

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

### **Reducing Restraint and Seclusion of Individuals with Traumatic Brain Injury**

July 27, 2006

KEN SHIOTANI: This is the webcast the use of seclusion and restraint with individuals with traumatic brain injuries. My name is Ken Shiotani. I'll be doing the technical introduction. You should see slides appearing 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 slides to match the audio by using the slide delay control at the top of the messaging window. We encourage you to ask questions of the speakers at any time. Simply type your question in the right message window on the right of the interface, select questions from speaker from the drop down menu and hit send. Include your state or organization in your message so we know where you are participating from. The questions will be answered at the end of the presentation. If we don't have the opportunity to respond to your question at the end, we will email you afterwards. Again, we encourage submissions of questions at any time during the broadcast.

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 loud speaker icon. For those of you who select accessibility features when you registered, you should see text captioning beneath the video window. At the end of the broadcast, the interface will close automatically and you will have the opportunity to fill out an online evaluation.

Please take a couple minutes to do so. Your responses will help us to plan future broadcasts in the series, and to improve our technical support. And with that, I will turn it over to Jane Hudson of National Disability Rights Network.

JANE HUDSON: Hi, I'm an attorney with the network. The purpose of this broadcast today is to outline the issues, behavioral challenges of individuals with traumatic brain injuries and the concerns we have about using seclusion and restraint on these individuals. We would like to help you identify both clinical and legal strategies to reduce the use of seclusion restraint for people with traumatic brain injuries. Protection and advocacy has been focused a lot on reducing seclusion and restraint on people with serious mental illness. We would like to encourage you to also start thinking about reducing seclusion and restraint of people with traumatic brain injuries. Speakers today are Harvey Jacobs, a licensed clinical psychologist and behavior analysis. His main purpose is to serve people with disabilities who are seeking opportunities to better their life. I would also like to introduce Marty McMorrow, director of National Business Development of the Mentor Network. His main goal is advocating for people with brain injury through the design of quality programs. And also translating technical behavior and analysis language into practical applications for people who are supporting individuals with traumatic brain injuries.

Before we start, I think it's important on the next slide to get the definition of restraint. There are many different definitions of restraint. So that we are all on the same page, I am using the definition from the federal statute, children's health act of 2000. Mechanical or

personal restriction that reduces the ability of the individual to move his or her arms, legs or head freely. Mechanical restraints on people with traumatic brain injuries are often cuffs on their arms, a belt around them, some people have four-point restraints. Secluded, we'll talk about that in a moment. Also a drug or medication can be considered a restraint. Used to control behavior or restrict the resident's freedom of movement. Not standard treatment for the condition. The next slide, definition of seclusion. This is the federal statutory definition in the children's health act. It's a behavioral control technique. It's not time out, which is part of the behavior management technique, part of approved treatment program separation of resident from a group for the purpose of calming. As you know, all of the advocates understand that individuals with disabilities can perceive themselves as being secluded if they are in non-locked settings. For example, staff members standing outside the door and the person is not allowed to leave the room. So we are trying to expand the definition of seclusion, the regulation for psychiatric residential treatment facilities for individuals under 21, also includes non-locked seclusion and so through the regulations we are expanding the definition. I am going to turn this over now to Harvey to talk a bit about TBI and other things. Go ahead.

HARVEY JACOBS: Thank you, Jane. Good afternoon, it's a pleasure to be here. Before we go on to the slides, we can go to the next slide for a minute. It's important we understand the definition of what a traumatic brain injury is. And there are several parts to it. First of all, it's an insult to the brain not of a congenital or degenerative process, so we are not talking about birth injuries, we are not talking about dementia and other types of issues. And it is caused by an external physical force to the brain. Most of you are familiar,

it can be from service vehicle accidents, assaults, sports injuries and the like. Second, it produces a diminished or altered state of consciousness that can result in a number of different impairments to cognitive abilities, physical functioning, emotional or behavioral status. And finally, impairments may be temporary or permanent and cause partial or total disability or psycho-social maladjustment.

Every year there are 1.5 million emergency visits annually. 80 to 90,000 people a year are severely and permanently disabled by a traumatic brain injury. And we have an idea, this is data from the Centers for Disease Control, that another 225,000 people per year experience mild to moderate disability that can -- affect their behavior and more. It's really a misnomer. They have significant impacts on a person's life to be able to work, to be able to be in the community, be with family members. Let's take these numbers in a different perspective. 80 to 90,000 a people a year who are severely or permanently disabled annually, relates to a small Boeing or jetliner with 130 people each day taking off and crashing and everybody in the airliner surviving but being disabled for life. 225,000 a year who experience mild to moderate disabilities is the equivalent of a commuter train every day, 650 people on it crashing, everybody surviving but not being able to carry out their day-to-day abilities for the rest of their life as well. So these are very significant things that when you think about it that way, you have to ask how long would it take for the National Transportation Board to take a look at the each use.

People are very safe in transportation but these are very significant types of issues. If we go to the next slide, look at sort of the prevalence of traumatic brain injury over time. And

this is the accrual of people in the United States who are now living with the consequences of a traumatic brain injury. We know that there are at least 5.3 million people, 2 % of the national population living with express disability relating to the traumatic brain injury. And other injuries such as from stroke, poisoning, loss of oxygen due to cardiac arrest, near drownings, carbon monoxide poisoning, tumors and the like, easily double the figure. To put this into perspective, probably 400,000 people in the United States right now living with the long-term consequences of spinal cord injuries. Probably 500,000 who live with the consequences of cerebral palsy, 2 million with epilepsy, 5 million who live with the consequences of long-term psychiatric disability, 7.3 million living with mental retardation and developmental disability. If you combine people living with the consequences of TBI, with other sources of acquired brain injury, more people in this country living with the consequences of that than of any other single disability. Brain injury will affect at least 1.5 million people this year. That compares to 10 to 12,000 people this year who will sustain disability due to a spinal cord injury, 52,000 sustain disability due to HIV And aids, about 175,000 people sustain disability to breast cancer. So it's interesting that despite the prevalence of disability from brain jury, remains with the national brain injury association of America called the silent epidemic. It is truly unknown to people until they or a family member face consequences of the injury.

I would like to go to the next slide. We'll talk about behavioral statistics and issues following brain injury here, but something very important to cover is that there are many challenges of people that they face following brain injury. And it does not guarantee you will have severe dysfunctional behavior, or many other types of problems. That's the focus

of the talk, as we talk about minimizing seclusion and restraint. Research data shows approximately 90% of all people who experience severe disability following a brain injury will experience some initial emotional or psychiatric distress, and that should not be a surprise to anybody. They have just gone through a life changing event. The role, goals, focus of life are severely changed. Most frequent types they are facing are issues of depression, anxiety, loss of sense of self, learned helplessness and the like. Research data shows some of the issues dissolve over time, but there's a large portion of people who continue to have problems, at least 40% continue to demonstrate substantial behavioral difficulties five years following their initial injury. As a matter of fact, behavioral and emotional issues for most people do not resolve over time but stay the same, sometimes can get worse.

If I can have the next slide, we can also see that about 25% of people experience behavior dysfunction that is significant enough to interfere with other activities of daily life. Community tenure, ability to go to work or other types of issues like that. This is just among people with severe brain injuries. When we look at people who are diagnosed with mild or moderate brain injuries, another quarter or so million people, 10 to 20%, having interruptions in their daily lives because of these type of issues. This notion of a severe, moderate or mild brain injury is really confusing. These categories were originally developed to talk about initial treatment when a person came to the attention of medical services. And they discussed the lengths of unconsciousness a person might sustain. You do not even have to have any type of unconsciousness to have neurological damage and experience some sequelae or effects of a brain injury. It's important to note that. What we

will be talking is a 3 to 10% who experience very severe behavioral dysfunction that may require intensive professional or residential intervention. Now statistically that's about 3,000 to 9,000 new people per year. But it's not only people who are newly injured. One, three, five, ten, 20 years out with severe challenges may need the services as well. So it's a larger population of people. Fairly small as it relates to the total population of people who follow disability following brain injury, but a significant source as well.

Not everybody who has the challenges needs to go into residential intervention, and some states some of the work done with Medicaid waivers helps the people in their communities and the hospitals and -- homes and the like, Marty will be talking about that as well.

If we can have the next slide. I would like to spend a little time on what causes some of the different behavioral challenges. And there are a number of reasons. Many times it's not just one single reason, but it's the multitude of interconnecting issues. People can demonstrate the behavioral challenges due to other processes or impairments from the brain injuries. A lot of times people will have problems with memory. Forgetting the sequence of skills or situations they are involved with. Forget what they are doing, and do something else. A gentleman identified as being a fire setter later on who forgot he left something on the stove which could mean the pot was burning. People may have problems with orientation, they may not remember where they are or what they are doing. And they may lose track of the environment they are in. We see this a lot of times with people who may be identified as eloping, going on a walk, a half block from their home and didn't know how to get back.

Problems with attention and concentration. We see it a lot in schools where a person who is experiencing tremendous problems with attending for more than two, three minutes at a time, some people for 30 seconds at a time, expected to sit in a classroom for an hour. They didn't do that. After a couple minutes they lose focus and they are distracted by other things and are identified as being a behavior problem. Tremendous problems with communication or comprehension. If you can't understand what people are saying to you, or can't express your needs to other people, there are going to be problems. You may be identified as a behavior problem because you are not listening to the other person. May be hearing fine, but don't understand what is being said. If you can't express yourself and your needs, one gentleman was a behavior problem because he would throw things. He couldn't explain himself to people, and people would ignore him unless he did something else to get their attention. There can be many perception changes. A person's brain can be acting normally but changes in the way they get information, visually, auditory, or sensations on the body, they may have a problem recognizing things they are seeing, may not be hearing things, so the information coming into them has changed. And they're responding normally to that information as you and I would, but with differences of information coming in, they will respond differently, and if people don't understand it, they'll be identified as having a behavior challenge.

Go on to some others in the next slide. There can be problems with judgment or reasoning, people cannot put all the pieces together and where they have problems with solving problems. People may often have problems with mental flexibility for those two issues, where they can't adapt to changing situations as well, or abstract situations to think

of different alternative, and may get stuck in patterns. Problems of stamina and fatigue. A friend of mine who experiences disability due to brain injury, says the only consistency is inconsistency. Some days I wake up and go all day, other days I wake up and fall asleep after three, four minutes. I don't have the endurance. We know what it's like to be bright eyed, and what it's like at midnight burning the midnight oil, and this occurs. Finally physical or medical co- morbidity that can occur. People react differently to medications and it can cause different effects that are not addressed over time. And there's a whole bunch of other things as well we don't have time to address.

On the next slide, other behavioral challenges as well. These might be related more to some of the neurological impairments. Many people might have damage to the frontal lobes or other areas, which may be disinhibition. It could get them in trouble because they are reacting to situations without assessing the situation. On the converse, some people may be much more inhibitory. They cannot initiate a situation and they may be determined as non-compliant and not following through. We can do simple things with such people to queue them into the situations they need to do, they can be successful. If we don't know, we see them as non-compliant. Many people have a lack of self or social awareness what's going on. They may lose the perspective because of the neurological deficits. How they are interacting or the social around them, and it may get them in trouble with other people. They don't realize that going outside just in your BVDs is not an appropriate situation they are not thinking how the neighbors will respond.

On the next slide, other things as well. People have sometimes problems acknowledging the difficulties that they had through a lack of self-awareness. The wonderful tongue twister we call -- it's a lack of awareness of what is going on. People may not understand they are having problems in some of these areas. It's not only the individuals, but other people, caretakers as well. There could be changes in frustration and anger management because of the situations, because of a lack of awareness, because of being overwhelmed with situations going on that can affect behavior. The last four things on this list are fairly interesting, because they have less to do with the specific brain injury than changes in a person's social situation. And we see these things not only affecting people who experience disability due to brain injury, but the same things as promoting behavior dysfunction for people who have lost their jobs, in communities where a major employer has left and there's a tremendous amount of unemployment in their situation as well. So with the identity change, you don't know what to do. The standard scripts and tapes that you followed in the past did not always work for you, and you will have problems. There is a loss of goal that you condition do -- you can't do any more for some people may be angry in the way you supported them before, or people may not know how to come to you. And unfortunately, there's a tremendous lack of resources, financial and others that affect what people can and can't do, which can cause types of behavioral challenges.

Next slide for a minute. Now again, as you see in the top of the slide, almost all people who experience disability following brain injury are not inherently aggressive or assaultive. This is really important. If you walk away from the webcast thinking it equates with behavioral dysfunction, we have done everybody a great disservice. But there are some

people who can have major problems when their challenges are not properly addressed, and it can result in a lack of responsiveness of request or non-comply answer. And we are talking about extreme noncompliance. Verbal or physical aggression, violation of personal or sexual boundaries, wandering, flight, harmful, self-abuse, or suicide. There are significant things that occur to a small portion of people with a brain injury. What you have to understand, short hand for this slide, not only the brain injury but the brain has been injured. When we see the behavioral challenge, the brain injury itself is not the sole cause of these behaviors. It's a combination of the way that the person new experiences the world in relation to the brain injury, and how they relate to the world, as well as how the world relates to that as well. Give and take, a reciprocity.

Let's go to the next slide. Now, these more difficult challenges are often call neuro-behavioral challenges. And it's a bit generic. Initially what it meant, behavioral challenges in which there is some contribution of cerebral damage that may be contributing to the challenge as well. Today it's sort of equates, if there's a behavior problem and brain injury it must be neuro-behavioral. But it can be caused by many different things. Pre-injury history. Traumatic brain injury is an equal opportunity impairment and disability. There may be things in a person's past that can also contribute to the challenges. People who experience disability to psychiatric impairment, physical impairment, emotional challenges, histories of addiction, or many other things, are just as likely to get a brain injury as people who don't and we have to take a look at the co-morbidity as they occur. Clinical issues with a propensity to be overly anxious, impulsive, but because of changes they are no longer able to do that, and these types of issues manifest themselves post-injury.

But it's not just the injury itself, it's the pre-injury characteristics as well. There are post-injury learning and experiences, especially if people are not getting the proper services. People may experience abuse, may experience PTSD from the actual cause of the injury or the treatment they receive afterwards that contribute to the times of issues. People may simply get over their head because of a lack of awareness of their capacities and the capabilities, and their inability to negotiate difficult situations, and they may compensate because of that. A lot of neuro-behavioral challenges are affected by others not recognizing the individual with the brain injury, as we will see in some case examples we will show you shortly, people may be identified with a psychiatric disability, or anti-social approach, and they may be treated in that way. And it may exacerbate the situation.

There's a whole global or holistic approach we have to look at when we look at the neuro-behavioral factors and the challenges. Unfortunately there's no one course of treatment for individuals with brain injury. People may come into the system for many different reasons. Some people enter through emergency rooms or emergency medical services and into the hospital, especially people who experience severe disability due to brain injury and are identified as having a severe TBI at the point of onset of the injury. Some people only come in to receive services in an emergency room and are discharged. They may have been knocked out in a football game, got hit in the head, fell off a bicycle, not feeling good, they go into the ER, checked out. Well, if you still have some problems, see your primary care provider or somebody else. And they don't follow through but weeks or months later they are noted as being irritable or problems with sleep or depressed, not the same as

before. Some people may not go to an ER, but some point later seek services from a physician or psychologist to deal with behavioral or emotional challenge they don't even correlate with a brain injury. And probably the most vulnerable people are those who never receive services because they didn't get a proper assessment, and they or others are not aware they had a brain injury. You do not have to lose consciousness to experience neurological disability, and have behavioral disturbances. If you've had a brain injury, if you are riding a bike by yourself and you fall off a bike and you knock yourself out for a few minutes, nobody else around, you may wake up and not realize you were knocked out and have loss of consciousness and sustain a brain injury. All sorts of ways they enter the system and all sorts of treatment they may or may not get.

The next slide shows the traditional way, which has developed over the past 30, 40 years, our continuum of care for people who experience a severe brain injury, pronounced loss of consciousness, and very visible deficits and injuries. In this case, people initially entered the emergency room or treated by emergency medical service, they enter into intensive care unit, neurosurgical treatments or other treatments at the time, then a medical hospital for stabilization until they are safe enough to go into a hospital-based rehabilitation facility, daily living skills, eating, dressing, walking, talking, feeding, and then transition to outpatient or post acute services and then go home or the community the problem, these services are decreasing very quickly. Perhaps five, seven years ago, it was not unusual for the continuum of care to occur for six months, a year or longer, for people with very severe brain injuries. Today the average length of stay for hospital-based rehabilitation can be as short as ten to 15 days. I have seen cases a person does not even get into the

hospital rehabilitation but is discharged from the medical hospital and sent home and their insurance policy may allow them 30 visits with an outpatient professional of their choice, and services are ended. And these decreased length of stays lead to poorer outcome that people are facing following a brain injury.

The next slide is even crazier. And if you are looking at it and you can't make sense of it, then we have accomplished our purpose. What happens is after the basic medical services are provided with whatever resources a person has from their insurance policies, Medicaid or the like, no one venue and people get bounced around from one service to another based on the fact that maybe they were able to get some funding from something, or an exacerbated problem here. People may spend time with family, homeless, he said -- end up in corrections. A tremendous number of do because of a lack of resources. A percentage, 2, 3, 4% in private or specialized homes. Some nursing homes, group homes primarily developed for people who experience disability for mental retardation or developmental disability. Others may end up in emotional disability programs as well. People are bounced around. A person may have exacerbated problem, overly aggressive or a suicide attempt, may end up in a psychiatric hospital for two, three, four days until they have let out, and let go to the family. They may end up in jail or homeless. People are bounced around over time. Unfortunately while the desired movement is towards less restrictive and community inclusive settings, the resources are not there for people and people are lost between the cracks, between the boards. For a significant portion of people, this is disastrous for them, their caregivers and others in the community.

The next slide shows some of the ideal approaches we want to see. We want to see moving toward less restrictive venues, and setting relevant to them. Being in a community program does not mean it's community inclusive if it's away from friends, family and other situations. We want people to have greater independence, self-determination but it comes with the responsibility for the choices and a focus on positive supports rather than restrictive seclusion restraint procedures. Data from the brain injury association of America, 95% of all people who sustain a brain injury do not get the long-term supports and services that they need. This is a catastrophic issue, when you consider the number of people living with challenges of brain injury in this country. I'm going to switch to two case studies, just give you a presentation of the individuals. And then I'll turn it over to Marty who will show you two other case studies and talk about some of the more appropriate approaches that can be taken.

The next slide talks about, I believe, Albert, and Albert was a young man, small sized adolescent, extremely smart who I happened to meet in a residential program teaching and treating people with psychiatric disabilities. Albert had been in and out of psychiatric hospitals for years with a history of bipolar disorder, and there were a number of behavioral issues which got him in there and kept him in there. Property destruction, excessive screaming, trying to run away from people, issues of noncompliance, and the like. When he went into the psych facilities, you can see the treatment approaches used with him on the next slide. He was engaged in episodes of seclusion and restraint. Couldn't have people tearing down the unit wandering around the unit, they were a danger to other people. Often placed in a locked seclusion room where staff would monitor

through the window until he calmed down. And Albert had his good days and his bad days. On his challenging days, he could be in the seclusion room many times, for many hours a day. Also times when staff could not get into the is seclusion room, staff held him face down t deal with the dangerous behavior. We'll save the punch line of how we were able to save Albert to later in the discussion. The next slide goes over Randy. Now, Randy was a little different but he was continually kicked out of group homes. He set fires in kitchens, ran away, noncompliance. He was on the verge of being sent away because of the issues. We'll talk more about Randy later on as well. I think the next slide belongs to Marty. So thank you for your time.

MARTY McMORROW: Good afternoon, I would like to introduce you to a lady I had an opportunity to meet a few years back by the name of Vickie. It's not her real name, of course. Vickie was about 33 years old. Very recently Vickie had been admitted into a very reputable rehabilitation program in Tennessee, but that was not her first stop following her brain injury. As it turned out, she had been treated in a skilled nursing environment for approximately a year before that. Following her medical stabilization at the hospital, she stayed at the hospital for about two weeks. A decision was made at that time that she would not benefit from rehab, and so therefore, she was placed in a skilled nursing environment. When I met her approximately a year after her injury, she was intensely confused and agitated, and I mean confused to the point that although she could speak quite clearly, she was unable to accurately identify herself on maybe two out of every times she was asked her name. Extremely confused, disoriented, didn't know where she was, didn't know who the people around her remember, and so forth. She was also quite

loud. Shouting, screaming, verbally and physical aggressive, particularly when other people were present. As a result of these behaviors, not so much at the rehab facility, but as I discovered later, more so at the skilled nursing environment.

On the next slide, demonstrates what was going on with Vickie during her year long stay at the skilled nursing environment. In her medical record when I had a chance to examine it, it consisted of about an inch and a half worth of medical restraint, mechanical restraint record, and about 30% of actual clinical document and treatment plan. In addition to her mechanical restraint, she was also given that she was non-ambulatory, and not able to get from setting to setting in essence she was in a passive seclusion situation most of her time. Given that she was female and in these circumstance, I clearly began wonder off the bat the impact of her post-injury experience with respect to the behavior she was exhibiting. Another young man I would like t talk about, Bill was 48 years old when we met. We were asked to come and evaluate Bill for possible admission into our program. When we met, it was about a year post-injury. He had spent the majority of that time at a very reputable rehabilitation program in the state of Kansas. At that time he was regularly aggressive, barely verbal, did make noises, and utterances but they were very difficult to distinguish what they were. He, too, was non-ambulatory at the time we met. He was engaged in a seizure-like behavior, consisted in placing his hands on the side of his chair and although it was described as seizure activity, to me it looked more like an attempt to actually raise himself from the chair than a bona fide seizure. Bill was being treated with gross poly pharmacy at the point we met. He was on 23 different medications, seven of those medications were specifically for his behavior management.

On the next slide, you'll see that Bill was being treated and had been being treated for some time in what was referred to as a low stimulation environment. His room was organized in such a way that he resided in a veil bed or restraint bed much of the time. The room was also configured so that there were trails that were created using mattresses in the event that he became free of the restraint bed. When he was in a wheelchair, he was typically poised to the chair. We were called to do the evaluation at the request of a third party. Both the facility staff, as well as Bill's family felt that Bill was doing the best that he could do given the severity of the injury that he had experienced. So, those are scenarios. We will return to those later and talk about some of the ways we approached them.

On the next slide, and in the next section, I would like to talk just a little bit about some traditional approaches to the managements of behavioral issues, and many of the environments as Harvey was talking about. And primarily here I would be really referring to psychiatric treatment environments. Often times medical treatment environments of skilled nursing environment. Other settings that are not specifically geared for folks with brain injury. Typical focus in these environments when people are displaying behavior that may be a danger to them self or others, is to protect these injuries from harm, and many of the procedures that we're talking about today, various sorts of restraint and seclusion, the rational for inclusion is to protect the individuals to harm from self or others. That can clearly be the focus. The focus is also whether it is stated or not, and in many cases, and over the years, these types of procedures have also been used behaviorally as reductive

techniques to reduce the possibility of the behaviors they follow. There can be a mix between a procedure designed solely to protect, and a procedure that may, in fact, be intended to treat. An important point, though, in considering restrictive procedures, in particular, is that when those procedures do not reduce the future probability of an aggressive act, or threatening act, or a self-injury act, when they do not produce an impact on behavior, they can often times exacerbate the situation and people can actually learn new ways of displaying difficult to treat behavior as a result of having experienced that.

On the next slide, I just really want to make the point that in many situations, if we look at treatment planning, often times for medical facilities or psychiatric facilities, typically there is a section of the plan that addresses behavior management, and in these settings, it is often times the case that behavior management really means three things. It means physical restraint in one way or another, it means exclusion or seclusion in one way or another, or it means medication for behavior management. And many people in this world speak about behavior management in those terms, and I would invite you to consider that if that is the case, then we would want to be very cautious going forward in our use of behavior management. It's clear we want to talk about other sorts of ways of treating the individuals that we serve.

On the next slide, just characterizing traditional staffing a tad. Every year when the brain injury association of America's resource directory comes out, I haven't done a layout, but in past years I immediately went to the program descriptions. I went to the staffing that were included as part of the rehab team in these various programs, and used to count out

the number of programs that actually included staff on their team who had either behavioral psychologists, or behavior analysis, and I was always moved by the fact that relatively few of these programs include that type of expertise on the team. Staff are rarely trained in techniques of behavior analysis or positive behavioral support as the primary motivation in the environments. And staffing ratios and deployment are rarely sufficient to meet the needs of individuals, particularly with severe injury and those who demonstrate severe types of behavior.

The next slide, just dealing with focus and a little bit. You know the focus in these programs is often on symptom management and the reduction of those symptoms, as opposed to a skilled development. And so you know, obviously then the emphasis is really placed on doing what's necessary to stop the undesirable behavior, rather than finding the root causes or doing any sort of a behavior analysis to determine what may be accounting for those behaviors. On the next slide, related to the environment, Harvey makes this point appear -- and has made it in a number of places about the effects of particular situations on individual behavior. For an individual who is coming out of a coma, in a complex hospital environment, that may contribute to behavior that might not otherwise be seen if that individual were in a familiar home setting with his loved ones present and so on. And so may contribute to the difficulties a person may be having. Other things that may contribute -- contribute, either not attending to what might be received as a request from a participant for particular types of care, or ignoring those requests in particular situations, continually correcting individuals for the things they're doing incorrectly, instead of the things they may be doing well. And of course, cluttered, crowded and loud environments.

The next slide really accents some of those things. Environmental design, we want to look at. Not only to contrast what we see in some programs as being traditional or less than ideal situations to street people, but also to lead us in the direction of more desirable ways of doing that treatment. If we see crowded areas, poorly designed units or lack of productive involvements for the individuals in those environments, we might want to begin to pay particular attention to that setting as well. Let's shift a little bit on the next slide. If we recognize what some of the problems may be in some of the environments where people with brain injury may be treated, then what are some of the things that we would look for instead? I think Jane will emphasize this in her section related to protection and advocacy. One of the first things we might look for in a program that's at least starting out on the right foot, a commission or stand or mission statement related to minimizing the use of restrictive intervention, programs which I have worked or led, we typically lead with that sort of commitment. We are committed not to use mechanical restraint. We are committed not to use medication for behavior management and so forth. So we would expect to see those sorts of things up front in the types of setting that might be viewed as more contemporary treatments for people with brain injury. Expect some basic competency and accountability, on staff and administration for effective programming. I think in this day and age, and with the literature advancing to the level it is, I think it's time for us to be clearer in terms of the expectation, in terms of who participates and what skills they bring to that particular setting. As I noted before, we may want to distinguish more clearly between management and modification techniques, and other things.

On the next slide, some other things we might look for is an emphasis on positive behavioral support. Social skills development. If our emphasis is not going to be on reduction of behavior, then it needs to be on increase of some other behavior intended to take the place of that particular behavior when that individual faces a difficult situation. What is it going to be? Do we see it when we look at the clinical records, do we hear it when we talk to staff in this environment? Also look at some of the environmental design considerations, are there environments within environment, in the event a serious behavior occurs, is there a place where that difficulty can be directed so that it doesn't disrupt the entire flow of the unit? Are there places where people can go to gain some comfort or reduce some stimulation, and can we help them learn how to take advantage of the opportunities when needed. In particular, I think we need to take a clearer stand on the way we expect staff to interact in the environments in which people are treated. And it is possible to break down desired components of staff interaction, and actually teach those components to our staff, and then evaluate whether or not they can display those types of skills in their interactions with other people. I would like to think maybe this was the wave of the future. Finally some basic accountability for evaluating treatment efficacy, treatments ought to have at their very root some type of outcome orientation.

On the next slide, if we are going to make commitments not to use restraint, seclusion, medication for behavior management, then we are going to need some alternatives in those situations where people's behavior may escalate to dangerous proportions. On this particular slide are just some procedures that we might use. It would be beyond our scope to go into detail on these. But some of them include redirection which in the case of brain

injury, a redirection technique may be resisted by a particular participant who is trying to remember that they need to accomplish something. So sometimes redirection can be very difficult to use with persons with brain injury. But in other cases, it can be very useful, and serve as a distraction in some cases. And asking again, if a person doesn't respond the first time we make a request, it doesn't mean that they are necessarily being noncompliant. It may mean that they have not perceived our communication accurately, what we need to know is request again. I know I'm that way on some occasions. I'm happy to do it, and other occasions I'm not. Asking again can be an effective procedure. Behavioral momentum is effective. And making a request that we strongly request the individual will respond positively to. If Harvey were aggressive against me, I may ask him to make a contact with me. Can you look at me? If Harvey makes eye contact at me I can shift gears for the intervention and say thanks for looking at me, and begin to encourage adaptive problem solving on Harvey's part, rather than simply correcting his unwanted behavior. If he looks at me, I may then be able to ask him, how about if we go together down this way, and if Harvey comes with me, I can acknowledge him and thank him for coming with me, and it shifts the whole focus of our intervention to stopping behavior to starting behavior. Functional placement training with respect to Vickie, and I'm going to pass over the other two for the sake of time.

On the next slide, what we have tried to do -- on the next slide what we really tried to do is create a summary of different approach to behavior change. We might view the one way column as being a traditional way of doing behavior management. Or behavior modification. On the second column, another way column, might view it as a more

contemporary approach. Now, let me shift to the next slide. We really don't have much normative data or many benchmarks to talk about, you know, whether or not mechanical restraint or restrictive procedures are being used too much or too little in a particular program. It's not typically the type of information people talk about, other than case example. So what we have tried to do here, I have taken data from a neuro-behavioral rehabilitation program located in Illinois, worked with collapsing data over a five-year period, for the individuals treated in that program. And bear in mind, these are individuals who have very significant problems, being referred from many different states for a highly specialized program. On average, there was a group of individuals in this program, the census averaged about 30 across the five years we took a look at. On average, across those five years, these 30 individuals engaged in episodes of unwanted behavior, that included physical aggression, and by that I mean striking out at others, hitting others with objects, kicking, engaging in behaviors that could produce injury to other people. These 30 individuals engaged in approximately, over the five years, the range of aggressive episodes ranged from 1200 to 1500 per year. Quite a bit of aggressive behavior from a relatively small sample. Other behaviors that were tracked in our data system which by the way we don't get the data by looking at incident reports, we get the data by embedding a data collection system in the treatment programs so we can track both desired behaviors and unwanted behaviors on an ongoing moment by moment basis. Other behaviors they exhibited in the episodes might include lack of responsiveness or request, verbal threats, property destruction, so on. On the next slide, given our commitment in this program, chemical restraint, mechanical restraint, were virtually unused in this group. However, it is important to note that lesser restrictive procedures involving physical interruption which we

define as a manual hold that lasts no longer than five continuous minutes, and manual restraint, greater than five minutes, were used with this group. And on average, of the incidents, less than 10% of the total episodes of potentially dangerous aggressive behavior exhibited by the individuals related in either a physical interruption or a manual restraint. The question really become, and we need some benchmarks to compare this type of information with other programs, we conclude that it's a good outcome, 90% of the cases we don't need to restrain or medicate, but we need more data. Jane will address related to what can advocates do.

JANE HUDSON: Hi, I'm going to talk about what advocates can do to reduce seclusion and restraint. In other words, I'm going to give you some ideas about what you can do to assist people in having more fulfilling independent, self-directed lives with hope and help them avoid seclusion and restraint. The next slide covers what I would suggest is a multi-faceted plan that they use. I'll quickly go through the steps and then discuss them in more detail. Step one is I recommend P and As establish seclusion and restraint reduction at a particular facility as a priority for the coming year. Step two, I also recommend that P and As encourage the leadership in the facility to seclusion and restraint reduction. That's what Marty was talking about. Leaders on first, before you can make a change. And along with the leadership, there has to be training with the staff and the facility. It's a cultural change to have a staff change from a behavior suppression mode to an interactive mode focus on people's strengths.

Step three. P and As definitely need to train consumers to be self-advocates. I'll talk about this more. Consumers need to know what their rights are regarding seclusion and restraint. And they need to be active participants leading the planning, the implementation, and the debriefing exercises. If you go to the next slide, step four is to get primary funding or agencies to investigate violations. The law is growing and growing on the use of seclusion and restraint. There are lots of limitations and actual out and out prohibitions of certain seclusion and restraints. You need to know what the federal laws are. I'll talk about these. Federal regulations and your own state laws, as well as the facility policies. If there are violations, they need to file complaints to get the facility to come in compliance with the law. Step five. P and As are actively doing this now, need to continue to advocate for safe seclusion and restraint legislation. The federal laws are falling more and more in place. But state laws, some states have good seclusion and restraint, others are not. We are encouraging P and As to work at the state level.

And step six, they have the authority to file. Especially in the cases someone has been harmed because of seclusion and restraint, even killed. They can talk to attorneys to get damages and to get the policies changed in that facility. P and As have also used media intensively. And to change attitudes as well as the facilities. Let me talk about each particular step. Step one is, establish a seclusion and restraint reduction and priority. I refer to P and A. I'm meaning a protection and advocacy system, which is authorized by Congress to investigate abuse and neglect and to provide advocacy, including legal advocacy for persons with disabilities. Protection and advocacy systems are in each state. The District of Columbia, and the territory. P and A establish priorities every year. They

get many requests for services and representation from people with disabilities. Protection and advocacy systems represent people with all disabilities. They need to establish priorities of what they will focus on this year, and systemic priorities, so more people benefit rather than just one individual. Protection and advocacy systems have advisory councils to help establish priorities. Many have consumers and family members but often individuals living in the community, and people who may be recovered, in recovery, and have certain experiences in the past. Also include residents in the facilities on the advisory council, so they get in the field reporting right when incidents are happening so they know what is happening at the moment. And P and As could meet in the institutions if the individuals could not leave the facilities. They also need to do research about a particular institution, in some states will is data collected, like California it is published, number of the incidents and the duration. P and As should encourage data collection. There needs to be transparency so we understand what institutions are outlying areas. You have done the research, gotten input from the individuals with disability, P and As can establish priorities to reduce seclusion and restraint. In the resource list we have the model priorities from P and As in different states regarding the reduction of seclusion and restraint. We are trying to establish a priority for the reduction for people with traumatic brain injuries.

Step two at Marty talked about, P and As have to work closely with the leadership of a facility to get commitment to reducing seclusion and restraint. One of the key elements in actually having an effective seclusion and restraint reduction planned. Many leaders will require the CEO of the facility they be called every time there is a seclusion and restraint incident. Some also require they be called and go over and are present during the

incident. And work on the reduction strategies during that time. Has to be a cultural change in staff. It needs to have ongoing staff training. There are many resources to train staff now. If you turn to the next slide. There is something on the Internet and also in our resource list, the road map to seclusion and restraint free mental health services. It was just published. It's a terrific manual. It's very hands on, step by step. It's directed to staff, consumers and advocates. It's a pick-up, turnkey manual. Also the national association of state mental health program directors has been one of the leaders in reducing seclusion and restraint in individuals with serious mental illness.

Many resources and strange materials, neuro-effects, trauma-informed care, leadership work force developments, risk factor, prevention tool, they have permitted for us to put it on our web site so you can check it out as well. Also there are various for profit companies teaching positive behavioral support, and reduction of seclusion and restraint use, and how to restrain and seclude individuals. I would really encourage P and As to find out what training program the provider is using. Research that Company and other companies, and actually attend one of the trainings. You need to know what is being taught. We can't just hear about this, we actually need to see it and live it to understand how staff and all these facilities are being taught to provide positive behavior supports and reduce seclusion and restraint. They are often good litigation and advocacy tools. In one case in New York, one of the experts was one of the trainers who said I taught this and this, and the evidence was that none of these strategies had been implemented and the individual who was harmed got significant damages. In all the trainings,

I want to encourage protection and advocacy systems and facilities to include consumers as training partners. Not only to relate their experiences, but to inform others about strategies for reducing seclusion and restraint, such as comfort rooms, debriefings, safety plans, etcetera. Training for self-advocacy is very important. By this I mean training individuals with disabilities about what their rights are and how they can avoid seclusion and restrain themselves. P and As have a congressional mandate to provide information referral and training. We would suggest put up posters about individuals' rights regarding seclusion and restraints. What is the federal and state law. And as Harvey and Marty mentioned, many people with TBI are in facilities with people with serious mental illnesses or people with developmental disabilities. You can conduct a broad rights training for everyone. It doesn't have to just be for the individuals with TBI. You may want to make accommodations and have training strategies, so people understand the information you are trying to share. You can also conduct joint training for residents and staff together, so the same message is heard by both.

Developing safety plans is very important. We have talked about this before, that an individual can talk about what their triggers are, what behaviors get them frustrated, starting to be aggressive, what are alternative strategies, and that staff and the individual know about the information in the safety plan so they can implement it. Debriefing is also very important. After seclusion and restraint incident, there needs to be an immediate debriefing to find out what happened, why it happened, how it can be avoided in the future. These should include the individual who was restrained when they are able, hopefully immediately but able to provide information about what happened, and how it

can be in the future, as well as staff, as well as the leadership again. Top leadership involved in this.

Finally, the development of comfort room. Gayle and others, I have some materials in the resource section, leaders in developing comfort rooms for individuals, places they can go where they feel safe, and as alternative to being in the environment causing their behavior to, causing them to have challenges with their behaviors. Next step, please. Step four is primary investigation agencies. I mentioned this before. P and As often file complaints with agencies if there are violations of the law. For agencies that receive federal Medicaid or Medicare funding, they must comply with federal seclusion and restraint laws. If they do not, the ultimate sanction is the funding could be taken away. Consumers, self-advocates, protection advocacy staff, can file complaints with the state agency in their state about violations of seclusion and restraint laws. Usually this is the Department of Health in the state. That agency will conduct an investigation, identify deficiency, give a plan for correction. And the ultimate is termination of funding, although that rarely happens. Nevertheless, the good thing in filing the complaint, get the state agency's attention on this issue. P and A can also look as a secondary investigation, a back-up investigation about how well the agency is doing in investigations and remedying the situation.

Next step. Next slide, please. The basic rights under federal law, review them briefly. Children's health act of 2000, citation listed there. It covers both adults and children and it does have provisions on seclusion and restraint. It prohibits seclusion and restraint for discipline or convenience. Only to ensure the physical safety of a staff member or others,

and only on the written order of a physician or other admitted by the state. And it must contain the duration and circumstances. The next slide, please, there are regulations on seclusion and restraint. Called conditions of participation. Basically you get funding if you comply with those conditions of participation. After the children's health act was enacted in 2000, the center for Medicaid and Medicare services issued regulation, conditions of participation for psychiatric residential treatment facilities for individuals under age 21, PRTF. These go above and beyond the children's health act, for example. Seclusion includes rooms that are not locked. And where the children's health act is restricted to protection against the locked room. These are in the final rule stage and we understand they are going to be issued again, hopefully this fall. Unfortunately CMS has not revised the existing regulations for hospitals, care facilities for individuals with mental retardation, or long-term care facilities. We are trying to work on a national level to get these revised so they comply with the requirements for the children's health act.

Next slide, please. Conditions of participation can cover many different things. The ones for PRTF has definition. Prohibitions on standing orders, time limit, when an order has to be renewed, monitoring requirements, debriefing requirements, reporting and training requirements. The PRTF regulations require direct reporting. We would encourage all P and As to get direct reporting. Sometimes there is a time lag when there is reporting to the regional CMS office, and then to the P and As. Better to have direct reporting. A handout on the web site Web prepared by advocacy, Inc., from Texas, with all the regulations. Accreditation agencies, and the joint commission, has standards for behavioral health care. There are standards for seclusion and restraint used if a facility is violating the

standards you can file a complaint and get an investigation. My organization, national disability rights network, does have the JACO standards for behavioral health care, and if you need us to look anything up, we are happy to do so for you. Legislative action, P and As are actively working with other advocates to get legislation passed to reduce seclusion and restraint. More and more the new frontier is schools. Children are being killed and injured in schools because they are being restrained appropriately, and several are working to try and get regulations and policies in their states to protect children in schools. Bob recently spoke at one of our national conferences of 14 elements of a good restraint law. And that handout is also in our material.

Next slide. As I mentioned, protection and advocacy can file litigation. We have the authority to do so. Litigation has been followed by several P and As in wrongful death actions and personal injury actions for damages when someone is harmed by misuse or overuse of seclusion and restraint. It will force facilities to develop policies and get their staff trained. There's a current action in Michigan just for that purpose. Next slide. P and As also use media strategies. Probably all know about the Hartford current series, 142 deaths resulting from restraint over a ten-year period. That spurred Congress to enact the children's health act. Many advocates are working with the media to raise the public's awareness of the dangers of seclusion and restraint and the overuse. Ohio P and A recently worked with the Columbus dispatch to try to reduce the use of chemical restraints for the children. In summary, you have a lot of strategies, a big tool kit you can use for reducing seclusion and restraint. Be sure to involve consumers in all your efforts from the planning stage to the training, to even helping you get information about developing safety

plans, debriefing, etcetera. I'm going to now, we are going to talk about the actual individuals we talked about before, Vickie, Randy, Albert and Bill. And how using more positive behavioral approaches can reduce seclusion and restraint. These are success stories. And then talk about the legal advocacy P and As can use to assist the individuals to avoid dangers of seclusion and restraint.

HARVEY JACOBS: Next slide, please. We'll start with Albert. If you remember, Albert was diagnosed with rapid cycling bipolar disorder, in and out of psychiatric hospitals for a long period of time. Some of the steps we did, very carefully review his history. Found out he had sustained an untreated brain injury at age four. And there was a lot of damage to his frontal lobes, which contributed to the compulsiveness, problems with shifting sets and other types of issues. Now, without knowing this, and taking a look just at behavioral presentation, it was possible, given a diagnosis of bipolar disorder. That did not take a look at the medical and neurological impact which was a disservice to him. We changed our approach on him, based on the new information. For example, some days he did very well and could sustain attention for 20, 30 minutes at a time. Other days he could only hold attention and focus for a minute and or two. We partnered with him, because ended to be successful. And so each day we would sit down and have a meeting, a team meeting.

We explained to Albert that within the team, that he was in charge to the extent that he was the president and CEO of himself. And he wanted to take that responsibility but needed some support. Identified the tasks he had to do during the day, and he would help

us set up a success plan for the day based on how he was feeling. For example, school it wasn't important he attend school for five hours a day, but that he would complete his academic exercise. Some days he could work a half hour, other days only two, three minutes at a time before needing a basketball break, quiet break, something else like this. But he persisted and he would complete his school assignments each day. There were some safe areas Albert could go to as well when he was feeling overwhelmed. We found he did not abuse those when he wanted to get out of things. He was very concrete and did not understand complex token systems or other types of programs. If he had something tangible in his hands, that he would work towards it. This is where it was great to find the shrink-wrapped and bubble wrapped toys, he would carry around with him for a day or two days, not open up until he had completed the task he had contracted to do in order to get this toy. Just saying to Albert, if you do the stuff over this day or those two days you will get what you want was too abstract for him. Being able to carry the toy, book, whatever it was he was working forgave him the motivation. We worked with a number of different techniques to understand his relationships with other people. Worked with staff to understand these things as well and how to work with Albert. And the short story to a long process, he was able to return home to the community and go back to school where he continues to progress to this day. I'll turn it over to Jane.

JANE HUDSON: Just the legal, next slide. Some of the legal and other advocacy that could be provided for Albert, of course assist him in getting a proper diagnosis, safety planning, represent him, be with him during debriefing. Also assist him in getting discharged to a facility that is more appropriate so he doesn't face the behavioral

challenges because of the facility. Also file a complaint for a violation of federal and state law. You could as a P and A be involved in training staff about the dangers of prone restraint. There's many materials about that, Albert was subject to that repeatedly. And training and advocacy to other residents being restrained in the facility. And also through the network, someone who has gone through what he has and give him hope he can have a better life in the future. We are going to skip, if you move to the next slide on Randy. You can read that at your leisure. We are running out of time and want to be sure to have questions. We'll move through the next two slides. Keep going to the next slide. And the next slide. And the next slide. And the next slide. We are going to talk about Vickie, Marty is going to talk about her and the approaches that helped her have a better life.

MARTY McMORROW: Yeah. I recall that Vickie was just admitted into a very reputable rehabilitation facility. She had been living in a skilled nursing environment for a year prior to this admission, and we were asked to conduct an evaluation to determine if they was a good admission candidate for a neuro-behavioral program. Imagine yourself going on to a hospital unit, going to the nurse's station, asking where you can meet Vickie, being pointed in a particular direction, being asked if you would like to read the medical record. I typically like to meet people before I read the records. I said well, no, I'll meet Vickie. The staff was quick to tell me that I better be careful. I think to protect against their own potential liability if I was to enter Vickie's room and that I should expect that she would immediately be aggressive against me. In fact, the staff were absolutely correct. When I walked in the door to meet Vickie for the absolute, very first time, within seconds of my arrival she began to scream, shout profanities, question my ancestry, throw things at me,

and of course I remained out of reach. I recall that she was also functionally not ambulatory. I knew, and I began to ask myself the question why when you just met someone would you respond in this way? And fundamentally, why is at the root of all behavior analysis questions, why do people behave as they behave. I tried to come up with some quick answers.

Obviously Vickie was not going to be able to answer the question why are you acting this way? I decided to come up with my own speculation as to why that was happening. The easiest conclusion I could come up with, and I think it's a relatively common sense one, was that Vickie was responding in this way because she wanted me to leave the room. She wanted me to go away. But, I was very concerned that if when she is throwing things at me and shouting at me and so forth, if I simply turn around and go, I could inadvertently strengthen her unwanted behavior. She could learn that in order to drive people away from her she could scream and shout and be aggressive. And as we see later, I believe she had learned that. I knew I could not respond that way. So very quickly had to come up with an alternative. Two of the alternatives are listed on the earlier slide. I tried to use interspersed requests and functional replacement. So as she was screaming, assuming what she wanted was for me to go away. I raised my hand and I said if you want me to leave, just ask me to leave. And of course she didn't do that. So, because she didn't respond, I didn't immediately tell her to stop doing what she was doing, I used interspersed request and asked again. If you want me to leave, just ask me to leave. Actually using the exact same words I had used the first time. After about six different trials of doing this, with her screaming, with me asking her to request in a more

appropriate fashion, Vickie said would you get the blanky blank out of my room. I said that's good enough for now, and I left. Obviously trying to find an easier, more efficient way of accomplishing the same outcome. If she would like me to leave the room, I'm prepared to leave the room if she will do that in a way that's more acceptable and less dangerous than throwing things.

She was not very oriented to time, so during the afternoon that we spent together, about three hours, I went out of the room, I immediately came back into the room, she was somewhat surprised to see me when I did. So she started screaming and hollering at me again. I just repeated the same request that I had made before, if you want me to leave, just ask me to leave. This time she said would you leave. Without using any, any profanities at all. I thought that was a good shaping step. And a success approximation of a desired behavior. By the end of the afternoon we were sitting together for periods of time, up to 30 minutes, during those 30 minutes of time I was orienting her to who she was, who I was, where we were, and kept imagining to myself, we are one year following her brain injury and we are just getting to work. And it was a very moving experience. We definitely wanted the opportunity to serve this young lady in our program. I thoroughly believed that she was traumatized by the experiences she had while in the skilled nursing facility. Imagine being confused and disoriented, and being restrained by individuals that you don't know. Imagine that you're female, imagine that the people restraining you are male. I say potentially trauma and she did not get the public support which she needed to continue in the program, and we need to continue to advocate for people to get the right treatment for their difficulties. Vickie didn't get that opportunity.

JANE HUDSON: Let's move to, we got a few questions. We'll try to answer as many in the last few minutes and answer by email the ones that don't get answered.

KENNETH SHIOTANI: Marty, some of the strategies you expect from staff and note the kind of training tools you use to instill those, and that's from Colleen in Kentucky.

MARTY McMORROW: Good afternoon, Colleen in Kentucky. The interaction components we teach to staff in the staff training programs, we have identified a definition for proactive interactional treatment. Identified five components of what we believe desired interaction entailed. Those five components vary briefly. Are positive. We all have some notion of what a positive interaction looks like, and a negative interaction. Positive is inviting people to be with you. Second components, to be early rather than waiting around for dangerous behavior to develop. We teach our staff very specifically to recognize the early signs of emotional upset, and to intervene early in the sequence of behavior that may lead to something dangerous, so early is the second component. Next component is all. That means all participants, all the time, all environments. Not just the people the most fun, but to interact with everybody in a very similar fashion. The next is reinforce, so we believe people do need to learn a little bit more about how to have a mutually reinforcing interaction with individuals, and how to use praise statements in their interactions and to recognize behavior that can be strengthened with verbal praise. And final is look, look for opportunities to teach. If you combine it, it spells the word pearl. Staff can recall the word pearl, typically they can remember the words that go along. Recall the words, they can

begin to describe what the desired behavior is. We have designed a way to teach it, using training materials that are also publicly available. And we have learn learned how to evaluate staff performance on a regular basis using this particular training.

JANE HUDSON: The time is almost up. All the resource materials mentioned are on the resource and reference list. I want to thank Marty McMorrow, Harvey Jacobs, Ken Shiotani, and hrs -- and HRSA. Thanks so much.