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UMASS MEDICAL SCHOOL - iSPARC
INCREASING THERAPY USABILITY FOR DEAF SIGN LANGUAGE USERS
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Live captioner standing by.

>> Good afternoon, everyone. I'm a project associate here at the implementation science and practice advances research center. Thank you for joining us for our webinar featuring Dr. Melissa Anderson and Dr. Wilkins and they will be showing increasing -- for Deaf sign language users.

Before we get started with the actual webinar I will go over a few house keeping items. Just so you know the webinar is being recorded and will be available for viewing on iSPARC's website along with the slides. If you are calling in over the phone, please remember to use your unique audio pin. We are offering captioning services for the webinar. I sent out the link in the chat box if anyone needs it. If you are experiencing any audio problems, you can check your settings and go to webinar audio tab on the dashboard. If you are having any technical difficulties, you can e-mail me the organizer at deared draw.Logan or use the question tab and the go to the webinar dashboard. And then we will be having a Q&A session after the presentation. We are going to ask if you have questions that you send them in through the questions box and you can send them in as you think of them rather than having to wait for the end. And with that, I'm going to turn it over to our presenters. Thank you very much.

>> Hello, everyone. I'm Melissa Anderson and I'm a psychologist here at UMASS medical school in Worcester, Massachusetts. That's part

time. The other part I do provide therapy for Deaf people as well as doing research on how we can improve our approach when we are counseling deaf folks and ASL users.

>> Hello, good morning or afternoon, I guess. My name is Alex Wilkins. I am a post doctoral fellow here at UMASS medical school here in Worcester. Like Melissa, I do some of my work in clinical and some in research.

>> So today's agenda, we really have four items that we will be discussing. First is to talk about who the clinical population is and we will go into what that means a little more in-depth. The second is to discuss what are the common barriers to treatment to that population. The third is where the current state of the field is for Deaf mental health. What has been done and what has not been done yet. And then the fourth are the barriers that are in place and how we can overcome those.

>> So I'm going to start about talking about who the population is. We are going to be focusing on the Deaf community in the United States of which there are more than 500,000 individuals who communicate using sign language. We don't have exact numbers, but we are looking at people who use unique language, a shared language. They have a shared culture including art. It's not necessarily the focus of hearing loss, but the focus is more linguistic and cultural.

You can see here a couple of examples of Deaf art. You see a group of people the a table communicating in sign language and beneath that you have an example of an older view -- overview of deafness including old terms like deaf and dumb, hearing impaired, hearing loss. As opposed to more of a cultural view of Deaf identity and then you see in this piece that includes the terms deaf, deaf-blind, hard of hearing.

>> Yes, right.

>> Hard-of-hearing, signer and those are more current culturally appropriate terms.

Through the years there has been a history of oppression from the hearing majority. Against people who use American Sign Language and there has been some opposing views on whether or not the people should learn to speak or be able to use sign language. Back in 1880,

this was a conference in Milan where it was determined by people who can hear -- so not members of the Deaf community, that deaf people would be educated and with a focus on oral language or speaking rather than sign language.

There have been a lot of barriers to access for information because of this and other things. Unfortunately there are huge disparities in behavioral health for Deaf people. There is an increase in mental health conditions and substance use disorders. For example, there is two to two and a half times more likelihood of mood and anxiety disorders compared to the general population for trauma exposure it's two times. And problem drinking is three times compared to the general population.

>> So now I will go into more of the piece about what the common barriers are for this population to access treatment. So like I -- like was just mentioned, deaf folks, their language is primarily American Sign Language and, of course, that is here in the United States. Every country has their own signed language, but in the United States we do use ASL. So the number of therapists, psychologists, social workers who are actually fluent or can sign is very few. That means that most deaf folks who want to go to therapy have to see a hearing therapist or a non-deaf therapist and it's up to that therapist if they are willing to bring in a qualified interpreter. Even though an interpreter is required by law, the Americans with Disabilities Act does require that. Unfortunately, due to willingness to provide the service or lack of funds, sometimes and most times a certified interpreter is not present. It's really important, too, is that the interpreter brought into these situations is very qualified and knowledgeable within the field of mental health. It is a very special type of certification. Not all general interpreters have those skills.

I do want to emphasize that written English is not a Deaf person's first language. ASL or sign language would be their first and then written English is acquire of a second language. It might be helpful to think about this group as a second language learner -- you know, a population who is learning English as a second language. Also, there are many Deaf people who have experienced language deprivation. And I will explain that a little more in-depth because you may not be familiar with the term, but you know 90 to 95% of deaf children are born into hearing families. And those hearing families generally don't know sign language. So those children are growing up in an environment that they are not able to access due to environmental learning and acquisition that way and so sometimes they

are not learning language until the age of four or five when their school age and accessing it in a different way because they haven't had that auditory piece up until that point.

Research shows that from zero to five the most important period in a human's life for language acquisition. The brain is just ready to acquire language. So if during those five years the child is not exposed -- that child is not exposed to any type of language, it heeds to cognitive issues, social/emotional issues and language issues in the future. We will show a short video to help better explain this situation and what language deprivation is.

>> If you don't mind, I wanted to add we do have now the newborn hearing screening test which has been implemented since the early 90s. I forget if it was 91 or 92. Before there were a lot of children whose hearing loss went unnoticed, oftentimes parents were not aware that their child was deaf or hard-of-hearing until they were three or four. So with the newborn screening test that allows us to know earlier for a lot of deaf kids.

>> Here is the video.

[Video]

>> I hope that it drives home the point to help you realize that language as a foundation is crucial to future development. It helps with cognitive development, social development, mental health -- the list goes on. The one truly important point to consider is when a Deaf person comes for therapy, part of their history could be this language deprivation. We don't know how long. It depends on the individual, it could be a longer time without language versus less time. But considering that is going to influence the consequences that have -- they bring through the rest of their life and some of the mental health situations you may see.

Another point to consider is that many deaf people show very low health literacy. Very similar to non-english speaking U.S. immigrants. This is a level very similar to those two populations. I think this quote really drives it home. So many adults deaf since birth or early childhood do not know their own family medical history. Having never overheard their hearing parents discussing this with their doctor. This means growing up of children missing out on their own family history, medical or otherwise. They don't know what they are at risk for genetically, generationally. The vocabulary to describe what they are going through. That's a big problem.

Another important consideration, like I just said that most therapists who are available, are not deaf. Not part of the community or the culture. And they are part of the majority oppressor group. So a hearing therapist as part of the majority, myself am a hearing psychologist but it's important for me to recognize that fact and to really understand my privilege when I'm working with my deaf clients.

So if I don't recognize this with my deaf clients, I run the risk of increased mistrust, fear, could be that my deaf clients can't find another therapist so they want to so there is a higher risk of them not speaking out. Especially for hearing people working with deaf clients we really need to recognize that even though I am trying my best not to be oppressive to my deaf clients, there is a history there and that is just forensic in the process and is going to be there -- intrinsic in the process and is going to be there.

>> And this, too, is similar with other minority groups. For example if an African-American client is seeing a white therapist, you would see this same power differential because of that history of oppression.

>> Uh-huh, that's exactly it.

>> Next we are going to talk about where we are now in the field, what we have done so far. In the field of psychology we talk about evidence based treatments and those are approaches, maybe you have heard of CBT, cognitive behavioral therapy. This are approaches that have been researched formally and they have found to -- they have been found to have results, positive results. Currently in the behavioral health system, we are shifting to using DBTs more and more because they are more likely to be funded. State contracts, for example, require STUs use these approaches that have already been found to work. And as I mentioned, CBT is one example. I can see here on the slide the list of other examples of CBTs that is an alphabet soup, more or less.

>> And again, it's important to emphasize that these have been tested on a hearing population. General hearing population.

>> Yes. And also to add to that, evidence-based treatments are studied not only on a hearing population, but also typically white abled body. It does provide a bit of a dilemma.

>> Yes. So it's often that type of bias that we see in the research

as well.

>> Again, the CBTs are usually a combination of talk therapy with workbooks or handouts. It may be like a take home workbook of a handout or forms that you do a hearing session. On the slide here you will see some example. Again, these assume that a person is fluent in English, able to write and express themselves in English. Able to read English and understand it conceptually and apply it as a new skill.

>> I should have mentioned this before when I was talking about acquiring English as a second language, there is not a lot of research about this topic, however, what we do know is that deaf high school graduates are about an average Fourth Grade reading level when they graduate. Hearing high school graduates are about at sixth grade reading level on average. So it's not too far behind but it is behind. So that is another consideration for us to think about when we are working with these clients as their reading capabilities.

>> So the handouts and the workbooks typically include some sophisticated language and strategies. For example, there might be scales for determining your mood and they might use some sort of high level words like misery, for example. There is a lot to think about when assessing your moods. There is often a lot of psychological jargon being used. There are many assumptions that are being made based on a hearing person's experience or hearing norms. Concepts like sometimes do you hear things that you don't know where they are coming from? And a deaf person might not have the background knowledge to understand what is being assessed? So a deaf person might actually hear something but not know where it's from and it's isn't necessarily getting at a delusion. So there could be a lot of misunderstanding there.

>> Definitely.

>> And what's available now really is not suitable for working with the deaf community based on their unique language and cultural needs. Like we mentioned, limited understanding of English is one person. Not really meeting the needs of deaf linguistically or culture.

>> We have a few people in the room with us so we are going to ask you guys, in your opinion, how many evidence based therapies have been developed and evaluated with deaf individuals? Do you want to take a guess?

>> We had someone saying zero.

>> And another zero back there. One, no idea. But you are correct. Zero is the answer. So far people have really -- or recently we started to try to adapt and develop things for the Deaf community, but historically that has not been true. The answer is zero. We will explain a little bit more later about what our current efforts are in developing some evidence-based treatments and therapies but at the moment it's zero.

>> Unfortunately that's true.

>> Now I want to talk about how we can try to overcome these barriers that we described. And linguistic barriers, knowledge barriers, cultural barriers, and how we can get passed that. So I will have different examples in this section about a few of the efforts that are in place to develop some behavioral therapies -- or excuse the interpreter. The evidence based therapies and we will share that with you now. And it's not just our work but others as well.

>> So this slide is very basic. Just a summary of what to think about when you are adapting CBTs. Original materials are usually pretty heavy, English based materials. And so the key would be to truly simplify things. Plain text, simple principles. If the English still doesn't fit your client, then an ASL translation would be better. There are different ways to accomplish that. Videos or a line of interpreting. Also making your own materials that include Deaf norms, Deaf culture, Deaf values and we will give you some examples later as well. And the fourth piece is to acknowledge the history of oppression. It's in the room. If you don't do that, you are not going to be able to build that trust and rapport with your client.

So there are seven different principles on how to adapt for your Deaf client. And what I feel is most important in my own opinion is really adapting the language. We don't want to give the impression that all Deaf signers are the same. The community varies widely. Some Deaf people are born into Deaf families are given language from day one. Others acquire sign language later. Some use a signed system that is more similar to English but it's not a true language. There really is a variety out there. So it's really important to individualize the communication with whoever you are with. And match their needs.

>> And some deaf people are hard-of-hearing and use some hearing whether it's through an implant or hearing aid and may not be fluent

in American Sign Language. Really, we have to consider all.

>> This is not a one size fits all approach. And that is hard when we try to develop one manual or one tool kit to match all Deaf people. That is a challenge. If there is lengthy English -- we try to simplify it or replace it with American Sign Language. Try to add visuals and pictures, videos, whatever you can use to match a that person's learning style as well. Here is an example.

So this handout has been adapted from an approach called cognitive restructuring. And this is for PTSD specifically. So this paper would help a person to identify negative thoughts and then how to parlay that into what they are feeling in their body. And then to give them the ability to adjust and restructure those thoughts and become more positive thinking. So you can see that the same approach here but with added pictures and visual -- the top left box here. That picture does include sign and then it's saying what happened. So we are adding ASL and linguistic content as well. And if you look at the third box in on the top, the negative -- what? For your English speakers it might sound funny, grammatically incorrect and the word order fits ASL structure. In English this would be what is your negative thought? Or what are your negative thoughts. But in ASL this is matches the ASL grammar and matches a Deaf consumer in that way.

So principle number 2. We talked about low health literacy in Deaf clients and then another term, FOI, fund of information. So if you imagine a hearing baby or a child growing up, they are able to environmentally acquire information that is happening around them. They are overhearing conversation. They are listening to the TV or the radio is on in the background. There is a plethora of places they could be picking this up. But -- in this instance they are sponges. When a deaf child goes out into the hearing world, there is not a lot of linguistic content to access. So that limits their fund of knowledge. They are not picking up as much incidentally. So some specific information that we would expect most people to know and common knowledge can be missing. There could be huge gaps for the deaf clients just because they haven't been exposed to it.

One example, when I was in graduate school I did a research study about domestic violence and I was asking people about their experience within their relationships. And I said in the past year has your partner hit you or kicked you, spit at you, swore at you, insulted you and I went through the litany of behaviors. And then I did add one question at the end and said, in your opinion is that person abusing

you? Many people who had said yes to all of the behaviors, yes, they hit me, they choked me, they did all of these things. Then later answered the question about is this abuse in the negative, they said no. One interpretation of that is to say that even though they experienced the behaviors, the person does not understand that those behaviors equate to abuse and that abstract concept of English. Try to figure out what this client knows and what they don't know and finding those gaps and then helping to educate them is important part of this work as well. It's not just to sit there to become a professor and preach at them but to provide resources instead. To help them fill in their own gaps.

So this example is from our current work. I know it's probably small and not able to be read easily as we are showing you here and I will explain it. This is a questionnaire to help the client understand, is my relationship safe or not? Is it healthy or unhealthy relationship? Again going back to the research that I had done and finding out that a lot of people are in the Deaf community are experiencing abuse and not able to label it as such, this was developed as a way to help them understand that.

The third principle is to use story telling. To leverage story telling as much as possible. It's a natural part of the Deaf community and Deaf culture. And it is how the Deaf community passes down their literature and stories, it's an oral tradition, basically. Video work and recorded work is how the Deaf community passes down their culture and heritage and so it's a natural part of their community and so to use that is impactful.

On the left you will see there are five people standing and together and this is from an effort here at UMASS. Those are all people who have identified themselves as being in recovery. And they all produce their own Vlog together to talk about their own recovery and their own recovery story to raise awareness of mental health in the Deaf community. The second picture you will see is a visual representation of a metaphor. So the mountain is the supposed to represent processes and journey of recovery and you see two people on this mountain. One that says few. On the side you have a direct path to the top and then the other with a more winding path to get to the summit. You know, some twists and turns and ups and downs and a little more challenging. So this is the type of visual metaphor to incorporate into your work as well because it does make things more clear and explicit.

Principle number four is to teach through example. So like I

just mentioned, if a client doesn't know what abuse means and you ask them, have you experienced abuse or trauma? Their answer is going to mean nothing because they don't understand the meaning of the word itself. So give an example is going to be hugely beneficial, more concrete example will aid the process.

>> Yes, there might be a situation to where a person is very attached to a particular sign for the meaning of a concept. So for example there are different signs for drug. One that is more general and one that is more specific. So if you use specific sign, the person might think you're implying a drug that is IV. An IV drug. So they might answer, no. If you ask do you use drugs using that sign whereas they do use other drugs.

>> Yes, similar for sign for abuse. It's kind of looks like somebody being hit but we know there are different types of abuses. So spelling the word instead would be more effective, but this one sign could be just physical abuse and their answer could be no, I don't experience that but we know there is emotional and various other types of abuses. Wanting to make it clearer so that it incorporates all. The other way to use examples is to actually get the client to give you examples. So when you are listening to this person maybe mentioning -- say, oh, when you are out taking some time on the walk, that's a coping skill. So pulling from their experience to add a concrete example to help them understand the abstract concept.

This is another example and the way it's meant to be used during treatment. So the red flag means on a downhill trajectory and the green flag are -- the things have turned around and are becoming better. So using their own example to fill in the bubble, feeling isolated or lying or not feeling physically well. If that's their experience, getting them to mention it as filling out the paper work with them so they understand from their own life experience what we are talking about.

6th principle is to try to use more activity. This isn't unique to just the Deaf population. There are many hearing people that would benefit from the same type of activities and approaches and strategies. If you are sitting there for an hour just talking, some people love it. Some people get bored. So hands on activities are a great strategy for any practice, really. It's something to do together and you can do educational games, role playing. Whatever you do, just make sure it applies to the discussion and the topic at hand.

So this is an example from our current video series that we are making. So now we will practice this so this therapist in the video is telling the person to copy them. Meaning they will do it together.

-- principle six is to take advantage of technology. We have so lucky to have so much technology at our finger tips. There are apps to track mood, to help with expression, art. So there is also ASL videos available. These are two videos I wanted to recognize in particular. They are from the center in -- deaf wellness center in Rochester in New York. So those are two applications of DBT. DBT skills in particular. So radical acceptance. And then the second is opposite action. So those two terms you may or may not be familiar with. They are popular terminology from DBT and in Rochester they made these two videos with deaf folks in mind.

>> So there are two things going on in these adaptations. There is translations into ASL, but there is also more narrative or story telling approach as a way to teaching these DBT skills. I do really like this approach. For those who don't know it's dialectical behavioral therapy. It's integrating behavioral skills with different self-assessment of your mood whether you are thinking about your past and how it applies today and kind of in a nutshell that's what DBT is.

>> So last but not least principle seven is to use peer-to-peer approaches. So the Deaf community -- members of the Deaf community often feel burdened to help each other or accountable to help each other. So leveraging those relationships, finding a peer specialist or a coaching program. You are in Massachusetts where we are very lucky to have both a Deaf peer specialist in a paid role in the Department of Mental health. Also we have Deaf recovery coaches and a Deaf recovery coach program. So we are very lucky to have access to these very valuable resources. So it's possible you can help your clients to connect with these resources to find some support if there isn't anything available in their area immediately, if there could be some on-line resources as well. There is an ASL grief support group that has recently been on-line. There is also on-line drug and alcohol support for Deaf individuals in particular. So there is a lot of resources to be connected to.

>> So I'm looking at the time and I want to make sure that we have enough time left for any questions. So I do have one more video to show. This is from a new approach that we are creating here called signs of safety. It's very brief description is it's related to trauma and addiction treatment and it's a Deaf friendly tool kit to

use with those clients. This is incorporating all seven principles into one approach. There are 12 all together in the series in the videos that we have. It's like psycho education soap opera, if you will. So hopefully you enjoy watching. So this is number nine of our video. And it might be that some information is missing because it's been in previous videos but I hope you enjoy.

[Video]

>> I see the credits. It really just shows the project took a village to get going and it's been since 2016 so it's been a great effort. The point is to really put those seven principles Deaf friendly therapies into place. So adapting the language, addressing the information, story telling. Use an example. You can active strategies and leveraging technology and useless the peer-to-peer approaches. So now I see we do have a little bit under ten minutes left so I would like to open it up to any questions.

>> Thank you very much. That was a great webinar. Very interesting. And if folks did have issues watching the videos, when we post the reported webinar, we will insert the actual video so that it won't be choppy like it might have been. And I apologize for that. If you do have questions please type them into the questions box.

So someone was wondering if there is a way for the ASL -- how to be ASL community friendly to connect in areas of a local provider. Is there anything you can offer about that?

>> I guess it would depend -- I'm hoping they would understand the question, but it does depend on where you are located. In some states they have a commission for the Deaf. So my recommendation would be that if that situation does arise where you cannot find ASL resources on your own, to reach out to your state Commission for the Deaf and Hard of Hearing. It could be that your state has local interpreting agencies, independent living agencies, a variety of different agencies and organizations that would focus on deafness and the Deaf community. I would say, yeah, hopefully the state has resources you can reach out to first. If not, those others would work as possible consults. If that didn't anticipate your question specifically, please -- restate it and then send another question back in and we will try to answer that.

>> Someone was wondering, are there any adaptations to assessments

such as risk, substance abuse intake, et cetera, that are available.

>> Not really is the short answer. Assessments with deaf and hard-of-hearing clients is more problematic than even therapy. There are tests that people typically use, but the standards for those tests are sort of thrown out the window as soon as you start using it in sign language, a different language than it was done in. There are some things in development but the short answer is no.

>> Some recent projects by researchers Debra -- [inaudible]

>> It was a five year grant through NIDILRR and this was for the purpose of developing accessible assessments in sign language, specifically for vocational rehab. There are a few tests within that category that focused on alcohol or drug use. And I do believe that they are now available on-line. If you have an interest in finding that information, please feel free to e-mail us and we can send that along.

>> This may be a follow-up to that, but could we -- is there a way to access those adaptive DBT guides?

>> Yes. If you are talking about the signs of safety, which I think you may be referring to that, right now we are running a small clinical trial and research study just to make sure that the materials are safe, effective. And so when we have enough data collected to know the safety -- you know, to know we aren't harming people, triggering people and causing them to become worse, then we will be posting those on-line and that will be free for public use. So we are still in the process of collecting data to make sure it's safe. Then it will be disseminated. If you do want to know as soon as they are available, you can follow our page. We have a Facebook page called deaf yet. And that is the center for empowerment and recovery. So we tend to post a lot on there about our research and any updates.

>> And just to be clear, the video that we showed you today is part of the seeking safety. That's the tool -- we've created an adaptation called signs of safety as part of the safety tool kit and that is not necessarily DBT.

>> So someone was wondering, are there any evidence based therapies that are particularly helpful and engaging of clients?

>> One of the reasons that we picked the seeking safety, there are the base model was that it does teach many coping skills, very easy to learn, very easy to understand and it also provides a lot of psycho

education -- cycle education to trauma and addiction and emphasizes power differential and recognizing the therapist's own privilege. So we felt that was a really important approach just considering all of the pieces -- working with the Deaf community and making sure it's simple and not heavy in English. So I will allow Alex to talk about the piece about addressing or being a good fit for Deaf people in general.

>> I've been looking at adapting motivational interviewing and -- or NET motivational enhancement therapy. And I'm hoping that would help address the power disparity that we have been talking about that -- and the experience that deaf people have in therapy it can increase the awareness by the provider and resources available.

>> I think those two, the CBTs, are the two that we are trying to employ and adapt to the Deaf community.

>> I know it's at one but is it all right if I ask one more question?

>> Yeah, yeah, sure.

>> So someone was interested about principle number 3. Can you explain a bit more about what you mean about using story telling and narrative. Someone wonders about the confidentiality if the client starts to talk about peers as well.

>> So, yeah, to start with the question related to story telling, so one way to use story telling is to try to find different videos that are already available on-line. Many deaf people on Facebook will post and tell their own story. So taking a look at some of those being what's available and what looks beneficial and then preventing it that way to your client -- presenting it that way to your client. How we left reasonable the story telling is really through that 12 series video set that we have or soap opera and it's not just one person talking about their story, as you can see. We really wrote the script with four characters and we follow their story over time. We see their struggle. We see them relapse. We see them later work their way up and have successful recovery. And so the whole while we are teaching those really important concepts from seeking safety in that curriculum but making sure that it's in a story telling format to be accessible.

The second part of that question about the peer approach and confidentiality, this actually is a big concern because the Deaf community is very small. An example would be I just started setting up my first deaf therapy group and right now it's exceedingly small.

A lot of people are concerned about joining the group because they are afraid that their private information will get out. A lot of deaf people know each other in the community and word spreads fast especially with technology the way it is today. It might have been in the old days that word got around town and now it can go international very quickly. So we just do our best to emphasis and re-emphasize the importance of confidentiality and respecting each other and that's what we can do.

>> Thank you so much, Dr. Anderson and Dr. Wilkins. We really appreciate your time today. So webinar and the slides will be posted on iSPARC's website. Look for it in a week or two. There is a survey that will pop up after the webinar. We really appreciate your feedback. If you can take a minute to fill that out. And be on the lookout for future webinars from us. Thank you so much.