

“The Deaf and Hard of Hearing Populations...Issues Impacting SMHAs”

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Speakers:

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This meeting is now being recorded.

This is Roy Praschil and I'm the administrator for NASMHPD's Legal Division. And I want to give special thanks to Stephanie Sadowski whose technical expertise makes these legal division webinars possible.

Today's webinar, the third in a series by NASMHPD's Legal Division, will be on “Deaf and Hard of Hearing Populations: Issues Impacting the State Mental Health Authorities.” Just a few housekeeping comments before we begin. Today's webinar is unique in that our presenters and some of our listeners are deaf and hard of hearing, which means that communication rules are different than if this was an all-hearing participants webinar. Several individuals on this call who are deaf will be participating by one type or another of delayed rendition of the spoken message. In other words, they will always be behind except when they themselves are talking. Therefore, the following ground rules must be followed: one, one person speaks at a time, to ensure this please put your phones on mute, which is “*6,” during the presentations, we will let you know when to un-mute; two, make sure that you identify yourself before you speak; three, give the interpreter/captioner time to interpret and transcribe, speak slowly and concisely; four, keep the conversation on one subject at a time; five, we will require questions to be submitted by typing them in the chat box on the right side of your screen, please do not ask questions verbally.

At the end of the presentations Lester Blumberg will choose several questions to be asked of the presenters. The rest will be conveyed to the presenters after the webinar to be answered as they deem appropriate. Just as a reminder for the presenters, to move your slides forward or backwards, click the arrows on the lower left corner of the screen. And, again, if you're experiencing any problems during the call, please call Adobe Technical Support, and the number is on the opening slide, which is up on your screen. Please note that there will be a number of articles, cases, and other resources that are related to this webinar that will be available on NASMHPD's website after the call at WWW.NASMHPD.ORG. I'm going to now turn this over to Lester Blumberg who's the General Counsel for the Massachusetts Department of Mental Health who will be moderating this webinar.

Thank you, Roy. This is Lester Blumberg. And it's a real pleasure for me to be moderating this webinar. I'd like to thank Roy and NASMHPD and the NASMHPD commissioners for recognizing the importance of these webinars for both the legal division and for the other divisions of NASMHPD who are participating or will have access to these materials. We have found that this opportunity to exchange information with our colleagues across the country is

extremely valuable, it expands our own knowledge and our ability to advise and assist our own commissioners and agencies in the work that we do.

Today's webinar is very special for a number of reasons, not the least of which that it involves a segment of our population and of our community that we don't often hear from and who struggle to obtain services and access to services in ways that those of us who are in the hearing community sometimes can't imagine. In fact, the technical difficulties that we experienced just getting this webinar going are just the tip of the iceberg of hurdles and challenges that are faced in the provision of services to individuals who are deaf and hard of hearing every day.

We are really privileged to have with us today online three primary presenters who have extensive experience and knowledge in the area of the provision of deaf services. They are not all lawyers. In fact, I think only one is practicing law. I'll introduce them in just a moment. We have asked them to address issues relating to deaf services in the context of the legal climate – the legal requirements that their states may have faced. Some states have faced lawsuits around provision of services to individuals who are deaf and hard of hearing. Some have had lawsuits threatened. Others have developed services without the threat of lawsuits. And we'll be hearing more about that as the presentation goes on.

I don't want to take too much more time before getting into the substance so I will introduce the three primary presenters. We do have some individuals here in Massachusetts sitting in the room with me who are part of our Division of Deaf Services who are going to be available to help provide some insight later on, I hope, and to participate in the conversation as the presentation moves forward. I want to reiterate what Roy said about the need to have folks please write their comments – questions and comments in the chat line. And as I said, I will try to – as Roy said, I will try to pick out questions that we will have time to answer and discuss later on in the presentation. I think what I'll do is when we get there, if there is time, I may ask an individual questioner to elaborate on a question and that person will be invited to join the conversation verbally.

If you have a burning need to make a comment, I'll ask that you type it into the chat, or at least type into the chat, "I have something to say," and we'll try to get to you. That being said, it is my real pleasure to introduce our three primary presenters, and in no particular order, Steve Hamerdinger is the director of the Office of Deaf Services at the Alabama Department of Mental Health and Mental Retardation, he's had that position since 2003, and has been involved in the provision of deaf services for more than 25 years. He has been named "Deaf Person of the Month" in November of 2008 by Deaf Magazine. He owns and operates a mental health consulting firm that provides consultation and training on mental health and deafness both nationally and internationally, and was appointed by SAMHSA in 2009 as one of two United States representatives to the International Initiatives for Mental Health Leadership Network on Mental Health and Deaf Individuals. He's got a whole list of other honors and positions that he holds, but I'm not going to take the time right now to list them all. Steve is deaf and will be speaking to us through an interpreter.

Jessica Kennedy is a graduate of the William Mitchell School of Law in Minnesota. She is an attorney for the Minnesota Department of Human Services. She functions both with general

counsel issues and data privacy. Jessica herself is deaf. She grew up with a deaf father and a hearing mother and siblings.

Finally, Roger Williams is joining us from South Carolina. Mr. Williams is currently employed by the South Carolina Department of Mental Health, and he is director for Deaf Services. He went to school at the Rochester Institute of Technology, has a Master's in Social Work from the University of Illinois, and he's currently a PhD candidate in Social Work at the University of South Carolina. He is the parent of four deaf children and two hearing children. He's a licensed foster parent and the spouse of a deaf adult. He himself is hearing and will be speaking to us during the presentation. He is also very active in a number of areas and was involved in the International Initiative for Mental Health Leadership Taskforce on Deafness. So that being said, I will turn the presentation over to the presenters. I'm not sure who's going to start, but take it away, Steve, Jessica, and Roger.

Steve Hamerdinger speaking: That would be me. Thank you, Lester. I appreciate the introduction. I've been looking forward to today. Roy and NASMHPD and Lester and all of you, we appreciate the opportunity. I'm speaking to you through an interpreter through the telephone, and that's very different from what I'm used to as far as communication. I don't have a direct visual contact with you. And it's very discombobulating; it's not very fitting with what we do in the deaf world. I wanted to start very quickly giving you a historical overview about deafness. How did we get here?

Historically, and you look at the hearing world, and by that I mean the larger society, people who are not considered to be deaf, and I will explain that term in just a moment. The hearing world has looked at deaf people as broken, they're disabled, they look at the ears as a mechanism that doesn't work rather than looking at deaf people as a linguistic and cultural minority. Deaf people perceive themselves very differently. It's true that my ears don't work, but that's not who I am. I am a person who connects to the world visually. I connect to the world through my eyes. Because of that, my cultural rules, my norms, my behaviors are very different and unique from the larger society. Services typically provided for deaf individuals do not take into consideration that history that I just gave you. What they typically do is try to make accommodations by putting someone in there who signs. They don't look at how deaf people behave, what their norms and values are, and how they perceive the world in general. Jessica or Roger, would you like to add anything at this point?

Hi, Steve. This is Jessica. Would you like me to discuss the foundations of accommodation? Otherwise I have no input at this point.

Sure, go ahead, Jessica.

Sure. There are two national foundations of accommodation. The first is Section 504 of the Rehabilitation Act. This was established in 1973, so it greatly predated the Americans with Disabilities Act (ADA). Section 504 of the Rehabilitation Act mandated that all federally-funded services had to be "accessible." It was one of, if not the first, civil rights statutes for persons with disabilities. Soon after – actually, not so soon after, it took quite a while for the Americans with Disabilities Act to be established in 1990. Through the ADA, all publically-

funded services had to be accessible with considerations given to the preference of the consumer. What this means is, personally, when I request an accommodation I make the request. I might say, "In this situation I would prefer to use an ASL interpreter," over another available accommodation, which might be a note taker.

Note, there are certain factors under the Americans with Disabilities Act. My preference is not necessarily controlling, but just being a factor, just giving the preference to the consumers is very significant. Also, under the ADA all public accommodations must offer equal access to goods and services. When I go to a play I have the right to request an ASL interpreter be provided for me if the play is open to the general public. Steve, did you have anything to add?

This is Steve. Later we're going to get into one more critical federal law/executive order that's going to play into our discussion today. But I would like to go ahead and proceed if we may. When 504 was passed, it was limited to programs, which were federally funded. Many of the states and local government entities felt that they were not obligated to follow 504. In 1984, *Handel v. Levine*, which was a case in Minnesota, led to the establishment of a program within Minnesota. First, this was a lawsuit that said deaf people deserve treatment. It was critical because it was targeted at a state level and it wasn't particularly focused on federal-level services.

Three years later, a very similar lawsuit was filed in Maryland. You may see it here, *Jane Doe v. Wilzak*. Again, it stated that deaf people deserve treatment, not just warehousing. The earthquake happened for deaf services in 1994 when *Tugg v. Towey* was decided. This is the result of services based on crisis intervention following a hurricane in South Florida. Teams of ASL fluent clinicians converged on South Florida to assist with mental health counseling and services. It was the early version of psychiatric first aid. I believe, Roger, you may have been one of those individuals who actually was dispatched to Florida. Is that correct, Roger?

Yeah, I was in that group, and one of the things that we did was demonstrate the effectiveness of direct services, meaning not using an interpreter but having clinicians trained in crisis mental health service who could sign directly. And it was only after the services that we established were then ended with the end of FEMA funding that this lawsuit was brought. Basically the court said "No," regardless of whether the funding is from FEMA or from the regular state appropriations for mental health services, the deaf community still had a right to that equal access meaning direct access with a clinician who signed.

This is Steve. I think it's important to recognize the larger societal context for this. It was more than recognition. People had a language preference. Not everyone in America speaks the Queen's English. There are a variety of languages and people are better served in the language that they best understand. This led to the Executive Order 13166 that was issued in 2000, and it addressed the limited English proficient population.

At the same time I would like to go back to the point that Jessica made, giving a preference to the consumers' preferred accommodation choice. This was largely ignored until 1998 and the case of Jan Devinney, herself a clinician. She had a psychiatric crisis of her own and she was admitted into the Maine Medical Center. They made the determination that writing notes back

and forth was sufficient for her and that she did not require an interpreter. She became very frustrated with that approach and she filed a lawsuit, and the determination from that was that the consumer has the right to choose how they want to receive services. It's an important case.

And around the same time the deaf community in Alabama started to become very restless with seeing a lack of progress related to the development of services within the state. Like other states have experienced, there have been lots of meetings and committees and taskforces that have been established and talked about plans that have been written up, but unfortunately not a lot of action has been taken. In Alabama, Verna Bailey, along with the Alabama Association of the Deaf, filed this lawsuit in 1999, and it was settled in 2002. I'll talk about the specifics later during the presentation.

Right now I'm aware of two major lawsuits, which are occurring in states relating to mental health authority; one is in Georgia and the other is in Missouri. There may be others that I'm not aware of personally, but those are two fairly large ones. Jessica or Roger, would you have anything else you'd like to add?

This is Jessica. I don't know of any others off the top of my head.

Okay.

This is Jessica. Which brings us to the present. I want to talk about a contentious current action, *Loye v. County of Dakota*. This is a more recent case than some of the others that we've been discussing. It came down about a year ago. This case originated in Minnesota and was decided by the 8th Circuit. I found the decision to be unfortunate; nevertheless, I think it's relevant regarding the cultural and language issues that the SMHAs encounter as they provide their services. I want to start with a brief background of this case. Here, neighborhood kids found mercury stored in an old abandoned building and took it home to play with. The plaintiffs in this action are a number of families who lived in the neighborhood and are all Deaf. The primary and preferred language is ASL.

The plaintiffs alleged that they asked for an interpreter from the police as early as 6:30 in the evening, when they first discovered that the children had been contaminated with mercury. Eventually, during the course of the evening, a special response team was brought in and a decontamination camp was set up at about 9:00 p.m. By 11:00 p.m. the response team began its services. The response team had each person, alone after 11:00 p.m., remove all of their clothes and jewelry. Individuals sequentially were then sprayed and scrubbed by the response team in the camp. They were then given suits or blankets to cover themselves and they boarded a bus, which took them to a hotel provided by the Red Cross because their homes were contaminated.

Even though an interpreter was requested at 6:30 PM, no ASL interpreters were ever provided during the six-hour decontamination process. The neighborhood homes were decontaminated for about a month and interpreters were only provided sporadically and incompletely at meetings about the decontamination process at their homes throughout this month. The plaintiffs sued under Title 2 of the ADA, section 504 of the Rehabilitation Act, and under the state's Human Rights Statute. The relevant provisions of each were construed to be the same.

In this case, the defendant is the County of Dakota. The county was responsible only for the response team decontamination services that began around 9:00 PM. The city was separately responsible for the police efforts when the police were called at 6:30 PM. So the city was responsible for services that were provided from about 6:00 PM, 6:30 PM until about 9:00 PM and then from 9:00 PM until the actual decontamination services were completed, probably after midnight, that was provided by the county. So you have two separate government agencies coordinating the response.

The plaintiffs split their claims between the separate entities. This complicated the analysis because it forced the plaintiffs to contend that the county was responsible for the city's failure to have the interpreters available for the contamination services later that night.

It was hard for the plaintiffs to assert their rights because the county was responsible for services from 9:00 until midnight; they [the county] were not asked to provide interpreters until almost 11:00 p.m. Whereas the city, who was asked to provide interpreters at 6:30 p.m., technically, they were not responsible for the services that were being provided at 11:00 p.m. Yet, instead of ruling that the county had no liability from multi-agency actions or for joint government liability, the court used this opportunity to discuss what is effective communication and meaningful services.

The court concluded that because the plaintiffs got the benefits of the emergency services, because the plaintiffs received the shelter, the medical care, and the decontamination, just like the hearing neighbors had, there was no harm and no legal violation. The circuit court appeared to agree with the district court that the plaintiffs' abilities to follow directions, that they got on the bus just as everybody else did, was evidence that the communication was effective. Yet, effective communication has been regulated to mean "clear and understandable."

Additionally, the regulations for Section 504 ensure that the communications are *as* effective as communications with others. The 8th Circuit, however, quoted the United States Supreme Court and opined that this 504 regulation does not intend identical results for achievement. There was presented evidence that the plaintiffs were unable to understand or participate in the meetings. This evidence was dismissed by the circuit court. Instead, the court seemed to understand that the legal standard was effective communication, which results in meaningful access to government services. The court then held that because there was no evidence that plaintiffs failed to receive a service when the meeting advice or the assistance was not understood by them, the plaintiffs received meaningful access to government services.

Again, I thought this decision was unfortunate. And after reading this case, this is what has become wholly apparent to me: to truly understand what effective communication and meaningful access to services are stakeholders require education and familiarity of deaf and hard of hearing culture, language, and education. This is why familiarity with available resources is important for deaf advocacy and the provision of state services. As an example, at the end of this PowerPoint presentation I've listed several resources available in Minnesota alone. There are also several national resources, and most states have their own commissions and advocacy groups.

If more service providers and government officials knew of these resources, they could better understand going through a six-hour decontamination process, being hurdled through a shower line, corralled onto a bus without being able to hear where that bus is going, why you're not going home, what's happening to your children, unlike the hearing people who had full access to those same instructions and details. With that understanding, which is provided in these resources, then, I think services would be provided more equitably. And I would hope that everyone participating in this webinar takes full advantage of the afternoon to discover what resources are available in their states. And with that, Steve, I'll hand it off to you.

Jessica, this is Roger. I'll pick up in talking a little bit. As we talk about effective communication in the mental health setting, and we're going to get to that in a second, I want to talk a little bit about where South Carolina was and then how effective communication within our program changed that whole process. In 1990, South Carolina had 12 individuals who were identified as deaf in in-patient settings, and it was costing about \$1.3 million to serve them in a year. The out-patient services did what many states continue to do, which is occasionally they would have an interpreter available. When a deaf person is presented with a particular situation, they would, kind of within the existing mental health services, provide some level of access to the services so that the deaf person could get in the door. They might write notes, they might have used an interpreter, they might have used a family member, but there was no system of providing that access. And what we saw was that the average length of stay for deaf in-patients was almost twice as long as it was for hearing in-patients.

And then in 1989, a complaint was submitted by Protection and Advocacy, the state agency that kind of sees how well we're doing in terms of ensuring that individuals who have a disability or whatever have access to services. It alleged that the department had failed to provide that access. Through some kind of serendipitous situation, the department agreed to provide those services. The complaint never got to court, but some of that was because at that time the director of the agency was on the board of the Protection and Advocacy group and would have been in the unfortunate situation of filing the complaint against himself.

Initially, those services were focused on the in-patient population, but they expanded to include out-patient services. And I think, again, the key is the topic that Jessica addressed, effective communication. In mental health it isn't just enough to do the words. If you're deaf and you're using an interpreter or you're using the captioning as you are in this workshop, you're missing an awful lot. Listening to what people hear or say is very different than what it is if you were actually seeing somebody talking to you in their own language. And if you've been watching the captions, and this is not slight against the captioner, you can see how much gets missed. And that same thing happens even if you're using an interpreter, even a good interpreter doesn't get all of the effect, the emotion, the paralinguistic information that is there that in the mental health setting can be very difficult.

In group residential in-patient settings, talking with peers often doesn't happen. If you're the only deaf person on an in-patient unit, there may be an interpreter there for a group, but all of that interaction that occurs with the other residents doesn't happen. And then lastly, the deaf community is much more linguistically diverse than the hearing community. Everybody on this

conference call who's hearing is hearing me in English, and I'm going to probably make a pretty safe assumption that all of you are able to understand my spoken conversation.

If I have a group of deaf consumers, given educational deprivation, educational neglect, and a host of other factors, a group becomes an exercise in just trying to figure out how to communicate with each other, even before we get to any of the therapeutic issues. And so effective communication has got to recognize that linguistic diversity and understand that just bringing in a sign language interpreter doesn't solve that problem for those individuals who don't have sign language skills. Or reading and writing for somebody who doesn't read and write may not be very effective. Steve, do you want to talk a little bit about where things were in Alabama and the mandates that ended up being placed on your state who went through more of the court process?

Yes, this is Steve. Thank you, Roger. In Alabama we were as bad or worse situation and before this action was taken, the Alabama and Department of Mental Health was not able to determine how many deaf people were being served through the department. They absolutely could not provide any numbers or statistics. In the late 1990s, '95 through '98, there was some effort to congregate some of the individuals to look at improved services with all of that nice, sweet sounding stuff.

The first obvious question that I had was, "How many deaf individuals have you served over the year?" And the department's response was similar to, "Umm." Secondly, I asked them how they were able to provide services. Again, the same response. Well obviously the first problem was the department didn't know who they were serving or how they were doing it. They were using children to interpret, sometimes as young as eight and nine years old, for parents who were consumers. They were writing notes back and forth with someone who was functionally illiterate, and also in one case an individual whose IQ was below 70. Those are what you might call extreme examples, but they're not overly-exaggerated in extreme examples because we see that fairly often within our field. We saw that the department wanted to do the right thing. And they settled.

And I'm going to touch on a few of the mandates really quickly. They wanted to have oversight from the deaf community, and so they established a planning committee, which they called their "deaf advisory group." They hired someone whose job it was exclusively to supervise clinical training and to develop linguistic competency. Similar to South Carolina, we were mandated to establish an in-patient unit, and like South Carolina, we saw this burgeoning need for community-based services. An important new principle that was placed into our settlement was specific and enforceable standards of care. We are charged with providing training to staff and to the in-patient unit, and also for community-based service providers. We established several regional offices. We were ahead of the curve with recognizing I think that, yes, interpreters are not equal access, but they are necessary. So we were required to make sure that the interpreters themselves were trained in the specialty area of mental health.

Related to that, we established what was called a "QMHI," or a qualified mental health interpreter, and we had to first define what "qualified" was. And then we had to establish a training that would help them increase their fund of knowledge in the mental health. We also

were required to establish a toll-free emergency response crisis line. That has not been something that we've been able to do up until this point, a lot of different reasons why that we won't get into today. And finally, one of the most powerful things that was in the settlement for Alabama was that if the legislature did not appropriate funds for this particular program that did not excuse the department from providing those services. In other words, the department will not be able to plead poverty.

You got to be kidding.

What happened was the program began in 2003. Again, we were unaware of how many individuals needed services, and we were able to track those numbers. We know exactly who needs services, what type of services they need, and what money is needed to provide those services. I think our experiences are fairly similar to South Carolina, and I think at this point I'm going to turn it over to Roger to talk about South Carolina. They've been there a little longer than we have. So, Roger.

Well, initially the services that started out as in-patient services have slowly graduated to the point that they're primarily an out-patient service. We have 20 staff across the state serving about 300 individuals. And they are coordinated at a statewide level, so clinical staff are sent from one mental health center to another mental health center so clients can get provided services at their local mental health center, but the coordination of that is handled at the statewide level. We also coordinate all of the interpreter services.

As Steve indicated, Alabama has really led the way in that, and, in fact, our interpreters, we make them go down to Alabama for the training. So, it is not that interpreters are not used, but that they are part of a continuum of service, which includes direct service provision. And, in fact, our interpreters spend most of their time interpreting between staff and staff; for example, a training or audits or all of the other fun things. And kind of the proof in the pudding is that our in-patient length-of-stay is now less for deaf patients than it is for hearing patients. And the services are provided directly to consumers in their own language, which is what we feel the courts have told us is the right way to do it, and it certainly is the preference that our consumers have expressed.

We use video phones between clients and staff. We use email. We do have a 24-hour crisis service. We have a statewide electronic medical record. If we look at our cost per client, it is way down. The blue bars are how much it cost us and the purple bars are how many people we see. Using direct services, the number is much higher, the cost per client is much less. We have tried to estimate what it would cost us to use interpreters, and based on conversation with consumers, how many would come in for services. And as you can see, the cost of using an interpreter is higher than if you provide it directly, and we also would end up having several consumers who wouldn't come in for services, then some of them would end up being hospitalized.

And on my last slide you can just see over time we've had a consistent drop in the number of patients we have in the hospital. We typically have zero. We have no in-patients in our system right now. For those of you who are not familiar with the South Carolina hospitals, the state

hospitals provide most of the in-patient, publically-funded mental healthcare. So when I say we have no deaf patients in the in-patient system, that's private and public hospitals as well, and that to me is probably the best indication that we must be doing something right. And so it's not just a matter of following the law for us, it's also a matter of the most economic and the most effective way of providing services. Jessica, I think you wanted to talk a little bit about the resources you had available in Minnesota.

This is Jessica. As I mentioned before, I wanted to provide a list of resources as an example of resources that are available in Minnesota. And there's an abundance of resources in every state. So this is my example of resources that are available in Minnesota alone, and the next slide also includes resources that are available nationwide for information regarding deaf and hard of hearing advocacy.

I would like to point out Minnesota may not be typical of some of the states. In South Carolina, for example, there is no state organization – state publically-funded association or commission or department that serves persons who are deaf and hard of hearing. So the resources vary greatly from state to state.

This is Steve. That's correct. It's the same here as in South Carolina. We do not have those resources and Minnesota is very unique in that respect. They also provide mental health services outside of the state, and they're under the same branch of government, but outside of that mental health authority.

This is Jessica. I won't lie, Minnesota is progressive when it comes to disability rights. It's nowhere near perfect, and I think *Loye v. County of Dakota* demonstrates that. But persons with disabilities in Minnesota are fortunate, we do recognize that.

Lester, I noticed you've asked a question of me about the number of deaf and hard of hearing individuals that we serve. Do I think that people have moved to South Carolina to take advantage of those services? No, the number of people we serve is still less than the number of people we think need services. When we try to do some demographic analysis of the population in South Carolina, how many deaf people we think there are, and I will tell you nobody knows how many deaf people there are in any given jurisdiction. There are no state estimates and it's no longer a question that's asked at the census level. So we can guess. But we are still probably serving about a third of the individuals who we think need services, and it's important to understand that in South Carolina there are no private providers who are reaching out to the deaf community, who are fluent in sign language, or advertise that they're providing services. So even though we serve more percentage-wise of the deaf community than the hearing community, bear in mind that we are the only game in town.

This is Steve. Roger, I wanted to add that Alabama, I believe that we serve a smaller percentage of people than also need the services. However, we're serving proportionally the number of deaf people in the deaf community as there are hearing people in the hearing community. I think there's a similar percentage. As a part of a back story, you're right, there's no statistics out there that tell us the prevalence rates for deaf individuals. These estimates, which we extrapolate from surveys which were done in the 1960s, those estimates held up. They're very conservative

estimates that held up for over 40 years, which is 1.8 per 1,000 of people in the general population. In the Alabama State Department of Mental Health, we serve a comparable percentage of deaf people compared to hearing people.

And I think, Lester, this is not the question you're asking, but my question would be if the State of South Carolina, as huge and as metropolitan a state as we are – sorry, that's Mark Binkley, our attorney, who's laughing next to me. You know, we are a state of only four million people. There are cities larger than our state. How can we be serving that many people when other cities are not serving anywhere close to that size? So the question to me is not why are we serving so many, but what is happening with the other states and jurisdictions who aren't serving enough? Because, deaf people are not moving to South Carolina to get services, and so, in fact, some major urban areas, New York, Los Angeles, that are kind of identified as more deaf friendly, have deaf people who do move there because there's a larger deaf community, and yet often they don't have access to mental health services.

I want to address the other question, Lester, that you raised. No, not the one about the weather, although the weather here is beautiful even if Minnesota has better services. The workforce issues are a major concern. Steve would be happy to tell you, as would I, of the challenge that we face in identifying and hiring qualified applicants. We have tried partnering with educational institutions. We've had limited success. Quite honestly, it will take us less time to train a Master's level clinician than it will to train somebody who's already a clinician and teach them sign language. So this is an ongoing battle for us. We actively serve as a site for interns and for individuals who are wanting to improve their skills. But we have never hired somebody in South Carolina who came from inside South Carolina. We have exclusively hired people who came from other states, and that is an ongoing battle.

Yes, we have similar problems here in Alabama. We're not able to fill positions as we would like. I would say that stigma, because we're the State of Alabama and people believe that our sewer system is still based in a house – a little wooden house out in the backyard with a wood carved of the door – a wooden moon carved out of the door, and our electric system is run by squirrels on wheels. Because of these challenges it's very difficult for us to overcome that historical bias that's often seen against states in the south. Many of the issues that Roger mentioned we have shamelessly tried to rip off, frankly.

This is Lester Blumberg. So I'm just wondering from the presenters where you are in your presentations, and I am wondering whether there are other people besides me who would like to type in some questions.

Yes, I think we can proceed with the question and answer portion. I believe that we're done with the forma portion of the presentation. Roger, Jessica?

I would be interested to hear from the participants what questions they have or what – you know, it is funny, Steve was talking about the South, four states that have or are in the process of developing statewide services, North Carolina, South Carolina, Georgia, and Alabama. It's interesting that we're kind of set developing a core down here, and yet, typically we're not

known for progressive outreach to individuals with disability. So I do find it interesting and I'd like to know what other questions might be out there.

This is Lester. I'm sorry. Am I jumping on someone else's comment?

No.

So while people are typing in questions, and I see a couple coming in, let me tell you a little bit about Massachusetts, which is not in the South and is cold, but not as cold as Minnesota. We – and as I mentioned earlier in the presentation, we have sitting here in the room members of our deaf services division including Greg Spara who is a deaf case manager who's been working with us for about six years, Dan Lambert who's the director of psychology here at Worcester State Hospital and oversees our in-patient unit, and Lucille Traina who is our statewide coordinator for deaf services.

So for about 25 years we have had a deaf in-patient unit in the state hospital system that provides both acute and continuing care services for individuals in the deaf community who need those services. The capacity has ranged as high as 15 or 20, but the census tends to be much lower than that, five to eight patients at any given time. There was a mention of length of stay. We have found that as we have improved our community services, our length of stay in the in-patient setting has decreased so that we are proud that we can say that it is not out of line with length of stay in our other in-patient units.

In 2004, we were approached by the Protection and Advocacy entity in Massachusetts with a pre-litigation demand letter around access to deaf services. We were fortunate at that time to have an administration that was receptive to hearing what the issues were and to responding. We were able to resolve the issues raised without resorting to litigation. And as a result, in addition to the deaf unit, which was there at the time, we have expanded our deaf services capacity to include a statewide coordinator, which is Lucille's position. We have hired four ASL-fluent case managers – well I don't know how many ASL-fluent case managers we have, but four deaf case managers, in addition to recruiting staff who are able to sign. We certainly recognize that the direct provision of services through sign language is better than interpretation, but I assume like most other states, we don't have the workforce capacity to fill that need.

We also have a statewide community advisory board that helps guide us in the provision of services to the deaf community. And one of the things, and this is relevant to the Minnesota suit that Jessica talked about, is that we have made sure we have a liaison with our emergency management system to ensure communication to the deaf community. We recently had a hurricane up here in Massachusetts, and I don't know how successful it was, but I know that there was a conscious effort to make sure that the deaf community was involved in the emergency notification and services that went out in connection with that event here.

This is Jessica. I have to add, good for you, good for Massachusetts.

Thank you.

It's wonderful. It's wonderful to hear.

Barbara Francis has asked, "What's a reasonable solution to this acknowledged problem?" That's certainly a broad category, but I wonder – I heard training as one of the issues that presenters have raised. I wonder whether the other presenters have any sort of high-level responses to how does a state cope with this recognized issue.

This is Steve here. I'm sure, you know, Roger and Jessica both are chomping at the bit. But I guess I would say, first, the most important thing is the recognition of deaf people and knowing that American Sign Language, the language they use, is not English. I think we have to start there. We have to know that interpreter provision is always second best. We recognize those two issues. Then you can build a program. Traditionally, all services and accessibility has been based on the notion that all you have to do is find someone who can sign and equitable services will be provided to deaf individuals. That's much different than a sign clinician. Starting there is an important place. Secondly, you will have interpreters and you have to use them as part of your workforce. Current with training –

Are you finished, Jessica?

That was not Jessica.

I'm sorry. I lost track of who was speaking.

This is Jessica. I'd like to explain the difference between English and ASL because it's a distinction most people don't grasp. ASL is its own language in the same way that Spanish is its own language completely distinct from English. And so if someone's primary language is ASL, you need to approach them as though their primary language is Spanish. So, if their primary language is ASL, you need to understand that if you give them a note written in English, they may not understand - just as someone's whose primary language is Spanish might not understand the note that you passed to them in English. There is a huge distinction and ASL is not signed English. That's all I wanted to add.

Roger: I think the other piece that I want to add in terms of what is the solution goes along with Steve's comment about recognition. More than just recognition, there needs to be, at a state level, some systematic effort to meet that need. What we have seen is that putting it down to the county level or the local mental health centers just does not work. Many counties, especially those that are more rural, is – there's never going to be a large enough population. I'll pick on one of our counties, McCormick County, for those of you who know South Carolina. We figure that maybe there are 20 deaf people in the entire county.

Needless to say, you can't justify having a mental health clinician who knows sign language full time working in a county that size. So it has to be at a larger level, there are places, we know, that have cities larger than our entire state, but we've got to have something of a population based in the millions before you have a large enough deaf population to justify having those kinds of specialized services being developed. And so it can't be just a requirement that's placed on the local county or the local regional mental health centers because it just will not happen. So

at the state level there needs to be some systematic effort to ensure that those services are met. The services – the states where it works best have a state coordinator of services for the deaf somehow associated with the Departments of Mental Health.

This is Lester. Jessica's comment about ASL not simply being translated English also raises for me the issue – subtly broader issue of what we – what I understand as the deaf culture. I don't think it's that dissimilar in concept to figuring out how to provide mental health services to the Asian community or different cultural communities where the receipt of services where mental health issues are maybe viewed differently than what we in the mainstream may understand. And I wonder if in just a couple minutes, because we are starting to run out of time, if one of the presenters might want to comment a little bit on personal confidence in the provision of deaf services.

This is Jessica. I'd like to discuss the deaf culture section. Perhaps Steve might know a little bit more or be able to recommend more resources regarding how the deaf culture issues impacts health services. I know that Steve is aware of some great resources about that area as well. Going back, however, to deaf culture, it is distinct from English and American culture. It's a visual culture. My favorite example to describe to some of my hearing friends is because it's visual, the first thing you might say to a good friend you haven't seen in years is, "Wow, you've gained weight," because it's the first thing that you see when you haven't seen them in a long time; whereas perhaps in the American/English culture, hearing culture, you would never say that to a woman. But American/English culture does not rely on visual cues.

At the same time, everyone is different, and so as much discussion as we've given ASL and ASL interpreters, it certainly isn't a one-size-fits-all culture or one-size-fits-all language. I grew up in a household with a deaf father and hearing siblings and a hearing mother, and our family certainly has a mix, and my ASL is not nearly as great as someone who perhaps grew up in an all-deaf household or went to a deaf university. Steve, do you want to talk more about culture and/or how culture affects the provision of mental health services?

That the entire process, diagnosis related to treatment of mental illness is based on indication and language. Oftentimes how ASL is structured -- interpretation provided into English can lead to misunderstanding, diagnosis, and wrong assumptions. Secondly, and just to give you a very quick example, just because I'm constantly looking around in the office or in my surroundings doesn't necessarily equate to me being paranoid. Every time I've gone to receive treatment myself, I'm also a consumer as well as a provider, every time I go to receive those services they indicate that I'm hypervigilant. Sure, of course, I am. I'm visually dependent on looking around to see what's going on in my environment -- that we see is what is normative.

I'm going to interrupt now and sort of exercise the prerogative and requirement of the moderator to recognize that we are almost out of time. I want to first of all encourage any of the participants to email to me, I suppose, or to Roy, any questions you might have, and we will try to continue this conversation via email. My email address is LESTER.BLUMBERG@STATE.MA.US. And I want to thank Jessica and Roger and Steve for the time they have put into this presentation and for the information they have given us.

I am always – every time I have the opportunity and the privilege to work with individuals in our deaf community, I am always in awe not only of their ability to overcome communication barriers, but I, quite frankly, feel that it's my loss that I can't communicate through sign language, through ASL. I find it beautiful and awe-inspiring.

I want to thank all of the participants for their time and their attention to this issue. It's ongoing, and we have a lot more work to do. I want to, again, thank NASMHPD and Roy and Stephanie, and particularly the commissioners for their ongoing support of enterprises like this one. They are extremely valuable, I think, to all of us, and we appreciate it. Roy, anything else we need to say or do before we sign off?

This is Roy. The only closing comments that I would like to make is a reminder that the resources that were mentioned during the presentation will be available on our website, and, again, it is WWW.NASMHPD.ORG. And we will also be requesting a transcription of the presentation, and that will also be available. So, again, thank you all for joining us. And, again, I apologize for the initial technical difficulties, but hopefully next time we don't have to deal with that.

Thanks everybody.