

Traumatic Brain Injury/Brain Injury Association of America

TBI Medicaid Waiver

January 31, 2005

ELIZABETH PRIAULX: Hi, everyone, this is Elizabeth Priaulx, the national southern with NAPIS. Thank you for being on the call, on the webcast, rather, and I just want to give a few introductory comments about how the webcast works. First, slides will appear in the central window and should advance automatically. In other words, if you all are trying to advance them yourself, you cannot do that. The slide changes are synchronized. You can use the audio by using the slide delay control at the top of the messaging window. We encourage you to ask the speakers questions at any time during the presentation. Simply type your question in the white message window on the right of your screen. And then select question for speaker from the dropdown menu and hit send. Please include your state or organization in your message so we know where you are and where you're participating from. The questions will be relayed onto the speakers periodically throughout the broadcast. If we don't have an opportunity to respond to your question during the broadcast, I'll be sure to email you afterwards a response to your question. So definitely we encourage you to submit questions at any time during the broadcast.

You can adjust the volume of the audio using the volume control slider which you can access by clicking on the loudspeaker icon in the real player controls on the left. Those of you who selected accessibility features when you registered will see text captioning underneath the real player controls. At the end of the broadcast, the interface will close

automatically and you'll have the opportunity to fill out an online evaluation. Please take a couple of minutes to do so. Your responses help us plan future webcasts and improve our technical assistance. So I just want to take a few minutes to introduce it was supposed to be Jane Perkins and Sarah Somers, unfortunately Jane came down with the stomach flu so I'm not worried because we have Sarah Somers here, an amazing Medicaid expert, who is known in our P & A network for providing technical assistance on Medicaid, EPSDT and general healthcare issues through a backup contract that we have with the national health and law program.

So hopefully you have taken the time to call national health law program to speak to Sarah or Jane, especially those doing Medicaid work. She's our esteemed speaker. It's too bad Jane can't be with us. Basically she'll have the first half hour or so of the presentation. She is going to provide just a brief background on TBI and some basics on Medicaid waivers, because we cannot assume that all of you are at the same level of understanding of Medicaid. So if it's too basic for you, you can go ahead and do other things and wait until the later part. And if you need the background, she'll be providing it. From about 2:45 to 3:00, we have a series of slides that are going to represent questions which about 10 or 12 of you sent in advance and I collapsed some of them so they may not be worded exactly as you sent them in but I appreciate the time you took to do that. Most of these questions aren't designed for Sarah to have to respond to, but more for people to ask and everybody to share their own understandings of the question and share what they've been doing around the country to try to get at whatever issue the question represents. So in other words, Sarah Somers is not here as a TBI expert, she's here as somebody with a

very strong knowledge of Medicaid who has actually helped on a TBI waiver case, but most of the TBI specific answers we'll get by sharing with each other.

And then from 3:05 to 3:30 we'll have time to take questions from you who may have thought up questions as Sarah speaks or haven't had a chance to send them in in advance. Without any further adieu, take it away, Sarah Somers.

SARAH SOMERS: Thank you, Elizabeth. I'm Sarah Somers, a staff attorney with the national health law program. We are a support Center for all of the P & As, we prepare monthly Q & A's and quarterly fact sheets. I'm not sure whether it's come out yet but our Q & A for January that we just finished last week talks about TBI and spinal cord injury waivers. That's sort of a companion piece to this which I think you've been given as a handout, is that right?

ELIZABETH PRIAULX: Yes.

SARAH SOMERS: All right. So we -- page one is our overview slide. Page 2 we talked about the agenda. I'll talk with the third slide. All right, so the background to traumatic brain injury -- excuse me -- I'm sorry, there is a fire engine in the background. I hope you can't hear it. Traumatic brain injury is qualified as an injury to the head caused by trauma to distinguish from other stroke or other kinds of non-traumatic brain damage that causes. It can cause amnesia, skull fracture, other neurological problems. It is the number one

killer and cause of disability for young people, according to the CDC. Also according to the CDC about 5.3 million Americans are currently living with TBI and there are up to 1.9 million cases -- new cases each year. The next slide, the long term effects as I'm sure many of you are aware, not only are they physical but mental and emotional. So in addition to the physical problems that inhibit many people with disabilities, the ability to live independently, the additional emotional and behavioral that can stand in the way of people living independently in the community. Something like half of the people who are injured each year become severely debilitated and the treatment costs alone, these aren't even the lost wages or other types of costs that can be figured in, treated costs alone are estimated to be more than \$4 billion annually.

For the next slide on spinal cord injuries, they impact not only mobility but also a variety of secondary health problems can arise from it from limited mobility, pressure sores, respiratory complications, spasticities and others. It's estimated again by the CDC that 11,000 people annually are affected by spinal cord injuries. Now, the next slide I'm going to move on to a little bit of Medicaid background to explain the structure of the program before we get into the specifics about TBI and SCI waivers. First of all, the Medicaid act, which is at 42USC1396 and following, the basic structure of Medicaid is that firstly and perhaps most importantly it's an entitlement. If you fulfill the qualifications for eligibility for Medicaid in the state which you live, you should get it. There is not supposed to be a cap on it based on money that's available. It's supposed to be like health insurance. Also, it's cooperative federalism, meaning that the federal government and the states cooperatively are responsible for the Medicaid programs.

For all the state expenditures the federal government matches it at least dollar to dollar. The matching rate is based on the relative wealth of the people who live in the state. So it's a relatively wealthy state like Connecticut the federal government matches state expenditures time to time. In poorer states such as Mississippi the matching rate can be up to 80%, meaning it's something like 2.3 dollars to every time. Medicaid is also required to be in effect statewide. The people should have equal access to Medicaid throughout the state and the comparability requirement ensures consistency for Medicaid beneficiaries and benefits. The medical assistance can't be less than -- people in similar eligibility groups. All right. Next these quotes, Medicaid's Byzantine construction makes it almost "Increasing Your Program's Capacity to Address Perinatal Domestic Violence" tell it to the uninitiated. These are in cases where judges have torn out their hair at the frustration in difficulty in comprehending Medicaid.

We have an advocate's guide to the Medicaid program where we try to condense this Serbonian blog down to its black letter law describing cases and citations for the various Medicaid provisions with detail on them. Now, Medicaid, the next slide, please, Medicaid is designed to be flexible in that I think of it almost like a federal skeleton with states -- with the state filling in the rest. There are basic rules about eligibility, some of them are mandatory and some are optional. There are Medicaid services, some of which are mandatory and some optional. The bottom line is for most people there needs to be a limited income and resources, certainly a limited ability to afford your healthcare. You

have to be a citizen and you have to be a resident of the state in which you are receiving Medicaid.

So next on to the eligibility categories. There are certain eligibility categories that are mandatory in that states must cover these people if they choose to offer a Medicaid program. States don't have to offer a Medicaid program but they all do. So the -- some of the mandatory categories, the examples here, pregnant women and children up to six years who are under 133% of the federal poverty level. Children 6 to 19 under 100% of the federal poverty level. Newborn children of eligible women. Supplemental security income or who qualify for a different option. Not all states offer a -- are required to give it to people with S.S.I. but they give it to people who meet a certain level of disability. These mandatory eligibility categories were linked to public assistance programs. For example, people who qualified for aid to families with dependent children qualified for Medicaid. Those links are being broken more and more often and it's more and more oriented towards people's level of income. But that sort of affiliation with the world of public assistance still persists to some extent. Now, in the next slide we talk about the optional categories.

States are not required to offer Medicaid to these people but they may. There is a menu of optional eligibility categories from which they can choose. And many of the crucial coverage categories for people with disabilities are, in fact, optional categories. Children between one and six who have low incomes but greater than 133% poverty, people who are medically needy. People who look like other Medicaid beneficiaries but have

somewhat more resources and income are allowed to spend down their income through incurring medical expenses and can qualify for Medicaid. The non-institutionized children with disabilities sometimes referred to as the Katie Beckett option, these are children who come from relatively higher income families. If they were in an institution because of special income accounting rules they would be eligible for Medicaid. If they're not in the institution, they're not. In order to prevent the parents from having to put their child into an institution to afford their medical care this option was created. Also elderly and disabled people who have incomes less than 100% of the poverty level, states may choose to cover those people and people eligible because they qualify for home and community based waiver services.

There is extra flexibility even within these categories. States may use less restrictive income and resource methodologies. They can choose to count income and resources in a way that makes more people eligible. Many states will disregard, for example, a certain amount of income earned by working people with disabilities. So then the next slide we -- you'll see a list of some of the mandatory services. These are all included in 42USC1396.

ELIZABETH PRIAULX: Somebody asked a question about one of the slides you just went over. You were talking about the medically needy and you said -- medically needy or individuals who look like general eligibility categories for Medicaid. But might have higher income that they can then spend down with medical expenses and the person asked, what is meant by look like other Medicaid.

SARAH SOMERS: I was speaking figuratively. People who fall into similar categories. Working people with relatively low incomes. People who have disabilities. People who -- what it used to be based on is people who didn't qualify for AFDC and could spend their way down. That doesn't exist anymore. They are people who if they had lower incomes would fit into one of the Medicaid categories, children, caretakers of children, does that answer the question.

ELIZABETH PRIAULX: I believe so.

SARAH SOMERS: All right. OK. So I'm on this slide describing the mandatory services, number 11. And the citation where you can find the complete list of services is at the top. And Medicaid was originally conceived as most medical care was, as a -- more of an institutionally based model of care that covered inpatient, outpatient, hospital, it also covers physician services, lab and X-rays, nurse practitioner services. It's a mandatory service for people who have a high level of disability who would qualify for nursing home level of care. In early diagnosis and treatment is a mandatory service. I'll describe that in a couple of slides. As you can see there is a relatively broad categories. Medicaid services are the description are often of the category of services. For example, like physician services. Similarly to the eligibility structure, these are the mandatory services that states must offer if they're going to cover a Medicaid program. Now, in the next slide it's a list of some of the optional services that can be covered under Medicaid.

Prescription drugs can be covered. Note that all states do cover prescription drugs because it avoids quite a bit of expensive institutionlization for people and saves cost in other ways. Home healthcare for people who aren't as disabled and don't need a nursing level facility of care but still need home healthcare can be offered. Other types of medical and remedial care, private duty nursing, dental services, physical therapy and related services can be offered. Intermediate care facility services for the mentally retarded are optional. Rehabilitation services, case management and personal care services and other services including transportation. The states can customize their programs and as you can probably see, these are services that are less than the institutional model for the most part. A lot of them are oriented toward providing services in the community. In the next slide EPSDT. Which is the early and periodic screening, diagnosis and treatment. Every Medicaid eligible individual under the age of 21 qualifies for EPSTD and the states are required to provide it. It includes not only checkup screening services that are provided at intervals but also includes the treatment that is necessary, quote, to correct or ameliorate a physical mental illness or condition and this is a much broader -- a much broader mandate than for adults.

States can choose to offer physical therapy visits to adults and they may say adults can get up to 20 physical therapy visits in a year. It's not -- that can't be done under EPSDT. If a doctor or physical therapist says that it's medically necessary for a child to receive more physical therapy than that, then they're entitled to get that. We have a number of publications about EPSDT. We have a litigation manual that we wrote for NAPIS with a 2001 publication date and we have a publication that came out last year which describes

the program in great depth. Elizabeth can probably tell you where you can find the NAPIS litigation manual and the other publication through our website. Now, next we turn to home and community based waivers. Home and community-based waivers are authorized and they are granted by the Secretary of Health and Human Services, and something that I didn't understand until relatively well into my Medicaid practice was what they meant by a waiver. What it means is that states can waive some of these core Medicaid requirements like state wideness, comparability, which means that it can be focused on a particular population or can be run as sort of a pilot program in a specific part of a state.

Also financial eligibility requirements can be waived which enable states to offer services to people who might not otherwise qualify. Similarly to the Katie Beckett option that was discussed earlier, the catch 22, can it be avoided of people not qualifying for Medicaid unless they go into the institution, a lot of times the waiver of financial eligibility requirement that keep people from going into an institution to qualify. The goal of waivers is to keep people out of the institutions. In the next slide there are three types of home and community-based waivers. One is the one that is relevant to what we're talking about here today. Individuals who are at risk of institutionalization, individuals who need the level of care that would be provided in a nursing facility or an intermediate care facility with people with mental retardation or hospital can qualify for a waiver, a state could write a waiver for that particular population. Most waivers are written for -- usually for one level of care. For example, a waiver will be written for people who need nursing facility level of care. And they may have a separate waiver for people who need ICFMR level of care which is a less restrictive level of care.

The other two types that we are not going to get into in detail today but that you should know about, one waiver is for individuals older than 65 who would be in a nursing facility and for children under age 5 with aids or HIV disease or who are born drug dependent. In the next slide we talk about the services that can be offered under home and community-based waivers. First of all, people on -- people may be able to get services that are covered for other adults under the Medicaid program. They may also be able to get optional services that aren't covered under the state plan. For example, a state's Medicaid program may not offer private duty nursing and may offer only a very limited personal care benefit. A state may design a waiver to offer much more expansive amounts or scopes of that type of service to protect people from institutionization. Finally, one of the most important things about the home and community-based waiver is that special services that aren't covered at all under Medicaid may be covered under a waiver.

Some of the classic examples being respite, which is not a Medicaid service, home modifications, which would not otherwise be covered under Medicaid. Let me say a word about the coverage of regular and mandatory state-planned services. These services aren't expressly covered under a Medicaid waiver but what the point is if people aren't eligible for Medicaid and they get on a Medicaid waiver they can qualify for the basic services as well as the special services to offer a complete benefit. On the next slide in order to get the waiver, states need to offer assurances that a number of assurances to the federal government. One of them being that they have put into place necessary safeguards to protect the health and welfare of these people they're placing in the

community. It is not simply to take people out of institutions. And not provide for them in the community. They have to also assure the feds that they'll look out for these people. They have to -- they have to assure the feds that they will evaluate the need for services and assure the feds that they will inform individuals about a choice of services, whether they can get institutional or waiver services.

The waiver also needs to be cost neutral. And what states have to do is assure the federal government that providing waiver services to this waiver population will cost no more than it would cost to provide institutional services to that same population over the same period of time. Usually it costs quite a bit less, but the point of this is that it is supposed to be cost neutral or better. And also they are required to give information to the feds every year about the impact of the waiver and whether these cost neutrality and other assurances have -- requirements have been met.

ELIZABETH PRIAULX: Before you move on, when you were going over the different types of waivers and you said waivers can be covered for nursing facility level of care we got a message from an individual in Minnesota who said that their TBI waiver specifically covers neurobehavioral care.

SARAH SOMERS: That's very interesting. Yes, in the waiver people can find the waiver application online through the website for the centers for Medicare and Medicaid services. The waiver application is a lot of check boxes, basically. States can check yes, we'll provide nursing facility level of care but they also, as Minnesota has apparently done, can

make it more specialized than that. Thank you for that comment from Minnesota. Now, we -- just a word about EPSDT. As I mentioned earlier, the mandatory treatment service for children under age 21, they are entitled to get any Medicaid service regardless of whether it's provided for adults. They're entitled to the mandatory services, the optional services, the whole slate listed under 1396da if it's necessary to correct their problems. The important thing so keep in mind about EPSDT for kids receiving services through a waiver, they're also eligible for EPSDT. That means they're entitled to the periodic and screenings and checkups that any other Medicaid eligible child is entitled to and also they are supposed to -- they're also entitled to the treatment services as well. I'm stumbling here because I've written -- it's posted on our website and I wrote an article in the clearinghouse review about it.

Problems can arise when states have placed an individual cost cap on services for children who are on waivers. And the questions may arise well, if I'm entitled to EPSDT I should be able to get services regardless of cost. And while that is true, the eligibility of a person can be affected if their services exceed a certain cost. And those are things, you know, if you've ever come up against this issue you should look into the fact sheet. It might offer helpful tips.

ELIZABETH PRIAULX: For those of you who go looking for the fact sheet which I believe is called home and community-based waivers versus the Medicaid plan or something very straight forward like that, it is only on the members only page, so for those of you who are listening outside of the P & A network you will not find that document on the NAPIS

website. For those of you calling within the P & A system you need the pass cord for the members only site and you would go under legal information areas and click on Medicaid, click on resources and see a whole bunch of Q & A's and fact sheets.

SARAH SOMERS: Of course, anybody can email me and I'll pass on any of these things to them. All right. Moving onto the next slide, we'll talk specifically about TBI, spinal cord injury waivers. One of the things I'm interested in hearing from you participants is whether CMS hasn't listed your waiver as being a specific spinal cord or brain injury waiver. States have waivers that target these specifically and the states listed in the various sources are Colorado, Connecticut, Delaware, Florida, Georgia, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Maryland, Massachusetts, Minnesota, Mississippi, Montana, Nebraska, New Hampshire, New Jersey, New York, North Dakota, Pennsylvania, South Carolina, Utah, Vermont, Wisconsin and Wyoming.

Let me make sure to make clear that these are waivers that are expressly for people with TBI or spinal cord injury. If a state has a more generic waiver that serves people who need a nursing facility level of care for whatever reason then people with TBI may qualify for that more general waiver. The specifically targeted waivers are identified in 27 states. Most of the waivers that are currently being offered serve a relatively small population. For example, North Dakota served about 21 people last year, Vermont served about 50. California served something like 500, which, you know, proportionately speaking is about the same size. So they are small, targeted waivers. Almost all of them serve people 18 to

64 and with the exception of South Carolina, it's waiver is written for people birth to 64 and Vermont's eligibility category starts at age 16.

So on the next slide the services offered are, you know, a lot of them offer the classic, you know, the classic home and community based waiver services like case management, personal care, respite and medical equipment. Some states offer some more unique services, or at least offer them expressly. Delaware will pay for personal emergency response systems. Idaho will provide -- will pay for crisis management. Kansas offers something and I'll be interested if anybody from Kansas is on the call to tell us if this goes on, called fleet cycle support. A specialized type of personal care services which consists of non-nursing physical assistance during the customer's normal sleeping hours. You may -- some people may have run in their states up against problems that a state doesn't want to provide personal care services or different types of services, during what are considered to be normal sleeping hours. This sounds like a response to that. Minnesota claims to offer vehicle modifications. And our participant in Minnesota can tell us whether that's accurate or not.

Those are just some of the examples of the special types of services states have tried to get into. Now, on the next slide we'll start talking about specific waiver. Florida's brain and spinal cord injury waiver. Currently it was originally started in 1999 as a 200-person waiver that has been expanded to 3 -- 300 slots for the waiver renewal period. The next slide, individuals to qualify have to be medically stable. They have to meet a state definition of spinal cord or moderate to severe traumatic brain injury. Anybody who is eligible for

Medicaid over 18 qualifies. People disabled people under 90% of the poverty level and individuals with incomes under the S.S.I. level qualify. In contrast to Medicaid eligibility it can be limited. With 300 people they don't offer it to every person who falls into these categories but you need to fall into the category in order to be covered.

On the next slide some of the services covered in Florida's waiver are listed. The adapted health and wellness service is -- it's described as a workout regimen that is provided in a health studio that is designed by a physical therapist to increase stamina and strength and other attributes that would enhance the ability to perform activities of daily living. The rehabilitation engineering evaluation is a benefit for participants in the waiver who need a more extensive evaluation than the typical assistive technology evaluation. And then other more typical services attendant care and companion services, assistive technology, life skills training. A community service coordination called community support coordination like case management but it's especially designed for people who are sort of graduating out of a state-only TBI program serving people with less severe disabilities.

Now, on the next slide Florida also participates in an 1115 demonstrate waiver. These are waivers that states may -- different type of waiver than the home and community-based waiver that states may participate in if they're going to engage in a project that advances the objectives of the Medicaid act. One particular featured 1115 waiver that states are getting involved in the last couple of years is the independence plus waiver. Essentially it is -- it enables the waiver participant to pick and choose his own service providers. And gives cash for the purpose of reimbursing them. As opposed to simply offering the

services. At this point, Florida allows up to 39 brain and spinal cord injury waiver participants to participate in the independence plus waiver. All right. For the last what time we're at here. I will give people a quick overview of a few cases involving TBI, spinal cord injury waivers. On the next slide I'll highlight four cases, Bryson versus Shumway from New Hampshire. I'm hoping that some New Hampshire advocates are on this fall. Dubois versus Medows, from Florida. Williams versus Wasserman, the Maryland home and community based TBI waiver case and finally the Tennessee P & A versus wells.

ELIZABETH PRIAULX: We have copies of those cases that you can call and request us to send materials, pleadings.

SARAH SOMERS: Great. Now, on the next slide, in Bryson versus Shumway, this was the -- the plaintiffs were involved in -- lived in nursing facility and were in the acquired brain disorder waiver. They raised a variety of claims against the New Hampshire Medicaid director, being denied due process as is required under Medicaid. That the state had not provided Medicaid services with reasonable promptness. The state hadn't used reasonable standards to determine eligibility and the scope of services, and some Americans with disability acts claims and a Constitutional due process claim. There are three cases that you could get on Lexus on this particular case. There may be one more. But in the first go around, the plaintiffs and defendants moved for summary judgment and the defendant got summary judgment on the claims to do with effective Medicaid services, the claims around reasonable standards and best interests of the beneficiaries. The court held off on ruling on the reasonable promptness claim and on the ADA and rehab act

claims but they did -- they did grant summary judgment on the due process claim for plaintiffs.

I've described this in more detail and you can read the cases. Basically, the court held off on deciding the -- you know, the fundamental alteration and the decision about whether services had been provided with reasonable promptness. The case went up to the first circuit after another decision and they had -- they went back down to the District Court, who has the most recent decision is a very nice sort of roadmap of what people need to prove when they are making a claim that the state can make a reasonable accommodation to get people off of the waiver. Let's see, the next slide basically the important holdings that came out of this. The sovereign immunity. The 11th amendment doesn't bar cases like this under the Medicaid act. Most -- the right to enforce most of the Medicaid claims was recognized. You know, this is possibly arguably but another case that stands for the proposition if you're going to argue for eligibility for Medicaid services under the waiver, you're going to have -- you're better off trying to make claims within the number of slots that the state has already offered.

Then finally, the fundamental alteration defense still goes on. My understanding is there is going to be a trial on this within the next six months or so, at least it's currently set for the next six months. The Dubois litigation in Florida in the next slide, basically there were 300 slots and the state was only filling about half of them. And people had been on the waiting list for several years so it was a class action raising again Medicaid due process and freedom of choice between institutional waiver services. ADA504 claim and another

Constitutional due process claim. The next slide as in Bryson the court wasn't impressed with the state's arguments that Medicaid claims couldn't be brought against the state Medicaid agency. They allowed plaintiffs to do that. A class was certified for all the people who were or would be eligible under the TBI spinal cord injury waiver and help as co-counsel on this. The counsel is southern legal counsel in Gainesville, Florida. We're negotiating it and I believe we'll reach settlement very soon. And they're going to fill the waiver slots and other things which we will update you on as soon as it's resolved. Which it hopefully will be very soon. In the last two cases a quick word about that Williams versus Wasserman. That was a P & A case filed before Olmstead and it finally came out that the court bought the state's argument that the plaintiffs were asking them to make a fundamental alteration by giving them home and community-based waiver services.

The last one, the Tennessee P & A the court held that the state was trying to argue that a developmental disabilities were only naturally occurring conditions as opposed to an acquired injury and the court did not agree with that. So that is -- I've talked a little more than I had time to talk but I'll leave it at that and we can come back to pick up questions.

ELIZABETH PRIAULX: You are right on time, Sarah according to our schedule.

SARAH SOMERS: Oh, good.

ELIZABETH PRIAULX: I just want to go back. You were talking about different services that states allege they have under waivers and it's always sort of suspect as to whether

these services are actually delivered and since you knew somebody from Minnesota was on the call, you said we'll see whether Minnesota actually offers modifications. Barnette says yes, in fact, Minnesota offers environmental modifications that include home modifications and vehicle modifications and we serve up close to 600 people. We have resource caps limiting the number of new participants somewhat but we do have unlimited conversion slots to allow anyone living in an institution can get a waiver. It can be problematic because of appropriate housing but these are questions somebody asks and we'll see on future slides. The eternal problems of no providers and no housing. So that was the follow-up from Minnesota.

SARAH SOMERS: Thank you, Minnesota.

ELIZABETH PRIAULX: On the next slide you'll see one of the first questions received and I have, I don't know, about six big questions. So since people took the time to send them to me in advance I wanted to spend at least the next half hour going over these questions. I did collapse some of them somewhat so they might not read exactly as they were sent in. I do want to let people know when they -- when they make comments through here, what will happen is you type in your comment and I can read it out and we'll get ideas from folks on the call of how they're handling a similar situation. But this call will be available to the public on the H -- excuse me, HRSA website. On the one thing it's a great thing. If you liked that overview of Medicaid that Sarah just gave, you can encourage your other advocates to your office to listen and get a great overview. You can encourage clients to go up and listen to it. Advisories boards and boards and councils. So it is going to be a

tremendous resource to you when folks ask you about TBI waiver options. On the other hand if there is something that you don't want the whole world to know, then probably don't raise it as a question here.

OK. So on the first slide you'll see the question was in states that have a specific TBI waiver, what have advocates done to encourage states to increase funding? Has anyone done legislative work to increase TBI waivers, what worked? How many slots are available? I think this is the struggle with folks. They say well, I want a TBI waiver, that sounds great but how do I get it done? So Sarah, if you have anything to say, you can say something on it or hopefully people will type in experiences that they've had and might leave a little lag time on this call. I do also know that a Center for mental health law has a document on their website about getting waivers for individuals with mental illness and while it's a different population, the steps that they write about are very much the same. How to collect the data, how to identify the folks in the state legislature that might be interested, how to make the argument that community services cost less than institutional services, how to document waiver waiting list issues and the like. That might be one resource for folks. I don't have the exact -- the -- center is WWW.VAZELON -- I can't read anything outloud without seeing it. Is that how it's spelled, Sarah? Dot org. I would type in waivers from mental health and you'll find take resources. I'm looking around the marquee and no one has submitted any thoughts on—

SARAH SOMERS: Let me make a comment then. In Florida, I think this is not uncommon, Florida has, in addition to the funding it receives from the federal government for Medicaid

services, Florida has a TBI trust fund and I believe it's funded in large part by fines from traffic tickets. And other moving violations. So it's linked closely to the cause of many TBI and spinal cord injuries.

ELIZABETH PRIAULX: And I know that on an earlier webcast we had someone from Delaware talk about some of the prevention statutes that they're putting into place where they have their monies and it strikes me if you have a statute like that to include money-generating -- tie intervention in with money-generating income for waivers. That might be good. If you're interested in how to design statutes like that you might want to look back on the HRSA website for other ideas about prevention statutes. Maybe you could tie into funding. And we did get call from Barry and he just said it helps to have a dedicated funding source which is what you're getting at, what happened in Florida. So as people think about what they've done that has worked, please feel free to type your question in. I can still go back to it. We're going to go to another question just to get folks thinking about the issues that came up. And it's that in those states with trust funds, how do the funds interact with the waiver? For example, how do they prevent the trust fund from supplanting the waiver funding? Our state has been looking at creating a trust fund but the state seems eager to see it as an alternative source of funding instead of an additional resource for people who don't qualify for the waiver

SARAH SOMERS: I'll make a comment on that. I think that that's -- the trust fund sets up a lot of issues that sort of illustrate the tension between maximizing your federal match under Medicaid and look out for people who aren't eligible. I think that there are some

policy issues in Florida related to that. They have a mental health trust fund and on one hand some of that money can be used for operating a home and community-based waiver and when you spend the money for Medicaid you get a federal match. On the other hand there is concern in disability communities and state health departments and mental health departments about what about the people who don't qualify for Medicaid? Medicaid is great but there is other people who are not going to be covered by it and you want alternatives for those people, too. So I think this isn't really an answer but I think you'll see that tension among policymakers, too, within the government there will be pressure to use it to maximize Medicaid. At the same time, you know, they have to be mindful of the whole universe of people with disabilities who may not fall under the eligibility qualifications. I think -- I personal take is to try to do a little bit of both. You want to maximize the money but also reserve something for those who aren't going to qualify.

ELIZABETH PRIAULX: I think it's, as we can see from folks sending it in, that probably other states have encountered this issue and if you are on the TBI protection advocacy web -- listserv or the listserv for TBI advocates by HRSA, you might want to continue the discussion of trust funds and how to ensure they're an additional source and not the scape boat -- scape goat of Medicaid budget funding. There is a message here from Barnette in Minnesota and he says that Minnesota got our waiver back in the early 1990's. The brain injury association was instrumental in pushing legislation forward. The sell was made easier because we already had home and community-based waivers in place. We currently have over 1,000 people on the TBI waiver now. The other number -- well, was 2003 data. So when he said before, I think, there were 600 people, now he has 1,000

people on the TBI waiver so it is really growing. I agree with that point. You know, you have to find a way to sell it.

A big selling point now is that the administration wants to waiverize everything. And also you can get consumer groups behind you if you try to design a waiver that supports consumer-directed services and money following the person. As Sarah talked about had happened in some states with TBI waivers. So thank you, Barnette. And I'll go to the next question. But please feel free to keep typing in comments to earlier questions. Have people had difficulty finding competent service providers when they do, when waiver funds are available in the state they can't find service providers. What have states and advocates done to create a competent infrastructure, housing, providers with TBI experience. This is the big question we all face at the last TBI institute training people -- we had a speaker that tried to comment on programs that our speaker was running out of New York where they would try to interest -- and I believe it was speech pathologists and providers of services to autism.

They found that folks serving individuals with autism had a ready skill set that lended itself well to serving folks with TBI and this speaker we had discussed how he had a program to approach folks like autism providers and others to train them on TBI-specific work. So they can expand the number of providers in the state. If anyone wants information about that program that he spoke about, they can contact me. But I don't know, Sarah, if you have any comments on large sterile class actions you've worked on and how they tie infrastructure development into expansion of waivers.

SARAH SOMERS: Well, you know, there is a Medicaid provision requires that rates to compensate providers should be at a level that will enlist providers to the same extent they exist for private pay or other non-Medicaid consumers of services in the area, meaning, you know, specifically meaning that the Medicaid reimbursement rate for providers has got to be decent enough so that providers will actually participate and it will make it worth their while. This is a big problem in dental services particularly. States -- many states just offer low reimbursement rates for Medicaid dental so you often have a big shortage of dentists who want to participate. This is also -- it comes up in the context of home and community-based services where there is -- there is an Arizona case where they claimed that the rates were not sufficient to enlist basically personal care attendant care, homeworkers in Arizona. That went to trial. That has been a longstanding case. And a lot of providers bring these kind of cases saying they aren't being compensated adequately. I don't know how -- what people who have been through these cases would say right now about bringing that type of a claim. I touched on the issue of enforceability under 1983.

There have been a lot of questions raised about providers enforcing that provision, it may be more difficult for beneficiaries to enforce it. North Carolina they're trying to move away from the big institutions for people with mental illness and there hasn't been litigation on this, rather it's this sort of full court press with the state working with the provider community. What you see coming up is that a lot of those vested interests are -- maybe against us. The nursing home lobby may be powerful in your state and they don't want this

broad base of community based providers competing with them. It may not be an answer but it's just an explanation of all the problems out there.

ELIZABETH PRIAULX: I'm glad you brought up that case because while they don't -- they basically the federal district court decision was that the state had to come up with sufficient providers to ensure adequate service and they actually had a whole system for people to be able to report and get services right away when providers were not available. That the settlement is worth reading just for the great language on how the Medicaid act should be enforced to ensure sufficiency of services but I don't recall it having any specifics about how the state should go about getting new providers. It just said you shall have the providers. And I remember it specifically did not include like you must pay this amount. I think the court said, that the judge was not going to suggest a specific amount, just make sure it would be enough to ensure the providers. So I think that lends itself to the whole issue nobody knows how to do it. Or the judge might have detailed it in the settlement. But it's worth reading that Arizona decision. And so thanks for bringing that one up.

Also, with that decision I should note they did have ADA claims in there but the decision was not based on the ADA claims and they didn't actually rule on the ADA claims. The other case I'm aware of where they raised ADA claims to try to get more equitable pay raises was California where folks were trying to raise more money to provide services in nursing facilities than the community. An ADA claim was raised that this promotes institutionalization because people can't get sufficient providers in the community because

the pay is lower so the judge threw out that claim. The ADA claims have not been all that successful to this point. It's more hang your hat on the Medicaid claim that Sarah talked about. So there are a couple of other questions that were sent in in advance. So far nobody has submitted thoughts on the other issues about trust funds and about working with the legislature. So we'll move to the next question. Which is that our state agency has incorrectly told individuals that they may choose receiving home health or only through the TBI. Individuals cannot receive services under both. This is not true. I'm wondering if other folks in other states have run into this problem? And Sarah, have you had other folks call you with a similar issue?

SARAH SOMERS:, no. I have to say I was hoping that the author of this question was on because I'm not sure exactly what the issue is. The services -- I assume the services aren't the same, otherwise you -- why would you care? I guess what's the issue?

ELIZABETH PRIAULX: There was more to this, which was that the state Medicaid plan provided home health services up to a certain number of hours, and the waiver provided home health services up to a higher number of hours. So she -- so the individual wanted to be able to get the services under the waiver so they could get the higher number of hours but still get traditional Medicaid plan services for other things.

SARAH SOMERS: Well, I know there is a regulation that says that if you qualify for Medicaid under more than one category you can pick the one under which you qualify. And I don't -- you know, I think CMS has said that also applies to waivers, but I don't know

if you can sort of mix and match. If whoever wrote this question wanted to email me I would talk to you more about it. I think you have to go with one or the other but I think you can pick. I wonder exactly what the services are that they're not getting.

ELIZABETH PRIAULX: And if any others of you have had that problem, then type it in so we know to bring this to maybe a future research by NAPUS to help you out.

SARAH SOMERS: A slightly different situation, it says in the state Medicaid manual when it describes home and community based waivers that you can't provided services under the waiver with Medicaid. I think some states confuse that. That's a more funding type of thing than it applies to the person getting the services. In other words, for the purpose receiving the services it shouldn't matter where it comes from or which pot it is being paid for out of if it's the waiver or regular state plan services. It seems some states have confused it and said you can't get these services at all because you're on the waiver. And I don't think that's -- depending on the service I think that's probably not correct. How is Massachusetts?

ELIZABETH PRIAULX: OK. Thank you. Again, as folks have comments on these questions, they can bring them up to us later or on the listserv and we can figure out which of these are more universal questions that folks are having problems with and develop technical assistance in the future. So it really helpful for us to continue to hear from you on these questions. How are states coordinating the employment services that are available through the TBI waiver with traditional vocational rehabilitation services? And I'm sure this

comes up in other areas besides coordinating VR services with waiver services but generally coordinating services through the school system and waivers, for example. That was the specific question. Do you have thoughts on that, Sarah?

SARAH SOMERS: I'm afraid I don't.

ELIZABETH PRIAULX: I know that you have looked into coordinating what is available through waivers with what's available through the school programs and you have developed some Q & A's on that topic.

SARAH SOMERS: Yes.

ELIZABETH PRIAULX: And, this is a different thing but it's the whole issue of two systems having to work together and one not being able to dump on the other system for the service. So if anyone is interested or having issues with what Medicaid should cover versus what the school should cover they can go to our website and get thoughts on that. I was hoping that other people might have written in with thoughts on that. The webcast is a kind of tricky way to solicit comments from folks. It takes a little more time to wait for thoughts than on a regular conference call, but if anyone, you know, has information about how they're coordinating VR services with TBI waiver services, that would be great.

SARAH SOMERS: Let me just say a word about the litigation just going back to that. As you can see, three out of the four cases are brought by P & A's and I'm sure that -- well, I'm not sure but I would imagine that the advocates who brought those cases would be happy to share their experiences and I think that three of the cases, the Florida, New Hampshire and the Maryland cases are -- probably have a lot in common with other home and community-based waiver litigation. They all raise similar issues, whether it's an MRI or a TBI or a generic nursing facility waiver. The Tennessee case is an interesting one because it puts TBI on the same footing as naturally occurring types of disabilities. And those are -- I'm not aware of other cases beyond this. If other people have had TBI waiver litigation experience, I would be grateful if you'd share it with the listserv and tell us what is going on.

ELIZABETH PRIAULX: You also asked our folks to reply if you did not mention their state as having a TBI waiver, so since nobody has replied to that I guess the folks on this call feel that their waivers were reflected in your list.

SARAH SOMERS: Good.

ELIZABETH PRIAULX: We have some questions. One was a general comment I think related to the voc rehab coordination issue and Debbie was saying do the states have cooperative agreements between Medicaid and VR. It seems like that is one strategy to have a cooperative agreement or something to rely how the coordination should work.

And maybe if Debbie, are you from West Virginia? I'm trying to remember. But maybe if Debbie, if you have a cooperative agreement in your state if you would be willing to share that on the listserv, that would be helpful to others struggling with this issue. And then Debbie also wrote, perhaps the states that have both TBI waivers and voc rehab services have an agreement that might spell out who is responsible for what. I think you're writing these in different sections. Debbie said she'll be sharing her cooperative agreement over the listserv. Thank you very much for that. And I'm going to go back to a question submitted by Robin. She writes, in Arizona we have an 1115 demonstration waiver virtually all services provided through managed care. Our home and community-based services covers persons at risk of institutionlization including persons with TBI. What advantages would there be with having a TBI waiver? In Arizona we have an 1115 demonstration.

SARAH SOMERS: Yeah. Well, I think the answer can be in part some of the special services that they offer. Like the -- some of the special services that I highlighted that they offer in Florida or Minnesota or Kansas, sort of these innovative services that are particularly geared towards people with these types of injuries and it can also be a benefit if you're talking about a dedicated funding showers -- source in Florida like automobile accidents. If you want to have a stable source of funding, that may be another reason to do it. Sometimes getting -- a lot of these waivers start out with relatively few participants and sometimes it's easier to get a foothold with a small, targeted waiver and build up from there. Sounds like that's maybe what Minnesota has done.

ELIZABETH PRIAULX: Great, thank you, Sarah. And Debbie wrote back and said she's going to be sending what they've done is reported to RSA and they don't have cooperative agreements but I guess they've developed -- reported these problems with R.S.A. and been straightened out that way. Any correspondence you could send on that issue would be helpful. Debbie is now saying she answered yes to the question about her being from West Virginia and not yes that she has a cooperative agreement. Thanks for clarifying that. Correspondents, anything like that that you could send to us without any identifying information would be great. I want to go back, we had -- let's see and make sure I got all the questions here. Lorraine Smith from Nevada says Nevada P & A doesn't have a TBI waiver as of yet but we got funding from the TBI advocacy. It sounds like one way they did it in Minnesota. That Barnette was saying, work with the brain injury association and other TBI advocates. So thank you.

And we got a comment from Barnette who says RVR can pay for the first 18 months if there are long term supports available to continue the support after that. You can be on the waiver and use it for home care. Use the RV to begin an employment program and then supported employment under a waiver. There is a waiting list now for certain VR services. They overlap with school services can be tough. The systems do point at each other at times. We have a coordinated case management option that creates a joint service planning team it does not work very well. So I think you were answering the question in the beginning about how VR will pay for 18 months and then after that you

have to go through the waiver. So that -- does that answer how it might have worked, Sarah?

SARAH SOMERS: Uh-huh.

ELIZABETH PRIAULX: OK. Thank you for that comment. And I'm trying to handle all these requests that are now coming in. I think we've got them all. But there is one that keeps coming up which is at the end of the webcast please fill out an evaluation form before signing off. I don't know whether all of you could see that as well as I can. Just in case you all can't see that, that's important to HRSA to make sure that they are providing information the way that is most helpful. So please don't be shy to ask a question here. But if it turns out that this is not the best place for you to come up with comments right away but you're thinking about it later and you want to ask a question or submit a comment about one of the questions that people have asked, please use the P & A listserv or the learning community listserv is what it's called to HRSA and TBI talk and please submit to Elizabeth any other items you'd like to see for webcasts in the future. I hope that you've gotten to know how -- how earnest Sarah is at being able to answer questions and help you all out and that you'll take advantage of the expertise available from her when dealing with Medicaid questions or considering TBI waiver litigation. I guess I don't see any other questions popping up as we speak. But please now you have a slide here on how to fill out the evaluation. OK. We got one more question from Barnette. Thank you. And he says thanks.

SARAH SOMERS: Thank you, everyone.

ELIZABETH PRIAULX: Thank you, Sarah. And thank you all for being on the call. And please continue to let us know how we can provide information to you in the future.

All right. Bye, everyone.

SARAH SOMERS: Bye.