

AN INSIDE LOOK: Addressing the Needs of Consumers Who are Deaf and Low Functioning
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Moderated by:

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>> Amy Heber: Well, it is about, we're less than a minute now starting, and we have three hundred and three participants from throughout the United States and Canada. So we want to welcome everyone, and we're looking forward to discussing the needs of consumers who are deaf and low-functioning. It is now two o'clock Eastern Standard Time, and our tele-training is beginning. I'd like to welcome everyone to today's session, entitled Addressing the Needs of Consumers Who Are Deaf and Low-Functioning. We have about three hundred participants who have signed on from throughout the United States and some from Canada, and I'm Amy Hebert. I will be your moderator for today. I work for PEPNet South coordinating activities for Alabama, Arkansas, and Mississippi. At this time I would like to introduce my colleague, Cindy Kant [assumed spelling] who will serve as co-moderator for this afternoon. Cindy will be receiving live questions from our panelists through AOL Instant Messenger and email. If you'd like to send a question to our panel, just address your email to PEPnet dot south at gmail dot com, or if you'd like to send an AOL Instant Messenger, just send an IM to PEPnet South. And this information was sent to you in your registration confirmation email, and it is also on our teletrain dot org website. You will receive three live questions during today's session, but I just want to let everyone know that all questions will be answered after today's tele-training and then will be posted to the webpage. Also, if you are pre-registered for RID or BEICEU, or if you are requesting a certificate of participation, you will need two verification codes that you will need to write on your form. So everyone please pick up your pens or pencils and get ready to

take down some information. Your first verification code is LT one one two W. L as in latte, T as in toy, the numbers one one two, and W as in work. LT one one two W. Again, the first verification code is LT one one two W for RID and BEICEU. For individuals who are pre-registered, and also for people who are pre-registered to receive a certificate of, you will receive a second verification code later on in today's training. So at [inaudible] minutes after, once again please record your first verification code, LT one one two W. Okay we also would like to remind you that you're required CEU participation verification form must be completed and returned to Jennie Bourgeois [assumed spelling] no later than August the thirty first, and you must have pre-registered for your CEUs. Please make a note that the audio version of this tele-training, which will be available in the future, will not make you eligible to receive CEUs. So please get your verification form to Jennie by the thirty first. Forms received after the thirty first will not be processed. Instructions for completing your participation verification form for the certificate of completion and CEUs are included on the form, and that form should already have been delivered to you with your registration confirmation email, and it is also on the website. You must also complete the evaluation survey to receive your CEU. But we also encourage everyone to complete the evaluation survey for this training. Following this training, an email will be sent to you with a link to the evaluation survey, and we value your input and feedback, so please take the time to complete the survey. I'd like to remind you that a PowerPoint to this presentation is available to you, as well as supplemental materials. We have various articles related to individuals who are low-functioning and deaf that are available on the teletrain dot org website. A special welcome to any participants who are deaf or hard of hearing, who are gaining access to this tele-training via the video relay service provider of their choice, and or through relay captioning, conference captioning provided by Sprint. So, with that out of the way, it is now a pleasure to introduce to you today's panelists. And I'm hoping Johnson is online. Theresa?

>> Yes, can you hear me?

>> Yes, would you please introduce yourself?

>> Hi, I'm Theresa Johnson. I am currently employed at Region Four Education Service Center here in Houston, Texas. I am responsible for doing outreach and technical assistance in working with educators, zero through high school, twelfth grade and beyond, as well as the colleges and universities as it relates to serving students who are deaf or hard of hearing. I have an extensive background in working directly with individuals who are deaf and considered low-functioning, and am responsible for the coordination of the LFD conference, which we'll talk a little more about later.

>> We are thrilled to have you as one of our panel members today. Also we have Nancy Carr. Nancy, would you please introduce yourself?

>> Good afternoon, everyone. I'm currently working as the Director of the Office of Specialized Services at Ramapo College of New Jersey. Prior to that I had the good fortune to work at the Vocational Services Center at the Lexington Center for the Deaf when there were some major low-functioning efforts occurring at various service centers around the

United States. It still remains an interest of mine through ADERA and several other activities that I've been, been involved with.

>> We're so happy to have you today. And our final panel member is Greg Long.

>> Hello, I'm Greg Long, and I'm happy that all of you are here. And I appreciate you participating in the conference. I am a professor at Northern Illinois University in the School of Allied Health and Communicative Disorders. As far as this population goes, it's been a lifetime thing with me. I have a brother who is two years older than I am, his name's David, and he is deaf and lower functioning. And in fact not only did I have my growing-up years with him, but about four years ago he came back into my life full-time because I had to assume guardianship and get services set up for him. So I'll, I'll talk to you more about that. And I've also been a Director of Research at a federally funded research and training center on low-functioning deaf persons, and we'll, we'll also talk a bit more about that as well.

>> Welcome to all of you. Greg, if you would lead off our discussion today by defining the population that we're discussing.

>> Sure, I'd be happy to. I think for many of us, particularly if we're working in the field, you have a good sense kind of inherently of what this kind of individual looks like when they walk through the door. And certainly what we know most is it's an issue of communication. Well while that was good, what we had at Northern Illinois University in the research and training center from ninety to ninety five, we did a big survey. And we asked over a thousand educators and rehabilitation professionals who worked with this population, and we said, hey, you know, what, what does it mean to be a low-functioning deaf person? And the one thing that pretty much everybody came back with was that this was a population that has very significant communication and language deficits, regardless of modality. So we're not talking that they're good in sign but not, not speech. We're saying across the board they have significant problems, and it's really kind of the, the hallmark characteristic of the population. If you've got problems with language and communication, then it also, some additional characteristics would be that the population probably doesn't achieve academically beyond third grade. They're gonna have limited vocational prospects because of the language deficits, and the ability to live independently without support is also going to be difficult. So overall it's a population that is in you know, need of supports to live as fully and completely as possible.

>> Theresa, would you like to add anything to that?

>> Well, David was pretty comprehensive in his description. I would add that obviously as many of us know, many of the individuals we're talking about also have other disabling conditions, including physical disabilities, sometimes mental health issues, developmental disabilities, and, and other things that, that just complicate their situation, and certainly complicate the, the needs that they have in terms of looking at them from a service provision perspective.

>> I would also add that I think our systems do not particularly serve this population well, if even adequately. If you think of all the strides have been made by a PEPnet-like model within postsecondary, and you see that a deaf person who wants to attend college has access pretty much to any college they would like to attend, there is no equal service system, and services are very sporadic, and of varying quality, and in some instances nonexistent.

>> If the term low-functioning deaf carries such negative connotations, what, what can you offer about that, Greg?

>> Well other than to agree with you, it's, it's difficult. The, the term has been around for a very, very long time, and there've been other terms that have been used, lower achieving deaf, developmentally disabled deaf, so on and so forth. And for whatever reason, low functioning seems to be the term that has stayed around the longest. When we had the R and T center, we just tried to make a different name, because we were sensitive to that kind of the negative connotations associated with it as well, and for several years tried to encourage people to use the term traditionally under-served persons who are deaf. It's not particularly catchy, but the emphasis was similar to what Nance Carr was just saying. It was that you know, many of these people are lower functioning because of environment and lack of access to services and appropriate education, more so than any sort of inherent characteristic about them. But yeah, I wish that we could come up with something that would not be quite so negative. Cause that's, I, I don't have a good solution for that one.

>> I don't think anyone disagrees with that. We all, we all believe that the term low functioning is less than desirable, and, and struggle with it. And I think the reason why, or at least one reason why it's, it's, it's been around for so long is because it's frequently used in terminology found in documents the federal government has, has put out, so in an effort to kind of speak the same language if you will, many of us have continued to use that term or that label. Of recent, the, the term or description at risk has been used quite frequently for a number of reasons, one being because there's a feeling that it encompasses a broader range of individuals to include those who are not necessarily college-bound, or would not experience success in college, but can with the right services and supports, be successful in other ways. So of course that's not ideal either, it's not the perfect label either. But we, we continue to struggle with it, and I, I'm not sure that we'll ever come up with something that we can all agree to and feel good about.

>> I agree.

>> Theresa, what, what services have been available for people considered LFD?

>> Well as Nancy said a little bit ago, you know, services have been sporadic. At times there have been programs and services provided that were very strong and very good. Those times typically have been when funding has been available, and funding has been cyclic. It's come and gone at various times throughout the last thirty years. Services should include a wide range of, of services, depending on the individual's

unique needs. And those may not be limited to vocational services or what we kind of typically consider the post-high school service, which would be job placements and vocational services, but also need to include a wide range of other services, such as independent living skills training, literacy training, family planning, and many other services depending on the unique needs of the individual.

>> I'd say historically that the last time there was any major emphasis on a service delivery system that would really substantially enhance this group was in the early nineties when there was a, the giant national supportive employment push. And additionally if you want to look at history, in many ways technology has aided the college-bound deaf population in so many ways, actually reduced barriers on the job in terms of email and video relay, and CARD and all the other types of technology that have been so successful. But in a way because this is a disability about communication, in a way technology has almost pushed this population group back even a little further. They don't often have the money to obtain it. They don't have the skills to know how to use it. They don't type, and so they aren't even present or using the technology most of us take for granted.

>> Greg, did you want to make a comment about the services that have been available?

>> Oh, I mean I would basically echo what Theresa and Nancy have said. We've, we've had many years of interest in this population. I mean the earliest program was probably Crossroads in Indianapolis, Indiana, and that's been thirty to forty years ago. And since then we've had kind of sporadic programs, and as we were saying, since the mid-nineties there's really not been much for this population as far as specific federal funding or grants, or anything available to really address their unique needs.

>> Well, talking about their unique needs, Nancy, could you talk to us about the needs and issues currently facing this population?

>> Well we'll get into the systems a little bit later, I don't want to spend too much time on that. But it does affect if the person's in a rural environment or an urban environment. We've often discussed, the three of us, the fact that to have a serious communication deficit, to have the presence of additional disabilities, usually there's low socioeconomic status, some reliance upon some sort of governmental systems such as SSI, Welfare, Medicaid, within that kind of a, arena, even access to those can be problematic for this group of people. Transition can be a major issue because K through twelve has reached out to this population and housed them, but that system changes dramatically at age eighteen and becomes an eligibility-based system. Some of these folks don't even have the skills or the support systems to make that transition happen and fall through the cracks. We all can think of consumers we've met that we've encountered that have gone through this. So it takes a different kind of outreach, it takes a different kind of knowledge skill set amongst the staff, and a facility or service community that's going to take on the extra responsibilities that serving such a population's going to require long-term.

>> Well what, what types of support systems should be in place?

>> I think if you operate within a VR system, you're always going to be looking at an employment outcome because that's what the VR system is always striving for, but within the system there's going to be independent living needs. Communication has to occur across all these systems, and that's often I think the single largest barrier. Also, family supports, training to whatever extent the person can benefit, perhaps some ongoing supports. Supported employment I think works quite well for this population group, and if you can identify some long-term funding where the person would receive follow-along services so that they don't get placed on a job and then not have the supports, and lose that job, and start all through the service system all over again. You've heard that term, revolving-door client. So it takes a complex, complete and broad array of a various type of services to really benefit this person long-term.

>> And I would, I would add too, kind of building on the family support notion, one of the biggest issues I think we have in terms of getting appropriate services for this population is hey you know, you've got case finding, how do you find who they are? And also, once you know, once they're identified in the system, there's no real case management. You've got zero to twenty-one, you've got tremendous entitlement programs and all sorts of supports, and then after twenty-one, the, the bottom falls out. And so I think part of the, the needs for this population are to provide pretty extensive supports to their families to help them know what sorts of transitional supports are available, what sorts of personal assistance might be available, so on and so forth. So I would, I would add that as a, as a helpful component to, to need services.

>> And I would simply add to, to what Greg and Nancy have already said that it's important that we remember that services are not an eight to five arrangement for this population. Oftentimes what we have found, even though a program may have some good services and very good intentions, they close their doors at five o'clock and go home, and this population oftentimes have needs you know, throughout the day, twenty-four hours a day. And having a program with services that might be able to reach out in the evening hours when, when problems arise, or, or challenges present themselves is ideal for this population.

>> At this point, I'm going to turn over to our co-moderator, Cindy Kant, to pose our first question from the, from, from an audience member. Cindy?

>> Thank you, Amy. We have had quite a few questions coming in, and I did want to say, we had one comment. There are a few people having problems hearing Nancy, so if you wouldn't mind speaking up, they would appreciate that.

>> Sorry.
[laughter]

>> No problem. And our first question is if you're living in a state that has a vocational rehabilitation system and you've gone to them for

help, and they're just not providing the support to the family members that's needed for this individual, what would be the next step? How could you get that communicated and perhaps get the additional support that you need?

>> And with this question are we talking about working strictly through the vocational rehabilitation system to get that support?

>> Yes.

>> I mean -

>> The question, yes, was if you're working in a vocational rehabilitation within that system.

>> Right. Well I think, I mean given that I'm, I'm a professor in a rehab counseling program, I'll, I'll take a first shot at this one and then let the colleagues fill in the, some more. In many states you have an option to go to a different counselor. So you know, basically if one counselor is not meeting your needs, it's helpful to look and see if there are other counselors who might. Certainly some states are still maintaining rehab counselors for the deaf. If the counselor isn't an RCD then that would be also be another first step to take. And then there are certain appeal mechanisms within various state vocational rehabilitation programs. So I mean those would be at least three steps that I might, I might look at right off the bat.

>> I'm gonna try and project louder now, this is Nancy. I think trying to not leave one system before you've tried to gain enter into the next system is also important. So if you are currently in high school or a junior perhaps, that would be the time to try and work within your school, your transition counselor, to be reaching out into the adult service system, and try and have a professional supporting you in that process so they can advocate for you as well, so the systems start to overlap and you don't get dropped through those cracks. There's also independent living centers, and they usually have a CAP program where they would advocate within the VR system for people who are not being served, or being underserved. You may also qualify in your state to be considered for developmentally disability services, so try and find out how your DDD system works within your state, and all the things Greg has said. Maybe you request another counselor, if there's an SCD in that state have somebody get in touch with that person and ask for suggestions.

>> I'd like to add one other thought. My, my, my first thought as that question was being presented was why? Why is that VR counselor, or why is the person that is being contacted not providing the service? And there could be some really simple reasons for that. One being perhaps the VR counselor that the person is working with really is not knowledgeable about this population. That often happens. You know, VR counselors sometimes end up with individuals on their caseload that they may or may not be as familiar with how to go about serving. So my, my first question would be perhaps the VR counselor isn't as familiar with the needs of this population, and is making some decisions based on not

having enough information. And if that's the case, then perhaps it's a matter of just educating them, and or like Greg suggested, looking for, requesting a different counselor. I would also want to reiterate the whole notion of using an advocate. I don't think we can overemphasize the value of, of accessing someone who understands systems, who can talk the talk, and perhaps be able to negotiate a system a little easier because of their knowledge of that system, more so than perhaps a family member of someone outside the system. So definitely look for ways to take advantage of the knowledge of someone else in the community.

>> And that's a perfect segue into our next topic of talking about what supports and services individuals need to live independently, if possible. So I'm gonna ask Nancy if she could explain the needs and issues, and how they differ from urban to rural areas for this population.

>> I think the main issue in a rural area is isolation, and because of that isolation, low expectations, if any expectations of what an LFD person might be able to do if they have the right supports. There may be no understanding that there are such programs available in other parts of the country. I think no transportation particularly impacts rural areas. I was very spoiled when I worked at the Lexington Center, and we did a fairly successful job of finding employment, and the people could take the public transportation system, the subways, the buses. We were able to get consumers from one borough to the other so that they could work. But if you are in a rural area and you're poor, you may not have access to even simple driving instructions, be able to have the assistance to obtain your driver's license, and really be trapped because you don't even have the basics within which to move on. In urban areas, think of really any major city in the United States, I know in particular Texas, Florida, California, New York, Illinois, they have substantially large populations of LFD type folks, and I think there are sporadic service programs attempting to provide some services. I think finances is a big issue in urban areas, because there are probably more consumers seeking services than there are service delivery systems that are adequately funded to provide those services. So there may be waiting lists, there may be selection of a program that's less than ideal because the primary program can't take on more consumers at that particular time. And I also think that staffing across all these issues is important. We, the three of us have spoken about this before, that retaining staff to work in such programs where there's high demand and high, high intelligence and high education skill sets required is always a challenge to the person running the service program.

>> What services are currently available for persons who are LFD?
Theresa?

>> Well you know, it really depends on where you're at, and I think that, that Nancy's comments about rural versus urban is, is a, a great example. In some areas there are no services available, and then it's dependent on people being willing to relocate to another area, for programs to have the funding to, to assist with that relocation, for families to be willing to, to consider relocation. There are lots of issues certainly connected to the whole idea of people living in, in rural areas and

having to relocate to where a program exists. There certainly are program across the country, not, not many, but I'm aware of programs in Arizona and Texas, Florida, Kentucky, New York, there, there are programs sprinkled across the country who are providing services to one degree or another. I think the, the issue is again, as we, we, we will probably say ad nauseum, is that, that there may be programs and services out there, there just simply isn't enough funding to provide the comprehensive array of services that are needed to really see the kinds of success that we would like to see in serving this population.

>> And so what would an exemplary program look like?

>> Well in my opinion, it, it should be a comprehensive program. There are good programs out there providing job placement for example, or programs out there who are able to provide day services, or you know, programs who provide independent living kinds of services. But really the ideal for most of the individuals we're talking about, and there are exceptions of course, but for most of the ones that we're talking about, a, a facility that can provide a wide range of services has the capacity to meet the unique needs of, of many different kinds of individuals who would be considered deaf and low-functioning, who might access that program, to include you know, independent living skills, job placement, long-term follow-up services, family planning, assistance with purchases and, and documents and, and finances throughout their, their lifetime, lots of services that would be able to address you know, the whole person.

>> And, and I'd like to chime in too from a, with a personal note in, in talking about kind of how the, these more comprehensive programs can be helpful. As I mentioned earlier, I have a brother David who is about two years older than I am. He left school at sixteen and was in an all oral program, had a vocabulary of maybe a couple hundred words. All his words were nouns, he you know, you could not sit down and have a conversation with him in any stretch. And he then stayed at home for quite a few years. It was, our father died when we were teenagers, and he stayed at home with my mom until almost thirty. When he was thirty I had completed my education and was getting more knowledgeable about what kinds of issues and, and services are necessary for people like him, you know, that population, and sent him down to the Southwest Center for the Hearing Impaired, which at that point had a very comprehensive program for this population, including a residential component. Now understand that David had been classified by VR at that point as too severely disabled to work, and so we were thinking, oh, geez, what to do. After basically eighteen months in that kind of program, he graduated to some apartments that they had available that were supervised, and then was ultimately able to get an apartment by himself where he was on a bus line, went to work every day, had a you know, case manager type person who would come in and check on him on a very regular basis, but gave him the type of independence that in no way, shape, or form would have been possible without the type of comprehensive services that you know, are in fact, were in fact available back then.

>> Well at this point we want to talk about barriers to service delivery. Cause we know there are tons of barriers for everyone, but specifically

what is the impact of services for persons who are in minority, or from a low socio-economic status? Nancy?

>> Well it's incremental. And when you take a person with communication difficulties, I'd say the major barrier is always going to be access. I already referenced technology, how much we take our online communication, a conference like today, our email, how we can apply for various services in that service delivery system now. But this kind of person would not have a computer, they would not have the financial means to have learned how to use a lot of that technology. Even applying for basic support systems such as SSI, low-income housing. I think that every one of the three hundred and three participants could tell us their own stories that they've heard about deaf people who have had difficulties even going and applying, and completing the very complex paperwork that's required to access these systems. Medicaid programs are not known for their quality in terms of health care, so I think that some of these folks as well often have serious health conditions, secondary disabilities that frequently haven't always been well treated, and also result in ongoing issues that get brought into the service delivery system sort of not managed well. And then there's the housing issue, that very often housing for these folks are very difficult to access, many waiting lists. In fact I think the State of New Jersey, I can say this because I'm from New Jersey, has one of the worst waiting lists for public housing in the United States right now. So getting access, getting hooked up with any kind of advocate that can help the person sort of monitor their way, like Greg was just describing he had to do for his brother. Greg's a very, very well educated person and found it difficult. So if you're poor and you're struggling, and you're a minority and you have communication issues, it's not a big surprise that a lot of these people are not often hooked up with the service system, or may give up, and maybe attempt it once and then not attempt it again, and just be pretty much service-less for a period of time.

>> Well I'm very excited that you guys will be able to provide some strategies for future success in a minute, but first we want to take our second question from an audience member. So I'm gonna turn it over to Cindy Kant.

>> Yes, we've had quite a few questions coming in. One was very interesting. We have a person in the audience who works in postsecondary, and was asking what type of resources, what at the postsecondary level would be appropriate for her to provide to these individuals that are coming in? And yes she knows that they should not be in college, but they're being inappropriately placed because there's nowhere else for them. So what would you offer to service providers at the college level? What suggestions?

>> Well I, I guess I can start off on that one. It's kind of, you know, that's a difficult question because when we think of postsecondary kinds of settings, we need to think about the whole variety of the settings that are out there. I did recently, a project with the MCPO, that's the Midwest Consortium for Postsecondary Outreach. It's a PEPnet Midwest, basically. And if you go to their website, it's www dot mcpo dot org, on that website, on their home page is a link to a project that I did in collaboration with them that's an internet-based, basically how to figure

out communication-related accommodations for students, for postsecondary students who are hard of hearing and deaf. And it basically runs a person through all the different things that you might look at, provides resource and web links for finding additional information, so you know, as a starting point, that might be a place to excuse me, to begin.

>> I happen to think community colleges can really sort of step up to some service provision for this group of people, because they already have a fairly strong financial base from which to operate, given their credit bearing students. But it would probably be some sort of non-credit program that might have basic independent living skills, communication skills, remediation, and even some sort of basic job placement training and or referral program. LaGuardia Community College, I know in New York City has a small model of a program like that. I would be remiss, I'd forgotten to mention this prior in our talk, but we did all want to tell you and share the sad news that Doctor Frank Bow has passed away. And he was a real advocate for this population group, and I was thinking back as we were talking here to the famous COED report, the Commission on Education of the Deaf, because that was a report that Frank had been involved with. And he recommended initially ten federally funded service delivery programs be set up for this population group, and it could've been ideal to be at a rehab type facility or at a community college. So myself, I think there's a lot of future with community colleges because they're also relatively affordable.

>> I would agree, and I know of some community colleges who are already offering, like Nancy says they are in New Jersey, offering programs even through their Continuing Education Department and their, their Lifelong Learning Departments, programming for individuals who have cognitive disabilities or developmental disabilities, addressing issues like literacy skills, remedial academic skills, even some of their independent living skills. So I think there might be a very appropriate place for providing that kind of instruction within the community college system, and perhaps having those discussions with your Continuing Ed directors or people who are offering coursework out in the community would be something that you might would, you might would consider. Many years ago I partnered with, I was working in the community college system and partnered with a rehabilitation system. And together we created a program for this population. They had resources I didn't have, and vice versa. And we actually sort of looked at how we could, could combine those resources and create a program that met the needs of the population we wanted to serve. They had buses and ways to transport, I had a campus and classrooms and some space. I had instructors, they had some instructors, and we actually created a, a plan for those instructors to collaborate and work together, and provide instruction to, to the students. And it also offered them a great sense of, just contributed to their sense of self-esteem, and gave them a sense of success being able to, to take those classes on a college campus, made them feel good about themselves, and it was a great way for us to collaborate with the community and work together on a, on a project. So that's, that's worthy of considering and replicating in other areas as well.

>> Theresa, that sounds like great strategies for future success. And now we'd like to ask Greg what strategies or suggestions do you have for

family members who have been unsuccessful in securing services for a family member who is LFD?

>> Sure, I think that goes along with some of the other things I've said, the importance of being diligent, finding an advocate, learning as much as you can, figuring out what the laws are, what the programs are, seeing if you can't befriend some of the, the counselors or other providers so they can help provide the supports. But yeah, it's, it's, families definitely need the supports.

>> And I know Theresa just talked about this a little bit, but what, what are some other strategies to be able to have federal and state agencies like DOR and the disabilities, Developmental Disabilities Council work collaboratively together. What do you have to offer for that?

>> Well, like I just said, I think you know, first of all looking for opportunities to, to network and talk with each other, and, and find the commonalities or the shared mission, if you will. You know, oftentimes community colleges or other academic institutions have a need to reach out to the community, and want to reach out to the community in a variety of ways, and rehabilitation folks are looking for, for resources and, and, and ways to, to bring in some of the perhaps academic or literacy needs or services for this population. So I think there's sort of a nature marriage if you will, of the two, if we kind of look for that opportunity to make it happen. I think that you know, we have a tendency, or we have historically been, we've had that tendency to sort of work within our own, our own parameters, our own world. So educators work with educators, and rehab people work with rehab people. But you know, if we stop to think about it, in most cases we're all working with the same student slash client slash consumers, and, and perhaps just sort of backing up and, and, and considering ways for us to better network, understand each other's systems, learn about each other's systems and how we can access them, and then you know, look at how we can partner and create programming that is about sharing resources and expertise, and, and, and pulling together for a common cause. I, you know, I also want to add, just to back up a little bit, when Nancy and Greg were talking about family supports, I think it's important that we not forget that in many cases we need to address cultural issues. Certainly I have, I have made my share of faux pas over the years, and when I've not known better in addressing a particular family issue, simply because there were cultural issues that I wasn't aware of. And you know, you, you learn sometimes by your own mistakes, but I think that another area of service delivery, and, and to, to consider is for us all to be more educated in order to better meet the needs of families and, and consumers by being more aware of the cultural issues that might come into play.

>> I also think that education has a really key role, even amongst other professionals. When Lexington first approached the State Developmental Disabilities Council in New York, they were not aware of this population group at all. So technically it always would have been defined as one of their responsibilities if the Developmental Disabilities unit defined what a developmental disability was. But it took a lot of networking, advocacy, not giving up, perseverance, education, schmoozing, however you want to define it, to get them to finally start just a small pilot

project to determine if they would go forth and provide a broader network, and that worked. So even getting one small pilot program started somewhere is a real start. And self-care for the advocate and the family member, because this is long-term, like Greg is now a guardian for his brother. So having that responsibility, acknowledging it, taking care of yourself, is gonna be really important in succeeding in your ongoing role as an advocate.

>> Well what about assessment techniques? What advice can you give professionals and family members about assessments when they're seeking out services for their family members?

>> Well I'll go ahead and answer that. A couple of things. One, got to think about what the purpose of the assessment is. Is it to qualify them for, qualify the individual for services, or is it that, or is it to develop a treatment or an intervention for them? Because both ways you can be somewhat strategic. Let me give you a very quick example. With my brother David, his verbal language skills are just horrendous. His non-verbal, his being able to put puzzles together, think things through non-verbally would put him oh basically at low average, so in the low eighties as far as an IQ goes. When he, when you tested that person for intelligence, you typically only test the non-verbal, and so he was never classified as being eligible for, for developmental disability services. Because I know how this is done, I talked to the psychologist and said hey, when you evaluate him now that he's under my care, give him the verbal scale too and combine both of them to get the full scale IQ that then makes him eligible for the kinds of services that he needs. It's a terrible way to have to manipulate the system, but it's one of the things that you might do. The other way, when you think about assessment for intervention, I would strongly, strongly encourage people to think about taking a more functional ecological approach. That is assess them on what needs to be known, what, what they have to be able to do. Think about what kinds of issues they have to deal with in an environment as far as helps or barriers for communication, because going our traditional way of saying hey, this person is at the thirteenth percentile or whatever is oftentimes very much not helpful for any type of intervention planning.

>> I like the personal futures model of assessment that came out of DDD, and I just want to add, along with what Greg said, ask the consumer what their goals are too. Often I think this population, everybody sits around, everybody writes the IEP, or they write the plan in the DDR agency, and the consumer themselves often doesn't have input. We're so success driven in our society, and we think of college degrees and our professional jobs. Maybe this person just wants a part-time job. Maybe that's their goal, and we have to respect that just as much. That's their goal. We have to supply the supports within what they can functionally do, and what they functionally want to do.

>> Absolutely. And I would want to reiterate again the value of looking at assessment from a very practical perspective, observing individuals in their natural environment, having them just go about their daily living and, and observing and watching to see what they're capable of doing. Oftentimes we tend, we, we want to bring them into an office or an

evaluation room and, and present them with structured evaluation instruments that are going to deliver a certain outcome that really doesn't get to the crux of, of truly what this individual can and can't do. So watching their money skills by taking them to the store and observing how they complete a transaction, observing them in a residential situation, looking at how they interact with others, peers, friends, family members, just being much more practical and pragmatic about how you assess will in most cases, reap you much more valuable information.

>> And in a similar vein also, check on what they can do with accommodations and support. So don't look at it just as what they, what they can do independently, but if given supports, if given accommodations, what are they able to accomplish as well? So be sure in doing these kinds of, of assessments that tremendous effort needs to be focused on what the person's strengths are. Because you know, we're normally trying to look at the deficits, and, and that's just too easy and it's not helpful. So what are the strengths the person brings into this?

>> Are there any new materials under development to help serve this population?

>> There is, and we can make it available on the website here. Back when we had the research and training center, again, at this point the document's ten years old. But there is a PDF file which runs about fifty pages that is a communique, you know, it's entitled Assessing Workplace Communication Skills for Traditionally Underserved Persons Who Are Deaf. That was developed as part of our efforts at the research and training center, so that's, that is one material, you know, one document or piece of, a tool that you can use that's out. But let me you know, turn it over to Theresa and Nancy, because I don't know that there's that many other new products that have been out.

>> There's not a lot out there, but I would also suggest that you turn to Doctor Neil Glickman [assumed spelling] for some of the work that he has done. He's, he's done quite a bit in the area of strength, strength-based assessments, and behavior, addressing behavior in, in terms of strength-based behavior models. He's written a number of books and articles in the past oh I'd say ten years. One, one book is, is either due to come out in the next few weeks or has recently come out, but if you Google Neil Glickman, I think you'll be pleased to, to find a number of, of materials that would be helpful to you.

>> And personal futures planning is a type of evaluation system that grew out of the DDD population. So you would have to adapt it a little bit for this population group, but I believe you could easily do that. There's also a nice assessment that's done in sign language that Rhineman and Balst [assumed spelling] developed in Oregon, and I believe you can still purchase that system. It's based on vocational skills, and what needs to be taught to the person prior to sending them out on job interview type activities. And I believe it's under a hundred and fifty dollars, and well worth it.

>> It's called The Transition Competence Battery, right?

>> Yes, um hm.

>> Right.

>> I was looking for that recently myself. Can you, Nancy, do you recall how to access that? Can you go to the University and find it?

>> Yes, I can put that on our follow-up written questions, post this online speaking event, and I'm sure Rhiman and Balst would be happy that we remembered this.

[laughter]

>> Yes, and Kentucky is using this in their planning model very effectively with -

>> Oh good.

>> - in their VR system with low functioning deaf individuals.

>> That's great to hear.

>> Yes. It is now time for our final question from an audience member, so I'm going to turn it over to Cindy Kant once again to pose that question.

>> Okay, great. Our final question is about a very important component in working with this group, and that's interpreters. Obviously, you're gonna need an interpreter for most services that would be provided. What competencies do the interpreters need, and when working with the special population, how might that change how they follow a strict code of professional conduct? If they see their role more as I'm just here to interpret, how would that change perhaps with this population?

>> Wow.

[laughter]

>> Any takers?

>> Okay, well I'll make a stab at it here. I guess I would want to start it with something that I, I hope won't be offensive to anyone, and that is as a rule I prefer not to use interpreters for this population. I don't find that in many cases it's very successful, because most interpreters will, will come to an assignment, may or may not be familiar with that consumer, and may or may not be trained in how to you know, adjust and be more than creative in terms of how to communicate with this individual. I've had many, many situations where a very qualified, very skilled interpreter was brought in to interpret for a consumer who I was working with on, in one way or another, and, and I would need to take over. Not because I was in any way near the quality of interpreter that the interpreter was, but because I knew the individual, I understood

their story. I, I had extraneous information that would help me with the communication, I was familiar with their little idiosyncrasies and their, their unique little characteristics in their language. And that is just so critical in being able to provide interpreting slash communication skills to this population. I've actually had employers call me and say please don't send an interpreter with this individual again, please send a job coach, send someone who's accustomed to working with him, because we, we aren't able to, to make the communication work. So I think, although you know, there's, certainly that's not always the rule, oftentimes what, what I personally have found is that it's more successful to have a staff person provide the communication slash interpreting service because of the uniqueness of the communication.

>> I totally agree with you, Theresa, and I think if you do have to hire an interpreter, you may, if you're the hiring entity, have to sit down and explain what types of communication you want to occur. And they may need to step out of the code of ethics rule, because often there's a need to re-explain, to change the index of the type of communication, to clarify, to repeat, to explain to the other hearing person involved in the communication that you need a few minutes to clarify. It takes a different kind of a role. I also think of the personal service attendants that exist in the deaf blind community, and I think that a similar kind of a role would work very well with this type of population. We just have to have that very skilled group of interpreters comfortable with changing roles based on the needs of their consumer that they would be working with.

>> I'm very glad that this came up because I know the research and training center for persons who are deaf and hard of hearing here at the University of Arkansas, it's a new disability rehabilitation research project, and they are going to be investigating the use of a life coach in, in terms of exactly what you were talking about, providing that ongoing support, more than just a job coach. So I'm really looking forward to seeing what's gonna be the result of that project. Well, I would like to thank all of our panel members for, for joining us today. Greg, Theresa, Nancy, thank you so much. I also want to thank all of you for, for joining us. PEPnet provides training and technical assistance for professionals and support staff who serve students who are deaf and hard of hearing, and PEPnet also demonstrates how technology can be used to provide access and accommodations within programs for individuals who are deaf and hard of hearing. To request training or technical assistance, contact the PEPnet center in your region. This information is provided for you on the PowerPoint slide. If you are in PEPnet South region, please contact the PEPnet coordinator in your state. Also we want to invite you to join us for the next tele-training on September nineteenth, An Inside Look, New Perspectives on Reading and Writing in Implications For Instruction and Testing, with Dr. Noelle Greg. You can now register for this tele-training at [www dot teletrain dot org](http://www.teletrain.org). We encourage you to fill out your evaluation survey, which will be sent to you in a reminder email. And now it's time for you to get your pencils and papers out to record your final CEU verification code, which is a series of numbers and letters. Are you ready? SL five zero seven. S as in salt, L as in love, the numbers five, zero, seven. Again, your second CEU verification code is SL five zero seven. Many thanks to my co-

moderator, Cindy Kant, for coordinating the live questions. A big, big thank you to Jennie Bourgeois, who is the mastermind and developer of tele-training. Without her, I tell you today's tele-training would not be possible. Also a big thank you to the whole PEPnet South team and central office, and especially to Doctor Marcia Kovich [assumed spelling], the director of PEPnet South. So please take a look at the last two slides of the PowerPoint for upcoming events. We are hosting another tele-training in September. Also, the Southeast Regional Institute on Deafness Conference is in September. The PEPnet Biennial Conference in April, and please save the date for November, two thousand eight for a conference being coordinated by Theresa Johnson, entitled Addressing the Needs of Students Labeled Deaf and Low-Functioning, At Risk, or Deaf Blind, and that will be held in Houston, Texas. So on behalf of the PEPnet South and all the regions of PEPnet, we want to thank you for participating in today's tele-training, and have a good afternoon.

>> Bye.

>> Thank you.

>> Bye.