

# Interview with Dr. Elaine Eisenbaum

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## SUMMARY KEYWORDS

developmental disabilities, disability, people, field, mental health, population, national training center, training, practicum, project, intellectual disabilities, service, clinicians, work, talking, experience, disability rights, therapy, lived, modules

## SPEAKERS

Jeff Sheen, Alexandra Schiwal, Elaine Eisenbaum

**E** Elaine Eisenbaum 00:00  
[Intro music]

**E** Elaine Eisenbaum 00:08  
I think at the end of the day, what we all want is a mental health service system that serves all people, and that no one has difficulty accessing services if they want or desire them. (Music)

**A** Alexandra Schiwal 00:24  
Welcome to the mental health Crossroads podcast where we explore the intersection of mental health and disability. This week, we're talking to Dr. Elaine Eisenbaum from the Human Development Institute at the University of Kentucky. We discussed her education history, current projects and how she ended up in the field of disability. (Music)

**J** Jeff Sheen 00:43  
Elaine, would you tell us a little bit about your professional background and how you ended up doing this kind of work?

E

Elaine Eisenbaum 00:49

Sure. Well, I actually got interested in the disability field when I was in high school. I got my first job when I was 15, and that was at the pool and the snack bar. And when I was working there, I met someone who had come to the pool who had Down Syndrome. And I just liked her. She would come almost every day and we would talk. The thing that I noticed about her was that she knew that people underestimated her because she had Down Syndrome. So she would take advantage of it. And I thought that was very funny and clever. She would come into the snack bar and plop down a quarter on the counter and say, give me a grilled cheese, knowing full well it was \$1. And that-that made me laugh because she took advantage of a lot of people who underestimated her and taught people not to underestimate her. So from then on, I just got interested in the field. My undergrad degree was in special education. And when I was completing that, and student teaching in high school, I saw that there were not a lot of services for people with disabilities. And I was very interested in disability rights. And my senior year in college, I really didn't know anything about social work. But as I was thinking about my career, I really enjoyed the adult field and disability rights. And I stumbled across social work and was very interested in the focus on social justice and rights for all people. So I ended up going into the Social Work field. And from there, I worked at nonprofits, working with people with disabilities, disability advocacy work, and worked at places that had housing for people with disabilities. And then I ended up going back to school to get my PhD. And I've worked with the University Centers for Excellence in Developmental Disabilities since then.

J

Jeff Sheen 02:46

That's really cool. I didn't know that. And I know that the more I talk to people in this field, most of them, most of us have some type of early experience in our formative years, that exposed us to either some kind of injustice or some kind of recognition that people with intellectual disabilities are not being valued in the way that we should value all people. And so I appreciate knowing that about your background. Similar experience for me, not at the snack bar, but kind of at that same time frame, kind of tuning in to the fact that things could be better for this particular population if we understood the issues better. So I appreciate you talking to me today about some of the issues.

J

Jeff Sheen 03:29

What is the best thing you've been doing? You know, since 15, you had that experience? But what do you feel like today is the best thing about the work that you're engaged in? What do you get the most joy out of?



Elaine Eisenbaum 03:40

Well, for me, my goal and in any of my work is-is just to be making a difference, to be making a positive change. So, this project and other projects I've worked on, I want to be a part of fighting for justice and equality for all people, and making sure that people have better access to the things they desire.



Jeff Sheen 04:01

So to that end, you know, you're involved now with the Mental Health and Developmental Disability National Training Center, can you give us a little bit from your perspective, a broad overview of the scope of that project, and what the big goal for that project might be?



Elaine Eisenbaum 04:15

So the project itself is to create a National Training Center, so that people can provide better services to people with developmental disabilities. Not only are we aiming to train clinicians and mental health providers, about working with this population, but we're also looking to provide training and education for people with disabilities themselves and their families to learn more about mental health, and to learn more about the mental health service system. So they have the tools to advocate for themselves, and to gain knowledge and information without necessarily having to go through the service system at all, so that they themselves can better meet their own needs and have the education to do so.



Jeff Sheen 04:59

So, when you think about being involved with this National Training Center, developing that what are the parts that you're most excited about? What are, the what are the parts of this project you feel will have the biggest impact on the individuals with intellectual/developmental disabilities.



Elaine Eisenbaum 05:13

I'm really excited about changing people's perspectives on people with disabilities and mental health. Historically, people with developmental disabilities have been overlooked when it comes to mental health. They've, people have underestimated them, they have thought that people with intellectual/developmental disabilities are not capable of benefiting from therapy. And to some degree, some of these myths still exist. And I think that that's our job is to make it clear that people with developmental disabilities

experience a broad range of mental health, they can absolutely benefit from therapy and mental health services.

E

Elaine Eisenbaum 05:55

And we're going to be working on that through our trainings. And that's, that's something that I think it's really important for mental health professionals to understand and to get to know the population and to understand that they can provide services to this population. It may involve making some adaptations to the way that they work with people in therapy. But those shifts may be very small. And they can, I hope, that when they go through our trainings, and when they learn more from us, that mental health professionals start to feel more confident in serving this population. And knowing that it really is not that different, they just need to make a few adaptations.

J

Jeff Sheen 06:37

So you touched on a lot there, I want to follow up with this idea. So there are a lot of components to this National Training Center and Mental Health and Developmental Disabilities. And one of the parts that your team in Kentucky is-is really focusing on is both a series of webinars and a series of online trainings. So can we talk a little bit more about, like for the webinars, who the primary audiences might be, where you're kind of going with the webinars? And then we can talk a little bit about where are you going with the training and who the primary audiences are there?

E

Elaine Eisenbaum 07:09

Well, with our webinar series, we are really excited because we have an opportunity to bring in some specialty topics. So, our goal is really to be responsive to the needs of society and the feedback we get from our audience members as time goes by. So these topics may range in anything from working in mental health therapy with the people with developmental disabilities, or it could be working in the foster care system with youth with intellectual disabilities, and mental, and mental health, it could be working in the criminal justice system, where we really intend to have a range of topics for a range of audiences. We will be offering continuing education for social workers and some other mental health fields. And we are actually in the process of completing a national needs assessment. And from there, we hope to get the feedback from- from people of what what they want to hear about, what do you want to know more about. So the great thing about the webinar series is that every time we have a webinar, we can pick a new topic, and we hope to pick those topics directly from the feedback we're getting about what training is needed.



Jeff Sheen 08:27

That's great. So there'll be a lot of opportunity to adjust and make, tailor the train the webinars in particular to what the pressing needs that are being identified from the population is being served by this project.



Elaine Eisenbaum 08:42

Exactly.



Jeff Sheen 08:43

So tell me a little bit more about the training modules, how those will be structured. And I know the grant has some focus on clinicians, as well as direct support workers. Tell us a little bit about the trainings and how they might work for different audiences.



Elaine Eisenbaum 08:59

So we've divided our online trainings, into two audience areas. The first is people who are mental health professionals or students. And I like to think of this audience is an audience who knows about mental health and knows about mental health interventions, but maybe does not know about working with people with intellectual and developmental disabilities. So for these trainings, we're not going to be teaching you, a social worker, or a psychologist already in the field, about how to do therapy, you already know that. We're going to be helping provide information to help better serve people with developmental disabilities, and information about this population, and how to adapt therapy and service systems to better serve them. And we'll also be providing historical information about the way people have been served, some injustices that happened, and how we're working to change that.



Jeff Sheen 09:57

One of the things as we're talking about this, we've talked about as a group, there's a lot of changes in the system, both on the mental health side, on the developmental disability side that needs to change. From your perspective, as a project director on this National Training Center, what are some of the most pressing policy issues that you see or pressing areas of research that you see need to be addressed to-to really shift things in this field in a more positive direction, in a direction that makes more of a difference for the people we're all trying to serve?

E

Elaine Eisenbaum 10:29

Well, when it comes to research, we know there's really not a lot of research about what works in terms of mental health services and interventions with this population. And, so what do you do when there's not a lot of research? How do you know what's best practices? How do you know what's evidence based? It's very difficult. And I think that what we need to do to address that lack of research is to really listen to the voices of people with developmental disabilities themselves, and their experiences and their feedback on what's working for them in the mental health service system and what's not working. We need that qualitative research, we need these qualitative ideas, because we don't have a large evidence base of research. So, that's, that's where I think we're at. And that's what we're hoping to integrate into the National Training Center, is the lived experience and the voices of people with developmental disabilities and mental health.

J

Jeff Sheen 11:26

That's fantastic. No, I mean, I think that's what we've talked about as a team is what are we bringing to the table? Right? What is this project, bringing to the work that's already being done in this area? Even though there's not a lot of groups that are working in this area, there are some. And what are we bringing to this field that's going to improve things, that's really going to move that needle forward in a direction that is really beneficial to both individuals with the lived experience, their family members, as well as those that are working in this field professionally? Can you say a word or two about some of the modules or some of the trainings, topics that you will have in that mix? I know we've got like the MH, or the ID 1-0-1, do you want to say a little bit about maybe some of the topics that are fresh on your mind.

E

Elaine Eisenbaum 12:12

Some of the modules, of course, there will be modules, intellectual disabilities 1-0-1, autism 1-0-1, basics, history, it will go over the historical treatment of these populations, disability rights movement, mental health and this population and how mental health has been diagnosed, or not diagnosed, or misdiagnosed in these populations, and moving towards today. And of course, some some basics on statistics, population statistics and information about the populations. These, there will also be modules about diagnosis and assessment when working with people with developmental disabilities, adapting psychotherapy practices for working with this population. So a number of different modules that people will be able to take. And within these modules, not only are we working with content experts who are clinicians to develop the content, we're also working with people with disabilities themselves, who will be writing content and video taping content, and also the trainers in this process.

J

Jeff Sheen 13:23

So that sparks me to ask you a little bit about the composition. So this project has an advisory board, can you tell me a little bit about some of the different folks that are on that advisory board?

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Elaine Eisenbaum 13:33

Sure. So when we created the advisory board, we actually put out a national call for people to apply to be on the advisory board. And we were so fortunate to have so many people apply for this advisory board. And so, our advisory board is comprised primarily of people with lived experience with disability and mental health themselves. And some siblings or family members, as well as a few professionals in the field, we aim to get a diverse group and represent a lot of different interests and identities.

J

Jeff Sheen 14:14

Having worked with you now for almost a year that I really appreciate about your work, and what you bring to this project is your passion and commitment to really making sure that the voices of those with the lived experience is absolutely represented in not, kind of, a token way, but in a very substantive and a very important, you're having those voices drive this project. And that's what I've always kind of picked up from my work with you. So I appreciate the things that you're saying that kind of reinforce. But it's the voices of the lived experience that are the primary focus of what we're doing. And if that's not built into what we're doing, we're not doing it the way we'd like to.

E

Elaine Eisenbaum 14:54

You know, I can recall from my own training in the social work field, that while we were taught about mental health diagnoses, and working in therapy with individuals and diagnosis and assessment and therapy, one thing that was totally missing from my experience, trying to be a social worker, was the lived experience of people with mental health diagnoses. That, we never heard directly from someone themselves and that is a huge component of training that I think, in general, not even talking about dual diagnosis, and people with developmental disabilities, in general, in the mental health field is missing, we should certainly be hearing from people with lived experience with mental illness. And so, I remember that I was teaching a class one time and I had a guest speaker come in and talk about his own experience of mental illness. And he described auditory hallucinations and tactile hallucination and I realized, it was the first time I'd ever heard

someone in a classroom talking about their own experience of mental illness and what it felt like for them, and it wasn't something that I read in a textbook. And it was so much more powerful to really understand from the person themselves. How does it feel for you, and what are the things you're struggling with? And one of the things he said was some of his biggest struggles did not come from mental illness itself, but the fear of the stigma and the prejudice that he would experience from other people. He was so fearful of it that he would rather people thought that he was strung out on drugs than know he had a mental illness. So, that was so powerful to hear from the person themselves. And so, I've carried that with me that it's so important. We can't really interact with people and know how to help them and support them and work together with them, if we're never listening to their experiences.

A

Alexandra Schiwal 16:56

Because we know that lived experience is so powerful, we want to provide a platform to share more of your stories, you can go to [MHDDcenter.org](https://MHDDcenter.org), to the voices page, link below, to hear more stories, and to have the opportunity to share your own experience through our digital storytelling initiative, so you can impact other professionals in a similar way. (Music)

E

Elaine Eisenbaum 17:20

We can't really interact with people and know how to help them, and support them and work together with them, if we're never listening to their experiences,

J

Jeff Sheen 17:30

Well, well said. One of the things that you and I share is a background in social work. And having gone through graduate school in the social work field, I don't recall ever even talking much about disability, at all, let alone Developmental Disabilities specifically. When I taught Social Work 1010. There's that kind of obligatory chapter on disability issues, it's usually chapter 15, or 16, which means it's typically presented at the end of the semester. And certainly disability, developmental disability, was never talked about at the intersection, or in conjunction, with mental health, they were never kind of talked about as somebody might be experiencing both. Somebody might be experiencing Down Syndrome as well as clinical depression. That was never even on the radar, as far as any of our conversations. And so I think that's similar to your background. And if social work as a field, and this isn't to speak for all social work programs, I'm sure there's others that, you know, other than the two that you and I attended, it might have addressed this differently. But there's a sense that we don't talk ever about them together, let alone very much

disability, at all, separately.

J

Jeff Sheen 18:36

When I think about where we're headed with this training for people that are going into this field, how important it is to understand what it might be like for somebody to live with an intellectual disability, and have clinical depression or clinical anxiety, or have bipolar disorder? And what does that do for how I then approach treatment with them, or how I support them to improve their quality of life? So I appreciate that kind of conversation about, we really have to do more, intentionally, to incorporate the voices of those who live these experiences, so that we can do a better job on our end of supporting them.

E

Elaine Eisenbaum 19:14

That's, yes, I certainly had a similar experience, Jeff. And I think that, I recall, when I graduated from my masters in social work program, that my friends who went out into the field, they would call me when they're out in the field and say, Hey, Elaine, I have this client who's coming in who has an intellectual disability, and presenting with maybe depression, or whatever it was, how do I work with them. So that's one of the things I really can recall strongly is, they were not getting the education in their programs. And that's, I think, our field in social work knows that we know we need to do more, and the whole field itself is working to do better in that area. So that's wonderful, and we're certainly hoping to support that. But a lot of times people aren't getting that training. And I remember them calling and asking me, and they certainly were able to serve the population, but they needed a little bit more information, and maybe a confidence boost for me to share with them. Oh, you know, this is this is how you interact with them. It's not going to be that different. But here are a few things you can do a bit differently or ask about. So I do think that we're moving towards, as a field, in social work, and I'm sure in other mental health fields doing better and our education. But that's certainly what this Training Center, something that I feel strongly about, it's kind of this early intervention approach. If we work with students to know more about people with developmental disabilities, have examples in our training of people with disabilities and mental health, they will be better equipped as they move out into the field to serve all people.

J

Jeff Sheen 20:57

Yeah, and I think you know, we're talking a lot about right now about the mental health side of things, not understanding intellectual and developmental disabilities that well. And then you and I both also work in the UCEDD network, the University Centers for Excellence on Developmental Disabilities. So you and I work in the developmental disability field. And

it's also the same kind of scenario where those, those of us that have kind of worked in the developmental disability field don't always pay much attention and don't always understand mental health issues and, and that system. And a lot of UCEDD networks don't have a really strong connection to the mental health side of things. And so there is some training, as well, that will be talking to folks from the developmental disability side of the equation about mental health issues. Correct?

E

Elaine Eisenbaum 21:45

Right! So with the modules I mentioned, there were two sets of groups. And the first is clinicians, or-or professionals in the mental health field or students, people we can assume know about mental health, but not necessarily about people with intellectual and developmental disabilities. The other set of modules is for people with disabilities themselves, family members, direct support professionals, or people in the developmental disabilities field. And I think of that group is a group who may know a lot about disability, but maybe does not have the knowledge base about mental health. So the goal of those trainings is to provide information about mental health and mental health service systems and how to navigate them.

J

Jeff Sheen 22:30

If somebody wanted to get into this field or follow a similar career path that you followed, what advice would you have? How would they go about doing that?

E

Elaine Eisenbaum 22:39

Oftentimes, especially like, say, I'm a social worker, I don't meet too many social work students interested in the disability field. And I think it's because they just don't know about it. And I've, I've found that sometimes when students have an experience, they go to an internship, at a disability organization, people really love the field and a great place to be. So seek out seek out a practical or an opportunity to volunteer or to get involved as a student. And I think that you'll fall in love with the field.

J

Jeff Sheen 23:12

So that that makes me think of a couple of my own experiences, because I had no idea that there was anything like a disability field to work in, when I was going to school. I had grown up with developmental disability being part of my family experience. And and so I knew about development, developmental disabilities from the lived experience of a sibling. And I had interactions, I'd watched my parents interact with the school system and

the service system on behalf of my sister, but I never, you know, and that was really what kind of lit my fire for social justice, is I saw some things that weren't working very well to support her. And that really kind of like, ticked me off, that the world should be better at doing these kinds of things. So it got me into the social work field, but I still didn't connect that with there was a disability field, until, like you said, practicum. I went to a practicum fair and there was this group, from the Center for Persons with Disabilities at Utah State University, which happens to be the UCEDD, and I liked the location of where they were. I said, well, I could go live there for my practicum, that would be great. And I walked into this practicum, and suddenly dawned on me, there was a whole field, or a lot of related fields, around developmental disabilities that I had no clue existed. And I felt like really a kid in a candy store as far as what I could do in this field. And I'm here 20 years later talking to you on this interview because of that practicum. (Music)

A

Alexandra Schiwal 24:37

A quick aside to define the acronym Jeff just mentioned, a UCEDD (pronounced: you-said) or UCEDD is a network established in 1963 for University Centers for Excellence in Developmental Disabilities, education, research and service, of which there are currently 67, nationally. As a member of the UCEDD network, we conduct research, provide services, technical assistance, training, and more. Go to [aucd.org](http://aucd.org) to learn more about this network. Link in the show notes. They are a great way to get involved in the field of disability.

J

Jeff Sheen 25:09

That turned into my full time job and my career. And suddenly it put my lived experience in this context of all of this professional stuff, all of this self advocacy thing, this whole world of disability rights and history that I had no clue about, until I stumbled into it through a practicum.

E

Elaine Eisenbaum 25:28

Right, sometimes it says chance encounters. And, you know, I'd love for more people to learn about what a great field this is to be in. Especially folks who have a drive to fight for civil rights and human rights, this is a great field to be in. As a child, I always was fascinated by, you know, civil rights and fights for for human rights and civil rights. And I didn't make the connection until I got into special education that this Disability Rights was such a huge part of, that I could, I could take that interest and fighting for rights and combine it with the disability field to work for disability rights.



Jeff Sheen 26:10

We've talked a lot as a project team, and there's a lot of things in the grant, but when we talk about providing resources and training for direct support workers, what, in your mind, does this project really have to offer those direct support workers, so those those folks that are working, maybe in a group home setting, or they're working in the disability service system directly to the frontline staff. They're interacting with individuals that have maybe mental health issues as well as developmental disabilities. They're doing that on a day in and day out basis? What do you feel like this project offers to that group of folks?



Elaine Eisenbaum 26:46

What, I hope that it offers is an ability to strengthen their knowledge base around mental health. And there are a lot of us in society who don't know a lot about mental health, and have never taken specific trainings on it or, you know. So I want people to know more about mental health, I want people to feel more confident in knowing about the service system, so that they can support people to advocate for them to get the services they need. And that's not always easy, because we do have a shortage of services for this population. So it really takes strong fighters, people with disabilities themselves have to advocate for themselves. Anyone around them, direct support professionals, need to have that knowledge and competence to advocate for services. And I hope that we can help them understand more about mental health so that they're able to do that. You know, for me, what I hope comes out of this project is a more inclusive mental health service system, where people with disabilities can get better access to services. Where clinicians can feel more confident working with this population and know how to make small adaptations, when needed, to serve this population better. So that's my hope is, we have a more inclusive mental health service system. And that people can get the services they need or desire. And that people have more education to self manage mental health, to understand their own mental health, and advocate for themselves when needed. (Music)



Alexandra Schiwal 28:24

We hope you enjoyed this week's episode of the Mental Health Crossroads podcast, a podcast by the Mental Health and Developmental Disabilities National Training Center. Remember to follow us on social media at MHDD center and visit our website at [MHDDcenter.org](https://MHDDcenter.org) to find training, resources and transcripts of the podcast. Thanks for tuning in. (Music)