsible adult. So failure to identify, how does this happen? Unfortunately, many physicians do not equate a concussion with a mild TBI and discount the symptoms of their patients. Unfortunately, many primary care physicians are not aware that a concussion or mild TBI may have long-term effects. They mistakenly believe that time heals all symptoms. Failure to identify has many, many consequences. For example, many people do not link the changes in their function to the experience of a blow to the head. So they fail to recognize the cause and effect relationship. This is similarly seen with parents and teachers who fail to seek the link or see the link between head injury and subsequent problems in children. How is a teacher supposed to remember a child who comes to school on Monday and says I was in a bike accident over the weekend and I was out of it for a little while, how is a teacher supposed to, years or months following that report, supposed to -- that link, that concussion that the child sustained to their behavioral difficulties or their learning difficulties that emerged after that concussion. No way. People who with an unidentified TBI also do not receive the services

that may be helpful to them and help their challenges. When we look at people with TBI there are three groups of individuals with TBI. Those individuals who are identified and receive the needed services. Those who have been identified with a TBI and not receiving needed services because they've been lost. And those who are unidentified and typically the unidentified are usually those with a mild TBI. So how do I define a mild TBI?

According to the American Congress of rehab medicine, a mild TBI includes any one of the following. A loss of consciousness, a loss of memory of events immediately before or after the injury. An altered mental state at the time of being injured, meaning that the person is initially dazed, confused or disoriented. CDC expanded on this in 2003 in a report they wrote to Congress in which they say that a mild TBI is any period of observable self-reported transient confusion, disorientation or impaired consciousness. It includes a dysfunction of memory around the point of time of injury and a loss of consciousness lasting less than 30 minutes. Usually a mild TBI consists of a loss of consciousness or period of -- loss of consciousness of less than 30 minutes, a coma scale and a period of a post traumatic amnesia of less than 24 hours.

Immediately following injury, the person may have seizure, among incidents in young children there may be irrelevant tab it. Lethargy or vomiting. Dizziness, irritability fatigue and poor concentration in adults. There are two types of mild TBI, the identified and the unidentified. In terms of the identified, of all the identified TBIs, only 15% sustain moderate or severe injuries. Thus 85% are those who sustain mild injuries. That's a huge number but about only 15% of these individuals have disabling symptoms one year post injury. Thus most injury -- individuals who sustain a mild TBI have no long term consequences because most of these individuals recover. In other words, if we were to use this information, we could say -- we could reframe it as saying that 15% of the individuals who sustain a TBI, sustain moderate or severe injuries. 15% sustain mild TBIs and have

persistent symptoms and 70% basically recover. So in terms of mild TBI and being symptomatic, CDC estimates that the incidence of symptomatic mild TBI is somewhere around 25 to 50 per 100,000 in the population. Thus the unidentified group is about 25% of those who are identified. Other estimates are quite larger. In non-disabled samples 7 to 8% have experienced a mild TBI and have persistent symptoms. This was found in our own study twice and in a study reported by Jonathan Silver and his colleagues in 2001 as they reported 7% in New Haven, Connecticut. So if we extrapolate these numbers of somewhere between 7 and 8% to the population of the United States, we have about up to 21 million people who have had a TBI with persistent symptoms. And most individuals with persistent symptoms are unidentified.

What are the consequences of an unidentified TBI? There are many. First, there are years of unnecessary -- years of unnecessary anxiety and disability. People wondering what is wrong with me? Why can't I do things the way I used to? And in his study Dr. Silver found the individuals who sustained a loss of consciousness, the 7%, those individuals had 1/3 more health difficulties, 2/3 more emotional difficulties, were 2/3 more likely to be on welfare or receiving disability, and four times more likely to have attempted suicide. So let's look at, again, consequences of brain injury.

Obviously there are sports concussions in adults and children. In children between 1997 and 2000, there were close to 41,000 reported injuries. 62% of these injuries were concussions. In terms of the frequency by sports, we see that women's La Crosse was the most frequent. Women's soccer was the second most frequent, then we go to men's hockey, men's La Crosse, men's football and women's basketball. Let's look at concussions in sports a little closer. In a study it was found that 50% of a sample of soccer players age 11-14 had signs of concussion. 54% of high school football players had a

concussion. And in a study conducted by ten athletic trainers who basically viewed ten high school football games, they estimated that there are 175,000 head hits a year in high school football. Head hits, not concussions. That's contact to the head. "The New York Times" reported that 51% of all NFL players have had at least one concussion and 30% had at least three. So what are the consequences of concussion? We don't know how many concussions a person can sustain before they become symptomatic. I've seen people who have had four and been fine and then it was the fifth one that put them down. I've seen people with up to nine or ten and it was one of those that caused them difficulty. What we do know is a concussion may have long term neurocognitive effects and what we also know is that 12% of those who sustain a TBI have a second injury. So an initial TBI puts the individual at risk for a second and unfortunately a third.

TBI on children basically it's estimated that about 475 children per year sustain a TBI between the ages of 0 and 14. About 92% of these are released from hospital emergency rooms. There are about 75 more --% more emergency room visits by children than adults with a TBI. What else do we know about TBI in children? According to the United States Department of education, there are about six million children currently receiving special education. And very few of these children have sustained TBI because according to figures released in 2006, about only 24,000 children in our schools have been identified as having a TBI. So with about 500,000 predicted, we're basically identifying about 5% of those who are there. In our own work in the New York City schools that we conducted over a five-year period we found there is a lag between injury and identification by our program of five years. So children were sitting in their classrooms with a TBI for at least five years before they basically were counted or stepped up as having had an identified TBI. We've done some research in regular schools, in one junior high school and one high school in the city and found about 10% of the sample of students we screened had

sustained a TBI. In Denver we screened some children this one quadrant of the school system, very young children being referred to Special Ed. and about 40% of those screened had sustained a TBI and were unidentified. Why are not kids identified? Most concussions go unnoticed. When they're noticed there is often no follow-up.

Some sequelae of a TBI do not emerge immediately. So kids grow into their injuries. In other words, as the child ages, material they're presented with becomes more and more complex so it's more likely to basically confront their impairments. And unfortunately -- unfortunately what we see is that because there is no notation between the child sustaining a brain injury and the onset of their cognitive or behavioral difficulties, we have a sudden onset disability and no connection is made to the preexisting blow to the head. Why are not kids identified? Well, I think we need to be real here. There are tremendous pressures on our school system especially on special ed. There is a reluctance to identify a new group of kids who may need services. School personnel are not adequately trained to either assess, identify or provide accommodations to children with a TBI. This results in a high rate of misdiagnosis. So we see often situations that if it looks like an LD or an ADHD, the assumption is that it is an LD or an ADHD. But often it's not. Often it's a TBI. So why are not kids identified? The biggest reason is because there is no screening. So what are the long-term consequences of unidentified TBI? TBI is often co-morbid with other conditions such as substance abuse, depression, criminal behavior, homelessness. So a child with a TBI often initiates a pathway to social failure. Let me give you a few examples. We did screening for our state substance abuse agency and we screened over 800 people who were being admitted into the program. As you would expect, about 50% of those we screened were identified as having a TBI. So the question you have for me, so what? So what these people had a TBI? Does having a TBI really matter? Well, we then linked our data with the state dataset and we found some interesting things. We

found those identified as having a TBI had more DSM-IV diagnoses meaning their mental health problems were more complex and they were probably more intractable to treatment. In addition, they had many more admissions to the program, meaning they were more likely to be treatment failures. And finally, what we saw in the group that had multiple injuries, when we assessed them, their average age was at 35 and then those with multiple injuries their first injury occurred at an average age of 14. So early identification of these folks, early identification of their injury, could have been a prevention of their subsequent substance abuse.

So identification can be seen as prevention. Identification can be seen as cost saving. Because somebody is going to pay the cost of this lack of identification. It's either a school or some social program or it's a jail. If we look at TBI and depression, it's well recognized that 60% of those who sustain a TBI are depressed at some point post injury. At any given time post-injury 20% are depressed and or anxious. From our research and the research of others as well we've published data suggesting that individuals with TBI who are depressed don't function as well or return to their lives as well as those who are not depressed. Let's look at TBI and criminal behavior. There has been a study that is reported that about 87% of those who are incarcerated have experienced TBI and another study about 82% of those who have been incarcerated in Australia have sustained at least one TBI and 65% of them with at least one loss of consciousness. In work that we've done with folks at a homeless shelter in New York City, we found that about 50% of those who we screened had sustained a TBI. The woman who is working on this project with us went ahead and administered the cognitive screen to these folks and found that their level of cognitive function was below the first percentile. So what are the implications here? The implications are that even if these individuals were placed into housing and it's been essentially no longer homeless, that with their level of cognitive impairment they wouldn't

be able to function. They would function better in their structure life on the street than they would in housing where they needed to cook, clean, shop and do all the other things that other individuals can do when they didn't have the skills to do that. So just as with the homeless -- with the substance abuse individual with TBI, we need to begin thinking about different types of programs for those with the co-morbid condition of substance abuse and TBI. For example it doesn't make sense to say that a person with a TBI should be able to profit from a 30-day program when they basically have learning and memory difficulties. Similarly with the homeless we need to think about providing rehabilitation to them in order to improve their basic daily living skills. Let's look at TBI and the war. If you look at a report published in July about 10% of the wounded soldiers returning from Iraq and Afghanistan have had a TBI. If we look at the more recent rand findings I presented earlier we see the numbers are much higher. If these soldiers were asked when they returned home about whether or not they reported a jolt or blow to the head, 70% report sustaining such an event and 20% report sustaining a probable TBI. The long-term consequences of this -- of these TBIs that are caused by blast injuries are not known. In terms of TBI and domestic violence, we know that about 30% of battered women who are seen in emergency rooms have had at least one prior loss of consciousness. And 67% reported symptoms that could be TBI related. Of 99 abused women 75% sustained one TBI and -- in 53 women an average of five brain injuries occurred in the year prior with almost 30% sustaining 10 injuries in the previous year. And it's also true that many partner abusing men have sustained a TBI. So basically TBI impacts both sides of the street here, the abuser and abusee. Lack of identification has consequences for all. It leads to misdiagnosis and inappropriate treatment. It results in a mismatch between treatment and cognitive impairment and it leads to failure. There are pathways to success and there are pathways to failure. For some with mild TBI the challenges are brief and they are lucky because they resolve quickly. Others with brain injuries face life-long challenges that require

interventions from multiple service systems. Some succeed and some become social failures. So there are pathways to success and there are pathways to failure.

Next slide. You probably can't read this slide so I'll try to decipher it for you. So there are four crossroads that pave the way to success or failure traversed by people with traumatic brain injury with people with persistent symptoms.

Crossroad one involves the self-identification by the person. These are individuals who seek medical attention and are more likely to self-identify. For some reason, they're seeking a kind of attention for the symptoms that they are having. Those with greater awareness of what is wrong with them and how they're different are more likely to self-identify.

So crossroad two in terms of paths to success or failure, the person must seek out post-emergency room services. If you feel that something is wrong with you, you must seek out services to help you with what ails you.

Crossroad three is that the service system must correctly identify the person with a TBI. So we can have failure on the part of the person who doesn't identify and then we can have failure on the part of the system who doesn't identify the person.

Crossroad four is that once identified, TBI appropriate services must be available in addition for these services to be available by the system, the system must recognize the complexity of traumatic brain injury and the consequence diverse services that are needed. Achieving post TBI success has several components to it. First it depends upon the person self-identifying as a person who has experienced a brain injury. Upon him or

her seeking services. Second, a service system is needed that identifies the person and provides the services that are responsive to the person's needs. Then we need to be able to identify the unidentified. In other words, those who get lost and those who are not yet found. We need to screen these people, but how do we screen these people? I will give you one example. The brain injury screening questionnaire that we have developed at Mt. Sinai. The brain injury screening questionnaire is based on the helps card that was developed by Picard, czar is brick and Picard and a grant we had as a comprehensive rehabilitation center based on the Lehmkuhl and a symptom checklist developed by Jeff Kreutzer at the medical college of Virginia that's undated.

The brain injury screening questionnaire questions of three steps. In step one events are identified that are associated with a loss of consciousness or being dazed and confused after a blow to the head. We found in our research that we can't just ask a person whether or not they've sustained a blow to the head that's rendered them dazed and confused or unconscious. You need to give them a whole series of events that serve as a memory jog. Just asking the single question doesn't do it. So if the person responds yes to that question, in other words, they've had -- sustained a period of lost consciousness or confusion after a blow to the head, what we want to know next are what are their symptoms. So does this person experience persistent symptoms after one or more events that are consistent with a TBI? Are these symptoms that they report unique to a TBI? And the third thing we want to know is whether the person has any co-morbid conditions that could account for the current symptoms. So we want to know if they have a psychiatric history.

I'm on 169. We study the symptom report of individuals with mild, moderate and severe TBI relative to a group of people without a disability, people with spinal cord injury, people

who were H.I.V. positive and individuals who had undergone a liver transplant. What we found in these individuals, those individuals without a disability reported on average of three symptoms. Individuals with TBI reported on average of 18 symptoms and the individuals in the other three disability groups reported on average 10 symptoms. So obviously what we see here is something that has been reported in the literature several times is that people with TBI report a lot of symptoms. What we then did is in the analysis of the symptoms to see which of those symptoms differentiated people with TBI from all the other groups. And this we reported in 2000 in an article that was published in "Brain injury." There were 25 symptoms unique to people with brain injury. These 25 symptoms occurred with statistically higher frequency in individuals with TBI than any of the other groups. 23 of these 25 symptoms were cognitive in nature. In other words, it's not as if people with TBI don't have physical or behavioral symptoms but symptoms that are unique to them are cognitive.

So in the brain injury screening questionnaire we then go through a process. In step one the person basically is given all the ways in which they may have sustained a brain injury. In a playground, car crash, etc. For each event we determine whether or not the person self-reports having sustained a loss of consciousness or period of confusion. If the person is negative on all of this, then they're negative meaning they did not sustain a brain injury. If the person is done with the screening instrument in less than two minutes. If they're positive on this, then we have documented as a result the number of blows to the head the person sustained, the etiology of these blows to the head, the duration of self-reported loss of consciousness or duration of being dazed and confused and the age of onset at each of these events. Following that the person is given 100 symptoms that we have found to be sensitive and specific to TBI and basically we then add up the number of sensitive and specific symptoms and associated a probability of a person sustaining a TBI

by the number of symptoms of these 25 symptoms that they report. So then once we know that, the probability statement we check to rule out the other conditions a person may have sustained that could account for a TBI.

So obviously the BISQ is not a diagnostic tool, it's a screening tool just as a mammogram is not a diagnostic tool, a PSA is not a diagnostic tool, etc. So what we know is that basically there is a person who has been screened for brain injury and when that needs to happen next. The person needs to be referred for neurocognitive testing, a medical evaluation or for whatever kinds of evaluation are indicated. Then we look to see following these evaluations is the pattern of test data consistent with a TBI? And then based on that, we can begin to develop an intervention plan. So essentially what we're talking about is identification will result in treatment, it will lead to program development and will lead to research that is needed to develop these programs and test their efficacy. Basically in children, identification only leads to services when there is a problem. If you identify a child as having a TBI in the first grade, that doesn't mean that you need to render services in the first grade. It means that you only need to pursue this path of further diagnostic work-up when the child begins to have trouble with school, if the child begins to have trouble in school. If there is no trouble then there is no need to do anything. There is a flag by which -- from which you can use -- that exists in the child's record that you can begin to use to identify the potential etiology of what is causing this sudden onset of failure and then provide needed services. So essentially I will repeat what I said earlier. People may say to me well, it costs money to have somebody identified, yeah. It costs money. It does. But it also costs money to have them fail one way or the other and also by identification, what you are doing is you're saving money because you're also identifying those who don't sustain a brain injury and you're saving those services that might have been provided or diagnostic services to those individuals because you might have thought they

had a brain injury when they did not. So I think one of the things that we can learn from this presentation is that screening basically has the potential of being a form of prevention. But ultimately what we see is a TBI is an underfunded mandate by both federal and state government in terms of both services provided and research support. So I have plenty of time to answer your questions.

The first question, what could be some of the long term effects from a mild TBI and how long could those affects last?

>> Well, the effects -- the long term effects of a mild TBI are no different than the long-term effects of a moderate or severe TBI.

So the person could have cognitive difficulties in terms of memory, executive function, processing speed and the like. They could have behavioral difficulties in terms of agitation, depression, bursts of temper tantrums for no known reason.

How long do these problems last?

Well, they can last a lifetime just like the residuals of a more severe TBI.

After screening and diagnosing a student with a TBI as learning disabled what's the next step in assisting that person?

Well, first I would say that if you're going to be screening and identifying a child as having a TBI, then you would have a different classification than learning disabled. And then you would basically be then doing a neurocognitive evaluation in order to isolate the person's

strengths and weaknesses and then what kind of strategies can be put in place to assist the child to become an effective learner in the classroom?

Question from Tennessee. While attending a NAMI conference focusing on mental illness specifically depression in veterans from the global war on terror, I reminded the moderator that TBI and PTSD symptoms often overlap and asked if these veterans had been screened for TBI.

The answer was no, not unless it was an identified condition prior to military discharge.

How do we get our VA medical centers to begin screening for TBI as a possible cause of resulting mental disorder?

I think that's an excellent question and I think advocacy is the only way to do it. I think you need to be banging on the doors of the VA in order to do screening. I think one of the most likely places you are going to find veterans with TBI is in their psychiatry clinics. I think that's an untapped resource for finding people with TBI. I think there are more individuals with an unidentified TBI who are being misdiagnosed and mistreated in psychiatric clinics all over than we care to imagine.

Next. What services and treatments are best for persons with TBI?

I think that's a good question. I think that -- I think the first thing a person would need would be a comprehensive evaluation that would include a medical eval, a neuropsych eval. if the person is having cognitive difficulties, psychiatric evaluation if they're having behavioral or mood difficulties. I don't think you can talk about their being a uniform set of

services that a person with a TBI needs or a uniform -- because every person with a TBI is different. All our brains are different and all our brains are impacted differently by a blow to the head.

What is the outlook nationally for getting the message out about TBI for both medical and educational professionals?

Well, I tend to be a hopeful person. And I hope that by doing webcasts like this and the other things that are going on by myself and others, by the wonderful things that Bob Woodruff has done in becoming essentially the spokesperson for individuals with TBI and not being afraid to step up and talk about his brain injury. I think it puts brain injury in the language of everyday life rather than being something that is run away from or people are scared to talk about. I think the more this happens, the better things will become for people with brain injury. I think bringing these numbers that I was talking about today to the -- to state legislators, to federal government is critical in order to get the resources we need. I think that people need to begin to see that we're not just trying to spend money, we're trying to save money by identifying people with TBI.

If an individual sustains a concussion, is he or she more susceptible to having another concussion?

Yes, 12% of those who sustain a brain injury sustain another brain injury. Why exactly -- why that happens, we don't know but you can just speculate about the attentional difficulties interfering, the reduced processing speed interfering, the memory issues forgetting to look both ways crossing the street are simple ways that could basically lead to a second injury. What type of research is available regarding brain plasticity and

rehabilitation in TBI patients? The literature on plasticity is not tremendous. There have been -- I think if somebody were to ask me what has been the greatest advance in the care of individuals with TBI I would say it's the improved acute and emergency care. And I think that has really saved the lives of many, many individuals. Look at the wonderful acute and emergency care that our soldiers are getting in Iraq that are saving tremendous lives. I think in terms of rehabilitation, there have been several evidence-based reviews on rehab. One -- there have been two on cognitive rehab that the lead author is Keith Cicerone that were published in 2000 and 2005 and the state-of-the-science review on TBI rehabilitation published in the American Journal of Rehabilitation Medicine in 2006 and I was the lead author on that. And there is significant evidence on the efficacy of rehabilitation. It is unfortunate that many insurance companies do not accept this evidence. And they continue to not cover cognitive rehab as a covered service. I think that is another area that we need to challenge and fight the insurance companies on and bring it to the attention to the federal government because I think this is basically discriminatory and biased.

What are the differences between the BISQ and the HELPS Card?

The HELPS Card essentially asks the individual five questions. Don't ask me to remember what those five questions are. That was, you know, 17 years ago. Each of the questions began with a letter in the word HELPS. What we found in using the HELPS Card and I would say somewhere between 50 and 100,000 of the HELPS Cards were developed is that the questions were too non-specific and too global. Then based on that we began developing the BISQ which then we went through several iterations on in terms of how do you ask a person whether or not they sustained a blow to the head? How do you begin to ask questions in terms of loss of consciousness, of being dazed and confused and then

begin looking at the symptoms and how do you use the symptom report as a way of reliably suggesting that a person has sustained a TBI? Basically the BISQ is a self-report measure. It can be completed by the person or with somebody who reads it to the person. We're challenged now. The BISQ is only available as a paper form in a scannable form that because of the nature of the scanning technology requires many sheets of heavy paper. And then they need to be sent to us and we scan them and send them back to you with a report. We hope to have available an online version of the BISQ that should be able by hopefully the third or fourth quarter of this year. We're actively developing that now and then seeking basically IRB approval and whatever we need to do to get it made available to people. If you'd like to be notified when this is available, please email me and I will get back to you as soon as I have some information. But it will be web-based, it will be available on Internet. People will complete it and as soon as they're in we'll get the report.

Has the population of people with psychiatric diagnoses been screened for brain injury to see what percentage may have had the diagnosis?

>> To my knowledge there has been no screening done in psychiatric settings. I think that's an excellent question and it's an area that we need to look at.

Is there research or data on the success rates of treatment for people with TBI?

I don't know how you define success. If you look at survival rates, we know that people are surviving better. We know that people -- basically but in terms of looking at success in terms of a long-term outcome, I don't think we have any comparative data in which to make those kinds of statements because we don't know what success is. Even if you were to look at something like employment, if you begin to take a long view of employment, we

know that, for example, in people with spinal cord injury you don't begin to see recovery curves in terms of return to work until folks are about eight years post injury. I wouldn't think that things would be much different with people with TBI so you really are now at least with moderate to severe TBI you're talking about looking at a long window and having the ability to follow people for a long period of time. What is the citation for the reinjury rates?

I can get you that figure. I don't have it off the top of my head.

Do you recommend the use of the BISQ to screen persons entering jail, probation programs, mental health, mental retardation services? What would it cost per person?

I don't know yet. What we're trying to do now is figure out the cost to us for this online BISQ, the cost of storage and all the HIPAA compliance issues. But I would imagine the cost of screening is going to be somewhere between -- [inaudible]. In many states TBI is incorporated into other disability definitions. How do you feel that the BISQ is identifying those with brain injury? Well, I think it hinders identifying folks with brain injury because the assumption is there is no uniqueness with people with a traumatic brain injury and the needs and impairment of people with a traumatic brain injury are similar to those with a developmental disability and we know they're not. It does people with a TBI a disservice.

What is the use of scan technologies in terms of identifying brain injury?

I think you are talking about the neuroimaging procedures? I think in terms of looking at folks with a mild TBI, that really is still quite in its infancy in terms of we know that CT and standard MRI don't do an adequate job of screening for TBI. We know that some of the

newer forms of neuroimaging using MRI like diffusion imaging may be doing a better job of it. But the verdict is still out on that. How many suicides occur each year that are TBI related? We don't know. In order to relate TBI to a suicide you need to know the person has been identified. Not all people with TBI have been identified. We really don't know what a good denominator is. Enumerator, I'm sorry.

What are your thoughts on the resource facilitation process for individuals screening for TBI?

Well, I think there are tremendous resources available in this country for people with TBI. Each state -- each state has a brain injury association that is a wealth of information and resources. We have the HRSA program which is a wealth of information on TBI. We have the 16 TBI model systems that are a wealth of information on TBI. Each of these programs is a resource on services that are available in any given area. So I think resources are there and available. I think they're underutilized and underfunded.

>> I'll read the next question. Some of these are longer. From New Jersey do you have any information on the fiscal consequences of TBI on the national or state level or do you know of sources we could contact for this information?

>> Fiscal meaning monetary?

>> Yes.

>> I think that there are estimates that the annual cost of TBI is somewhere between \$50 and \$60 billion a year.

>> People with TBI are often misdiagnosed with PTSD. How different is the treatment for each?

>> Well, obviously there are many, many symptoms that are overlapping between PTSD and TBI. I think the high anxiety state of an individual with PTSD I think really needs to be the focus of initial treatment. Unless you can mitigate and reduce some of the severe anxiety symptoms it is going to be difficult for the person to participate in other forms of rehab. My first line in terms of treating people with co-morbid PTSD and TBI would be try to work to get a reduction in the PTSD symptoms and then work on the TBI-related symptoms.

>> It seems that people with brain injury receiving services and support some live independently have tremendous trouble with support staff. The number one issue involves the balancing of individual rights and safety concerns and risks.

Can you speak on any ideas or policy that could improve the independent living support system that is currently in place?

The current system is very similar to the supports given to people with developmental disabilities. How can we advocate for supports that focus on choice and personal goals and assisting people to create a purposeful life?

>> I think that's two very good questions. I think there are a number of ways to do that. I'm a big advocate of choice. And people participating in making their own decisions and I think one of the ways to achieve that is through personal futures planning and creating

individual circles of support to help people achieve their own goals. We have some -- we work with Beth mound in terms of developing materials on personal futures planning as it applies to traumatic brain injury. Those materials are available for free on our website and you may download them and distribute them as you wish.

>> Will the information you shared today be available for local activists to share with their legislators, professionals and support groups?

>> You bet. This webcast is going to be archived by HRSA and the link will be sent out to all the people who are listening in. The link will also be on our website. If you would want - - and the slides will be there as well. If you want -- and the link will be sent out I believe in about a week?

>> Yes.

>> And also if you want another -- any more information or another copy of my slides, that will be -- you can email me directly. The other thing as Kathryn said earlier there is a paper coming out in the next issue of brain injury profession that's a written version of my talk and the paths to failure and success slide you couldn't read is going to be in that as well and you can get copies of that when it comes out from me. I will send them to you.

>> This is from Minnesota. We wonder if those who have sustained or experienced another chronic or acute condition, example, cancer, heart disease, have a different experience with depression, that is other than 60% than do those who have sustained a TBI.

>> Well, I think that the depression secondary to any health condition is high. There is no question about that and the research we've done with individuals with stroke you see very high numbers of individuals who sustain a stroke have depression. They found the same thing with individuals with cancer. I don't know the literature on diabetes. So I think, yeah, any time there is a health condition there is an increase in depression. I think if you begin to look at this, I think, though, the phenomenon of depression differs from group to group. So even though depression score may be the same, I think the person's experience of being depressed is for different reasons.

>> Is it possible to develop a functional description for individuals with TBI when getting comprehensive neuropsychological evaluation is impractical due to costs and lack of qualified neuropsychologists in the area? Is there a way to provide it so we can provide services within rehabilitation programs?

>> That's a good question. I don't think there is any functional assessment that I'm aware of that has been used to differentiate a person with a TBI from a person with another disability group. So the functional issues that you are going to identify are not going to be necessarily TBI specific. So you really won't know the functional difficulties are really TBI related. Having said that, what would be some of the things that you would be looking for?

I think you'd be looking again the question is what is the standard, but I think what you would be looking for is people who say it takes them longer to do things. You would be looking for people who say that they are unable to sustain their attention long enough to watch a TV show. Or read long enough to read a book or a magazine. Or remember what they saw or what they read. People who forget what they went to the store for or basically it takes them a tremendous amount of time to do their shopping because they are so

disorganized so they go from aisle one to aisle five to aisle three to -- you know, they go back to the cooler, the refrigerated items. Once for the milk, a second time for the cheese, a third time for the yogurt. People who have difficulty doing processing. They're unable to do household chores and watch their children or unable to basically plan or get themselves organized. So those are the typical kinds of functional difficulties that people have with a TBI. I don't think that there has been any functional assessment that has been able to differentiate those functional difficulties of a person with the TBI, though.

>> In a case involving a child with mild autism who sustains a severe TBI, what testing, if any, can help delineate the deficits associated with TBI versus autism.

>> The assumption I would make would be that the child with autism would have had comprehensive testing prior to sustaining the brain injury so the difficulties that emerge following the brain injury or things that got worse following the brain injury would be things that were TBI related.

>> Are medications used for other conditions also used to treat those with TBI? Or medications helpful in cognitive or behavioral functioning?

>> The answer is yes. Unfortunately, the evidence-based trials that we need in order to support the efficacy of these treatments is not terribly good or not terribly robust meaning that there are very few studies looking at drug trials in individuals with TBI. I think more drug trials are needed. I think the one thing that we do know is that people with TBI often have -- it takes a lot less medication for them to have a reaction or response to the medication so you want to basically titrate them slow. Start with a very low dose. I think

you also want to be very careful in terms of the polypharmacy you're using because the drug interactions may be different.

>> This is from New York. A recent study of parenting classes in the -- suggesting there is a significant number of preventable mild TBI cases. There is some evidence that suggests that consequences of an inflicted head injury or more significant than an impact injury. Do your findings suggest between a link of mild TBI in such cases when recognized will show links between inflicted head injury in children and learning disabilities?

>> Okay. I haven't seen any data on that specifically. But I think what you're talking about is I think obviously brain injuries that occur in that young age are prognostically not very good. I think one of the things that occurs to me oftentimes is a tremendous need for parent education in ways in which to manage the behavior of their child so that physical means are not used. I don't think we do enough education in terms of parent education, in terms of the danger of physical -- the physical use of force. And the potential destructive role that may play on future development.

>> That was the last question. Okay. Well then thank you all for attending and I would like to take this opportunity once again to thank Dr. Gordon very much for coming down from New York for this webcast to share this really I think vitally important information with us today. As you got Dr. Gordon's email address write to him directly if you have questions that we weren't able to get to today. I thank Heather for helping field the questions and with that we'll say goodbye for this webcast. Thank you.