Understanding Long COVID: Implications for Vocational Rehabilitation Professionals -

Session 5 - The Stigma of Long COVID: Ethical Implications for VR Professionals and Conclusion

LINDA HEDENBLAD: So let's talk a little bit here. My name is Linda Hedenblad. And Nichole Tichy is going to join me as well. And we're going to just quickly go over what is stigma? Why is it important to the topic of long COVID? And what can we do about it?

We're going to look at the stigma behind long COVID understand our own personal biases or the impact of those, and explore ideas to reduce stigma. All right. So let's start off with this University of Sussex poll. So 998 people with long COVID responded to a poll talking about their experience with stigma.

95% said that they experienced at least one type of stigma with 76% saying they experienced it often or always. Now the three types of stigma they were looking at was external societal stigma, how people within their immediate orbit were reacting with stigma, and then the stigma that folks felt internally. 63% experienced stigma such as people stopping contact with them. 91% experienced stigma such as assuming that other folks don't believe in long-term COVID. And 86% felt a profound sense of shame.

Now, this is really startling to me, especially when we consider that 14.6% of adults who've ever had COVID are currently living with long COVID or that two to four million people are currently out of work with long COVID. This is a lot of people circling around our environments that are impacted by stigma.

So what is stigma? And why do we stigmatize? Well, stigma is really interesting. So stigma only occurs when there's an attribute that's different from the air quotes, quote unquote, "normal" part of the population. Now, there is no actual normal part of the population. But that normal part is in relation to the attribute.

So if for example, you've been convicted of a crime and spent time in jail your attribute could be known as being a convict. Now, in the normal environments that you're in, that attribute becomes a stigma.

Now, if you're in a different environment where everyone in the room, for example, has also been convicted of a crime, then that attribute is no longer a stigma. So stigmas only exist as

specific attributes when compared to a quote unquote, "normal" group. And there are so many different attributes that folks have, that people have in general. And we're not going to go into those. But we're definitely going to focus on long COVID.

So these are unprecedented times. And yet they're kind of not. We certainly haven't had a global pandemic in my lifetime. I am a 60-year-old, white female with some very shockingly interesting glasses. But this is new to our lifetime.

So there are some parallels that we could make with HIV/AIDS, fibromyalgia, chronic fatigue syndrome. The closest I would say would be the impact of stigma during HIV/AIDS, which was also a very traumatic and frightening time when an illness struck people in a way that no one understood. And in grappling to understand that with all the fear and so forth, it really encouraged previous stereotypes and prejudices. And all kinds of stuff started boiling up out of that and really impacted a lot of folks, particularly gay males.

And now this time, we have an illness that was very misunderstood. The first people it targeted were people with disabilities and the elderly. So we ended up with a lot of ageism and disabled creeping into our societies at that point and even maybe a little thread of eugenics.

Well, older people and people with disabilities, they can be weeded out of the herd. There were some really frightening things that were happening right at the beginning. Now, we're building this plane as we go as we fly it.

So we're learning quite a bit about long COVID. We're learning about COVID in general. And this is not something that's going to go away. One of the things that I thought was really shocking was-- today that I learned was that you can if you catch COVID multiple times. Each time you're at risk of getting long COVID. This is something that we could be dealing with for a very, very long time.

Now, Nichole Tichy is going to jump in here and add some of the multicultural and diversity implications. And then we're going to wind up with what can we do knowing that this attribute of long COVID is something that people are experiencing stigma with. What can we do to minimize the impact of that stigma. So, Nichole?

NICHOLE TICHY: Thanks, Linda. So as Linda mentioned, I'm definitely going to try and quickly discuss the multicultural and diversity implications, mostly because it's an important topic. So for those of you who are certified rehabilitation counselors, the code of ethics has recently been updated to include section D, which focuses on multicultural and diversity implications. And that's not just specific to COVID. That's for everybody practicing in general.

But throughout this presentation, we've kind of heard bits and pieces of multiculturalism peppered in. So Linda just mentioned about at the beginning of the pandemic, there were populations that were targeted. In the beginning of the presentation, we also heard that there were significant impacts on socioeconomic status, race, ethnicity and how that might have

impacted an individual's either access to services or their social networks and how those social networks kind of understood COVID or long COVID.

And so as VR counselors, it's really important to consider this intersection of disability poverty, socioeconomic status, race, ethnicity and how this can impact an individual's experience and presentation of symptoms when it comes to long COVID. Any other one of the other pieces of information, that kind of has come out is that throughout the entire pandemic it wasn't just COVID-19. Many individuals also experienced additional stressors that were kind of related to race, specifically. So racial tensions that are experienced simultaneously can potentially impact an individual's ability to cope and even request services. So this kind of fear of stigma can often prevent folks from feeling comfortable in requesting services.

And on that note, I wanted to also talk about social justice. There are many definitions of social justice. But one that is commonly used in the space of counseling or other human service professions is that social justice is the view that everyone deserves equal economic, political, and social rights and opportunities whereby professionals aim to open the doors of access and opportunity for everyone, particularly those in the greatest need.

And so I'm going to blaze through this really quick. But at the end of the presentation, there is a link to the multicultural and social justice counseling competencies. And so this is really important as it further emphasizes the importance of self-reflection and awareness when it comes to personal biases and the impact of an individual and a counselor or other professionals marginalized and privileged identities on that particular relationship. And so, Linda, I'm going to turn it back over to you.

LINDA HEDENBLAD: All right. Well, thank you. So stigma hurts everyone by creating more fear and anger toward ordinary people instead of really focusing on the disease that's causing the problem. And as humans, we still struggle with this myth.

And I think you probably know some people who have different attitudes about COVID and long COVID and about vaccine and anti-vaccines. And it's a whole bundle of cultural and political and attitudinal and informational stuff that is all tied to long COVID. You can't talk about long COVID without hauling that all that COVID stuff with us.

So what do we do with that? Well, as individuals and professionals, the first thing that we can do is really know what long COVID is and what it isn't. The fact that you're here, the fact that you are in this presentation is an amazing first step.

Second thing is you want to explore your personal feelings, experiences, and beliefs. It's time to take our own personal fears, biases, prejudices and really put them in check. And the best way I've found to do this is have a good, long conversation with myself. And then when I'm done, if I have a hang up go to someone that I trust and really just talk through those kinds of things, we want to examine the language that we use. Because the language that we use can further stigmatize people.

And again, the people that are being stigmatized are the ones that are struggling with a long-term illness. We want to express accurate empathy. That means really good listening skills. You want to know about the experience of a person with long COVID don't make an external judgment. Listen, invite questions, that to get to know the experience of the other person. Someone had asked, what can I do if I'm working with someone who doesn't believe in vaccinations?

You know what? There's not a ton you can do there. However, if the person is ambivalent about whether to explore vaccinations or not, using tools like motivational interviewing can help them explore that ambivalence. The last thing that we should do-- that we really should not do is throw all kinds of information and lecturing and so forth at that person. Because as we know about people who are ambivalent-- the more you do that, the less likely they are to change.

We want to understand our ethical responsibility as VR professionals. I highly encourage you to check out that new CRC Code of Ethics. It's got a whole bunch of new good stuff in it. And we want to advocate.

We want to advocate on in our offices, in our families. We want to advocate on behalf of our clients. We want to advocate with our clients. We may even want to direct our clients to places where they aren't going to experience stigma, which may be groups with other individuals that have long COVID as well.

So I think that our time is up. And it's time to move on to questions. But before I do that, I do want to say one thing. At the beginning of the pandemic, there was the be kind. And I think sometimes we lose track of that. So when we're thinking of stigma, let's be kind. And let's open it up for questions.

SPEAKER 1: OK. I'll start with the first one. This is a question from Leah Wheeler. With VR eligibility, people need to have a permanent disability. How do we assess long COVID for permanency?

ROSEANN ASHBY: So we don't know. That's the issue. We do not know the length of time somebody experiences long COVID. And we heard that today some people get over their symptoms and for weeks they probably wouldn't be coming to VR if it was that short of time. But we also have the people who are experiencing it for a longer time.

And we talked about the two to four million people that have lost their jobs. And so I think given that we don't know, it makes sense, in my opinion anyway, to err on the side of giving assistance. That would be my answer to that question.

SPEAKER 2: Thanks, RoseAnn. Annette asks, how many of these symptoms does an individual have to exhibit to be diagnosed with long COVID?

ROSEANN ASHBY: I don't think there's any particular number of symptoms. I mean, that would be what I would say. And again, I welcome other panelists to chip in here. But we don't usually

count up numbers of symptoms in terms of eligibility. It's really, how do those symptoms affect the person's functioning particularly in an employment setting?

SPEAKER 1: This is from someone else. Is there a new DSM diagnosis regarding long COVID?

ROSEANN ASHBY: I believe that our friends from CDC mentioned and a diagnosis code. I can't remember what it was. But does anyone else remember that?

NICHOLE TICHY: So I can jump in. I don't know about DSM diagnosis. But the folks at CDC did mention a new ICD-10, which is what medical professionals can often use for billing and coding and things like that. But the DSM has not been updated to include long COVID that I know of at this point.

ROSEANN ASHBY: But it would have, I guess, the codes for the various symptoms like anxiety or depression or some of those? I guess there's no--

NICHOLE TICHY: Correct.

ROSEANN ASHBY: So that would be one way to approach it. Thank you.

SPEAKER 2: Another person asked about students with disabilities. Do you have any guidance for students at community colleges for your programs and graduate programs?

ROSEANN ASHBY: When Tracy talked about accommodations, students are entitled to accommodations if they are experiencing long COVID. I'm not sure exactly what the questioner was getting at. But they may need-- if they're struggling with concentration, they may need to request an accommodation to have more time on a test. Certainly, they can and should do that if they need it.

SPEAKER 1: And here's another one from Stephen Babcock. He said the diagnosis listed under IDE are much more limited in definition than the definition of a disability under Section 504. Has IDEA been amended as a result of COVID? I think that's true again, RoseAnn.

ROSEANN ASHBY: Yeah. It's not been amended. But we did talk about guidance from the Department of Education. And Nichole mentioned that specifically. And they did talk about the fact that students with disabilities or students who have long COVID can have a health-related impairment. I'm not as familiar with all of the coding in IDEA. But these students can qualify as individuals with disabilities under IDEA. And it also can be further complicated if they have some preexisting condition or other disability.

SPEAKER 2: Thank you. All right so Dave asks, what kinds of workplace accommodations might help someone with brain fog?

TRACIE DEFREITAS: I can jump in there. This would fall along the lines of those that I mentioned earlier related to concentration and memory. Those types of things can come into play.

Remember, those things that are going to help us pay attention and concentrate and figure things out might help.

So it could be things like reducing distractions or providing a private space for someone to work in. It could also be things like increasing natural lighting or making it so that the person has some uninterrupted work time so that they're not constantly disrupted when they're performing their job duties.

It could be things like using written instructions to kind of keep people on task or so that they can go back to that. So they don't have to remember every small detail throughout the day. It could be providing things like meeting minutes. So sometimes when we're in a meeting, it's difficult to stay engaged in that meeting and concentrate. So perhaps, providing meeting minutes afterwards which truly can be a benefit to everyone who might attend that meeting. So there are lots of things that can be done.

I would say that, of course, it would depend very much also on the job tasks involved. So it would help to know more about what specifically needs to be done in order to help with that type of situation.

SPEAKER 2: Thank you.

SPEAKER 1: So we have someone else who has said, I am curious, are there states that allow for COVID or long COVID as a standalone diagnosis for VR eligibility?

ROSEANN ASHBY: I don't know the answer to that. I don't know if any of the other panelists know.

SPEAKER 1: I'm going to take the liberty of actually responding to this. I don't believe there are any states at this time. But it's under discussion. So there is no state currently to the best of my knowledge after conversation with CSAVR, the Council of State Administrators of Vocational Rehabilitation that have a standalone diagnosis for COVID at this time.

SPEAKER 2: And Ashley has a similar kind of question along that same vein and works for Missouri Volk rehab. And they don't have this as a diagnosis they can use. And Ashley wonders where can where can she go to start to advocate for this population and what have other states done to get long COVID as an approved diagnosis?

ROSEANN ASHBY: So I think-- again, just my opinion here, we really need to look at how it manifests in the individual and how the conditions that it creates-- that create the need for the person to get services from VR and to be eligible for VR.

And so maybe long COVID is such an umbrella term. And it covers so much . But maybe to really focus on some of those more critical and frequent symptoms and impairments that people have and try to approach it that way. That's just my thoughts.

SPEAKER 1: And we have another one. I think this one is specifically for the Job Accommodation Network. Fatigue can be seen as less as a less visible condition that may be accommodated by adjusting work hours, being flexible with work requirements, and so forth. Would this be considered a reasonable accommodation?

TRACIE DEFREITAS: It's a good question. And it's important to keep in mind that no one can define what is truly reasonable but the employer. So those are types of accommodations that could certainly be requested in the workplace. But ultimately at the end of the day, the employer needs to take a look at what's being asked for and decide if it's something that's possible to provide.

So would I typically would encourage someone to do is ask for what you believe you need and then let the employer kind sort through that and figure out if it's something that's possible to provide. There's no comprehensive list of what's considered a reasonable accommodation.

SPEAKER 2: Jackie asks, is it a violation of the ADA if the employer will not accommodate via light duty work?

TRACIE DEFREITAS: I can jump in on that one too. As far as light duty is concerned, what we need to remember is that it can be a type of accommodation. When an employer doesn't have a light duty program, it's not something they need to create. So if it's not available, an employer doesn't have to go to the extent to create it as a form of accommodation, they absolutely can. They can always go above and beyond. So it really kind of boils down to what's available.

If there is light duty, let's say they reserve it for those who might be on worker's compensation, an employer will need to look at that as a viable option for accommodation if there's a position available. It could also be restructuring how the job is performed in some way. So if it's possible to do that without removing essential job duties, an employer might need to consider that.

So to say whether it is or isn't a violation of the ADA is very much going to depend on the facts of each situation.

SPEAKER 1: OK. RoseAnn, I think this is, again, do if Social Security is accepting this as a disability for SSI or SSDI?

ROSEANN ASHBY: I don't know the answer to that. I'm sorry.

SPEAKER 1: No, no.

SPEAKER 2: Devia asked, what's an example of a compact material handling device?

TRACIE DEFREITAS: These devices certainly very sort of visualize a fork truck that has a platform on the front of it, something small and easily manageable. That platform can be raised and lowered and could be used to move something. Just for the sake of example, think of a box of copier paper-- so the size of something of that nature.

So it's something that somebody might need to use to move small items, heavy items, maybe something over 30 pounds, for example, in certain work environments. That's just one example. There could be other types of examples like that, which could include things like carts that also raise and lower. We do offer various solutions like that as examples. So if you're looking for more products of that nature, Jane can certainly help you with that.

SPEAKER 1: Gita shared with us that said she says as a provider, I have used ICD-10 codes for COVID positive. And there is also one for a history of COVID. So just passing that on. Jill asks, how do medical professionals distinguish long COVID from other diagnoses that may have more serious implications? Anybody?

ROSEANN ASHBY: I don't know if anyone from our first panel is there.

SPEAKER 1: I know. I don't know they're still here.

SPEAKER 2: Well, Randall asked-- so he talked about the people who are struggling with shame. Do we know if they're persons who are compliant with COVID directives and vaccinated? It seems peculiar to me that people would be ashamed of catching a contagious virus even if it was COVID. Shame is experienced when one feels or is made to feel they did something wrong?

LINDA HEDENBLAD: I think that's really true. And it really does relate to the environment that you're in. A lot of stigma, people do internalize. And that does become shame. And that shame can result in a lack of wanting to reach out for medical services or to tell people what's going on.

We can compare long COVID internalizing of stigma and shame to what it's like for people with HIV or what it's like for people with depression, other types of mental illness or some of the other disabilities like fibromyalgia that are often misunderstood and characterized as something as more of a malingering than an actual disability.

SPEAKER 1: LaWanda said, wouldn't the diagnosis depend on how it affects people? The conditions it creates would be the diagnosis, not long COVID.

ROSEANN ASHBY: That's exactly right. And that's what I was trying to say. And this questioner said it very well.

SPEAKER 2: Yeah. We had an anonymous attendee then say might post-viral syndrome be used rather than a COVID-specific diagnosis?

ROSEANN ASHBY: It certainly is a post-viral condition. So maybe.

SPEAKER 1: And Nina, stated, I wonder if shame is-- and this might be for you, Linda-- I wonder if shame is less common now that so many people have gotten COVID in people's social circles.

LINDA HEDENBLAD: I think that's really interesting. Long COVID, though, does seem to have its own experience of stigma that's a little bit different than having COVID. I will say that just less than three months ago, I was getting off an airplane wearing a mask. And I was approached by two people who started harassing and bullying me for wearing a mask. And that actually really shocked me. Because I thought, wait, this is October 22. Aren't we kind of past that?

So there are some lingering stigma, stereotypes, misunderstanding anger, fear. And as we go into the next round of a COVID and whatever that brings, we'll have to see how this all evolves. And I think, John, that ends our time for this. So I'm going to turn it back over to you.

JOHN WALSH: Well, I want to conclude by just extending my heartfelt thanks to all of you who joined us today. I really also want to extend my sincerest appreciation to all the efforts of our presentation team. They really put together some excellent information to begin the conversation around post-COVID conditions and the implications for VR professionals.

In addition by registering today for today's training, you will also start to receive our monthly newsletter to learn more about the available training offers by the Center for Innovative Training in Vocational Rehabilitation or CIDVR. So again, I want to thank our presenters for the great sessions they held today. And also, thank you for the time, taking time out of your busy schedules to participate in this mini conference. Be well, everyone, and look for more topics on this area.