DDNJ Author Insights

Ep. 13 Joan Beasley and Luke Kalb

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SPEAKERS
Matt Wappett, Joan Beasley, Luke Kalb

Matt Wappett 00:15
Hey everybody, welcome to the Developmental Disabilities Network Journal Author Insights Podcast. We appreciate you coming back. I'm Dr. Matthew Wappett, the DDNJ Editor-in-Chief and Executive Director of the Utah State University Institute for Disability Research, Policy and Practice. Utah's UCEDD. It is my privilege to also host this podcast. I know I say this every single time, but this podcast is one of my favorite things to do because it gives me a chance to sit down and talk to so many different researchers and professionals who are out in the world making a difference. In fact, many of the people who we have on this podcast are literally changing the world in their own quiet way. And today's guests are no different. They've kind of been remarkable collaborators and have done some incredible things in the area of mental health and developmental disabilities and we're excited to visit with them. So with that said, before I get to our guests, I want to say that this podcast is another part of our ongoing commitment to increase the accessibility of the Developmental Disabilities Network Journal for a wider readership. And for folks who maybe aren't academics, we recognize that not everyone has time to sit down and read an entire article these days, let alone an entire issue. And more and more people are choosing to access their information through podcasts and audiobooks. In fact, I've said this on the last few, but I've read more audiobooks this past year than I have read with my eyes, which I think is a first for me. But it's a lot easier for me to just consume information as I'm walking, talking, driving, eating, whatever the case may be, if I just have to listen. So this podcast kind of capitalizes on that. It means that you can access our content and get to know our authors while you're on the go. And you can more readily share this information across social media and other online platforms. And we encourage you to do that. But we recognize that this podcast again, is just trying to provide multiple avenues for people to understand what we're trying to do with the journal and to get the message out about the great research that's happening in the field of developmental disabilities. So with that said, I'm going to give you the standard sort of a plea, please be sure to subscribe to our podcast feed. You can do it on Apple podcast, Spotify, Stitcher, overcast pod bean, which is where our main pages, if you just type in DDNJ Author Insights that will come up on a Google search. And you can really access it anywhere that you get your podcasts. So if you do listen regularly, please leave us a rating and a review, and share this podcast with your friends and colleagues on Twitter, Threads, Instagram, Facebook, whatever the case

may be. Those ratings, reviews and shares actually help us get the word out and share the important work that's been done in the field today. So we really, really appreciate you taking the time to do that. We also want to acknowledge that the authors, and in today's episode, the editors are more than just a name on the page. We try to use this podcast as a way to help you get to know the people behind some of the research. Reading in an academic article doesn't give you a good sense of who the people are who are doing this work. And, you know, sometimes to create connection, belonging to create just that sense of being part of something, it's good to know who you're reading, who you're working with. And so another reason that we started this podcast was to give you a better understanding of the many diverse voices who are working in the developmental disabilities field today. And we want to provide some insight into what motivates them. Where do they get their ideas from? Why do they do what they do? All of these things I find as a researcher myself, to be helpful, and helps me contextualize my work and understand how other people approach their work. It helps me find new collaborators. It's just really, really helpful to recognize that the people who are writing sometimes these dry and boring academic articles are really interesting people behind that academic language. So anyway, today we definitely do not have boring people on the podcast. Today, I get the opportunity to visit with Dr. Joni Beasley and Luke Kalb, who were the guest editors on our most recent special issue that was focused on mental health aspects of intellectual and developmental disabilities. I've worked with Joni and Luke over the past few years. They've been remarkable collaborators, friends, colleagues, and hopefully you'll get a feel for that, as you listen to our conversation. Just by way of background, Dr. Joan Beasley received her Ph.D from the Heller School and Social Policy at Brandeis University. She has worked to improve mental health services for people with IDD for over 40 years. She is the author of START, which is an evidence-based and evidenced-informed crisis prevention and intervention program that's been implemented across the U.S. And Joni believes that research and, especially inclusive research, is key to moving the field forward. She is currently the principal investigator and co-investigator on several inclusive projects, including a federally funded five-year comparative effectiveness research study to compare telehealth with in-person services for people with mental health issues and intellectual and developmental disabilities. Her most recent efforts have focused on the development, and the use of patient-reported experience measures for people with IDD regarding their mental health service experiences and she will talk about that during the conversation today and you'll probably get a sense that Joni is a colorful character and passionate about the work that she does. Now, on the other side of the microphone, too, we have Dr. Luke Kalb. Luke is an assistant professor in the Department of Neuro Psychology and the Center for Autism and Related Disorders at the Kennedy Krieger Institute. He also serves as the chair of the National Research Consortium on mental health and intellectual and developmental disabilities, which was the sponsoring organization for this most recent special issue. Luke got his Ph.D from the Department of Mental Health at Johns Hopkins Bloomberg School of Public Health, and His research focuses on improving mental health outcomes among vulnerable populations, with a particular focus on youth and individuals with developmental disabilities. His primary research interests involve understanding the phenomenology, epidemiology, and treatment of mental health crises. He has also worked within the field as a frontline, right crisis worker, and he will talk about that today. He has an extensive research portfolio looking at the effectiveness of community based mental health programs, psychometrics and measure development. He was very, very helpful in reviewing the statistics, and the measures that were used in many of the articles that were published in our most recent issue on mental health aspects of IDD. So, with that said, that's who we're talking to today, and I am excited to welcome Dr. Joan Beasley, and Luke Kalb. So although I know both of you, I'm imagining that most of the folks who listen to this are not going to know both of you. But you never know. But either way, tell us a little bit about your background and in the reason that you got involved with studying mental health for individuals with intellectual and developmental disabilities and why don't we start with you first, Joni, and we can go to Luke.

Joan Beasley 08:51
So hi, I'm Joni Beasley, and how did I get started doing this? I was a mental health clinician for many years. I was trained as a structural strategic family therapist from the Philadelphia Child Guidance Center and took a job for a very short period of time while building my private practice to work in residential programs for people with mental health conditions. And this issue came up with the Department of Developmental Disability Services where they had people who are having difficulty who they thought might have mental health conditions and I worked with a wonderful psychiatrist named Robert Softner and he believed that people could in fact have mental health conditions. He was a pioneer in the field. He and Anne Hurley were my mentors back and this is we're talking about 1981-82. And I realized that because people with IDD was so underestimated, that providing mental health supports had an enormous impact on how they did, how they responded. And it just sort of turned me on. I was like, really turned on to the work. And seven years later, I developed a project called START. And have, I never went back to being a family therapist, Actually that sort of didn't happen. You know, you start on one journey, and you say, temporarily, you're going to take this road. And then 20 years later, and in my case, 40 years later, you realize that that was not the road you were supposed to be on to begin with. And so here I am.

Matt Wappett 10:38
Yeah. So now that works on-going with the National Center for Start Services. How many states is Start in now?

Joan Beasley 10:45
Start is in I don't know, and I am no longer with the National Center for Start Services. I think the START model has touched over 30 states. Some states are still there, some are no longer. And 1000s of people have received START services. I'm gratified, but I'm also sad by that because when I developed START, I really intended to build capacity so that you wouldn't need a crisis service like START. And it seems like the need has built over these many years. I currently work as a researcher as a research professor. I mentor graduate students, undergraduate students in research in mental health aspects of mental of IDD. And I have a couple of very large projects that I'm working on. And when Luke introduces himself, he was a graduate student that I met when he was completing his work, his doctoral work at Johns Hopkins. And that's how we met. So I hope that I have helped to influence the field in some way.

Matt Wappett 12:01
Yeah, absolutely. Well, let's use that as a transition. Luke, give us a little bit about your background.

Luke Kalb 12:07
Sure. So I'm assistant professor at Johns Hopkins School of Public Health and the Kennedy Krieger Institute. I got started in this field, I walked into a large psychiatric center called Sheppard Pratt, it's very

old institution in Baltimore. It's actually one of the first psychiatric hospitals in the United States, and asked for a job and they said sure, and they put me on the boys unit. And I loved it. And the boys unit was actually adjacent to the Developmental Disabilities unit. Its one of seven units in the U.S that served with a crisis unit for children and adolescents with developmental disabilities. And they said, if you're going to work on the boys unit, you got to work on the autism unit. I said sure and I ended up spending three and a half years there. Ended up shifting to the Developmental Disabilities unit. And my job was to provide discharge plans for families. So my job was to find community providers for families when they left the hospital. And I was immediately became aware that when I said the word intellectual disability, or autism, people hung up the phone, and then I saw the horror stories of families coming into the hospital after sitting in the emergency room traumatized the child was over medicated. And they were sent back home after the hospital just to face the same reality. And I said, you know, this has got to change. And so I ended up embarking on a research career thinking, you know, like, Joni, my hope was that I would, by shedding light from a public health perspective on this issue, we would do something about it. And I've definitely shed some light, and there's the light says that there's still a lot more to be done. So, you know, I've spent, you know, most of the last decade of my life conducting research on mental health and around crisis, and it's about intellectual disabilities. And Joni, I met her as a graduate student, because she was one of the few programs that actually did something about it. And so we've developed this relationship and done lots of research over what is probably like 9, probably close to a decade. It's been a while.

Joan Beasley 14:14
Yeah. It's incredible. The connections that we make. It frightens luke.

Luke Kalb 14:21
I mean, if you start adding it up, it's a long time.

Joan Beasley 14:24
It's freaky. When we got the last grant, Matt, Luke said Oh, my God, that's five more years of you. It was like, it was like something really like.

Luke Kalb 14:34
I think I said together, not you.

Matt Wappett 14:39
I have more Yeah, there's a difference between together, right.

Joan Beasley 14:42
But he but he did start with oh my God. It wasn't like, oh, hooray.

Luke Kalb 14:47
I was shocked that we got it. I've written many more grants that were not funded than were.

Matt Wappett 14:54

Yeah. Well, you both done incredible work, and it's been a privilege to work with you on this most recent issue of the journal. Getting back to kind of the focused conversation, I have a feeling we're gonna ramble a bit because we know each other. This is what happens when you have a relationship, but both of you have worked in mental health for many years. And I know this is a loaded question. You could probably talk for hours on this, but what are some of the major systemic barriers that we're still struggling with around mental health for individuals with intellectual and developmental disabilities?

Joan Beasley 15:32
So I can start because Luke just told me I should. So, the major barriers are the dehumanization of people with intellectual and developmental disabilities. So first and foremost, people with IDD are not considered to have the capacity to have mental health needs. It's exhibition of distress. It's considered a function of their cognitive or developmental delays. And so there hasn't been a lot of effort to really accommodate and include people with intellectual and developmental disabilities in mental health services. So, I would say stigma is a big issue. The second thing I would say is stigma regarding mental health issues. Has kept people, families from seeking mental health services for children and adults with autism and ID and for people with IDD seeking out mental health services. I remember a colleague of Luke and mine. Her name is Susan. When I first worked with her and her son many years ago, she said it was a heartbreak to find out that my son had intellectual disabilities. And now you're telling me as mental illnesses as well. It's too much to bear. So, they are the most sort of disenfranchised people with disabilities. The third issue is that in all the infrastructure and the way funds are paid, resources are allocated. You're supposed to have either one thing or the other. You're supposed to have one form of disability or health need or another. It not well integrated. We talk about integration; we talk about coordination, and collaboration. But from a structural and policy standpoint, there's still a lot of there's still a lot of territoriality that creates obstacles for people and competitiveness in terms of resources. And I would add that people with intellectual developmental disabilities come from a wide group of diverse populations across the United States. And to not identify diversity, language differences and other differences as part of the story is very difficult. I just, and then I'll stop talking like I promise. I I just visited a state where I was visiting an outpatient mental health centers that said they included people with IDD in their treatment. There was no training, no accommodation, no OT services, no augmentation of how we communicate with people. And shockingly for me, there was no deaf clinic. So when you work in the disability field, and you don't make accommodation to people with disabilities in general, you know that people with IDD are not going to be accommodated. So those are the biggest barriers that I see.

Matt Wappett 18:58
Yeah. Luke, what would you add?

Luke Kalb 19:01
Sure. So that was very well articulated Joni. I would add to that a workforce shortage. So there's a paper in 2020 by Jonathan Cantor from Rand that I cite all the time. And nationally he's shown that in autism, only about 12% of mental health facilities will see a child with a developmental disability with autism. And with intellectual disability, that's probably lower. So that's 9 out of 10 facilities that a family will seek services from, they'll be told no, that's shocking. And as autism increases, and then it's going to be more common today, one in 30. You know, so every child in every classroom in the United States

likely meets criteria for autism. And that's just one part of the intellectual and developmental disability spectrum. So I can tell you here at Kennedy Krieger Institute our waitlists are out of control snd we are working diligently to fix that. So we just have a major shortage, and there's a trickle down effect on families and institutions and public health at large. So it's something that really needs to be fixed. We need to train more providers.

Matt Wappett 20:11
Yeah.

Joan Beasley 20:12
So can I just add to that? So I think part of what contributes to the shortage is the joyless work that is expected of people. So because, and I'm not kidding Matt.

Matt Wappett 20:24
No, I totally agree.

Joan Beasley 20:25
I think that not being equipped to do the work properly, not being trained, not having the resources you need to have a positive therapeutic intervention. Not being taught positive strength based strategies to engage your patient and their family. All of these things contribute to the to the workforce shortage. You know, when I was a mental health clinician, I was an outpatient mental health clinician for several years before embarking on this journey. And, you know, I found it a little boring, like, the point is, is that the challenges that you face as a clinician contribute to your motivation to do that clinical work. And if you're not supported, and encouraged to do that work with the resources needed to do that work, you're not going to do that work.

Matt Wappett 21:20
Yeah. Yep. And yeah, you I mean, you both brought up I think some really thorny problems that we continue to really struggle with. And it is yeah, it's overwhelming just to listen. You know, as this is a field that I'm personally interested in as well. It's overwhelming when you sit down and you look at it, and you're like, oh, yeah, these are big systemic things that it's hard for an individual to address. So kind of on that note, a few years ago, guess this would have been in 2019. You both got together and started the Mental Health and IDD National Research Consortium. What was your motivation behind starting the National Research Consortium and what were you hoping to achieve with that?

Joan Beasley 22:10
So, I was hoping to achieve inclusive strength-based research so that we would move the field in mental health and IDD. To be more productive and effective in the strategies that we employ in helping people with mental health needs who have IDD and why I thought it was necessary to have this consortium and I remember calling you Matt and calling you Luke to ask you to be a part of it was there really wasn't any funded research. We started to have funded research in intellectual and developmental disabilities. Very little in mental health aspects, and certainly none in strength based approaches to those aspects and very little inclusive research in mental health and IDD. And I just want to say the reason why I call it mental health aspects of IDD is because having an intellectual and

developmental disability is the same as not having an intellectual and developmental disability. We all have mental health challenges at one point or another in our lives, whether faced with crisis situations, trauma, or innately as part of who we are, and it's true for people with IDD. They are not dual diagnosed. It's an integrated understanding of how people have mental health needs and also have intellectual and developmental disabilities. So Luke knows I get very, like, hyper-vigilant about the dashes and the duels when it's described in that way. So I'll hand it over to you Luke.

Matt Wappett 24:04
Yeah, no, I think those are important distinctions. Luke, what would you add to that?

Luke Kalb 24:10
I'm just gonna repeat what Joni said. And Joni was, it was really her brainchild. I mean, she was she thought it up she orchestrated it, organized it, resourced it. Had this structure through START that she built over many years to make an impact on the field. And so, you know, kudos, kudos to her really.

Joan Beasley 24:29
Well, let me just add. Luke contributes a great deal to the process in his leadership as an extraordinary and very, he's just he's got a wealth of knowledge as a researcher, but also as a teacher. He's very good at mentoring. One of the goals of the consortium is to mentor young researchers who are interested in doing the work and to offer them a helping hand rather than just criticize them and reject them when their proposal isn't correct or they've sort of taken a wrong turn. And Luke is is a very important part of that process. And Johns Hopkins, Kennedy Krieger has donated space and time to this effort. Every year we have an a wonderful annual meeting, which the space is totally donated by Kennedy Krieger. And Luke has certainly been a leader in making sure that happens. It's been a great partnership.

Matt Wappett 25:37
I would agree. I appreciate having worked with both of you for the last few years and just getting to know the different strengths that you bring to the table. It was incredible, actually, it was great. to sit down with Luke. You weren't on this meeting Joni, when we were going through the articles and trying to decide feedback, and just your background and methodology. Luke was really helpful. And I think doing that I gained a tremendous respect for how quickly you can see some of these methodological issues that those of us who maybe are not if that same ilk, don't pick up on it. But you did do a remarkable job

Luke Kalb 26:17
They put me through the fire here in my training, for sure.

Matt Wappett 26:19
Yeah.

Luke Kalb 26:20
I can tell you my exams for my dissertation were with the Dean of Emory, and now chair of biostatistics. So Danny found and Elizabeth Stewart, I've much to be indebted to both of them further training.

Matt Wappett 26:36
Yeah. Well, so I'm going to the process of putting together the journal, as I've said earlier, but as we put together this journal, with the National Research Consortium, with both of you as our guest editors. It was a learning process. And I know that I learned a lot of things as we reviewed abstracts and articles and everything, but we're so what were some of the big lessons that you learned as we pulled together the articles for this special issue of the journal and I'm going to start with you this time, Luke, and then we'll go to Joni.

Luke Kalb 27:07
We would have liked to see more strengths based work. I think that was what we were really pining for what we're really hoping for, and as a consortium, what we've seen the same challenges with the applications we get as well. So if any of the listeners out there in podcast land, if you're doing strength space work, and want to do research, I encourage anyone to go in and and visit the National Research Consortium website. So I think that's what we were looking for. And we got some on the cusp, but there just still needs to be more work there. And at minimum, at least we can shine a light on that and say and encourage the field to lean into that more.

Matt Wappett 27:27
And we link to that in the show notes. Yeah, Joni, what were some of the some of the big lessons you learned as we went through this process?

Joan Beasley 28:01
I think that there's a questionable rigor applied to research and IDD that I found concerning. So, while we weren't looking for,you know, it's exemplary work that should be published in a, you know, a large national journal, I felt like the submissions were not research-based submissions to a large degree. And that really made it difficult to accept them into a journal where we were asking for research-based articles. And this also, as Luke will state happens with the NRC. Like there's so and I also think what it proved was that we need journals like yours. And we need consortiums, like the NRC to build capacity but we're not there yet. And that that's not a problem. It's not a bad thing. It's just a learning thing.

Matt Wappett 29:10
Yeah. Yeah.

Luke Kalb 29:12
So I don't disagree with Joni, but maybe to put it a little bit softer to the people submitting to the journal. I think community-based work, which we got a lot of community based work, still requires partnership with people with formal training and research methodology. And especially it's really important that we have people with lived experience with disability partner with people with scientists as well because that's a collaborations we really want to see. That way we can get that clear vision and focus, but with results that we can replicate. But we're not there yet, and that's really a new vision. I think the idea that people would work with a community scientists, people with lived experience of disability. I mean, that's a whole new thing. And so we're hoping to accelerate that as well. And the field isn't there yet in terms

of making that scientific product. So I agree with Joni. And I hope that this can be like a stepping stone towards that.

Matt Wappett 30:16
Yeah,

Joan Beasley 30:17
So to harden it up a little bit. I think that, as somebody who has a sibling with ID. My oldest sister has ID, and has lived in this world for my entire life. Making things accessible does not mean that you have to eliminate the rigor and expectations of it being legitimate research. And I think what I sometimes see is the lack of effort in applying that rigor because it's going to be in a journal that is more accessible to people with disabilities. So you don't have to worry about that they don't need that those kinds of methods. In fact, they do. And in fact, they would appreciate it being explained to them and examined in the same way as anybody else would and just making it more accessible? So, I think that the fact that listen, I'm happy to whoever submitted. I appreciate you a lot. It is not nothing to do with that. It has to do with the fact that the community at large is not prepared the way they should be to create inclusive, accessible strength- based research in IDDMH. And that's what we do.

Matt Wappett 31:38
Well, I would argue in research in general, I mean, there's a lot of lip service paid, I think, to participatory research methods, but there's very few people who have actual legitimate training and experience in doing that. And doing that effectively with people with intellectual and developmental disabilities, especially. I think that's a big challenge that we see in the journal submissions as a whole is you either have a community-based approach that's very participatory, but not rigorous, or you have just a bunch of researchers and you don't have those two worlds coming together to the extent, I think that we would like to see as well. Yeah, it's a continuous.

Joan Beasley 32:19
And it doesn't always have to be qualitative. So our friend, and colleague, Melanie Hecker, who ended up getting another job and leaving our research team after the first year, was doing data, hardcore data analysis with Luke and looking at, we'll Luke talk about that. I mean, this is a person with a disability, who you work side by side with as a co- investigator.

Luke Kalb 32:43
Yeah. So what what I was going to say is, one is I want to shout out to Jessica Kramer, because she does real participatory research. She's legitimate researcher, understands methodology, understands how to work with people with disabilities and marry those two worlds.

Joan Beasley 32:58
She's our partner.

Luke Kalb 32:59
She's our Co-PI on the large PCORI grant. So she really she really lives it and walks the walk and talks to talk. And I would say that the PCORI grant we have does it as well. We have people with real lived

experience on the team, we have a family member who has a son with developmental disability on the data team. She contributes. She does part of the data analytic work. But to make all of that happen, it requires substantial support. And so these community based projects that came in to this submission, were people just doing it on their own accord. And that's a big difference is when there's real funding and real support to do this, you can really make it authentic, and have a high quality product. But when the community is is trying to do it themselves, it makes it far more challenging.

Matt Wappett 33:45
Yeah. Yeah.

Joan Beasley 33:46
You know, I think that's a good point. That there aren't a lot of funded projects. So that's why we got a lot of informally created projects because they didn't have those resources, which is what the NRC is trying to help remediate a little bit.

Matt Wappett 34:04
Yeah. Well, on that note. That kind of plays into the next question, which has come up throughout this interview were we've talked about strengthed-based research and positive psychology that really informed the direction that you went Joni in your career. Why, you know, positive psychology seen a huge explosion in the last decade. I mean, you've got mindfulness and stuff being talked about in popular culture and people talking about strengths-based approaches and it's kind of become hip and cool. And yet we still don't see that positive psychology framework being applied with the population of people with with disabilities. So why do you think that is why is there a disconnect there?

Joan Beasley 34:49
Because they're not viewed as having character strengths. Okay. So when I first developed START we have this thing called the cross systems crisis prevention plan. And one of the things we asked, this was since 19, that was in the 70s that I developed it, is what are the strengths that the person brings to the table? And people would only talk about their skills. They would only say, well, he listens to instruction. He takes his medicine. He makes his bed. And I was like, well, what are the strengths that he brings to the table, and they were unable to define them. And, you know, John Lyons does the Cannes child and adolescence needs and strengths. I am trained in that and getting people to talk about the actual strengths in the child rather than just the strengths that their family brings. Tough going. We're not trained to see what we are needs based. Providers are needs based. Researchers are needs based. So it's very, you know, you sort of, you're sort of trained to kind of worry about what's wrong, not what's wrong. And what what happened with the movement in positive psychology, is which and mindfulness, which goes back to like, even before I was born. Is that there was there was a method to articulate and describe and ascribe to those character strengths. That was research base that we could then move forward with. The START Model embeds positive psychology in all of our practices. And it has helped us to influence everyone around the person with disabilities to actually feel hopeful and promote the well being of someone rather than just trying to control them. And that is a key to doing good crisis prevention and intervention.

Matt Wappett 36:57

Yep, absolutely. Luke, what are your thoughts on the positive psychology thing?

Luke Kalb 37:03
So I would say that trend in developmental disabilities follows the trend for people with disabilities in general. And that is, there's always a lag for everything that gets done for people with disabilities, right. So mental health treatment, I mean, we can think about just measurement of mental health, even recognition. You know, overshadowing was a large problem for many, many years. Right? The idea that talk that therapy could even work with people with disabilities is a relatively new concept, right? Medication certainly got there quickly. You know, the FDA got on board to approve Risperidone many years ago and then shocking, we see tons of Risperidone all over the place. But, so positive psychology is much younger than the psychology field in and of itself. So there's, there's a big delay and a good example would be the Via Institute, which is the popular measure of character strings has been around for a number of years. Its application of people with disabilities is not clear. And one of the studies that that National Research Consortium funded, was looking at its usefulness or validity, and people with disabilities using a gold standard method, we found that it doesn't work very well with people with disabilities. So our measurement is behind and right, if we, we can't measure strengths and people with disabilities, how do we design interventions to promote them in the first place? So there's just a lag that's taking place. And again, that's what we're trying, there's still a lag in mental health interventions for people, like I just talked about providers. Trained providers is a massive lag. So you know, but there's gotta be people at the forefront that are pushing this narrative forward. And that's what I hope, you know, Joni, and I have helped do.

Matt Wappett 38:51
Right. And that's a big mission of the National Research Consortium in general, right, is to try to take a more strength- based approach to this mental health and disability work and because nobody else is funding it. I think we've all discovered that. Nobody else is promoting that work. And so I mean, it's incredible that you've been able to sort of create a mechanism to help support movement in that direction.

Joan Beasley 39:16
Well shout out to WITH. The WITH Foundation is funding it. The WITH foundation, which is now sort of closing its doors. It's it's on its last award, but we we've had several really important projects funded to the WITH Foundation. I think a quarry would fund it, if scientific rigor could be applied to the measurement. I think the NIH would fund it if scientific rigor, which is one of the reasons why we want to train researchers. And we want to publish articles that insist upon scientific rigor. Because if you don't create the standards, you will never move the field forward. And we will never become part of the dialogue. And what I don't know if people understand is that published research influences policy. Policy influences resource allocation. And all of those things influence systems change. And if you really want change, you really need the evidence so that people have the belief that that change is necessary. Otherwise, we're just talking amongst ourselves and patting each other on the back and saying, oh, woe is me, or aren't we great, but too bad they all aren't. And that's really not what we're aiming toward. We're trying to make it part of the normal best practice. And that's a well unique to this group. It should be, as Luke said, it's all disability research that needs this boost, you know.

Matt Wappett 40:51
So, one of the one of the questions that I had here was what's the most important thing researchers should be doing to move the work of mental health and IDD forward? And I think it's come up several times in both of your answers, right, increasing that rigor, are there other things that researchers should be looking at or considering or doing that would really help move the field of mental health and IDD research forward?

Luke Kalb 41:19
I would say training the next generation. So including you know, there's like LEND programs across the United States. How much of their curriculum looks on stretched-based approaches? Probably not. Right. So if we're going to want to increase the awareness and knowledge, you know, this journal, this submission can help do it. But the studies that are out there funded by the NRC and other there are other strengths based studies that rises to the top and that people become aware of them, I think is important.

Matt Wappett 41:54
Yeah, Joni.

Joan Beasley 41:56
So, I've been on this sort of mission to implement a patient experiences response measure called the Prem. For people with IDD and mental health service experiences. I think that research of any kind will move forward when we have access to direct feedback by the patients, not about their mental illness, but about how we're doing with them. Because one of the basic underpinnings of strength-based approaches is to give people the opportunity to have a voice. It doesn't matter if I have strengths if I if I don't have access to them, or are not allowed to use them. And so one of the things that I'm working on, and Luke will be working on with me, whether he likes it or not, is measuring outcomes associated with using a prem in outpatient settings. Actually, you're doing it to whether you like it or not, Matt. So yeah, we're all in this together kids. And in part of it is, I'm trying to find mechanisms. I think we all need to find mechanisms in which we can make it accessible for people with disabilities to actually have a voice in what it is we're measuring. Because one of the things that I think is a problem with positive psychology, is the outcomes that are being measured may not actually be the outcomes we should be measuring. And so we're not getting anywhere. And we all know it's helpful. But we have having trouble defining where helpful means. And I think talking to the patients would be very informative to find out what helpful means.

Matt Wappett 43:43
Yeah. Well, and I think that goes to a lot of what I've heard over the last couple of years doing this as we need to find ways to help people with disabilities, all disabilities, right, have a voice and communicate their wants and needs more effectively. And we still struggle with that as a culture, and especially I think, within research and clinical settings for sure.

Joan Beasley 44:12
That once it's in strengths and abilities, so, right. So we're over focused, I think on well, they need we need to give them the opportunity to tell us what we they need. No. We need to give them the

opportunity to tell us what we're doing right and what we're doing wrong. We need to give them the opportunity to tell us what they expect, not what they need, but what they want from us. We don't really self evaluate enough in terms of, you know, it's always like they're, you know, we're giving it to them based on their needs. Well, maybe we need to have more dialogue based on what they think we should be doing in the first place. You know.

Matt Wappett 44:58
Right. More interactional.

Joan Beasley 44:59
More interactional. More experienced base.

Matt Wappett 45:01
Yes, yep. Yep, absolutely. I couldn't agree more. Well, so as we're getting to the end here, and I want to be mindful of your time. The last two questions I ask these of everybody who comes on the podcast because I always think it's interesting to see kind of why people do what they do, and kind of the different ways that people are trying to improve the work that they do. So I'm going to ask both of you these questions. The first one is, what motivates you to do this work? Why do you do what you do? And we'll start with you, Joni, and then we can go to Luke.

Joan Beasley 45:42
So my very good friend, Dan Tomasulo has done a lot of work on hope. And he says that hope is a verb. And as an action oriented person, I feel like my whole mission is to provide hope. And when you work in the hope field, you feel hopeful. So it, there's a lot of joy in saying, yeah, we have these issues and problems and challenges, but there is hope. I have a plan. We're going to move forward. That's why I do this work.

Matt Wappett 46:19
I love that. Luke, I'm sorry, we're gonna put you on the spot after that answer.

Luke Kalb 46:25
I was gonna say that's a hard act to follow. I would say I still feel indebted to those families in the hospital.

Matt Wappett 46:35
Yeah.

Luke Kalb 46:36
And, you know, naive naivete is a wonderful thing. And having hope and optimism is how we all get started. And it does propel us going forward when we face challenges. I remember thinking, oh, if I develop this measure of this crisis measure, we can identify these families, we can get prevention in place. But the reality is, it's very difficult. There are so many countervailing forces we all face in our daily personal and professional lives that the world is infinitely more high dimensional and complex than we ever realize. And you realize that wisdom and time. But the hope of the future is a beautiful thing.

And it is the wave we need to ride forward. So I still have the younger Luke hope, and I have not given up on that, but I've realized that change is incremental. It's like a lego block. And we each have to lay our own brick in that process. And so I'm hoping I'm laying a brick that somebody else can build on top.

Matt Wappett 47:47
Yep. it is. It is.

Joan Beasley 47:49
Look where we are all from though, Matt. So you're from Utah?

Matt Wappett 47:53
Yeah. Well, I live in Utah, I wouldn't say I'm from Utah.

Joan Beasley 47:58
You live in Utah. I live in Boston and Luke lives in Baltimore, and we're collaborators. And this work of hope, and strength-based thinking has brought us all together.

Matt Wappett 48:10
Yep. Yep, absolutely. And I think, you know, common people with common outlooks tend to be attracted to one another. And it hasn't been a privilege to work with both of you over the last few years. But kind of going back to what Luke said, one of the things that is sobering, and I continue to struggle with this is when you recognize that going back to the very beginning of this interview those that stigma and those attitudes, and that ableism, and everything is embedded within these institutions and these policies and these programs. And that you as an individual, it's very difficult for you to change those. That can be difficult. I know, I know, you.

Joan Beasley 48:19
Maybe I feel like I've made a little progress there.

Matt Wappett 49:00
Oh, no, you absolutely have.

Joan Beasley 49:02
So if I can do it, anybody can do it. It just takes like, it takes a willingness to repeat yourself over and over and over and over again. And just understand that it's okay people don't get it the first time or the 100th time or the 1000th time. Just keep repeating yourself, but you have to be respectful. You have to listen. And it's slow and steady. I've been doing this a long, long time. And it is different now. I mean, it's it's much different than it used to be. My sister, who's 71, was in the idiot and moron classroom when she was a child. Idiots, morons, and mental deficients. So, you know, we have made progress.

Matt Wappett 49:50
No, we absolutely have. Yep. Yep. I always tell my classes, you know, it's funny that I went into this field I was born in 1973 and that's the year that Geraldo Rivera put out the Willowbrook expose on TV and everything. And we started to see deinstitutionalization. And it's kind of formed a theme, but you

know, we're fighting hundreds and hundreds of years of history, right with moving people back into the community and trying to provide these supports in a different way than they were provided for hundreds of years. So, we are kind of making this up. So, on that note, the last question here is, and this is my favorite question. What is one thing you've been doing to make your work more inclusive and accessible.

Joan Beasley 50:37
Well, I work side by side with people with disabilities and really it's only been in the last five or six years that I've actually done that. And it has changed everything for me, and I think made me a much much better researcher, and have much more insight into why I do what I do.

Luke Kalb 51:07
I would say. I'll reflect on a recent experience for a study that I'm completing. So I just finished a randomized trial to develop a crisis prevention program for children with autism. That program was developed with parents who have a child with autism. They help provide a direct insight into the manual that we developed and we studied. A good approach. I would say in the future, the next step needs to be a person with autism needs to be involved. So I'd say we got part of the way there, we didn't get all the way there. When we finished the trial we sent out the results in like an infographic to all the participants that took place in the study. the intervention, and the control group. It is mind boggling to realize that until very recently, researchers did not make participants aware of the findings. Those findings went directly into the scientific literature, which is about about as inaccessible as it could be possibly made. Not only behind a firewall that costs money, but the language is completely inaccessible. The funder did not require that. I would like to see funders require that in the future that if a person takes their time and their effort to participate across all fields, the family or the person with with a mental health or any type of physical or medical condition should be made aware of those findings. So that was not done in my prior work, and it's certainly a standard now. So, you know, again, getting there. It's not the perfect place to get there. But it's a step in the right direction.

Matt Wappett 52:42
Yeah, Yep, absolutely. I totally agree. I think, yeah, we're slowly making progress to be in a more inclusive and accessible research world, I hope. But it takes effort. And it takes commitment on the part of people like both of you. So I want to thank both of you for your time today and just for helping us pull together this latest issue of the journal. So I hope that you have a great rest of your afternoon.

Joan Beasley 53:06
Oh, thank you. And thank you for the opportunity, Matt and Alex, thank you.

Luke Kalb 53:10
Thanks, Matt. Thanks, Alex. You both are great.

Matt Wappett 53:12
You bet. Thank you both. So that's it for our conversation today with Dr. Beasley and Dr. Kalb. I really appreciate you hanging in there and listening to it. It was a fun conversation. I really appreciate the time that Joni and Luke took to visit with us and to share their perspectives. They really are doing some

remarkable work out there. And I would encourage you to reach out to them to get involved with the mental health and IDD National Research Consortium. And to really kind of follow the developments in this field. It is a dynamic field. There's a lot of work going on in this field today, and we're hopeful that we can maybe do another special issue in a couple of years and really see how things have developed in the area of mental health aspects of IDD. So, with that said, here at the end, I would like to thank our DDNJ managing editor and author insight podcast producer Alex Schiwall for her hard work to get this podcast out. Alex does a lot of the heavy lifting behind the scenes. Alex is who you correspond with if you send comments related to the podcast or the journal and she really does hold this ship together. So thanks to Alex. We'd also like to thank the USU Institute for Disability Research, Policy and Practice for their financial and in-kind support for this podcast and the journal. The journal also received support from the Utah State University Libraries and Digital Commons and we are grateful for their ongoing efforts to keep this journal going. As I mentioned earlier, please make sure that you subscribe to our podcast feed on Apple, Spotify, Stitcher, Overcast pod bean or wherever you get your podcasts. Leave us a rating and review, share the podcast with your friends and colleagues on social media. This all helps us get this information out and share the great work that everybody's doing. You can learn more about the Developmental Disabilities Network Journal, at the DDNJ website, which is digital commons.usu.edu, backslash DDNJ. And you can download podcast transcripts in English and Spanish and learn more about our podcast guests at the Institute for Disability Research Policy and Practice homepage, which is IDRPP.usu.edu backslash about backslash Developmental Disabilities Network journal, just go to the main page IDRPP usu.edu. Click on the about tab and the journal and the podcast information will come up. Thanks so much for tuning in. Thanks for hanging in there. Keep up the good work. You are making a difference and we want you to know that what you do matters. Stay tuned for our next episode next month and have a great rest of your day.