

Ep 12. Reimagining Disability, a Call to Action: Julia Pappageorge and Paritosh Joshi

SUMMARY KEYWORDS

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SPEAKERS

Matt Wappett, Paritosh Joshi, Julia Pappageorge

Matt Wappett 00:16

Welcome to the Developmental Disabilities Network journal author insights Podcast. I'm Dr. Matthew Wappett, the DDNJ Editor-in-Chief and I'm the executive director of the Utah State University Institute for Disability Research, Policy and Practice. And it's my privilege to host this podcast. In fact, this podcast is one of the favorite things that I get to do because it gives me a chance to visit with lots of different people across the US and even international folks. People who are out there in the field of disability making a difference and trying to make the world a better place. In fact, many of the people we have on this podcast are literally changing the world in their own quiet way. So this podcast, as many of you are probably familiar with, is part of our ongoing commitment to increase the accessibility of DDNJ for a wider readership. We recognize that in this, this newly technologized world as technology continues to increase, that not everyone has time to sit down and read an entire article, and that we're accessing information in a variety of different ways. Personally, I listen to tons of podcasts and audiobooks every week. And so I believe I've said this on an earlier podcast, but in the past year, I've actually listened to more audiobooks than I've actually read, which is a first for me. So the launch of this podcast is actually an attempt to bring the content in some of the articles to a different platform, so that it's hopefully a little more accessible, and maybe makes it a little more personal as well. So what this means is that you can access DDNJs content while you're on the go and listen to it in the car. You can share it easily across social media or other platforms. And we just feel like it's important that we're providing the information in a variety of formats to accommodate different learning preferences and accessibility requirements. So you're going to hear me say this a couple times, but we really really are trying to build our listenership. Please be sure to subscribe to our podcast feed, you can find us on pod bean, Apple, podcast, Spotify, Stitcher, overcast Wherever you get your podcast we should be listed. Also, please leave us a rating and a review, and share the podcast with your friends and colleagues on social media. Those ratings and reviews and shares, help us get this information out there. But it also helps elevate the visibility of the podcast and the journal in general. So thank you so much. For those of you who have subscribed and those of you who have left reviews, it does make a difference. And we appreciate you. So we'd like to acknowledge that we don't have a chance to interview everybody who publishes in the journal, I know that some folks are like, Well, why did you choose these people or not these people, unfortunately, we have limited time. And a lot of it comes down to availability, kind of

what we think listeners might be interested in diversity is a big one, just making sure we're sharing different perspectives and from different types of voices. And so a lot goes into deciding who we're going to highlight on the podcast, although we try to highlight as many authors as we possibly can. So the other thing that I think is really cool about this is that this gives you a chance to hear from the authors on a page, an academic article can seem pretty dry. And we'd like to acknowledge that the authors are people too, and they're living lives and they're fully fleshed out human beings with wants, needs, desires, funny stories. And so this podcast hopefully also puts a better face and a different face on some of the names that you see on the printed page in the journal. So anyway, like I said, this is really fun, and we really just enjoy making this content for you. So today, we have the opportunity to visit with two new authors. Paritosh Joshi from Teachers College, Columbia University and Julia Pappageorge from Northwestern University, who wrote an article titled Reimagining Disability a Call to Action. In Volume three, Issue two of the Developmental Disabilities Network Journal. That was our fall 2023 issue. Both Julia and Paritosh, this was their first publication. We did not know that when we accepted it and published it, but found that out in the course of this interview, so of course, it's always a privilege to publish new authors. People who are thinking in new and different ways about the world of disability and disability services. So by way of background, Paritosh Joshi is a graduate student in clinical psychology at Teachers College, Columbia University. His background includes a Master of Arts and sociology and research experience in public health, and he is working on understanding health issues from an interdisciplinary and intersectional perspective. Paritosh is passionate about reducing mental health disparities and promoting health equity, and really hopes to engage as an activist in his research, which I feel is becoming infinitely more possible these days sort of combining that activism advocacy and research. Which again, is so so important when we're dealing with issues of health disparities and equity. Paritosh's co-author was Julia Pappageorge. Julia is an interdisciplinary educator and researcher based in Chicago at Northwestern University. She got her Master's of Education and Instructional Leadership with a specialization in Educational Studies from the University of Illinois at Chicago. Her research explores the ways that cultural, political and economic factors influence urban education factors influence urban education and perpetuate social inequalities. So, Julia digs into these issues. You'll see this come out in our interview today as we talk about the social model of disability, and how that model can apply. And not only an educational but in a medical context as well. So as a scholar, practitioner of critical and socio cultural pedagogies, Julia is dedicated to bridging theory and practice. She has also committed to studying and applying and learning from transformative educational approaches. Beyond her professional endeavors, Julie enjoys spending time with loved ones, exploring museums, and forests, searching for meteorites, which I wish I would have asked her more about that. I don't know many people who search for meteorites, but definitely something interesting and reading poetry and speculative fiction. So anyway, we're excited to have Paritosh and Julia on the podcast today and hope that you will enjoy this conversation with them about the social model of disability as applied in a health care context. Julianne and Paritosh thanks for joining me today. We're excited to talk about your article in the Developmental Disabilities Network journal. Before we jump in, why don't you tell us a little bit about your background and the path that brought you to this project or the article that you wrote for the Developmental Disabilities Network Journal? And we can we can start with you, Julia, if that's okay.

Julia Pappageorge 08:21

Great. Thank you so much for having us here today with you. I'm very glad to be here. My name is Julia Papageorge. I'm an interdisciplinary educator, and I'm also a researcher. I've recently graduated with a Master's in Education and Instructional Leadership from the University of Illinois at Chicago. My main focus is investigating different ways that social inequality and different cultural, political, and economic factors shaped the processes of schooling. I'm really interested right now in focusing on urban education in urban environments, but might change in the future. So I'm very curious to understand how those different factors intersect and impact things like access to education so, recognizing that those with disabilities often encounter obstacles in their schooling and getting and obtaining accommodations and necessary support. That's what brings me to this work. And I'm very passionate about addressing those disparities and making education more equitable and accessible for everyone.

Matt Wappett 09:39

Great. As you think about that, that's something that I'm very passionate about to. The more we understand the systems that we live within, can get really depressing when you recognize you're not in as much control as you think are. There so many forces that act on us and that shape our or behaviors and everything. We're often not mindful, I think, of how just how impactful some of these systems are. So Paritosh, let's go to you. Give us a little bit about your background and how you came to this project.

Paritosh Joshi 10:16

Well, first of all, it's great to be with all of you here to talk about our article. My name is Paritosh Joshi. I'm currently a master of arts student at Teachers College, Columbia University and I'm hoping to become a clinical psychologist eventually engaged in clinical psychological research and mental health advocacy and policy. I would say this article really came to me when I was thinking about, so I'm broadly interested in studying the social determinants of health disparities. Looking at health inequalities and health issues from a systems-level perspective and really thinking about how different social identities really manifest themselves. When we're thinking about how we interact with our institutions, how we arrive at a point where we feel as where we're really looking at a top-down approach rather than just a one-on-one perspective. I think one of the main reasons why I really wanted to work on this article with Julia and especially look at disability from a social model was it's actually in reference to what you kind of said, which is taking back this idea of control. You know, you talked about how it can feel a little bit hopeless sometimes where you realize that a lot of these things are out of your control, in terms of systems-level change, broad bold action. But I think the key thing to think about is it often comes down to the way we conceptualize and do our research and engage in policy work, right. And that's why the social model is something that's really imperative to look at because it empowers people who have disabilities, people who are in positions of authority who can make these changes as opposed to ascribing limiting beliefs or making it seem as if people with disabilities have some sort of shortcoming.

Matt Wappett 12:29

So in listening to your intros, you both have a background in mental health it sounds like. What was it, and this is a question I didn't include in this, but I'm kind of curious. You know, a lot of folks who are in the mental health field don't focus on disability or think of disability as an aspect of mental health. I think that's changing slowly but coming from a mental health background, what was it that made you interested in the social model of disability and just investigating disability more deeply?

Paritosh Joshi 13:02

For me I would say it comes from the fact that I like to take a very activism-centered focus to my research. And I think that oftentimes it goes for the field of mental health, as well as the field of health equity and health in general. It takes a very medicalized approach to its work. It looks at how people, because of their condition, or illness or disorder, are somehow characterized by that. And, you know, we think of disability as something that might be different from some sort of mental condition. But in reality, if you think about it, you know, mental health, in some ways can be a debilitating force especially if you look at it the long term effects of not being treated, which happens to a lot of people, especially people who are marginalized, or especially if you're a member of an ethnic minority population. And that's why I think it's really important to take that perspective and take a more inclusive approach as you said.

Matt Wappett 14:13

Absolutely. Julia, what were your thoughts on that question?

Julia Pappageorge 14:16

I thought that yeah, understanding how we worked within the Department of Psychiatry. We both have a background in psychology and sociology. We have a lot of similar values and shared interests, which has been really wonderful to learn more about each other, but my interest there is better understanding from like a health equity perspective, like in what ways do all these different systems of health and systems of care pathologize people, and how does that really like limit us. How could those systems be better? So, like Paritosh said, I think that goes from both for mental health care and other forms of healthcare as well. But thinking about the context in which I'm very curious to thinking about the context in which these systems are created, and also ways in which they could be better for people with disabilities and also for everyone.

Matt Wappett 15:30

Yeah absolutely. So we've kind of touched on this, but I'll go back to you, Paritosh since you're the lead author here. Can you give us a quick summary of your article in just a couple minutes?

Paritosh Joshi 15:46

Absolutely. So the article is, as you can tell from the title, it's looking at a call to action and reimagining the way in which we view disability. What it really touches on is how the medical model has dominated the medical profession as well as other health related professions for quite a while, and it looks at individuals disabilities and thinks about them from a medically based perspective. In some cases, what it does is and of course there are benefits to the to the medical model, right? Especially if you're looking at how you can clearly pinpoint certain parts of the body or looking at how specifically one's disability can be treated medically. Especially because there's been plenty of advancements within medicine. It's a very, very important component to look at. But what it does end up doing unfortunately, though, is it insufficiently tackles a lot of the structural factors that marginalizes people who have disabilities. In turn, what it does is, as I stated earlier, it provides limiting beliefs. It says that if you have a disability and people don't "correct" your disability, then you're not going to be able to be a full part of society, right. And so it's a very limitations a weakness focused approach. And in arguably, what it does is it

marginalizes and maybe excludes or stigmatizes people. The social model, what it does is, it looks at how disability is socially constructed, how it's defined, and how a lot of our systems need to change rather than people who have disabilities. It's looking at removing these barriers and roadblocks in order to make sure that people who are marginalized are empowered, rather than maybe unintentionally or intentionally marginalized from their place of work or other institutions.

Matt Wappett 15:46

So you've kind of answered this, but I do want to dig into it a little bit more, and maybe get your perspective, Julia, on why is it so important for the medical field to explicitly acknowledge the socially constructed nature of disability? Especially, I guess, in adding I know, I didn't send this question to you, but especially looking at it from a health equity perspective.

Julia Pappageorge 18:33

I think that's really important because it's shifting this over-emphasis on the individual to removing the blame on individuals with disabilities, to looking at, oh, we live in a world that's like socially designed, built designed, legally designed environments that are not accessible to everyone. And that's a problem. So I guess it's really important to embrace that social model because it shifts the focus from individuals and blaming individuals for their impairments to what's actually the issue is that there are structures and attitudes that are very limiting. I do have one thing to add, which is the importance there for having providers have a better grasp of the social determinants of health and the intersections with health equity and disability so that they can provide better care and so that our our systems can provide better care. Because when there is an explicit acknowledgment of the socially constructed nature of the disability, then we can have more competent, more holistic, patient-centered care.

Matt Wappett 19:50

That's easier said than done. I think.

Julia Pappageorge 19:54

Yes.

Matt Wappett 19:58

Right, doctors are trained to look at an individual, to diagnose what's wrong with them, and then to try to remedy, normalize whatever the case may be, right, through medication, surgery, other interventions. The medical field has a hard time wrapping their head around systems, right, and the systems of care. And I guess this kind of is a rough transition into the next question, but why do you think the medical field struggles so much with understanding these various forces on our lives? And specifically on the lives of people with disabilities? I can go to you Paritosh if you want to tackle that.

Paritosh Joshi 20:48

Yeah, big question.

Matt Wappett 20:50

It is a big question. I know that we don't have time to address it all. But you know, it's an interesting one.

Paritosh Joshi 20:57

I think the biggest roadblock, as simple and complex as it is, is in some way, it's a profit-based motive. Because the medical system makes a lot of money from pathologizing and medicalizing conditions. If you tell people that problems can be solved through medication, through surgery, through some sort of biomedical intervention, then those systems and you know it has been successful, right? We've seen over time conditions get medicalized. A lot of investment in new drugs, new clinical trials, looking at all these different sorts of methods where people might feel compelled to just take whatever a doctor prescribes them or some sort of medical professional tells them to take. And the issue is that again, it's just because it's profitable, doesn't mean it actually centers the needs of people who actually have those experiences. It doesn't actually end up happening where you have people who are in positions of authority who have actually have lived experiences with a type of disability or a disability that may not necessarily fall under what people traditionally view as a disability. Right. I know there's there's many different moving parts that it touched on, but I really do think that a capitalistic model applied towards medicine and just purely enabling a free market approach. And the way the healthcare system is designed, leads to a degree of privilege and protections for people who want to pathologize medicalized conditions. And that's been maintained over time. And it ultimately it comes down to the self interest of people who are hoping to engage in bold activism and change the way we look at disability and think about critically think about, okay, who's actually benefiting. Just because you give someone a surgery or some kind of medicine, that might fix just their sense of maybe whether their condition is getting better, but may not actually result in them feeling empowered, and they may still feel excluded.

Matt Wappett 23:38

Well, you have now touched on something that I am very passionate about. This idea of the capitalist motive in our healthcare system. Which it's in the interest of the system to pathologize and to keep us to a certain extent ill because as long as we have to keep going back and keep remedying, intervening, and whatever's going on in our bodies, right. They can continue to make money. I'm not going to go on that soapbox. I could really go down that road in a very non objective manner. On that note, you know, sorry, go ahead. Paritosh.

Paritosh Joshi 24:27

I just wanted to say it's important because I think a lot of these system level issues and if we weren't thinking about these models of disability, they are whether or not we want to admit it, they are in some cases socio political issues. You can't remove the the political and economic systems of oppression without thinking and you can't remove them and only think about these disability systems. You have to. It's imperative, and it's something that a lot of the field of health equity needs to embrace whether they run away from it or whether they choose to actually dive deeper.

Julia Pappageorge 25:14

Absolutely

Matt Wappett 25:14

Do you want to add anything to that, Julia?

Julia Pappageorge 25:17

Yeah, as Paritosh, as you were talking, I was just thinking more on what you were saying about those political processes, socio political processes. And how like, who gets to define what's the problem? And what very convenient, lucrative solutions is very much like, at the heart of that to. Something I've been thinking about is how siloed I think historically, the medical field has been to and has been structured. I really wonder how much collaboration there is between medical professionals and like scholars in the social sciences. I think there's a lot of room for cross collaboration and knowledge exchange there, especially in disciplines like Disability Studies, Sociology, Anthropology because I think, you know, what this structural issue, there's going to need to be a lot of working with people to better understand the intersectional ways that oppression is working across systems. Yeah, so I think that would be really important for creating more nuanced understandings of disability, and also as a social phenomenon to. So something that I'm, I haven't thought too much about. So there's a little bit raw, but I kind of wanted to talk about it. Paritosh and I met working at Feinberg School of Medicine, which is Northwestern's School of Medicine. And while we weren't involved in the medical school, I'm just kind of curious as like our place of work, you know, I wonder how they are preparing medical students to be in the field. I wonder what kind of systems change they're implementing. And other medical schools are too for, like embracing policies that talk about the social model, or what what's required of the medical curriculum? What kind of cultural competence training is everyone receiving? I mean, we can't rely entirely on those as the guardrails for preparing people but like, they're huge in terms of the role that schools play in the curricular role that schools play in preparing students to have an understanding of the socially constructed nature of disability.

Matt Wappett 27:52

Well, I think, you know, I can't remember which of you mentioned the siloed nature of our systems earlier. But I do you think that the siloed natures of higher ed lead to some of this fragmentation. I think about a past institution where I worked where they had a medical sociologist and a medical historian, but they were in the Sociology Department and the History Department. They weren't housed in the medical school where they would have regularly interacted with the medical students in the medical faculty. So, you know, although that work happens, I think you're right, those intersections and those opportunities to look at how these systems interface are oftentimes limited by the way we've set up our schools and our education systems and everything else.

Paritosh Joshi 28:42

If I might add to that. I think it's also not just the way that they're set up and the change that needs to occur. It's a matter of a passive versus active work that's being done right. I think that you see a lot of universities and workplaces to engage in this sense of virtue signaling where they say that they put out statements. They say they had these offices. They say they're going to put forward these accommodations, but in reality, you know, are they having first of all, do you have people working in the office who either have had a lived experience with a disability or are acutely aware of exactly these barriers that need to be dismantled? I don't know. I have questions about that. I have serious reservations about what steps some universities are taking in order to make sure they revamped the higher education system because that would require, again, coming to terms with their shortcomings. It requires looking at how they can make sure that they actively involve people who have lived

experiences and acute awareness of exactly how and who needs to be brought in. Sometimes it can be very tricky for universities, especially to acknowledge that, hey, we really messed up, rather than just put forward to saving and just just do some cleanup. And that's where it's going to be a long fight to.

Matt Wappett 30:21

For sure, well, I want to shift the direction here a little bit and go back to something that I was thinking about when you were talking earlier. You know, the point of the medical field is right to remedy, to fix a particular condition. Let's take something like blood pressure, right. I can go in and have high blood pressure. They can give me a medication that will lower my blood pressure and all of a sudden I'm okay again. I know I didn't send this to you ahead of time so I'm happy to give you time to think about, but what are the psychological implications for a person with a disability when they go in and it can't be changed or addressed by a medication or by an intervention? I think a great example would be down syndrome, right? No matter what a medical doctor does they're not going to get rid of that extra chromosome, right? That's always there. So I mean, as a people with disabilities, especially lifelong, long-term disabling conditions. What are the psychological implications for you know, your interface with that medical system? And recognizing oh, and even for doctors to tell you, Oh, you can't be fixed? I mean, and so I know anyway, that's not a well worded question, but I am interested in your thoughts on that.

Julia Pappageorge 31:52

I imagine it would really depend on the person receiving that information and depending on, you know, a myriad of factors. Do you mind rephrasing the question in a way that's is more focused on the system in that way? Or like the medical or? Yeah, a rephrasing would be helpful.

Matt Wappett 32:17

I'm really more interested in the impact of these systems and this is kind of, anyway, I know, this is coming out of left field, but it is an idea that I'm interested in. Again, the intent of the medical system is to fix, to remedy, to rehabilitate. And a lot of disabilities can't be fixed, remedied, or rehabilitated. They are lifelong conditions. So I'm really just kind of interested in your thoughts on the psychological impact to a person with a disability when in their interactions with the medical system when they recognize or are told explicitly, oh, we can't do anything for you. We can't address this. We can't normalize you. I mean, and especially from a health equity perspective, I think this is really the root of a lot of issues that people with disabilities face because I think that the medical system doesn't know what to do with people who can't be cured for lack of a better term. So kind of answering my own question there I guess. But I am curious in your thoughts on that, if that makes sense. Sorry. This is why I write questions out ahead of time so that you don't end up listening to me verbally process.

Paritosh Joshi 33:48

I could take a crack at it. I think that what you described is essentially people saying, well, it's your fault you have down syndrome. It would come across to that person and to any person who is interacting with the system that has, by default, used the medical model, right? Because essentially, you are saying that well, we could try and make you normal, but I don't know if you're ever going to fit into society. And so it's putting the burden on the individual who is currently experiencing that condition. And what it does is it could lead to this sense of restriction that while there's only so much I can do,

there's only so much I can really partake in because I'm never going to be as good as maybe the average person. It can lead to this inferiority complex because you're not addressing first of all, you're not addressing the fact that there may be limitations to ultimately how people view them and their abilities, rather than viewing them as having a kind of a different ability and different strengths, you're viewing them as having no strengths at all. And well, you're not close to what the average person is so you know, you're just not going to be capable of fitting in. Which again is very debilitating. But also, you're not addressing the individual. And you're also not addressing the systemic level problems, which is the fact that they're going to experience a lot of bullying. They're going to experience possibly job discrimination because someone thinks and has these limiting beliefs. And that's where I think it would lead to a cascading set of negative outcomes.

Matt Wappett 35:53

I think you said something that really resonated with me, which is it places the burden for change on the individual. And when the individual can't change, right, like you said, leads to a sense of inferiority, powerlessness, victimhood, depending upon that individual. And as we know, and as you pointed out, I think so astutely in your article, a lot of these things are not based in the individual. Many of these factors are based in the systems that individuals happen to live, learn, and work within. And that's where I think your article is so important is that it's arguing, right, we shift the focus of intervention, not from the individual, but to the systems, right. Because in many cases, individuals can't be changed. So one of the things we like to do with this podcast is kind of dig in behind the process of writing these. Because a lot of times, again, academic articles can be dry and boring. And you don't recognize that the people who write them are people to and they have lives, and there's experiences and lived experience that brings them to these topics and everything else. So one of the questions I like to ask in all of these podcasts is just if you would share with us a memorable story or event that led you to this project, or that occurred while you were working on this project. And we can start with you Julia on that one. I want both of you to answer that question though.

Julia Pappageorge 37:44

Yes. Well Paritosh and I did talk a little bit about this. There were many moments that stick out to me as like, memorable as we wrote this. For me also, just from the standpoint of this is my first published paper. I'm an early career scholar. I'm figuring out what this is like from the inside. So I think in that way, it was novel, and fun dare I say in some ways, of course. But there was a moment when we were getting feedback in the revisions process and our reviewer wrote a note along the lines of wow, this is like, this very activist approach. And I remember we were talking about these comments afterwards together. And we're smiling because we were like, yes, this is the direction we really want it to go. That's why we're calling it a call to action. We're really trying to embed within our paper this idea that yeah we each have a role to play also in changing the systems, but also in our personal lives, whether it be in the communities we're part of, if you're at school, or even, you know, with friends and loved ones, family members as well. So that was something I think we both felt like resonant. We're like, yes, it feels nice that that's being recognized, because that's at the heart of our paper and it's also at the heart of something Paritosh mentioned at the beginning, but like developing practitioner activist praxis, like that's something that's very important to both you and I. You know, how are we using our skills in service of creating a world that's more accessible?

Matt Wappett 39:46

Yeah. I love that concept of praxis. Your good education researcher. I can tell. You bring praxis in. I think praxis used a lot in education, but not as much in other fields, and yet I think it's a very important concept.

Julia Pappageorge 40:02

And praxis I don't even know what praxis is. Even as an education student, I was like, what does this mean? I like to think it's like, practice. How are you practicing being a practitioner? In what ways are you going back and forth between? You know, at the end of the day, we generated a paper which is knowledge that can be shared. It's one piece amongst hundreds of 1000s of papers and podcasts and YouTube videos and stories from friends. So it's like, just kind of going back and forth between reflecting on what I'm doing, and how my work can improve systems. But thank you.

Matt Wappett 40:51

Absolutely. Paritosh, what about you?

Paritosh Joshi 40:55

I really would have to echo that story as well, because that's something that we discussed. But I think the other component of it is that I think the comment, if I recall correctly, was written in a way that was negative or critical. The person said this paper is very accurate. It came across as if we were doing something incorrectly. So what I'll add to that is, and I know, we've been talking about these ideas in our conversation today, but these are very novel approaches to combining scholarship with activism. A lot of people aren't doing that. And the reason why is because first of all, it can be uncomfortable for practitioners, scholars, and researchers to confront their own biases and want to think about how just a purely theoretical approach or purely research approach can be linked to broader reform. It can be difficult to think about, okay, you can write about problems. You can talk about these issues. How do you implement them? That's the gap that I've often seen within health research. And that's what we're really hoping to tackle because you have to take an activist approach. If you want to be someone who wants to advocate and really move the ball forward for people who have disabilities, or people who are marginalized of any identity, you need to take an activist approach and you need to think about how you can move your field in a more progressive direction And really center the experiences of people not who are making profit and the people who are in positions of power, but people who can who really could use the resources and people who obviously have the knowledge of what it's like to be someone who has a disability, or someone who has been negatively impacted by the healthcare system. So that's what I would definitely add. And the other component I would add to is that, the mindset shift starts at the top, right. We got this comment, we got this feedback. Now it's our job to make sure that we get into these positions where we're editors or where, you know, having conversations with editors of journals, or other people who are in these positions where they can really make sure that comments like these are not viewed through a critical lens, but through a perspective that is praised. And that we encourage more and more researchers to question. Okay, that's great. You wrote a paper you did a study? What are you going to do more? What are you going to actually utilize to have both policy reform take place?

Matt Wappett 40:55

Yeah. Well, I think you you bring up one of the challenges that we struggle with in the journal is there's this tradition, within academic research, right? That research is somehow going to be objective and the individuals removed from it, and we're trying to present things as unbiased way as possible. And yet, you know, the more and more we understand about society and ourselves and just the psychology of being the more we recognize that there is no such thing as some objectivity out there. Some concept of objectivity. Everything is viewed through our personal lenses and through the systems that we live within. And so yeah, that subjectivity is impossible to remove from any writing and you're exactly right, that subjectivity is what I think gives power and weight to a lot of the research, especially when people are speaking from a position of lived experience. Especially if you're from a marginalized population, right, or a population that is oppressed in some way, shape or form. Often times the only power that you have is that subjective voice and the voice of your experience and I think that's so important that you bring that up. That's something that we really try to strive for. Although reviewers don't always like the activist approach. I am very well known for saying I like it. So I liked publishing this article. I think it's super important. And I do just want to go back to something you said, Julia. We are really excited that this was your first publication. That's one of the goals that we have is to support emerging scholars. We know that it's hard to get into journals and to play that game. I had no idea actually when we got your article that this would be your first, but we're excited that we were able to do that. And to give you that experience. So yeah, thank you so much for submitting it.

Julia Pappageorge 46:24

Thank you. And for anyone listening, please consider DDNJ. They are trying to get published and share your work.

Matt Wappett 46:33

We keep trying. So let's go back to this call to action. Your article, it says right in the title right a call to action. What are some concrete actions that our readers and listeners can take to address some of the issues that you raised in the article?

Julia Pappageorge 46:51

So we really want people to apply the social model of disability because that will help us combat ableism. It will help us make more inclusive environments. Some concrete actionable steps that readers and listeners can take is first, just shifting the focus internally about instead of, you know, how we conceive of disability, like that's a that's a big shift for for many, like, between problematizing disability as an individual's problem versus it's the consequence of a social, environmental and attitudinal. Those barriers and hurdles that restrict people from fully participating in and being included. So if we can focus more on removing barriers I think that's a big actionable shift. Another thing, there's like three things I'm thinking of. A second important action step is educating ourselves about the diversity and complexity of disability experiences. We've talked throughout this conversation about, like how our different identities intersectional identities, marginalize people in different ways. And I think that's important to consider when we're becoming more aware of the pretty complex ways that ableism interacts with other things, racism, class privilege, things like that. And so I think that can be helpful for helping us better understand and dismantle our unconscious bias, which is like lifelong work, I think And as well as the biases of those of others. The last thing that I'm thinking of is how we foster solidarity and participate in initiatives, whether it be for inclusive education, or ensuring equal employment, advancing disability

rights and protections. I think that within all the institutions that we interact with, whether it's our schools or our places of work, there is likely already actions and movements within that organization to improve it. Make it more accessible. It's like, be a part of those. I feel like there's a lot of different ways. Those are some of the some of the calls that I was thinking of. I'd be curious to hear what you think Paritosh?

Paritosh Joshi 49:25

Yeah, absolutely. I totally wanted to say I concur with everything you just said. What I would also say to is that in order to engage in a systems wide approach, you need to take a long-term view in the future. And look at how these systems can be changed, but it also has to be informed by the past. And that requires a review of how far the field has come and how that informs how far the field has to go. Right. So you start off with the religious model disability which basically says God made you and you're disabled for a reason and it's all your fault. To the medical model, which says it's your fault, but hey, we can make you a normal person; we can make you better and as good as possible. To a social model, which removes the blame from that person and removes fault, and says, okay, it's not your fault, it's the system's fault for not adapting, and making sure that your needs are met, and that you're encouraged to be your full self. So that's number one. The other component of that, too, is making sure as Julia stated, and I'll reiterate, is combining different models, right. So, one of the articles that we referenced in the paper, under our implication section, looks at the black feminist model disability framework, right? And so it takes that intersectional approach, which is very important, and is essential to think about how different models nicely complement each other. Right? The medical model can complement the social model. It's just a matter of making sure you don't go all in on each because it's important to look at yes, there is a component of thinking about how certain medications and treatments can help. But it's also important to think about how systems can better serve people. And the other thing I would also like to touch on is it ultimately starts within our academic institutions. So that's where we challenge these ideas of what is a disability? Who created that definition? Well, ableism is something first of all that needs to be dismantled. But how is ableism? First of all, defined and what are examples of it because you cannot dismantle something, and you cannot eradicate institutional oppression without exactly knowing what it is. And that's where I think you start to shift culture. That's where you start to shift how, especially young professionals and people who are in higher education, can really make sure that academic spaces are delineated and made in a way that are not limiting. And where pedagogy and research and activism flourishes in a way where you have individuals with disabilities making decisions in academia and beyond and writing papers and talking about, you know, different approaches to researches as you have referenced Dr. Wappett.

Matt Wappett 53:03

Yeah, no, and I appreciate both of your focus on, on the systems that we live with. And I like Julia your notion of getting involved. I think it's very easy to say, oh, this is a systemic issue, I have no control here, therefore, I don't need to be involved in right, these changes. And yet, things don't change unless people get involved. And then Paritosh I love your idea when thinking about the systems that we live with, and how they're reflected through somebody's life. You know, I think about Michelle Foucault who said, right, schools are the ultimate, sort of, I'm going to totally butcher this quote, right, but something about how schools are, right, the first sorters of humanity, right, and you go to school, and all of a sudden, you're diagnosed, classified, sorted. You're in special ed, you're in regular ed, you're in gifted, whatever the case may be. And those labels follow you through your whole life on the basis of how

somebody judged you when you were in kindergarten or first grade, and it limits opportunities or opens up opportunities, depending upon how you were categorized and sorted as a child. And so I do agree these systems have lifelong implications for the opportunities that people are given. And they can seem so powerful and overwhelming, and yet, we don't somehow acknowledge this power and get involved with trying to shift it. We're kind of doomed to repeat the past I think as you mentioned. So, couple of last questions here. And these are more personal, again, to understand you as individual researchers, and I'm going to call both of you activists because of the work that you're doing. What motivates you to do this work? Why do you do what you do? And I'm going to start with you Paritosh and then we will go to you Julia.

Paritosh Joshi 55:07

Yeah, that's a really great question. I think it, it gets to the heart of exactly why this paper was produced and why it you know, the both of us were able to make sure it came into fruition. I would say what would motivates me is, first of all, I'm going to be a clinical psychologist, I hope to be a practicing mental health professional, as well as a clinical psychological researcher. And I think for the longest time, I've been told, especially just as I've gotten deeper into this field, and I've done research in health equity before, is that well, you're you're going to do research, and you're going to practice. And that's a binary option you have and maybe you could teach, but even then teaching isn't considered as much of a priority and a lot higher institutions, right. It's like, can you bring in grants, can you bring in funding? Can you make sure that you get papers published so that way your department and you, as a researcher, and scholar, maybe look good, right. Those are more or less the things that are stressed, right, at higher education and I, obviously, really want to modify that perspective and think about how research can inform policy. And I think that it's it's important to be intentional about the work that you do, and to be active and think about how you can move your discipline forward and how we can advance health research in a way, again, that is not just robotic in nature, where you have to be objective, just because everybody says you have to be objective. You have to think about how we're neutral, and maybe the way we do research and the way we write papers and just being matter of fact, but rather, we have to think about how we are going to be truthful and honest about where we need to improve. Because without humility, and without actually being honest about what needs to be modified and changed. We can't have a reckoning and we can't really alter systems of oppression, we just can't do that. And that's what drives me. Because if we want to create a just an equal society, then we need to go beyond what is expected of our roles and move the needle in terms of what we as researchers and scholars can do.

Matt Wappett 57:52

Absolutely. Couldn't agree more. Julia, what about you, what motivates you to do the work that you do?

Julia Pappageorge 57:59

As Paritosh put it with around expectations of of our roles? It's like, there's so much there. It's really making me think in this moment. I think, for me it makes me wonder what those expectations are as an educator or as a researcher. Something that you've spoken so, so well to Paritosh. Then kind of looking beyond those expectations to improve the fields that we're in. I think, for me, I'm really motivated by loving people and caring about people with disabilities. I think that's if I tried to think, really at the core of it with what that's about, I think that's my biggest motivator. And so then I want to in my work use my skills, whether it be an advocacy or communication, and really think about how I'm using

those skills to amplify problems and solutions as defined by the people who experience them the most acutely. But as I was thinking more about this question, I get a lot of motivation and inspiration from studying justice movements. Whether that be the disability justice movement, or independent living movements. Those are really inspirational for me. Something we touched a little bit on in our paper to is the disability justice movement. And I'm very curious about how not only how justice movements shape culture, but especially how different movements, how interrelated they are. There like very much models for ways of living to where it's like, I think about like the Black Panther Party and how they offered a lot of support and courageous leadership in partnership with disability justice activists in the United States. So I guess what I'm saying is I am motivated by how we can create collective power through diverse coalition's through continuously learning and processing and back to that idea of praxis, like, it's like a long trajectory. And I think I'm motivated to be a part of struggles for dignity for people because we are interrelated.

Matt Wappett 1:00:40

Absolutely. Absolutely. Well, I appreciate your candid answer. I think there's a there's a genuine recence on the part of researchers in the higher ed folks to say that they're motivated by love and compassion. And yet, I appreciate that you said that, because I do think at the heart of any of the human services, right. This recognition that we're interdependent, and that we need other people. And that caring for other people is also a way of caring for ourselves, because it comes back to us. I appreciate the courage that it takes to say that because I don't think you hear that enough. And yet, I think it's an important part of all the work that we do in the human services.

Paritosh Joshi 1:01:37

If I could add one thing on that point is that you have to be interestingly motivated to do this work, because it's not easy to go against what people typically encourage you to do, which is again, just, you know, stick to engaging in objective research, go to conferences, maybe look at, you know, building upon an existing line of work, but rather showing emotion and showing that passion and saying, hey, listen, we really deeply care about helping people who have a marginalized identity. And because this is something that is at the core of our foundation, and it's a core value. And I just wanted to say I appreciate you inviting the both of us on to talk about this, because that's exactly what we need to be doing more of and that's the another direction in which the field of research needs to move.

Matt Wappett 1:02:44

Absolutely. I couldn't agree more. So the one question that we asked in all of our interviews, because again, the focus is to make this research more accessible. People who do this work are always trying to make things more inclusive and accessible, at least that's a common pattern. So what's one thing you've been doing in your personal or professional life, to make your work more inclusive and accessible, and I'll start with you Julia this time.

Julia Pappageorge 1:03:12

So one thing that I'm doing or that I tried to keep in mind. I give a lot of presentations for work oftentimes via Zoom, you know, 30 plus people. So something I learned about in school is called universal design learning, UDL. So when I am creating curricular materials or learning materials, presentations, I really tried to consider using UDL principles, so UDL means providing multiple means

of engagement with the presentation, and not over relying on one kind of display information. So it would be creating products or resources that are usable to the greatest extent possible by everyone without too much specialization. So, for me, I really think about, you know, is there multiple means of engagement? Like, is there audio material? Is there visual materials that are tactile things if possible, and not over relying on on one form. But, of course, like, if it's via zoom, like, you can't have the tactile necessarily, but you could, you could ask people to like, you know, bring an object in or something. It could make it more interactive. That's one thing that I think about in my own work.

Matt Wappett 1:04:44

Yeah, absolutely. I couldn't agree more UDL is super important and all that we do, and I don't think enough people recognize that. So Paritosh What about you? What's one thing you've been doing to make your work more inclusive and accessible?

Paritosh Joshi 1:05:01

Yeah, I think this is definitely an important topic to think about right? Walking the talk is essential. So I obviously am someone who is a mental health researcher. I am pretty involved within the life of academia at this point. But what I really like to do is think about publishing and magazines. And I think what that means is, magazines, it could be podcasts. I try to, or even just mainstream news media articles. That's what I really strive to do. And the reason why I think that's important is because, like I said, most people don't have the time to read in an academic article. But what they do oftentimes do is look at, let's say, The New York Times, Wall Street Journal or other local community based forums. They also might be more likely to just listen to something that is audio, such as a podcast, and also talk about the work that I do with in my own social circle. That route means starting conversations that might be uncomfortable, but that are necessary and that needs to take place among the people around you. And that may not be directly just tied to work. It's, again, thinking about implementation. Because it's one thing to think about the work that you're doing, it's another thing to think about, okay, how are you really incorporating these concepts into your daily life and making sure that we can create a more just society. And that requires making sure you surround yourself with the people who want these types of changes to take place, but also making sure that you can probe and make sure that we sharpen each other's lines of critical thinking and help each other eradicate our biases. So those are the two main ways in which I really strive to make my work accessible.

Matt Wappett 1:07:19

I think that's super important. And something that nobody's actually brought up is this notion of using the mass media as a way to make work more inclusive and accessible. You know, the interesting thing with the mass media is an academic articles not going to show up in news aggregators, and things like that. And yet a lot of people get their news through these automated feeds that only draw from mass media. And so to get some of these big ideas out there, I think you absolutely do need to work with the popular press and I think there's a bias in academia, certainly towards peer reviewed write academic journals. And yet, there's a very, very limited audience. So okay, here at the end, any last thoughts or ideas that you want to share that you haven't had a chance to express yet?

Julia Pappageorge 1:08:26

I just have a one thing to add on to like, thinking about making our work more inclusive and accessible. Yeah, is what like practice that I try to do is when I'm in the world, you know, especially at museums, which are one of my favorite places to go. Like, I try to learn from the environments that I'm in. I'm like, I try to see like, essentially, like, we can get practice on reflecting about the spaces that we're into and when we're there, and so, yeah, I'm a little frazzled. But I think that was something I was thinking of.

Matt Wappett 1:09:09

Yeah, no, I appreciate that. You Paritosh, any last thoughts?

Paritosh Joshi 1:09:14

Well, first off, I would say that people want to engage in this work, there are going to be times where it can be tiring. It can feel as if you're pushing up against the brick wall, but that's where you know, you will grow the most because you learn about how attitudes and beliefs in our society have become hardened over time and have become more concrete, and what exactly needs to be done to change them. The more challenges and the more work you have to do in order to take an activist approach to the work that you do, the stronger the more resilience and the more polished your work will become within the future. And ultimately, that's what results in you being able to move the field in a different direction. And for you to be able to get your work more well known and noticed by mainstream outlets, or to have people especially who are practitioners who might think what you're doing is novel, to be able to want to add that to their work.

Matt Wappett 1:10:34

Yeah. Well, I want to thank both of you for taking the time today, I've really enjoyed this conversation and have learned a lot from from your perspectives. It's heartening to me to know that there are emerging scholars who are continuing the strong tradition of trying to change the systems that we live, learn and work in. Because it's so important, and I think like, I believe you said a little bit earlier Paritosh, we have to take the long view, right, it takes time, it can take multiple generations to make these changes. And so I've just really, really enjoyed visiting with you. So thank you both for your time today and for your contributions and for the work that you're doing.

Julia Pappageorge 1:11:27

Like wise. Yes. Thank you so much grateful we could be here together.

Matt Wappett 1:11:34

Yeah, absolutely. So that's it for our conversation. today. I'd like to thank Julia and Paritosh for their time, and for their candor, and just for engaging and what I felt was a really interesting conversation. As always, we want to thank everybody who helps support the podcast and helps make this possible. We want to thank DDNJ, managing editor and insight author, Insight Podcast Producer, Alex Schiwal for her hard work to get this podcast out. Alex has been doing this from the very beginning. In fact, the name of the podcast came from Alex and we're really just excited to have her on board and are very grateful for her skills, and making the journal and the podcast happen. We'd also like to thank the Utah State University Institute for Disability Research Policy and Practice, Utah's UCEDD, for their financial and in-kind support for this podcast in the journal. We also get support from the Utah State University Libraries and Digital Commons and we're very grateful for their ongoing efforts to support our work. So

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