Hadley

Hadley Presents – A Guide to Rehab

Presented by Ricky Enger

June 4, 2019

Ricky: Welcome to Hadley Presents. I'm your host Ricky Enger, inviting you to sit back, relax, and enjoy a conversation with the experts. In this episode we discuss finding and utilizing rehabilitation services after vision loss. Our experts are Kendra Farrow of Mississippi State University, interviewed by Hadley Learning Expert Steve Kelly. Welcome to the show, both of you. How are you?

Steve: Hey Ricky. How are you?

Ricky: Wonderful-

Kendra: Hi-

Ricky: Steve. Hey Kendra. So good for you guys to be joining us. This is an incredibly important topic, and I know there is a lot to cover. We'll probably just barely scratch the surface, but there's going to be a ton of wonderful information here. Let's start out by actually having you guys tell us a little about yourselves, and kind of what you do. We'll start with you Kendra.

Kendra: My name is Kendra Farrow I work at the National Research and Training Center on Blindness and Low Vision, which is located at Mississippi State University. In our center we have several grants. One is a research grant, and the other one is a technical assistance and training grant. I work primarily with the technical assistance and training grant, and I also do a lot of information referral for the questions that come in through our website or people who call us just wanting to know how they can connect with services.

One of the really neat things about what I do here is that I have a national perspective. Before I came to the NRTC, I worked for a nonprofit agency, and in that role I was a certified Vision Rehabilitation Therapist. I went to people's homes, and I showed them how they could maintain their independence after they lost vision. I have both the side of being out there doing the services, but now I'm at the national level training the trainers and connecting people with those services throughout the country. It's just a whole different side of the services that are available.

Ricky: Absolutely. That is awesome. How about you, Steve? First of all, I want to welcome you to Hadley. Tell us a little about your background and kind of how you got here.

Steve: Well, first of all, I am absolutely delighted to be one of the newest members of the Hadley team. Prior to coming to Hadley, I too worked at a nonprofit for approximately 12 years. I also have a certification as a VRT, and I've got two other certifications as well. A CRC rehab counselor, and a CATIS certification, which is just a certification for assistive technology related to blindness and low vision. I too have had a fair amount of experience working with people out in the field. To be honest, I enjoy what I'm doing right now, which is kind of advocacy, I see, on a little bit larger level, and creating lesson plans, and learning objects for a larger number of people. Although I'm still getting emails and phone calls related to what we've been doing on the discussion groups. That's great.

Ricky: Yes, absolutely. Well, I can't think of two people better qualified to discuss rehabilitation services, and, you know, what do you do when you're experiencing vision loss, and how do you fgo about what's available to you and go about actually getting access to those services. With that, I'll turn it over to you, Steve. I know you've got lots of great questions.

Steve: Thanks, Ricky. Kendra, I think that this is probably a continuation of some of the conversations that you and I have had at conferences over the years. I just feel like a microphone has been dropped down between one of those conversations. Every time we get together, we kind of kicked this can around. If you don't mind, the first thing that comes to my mind is, how many times have you heard this in the past from a client? "The doctor told me there's nothing more he or she could do." What does a person do when they hear that from the doctor related to a diagnosis for their vision, or for their vision loss?

Kendra: It is absolutely devastating to hear that from your eye doctor. A lot of times people shut down, and they don't really hear too much that they say to them after that. When they're speaking about what they can or can't do, they're talking about from the medical perspective. There is so much more that can be done past the medical perspective. We can look at the adaptive skills, about changing up how you do things to make them still accessible to you. There are ways to do almost everything. We haven't quite figured out driving the car yet. That self-driving car is still coming. But as far as accessing print, accessing your household devices, washer, dryer, thermostat, all those things around your house that are challenging, there's definitely ways to do it. It's just a matter of figuring it out.

I think the thing that's most important for people to know is that there are ways to do it and there are professionals out there who can help you to learn those skills that you need to remain independent. There's even services that can help you keep a job. A lot of people don't realize that, and I have had many people call me and say, "Well I just quit my job yesterday, so now what can you do to help me?" That's so discouraging to me because we could have actually helped them, potentially, to keep that job. But I think it's really important for people to just realize there are ways to adapt almost any activity.

Before giving up on something, before walking away from your golf clubs or your gardening equipment or giving away your woodworking tools, check out first to find out whether there are ways to adapt the activity that you love to do.

Steve: One of the most common things that I would hear is, "I stopped using the computer, iPad, phone," you name it, "Because I couldn't see the screen anymore." I think one of the things that I realized after hearing that is that, unless you have a family member or someone that you're close to, a neighbor who has had a vision loss, who's gone through the process, you as someone who's probably had pretty good vision your whole life... If you're someone who has an acquired vision loss, you have no idea that, that iPhone that you just purchased actually has accessibility built into it. You just have to know how to turn it on and learn it. You don't know that. You just assume that the only way that that device is going to be used, or your computer, is visually. You've never heard of a screen reader before. You've never heard of a screen magnifier.

Where is that disconnect? I don't think that doctors... I agree with you, the doctor is not saying, "There's nothing more I can do," because they feel that... I think what they're saying is that, medically there is nothing more that can be done in some cases with macular degeneration or diabetic retinopathy, you name the disease. They've kind of reached the end of the medical procedures that can be done. But why is there that disconnect? The clients are often left in this limbo of, "What do I do next?"

Kendra: I think it's because the services are not traditionally provided within the medical system. You break your leg and the cast comes off and they send you to a physical therapist. It's all within the medical model of services. But when you lose vision, and you get kind of to the end of the medical treatment that can be done, and yet your vision is still not 100% the way you would like it to be, to really function effectively with your vision, there's not a lot that that can be done within the medical model. Now, traditionally, the services provided are more under the social service model and not under the medical model. I think that's where the disconnect comes in. You go to the Vocational Rehabilitation Service Program. Even if you don't necessarily want to be employed after losing vision, you still go there because that's the entry point to pretty much all the services that are there.

Steve: Thanks for clarifying that, because I think oftentimes people have no idea what we initially mean when we talk about the medical model versus the social services model. I'm not always sure that the doctor is aware sometimes of the social services model or offers it the same credibility as the medical model.

Kendra: Yeah, I think that, that's probably true. A lot of times when I've worked with people that their doctor didn't tell them, and they're kind of upset about that, that their doctor didn't tell them, I tell them, "Well, look what you've learned. Now go back and make sure you tell your doctor how important these services were, and how you found them." Because it's important for them to get that feedback and to know that there are services out there so they can hopefully remember, and tell their next patients that are in a similar situation.

The other thing is too, that sometimes you visually can have a pretty good acuity and yet you're still having functional difficulties. You might be corrected with the treatments to, say, 20/40, 20/50, but you're still getting a lot of fatigue when you sit and read a book. You can't read for more than 20 or 30 minutes at a time, but you love to read. You need the services and sometimes the services drop you through the cracks because you might not be eligible for the services at that point, because you're just not quite at the level. Usually 20/70 is the level, but in some states you're not eligible for services unless you're legally blind, which is the level of 20/200 vision.

Steve: I know sometimes, we kind of lose people when we start talking about the 20/70 versus the 20/100, and the quote, 'normal acuity' is generally corrected to 20/20. Anything higher than that, like 20/70 means that it's less than perfect acuity. 20/100 is further away from perfect acuity and so on and so forth. I think you bring up a great point because I've heard this many, many times. Someone who has, say, a 20/70 acuity, which means functionally anyhow, that a person might be having trouble reading the newspaper. Generally speaking, that person doesn't consider themselves blind.

Many times, the person who is, quote 'legally blind', which is 20/200, that person has a lot of functional vision. In fact, in many, many states, a person with 20/200 vision is able, with training, to drive a car, say with bioptics. That person may not consider themselves blind. I think a lot of times those folks are not going to go out and seek the services of a blindness professional. "Why would I do that? I'm not blind."

Ricky: How do you go about kind of seeking out those services, whether you have entirely become legally blind or you're just having some difficulty seeing some things, and you're wondering, "What's out there for me?" It seems like just this vast array of things that you would have to think about and know about. Is there a good place for somebody to start?

Kendra: There's definitely stuff out there in at least every state, but depending on where you live, it looks very different. I'm going to try to explain some, just places you can go to start searching. One of the places you could go is the website that's hosted by my organization with our technical assistance center. The website is oib-tac.org. On that page you'll find something that says, state contacts. On there is just a name and a phone number and address for every single state and territory. That is the contact person, the entry point, to the state services in your region.

The other place that has a real national list that you can search through is on the VisionAware website. It used to be at AFB, the American Foundation for the Blind, but it's now at the APH, American Printing House for the Blind website. It's a directory of services, so you can go in there and you can search for low vision services. You can search for libraries, like the Talking Book Library. I would suggest you just go in there and tell it to tell you about everything that's in your state. It'll just list out all the different things, and then you can sort through and get an idea of everything that's available.

Things like talking books, even if you have 20/70 vision, and you don't consider yourself necessarily blind, they do have large print books, they have the audio books, and you're eligible for all of that if you're having difficulty reading. You don't necessarily have to meet a certain acuity criteria to be there. It's just a matter of getting someone to help you fill out that application and your eye doctor can do it, or someone from a rehabilitation center can do it.

I like to tell people that blindness, vision impairment, whatever, it's a spectrum disorder. You might be really high functioning visually, and yet if you're having difficulty, you're on that spectrum of vision loss. Think of it that way. We know that there's people that are very high functioning, visually, still driving, and yet they need the talking book. I mean, it's a real disconnect, but that's just the most efficient and effective way for them to complete the task. It's not always a visual solution to what you want to do, even though we might call it low vision services in other places.

Let me go back to the different professionals that you're going to find within these agencies. I'm just going to go through the job titles, and a little brief description about what they are real quick. There's the Vision Rehabilitation Therapist. That's what Steve and I both are. Vision Rehabilitation Therapists help people with activities around their home. Pretty much anything, whether it's using a computer, using low vision devices to access printed material, cooking safely in the kitchen, accessing those appliances around the home that have the little dials and touch pads and the microwaves, and everything that you have to operate within your household.

Then we have orientation and mobility specialists. These individuals teach people to travel safely outside the home. If you need to cross the street to get your mail, if you need to learn how to use the fixed route buses in your community to get around. If you don't feel safe driving anymore, all of those kinds of things they are going to help you with. If you think you want a dog guide, they can help you learn how that process works and get you the training you need to be able to enter those programs.

Then there's also low vision therapists. Not all agencies have these, but they are specific to the low vision devices, and they work with individuals to adapt the environment and make sure that you know how to use those devices for magnification. We also have, Steve is one of these, the computer access trainers. They teach you, specifically, the really detailed stuff when it comes to how to use an iPhone or a computer, because those get into a lot of details in there. There's different programs for doing different things depending on what device you want to use.

Those are all the traditional professionals that you're going to find in these different agencies. Some of them have gone to a master's program and they're certified, and some of them are not. Some are simply hired by the organization, trained by them, and they're what we call agency-trained professionals. They know a lot of the information. Some of them are really good and very well trained, and other ones just isn't quite at the same level. You're going to find a real variety of knowledge with these professionals in the traditional list of professionals there.

Steve: How would you tell the difference and, frankly, is it that important to know the difference? A follow-up to that is, sometimes I think that one of the reasons that a doctor may or may not make a referral to the social services is, I get the sense that sometimes a person may feel as though these are just volunteers or do-gooders, for lack of a better word. How do I know that this is actually a professional who's got a master's degree with a national certification?

Kendra: They typically will have a C by their initials. If it's a vision rehabilitation therapist, they go by the initials VRT and it will be a CVRT if they're certified. If you're not sure, maybe you can't read their business card, you can ask them too about their background, how they learned to do what they're doing. I'm sure that they'll be happy to share with you the training they've received to be able to do their job.

Steve: I think maybe it's just important to let folks know that there is a national certification for a lot of these positions, and people do achieve those certifications, and in other places perhaps they don't, and maybe it's not necessary to have that certification. But it could be a good thing to ask or to know about.

Kendra: It's just good to be aware that not every professional meets the same level. If you are somebody who lives in one state part of the year, and another state another part of the year, you might find that services look very different. Don't give up if you've had a bad experience one place, and you happen to move to another location. You might have a completely different experience with services.

Steve: How about the role of an occupational therapist that is in the medical model. How does that fit in? Because oftentimes I think people are going to encounter an OT in some of these agencies or low vision clinics.

Kendra: They have started fitting into the low vision pictures since 2002 when Medicare and Medicaid allowed them to start billing for low vision services. Sometimes you'll even find OTs that are working with an eye doctor. Usually it's a low vision clinician. A low vision clinician tends to be an optometrist that's had some extra coursework related to low vision devices. If you have the opportunity to have a low vision evaluation, we really think that, that's a great idea, because what they're going to do is way beyond your normal medical eye exam. It usually takes somewhere around an hour, maybe as much as two hours to meet with them. They don't dilate your eyes. They're going to look in your eyes briefly, and they're going to do probably a more detailed acuity test. When you're looking up the eye chart, they're probably going to have a different chart, and get down to a more detailed level of what you actually see and don't see.

Then they're going to show you different magnification aids. Oftentimes they sell the devices, so there's a pretty big push to buy the items that you see, that are demonstrated to you on that appointment. They can be very helpful to you, but you need to be really careful about asking some questions. For instance, "Could I take this item home and try it out for a week before I commit to buying it?" Often that's not an option, but sometimes it is. It's hard to know how it fits into your environment when you're only seeing it in the doctor's office.

Coming back to the OTs, the OTs will work with these low vision doctors to kind of follow up and help you learn more about how to use the device. That's a pretty good model when you find both the OT and the low vision doctor working together, because you know you're going to get a lot of training in that situation. If the low vision doctor is working just by themselves, you're just going to get that one appointment, and you often don't get a lot of follow up then from them in your home.

Steve: I think one of the things that has come up in our profession is you have a specialized professional called a Certified Vision Rehabilitation Therapist, and you also have an OT who may or may not have some specialty with the field. What is the difference between the two? Can you just give me in general terms?

Kendra: As it plays out in vision rehabilitation services, the OT is focused on the person completing tasks in a visual way. Whether that's with a magnifier, or electronic magnification, or using contrast, everything is focused on the task using vision. Where the vision rehabilitation therapist is different is that they will look at the visual options, but they'll help you to decide, "Is it better to use a visual way to complete this task or a non-visual way?" An example might be, setting the knobs on your stove. How the knobs are at the back of the stove on most setups? So to lean across the stove burners to use a magnifier to read those styles would be the visual way of doing it, and yet that's unsafe if the burners are on and you're trying to find the off position.

The most efficient and safe way to do it will probably be to reach over there and have a tactile mark that you find with your finger to verify that you're getting the button turned into the off position. That's the easiest way I can explain it. You would just look at each task and then decide, "Is it better to do this in a visual or a non-visual way?" You would decide together, the professional and the client together. Sometimes the OT is going to know those non-visual ways and suggest them, especially if they're not safe, like the stove. Yeah, they don't always go, that's not their first thought. Their main focus is going to be to use the vision to do the task.

Ricky: This has all been incredible, and probably literally life changing information, for some people who are losing their vision. There's just so much to take in. If each of you had to kind of distill this into a single piece of advice that you would give someone who is looking for rehabilitation services, and they're experiencing vision loss, what would you say to that person? We'll start with you, Kendra.

Kendra: I would say to not give up. To make sure that you look around and have people help you. Search online if you can't do that anymore. Google things like low vision and the name of your town or vision rehabilitation services. There's all kinds of things. You might even put the word, blind in there just to make sure that you're not missing out on something that would be helpful to you. Really research it, ask your friends, ask your family. It's one of the best kept secrets out there. One more thing that we didn't talk about is, if you're a veteran, you definitely should ask about services at the VA, because they have awesome services for the veterans who have vision loss. You don't want to miss out because they're really great services that are available through the VA.

Ricky: Fantastic. How about you Steve?

Steve: Stay engaged and remember the services you're looking for might be labeled “blindness” or “low vision”. I just want to second, also, what Kendra said about the VA. The VA offers great services and you'll find a great number of vision rehab therapists through the VA. One thing that we didn't touch on is that you'll find a great difference in the fee structure between social services and the medical model. Oftentimes with social services, there's no out-of-pocket fee, or they're available on a sliding scale.

Ricky: Excellent. How about some quick contact information for both of you? If people either want to visit a website or perhaps send an email to either of you to follow up, where's the best place they can go to see what you're up to or perhaps contact you?

Kendra: Our main website is blind.msstate.edu, and we consider our three websites, which you can link to all of them through that main website. We consider them to be your source for blindness information. That's our new tagline. Please come. Check it out. Look at our research projects and see the plain language summaries that we have. We have continuing education courses, mostly for professionals who are in the field, but anybody's welcome to take them. There's no cost.

Ricky: Steve, how about you? Where can people find you?

Steve: I think the easiest thing to do is just send me an email. It's Stevenk@hadley.edu. Hadley Is a great place to just get started. Click on the discussion groups and just get involved.

Ricky: I want to thank you both so much for sharing this information with all of us. It's incredibly important. You've done a great job of, kind of, making it informative and approachable, which is really, really important. Thank you again for joining us. For those of you listening, you'll find all of the resources mentioned here over in our show notes. We appreciate you listening.

Got something to say? Share your thoughts about this episode of Hadley Presents, or make suggestions for future episodes. We'd love to hear from you. Send us an email at Podcast@Hadley.edu. That's P-O-D-C-A-S-T @ Hadley.edu. Or leave us a message at 847-784-2870. Thanks for listening.