National I&R Support Center
Webinar: State Systems and Resources for People Living With Traumatic Brain Injury
Wednesday, January 15, 2020

Welcome. My name is Nanette Relave and I'm with the National Information & Referral Support Center. On behalf of ADvancing States and the National Information & Referral Support Center, a project of ADvancing States, I would like to welcome listeners to today's webinar on State Systems and Resources for People Living With Traumatic Brain Injury.

Let me cover a few housekeeping items before we get started.

The slides, audio recording, and transcript from today's webinar will be posted to the ADvancing States website within the next several days. Please visit the National I&R Support Center project on the ADvancing States website and see our webpage on I&R/A Webinars. This weblink is also posted in the chat box for your reference.

All of our listeners are on mute during the webinar to reduce background noise. But we welcome your questions and comments through the Q&A function available on your screen. Please feel free to submit your questions at any time during today's presentation, and we'll address questions following the presentation. Just to note, today's webinar is scheduled for 75 minutes, until 4:15p.m. Eastern time, to allow enough time for our three presenters and for Q&A.

We also have real-time captioning for today's webinar. On your screen, you should see a Multimedia Viewer Panel on the bottom right where the captioning will appear. You can minimize this panel or have it open, it will not block the slide presentation. You may need to enter the Event ID number (4269250) to see the captioning.

The effects of traumatic brain injury (or TBI) can lead individuals living with TBI and their families to seek information and assistance for a variety of needs. We're glad that you have joined our webinar today to help strengthen or refresh your knowledge of brain injury, the role of state TBI systems and programs, and I&R services for this population. Our presenters are Rebeccah Wolfkiel, Executive Director of the National Association of State Head Injury Administrators; Stefani O'Dea, Director, Office of Older Adults and Long Term Services and Supports with the Maryland Behavioral Health Administration; and Gabriela Lawrence-Soto, Grant Project Manager with the Massachusetts Rehabilitation Commission. We have a great presentation for you today with that I'm going to turn it over to Becky to get us started.

Wonderful. Thank you so much , Nanette. Welcome , everyone. We are so grateful that you have joined us today to learn more about traumatic brain injury and how state systems and groups across the country can help support this large group of individuals living with brain injury and their families. As Nanette mentioned I am Rebecca Wolfkiel, Executive Director of the National Association of State Head Injury

Administrators, and I have been in this role for a little over two years now. Prior to my role as executive director I did work in policy for the Association for almost a decade . Very familiar with the brain injury community and supporting state systems and community resources. NASHIA is the only Association that represents state head injury administrators, state employees across the country who are working to create systems of care for individuals with brain injuries and their families. We work very closely with a number of other national and state organizations that support individuals living with brain injury in other ways . But remain dedicated and focused to creating infrastructure within state governments to help this growing population of individuals living with brain injury. I wanted to begin today with a very quick overview of what brain injury is, some leading causes, and some data points to illustrate the truly epidemic , it's a large population of individuals who are living with brain injury and not enough people know that. We are very fortunate today to be able to bring some of this information to you all.

Brain injuries are incidents that happen after birth . Two types of brain injury. There is non-traumatic, which can occur through a loss of oxygen or a stroke, infectious diseases . And then, of course, there is the traumatic brain injury that we will be focusing our time on today. That is caused by a blunt force trauma to the head by an external force or object.

The impacts of brain injury vary quite drastically. But, there are often long-term lasting side effects. They can, these impairments can include cognitive processing, functionality, memory disruptions , even movement disruptions. The senses, so challenges with sight or hearing . And, quite often, there are emotional and behavioral functionality impairments. There is a growing recognition of the often dual diagnosis of mental and behavioral health issues that go alongside a brain injury.

The leading causes of brain injury are falls, motor vehicle accidents , and being struck by or against some type of object . Many people don't quite recognize that falls are the leading cause of traumatic brain injury and this really does impact children 0 to 17 years of age and older adults the most. In fact, 81% of older adults 65 and over who present themselves at an emergency room visit due to a head injury, is the result of a fall. 48% of children age 0 to 17 that present themselves at an emergency room for a head injury related visit are also the result of a fall. Very, very significant.

Specific common causes of a brain injury, just to paint the picture a little bit better, the non-Traumatic Brain Injury can be caused by infection . As I mentioned before, like meningitis, brain tumors, stroke, hypoxia , and loss of oxygen to the brain , lead poisoning. And some common causes of traumatic brain injury , in addition to the ones I just mentioned, can be sports and recreation related accidents, work accidents , military combat is a large cause of brain injury. Assault, intimate partner violence, abuse, including both older adult abuse and shaken baby syndrome. And there is now also growing recognition of the

connection between brain injury and gun violence- homicide and suicide attempts as well.

Really it is a national epidemic . The CDC estimates that approximately 2% of our entire American population is living with the result, the long-term result of a brain injury. That doesn't mean that only 2% of our population have sustained a brain injury, it just means that they are 2% of our population that has had either a severe enough brain injury or a number of smaller brain injuries that have created a lasting impact and a disability as a result of the brain injury. Each year there are over 2.8 million TBI related emergency room visits. Over 837,000 of those incidents are from children. I do want to point out that there are many more brain injuries happening each year. This number only is folks that actually present themselves to an emergency room there are many times that injuries occur that the individual does not report to an emergency room.

Almost 155 people in the United States die each day from injuries related to TBI. Again, it is significant. Individuals with brain injury are served by every state system. Many times the state system may not know that they are assisting an individual with brain injury. They may be reaching out for services and not identifying themselves as an individual with a brain injury. They may not know themselves that they have a brain injury, but all state systems are working to assist individuals every day with brain injury, whether or not they know it. Every state does have a brain injury program. It looks different in truly every state. Brain injury programs and individual state employees who are administrating those programs can be in Department of Health for some are in Department of Vocational Rehabilitation. Some, like our presenters Stephanie O'Dea, are in the behavioral health administration. Some are in the aging and disability agencies. Some are in other agencies. It really can make it challenging for the state employees who are working in brain injury to find one another. It is also challenging for constituents to know where to go to find services as well. We at NASHIA do try to help state organized, I should say that in another way, I think, we at NASHIA try to help educate the TBI community on where their state programs are located. We to have a link on our website that has a point of contact for every state program regardless of the agency in which it is housed and how many individuals are working within that program.

Due to the complex nature of brain injury it is very important that the state TBI program manager coordinate with other state programs who may be serving large or significant populations of individuals living with brain injury. Some that I listed on this slide, again, special education, vocational rehabilitation, mental health, corrections , the ADRC all are serving significant populations of individuals living with brain injury whether or not they know it. Oftentimes the state TBI program manager tries very hard to educate other departments and agencies within their state about the reality that they are helping people with brain injury and then also helps to try to provide some tools on how to better assist and communicate with those individuals and provide specific support that are needed. We at NASHIA do help to

try to promote those partnerships in collaboration, provide some best practices , and even opportunities like this webinar today. We hope it will help spur some partnerships between state agencies.

State TBI programs all are funded from different, a variety of sources. Some states have several funding sources that resource that agency and some may only have one or very small one. Some examples of funding sources for the TBI state programs are brain injury CMS waivers. Almost half of our states have at least one brain injury Medicaid waiver . Some states have passed legislation that allows for dedicated, what we call, trust fund, dedicated funding stream that help support the TBI program. Most often it is a fine that is included on a traffic violation tickets that then is dedicated toward the TBI program. Other states have dedicated general funds that support the programs activities and there is a federal grant program out of the Department of Health and Human Services Administration for Community Living that is another significant funding support for state programs. >> The ACL TBI state grant program was created in 1996 it was originally administrated by herself and moved to ATL within the last five years. This federal TBI Act of 1996 did create this competitive grant program to be run out of HHS to help support state to great infrastructure or build upon existing infrastructure that serves individuals living with brain injuries and their families. The TBI act is the only piece of federal legislation that provides funding and support for civilians living with brain injury. There are some other veteran and defense federal funding streams, but for our civilians this TBI act is the only piece of legislation and the ACL TBI grant program is the only direct funding opportunity for states.

This map on the screen shows the current grantees of the ACL TBI grant program. It is structured in a way that there are mentor states and there are partner states that collaborate together on specific population areas. The grants are tiered and allow for states to hire staff and to make outreach to specific stakeholder groups and populations among their states to educate community providers and others about various issues related to brain injury. You can see on this chart I mentioned that the grant program at ACL encourages collaboration between the states. The collaboration occurs around issues specific workgroups. These are some of the work groups that our states are focused on right now. You will see the states that are focused on issues like opioids and mental health and the significance of those two things in the brain injury population . Criminal justice, underserved populations, transition unemployment , so, really important topics that individuals with brain injury have unique needs and disability, Visibility for states to work together to create solutions and best practices is something that NASHIA is a strong supporter of .

Today with us we are joined by two of the board members to provide some real-world examples of how states have successfully created trend one systems for individuals living with brain injury. Stephanie O'Dea with Maryland , Maryland program, is younger and does have less resources available and then the state of Massachusetts, who we like to say is our

first state brain injury program in the country they have had a lot of time to put mature systems in place and have really been a leader in the TBI community. Both states are looked at nationally as leaders . I think you will learn different things due to the different challenges that the states work among within their respected environment. I should have put this, should have put this at the beginning of my presentation, but before I move on the quick overview of types of services that NASHIA provides. NASHIA has been around for 30 years and to support state systems we do provide resources and information to states. We provide training and professional development, connections. We provide best practices and access to state and national trends. Also do advocate at the federal level for additional resources that our states can use to build capacity and strong systems. With that I am going to pass it back over to Nanette so that Stephanie can take it from here. Thank you so much.

>> Hi, everyone. This is Stephanie O'Dea. I'm going to just take a minute to figure out how to advance the slides. There we go.

So, I am from Maryland. My role here in Maryland , my title at this point, it has changed many times through the years, I am currently the Director, Office of Older Adults and Long Term Services and Supports with the Maryland Behavioral Health Administration, which is an administration under the Maryland Department of Health. I have actually worked with our brain injury program for 19 years. Before I worked for the state I work for a community-based rehabilitation provider, neural rehabilitation provider. Really, almost my entire career has been working with individuals with brain injury. I'm also a NASHIA board member. I'm the past president of NASHIA and I'm also currently the membership cochair. Our work with ADRC and a lot of our opportunities within our brain injury program in Maryland really all started with a national effort on long-term care rebalancing. Maryland participated both in the MFP project and the Balancing Incentives Project. As most of you know, that was aimed at rebalancing long-term care services, so we could really enhance what we can offer people in the community and not rely so heavily on institutional services.

Part of our rebalancing efforts , again, I think this is probably common in most states , our focus was on enhancing our community-based waivers, implementing community first choice, which is a 191k program, and developing a no wrong door simple point of entry system. We call that access point. The historical background on that was that our state was one of 12 states that had received a grant to develop aging and disability resource centers in 2003. When we have this federal funding coming in through Balancing Incentives Program and the Money Follows the Person program and we had to think about what our no wrong door system would be the decision was made to look at those really robust two very robust local aging and resource disability centers and enhance them with these federal funds so we would have a statewide system. We call that Maryland access point, as I mentioned. The website is here on the slide. We have local offices that are housed within our local areas. We have a website that the link is here that will allow people to search for

information and resources about long-term services and supports . The local options offer counseling. My role is that the lead agency on brain injuries. As Becky said, that lead agency role, which is really a decision that the state makes, the states decide who their lead injury on brain injuries going to be. And in Maryland is a behavioral health demonstration. We are pretty unique it is typically not behavioral health.

There is a lot of reasons that went into the decision here in our state to identify us as the lead agency. I think it has been a wonderful opportunity for us to be able to help understand the link between brain injury and many behavioral health issues. We do issue a 1915c waiver for those individuals with brain injuries. We have a pretty small program in terms of the number of people served. It is a pretty expensive service. Our program is really designed to support, not every Maryland or with a brain injury, but individuals with a more severe injury who is struggling with , usually, pretty severe cognitive and neurobehavioral issues as a result of their brain injury. So, because we administer this Medicaid waiver program I think it was an opportunity , we kind of knew a lot more about what was going on with our state Medicaid agency and about the long-term care reform initiatives. We were able to get in from the beginning into this stakeholder meeting and figure out where the opportunities were to expand our waiver program, to partner with our Department of Aging around the new design. We also , for many years, have contracted with our Brain Injury Association of Maryland.

Every state has a lead agency, a state-level lead agency. Pretty much every state has a local nonprofit entity that provides information and assistance and advocacy at the local level. They are typically a brain injury affiliate or brain injury alliance affiliate. As a lead agency we partnered very closely with our brain injury association to actually do some things related to our waiver. They provide education and application assistance and transitional case management. They also provide ongoing administrative case management to individuals enrolled in the program. They also , our contract does support their information assistance, all callers. And they provide a lot of training with us for various state agencies and community partners. I will talk more about that in a minute. So, the name of the game for , I think all of us that work in this very small brain injury world is partnership. We do have very few resources in this country dedicated to brain injury. Some states have more than others. Federal funding is still pretty low. Some states have no state funding dedicated many states really have very little in terms of dedicated resources. So, I think a lot of the work that has been done in the field has been done by trying to partner with other agencies and capitalize on the opportunities.

Again, for us in Maryland it was long-term care reform. The state agency used their money and incentive programs to enhance the Aging & Disability Resource Center is. They are also allowing us to use some of those funds to develop our contract with the Brain Injury Association of Maryland in order to link with those ADRC. I do want to take a moment and acknowledge the people that do the day-to-day work on this. Because I have been here for so long and because I was here in long-term care reform I was on the front end of envisioning what this might look like

and think about the opportunities that haven't been doing the day-to-day work. I want to acknowledge the people that are. At our Maryland Department of aging. Carrie Frzier and Liz Woodward in my office. Anastasia Edmonston is our TBI grants project coordinator. She is the statewide trainer. At the Brain Injury Association of Maryland, the executive director is Bryan Pugh, associate director Caitlin Starr and case manager and trainer Jessica Nesbit all have played a big role in this. I also wanted to acknowledge Rebecca Raggio, the Marlyand Medicaid MFP Director. Here is what we have done to partner with the Aging & Disability Resource Centers , or Maryland access point.

One of the things that we did many years ago, and this is where it began for us and probably 2013, it has sort of morphed over time, but early on we tried to explain to our aging partners and Medicaid partners the way brain injury looks in our state. You're not going to see a lot of different offices like you might see in mental health and substance use. You have your lead agency and you have got your nonprofit. That's about usually what most states have we worked with them to designate the brain injury Association of Maryland as a primary brain injury resource for Maryland access point. So, let's talk a little bit about this. Basically, when you search their website for brain injury resources, if you're looking in a particular county, you might find a particular program but you're always also going to get the Brain Injury Association of Maryland. If you have kind of more complex questions, and I'm going to talk about this later, you have an entity you can call to have a conversation with you about what's going on for you right now. There could be lots of different resources that you need to address that.. I mentioned the map website and making sure the listings come up when you search brain injury , including the brain injury Association of Maryland early on in our conversations we were asked to give the department of aging a list of all the brain injury resources in our state and that is a very collocated thing to do, because brain injuries are complicated and often people need a resource. I will talk more about that when I get to lessons learned. .

We have done a lot of training and education. Our office conducts training with our ADRC staff or Maryland access point staff. We have done that for years. On top of brain injury and aging, also on mental health first day. Our trainer in our office is a certified trainer for mental health for state and person centered thinking. We have done a lot of that training for ADRC staff. Sometimes during a brown bag webinar, but also sometimes and in person training. Most recently this year we have been offering, we have also sponsored the Brain Injury Association of Maryland conference, which in our state brings in several hundred people. It's really a very robust conference with a lot of diverse group of people that are attending. We have a lot of individuals who sustained a brain injury. A lot of family members and providers. A lot of people who have never known anything about brain injury before that are going there for educational opportunities.

We partnered with our Department of Aging on a resource table. It's a great opportunity for Maryland access point to provide resources . This year in addition we actually have a scholarship program that will be rolled out for the ADRC staff. They will be able to attend that

conference for free. Brain injury screening is a big deal in our brain injury world. The reason is one that Becky touched on a little while ago when she said a lot of times individuals with brain injuries don't disclose they have had a brain injury and/or they don't even realize they have had a brain injury. The reason is that's a lot of times not the way people are talking about it when you're in the middle of your medical emergency. People might tell you they never had a brain injury and in the same breath that they were in a coma for two months 10 years ago. Those two things are possible to happen to both be true. When we are thinking about screening when you're thinking about who you are talking to on the phone, understanding how to know whether that person might have had a brain injury and may need resources related to that is very important. In our state we were really only able to get a couple of questions added to our state ADRC phone screen . We were really only able to get some very specific questions added. One related to having a history of a brain injury or substance use disorder, mental health issue. And if the person answers yes to having a brain injury they are supposed to be referred to the Brain Injury Association of Maryland. Not only to what the ADRC can provide, but in addition to. So, it has been a little hit or miss with gathering data on that. In 2017 about 10% of the individuals were administered that level one screen and answered yes to having a brain injury.

Here are some things we learned through the years . I touched on this a little bit. As we are thinking about putting brain injury resources into a web-based platform as most no wrong door systems have done it's a little bit of a tricky thing. Some individuals have had a brain injury and they may not be living with a disability as a result of that brain injury, but they may have some lasting symptoms , headaches, dizziness, sleep disturbance . They may need a specific clinician or type of a physician. Those particular clinicians may not have the brain injury in their title, but there are some very common clinicians that are involved with treating individuals who have had a brain injury. Psychologist, neuropsychologist, neurologist, neuropsychologist, neural ophthalmologists. That doesn't include the different therapists that might be involved. Physical therapy, occupational therapy, speech and language. As you can imagine, it would be hard to enter all of those resources in any web-based system. Some individuals may be living with a disability as a result of their brain injury and their needs might be like many other people with disabilities . They may be related to entitlement programs or transportation or housing. The ADRC is certainly already very well equipped to answer questions about that. They may be calling because they have a very specific and unique needs and need very specific brain injury services. That varies from state to state, as Becky mentioned. About half the states have brain injury waivers. Half the states have trust fund programs. Every state is a little bit different . You got to do a bit of research in your own state to figure out what's available. That is the reason why on the Maryland access point website rather than trying to get every possible clinician and type of service or resource injured that's why we landed on having the Brain Injury Association of Maryland pop up anytime brain injury was searched. .

We have done a lot of training with the ADRC in our state. The seems like the core components that seem to be most pertinent are some general brain injury 101, just understanding what it is and how often it happens and what you see as a result of brain injury. Another big piece is helping ADRC staff know what to listen for on the phone that might suggest a person could be living with a brain injury. Maybe they either don't realize it or have not got to disclose . Maximizing person centered approaches is important. Understanding brain injury resources, like I have just described, is important. The risk of falls as we age is certainly very pertinent . Understanding how to communicate with a person with a brain injury related to disability is key since the bulk of the communication is by phone. And understanding brain injury conditions.

Screening , I had mentioned in our state we were really only able to add a question that says have you had a brain injury to our phone screen. That is not a best practice for screening. Hope one day we can improve upon that. That was really what we were able to do early on when we had our opportunity. I have given you a resource here to Ohio State University's TBI identification method. The best most reliable way of identifying a history of a brain injury is really done by having a conversation and asking a series of questions. This website has a ton of great material on it that suggests you take a look at.

I do want to say, we also realize that having a long conversation about whether or not someone may have had an injury in their past not is always wanted or needed. Callers may be calling with a really specific question. They certainly don't want to go through a very long lengthy interview about any possible injuries they had in their past. Figuring out from state to state and caller to caller when that is appropriate is important. With that I'm going to turn this over to my colleague Gabby from Massachusetts. Thank you.

Hi, everyone. I'm Gabby. I work at the Massachusetts Rehabilitation Commission within the community based services department.Before entering into my current role as a project manager for one of the ACL implementation grants that I have been manager of for the last two grant cycles, I wanted to share with you all that I have worked in the capacity of an intake and ongoing case manager at one of our local aging agencies. And then I transitioned into working as a case manager for adults living with brain injuries. Both acquired and traumatic brain injuries and other neurological disorders as a contracted provider of Mass Rehab. In my current role now I am working towards building capacity for serving individuals with brain injury across other systems by providing brain injury training to the existing workforce, promoting and teaching others how to screen for brain injuries, because identification is still a challenge. Teaching folks how to accommodate for symptoms of brain injuries within their systems and then how to access us being the brain injury service delivery system.

Within NASHIA I'm a member of NASHIA and I serve as the chair of the training and education committee my goal today is to share how we view partnerships, federal grant opportunities, and timing. Timing is

everything whether it politics or whatnot timing has been important. In order for us to be able to expand our information or resources in Massachusetts so that people, more people can access brain injury services. >> MRC is our lead state agency for disability services. I'm not going to start with we are the lead state agency for brain injury, I want to start from the beginning. We are the lead state agency for disability services. We were established in 1956 with the vocational rehabilitation being our first program. As the federal definition of disability has expanded over the years new funding streams have become an opportunity for the agency to also grow its programs so we are better able to serve individuals living with all types of disabilities and we are also able to meet their unique needs through comprehensive services that will maximize their quality of life and meet their goals to obtain economic self-sufficiency in the community.

MRC has accomplished this with the many programs found within three of our divisions. Employment services and career exploration in the vocational rehabilitation commission. MRC is the designated state agency for Social Security, for the Social Security Administration to provide disability termination services. And, lastly, we have our community living division, which houses several of our population specific programs. For example, MRC contracts with our 11 independent living centers to provide services across the state to individuals who would otherwise have difficulty remaining independent . Other services we provide our services for transition, youth age group , individuals with disabilities. We have our home care programs that service individuals who are between the ages of 18 and 59. And then those individuals that transfer over into other service when they meet the age eligibility criteria.

For the purposes of today I would like to highlight the community-based services department which is charged with providing community support and services for individuals with brain injuries . And a variety of disabilities . This department is made up of the Statewide Head Injury Program and the ABI, the acquired brain injury and Moving Forward Waiver programs which I'm going to discuss further in this presentation.

What is the brain injury system in Massachusetts? Historically, it has been the mass rehab commission . We are the state lead agency for brain injuries. And within mass rehab it has been the statewide injury program and the statewide brain injury association. Back in 81 families got together and created the nonprofit advocacy entity that we now know today as a brain injury Association of Massachusetts and in 1980 to the Brain Injury Association of Massachusetts has provided support to brain injury survivors of any age and with any type of brain injury and their families. They offer programs to prevent brain injuries, which includes education for the public on the impact of brain injury. Most importantly, the Brain Injury Association advocates for community services.

Having identified a gap in the community the Brain Injury Association then helped a group of parents and moms who needed services and support

for their adult children that were living with traumatic brain injuries at the time to advocate for the creation of the statewide head injury program in 1985. SHIP is the oldest program of its kind. Traumatic Brain Injury services , which I will highlight soon, I want to also share that over the years we have been able to build a statewide brain injury program and include the waivers. In 2008 MRC implemented the traumatic brain injury waiver followed by the acquired brain injury waiver in 2010. And then the Money follows the person in 2013, which now we know it as moving forward planning . The waiver program began with MRC staff supporting that and UMass medical school in operating the waivers and then in 2014 changes were negotiated with the Hutchison settlement resulting in mass health , moving case management for waiver participants to MRC, which we have two waivers for individuals living independently and then for the Department of developmental services servicing individuals living in residential programs. I will have a little bit more to talk about that later. In the meantime, I want to note that the money follows the person, that's how we got to the name of moving forward planning. They provide case management to help individuals and families navigate long-term services and support. They help individuals transition out of nursing facilities, provide home modifications, help individuals start to think about work, and educational opportunities.

35 years later SHIP continues to support individuals living with traumatic brain injuries and their families to access services in the community that maintain or enhance independence in the home , communities or at work. This program is unique in that it serves residents of all ages with a confirmed Traumatic Brain Injury and of which that Traumatic Brain Injury is the primary reason for their disability. The importance, this is important, because up until the waivers when they came in in the two thousands, this was the only state wide injury program available. The other waivers have now allowed MRC to serve consumers of all brain injuries. To build on what Becky's presentation was, I want to share with you all that the statewide head injury program is funded through the state appropriation. We to have a trust fund and the trust fund is made up of surcharges that come from DUIs and from speeding tickets. And at the statewide head injury program is responsible for managing the state wide brain injury waiver which provide supplemental 100 individuals within the SHIP program, who meets the clinical and financial eligibility requirements.

Here is a quick list of all of the SHIP services that are available. The statewide head injury program. I wanted to highlight some of the most utilized services. Out of the 910 people that are actively receiving services, not to say we don’t touch more than 910 people, there are people that are receiving other communication or information for referral. These are the ones that have paid services from the list offered. 59% are in case management through some kind of coordination. 10% are getting day services. Another 10% are utilizing the 24-hour residential and supported living programs.

As far as the Medicaid waivers in Massachusetts, we have nine of them. One is operated by the executive office of Elder affairs. The frail elder waiver. Massachusetts is responsible for three of the waivers .

One of them being the Traumatic Brain Injury, as I said. The acquired brain injury waiver that is for the community. And moving forward planning. We do this in collaboration with the Department of developmental services, where they have the two waivers that are related to residential services. I want also highlight that they have, three other waivers: consumers benefit from, which is the adult support waiver, community living waiver, and the intense supports waiver.

In looking at this I just wanted to highlight, you know, brain injury individuals, there is no one place where there getting services. They are getting service from many systems, often times. In looking at where people end up when they end up in facilities and then when they come out of a facilities how they are in the community. This is very important to us . To think about capacity building. How do we build capacity and how can we do that? So, we spent lots of years focusing on training. Identifying and teaching people how to screen. We use the screening tool and now we are moving toward using the Ohio State modified screening tool. And, really, the TBI up limitation grants have helped us build that capacity and develop the workforce. I have listed here a couple of the grants that we have had, the multicultural community outreach grant. This helps us reach out to the Latino community, the aging community to learn more about them and teach them about brain injury and how, also for our staff, who have been cross trained, learn how to work with multicultural organizations and building the linkages between the two.

There are two cycles of grants around veteran services. We know there are a lot of veterans coming back with the injuries for being Traumatic Brain Injury come and how do we them to brain injury services? How do we build linkages with that population? And then in 2014 we started looking at elders. We had an epidemiologist report that showed a lot of elders in Massachusetts were sustaining a brain injury at a high rate in a given region of the state. We decided to reach out to the executive officeof Elder affairs and work with them and the ADRC , building, again, that connection between the two of us and also others in the community. How can we work together to get them connected to brain injury services and how do we work together when consumers have both services from an independent living center and an ADRC. Recently we have a new grant where we are focusing on brain injuries, substance abuse disorders. What does that mean and how do we educate the substance abuse symptoms about brain injuries and how do we best work together?

So, in thinking about the steps . The first slide I showed you was the MRC in the brain injury Association. I probably say now we have extended it. I put these in a bubble, because any given one of them can work on their own, but the beauty is over the last few years we have been able to expand information and refferal by educating each of these systems and making them aware of what we can do, having staff learn about these other systems do and what they do and how they work , so we are all able to better serve these individuals.

An example of this, I want to go back to the ADRC in that you know, we are not working in a silo. We have to look at people as a whole. Here we have had ADRC since 2003, like Stephanie said, we have 11 of them here. We are very fortunate that we have been able to partner up with the executive office of Elder affairs and several of the ADRC is to be able to provide ongoing training. Training for the ADRC staff, but also have some of them, to teach our staff about what they do, how they do it. Staff have cases they know they can call their options counselors. Counselors, that was piloted in Massachusetts in 2008. It became something , a service that is available statewide within the ADRC. Leveraging the options. They're the ones going to different settings and meeting all kinds of people and just giving them the tools to be able to recognize someone with a brain injury. How do you adjust and work with somebody with a brain injury? How do you connect them back to the brain injury Association? Or to the MRC for ongoing support? So, some of the ways we have been able to do this is going to each other's meetings. You know, partnership meetings, have crosstraining, it has been important for us to do. Being able to elaborate, for example, the waiver department goes to different facilities on a monthly basis. So, using that time to make connections with nursing facility identify people that have brain injuries, connect those individuals to other , maybe waiver participants who have transitioned out and they can learn more of that experience transition. Leveraging support groups from the brain injury Association to connect family members to other families of survivors and talk about that experience. What does that mean? And giving these resources to the ADRC staff so that they know if they have someone that they have identified with a brain injury would they want to go to a support group? Where is that support group? Attending each other's conferences has been a huge part so that we, again, spread the word about brain injury. How to identify and expand other disciplines knowledge about how to work with individuals with brain injury.

So, I want to highlight here Mass Options. This has been really good for all of us, because it has been an opportunity for us to have somewhere to access the agencies , statewide resources. I just want to say that that mass options is owned and managed by the executive office of Elder affairs. This is a resource that is part of the Elder affairs sustainability plan. They were a recipient of a program grant from the centers for Medicare and Medicaid. That was back in 2014. Mass rehab is one of the agencies that is receiving referrals from this site as well as the Department of developmental services, the Department of mental health, the independent living centers. I want to say that mass options is a free resource linking elders, individuals with disabilities, caregivers, and family members to services that will help them or loved ones with the ability to live independently. And helping individuals avoid that frustration of calling people, calling multiple agencies and having to navigate various networks . And folks get connected to trained specialists that can help make the warm call transfer while they are on the phone with the appropriate community resource or organization. It is important for us to help share , you know, our contacts. I want to go back to that slide with the touch points. Making sure that staff turnover shares who is responsible for what and who is the main contact.

They should be connected. That's really important. The website for mass options , if any of you want to check it out, is on the bottom. You will see it here on the bottom left hand, right hand side of your screen you can go on there. They have and FAQ if you want to learn a little bit more about it. Again, I wanted to highlight them as a resource for folks in our state to be able to get connected with the brain injury Association, mass rehab, and I just want also highlight that within the brain injury Association these grants, for them to have their staff cross train as well. Also to beef up their database so we are keeping track of who is being trained with brain injuries, so that if ever any of our partners are saying, hey, I have a consumer that needs a therapist , not just a regular therapist, but someone that knows a little bit more about brain injuries we can draw that list and say, hey, check out these 10 therapist or these 15 therapists who have experience with working with individuals with brain injury. That will make that much more of a difference for someone with a brain injury than having someone who is not trained.

As I said, no one entity has a capacity to serve all brain injury individuals . We have a lot in Massachusetts. We are fortunate and we recognize that, but there is still more to come pick a lot of folks here will tell you we need more. We need more. And we do. And I just want to say that it's very important for us to have an interdisciplinary approach. You all as I&R staff, you guys are the gatekeepers . There is definitely something that you all can do as individuals and things that you can do as an agency. For example, site visits or attend meetings with your local brain injury Association. That is very important.

The ADRC has allowed us to have that level of interaction where we are going there at least twice a year for ongoing training. We have communications with the local agencies, providing them educational materials and fostering that relationship, exchanging updated contact information. As I said, finding ways to kind of reconnect if people have turnover. Collaborate doing crosstraining . As much as we can teach about brain injury we would love to hear about your agency and how you connect people and what would help you connect people to brain injury services or what you need to know to better serve individuals with brain injuries within your system. We love attending , you know, or we encourage you all to either attend or recruit us to come to your health and resource fairs, meet and greet. Those are important . Recruit or attend conferences. Have us come and speak at your conference or come to ours. You could do that as an attendee, as an exhibitor. As a presenter. Just having that presence across discipline is really important. And taking advantage of educational webinars. There are a lot of them on the NASHIA site. Also the local brain injury offers ongoing brain injury and education. I would say request and disseminate educational materials. We are always creating infographics and materials. Exchange that information. Always accommodate symptoms of brain injury whenever possible.

In thinking about this what can you do ? There are some things that you can do in terms of how you identify , some things that you can do to

recognize during a call if you're working with someone that may have a brain injury. As Stephanie mentioned before, a lot of brain injuries go undisclosed or unidentified. Always be mindful that someone with a brain injury may have cognitive processing that may be slow. There may be some functionality issues. Memory . Apply some of the techniques that you use for working with elderly people with dementia. Some of those transfer. Things with movement. In person be mindful of movement. Be mindful of the senses like vision, hearing, lowering lights , removing sound , there is emotional and behavioral functioning. Things that will come up. Personality changes. There may be issues with depression that they may not have had before their injury. And then there are some individuals that develop unhealthy substance abuse or may have exacerbated unhealthy substance abuse if they had an injury prior. Some other things to look out for may be language. Some folks may have abilities getting out what they want to say. There may be some long pauses in conversations. There might be some word finding issues. Organizing thoughts. Maybe they may not organize their thoughts as well as they were before injuries. They may not be able to ask/answer directly your questions.

Another thing that could happen is there may be some emotional regulation or depression or anxiety. Some individuals may not have had anxiety or depression before their injuries, but they may develop that after. It's very common. And their emotional response may not match the situation. Look out for that. There may be some anger. Like a lot of irritability. Things that you may think, oh, this wouldn't irritate me it may be more irritable to that individual. There may be some weeping. There may be issues with isolation or they may be estranged from a family member or a supporter. Sometimes when having a brain injury individuals may burn out their loved ones or providers. Look out for that and find ways to keep them connected for additional support . Right now I'm just going to turn it over to Stephanie to round out the rest of the presentation.

Thanks, Gabby. Some other signs , we thought we would leave you at the end of this presentation and we are wrapping up here , like Gabby has been doing, with some practical things to help you as maybe a I&R specialist recognize you may be dealing with someone with a brain injury. Just thinking about physical symptoms that someone might be experiencing after their brain injury. If you notice their speech is really labored or maybe it sounds like they are intoxicated, but you are pretty sure from what they are talking about they are not, if there reporting any adaptive equipment or need for sensibility. If they’re reporting they are isolated. There is more than one contributing factor. These are just signs. These are in combination, possibly , signs that this person may have had a serious brain injury.

Other things to listen for that's very common after brain injury is, if you're talking with someone and they are unemployed during most adults peak years of employment , especially if there reporting they were gainfully employed in the past that's another clue that perhaps there was a catastrophic injury or something. Alcohol and drug use is

disclosed . As you heard both Becky and myself , and Gabby, talk about very common after brain injury. Very common before brain injury. Commonly a control bidding factor to the injury, chronic pain is a very common thing to have happen after a brain injury. Usually brain injuries don't happen in isolation . Injuring the brain itself could lead to chronic pain, but usually there's also orthopedic injuries involved in the catastrophic injury. Throughout the conversation some how your discussing medications and there's a lot of medications on board for a relatively young person that's another indicator.

What do you do if you think you're talking with someone who has a brain injury and haven't disclosed it? You know, I think it's very reasonable and, certainly still polite, to ask if possibly they had a serious injury. You don't have to ask if you had a brain injury, but asking if possibly you have had a serious injury in your past and do you want to tell me about that? It may actually lead them to divulge some other relevant information. And document that. Whatever system you are using to be able to document notes about the call make sure that gets captured there. A lot of times it's all about capturing the story. Especially, I think, when you're talking about someone who maybe is a repeat caller. Maybe it somebody who is a little challenging for everybody in the office to speak with because of the way they are interacting and communicating and behaving. If someone realizes that person had a brain injury I think we all tend to be a bit more understanding once we know about the contributing factors. Making sure that's get documented so people know what they are dealing with. And then adjusting service plans and goals as appropriate. This next one , this fourth bullet points, to me is a very important accommodation to make with probably lots of people, not just people with a brain injury, but anyone who may have cognitive issues for any reason. That's just doing a follow-up summary via email or letter, depending on what that person has available to them about what you talked about. It always takes a little bit more time to do it, but it prevents that Groundhog Day kind of scenario from having to give the same information to the same person over and over again. Last, as we talked about many times today, referring to the brain injury Association alliance in your state or the state agency or the TBI program. With seven minutes left we would like to thank you very much for your time and attention. I believe our host is checking the Q&A box for questions.

Thank you so much. Becky, Stephanie, and Gabby I want to thank you for this fantastic presentation. I think from an I&R perspective those last slides are really just so helpful, such great tips for a wide range of individuals and families that specialists might be working with. I think as well your emphasis on from a resource database perspective ensuring that your providing those connections or referrals to the brain injury alliance or association is very, very helpful as well. Particularly with the complexity of needs and providers that you were talking about who may be serving individuals. We are just going to open our last few moments here, open up the Q&A to see what we have. We also have a couple of very quick evaluation questions. While we are answering

questions we are going to bring those up as well. We appreciate it if folks take a moment or two to answer those.

We have a question , we have a question from a listener who is interested in learning more about other state's brain injury waiver programs. This person is a state TBI lead and it is something they are looking into. We had a chance to hear from two states today. If somebody wants to get the lay of the land for state brain injury waiver programs , maybe just remind folks or refresh us about where they can find that information.

Yes. Thank you. That is a great question. Frankly, a common question. We have assisted states with connecting with other states that have been successful in securing waivers and also doing some research and polling members, asking specific questions that might be helpful for that state as they develop their waiver. The best advice I could give would be to please reach out to me directly and my email, I think, is on the webinar. I am happy to talk with that individual and provide some good resources and connections for them.

Great. Thank you. As I think you were talking about the tools from Ohio State University one of our listeners jumped in. They were asking if we could put the resource in the chat box. I just want to share for any listeners who want to go and find those OSU tools we are going to post the slide deck and the link is in the slides. That will be available for you just to go into the webinar archive and you should be able to find that . When we are hosting a webinar we try not to jump around too much. We don't want to disturb anything with the actual functioning of the webinar. Again, those will be available following today's webinar. I'm just going to turn to my colleague , our webinar administer for a moment. She is going to check quickly and see if she had any specific questions coming in.

It looks like those are all questions . If anybody has any questions feel free to submit those today Q&A or the chat box.

As we are getting to the end I wanted to turn back to those last slides where you're talking about what to listen for. I love that many of the folks are on the phone. Some of the things to listen for that you were talking about may also be very similar to some other things that would lead a person to contact an I&R service. Maybe that's being in the early stages of dementia, developmental disability or other things. Any suggestions around that? People with a variety of conditions may present in some – I know you have the one questions about the asking . Has some but he had an injury in their past? Anything else you can think of?

In terms of identifying if we are talking about a brain injury or some other disability?

Yes.

I think the only way to know is to have that conversation and see how much that person will divulge. I think sometimes it doesn't matter. Just broad cognitive accessibility for folks. People have struggled with , you know, memory and organization for lots of different reasons, not just brain injury. I guess it depends on how relevant it is to the situation. If it's a person looking for a service and it's in your state that you know exists and having that brain injury would be what qualifies them I guess it would be really important to understand whether not that injury has happened. I think our tips are just broadly to be thinking about is this a possibility? And whether or not you need to know, whether you need to ask more in-depth questions depends on the purpose of the call. For that person whether you think it's going to benefit them or not. Do you have anything to add to that, Gabby?

One of the things we struggle with like, for example, in Massachusetts we have our statewide head injury program and our waiver program. We spent a lot of time in injury, and training to get our providers to know how to work with consumers. Often times there are people getting served outside of that. As an I&R individual I think to keep an eye out where most are going and ask yourself does this resource, are they equipped to handle working with individuals with a brain injury? Can I connect them with this brain injury resource to see if we can build capacity in that other area? Not only will you do the work when you are with them on the phone, but think about who you are handing it off to. It is important but often times a person with a brain injury can have dozens of people on their team, but maybe less than half of them know that they have a brain injury. When it comes to holding onto important information about their history it's hard to repeat that five or six more times. Think about ways in which you can help facilitate that or where you are connecting your individuals to, for them to also ask about the brain injury with the person’s permission. Like if you asked them to disclose they have a brain injury. Do you mind if they share that? It helps the next person working with the individual so the clients have, the person will have a better experience. And everyone, the treatment or service planning is informed with brain injury. And they can make the appropriate common accommodations for that.

Great. Thank you.

We have a question come in asking is it possible to clarify the difference between brain injury resulting from a stroke versus dementia resulting from a stroke?

Yeah. Dementia is a degenerative condition. And so, there are many people with brain injury who developed dementia. It can be a contributing factor to developing dementia. So, they are not mutually exclusive. They could both end up happening. The stroke itself is an injury to the brain. As is, and I don't think it was on Becky's original list, but an overdose, which many of us are seeing in our states. In great frequency as people surviving an overdose from drugs or alcohol can, depending on the circumstances, Could have , really is an injury to the brain. Those are two nontraumatic injuries to the brain.

Yeah. There is also that normal aging process , individual’s brain starts to shrink over time. There's a lot of vulnerability to our brain as we age and then you have these insults to the brain. They come from inside you like a stroke or they have some external factor that causes an injury to the brain. The best analogy I have received in terms of understanding those cognitive impairments is you take peanut butter and fluff, you know, that soft marshmallow sandwich and you stick it together. Then you try to unwrap that and figuring out that you can't put it back together. You will end up with someone who has these impairments and what you do once you know what those impairments are? That is the part that is most important to your work . What you do if someone has memory impairment? What can you do to help facilitate that they know how to get from step a to step B , step one to step two. One of those things that need to happen together? Adding more formal support so they can get through successfully.

Thank you. Very helpful advice. We will take one last question I think it's really appropriate for the audience. One of our listeners asks, do you have training materials for I&R call specialists that you can share and who does the training?

Maybe reiterate some recommendations for specialists in states and communities if they would like to bring in-service training in around brain injury.

I think many of our states are doing this work with our grant funds and all of the materials we develop are certainly available to the public. So, I think the best points of contact is still Becky, our executive director at NASHIA. I believe she can link whoever it is that is requesting the materials with the appropriate state contact.

Yes. I would say too that I'm sure that we have some, you know, legacy documents that we could very well update that would compile some of these state initiatives that Stephanie and Gabby mentioned . Yes. Please do reach out to me for materials and we will make sure that we can arm you with everything that we can.

All right. Thank you again so much to our presenters. Thank you to our listeners for joining us today and for our captioner . With that we are going to close the webinar. Again, all the webinar archive materials will be available on our website. We want to wish everyone a good start to the year and we hope that you will join us again for our next webinar in February. Thank you again and with that we will conclude today's webinar.

[Event concluded]