

Being a Human Doing Instead of a Human Being with Ron Wright

Caitlin Owens:

Hello, and welcome to another episode of Disability Exchange. My name is Caitlin Owens and I am with the Iowa University Center for Excellence in Developmental Disabilities. I'm here with my co-host Judy Warth. Judy, you want to say hi?

Judy Warth:

Hello. Welcome straight from Iowa city.

Caitlin Owens:

Today our guest is Ron Wright, who is a former LEND trainee, which, again, LEND stands for Iowa Leadership Education in Neurodevelopmental and Related Disabilities, a program that we run here at the Center for Disabilities and Development. We're really excited to chat with him. Welcome, Ron.

Judy Warth:

He just flew straight in from Chicago to join us today.

Ron Wright:

Oh.

Caitlin Owens:

Yes.

Ron Wright:

Yeah. Yeah.

Judy Warth:

Are your arms tired?

Ron Wright:

They are. They are tired. Getting more tired because I'm holding up this cellular phone instead of using my laptop like I want to.

Caitlin Owens:

Well, Ron, do you want to introduce yourself to our audience? Tell us a little bit about who you are and things that are important to you.

Ron Wright:

Okay. Well, I'm 63 calendar years old, 64 conception years old. People don't know that I've been on this earth nine months longer than I've been given credit for. Right now I feel nervous because I'm not used to being interviewed for a podcast. This is my first, and I don't really know how to start this, but I'm just going to launch in with what pops into my head.

I was diagnosed autistic formally in July 2016, and that's one of the ways I was able to join LEND in August 2018, was this diagnosis. Before that, I did suspect that the diagnosis of autism or Asperger's syndrome as it was known then, did apply to me. I read a book that I found in the Iowa city library called Nobody Nowhere by Donna Williams.

She lives in Australia, or did at the time, and the way she described what her life was like, the way she thought about things I realized was really descriptive of me. My life until then made a lot more sense then. I think that was 2005 that I read that book, the fall of 2005, and I sought out a support group. I didn't know if I would find any, in December or January 2006.

I found there was one for adults with Asperger's syndrome in Iowa city, and that had formed just the month before. So I attended. In January was the second meeting, and that was a real relief to be in the same room as people who had the same mannerisms or traits that I did, without having to explain anything. I felt really comfortable there.

I can't remember if we met for one hour or two hours. I think it was one hour at that time, and we later expanded it to two hours. Learning about how I was different from other people and just the way, my perspective on things, I felt like I didn't have to justify my opinion anymore.

I would get that from my family members sometimes, that I would have to explain why I saw things a certain way. I didn't like that, but that was probably because they had really bought into the neurotypical perspective. Like I said, it was a relief to be in the same room without having to explain myself to other people.

I literally felt physically comfortable there from the very first meeting. The facilitator had developed an outline of how the meeting would be structured and would post that at the beginning of every meeting so that when people came in, they would see...

It's a real reassurance when you don't have the sense that you belong in society, that neurotypicals seem to be born with, or they absorb it through osmosis, having this structure visually as a reminder, as well as a reminder to not interrupt somebody else, to let them finish talking. Because when we're in an environment where we suddenly feel so at home, I can see it's a natural way of relating to somebody else, that I can identify exactly with what you're saying.

This is what happened to me. And sometimes people needed reminders to adhere to the structure that we had put in place, or that she had developed. I attended those meetings from January 2006, practically every month, for the first five years. We moved to twice a month at one point because I really

didn't know of any other place where I would feel that comfortable with people that I didn't know up until that point.

And so, having twice a month was really great. And at one point, I think after two years, I became facilitator myself and I would lead the meetings, send out reminders every two or three days before to people that, hey, we're meeting at this time, at this place, and also develop my own ideas of what I wanted to introduce to the group.

I had a meeting at my place where we watched the movie, *Horse Boy*, which is the topic or the subject is a young boy who's probably five years old. And their family was living in Texas at the time. The father was working with horses, and he kept his son away, deliberately from horses because he thought it would be... It's such a large animal that his son would not really do well around that animal.

But it happened that one time his son broke away from him and ran up to this neighbor's horse. The horse was really gentle with him. And the son calmed down too, did not have tantrums. So he wondered if there was a place that had a therapy treatment or a shaman specifically. The movie came out in, I think 2009, and was available at the public library in 2012. So I had people over to watch it.

That was my idea for where else we can go with this group instead of meeting in the same room and talking for two hours and then going our separate ways. I wanted to do more things. But I didn't seem to get a lot of response from... Or at least maybe I interpreted it wrong. So around 2016, I had tapered off and stopped attending meetings except maybe once every three or four months.

I didn't know what other outlet to socialize with people. At work, the jobs I had, I would be conversant with people, but it wasn't really anything more than small talk. In my memory of it, was not very social. Other people seemed to be really at ease with somebody else. And for me, it was more of an effort to socialize with people at work. It was deliberate.

I can still see that in me, but other people, when they look at me, and I'm in conversation with someone, they say that I seem to not have the traits of autism. So I take that as a compliment. I mean, I've spent a great deal of time on my own, beginning with 1991, when I sought formal counseling for the very first time. I was really distraught emotionally, living in Phoenix and working there for the previous seven years.

Had just struggled with how to relate to people and not knowing any answer. And so, it was a big risk. I mean, having been raised in a family where I was taught by my father that you don't cry when you're hurt. That's really devastating for a child, in my opinion, to be taught that how you're feeling is not okay, and grow up, which is really... It's impossible for anyone to act any age except what age they are.

So I didn't get any reception from my family that my hurts were valid, that there was a listening audience, or at least some consolation. I was the seventh born of 10 children. The second and third born to my mother and father were twins and they died within three days of birth. I try to remember them when I'm talking to people and they ask about my family. But I did not grow up with them. I was the seventh born.

The environment that I grew up in was all I knew really. I didn't really know anyone else's family was different than mine. And so, without a perspective, I didn't know that there's another way to raise children. It wasn't until I got into 12-step support groups in Phoenix in 1991 that I knew that this little life that I lived was really pretty... I don't want to say hurtful, but there was no emotional support there.

And so, there needs to be a grieving process, go through admitting the loss of that support that could have been there. I liked that environment. In Phoenix, there were... I was there for three years, then I moved back to Iowa in October 1994. But in Phoenix, for 12-step adult children of alcoholics groups, there was at least one every night of the week.

So I gorged myself on that support because I really needed that support, that feeling that I belong somewhere. When I finally did decide to reveal more about my life, it was a relief to hear people receptive to my story and I wasn't shut down or shamed for it. That was my precursor to Asperger's syndrome support group, was having ACOA support groups. Then-

Judy Warth:

Ron, I remember the first 12-step group I went to, I remember saying to someone that this isn't about alcohol, this is about life and having people who really wanted to listen. So I could see how that would be so incredibly attractive when you felt like you hadn't been heard.

Ron Wright:

Yes.

Judy Warth:

I know that Mike had this question on here, about how did you feel when you first got that diagnosis?

Ron Wright:

I felt relieved that my assessment of myself was accurate, and that it was also... He described ADHD also, which I can see is appropriate. I feel as though the work I've done over the years, I've mitigated some of the severity of what people would see in me. But yeah, it was a relief to have that confirmation because, although I did not get any...

I'm not sure if I can use this anywhere, maybe if I went to a college or university, and they had a scholarship for someone with autism diagnosis, that would be a place for me to bring up that diagnosis. But otherwise, I don't share it openly with many people because it's either doesn't apply or may not be appropriate at that time. But people in the LEND community, especially the class that I was attending, they do know that.

At the time I was attending, at the beginning, I did not have a full-time job. But in November, about a week before Thanksgiving, I had called up this job that I did work at before as a carrier driver for lab samples from the VA clinic in a surrounding town to the VA hospital in Iowa city. And he said, "Yeah, I need a driver."

So I divided my time between really three jobs. I consider LEND to be almost at least a part-time job because of the requirements of that community, that class. I remember one of the students, my fellow

classmates, asked me why I didn't join in. And I think what she was saying was, why was I so closed off emotionally?

I didn't know how to answer that because I felt like I was doing my best. But it was, what I was doing was more of a doing-ness than a being-ness. And I didn't really feel comfortable or at home in my own body. I don't know if that makes sense to you or to anyone. But I still feel as though I don't share a lot of myself emotionally with people.

I don't know if there's anything I can do, but it's more of allowing and trusting that the people I'm with will appreciate this side of me. So it's just a matter of feeling comfortable and knowing when I can contribute and knowing more of myself really, what I'm capable of. Also, believe it or not setting boundaries, being able to say, "No, I'm still working on that," sense that I can say no to somebody and it will be okay.

Judy Warth:

Ron, I'm curious, how would you describe your character. If you were going to pick three or four words to describe your character, what would you choose?

Ron Wright:

What would I choose? When you say character, do you mean my mannerisms or internally how I-

Judy Warth:

Internally.

Ron Wright:

Okay.

Judy Warth:

Who is Ron Wright in three or four words that would give us the essence of you?

Ron Wright:

That would be actor, writer, emotional wreck, and some kind of, I don't know if I want to say advocate or ambassador.

Judy Warth:

You could go with both.

Ron Wright:

When I was younger, I saw myself as a mediator between someone who may have a disagreement or upset with somebody else, even though that's not my role. I realize now that was my way of feeling that this is one thing I can do. I can do this, be a mediator between two people if they wanted it. But that's the descriptors I would use.

Caitlin Owens:

See you being a good mediator. You have a very, just calm presence. Can I ask a question about something? Earlier when you were talking about how it felt to get your diagnosis later in life, and you talked about I think... It sounds like it just confirmed these things that you had wondered about and had largely, it sounds like, pieced together yourself over the previous decade.

But I read something once, I'm trained as a therapist, about how a diagnosis should expand somebody's world and not contract it. And that's always really stuck with me. I wonder if that resonates with you at all, specifically thinking about how you shared that for you personally, to receive that diagnosis, it was welcomed information that just helped you understand your life thus far, but that it's not something you feel the need to share about yourself with other people, which I think is totally valid because it sounds like there's just a lot of other things about yourself that maybe you share first or... Anyway, I just wondered if that was something that resonated at all.

Ron Wright:

That a diagnosis should expand environment-

Caitlin Owens:

Yeah. It should expand somebody's either conception of themselves, or their world, or even their access to services, rather than constrict. And so, I wondered if a reason for not sharing it with other people has to do with not wanting to limit what they maybe think you're capable of. Or if it's just something that you just simply don't really feel the need to share.

Ron Wright:

Well-

Caitlin Owens:

That's okay.

Ron Wright:

I would say, part of it is because, to me, it's I don't really reveal much about myself. I don't complain. I don't see the point in complaining or blowing off steam. Although I do see the point in that blowing off steam means you have something you can't control and there's no way to control it.

But complaining, on the whole, to me seems that I'm weakening myself, that I'm saying I'm helpless. Because I like to feel as though I can do something, and if I'm complaining, it means I can't do anything. There are times that does apply, but I don't want to come across as a complainer.

But part of that is revealing that I'm frustrated and hearing myself complain about something would probably benefit me because I would hear the frustration in my voice that I... Like the traffic on the drive here. I thought four hours would be enough time to drive from Chicago. And it would if I didn't have to stop for gas twice, but because there were so many vehicles slowing me down that it was frustrating. So I should have left sooner.

But one other thing about the diagnosis, that it did, was it provided a boundary, a container for my sense of self, because one thing about autism is I get lost in a feeling, or sensation, or something that I'm trying to control or steer in a certain direction. Not having boundaries, not having a sense of what is appropriate or inappropriate, I believe is a trait of people with autism, because they don't have some internal sense of constructing an interpretation of who they are, where they begin, where they end, what's not appropriate.

Having the diagnosis did that for me. And whether others on the autism spectrum can relate to that or say yes that I endorse that, I don't know. But to me, I already feel so expansive, that it's helpful to have reminders to have boundaries, to recognize when I feel tired.

Yesterday, I was at an Airbnb and the hostess was really wonderful. I felt tired after I had something to eat in the morning, and she said, "Oh, in another hour, we're going to go to this park where they have this really long set of stairs that goes up and up this hill. And there's all kinds of people there." And I thought, "Oh, that would be nice to go with them."

But then I started feeling dizzy and I had to sit down and I said, "Maybe I should stay here and take a nap." And she said, "You can do that." She said, "Maybe you need some magnesium. Magnesium would help. She gives me two pills, supplements, and I take that. And after a while, I feel better, but I think I still should probably stay home. But I say yeah because it's not often that I relate to someone so easily and be conversant, have the same interest in common.

And she has an adorable eight month old baby. So I said yes and maybe I suffered. Maybe I should have said no and stayed at home and gotten rest, which I certainly needed. In the middle of the day, I don't usually take a nap, but I did need it yesterday. So having some boundaries, some reminder that I'm limited is helpful to me, even though I may not like it.

I don't like that boundary, that hard stop. It's probably better for me to recognize that and pay attention. Yeah. So whether other people see this trait, this characteristic in people with autism, that's one thing that I do recognize in common.

Caitlin Owens:

That was beautifully said. This is on the same topic, but pivoting just a little bit. What would you offer as maybe your words of wisdom or encouragement to somebody who was either seeking a later in life diagnosis or had just received a later in life diagnosis?

Ron Wright:

If there is a way that you can confirm that, then take steps to get that diagnosis, whether that be a university agency or a department of a university, or an individual therapist or psychiatrist. Mine was when I reapplied for a social security benefits. I was receiving them in 1997 after I was released from hospitalization. I just felt depleted. I did not feel motivated to do anything.

My therapist suggested I apply for financial benefits and I did receive them after I appealed the first denial. And so, having been more than five years since my benefits had ceased, I needed to get a new diagnosis. This psychiatrist gave me that diagnosis. So yes, if that's what it takes. If it's some social security agency or another governmental agency, that's another avenue.

It's definitely worth it because it may confirm your suspicions, your idea, or it may give you a different perspective on you. And may say, "No, this does not apply to you, but something else does." So I would suggest, yes, go ahead and seek and keep seeking until you find something that gives you the answer that resonates internally with you.

Judy Warth:

Ron, you've talked about work a few times and some of the good, bad, and ugly of it. Do you mind sharing a little bit about what you've done for work and what you're currently doing, and what you like, and what's helped and maybe not helped?

Ron Wright:

Yeah, I can do that. What I've done primarily is labor-oriented jobs or semi-skilled labor jobs. And by that, I mean, I can drive a forklift, load and unload, semi-trailers, move pallets of product around in a warehouse. I think anyone who develops that skill can do that. And so, also I worked at Pearson, which they develop and send the printed tests to high schools and elementary schools, and putting test books in a box so they can be shipped out. I mean, thousands and thousands of boxes.

That is another job that somebody else can do easily. What I'm doing now is a paraeducator at a local high school. I'm in a classroom with three other paraeducators who are working with the teacher to teach the students as much material as we can get them to absorb and taking them to PE classes.

I don't know how much of a difference I'm making there, but the teacher says she's really grateful for me to be there. I feel as though I'm contributing something of me to this job, whereas other jobs, I never got a sense that I was making any difference beyond the physical labor I was providing. So, for me, that's really rewarding to hear that and to hear the teachers say that she has told the vice principal, thanks.

I heard this from the vice principal, to say, "The teacher is saying thank you for putting Ron in my classroom."

Caitlin Owens:

That seems like pretty strong evidence that you are making a difference. And just having known you for a short while here, I can imagine you being such a calm and stable and just important presence in the life of a child. That seems like a role that you would be well suited for, again, just based on the 40 minutes that I've known you.

Judy Warth:

Yep. I remember when I first met you, Ron, you told me that was what you hoped to do. That was your dream. So that merits a ton of kudos. I know the room you're in and I know the people you're supporting, and to get that kind of praise really speaks volumes.

Ron Wright:

Well, thank you. I don't know if you were interviewed, but I think I put your name down as a reference, or Michael's.

Judy Warth:

I did talk to them. You called and told me to make a call. I did what Ron Wright told me to do. You said, "You need to call and make this happen, Judy. I did my part."

Ron Wright:

Oh, I don't remember doing that.

Judy Warth:

And now you've made me proud.

Ron Wright:

Oh, thank you. Yeah. I'm grateful that I was interviewed and was hired because I have zero classroom experience, not even a paraeducator experience before this. So I really appreciate that I can contribute something and be a part of this little group of this little classroom. Yeah. It's really, really nice.

Judy Warth:

Ron, I know that Mike was hoping that you might share your poem with this. Is that something you want to do?

Ron Wright:

I thought of something else. Is that okay? It's a-

Judy Warth:

Absolutely.

Ron Wright:

... a song that came to me and I've been stuck to how to go further. But then again, I haven't really spent time and listened to what comes next in the song. but the song came to me a few years ago and I still remember it. It's called Lily of the Valley. I don't really know what a lily of the valley looks like, but I was thinking of a woman named Lily when I wrote it, or at least how I saw her. And it goes like this.
(singing)

Caitlin Owens:

Wow, that was beautiful. That was

Judy Warth:

That was beautiful, Ron.

Ron Wright:

Thank you.

Judy Warth:

Thank you for sharing.

Caitlin Owens:

Yeah. We like to wrap up our podcast by asking everybody the same question, which is, what would you like your legacy to be?

Ron Wright:

I think I would say I would like it to be that I formed a bridge between people who are diagnosed autistic and those who are neurotypical, that I provided some level of understanding that wasn't there before. And that both worlds, or at least the world of autistic people, became a little more clear to those who are baffled by it.

Judy Warth:

Ron, you have given us so many gems in this time. I can't wait to go back and look at the transcripts and pull out bits and pieces. I had already written down being a human doing versus a human being as a strategy for living. And some of the descriptors that you talked about, what it's like to live with autism, are some of the most profound things I've heard professionally ever.

So thank you very much on behalf of all of us. We want to thank you for your time, your wisdom, and for working so hard to get here and sharing of yourself.

Caitlin Owens:

Yeah.

Judy Warth:

Your song was amazing.

Caitlin Owens:

Thank you.

Ron Wright:

Thank you, Judy. Thank you. Thanks, Caitlin. I haven't met you, but it would be nice to meet you.

Caitlin Owens:

Yeah. I think we met one time in super passing, but literally just like... I think actually it was the day I started that you said you were in the LEND office. But anyway, yeah. Thank you so much. This was a really enjoyable conversation.

Ron Wright:

Well, thank you.

Judy Warth:

And thank you-

Ron Wright:

Thank you for inviting me. I'm really glad to have been invited on your podcast.

Judy Warth:

And thank you to our listeners. Disability Exchange is brought to us by the University Center for Excellence in Developmental Disabilities, and supported and made good by the University of Iowa, Midwest Public Health Training Center. Hopefully, this is made great by our listeners as well as the people who come and share their stories, uplifting the voices of people with disabilities. Thank you all. We'll see you next time.

Caitlin Owens:

Thank you for joining us today on Disability Exchange. Disability Exchange is produced by the University Center for Excellence in Developmental Disabilities, which is housed at the Center for Disabilities and Development at the University of Iowa. Special thanks to Kyle Delveau for the music contribution.