

Acquired Brain Injury

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>> RAY ZARDETTO: Hello, I'm Ray Zardetto and welcome to Disabilities At Work Radio here on the VoiceAmerica Business Network. Each week at noon Eastern Time Disabilities At Work explores issues, ideas, initiatives and innovations involving the workplace and people with disabilities and discusses them

with prominent members of the business, government and disability communities.

Disabilities At Work Radio is brought to you this week by two distinguished organizations dedicated to improving the lives of the disabled, the Kessler Foundation and the New Jersey Division of Disabilities Services. And we will talk a little bit more about each of them later on.

As for today's show, if I were to ask anyone in the audience, any of you ladies and gentlemen, if you know the number one cause of death and disability for American children and young adults in this country, I wonder how many of you would know that the answer is brain injuries. In fact, the numbers are stunning. Over three million new cases of brain injuries occur each year. Three million. And this can result, this has resulted in 17,000 permanent disabilities and over 12,000 deaths in children and young adults.

These figures come to us courtesy of the Centers for Disease Control and Prevention. You can also find them on the website of the Sarah Jane Brain Foundation, which is a nonprofit organization dedicated to the study of brain injuries and to helping make better the lives of those with brain injuries and their families.

So today we are going to discuss the staggering problem of brain injuries with a distinguished panel of guests. So let me introduce them to you now. First, Ann Glang, a Senior

Fellow, Research Professor at the Teaching Research Institute and a Research Scientist at the Oregon Center for Applied Science. And Ron Savage, the President of the North American Brain Injury Society, Founder of the Pediatric Task Force of the Brain Injury Association of America, and Senior Consultant at the Center for Neurological and Neurodevelopmental Health in Voorhees, New Jersey.

Both Ann and Ron are members of the Sarah Jane Brain Foundation's advisory board. So Ann, Ron, let me welcome you to the program first.

>> RON SAVAGE: Thank you very much.

>> ANN GLANG: Thank you.

>> RAY ZARDETTO: Thank you for joining us. And rounding out the panel is Patrick Donohue who is the founder and president of the Sarah Jane Brain Foundation. And, Patrick, I'd like to start our discussion on the show today with you by asking you exactly who is Sarah Jane?

>> PATRICK DONOHUE: Well, Sarah Jane is my five-year-old daughter who was born in June of 2005 and she suffers from a severe brain injury when she was just five days old. The baby nurse that we had hired to be with us for the first month of her life and teach us the ropes violently shook her when she was only five days old, breaking four ribs, both collar bones and then causing this severe brain injury, which has left her permanently disabled and changed her life and my life and our

entire family's lives forever.

Um, and she is my daily inspiration. And what ended up happening was about a year into the daily routine of taking care of her, I started to read up as much as I could on neuroplasticity, neuroinformatics, and anything I could get my hands on about the brain. What I quickly realized was -- by the way, I only understood only about ten percent of what I was reading. What I quickly realized was how little we knew about the brain, never mind the developing brain, that as a layman, the way I describe it is, we relatively know about the same amount about the brain as we knew about cardiology in the 1850s. We probably know about five percent of what we will eventually know.

On top of that, I realized how fractured the field was, that there was no one repository of knowledge or information, and it's all over the map. And people are working in individual silos all across the world dealing in this field and it reminded me of the computer science field of the 1950s and 60s where you had brilliant people out of the world working in it, but nobody knew what anybody else was doing.

So what ended up happening was I fast forwarded 50 years and I started thinking, well, what are the breakthroughs occurring today in those fields and they are all using open source principles, whether it's Wikipedia, Lennox Operating System, shared knowledge is where the breakthroughs were

occurring.

Think of the human genome project, I think that is a good example, and so I started to research to see who was using those principles in the field of neuroscience and specifically pediatric neurology. I figured that is where the breakthroughs would occur for Sarah Jane. And so I researched high, low, called and e-mailed people out over the world and the bottom line is that no one was using those principles.

NIH started a thing called the Human Brain Project about 15 years ago, but Sarah Jane is going to graduate from Yale by the time they complete the damn thing. And one of the things that you quickly realize is that I'm not really a patient person when it comes to helping my daughter. And so that's what sparked me on, you know, the mission of starting the Sarah Jane Brain Foundation.

>> RAY ZARDETTO: In knowing just a very little bit about what occurred, I would say, if I had to describe it, that the initial diagnosis that the doctor made of your daughter's condition when it occurred was a pretty bleak diagnosis, I think. And I'm just wondering, you know, how you reacted to it then and what prompted you to -- because I think a lot of people might have just accepted the doctor's diagnosis at that point, but what prompted you to do what you are doing now?

>> PATRICK DONOHUE: Well, one of the unfortunate things is one of the doctors that we first-- one of the first doctors we ran

into basically tried to, you know, state that her injuries, from a scale from one to ten was an eight, and that Sarah Jane would probably never walk or talk. And this was a child who was less than a month old.

While I was fortunate enough to have other contacts that I had spoken with, which the consensus in this field is that the answer, really, is that nobody knows. So I was fortunate enough to have, you know, second opinions from people basically saying that nobody really can make a prediction about a brain injury with an individual and certainly you can't really make most predictions about brain injured children just because there is not enough information or data and we just don't know enough about the brain to make those types of diagnoses.

And so, I mean, the bottom line is that the philosophy that kind of wakes me up every single day and keeps me going is that things work out best for those who make the best of the way things work out. And so that's what sparked me to continue looking and searching and trying to find more.

And the reality is that what my goal is, is that I'm certain 50 years from now, you know, a case like Sarah Jane, there will be tons of different types of treatments and protocols, and, and -- that will exist, um, but I'm not interested in wasting 50 years. So my mission is really to advance what we know about the brain and certainly advance what we know about brain injury 50 years in the next five years

because Sarah Jane is five, and, you know, I'm not going to wait until she's 50 for the science to catch up.

>> RAY ZARDETTO: And let me ask -- let me bring Ron and Ann in with a couple of questions here. I'm just wondering, on a very base level here, how do we define a brain injury? I mean, how severe does the trauma to the brain have to be for it to qualify as a brain injury?

>> RON SAVAGE: Well let me just start with a little definition thing and then have Ann really take this on. When we talk about acquired brain injury, the acquired part, what we are talking is from birth on.

In other words, Sarah Jane was a very young child, you know, just a few days old when this happened to her, or she could have been 11 years old, or she could have been 16 years old, or 22 years old, but it's acquired after birth. This is not a developmental disability or something else.

Then when we look at acquired brain injury, we break it down into two large groups. Some brain injuries are caused by an external physical force. In other words, a child is in a car crash, the head hits the windshield or they fall from playground equipment or off the deck at their house. Or maybe it's a sports injury or an assault, shaken baby syndrome. So those external physical forces, something from the outside in, jarred that brain and did damage.

And then we have a group of what we call internal

occurrences. So you can have a brain injury because maybe the child had a stroke, or the child had a tumor resection.

Infectious diseases like meningitis and cephalitis and even neurotoxins like carbon monoxide poisoning, all of these things can cause brain injuries

>> RAY ZARDETTO: And it's kind of a difficult thing, as Patrick was saying before, however, because the brain is probably the least understood part of the body, certainly one of the least most understood parts of the body. And so, I mean, how do you distinguish between someone who just takes an accidental knock on the head versus somebody who may have a concussion or someone who got something that is much more of a traumatic kind of brain injury? Where do we kind of draw the line between something that is not particularly serious and something is much more of a brain injury?

>> ANN GLANG: I think I could tackle this one. The thing that is so challenging on the positive side and the thing that is so very, very difficult on the negative side is that you have a very, very large range of effects from brain injury.

So you can have a child looking, walking, talking, speaking, behaving very, very normally, and yet have some significant cognitive impairments that are very hard to see. You can have a child who looks very -- who maybe has some physical challenges associated with the brain injury, but it does quite well in school and everything on all ends of the

extremes. So it's very, very difficult.

When it comes to, you know, what Ron and I are dealing with, which is primarily is in the school setting, because that's where kids are being served, is in the schools. And when you look at brain injury in the schools, you have some very clear definitions, um, based on special education law about who gets services and who doesn't, and that's related to the disability.

So it's very complicated, there's a lot of angles and aspects to this, and I think when Patrick says where we were in cardiology in the 1800s, with this disability in the schools and in terms of services and supports, we are maybe where we were in the 70s, maybe before that even. So we have an extreme lack of awareness, we have lots of work to do.

>> PATRICK DONOHUE: And if I could chime in, even the nomenclature that she used to describe brain injury, I mean the terms they use are mild, moderate and severe are basically the way brain injuries are defined. But if you take just a simple definition of a mild traumatic brain injury, the brain which has a consistency of, say, hard Jell-O, if you stick, you know, that hard Jell-O in front of a car going 20 miles an hour, that's actually classified as a mild TBI. So, you know, you go stick your cell phone in front of a car going 20 miles an hour and expect that to work and function properly. And you know, the complexities here all over the map. And the frustration

piece is that a lot of the burdens are put onto the families to make determinations about the care for their children. And it's random and, you know, from one state to another, and it's arbitrary from one school district to another. And it's a crap shoot from one doctor's office to another.

And so the concept of what we started to do with Sarah Jane Brain Foundation, when we launched this, is I saw how scattered things were so I decided to use those open source principles and what I came up with was for the first time in medical history, putting all of Sarah Jane's medical records online in an open source format. My thinking on it was bare minimum; I'm going to get more eye balls on her case. I'm going to get some research scientists from Switzerland at three o'clock in the morning instead of watching March Madness, you know, he or she likes to look at EG's. Or a physical therapist in Florida looking at a video of Sarah Jane and suggesting a different rotation.

And as we started to develop that, what happened is, many of the doctors that are involved with Sarah Jane basically said to me, you know, Patrick, if you can get fifty or a hundred or maybe even a thousand families to participate in an open source initiative like that where you are sharing information and understanding, we could really advance the field of brain injury, you know, more so than any other field. And if it's successful, it can be a complete paradigm shift on

how, you know, collaborate and collect research data and share it amongst one another. And that's kind of how this whole project started.

>> RAY ZARDETTO: Great. Well, panel, we need to take a short break at this point. And when we come back, I want to talk a little bit about the prevalence of brain injuries and also talk about where we are in terms of research and some of the breakthroughs that we have either seen or may be on the horizon. But we need to take a short break first, so ladies and gentlemen, stay with us, I'm Ray Zardetto and this is Disabilities At Work Radio.

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>> RAY ZARDETTO: Welcome back to Disabilities At Work Radio here on Voice America's Business Network. The show this week is brought to you by the Kessler Foundation and the State of New Jersey Division of Disabilities Services.

I'm Ray Zardetto and today we are talking about brain injuries with a panel of distinguished representatives from the Sarah Jane Brain Foundation, a nonprofit organization and one of the largest organization of its kind dedicated to the study of brain injuries.

And we are happy to welcome a new member to our discussion panel here, Dr. Joseph Tepas, University of Florida Professor of Surgery and Pediatrics and Chief of the Division of Pediatric Surgery at the University of Florida. And Dr. Tepas is also on the advisory board for the Sarah Jane Brain Foundation. So, doctor, welcome.

>> JOE TEPAS: Thank you. It's good to be here.

>> RAY ZARDETTO: Actually, it might be a great time to bring you into the discussion. We were talking during the first segment about some of the staggering numbers that are involved in brain injuries, over three million new brain injuries are reported a year according to the Centers for Disease Prevention.

And I was just wondering if we can put that into some perspective to begin this next segment of the discussion. I mean, when we talk about the prevalence of brain injuries in this country, how prevalent are they when you compare them to incidents of, you know, major diseases like cancer, heart disease, even asthma and some of the other well-known maladies that we have to deal with?

>> JOE TEPAS: Well, I can answer that question in a fair amount of specifics by pointing you to the original work that was done by Sue Baker in 1975 regarding trauma as the, quote, untreated modern disease. And in that particular, uh, monograph, which was actually produced by the Institute of Medicine, she points out that when you look at the actual years of life lost from injury in general, and brain injury's obviously a mainly driver of that, and you compare that to the volume of dollars of researched, you see that that is the one area that has the most dominance, both in our county and globally as far as a cause for disability and loss of life

against the paltry amount of dollars that are spent for research.

The curve for, or the boxes for, money that is spent in investigating AIDS or heart disease or cancer far exceeds the actual loss of years of life from those diseases. Trauma is just the opposite. Trauma is the primary killer of everybody under the age of 44 and yet has miniscule amounts of dollars that are dedicated to its research.

Now I follow up that comment by telling you that, you know, if you are diagnosed with cancer or heart disease or something like that, you obviously have reasonably objective symptoms that quickly force you to seek medical care. But there are children who are sustaining, quote, minor brain injuries, as well as those who are getting more significant injuries, who are actually experiencing significant anomalies in the function of their brain and in the future development of their brain that are literally under the radar and don't even manifest themselves for years after the event, often times with the event being forgotten.

So when you put those two things together, the short answer to the question is its staggering and its epidemiological pervasiveness in our society. And it's unsettlingly quiet in that there is a huge amount of it that is way under the surface that is emerging in everything from cognitive to behavioral problems to early dementia that we are

just now beginning to get an even slight understanding about. That was about a million words but that tells it.

>> RAY ZARDETTO: But it's a very compelling story though because you, you know, I think certainly just these numbers are stunning to me. And I would agree, it seems as though this whole situation has been under reported, no matter how you look at it. And so --

>> JOE TEPAS: Right. Under reported and under diagnosed. No question about it.

>> RAY ZARDETTO: From that point of view, I guess you could understand why the dollars have not been there in terms of research and everything. But in terms of research, in terms of what we are seeing with the breakthroughs now on the horizon, and I'll throw this out to anybody on the panel, what can we hope to see soon? What are we seeing in the way of breakthroughs in some of the research work that is going on in this area?

>> JOE TEPAS: Well, I don't want to steal the thunder from my colleagues on the panel, but even that question can be answered by focusing on various and [inaudible] elements within the area of management of this disease and of course the most impressive and important vaccine against the disease of injury is prevention.

We certainly are not spending as much money and effort as we should be in conveying efficiently a prevention message

that enables young parents, especially, to do some fairly simple things that would significantly enhance the safety of the environment in which they raise their children.

>> RAY ZARDETTO: And what would some of those be?

>> JOE TEPAS: Well, for example, just the whole process of appropriate child restraint, use of helmets, safe walking programs. Many of these things exist in spots throughout our country, but have not been globally disseminated. And, interestingly enough, a classic example, one of the papers that was discussed and presented a couple of years ago at the Injury Free Coalition, where an extensive and very expensive system of helm safety and preparation prevention for the natural disaster of an earthquake in Southern California was developed and no one thought to remember that there is a significant amount of that population that don't speak English. So these are the simple things. This is the low hanging fruit, so to speak.

You know, you walk around some of the major cities in our country and you see no sidewalks, and then you wonder why children don't cross at crosswalks. So there is a lot of just basic environmental engineering. There is a tremendous amount of educational initiative regarding, you know, safe play and the need for exercise, um, things of that variety that is either not delivered because the methodology or the modality isn't there or the ability to do it and the funding to produce an effective and compelling message is not provided. That's

number one.

But then in the answer to your other question, so when prevention fails and the injury occurs, you know, over the last 25 years we have seen a dramatic evolution in our emergency medical services and trauma systems that have enabled us to significantly improve outcome from massive and devastating injury. And some of the processes that we are learning regarding how the brain reacts to injury, things that we can do to minimize ongoing injury, various asundary (phonetic) biological and biomarker research studies, looking at how the neuronal cells are forming, these are all things that are going to help us describe a more effective, efficient and hopefully cost efficient system of caring for these patients as well as defining more effectively their prognosis so that we can plan for long term surveillance, rehabilitation, reintegration in a more intelligent and effective manner.

>> RAY ZARDETTO: We talked earlier about the levels of severity when it comes to brain injuries, and so, using that as a context, let me ask a very simple layman's question about this thing, which is, do we see a day when we will actually be able to cure brain injuries?

>> JOE TEPAS: Um, that's a very difficult question to answer. Obviously we cure them with the effective vaccine of prevention, but when the injury occurs will there be ways that we can control neuronal dysfunction and stimulate neuronal

regeneration, reprogram neuronal circuitry? Um, I think to some degree the answer to that question has to be a qualified yes. The timeline, however, remains to be seen, but when you look around you and you realize what we are beginning to understand about how cellular physiology and the human genome and molecular biology actually work, then it becomes apparent that the more we become comfortable in understanding these areas, the better we will be able to at least predict, if not manipulate, some of these cellular functions. So I think the answer that is to be an unqualified yes, but don't expect it tomorrow.

>> RAY ZARDETTO: Right. And to the other members on the panel, I mean, again, we talked earlier about the severity or the levels of severity of brain injuries, you know, for someone listening to the program, I mean, can you give us just a very quick summary of what each of the levels means or how one of the injuries qualifies as a less severe injury than another one?

>> RON SAVAGE: We use -- the common classification system is mild, moderate and severe. In terms of, you know, quantifying a brain injury it's based upon some medical measures. And, you know, what happens, all of us that are sort of all in the field practicing, know that you might have a significant bang to the head that might not render you unconscious, but you might end up with long-term psychological, cognitive, even psychiatric

problems afterwards.

So even though those medical designations of mild, moderate and severe are good for Dr. Tepas and others to use, it doesn't necessarily translate into functioning. And that's why the example was given before that even for people with so-called mild brain injuries, especially children, we may be, one, underestimating the numbers and, two, underestimating what the needs and the deficits are from those kids.

We certainly know in the NFL right now that concussion is a huge issue in terms of looking at these NFL athletes that are getting concussions, multiple concussions, and actually having to leave the sport. By the time they get into their 40's and 50's, going into early dementia and Alzheimer's, but we have a lot of young kids playing sports in this country who get the proverbial ding to the head or the bang and it might not knock them out, but what does it do to them? That's a huge group of children that we are just beginning to start to recognize and start to treat better.

>> RAY ZARDETTO: And it's not just football when you think about it, because, I mean, soccer, the children play with no helmets and thing like that. So I don't know if it's ever practical to say the kids won't be playing sports any more, but how do we --

>> RON SAVAGE: Well, you know, it's like Dr. Tepas said, you know, and I sometimes get into a little trouble when I say

things like this, but, you know, when I take my granddaughters to the park, the amusement park, there are always this little wooden cardboard figure outside that says if you aren't this high, you can't get on the ride. But we have children in this country that are playing contact football as ages 6, 7 and 8. The equipment never fits them, the helmets certainly never fit. And is that something that we need to look at differently?

And even in soccer, even though sometimes people will talk about head bans, most soccer concussions are either head-to-head impact or head-to-ground impact.

So we have started to take a more in depth look at how children experience concussion and what kinds of sports. And one of the classic examples is cheerleading. Even though under title nine, and we did a great job in terms of having equal sports for both sexes, cheerleading is not a sport under title nine, it's an entertainment. So cheerleaders who end up, you know, they are tossing themselves, they are falling, everything else and getting hurt, we have not even begun to put in measures for them in terms of concussions based on assessment.

>> RAY ZARDETTO: And, you know, I was wondering, given your position and the work that you do as a research professor, if you can give us your perspective relative to where we are and where you think we are going?

>> ANN GLANG: You know, I was just going to add to what Ron was saying that one of the things that happened, I'm not sure

when it happened, it may have been like in the 90's, but gymnastics was a big sport in, across schools in America up until I believe it was in the 90's when somebody said, you know, this is a dangerous sport and schools could be held liable for any injuries that happen. So gymnastics stopped being covered and being a school sport in many schools across the country, if not all of them, and lots of those kids went into cheerleading.

So we do have lots and lots of injuries from cheerleading. It's boys' football, its girls' soccer, its basketball, it's cheerleading. And that's, you know, huge numbers of kids. So the under recognition, the under diagnosing from not just sports injuries, but obviously motor vehicle crashes and all of the other ways kids hurt themselves, it's a very big problem.

[Talking simultaneously]

>> RON SAVAGE: In terms of those numbers, which we have given out these millions of kids, but what if for every kid with a brain injury in this country we turned down the Amber alert light? I mean, you start talking about millions and millions of kids each year, you think of how many each day and how many every hour, the Amber lights would be on 24/7 across this country.

It's a silent epidemic that we have not been able to grab a hold of yet and really shake out and then, you know,

sort of start to structure something around, which is why when Patrick Donohue brought together over 50 of us to really think and to develop a national plan, a pediatric brain injury plan, it's the first time ever in this country we have addressed this from a nationwide focus.

>> RAY ZARDETTO: That's actually a good point because we got to take another break. When we come back I do want to expand on that point some more because the open source principle that Patrick discussed at the start of this has actually expanded now to where the work done by this foundation and, of course, many of the related activities are now more than just local, it's more than national, it's international. And, you know, brain injuries aren't just specific to the U.S., they are everywhere around the world. I want to talk about that some. And also talk a little bit about the Zachary Lystedt Project when we come back.

Before we go to the break, let me invite everyone listening to the program to join our tteam at DisabilitiesAt. And please visit us on Facebook at Disabilities at Work.

We will take another break and we will be back to talk more about the situation regarding the brain injuries both here and around the world with this distinguished panel from the Sarah Jane Brain Foundation. I'm Ray Zardetto and this is Disabilities At Work Radio.

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>> RAY ZARDETTO: We are back on VoiceAmerica Business Network, this is Disabilities At Work Radio and I'm Ray Zardetto.

Today's show is sponsored by the Kessler Foundation, which is dedicated to improving the lives of the disabled and does so through rehabilitation research done by the Kessler Foundation Research Center and through the work of the Kessler Program Center which prepares the disabled for the demands of the workplace. And for more information you can visit their website at www.kesslerfoundation.org.

Also sponsoring our show today is the New Jersey Division of Disabilities Services, part of the State of New Jersey's division of Human Services. And this division focuses on helping people who have become disabled as adults so they can live more independently in their communities and Disabilities At Work Radio thanks both the Kessler Foundation and the New Jersey Division of Disabilities Services for their consideration and sponsoring this week's show.

We are going to return to our discussion now about brain injuries. And, again, our panel is Ann Glang, Ron Savage, Dr. Joseph Tepas, and Patrick Donohue. I wanted to continue the discussion now with Patrick, first, to discuss another related project to the Sarah Jane Brain Foundation project and it's the Zachary Lystedt Project. And Patrick, why don't you fill us in on that?

>> PATRICK DONOHUE: Sure, well as Dr. Savage had mentioned before, sports related concussions and brain injuries are obviously a huge subset of the three million brain injuries

that occur each year. And there was a young man in Washington State named Zachary Lystedt who was a 14-year-old star football player who had sustained a concussion playing football.

He sat out for a little while and then they put him back into the game and on the last play of the game he suffered a second impact, which left him permanently disabled. And him and his family, a very brave family, decided to take the situation and effect change.

What they did is they passed a law in Washington State, a similar measure was passed in Oregon called Max's law, with the very simple core principles of that, number one, parents and youth athletes and coaches have to be trained and educated about the risks associated with head injuries and concussions. Number two that if there is a suspicion of a concussion or a head injury that that youth athlete has to be immediately removed from play or practice. And the third piece is that they can't be put back in to play or practice until they have been medically evaluated by a licensed healthcare provider.

Now that may seem like it's a fairly common sensical law, and on top of that the law they passed was budget neutral, but while there may be some guidelines out there, you know, in different areas, until they actually made it a law did they see a significant change in both Washington and Oregon.

And so we partnered up in January right at the start of the Super Bowl week with the American College of Sports

Medicine to initiate those core principles and legislation in all of the remaining 47 other states. Texas had a law in place as well to implement these types of Zachary Lystedt laws all over the country and since then, there have been laws passed now in Rhode Island, Connecticut, Virginia, Oklahoma, New Mexico, and there is legislation moving through the different legislatures in about another 15 or 20 other states around the country.

So the idea of the Zachary Lystedt Brain Project was to advance these core principles through legislation, through public awareness, and then increasing, you know, the research and understandings around these sports related concussions and brain injuries.

>> RAY ZARDETTO: Well, aren't these teams required to have a licensed physician at practices, at the games to be there to look exactly for those kinds of situations?

>> PATRICK DONOHUE: Absolutely not. Many, I think there is -- I forget what the number is, but it might be upwards of 60 percent of high school don't have athletic trainers at their sporting related events.

So, I mean, it's a massive, massive problem. And just to give an antidotal type of story, in Washington State a few weeks after they initiated the law and they started training, there was a high school coach who, during a scrimmage, saw a kid get a ding and seemed a little dizzy. And under normal

circumstances, the coach said that he would just have sat the kid down for a little while and put him back in. But because he had just been specifically trained around this, he sent the kid to the emergency room and they found that he had a bleed on the brain. And under normal circumstances if he had gone back into that game, every doctor who saw him said if he had gone back in and sustained another head injury, the likelihood of permanent disability, if not death, would have been almost certain.

So I mean these are things that are happening all over the country. And to put things a little bit more into perspective, you talk about the numbers in the previous segment, what happens here is that little Suzie or little Johnny there, they are playing soccer when they are eight years old or they fall out of a tree and they get a concussion and within a day or two they seem to be normal, happy-go-lucky, doing well in school, socializing again, but all of a sudden they are in high school and using executive functioning of their brains, these kids are going from A students to C students, but they are being misdiagnosed as ADHD, behavioral problems, drug problems, family problems, when in fact it's the brain injury they sustained six years earlier that was never tracked and treated properly.

And just to give you one really staggering number, I think it was in Minnesota, the CDC did a study where upwards of

80 percent of the kids in our juvenile delinquency system have some form of a brain injury. 80 percent.

Now in Texas alone, there are a hundred and six thousand kids under 18 years of age in the juvenile delinquency system. That means 50, 60, 70, 80,000 kids that are going through this juvenile delinquency system that are not being tracked and treated with a brain injury, and then they are being dumped into an adult system and we wonder why we have such a high recidivism rate of crime. I mean, this is literally a public health crisis that is going on out there and, you know, I truly believe that these Zachary Lystedt laws are going to really help raise awareness and understanding across the board dealing with these types of concussions and brain injuries.

>> RAY ZARDETTO: And I think, um, probably one of the most important facets to discuss now would be, I mean, first of all, the idea of the brain injuries and the massive, massive problem, as you called it, is not limited to just to the United States. This is a worldwide phenomenon I would assume. And so, you know, how important is it that we link up with doctors and researchers and experts in other countries and on other continents to work this?

[Talking simultaneously]

>> PATRICK DONOHUE: I had the good fortune with Dr. Gene Gillette, who was the pediatric neurologist out of Canada, and we cofounded the International Pediatric Brain Injury Society.

We now have representatives from 80 different countries, because many of us that have had the experience like everyone on the panel here to work with colleagues in other countries, we have the same discussions.

A large number of kids are injured, this is how they are injured, some countries it differs. For example, in India, a lot of 10 to 16-year-old boys suffer brain injuries from falls because they are doing a lot of labor and going up into high-rise buildings and bringing the materials to the men that are constructing the buildings, and these kids fall.

So every country, these kids get brain injuries in a different way, but we are all seeing the same thing, and one of the things that is critical to bring into the show that we are finding is, we mentioned the research before, it is the longitudinal studies.

We have a number of longitudinal studies in the states and other countries that have looked at kids over two, three, four, five, ten years. And what we are finding is that injury, that early injury to a developing brain, you know, a child's brain is still in development up until their early 20's, that an injury to a developing brain can have lifetime consequences.

And so now as we are looking at this from an international perspective and we are getting more people involved in the -- our pediatric acquired brain injury plan from other countries, it is, in a nut shell, we are all sort of

seeing the same thing, even though our kids may be injured differently, this brain injury can have a lifetime of consequences for that child in that family.

>> RAY ZARDETTO: This is a fascinating discussion and I want to continue it, but we have to take one more break. When we come back, a few more questions about the foundation, about brain injuries and about what people who are listening to the show today can do to help.

So ladies and gentlemen, stay with us. I'm Ray Zardetto and this is Disabilities At Work Radio.

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>> RAY ZARDETTO: Welcome back to Disabilities At Work Radio, and remember that Disabilities At Work Radio can be heard each Wednesday at noon Eastern Time on Voice America's Business Network.

I'd like to get right back into our discussion about brain injury and what is being done about it and what can be done about it with our panel.

And I'd like to start by asking -- and Ron, I'm sorry, Pat had ended the last segment talking about sometimes the misidentification or the lack of diagnosis in suspected brain trauma or injury, and I thought maybe you would want to pick up on that point a little bit.

>> ANN GLANG: Yes. And I think the numbers really speak to that. In 2008 there was a study by CDC, the author was Alosna (phonetic), and, um, they found, or they estimate, that there is about 135,000 children in youth, ages 5-19, who have a

disability from traumatic brain injury. But if you look at where those kids are served, as I said before, those kids are in school, they are being -- they are in your classrooms across America today. And if you look at our special education system, that is the part of our educational system charged with supporting children who have learning, behavior, social, cognitive problems offers special education programs. There are 23,000 students labeled as traumatic brain injured on the Census numbers. That's about 17 percent of the kids we would say are actually being served under traumatic brain injury label.

Now it could be that they're, as Patrick and Ron were saying, it could be that they are labeled as, uh, learning disabled, as emotionally disturbed, something else. But, um, I think our fear in this area of research is that many of these kids are not diagnosed at all, are not identified at all. And that's because of those forgotten injuries that Dr. Tepas was just mentioning. So you have a child who is age two, is in a car crash, parents, uh, take the child to the hospital, child comes back and is, is doing pretty well and, they, you know, are healing physically and, developing, um, as you would expect, but maybe they get into about third grade, where the demands increase and they are expected to be an independent learner and they start to really, really struggle. Well at that point, nobody remembers the brain injury.

>> RAY ZARDETTO: Yup.

>> ANN GLANG: So, now, now they are a nine year old, and maybe they are going to be labeled as something else or maybe they're going just to be called a troubled child, a child with a poor family, a child who doesn't have the support at home. So, we have lots and lots of kids falling through the cracks. And, um, I think that's why we're all so excited about the work the Sarah Jane Brain Foundation because we see it as an opportunity to fill those cracks.

>> RAY ZARDETTO: Are there particular kinds of cognitive impairments that you associate with brain injury? You know, specific ones, or can it be a whole wide range of them?

>> ANN GLANG: Well, there are few that are hallmarked, um, that are really problematic at school. One being memory problems where a child has something one day and doesn't the next. That's very hard for teachers to deal with because most kids with disabilities have kind of a, a stable profile. But when you come in one day and you know the information and the next day you don't, that's a problem.

Executive functioning is kind of the catch-all term for another hallmark, which is the ability to plan and organize, have goal-directed behavior, self-correct, monitor your behavior. Those kinds of - those kinds of skills are often affected. And, um, that really gets kids in trouble. They say things they shouldn't, they have trouble with assignments like,

write a report because there's many, many steps involved in that. It's easy when they're in first grade and there's - they have one, you know, one step tasks, like take your paper and put it in a box. That we can do. But when you get into much more complex sequences of skills, um, these kids often have a lot of trouble.

>> RAY ZARDETTO: And so, if, um, if a parent or someone suspects that, um, someone they know or one of their children or something, has suffered some kind of brain injury or showing some kind of symptoms like you just described, I mean, what steps should they take? What is the first thing they should do?

>> ANN GLANG: Well, in the school setting, um, where you go is to, um, the principal or the school psychologist and say I have some kind of concerns about my child's learning. Or some concerns about my child's behavior. If you can say I suspected that they may be are having some effects from an event that happened, you know, some time ago, or this seems to be consistent with some of the things I'm reading about brain injury, that is helpful to someone who is doing an assessment. Um, I don't know Ron or Joe; if you want to talk about, um, maybe more of a medically focused, um, approach?

>> RAY ZARDETTO: Yeah, that would be interesting.

>> (UNIDENTIFIED SPEAKER): First of all I think that, yeah, I think that - you know, and one of the things that, that Anne really helped to clear up with everybody is the difference in

how we see in our hospitals, you know, in doctor's offices, we see all these kids, but that information doesn't translate over into schools. But that, that - one of the things we'd like to do through the Sarah Jane Brain Foundation is to really connect the service delivery systems. Connect the hospitals with the schools, for example, so these kids are managed from the hospital through rehabilitation and right back into the school system. Or maybe if a child with a so-called concussion and mild brain injury that is seen in the clinical office, the physician's office or neuropsychologist maybe does some evaluation and then to manage them back into the school system. When Ann said these kids fall through the cracks, uh, professionals created the cracks. The kids didn't create them. What we're trying to do with the Sarah Jane Brain Project is to connect all of these service delivery systems, and once we pick these kids up in those early medical centers to be able to manage them all the way back and for, you know, through their life.

>> RAY ZARDETTO: Alright, Patrick, we're down to the last couple minutes of our show, and what I'd like to do is, um, get back to you and, uh, and the Sarah Jane Brain Project again for a moment.

>> PATRICK DONOHUE: Sure.

>> RAY ZARDETTO: If people are interested or they want to help, um, what can they do, what should they do at this point?

>> PATRICK DONOHUE: Well, I mean, what you have heard in all of these segments is this daunting public health crisis. The positive and hopefulness that we also want to convey is that, um, the group that you heard from and many of their colleagues have gotten together and actually developed a national pediatric required brain injury plan, uh, that develops a seamless, standardized evidence based system of care that's universally accessible for all of the millions of kids and families regardless of where they live in the country. Um, so there is now a plan in place, um, the key is now going to be getting funding and support and actually have a concurrent resolution, um, with Congress H concurrent resolution 198, um that is now just waiting for the members of the Congress committee to move it through their committee, um, what's going to happen next is Congress endorsing this plan and encouraging federal, state and local governments to implement it. Um, so if they want more information, they can go to our website www.thebrainproject.org. Um, they can contact us directly, if they have, you know, suspicion of any issues that they have, um, if it's a parent or a professional, we can connect them to, um, our national and international network to help them as well.

>> RAY ZARDETTO: And what about, something like connecting or contacting they're, uh, Congressional representatives with regard to this, um...

>> PATRICK DONOHUE: Yes, we now have over 100 members of Congress that have endorsed this plan, um, so if they can - if they elect to go to our website and get more information about it, um, they can find out if their members already endorse the plan. There are a few key members of Congress that are critical, Congressman Frank Pallone out of New Jersey, he is a critical person that if families want to contact his office and encourage him to sign on, that would be helpful as well.

>> RAY ZARDETTO: Alright, very good. Um, I want to thank my guests for a very enlightening discussion on our show today, Ann Glang, Ron Savage, Joseph Tepas, and of course, Patrick Donohue, representing very well here today, the Sarah Jane Brain Project and Foundation. Um, I hope, you know, I hope, uh, you continue to do this good work and I hope all good things flow to you all for this. Patrick, congratulations, uh, for this great work that you are doing. You know, you took what was a very, very bad situation, I think, and you, you know, you turned it into something good for a lot of people, so congratulations for that.

And, uh, let me just close the show by saying that we will be on the air again next Wednesday at noon Eastern Time, back with another show exploring ideas, innovations and initiatives involving the workplace and people with disabilities. And again, I want to thank our sponsors for this week, the Kessler Foundation and the New Jersey Division of Disability Services.

So thank you for listening, I'm Ray Zardetto and this is Disabilities At Work Radio.

¶ [Background music] ¶

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