You First Podcast - Episode 7: The Right to Recovery

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Keith Casebonne: Hi. I'm Keith Casebonne and welcome to "You First," brought to you by Disability Rights Florida. The purpose of You First is to discuss the rights of individuals with disabilities, putting your rights first.

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Let's talk about recovery. If you simply look up the word "recovery," you'll find definitions such as "the process of healing after an illness or injury," "regaining something lost or taken away," "the return to a former and better state or condition."

Those definitions are rather open and subjective, and don't really capture what recovery truly means, especially when you seek recovery for yourself.

Perhaps a better way to describe it is, "Recovery is a process of change through which an individual achieves improved health, wellness, and quality of life. Recovery is person-centered, holistic, and integrated, and involves family and other allies. Recovery is also ongoing, outcome-driven, and based on research."

Those principles of recovery, and many others, are tenets of recovery-oriented systems of care, a modern approach to treatment and recover that is growing in popularity across the state, the county, and the world. Taking that one step further is an even newer concept, the right to recovery.

To tell us more about that are our guests, Dana Foglesong, Manager of Recovery and Resiliency Services at Magellan Complete Care, and Wesley Evans, Statewide Coordinator of Integration and Recovery Services at the Florida Department of Children and Families.

Dana and Wes, thank you so much for joining us today.

Wesley Evans: Thank you for having us, Keith.

Keith: Let's start with a kind of basic question, I suppose. Why should individuals expect recovery?

Wesley: I think individuals should expect recovery because recovery is about moving forward in our lives. I think that every individual has the right to the life that they choose to live. Oftentimes, individuals living with a mental health, substance abuse diagnosis don't always have the hope that they can recover and have the life that they may have wanted at one time, because life happens.

I think if an individual is provided with an opportunity to experience hope and the type of services that are needed and necessary to deliver that hope, but also the opportunities to recover to move forward in life.

Dana Foglesong: From my perspective, I think that individuals should expect recovery because it's possible. Wes and I are living examples that having a mental illness does not mean that your life is over, and I think that, at least in my experience, I didn't have that messaging.

When we expect recovery for ourselves, I think we have a better chance of reaching that. Sometimes the expectations center around stabilization, or maintenance, or just keeping people OK enough that they can live in the community, but not really thrive in the community.

I think if we have higher expectations for ourselves and what we expect out of services, we're more likely to embrace that process of change, and work through the challenges that come with the recovery process. Recovery is not easy, but it's totally worth it.

Wesley: Absolutely. Recovery is possible, but it's not a destination that one arrives at. Recovery is a journey, and it is a process.

Keith: I'm sure a long process, and...

Wesley: Yes, it can be a long process.

Keith: ...an emotional process and journey, at times. Why is it important for individuals to be given options for the type of services they would like to receive?

Wesley: I think it is important that our service delivery system is person-centered and recovery-oriented. Oftentimes, I think what we see are what I experienced in my own life when having to seek services, was a cookie cutter approach. One size did not fit all, when we're in the people business.

Individuals have different needs, different goals, different things that they want to achieve in their life, along their journey of recovery, and we need to be offering services that are not only based in the community, but are meeting individuals where they are.

That's part of the right to recovery, is that individuals have the right to choose the services that they want to receive, not just services that are ascribed to them.

Dana: People are unique, so everybody's going to need something different. What's going to work for one person is not going to work for another. I also think that choice is a huge part of recovery. Without choice, and having that ability to really define what's next for you, it makes it pretty difficult for that recovery process to take hold and sustain.

Wesley: Absolutely, I agree. Oftentimes what we see is that individuals who may have been trapped within the behavioral health system itself -- and I was one of those individuals -- choices are taken away. That's not always because that individual is necessarily under court sanctions. Because of the way the system, in some way, is structured, the ability to choose and make a choice for yourself is taken away.

What I have experienced sometimes was that I was receiving services, and it was the professionals versus the others. It was, "No, I'm a professional. I know what's best for you, and this is what you're going to do."

Keith: That creates confrontation. That doesn't promote healing and recovery.

Wesley: Not at all.

Keith: What has the history of the system taught us about recovery from a behavioral health diagnosis?

Dana: If you look at the history of state hospitals, for example, in the early 1900s there was a huge focus on recovery. There were places for people to have work, something meaningful to do during their day on the hospital grounds. My grandmother worked in a hospital in the DC area during the '50. As a nurse she was literally putting people like myself in ice cold baths.

We went from this thinking in this country that people could recover, and we know how we can help them recover, by giving them things to do, giving them purpose. Then we transitioned into almost, I would say, an oppressive, torturous environment.

Now we're going back up the bell curve, where we're really recognizing what people need to be successful in the community, and focusing back on those recovery principles.

Keith: Why do you think that happened, that it went down like that at one point?

Dana: There's always been stigma and discrimination in this country. Perhaps, as society evolved, it maybe evolved in the wrong direction. I'm not sure if media had to do with that. I know, as a person in recovery that deals every day, still, with a mental illness, the media still is very negative.

Any time there's something in the news where there's a tragedy, it's always a question, "Well, the person that committed this particular crime, did they have a mental illness?" Perhaps it was the influx of the media back as that became popular in the '40 and '50s.

Keith: It makes sense.

Dana: It's definitely something, stigma and discrimination that people legitimately face and that we have to address.

Wesley: Any type of behavioral health diagnosis went underground. That's really maybe where stigma started to grow, in some respect, as to what we're seeing, the impact today.

In some ways it was the C-word, as cancer used to be, you just whispered it. Sometimes we saw family members being locked away because the family doesn't know how to address or cope with the individual and their actions, and the individual doesn't know how to cope with what they're experiencing.

The stigma started when it was viewed as a character flaw, and not seen as an illness of the brain in some way.

Keith: It's very fascinating. What has led us to the point where now, today, individuals should expect to recover?

Wesley: There's been a great deal of research that has been happening over the span of decades. Research has shown and demonstrated that individuals do recover and do move forward. [laughs] Dana and I sitting here today, I think is proof of that. Both of us cycled in and out of the system for a very long time.

I think having that evidence, along with the research and the studies that have done out there, show us that it can happen.

I think in some ways, though, it's about getting the message out there that yes, an individual or a person living with depression, bipolar diagnosis, a diagnosis of schizophrenia, I think it is demonstrating to the communities and society that individuals, given the proper interventions, and even taking preventative measures and providing a healthy environment promote recovery.

Dana: The research, as Wes said, is really good for recovery rates. Schizophrenia, bipolar disorder, people are recovering from those illnesses. I think, unfortunately, the focus is not on the success stories, but on those individuals who are still really struggling.

Part of Wes' and I's work is to really change the narrative, so showcase that people do recover. We live in a world where I know more people in recovery from mental illness than I do the general population. For me, the evidence is so real.

I am hopeful that people can be encouraged to come out and not live in shame that they have a mental illness or are in recovery from that, because that is going to help us start to change the mindsets that are keeping that expectation of recovery down.

Keith: It seems to me that, unfortunately, the mindset of many people is that the recovery from mental illnesses equals a prescription, that you take this medicine, "Oh, OK," and it's so much more than that, and so different from that. I can see what you're saying about needing to change that perception, and that people's perceptions are still stuck in the past.

Wesley: It is so much more than taking a pill every day.

Keith: Absolutely, yeah.

Wesley: I like to say -- and this is very true for me -- "Where you find connections, you find recovery." It's about building those connections with others, with natural supports within your community, and individuals and activities that are of interest to you, that have a positive impact on your life.

For me -- and I've seen it just in my work -- individuals spend years within the mental health or behavioral health system, and are in many ways, taken away and out of their communities. That is their life. That is their life, day in and day out, going to day treatment and/or going to various support groups, and then back to maybe an assisted living facility.

It's that cycle, every day, every day, and then perhaps at some point, an individual, unfortunately, might cycle in and out of a crisis stabilization unit, and then it's back to that cycle.

Meanwhile, the individual really knows only that world, and may not have opportunities or be exposed, or have those opportunities to be exposed to the other parts of society that are out there, in many ways, that an individual may find a benefit in connecting to, that may assist them in their recovery.

I think in building connections within the communities with other individuals who are role modeling recovery, and seeing examples of persons that have recovered is really helpful. Dana spoke about how it would really be valuable if individuals could come forward and talk about the difficulties that maybe they've experienced with depression.

If we bring it out of the shadows, it's not so secretive, and it will help individuals to see that it's OK to talk about this. It's OK to reach out.

Dana: I think that mental health and substance use conditions are very different from other medical conditions, because in the mental health and substance use world, your character gets questioned, your personality gets questioned. That goes to the core of your being, and that hurts at a deep level.

When we're talking about recovery, we're also talking about reclaiming parts of ourselves that may have been broken just in the process of the judgment, and things that come along with that. I think low expectations, if you look at other conditions, recovery is the expectation.

If you have cancer, people want you to recover. If you have other, a surgery, the goal is recovery. That is often not the goal for people like us, so we need to, again, change that narrative so that recovery is the expectation.

Keith: It's so wrong, unfortunately, that people don't think you have the right to recover.

Wesley: Right, and self-stigma has a big role to play in there. What I've experienced for a very long time, initially, in the throes of my crisis, a doctor told me that I needed to apply for disability -- social security disability -- because I would never be able to work again.

At that time in my life, I certainly could not hold a job, whether it was full-time or part-time. I couldn't do it at that point in time in my life. That is what I started to believe, that I didn't have the ability to move forward in my life. That didn't provide me any hope at all.

I did just that. I applied for social security disability, and received social security disability for many years. That's what I needed at that time in my life to assist me, but also during that time, I really identified with my diagnosis, and really could not see past that. "Oh, no, I can't do that because I live with this diagnosis." That was the message that was communicated.

If we can change the conversation in the beginning and offer hope, and pass along the message to individuals that you can recover and move forward with this.

Keith: It shows that recovery truly is a path that's unique to everyone, because for you, at that time, as you said, that's where you felt you needed to be in your stage of recovery. Someone else may have taken a whole different direction, and that's what this is all about, it sounds like.

Wesley: Absolutely.

Dana: What I think was harmful about that statement was that it negated a future for you, so while that was what you needed at that time, it was also telling you, "Your future is also gone."

Wesley: Absolutely.

Dana: We need to be careful about the messages, the language that we're using, especially when younger people like myself -- I came into the system at 17, and my whole life was ahead of me, and when I had a similar experience where a psychiatrist said, "You need to get on disability, because you're never going to get better," I internalized that, and I was like, "OK, that's it." I felt my life was over.

Keith: It's like hitting the wall.

Wesley: Absolutely, yes.

Dana: Unfortunately, we hear that a lot, that that's still being said to people.

Keith: What is it about our current service delivery system that might impact an individual's ability to recover?

Dana: Unfortunately, there's still some times disempowering practices. There's a general awareness now, I think, about recovery and what that means. We've gotten pretty good about using recovery language, but that hasn't always translated into practice change.

An individual receiving services shouldn't just hear about recovery, and that that's possible and expected for them, but they need to see that in those services that the recovery principles that you mentioned are reflected in what they're receiving.

I also think that too often systems make decisions about who will and who will not get better. At a certain point in my journey, I was pretty much pigeonholed, that the best thing for me was to maintain the maintenance and stabilization, and so I kind of felt like a throwaway.

I think a lot of times, unfortunately, at a certain point, when you've had enough diagnoses, you've had enough failed treatments...For me medication was a challenging thing, so I had a lot of medications that didn't work. I had a rap sheet of all of the deficits, all the things that were against me in terms of my recovery.

At a certain point, I think that impacted the way people viewed me, and the people that were giving me services, the way that they viewed me. It's so important that everyone is vigilant working in our systems to not make those decisions about people's recovery.

Wesley: I think having more continuity of care within the service delivery system is sometimes very challenging, but I think if we had more continuity of care and focus on long-term recovery maintenance, in some ways, we're very reactive.

I think if we were being more proactive in taking a proactive approach that would be very beneficial. In my experience, there was no partnership relationship. It was a hierarchical relationship. Again, that sometimes induces conflict.

I think if we can focus on developing a partnership relationship between a person receiving services and a person providing services, that that can be beneficial to an individual's recovery process.

Keith: Sure, definitely. What are some of the current challenges that might slow down a person's recovery process?

Dana: There's some real socioeconomic barriers to people's recovery. If you look at the people that we're talking about, we mostly live in poverty. Access to resources is a huge issue. One of the big ones is housing. If you do not have safe, stable housing, recovery is going to be very challenging. Having your basic needs met -- food, housing, feeling secure -- is going to really be helpful to somebody's recovery.

There's also the reality that when your resources are low, you may not have access to alternative treatment or services and support. For me, the thing that really helped me recover was having a choice in my services. I was in a really innovative program that gave me a little bit of funding to do and pursue things that I wanted to pursue, and also paired me with a care specialist.

Many people do not have access to alternative or special services and supports.

Keith: Are there currently evidence-based practices or programs going on in Florida, or even around the country or the world, that are assisting individuals in their recovery process?

Wesley: There are, absolutely, efforts going on currently around the state that are evidence-based, and one of the most helpful is currently in the state we're seeing initiatives that center around providing peer services. That has shown to be very effective. Dana and myself are both certified recovery peer specialists.

Peer is defined as someone with shared experiences, and peer specialists role model recovery, and they utilize their lived experience with a mental health or substance abuse co-occurring diagnosis. They use that lived experience as a tool to assist others, and they pull from that lived experience to work with others from a mutual platform in developing a mutual rapport with the person that they are working on.

I really feel that that's a very strong argument for the possibility of recovery. What we're seeing a lot of throughout the state today is peer services being offered more and more, but we also know the evidence is there to support the utilization of recovery peer specialists.

Keith: We're going to do a future podcast on peer specialists and peer recovery, so look out for that. What role does delivering the message of hope play in an individual's recovery process?

Dana: Hope is huge. It is absolutely essential. Recovery emerges from hope, and I think it's this beautiful catalyst for recovery.

You can't really expect somebody to take personal responsibility for their life, take medications, go to the doctor, go to therapy, do whatever they're supposed to do, if they don't have hope that their situation's actually going to get better, if they don't have hope that they can have a future, that their goals and their dreams are possible, it's just not going to happen.

Wesley: Hope plays, like Dana said, a very large role in one's recovery. For myself, I had no hope, and I didn't have hope for years. That caused me a lot of pain, and it really only fed the fuel for what I was feeling in my life at that time.

Around me, I was not surrounded with messages of hope. If I was, I didn't see them. I didn't see them at all, and those messages were not communicated to me, because I didn't have it there in front of me. It was very difficult to see through the fog at that time.

When I did first find a community-based support group that centered around individuals who were in the community, going to the support group, that were surrounded by their peers, I really first started to see a spark of hope, because I saw individuals who were sharing stories of their experiences, but they were doing better.

When I started to hear those stories and how they overcame the challenges that they have experienced, I started to believe that I could do it as well.

Keith: Powerful.

Wesley: Very powerful.

Dana: The message of hope needs to be powerful, and it needs to be consistent, because when you are dealing with something like depression, which is what I've been dealing with for a [laughs] very long time, in that state of feeling helpless or hopeless, it's hard to cut through.

If we have people around us, whether it's our support system -- family, friends, providers, whoever it is -- if they have that powerful and consistent message of hope, that's going to help us really see that there is hope.

Wesley: We also have to be mindful, and I think this is important for our service delivery system, that individuals need to be surrounded with messages of hope, just like Dana talked about, that it needs to be consistent.

We need to make sure that we are surrounding individuals with hope when they go and access services, so that right when an individual is walking in the front door, a message of hope and possibility is communicated to them.

Keith: Wow. That's a good segue to my last question. What should one expect from service providers?

Dana: The expectation should be for any health care provider to be listened to and respected. What's interesting for me, though, is what changed the most in my experience is when I actually changed.

For example, I had a psychiatrist who I viewed as the absolute expert. I would go to the appointment, and I'd be all nervous that he would change my medication or something. I would just sit there and listen. I wouldn't really speak up for myself.

When I started to view myself as somebody that had something to offer in that relationship, where I started to see myself as an expert in my own experience, that relationship started to shift.

I began to speak up for myself. I was able to express myself in a calm manner, and I started to really see things change for me. That was really important in my process of recovery, to have that relationship with a doctor, but it was actually I was the one that made the first change.

Wesley: I think it's important for services to be person-centered as well as based upon strengths of the individual receiving services.

Keith: That person-centered approach, it seems to me that everything else, that leads, and everything else follows. If they have that approach, everything else can hopefully fall into place.

Wesley: Absolutely. One size does not fit all.

Keith: This has been so informative. It's been a great pleasure talking to both of you. Thank you both so much for talking about this and sharing your insights with us.

Wesley: Thank you.

Dana: Thank you.

Keith: If you'd like more information about recovery-oriented services and peer support, visit www.peersupportfl.org. That's www.peersupportfl.org.

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