

Ep. 17 Hannah Sahana and Shelly final AS

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Developmental Disabilities Network Journal, health equity, barriers to healthcare, medical education curriculum, disability education, interdisciplinary healthcare, implicit bias, social determinants of health, patient-centered care, inclusive care, medical students, self-advocates, healthcare access, public health.

SPEAKERS

Hannah Ship, Matthew Wappett, Shelly Baer, Sahana Shankar

Matthew Wappett 00:15

Hi there, everybody. Welcome to the Developmental Disabilities Network Journal Author, Insights Podcast. I'm Dr Matthew Wappett, the DDNJ editor in chief and executive director of the Utah State University Institute for Disability Research, Policy & Practice. And as always, it's my privilege to host this podcast this I've mentioned this, and I mentioned this almost every time this podcast. I love to do this podcast because I get to meet with really cool people and learn. And I love to learn. It's one of the advantages of having ADHD, is I'm always my mind is always looking for new, interesting things. And, you know, this podcast is really just a great, a great support for my ADHD, because it allows me to kind of learn all sorts of things from these incredible researchers who are working today

Matthew Wappett 01:07

so, and it's just amazing to see that the folks we have on, I mean, they are incredible people, and many of them are literally changing the world in their own quiet way. And our hope is that we can promote some of those efforts through this platform. So anyway, this podcast, again, is part of our ongoing commitment to increase the accessibility of the Developmental Disabilities Network Journal for a wider readership. We're trying to provide this information in multiple formats, and this audio format, again, will allow you to understand what's in the articles in the journal, but it also helps you get to understand some of the researchers behind the work, behind the articles.

Matthew Wappett 01:48

articles tend to be pretty one dimensional, and you don't get to know the people behind it. And it's really interesting sometimes to understand why people are doing this work and what drives them and what motivates them to do some of this work that's incredibly difficult. And in spite of tremendous odds, right, there's something that drives people in this field forward, and this podcast gives us a chance to dig into some of that. So, it's a chance again, to understand the content better, but then to also understand the people behind the content. So today we're excited because it's our second in a series here of podcasts about health equity and particularly barriers to equitable health care for individuals with disabilities. Last month was one on a needs assessment in the state of Connecticut around barriers to healthcare for

individuals with disabilities. And today we're going to be talking about a medical education curriculum that was piloted in Florida through the Florida UCEDD and LEND program,

Matthew Wappett 02:57

and that's intended to help doctors gain the knowledge and experience that they need in order to be more effective when serving individuals with disabilities and families of children with disabilities. So, before we get into it, just a quick reminder, please subscribe to our podcast feed. Wherever you get your podcasts. Please leave us a rating and review. Please share the podcast on social media. If you use social media, please share it via email. Do whatever you can, because your efforts to share this information helps more people learn about this important work. They make a difference, and it really helps get the word out about some of these really cool things that we are talking about. So, today,

Matthew Wappett 03:56

I couldn't handle the blood and guts, and so I went for the PhD, which supposedly stands for phony doctor, but we have actual medical doctors here today. We have Dr. Hannah Ship, who is an internal medicine resident at UCLA. She has a dual degree; an MD and a master's in public health from the University of Miami Miller School of Medicine. She's passionate about health equity and advocates for the deaf and hard of hearing communities and helped design a medical curriculum on language disability and healthcare access, and we'll talk about that today, and she's been recognized as an emerging leader by AUCD. Dr. Ship, as you'll hear in our conversation, is really working to advance health equity and language, justice and healthcare with disability culture at the forefront. We're also joined by Dr. Sahana Shankar, who is a second-year medicine pediatrics resident at UCLA. She has a strong commitment to serving patients with intellectual and developmental disabilities, and as you'll see is

Matthew Wappett 05:00

Personal for Sahana. She completed her undergraduate and medical school studies at the University of Miami and is dedicated to pursuing a clinical career focused on providing primary care to individuals with IDD across the lifespan. So, beyond her clinical practice, Dr. Shankar is passionate about educating medical professionals on how to deliver optimal care for this patient population, and her advocacy and leadership in this area were recognized by the by AUCD, which also honored her as an emerging leader. So, we're excited to have Hannah and Sahana on here today. We are also joined by Shelley Baer, who I know that many of you know. Shelly has been involved in the AUCD network for many, many years. Shelly is a licensed clinical social worker who works at the University of Miami School of Medicine-Mailman Center for Child Development, and as the director of leadership training initiatives, I had the wonderful privilege of attending the AUCD Leadership Institute with Shelly way back in 2014

Matthew Wappett 06:07

and she just does remarkable work. She has a remarkable history and story, and I think that will come through in our conversations today. Shelly currently coordinates the center's pipeline leadership program, so the Emerging Transformational Leadership Program (ETLP), Project Self- Advocate Leadership Training (SALT) and Student Emerging Leaders Program, all of those separate leadership training programs. She also assists in managing aspects of LEND and shares her story with the LEND

trainees and medical students, and she was integral in helping to develop and lead the curriculum that we'll be talking about today. Shelly was diagnosed with juvenile rheumatoid arthritis at age three, but it has never slowed her down. As any of you who know her are well aware, she pushes the boundaries and doesn't let her disability hold her back. So anyway, we are excited to have Hannah, Sahana and Shelly on the podcast today, and we're excited to jump into this conversation.

Matthew Wappett 07:11

Thanks for joining us today, Sahana, Hannah and Shelly, we're excited to talk to you about this article. Disability Education in medical schools, a paradigm shift for inclusive care. So, before we really get into things, we like to kind of get to know our authors a little bit. So, could you tell us a little bit about each of your backgrounds and the path that brought you to this particular article? So why don't we start with you, Sahana.

Sahana Shankar 07:40

Hello, everyone. I'm Sahana. I'm right now a resident at UCLA training in medicine pediatrics, with the goal to care for people with intellectual and developmental disabilities across the lifespan. This is very personal for me. I have a younger sister with a rare genetic syndrome. So, I started out by volunteering in her school and fell in love with this community. I took a lot of time reflecting and decided that medicine was the best way for me to spend my life working with this community. And so that continues to drive me today, and my goals include both practicing primary care for patients with intellectual and developmental disabilities across the lifespan, as well as providing medical education to trainees at different levels.

Matthew Wappett 08:35

Perfect. Thank you, Hannah. What about you

Hannah Ship 08:39

Sure? So, I'm Hannah. I Right now in an internal medicine resident physician at UCLA as well, and I have my MD MPH from the University of Miami. I really started out in this field learning American Sign Language to better support a friend who became deaf, and then really, you know, began to fall in love with the language and met so many people who are deaf and hard of hearing from different communities around California, and started to notice the same struggles that we that people were having in achieving health care and so on my path to become a physician and to help people and better support public health. This was a theme that I kept seeing, and a group that I felt like wasn't getting enough support in achieving health care. So, you know, I met Sahana at the University of Miami, and the rest was, was history. We joined a big group, and since then, have really been focused on disability clinical communication and healthcare access in order to better our communities.

Matthew Wappett 09:48

And Shelly, of course, isn't going to be a stranger to a lot of the folks who listen to this, but Shelly, tell us a little bit about your background and the path that brought you here.

Shelly Baer 09:57

Hi everybody. I'm Shelly. And thanks for having us and I, I'm the Director of Leadership Training Initiatives over at the Mailman Center for Child Development, which is a LEND and a UCEDD, and Sahana and Hannah were our LEND trainees back in the day when they, you know, were in their medical school training. And I run our Pipeline Leadership Programs, and I work in our LEND curriculum, and I'm also involved in assisting and educating medical students about disability. And I have a disability myself. I have a visible physical disability, so I use a scooter to get around. I'm an ambulatory wheelchair walker, wheelchair user. I do walk, but I sometimes roll for long distances. And when I met, we were already teaching medical students at the University of Miami School of Medicine. It wasn't quite embedded yet. They had a redesign of the curriculum called the Next Gen Medical School Education. So, I met Sahana and Hannah, and they wanted to assist in creating, you know what the article was, is about creating that new curriculum for medical students, and now, glad to say, it's embedded in the medical school education at University of Miami. So that's kind of a little bit about me and how I am drawn to this work.

Matthew Wappett 11:28

Yeah, no, that's awesome, and it's great to have two former LEND trainees on it's pretty rare that we that we get that, but we're excited to have this conversation. So, Hannah, you, I believe, were listed as the first author on this. So, I'm going to ask you to give us a quick summary of the article in just a couple of minutes, for those who maybe haven't read it yet.

Hannah Ship 11:50

Sure. So, the article really summarizes the creation of our four-year disability education curriculum and its aims to improve patient care for people with disabilities. The curriculum is pretty comprehensive, so it has three mandatory sessions on topics like interdisciplinary healthcare teams, implicit bias, health disparities, disability culture, shared decision making, communication. And I could go on, but we like to have these three sessions as the main part of the curriculum, but we also include a lot of opportunities for students to get further involved, including elective courses and kind of connecting them back to lend or extracurricular activities to give students this like well rounded, reality-based experience with people with disabilities. And I would say the big focus of our curriculum is this lived experience of people with disabilities. We not only had people with disabilities on our team, but our interdisciplinary team kind of brought this diverse range of perspectives and expertise to kind of better align with students medical training and help introduce these topics to medical students when they would be most open to it. So, as I mentioned before, we formed strong community partnerships that really brought these real-world insights into the curriculum, making it authentic impactful. And yeah, I'd like to say that we've been pretty successful so far and are really excited about the idea of increasing and improving medical education that's centered on disability.

Matthew Wappett 13:26

Yeah, well, and that, I think, goes to the next question here. I think a lot of people might be surprised to learn that there's not a lot of disability education that happens in medical school. And I know that some of the folks I've talked to right they say, well, doctors are diagnosing disability, so, they must know something about it. But that's not actually the case. Is it?

Hannah Ship 13:53

No, you're correct. Historically, medical training has been focused more on the biological aspects of disease rather than the broader social and environmental factors that impact health. And I'd say the field of medical education is just now realizing the importance of recognizing the impacts of social determinants of health and health disparities as they affect patient outcomes and just generally, people's health and so, people with disabilities are often an unrecognized population with health disparities and often experience these disadvantages, compounded with other social determinants of health, like language, race, socioeconomic challenges and limited access to resources.

Matthew Wappett 14:36

So, tell us a little bit more about you've kind of brought up these social determinants of health. But why? Why is it important for the medical field to more explicitly pay attention to these social determinants and disability issues specifically? and I don't know Sahana or Shelly, if you want to jump in on that one.

Sahana Shankar 14:55

As far as social determinants of health, as we a lot. Of healthcare outcomes are determined more on social determinants of health, rather than the maybe 15-minute clinical encounter that a physician has with the patient. So it's extremely important for us to focus our education and our care for patients around these other aspects of their life that may not be their exact blood pressure reading, rather, their blood pressure reading is a reflection of everything else in their life, their access, their access to food, their financial ability to afford blood pressure medication, to come to the doctor, transportation in getting there, their disability status if the healthcare facility that they are trying to arrive to is accessible and is working and is willing to provide that patient with accommodation. So, I think it's absolutely critical for our medical education to be focused on these social determinants of health, and I am happy to say that medical education is definitely moving that way. As far as disability. Specifically, I think it's important for us to realize that one in four adults in the United States have some kind of disability. So, it is absolutely relevant to every single healthcare provider for them to be well educated and well trained on how to best care for people with disabilities. Lack of comfort with patients with disabilities results in a lot of the health disparities that we see. So, that's another driver, I think, that we've all experienced clinical encounters where there's clear physician discomfort with a patient with a disability, and we see how that manifests in less-than-optimal care being delivered.

Shelly Baer 17:03

Yeah, just to build on what you were saying, Sahana, I totally agree, and I do think, obviously it's personal for me, because I have a disability. But disability is the largest minority people with disabilities, I'm sure you all know. And I think a couple years ago, the CDC classified people with disabilities as a recognized minority group as they weren't classified as that group before, which can help with funding issues. But I think it is kind of surprising that it's not more fully integrated into medical school, I somehow had, I'm curious, like, do you, did you get any training at all? Because I think, like pediatricians, like, if you're maybe when you specialize, you would get more training. But in medical school, it's so much information that you need to cover. And I remember when I first started doing it, it was once a year, and we would speak to the medical students once a year, I think in first year of their training. So, it is we've noticed that it is changing and it's improving, because I think you're both saying that it's going to impact your career. Whatever you specialize in, you're going to encounter somebody with a disability, whatever specialty you go into,

Sahana Shankar 18:36

exactly, Shelly, I think that there's no doubt that we don't spend enough time, enough time on disability. And I think that at the University of Miami, we were very fortunate to have disability champions such as yourself and our lead faculty mentor, Dr. Brosco. So, we were very fortunate that we kind of had the catalyst and the institutional value for disability education that we were able to build these three sessions as a part of the mandatory curriculum. But I think our goal with this paper is to kind of share the many different places that disability education can be held in a medical school setting, from mandatory, clinical, mandatory curriculum to elective opportunities and kind of like that whole spectrum, depending on the resources an institution has to offer. So, that I think that I hope that with this article, we share multiple different avenues and also the value of being creative. So, we, for example, we took valid consent, informed consent, and we took that session and we took a case of someone with a disability and use that as the case that we learned from. So there, there can be creative ways for us to include a disability into the jam packed required medical curriculum.

Matthew Wappett 20:14

So, it sounds like at the University of Miami, Miami, there's a few champions, right, who've been pushing to get this integrated in the curriculum, but it makes me wonder, what happens at a medical school where you don't have those champions? Why is it that you think that maybe the medical field still hasn't fully integrated disability related education into the curriculum?

Hannah Ship 20:40

I'm going to take something that Sahana and I had talked about previously, but it really seems like medical education to this point has been focused on these standardized exams and learners prioritizing material, regurgitating it, circling the answer C and kind of moving forward, but there was not a lot of structural accountability that medical schools were included were forced to include on these subjects of minorities and social determinants of health, and how these things can affect our patients outcomes and well-being and so without this accountability, You will just find that it's led by these, these champions of disability or diversity. It seems like now most medical schools are having a shift where they're moving less. They're moving away from just overt memorization and more towards of application of ideas and also including the framework to train medical students to better, to have better cultural humility and communication styles, to better address the needs of most patients, especially those that are diverse and have diverse wishes, wants and needs.

Matthew Wappett 21:59

Yeah, so how has it been received? How has the how the students who've participated in this curriculum, what's the feedback you've gotten?

Sahana Shankar 22:07

I think that's the most inspiring part. I think that the students consistently tell us how impactful of an experience this has been for them. So, we have pre post questionnaires, and we get both quantitative and qualitative feedback on the mandatory curriculum, and overall, the feedback has been very positive. And I want to shout out Shelly right now, the highlight every time is the panel of people with disabilities. But I think integral to this curriculum is the interdisciplinary team of self-advocates, of

medical students, of physician's kind of looking at many, many different disciplines coming together to share their kind of perspective and lived experience, and medical students seem to really hold on to the stories that Shelly and other self-advocates have been so generous to share.

Shelly Baer 23:14

Yeah, I just ditto that. Thank you, Sahana for the shout out. I really appreciate that. I, since Sahana and Hana are no longer there, they've passed the torch to another medical student who has taken it on and is continuing the curriculum. And it's so it's still occurring, and I still hear the positive feedback. You know, same thing, exactly, Sahana, what you were saying. It is really making an impact. And every now and then I'll run into somebody on campus, and they'll say, Shelly, I love what you said. I'll never forget that statement. You know, it's just very rewarding to hear that because, you know it to know that I can affect if they treat a patient with a disability better because of what something that I said, that that makes my day, that makes it, that's all worth it to me. That's why I do this. That's why I love to share my story of growing up with a disability and lessons learned, and what it was like for me. We have and they were saying that we have a patient panel. We also have a parent panel, so the in one of one of the sessions, so you have parents who have adults with disabilities, intellectual disabilities, and the two other patient panels that share, share the time with me. One has autism, so it's an invisible disability, and then he has another one has cerebral palsy, and he's African American, so we have the real diversity there, and that really makes a strong impact, I would say,

Matthew Wappett 24:43

Yeah, this is something that I think should be happening everywhere, and I know that it's become a relatively hot topic recently, the most recent issue there, we had several articles related to this topic, and it's, I think it's heartening to see progress being made in this direction. But one of the things we try to do on this podcast is kind of paint a broader picture than just what's in the article. And you know, as you're working on any project, developing the curriculum, writing the manuscript, everything else, there's things that happen. And so, I was wondering if you would each maybe take some time here and share a memorable story or event that occurred as you worked on this article and even the development of the curriculum, and we can start with Hannah. Hannah, why don't we start with you, and then we'll go to Sahana and Shelly?

Hannah Ship 25:32

Sure. I think a very strong memory that I hold is the first or the third session, the communication focused session, where medical students are now in their clinical phase of study, and so they're actually seeing patients. That third session has a video that I helped to create that basically just interviews patients. It interviews health law advocates. It interviews disability lawyers. It interviews kind of experts in the field, and creating that video has a lot of memories for me, and just hearing the diversity of so many different people's experiences with the healthcare system and how we all, you know, crave interactions where we feel heard and seen, and we are able to be recognizing the values that we want recognized in our healthcare system. And I think really hearing the different stories from, as Shelly said, you know, family members and people with disabilities and people who use American sign language to communicate, and really just all of the different ways that health providers can do better. And so, I think hearing all of that was really impactful for me, and also all of the friends that I've made along the way has been really great.

Matthew Wappett 26:49

Yeah, Sahana, what's a memorable event that occurred to you with you as you worked on this?

Sahana Shankar 26:57

I think for me, the interdisciplinary team was just such a special experience to from the very beginning, you know, just bouncing off ideas, brainstorming and what we wanted this curriculum to look like, but knowing that we had so many different perspectives, and, most importantly to me, self-advocates there, I really feel proud of our Nothing About Us Without Us energy and in creating this curriculum and knowing that central to what we were choosing to highlight was the perspective of people with disabilities, making sure that what we were talking about was actually relevant and actually accurate. So, that, to me, was such a special experience. And everything from the initial brainstorm to, you know, being alongside one another, whether it's on this podcast right now or at AUCD presenting, you know, our work in different domains, it's been so special, and I think it really instilled a core value for me that it is integral in doing this work for the rest of my life, in my career, to always make sure that self-advocates are a part of that process.

Matthew Wappett 28:21

Yeah, Shelly, what about you?

Shelly Baer 28:24

Well, I think the whole the whole process, was memorable, working with Sahana and Hannah and the other self-advocates, people with disabilities, and I really appreciated how Sahana and Hannah were very mindful of the disabled perspective, the person you know, our perspective, and wanting to get it right. And there were many edits. We went through a lot of iterations to this curriculum and what to cover, what is important to cover. And you all listen to us, and that's rare, because, as you know, it's usually we're often being told what is important, and not listening to our voices. I mean, I have, you know history working at the Mailman Center, and Dr. Brosco is my mentor. And of course, he was our big champion, and he helped guide, guide as well. But I think it was we had such a great team, and I learned every I always learned from you all, and you are the future you know, you're our future physicians, and it makes me proud that I got to see you all grow and embrace this perspective that not many physicians have. And it's not it was always personal for you and Hannah, you too, and some of the new trainees that we have now in medical school. It's personal for them as well. Cool, but I just, I loved doing it, and I love, you know, having to creating this curriculum with you all, and value it so much, and love that it's now embedded in our for our students, in our curriculum,

Matthew Wappett 30:16

it's um, it is going back to something that you mentioned earlier, you know, it's a lot of times, just education in general has been very much about rote knowledge. And just listening to each of you share this experience, the big thing that pops out to me is that importance of stories, right? The personal perspective. Those stories are so powerful and really provide a context, I think, for helping people understand exactly how important this is. So, in your article at the at the very end, you have a call to action, right? So, what are some concrete actions that are listeners, readers of the journal or even medical schools, right could take to address the issues that you raise in the article.

Sahana Shankar 31:06

I think that something that every single person can do today is take the implicit bias test. I think it's extremely important for us to first recognize our biases, but then to take action. So, I think taking that implicit bias test wakes us all up. I think that a lot of us are surprised by some of the biases, the implicit biases that we may hold to Harvard. I think, yeah, exactly. So taking that, I think we include that pretty early in our curriculum, because I think it kind of wakes, like I said, wake students up and makes them realize that, you know, a lot a lot of people you know, hold these biases, maybe without realizing them, and can kind of serve as a catalyst to for action. So, then, kind of choosing a few different steps that you can take with those results to kind of work on removing or minimizing those biases. So, something that is extremely important is spending meaningful time with people with disabilities, hearing their stories, working alongside them, becoming you know, close friends with people with disabilities, really including them in your communities and your circles is one example, for example,

Matthew Wappett 32:34

yeah, and we'll be sure to include a link to that test in the show notes. It's if anyone hasn't done that. It is eye opening, to say the least. Hannah and Shelly, any concrete actions that you would suggest for readers?

Hannah Ship 32:50

I think it depends on where the readers are coming from. But of course, you know, all of us in society can better support policies that promote accessibility and inclusivity, you know, not only in healthcare settings, but across all of society. Of course, our article is really advocating for the inclusion of disability education in medical and health professional curricula. And so, we would want to encourage healthcare institutions to adopt inclusive practices and make sure that they're providing this ongoing education for their staff, because we do know that this has real outcomes in people's health, and definitely believe that everybody has the right to have healthcare access.

Matthew Wappett 33:40

Yes, yeah. Shelly, anything to add?

Shelly Baer 33:46

I think they covered it. I Sahana stole mine. Was having a meaningful, meaningful interaction in with people with disabilities. I was thinking, that's really important. And I think if you don't have anything in your medical school yet, you can advocate to bring it. Bring it. We're happy to assist.

Matthew Wappett 34:15

Yeah, well, and that's one of the questions I'm sure that will come up, is, is this curriculum available for others to use. I know there's a good outline of it in the article, but is there more that people could get if they wanted more guidance? So, Hannah, sorry, I cut you off there,

Hannah Ship 34:33

of course. So, it is available, you can feel free to reach out to us. The third session is fully downloadable on the Association of American Medical Colleges. That's the AAMC, their med Ed portal. It's under the

title, shared decision making at the intersection of disability, culture and language accessibility, an educational session for medical students. And that's one of the sessions the other two, the first one is called, is focused on interdisciplinary health care workers and how to approach holistic care for people with disabilities. And then the second one is on disabilities and health disparities. And so those two generally involve some other curriculum that we're happy to share.

Matthew Wappett 35:27

Yeah, perfect. And we'll make sure we include links again to these resources that are available. And of course, people are always welcome to contact you. Your emails are in the article, and we'll make sure we put them in the show notes as well. So, the other thing that we like to do on the podcast, the reason we started the podcast, was to again, provide this information in another format, not just writing. Not everyone wants to read an article these days, and sometimes we learn right driving in our car, listening to podcasts and other things. But we also do it to paint a picture of the researchers who are behind this work, right? Who are the people who are doing this work? What is it that motivates them and you address some of this, I think, in your introductions, but one of the questions that I like to ask towards the end of our interviews is, what motivates you to do this work. Why do you do what you do? So Shelly, I'm going to start with you there. We're going to put you on the spot first this time.

Shelly Baer 36:28

Oh, no. What motivates me? That's a good I, I, I'm a clinical social worker. Is my background, and I never, ever wanted to work in disability, even though I have a visible disability, so I've definitely evolved. But I love teaching, and I love shaping future leaders, you know, in LEND and the leadership programs that we run. And since I've had so much experience in the medical world, you know, having my disability, I've had tons of surgeries, and, of course, I've had horrific experiences with physicians and but just overall, my day-to-day job is really sharing my story with a purpose, so not just the Oh, was me, poor me. I have a disability. It's not like that, as you all know, but you know, I share it with a purpose, and that just keeps me going. And I've been doing this now for 13 years. I've been at the mailman center, and not just training medical students, we train all the interdisciplinary LEND trainees that come through. So I think it's very rewarding and gratifying kind of what I said earlier, you know, knowing that just because of something I may have said will totally shift the way somebody perceives and looks at disability that they had never thought of before, like opening up their eyes, like it's really nice to see those aha moments on trainees faces. So, I think that's what keeps me going and really motivates me to continue with this work. And of course, getting to hang out with Sahana and Hannah all that, not all the time, but a lot of the time when they were still in Miami was a lot of was very fun and gratifying and inspirational to see their hard work and their dedication, and they presented at so many conferences, Sahana and Hannah. So, I just love that, you know, and getting these articles published. And I love seeing that

Matthew Wappett 38:36

that's awesome. Thanks, Shelly, for sharing that. Thank you for asking. Yeah, absolutely, Sahana, what is it that motivates you? Why do you do this?

Sahana Shankar 38:46

As I shared earlier, my initial driver was very personal. My sister has both intellectual and developmental disabilities, and seeing her journey has been really inspirational for me, but also through her becoming a part of this community and getting to learn from so many incredible people, and realizing that I just have such a passion for working with people with intellectual and developmental disabilities, and knowing I just kind of knew that I wanted to spend the rest of my life immersed in this community, so I kind of went down the path towards medicine. But then kind of what informed me doing specifically medicine pediatrics, was recognizing the huge care gap in care for adults with disabilities. So, I initially was going to do pediatrics, but actually added in the medicine for that reason, and my goal is to be able to be a primary care provider for patients with disabilities across the lifespan and through. Through my experience in medical training, I have come to recognize the knowledge and comfort gaps and a lot of physicians and physician trainees, and that really drove me to want to be in the space of medical education. And through this project, found a real passion for med ed, and it's something now I'm trying to work on at a resident level, and you know, in the future, look towards kind of across all levels of medical training.

Matthew Wappett 40:32

Yeah, thank you, Hannah. What about you? Last, but certainly not least. What motivates you to do this work.

Hannah Ship 40:42

Sure. I mean, I think I can agree with both Sahana and Shelly in that, you know, I've had a lot of experiences with family members, with friends, with generally, with patients where they haven't necessarily gotten the care that they've wanted. And generally, I went into medicine to help people to have a focus on health equity, to really focus on that human connection that we're fostering in a healthcare sense. And what is healthcare? It's really just everybody wanting to be their best self so that they can experience the world. And so, I love the idea of being able to support everybody's self-determination and achieve in achieving that. And so that's really what drives me in this work. Of course, I also have a huge lens in in public health and social justice, and that just really overlaps here with people with disabilities and people with non-English language preferences. So, you know, every time I see a patient, I hope that I can go to them, and I can be humble, I can let them teach me from their experiences and also that I can serve them the best that I'm able to. So, I think that's what continues to drive me and every patient I see is different and exciting, and we'll continue to learn from them

Matthew Wappett 42:08

that's amazing. Well, actually, all of your responses are amazing. I'm, I'm, it gives me hope for the future. I come from a family of medical doctors, and so I'm, more the old school, and just this more human approach is incredibly inspiring to hear. And I'm excited to kind of see where you all go with this, because it is a huge need in our community. So, one of the last, the last question that we ask, and we ask this to all of our guests, because one of our focuses is trying to make information research as accessible as possible. And everybody who's in this field is always trying to figure out how they can do better. So, what is one thing that you've been doing to make your work more inclusive and accessible? So, Hannah, let's start with you this time.

Hannah Ship 43:06

Sure, I think one of the things that we've been doing to make our work more accessible and inclusive is, you know, trying to utilize more plain language summaries and interacting and things like this, where we have our work across different formats to be able to accommodate various needs, including caption videos and easy to read documents, and really trying to make it so that this work can be shared easily,

Matthew Wappett 43:35

that's perfect. The plain language summary is something we believe in, too. So important Sahana, what about you? What's one thing you've been doing to make your work more inclusive and accessible?

Sahana Shankar 43:49

from a clinical lens, something that I try to practice is really the patient centered approach, really trying to practice value driven care, keeping in mind the medical versus social model of disability and really carving out the time required to give the best possible care for each patient. So if I know I have a patient that's coming in that may need a little bit more time, I block that extra time off in my calendar, and I know I'm grateful to have that flexibility, but other things that you can try to do is, you know, offering telehealth versus in person, putting in notes in the encounter to provide accommodation, sensory accommodation. So those are kind of like little things that I've been trying to do on a day-to-day basis in my clinical encounters to really provide patient centered and value driven care.

Matthew Wappett 44:46

Yeah. Thank you, Shelly, yes. What about you?

Shelly Baer 44:51

We, um, we recently developed a new, newish clinic here at U Health um, for adults with intellectual and developmental disabilities called PATH a path clinic, because, as you know, that adults often fall off the cliff after they leave their pediatrician. There's a huge gap there of finding a provider that would like to see them. So we have that now, but we were very intentional in making it very inclusive, with larger exam rooms and a sensory friendly waiting room, we had autism friendly from our Center for Autism and Related Disabilities (CARD) card center that we have in Florida that came in and did a training with the support staff, with the you know receptionist to the nurses that did a training for them on how to work with adults with autism, the whole range of spectrum. So that was really nice, and that we thought that was really important to be very intentional about inclusivity in the medical space at this new clinic.

Matthew Wappett 46:00

That's awesome that you're doing that it's such a huge need. We see that well, we see that all over the place, right, where it's just really hard to find providers who are willing to work with this population.

Shelly Baer 46:13

Thanks. Thanks for that question. Yeah, absolutely.

Matthew Wappett 46:17

Well, we're coming to the end here. Any last thoughts that you'd like to that you'd like to include before we sign off.

Hannah Ship 46:28

I mean, thank you for having us, and thank you for helping us to share our work. We are excited to see where this can go, and we're always open to feedback, and I think we're excited to see where it goes from here. Yeah,

Matthew Wappett 46:44

I'm excited to see it too. It's a, it's a, like I said, an incredibly important topic, and it's one that you know, unfortunately, has kind of gone by the wayside until very recently. And it's exciting to see the work that you've done and the resources that you've provided in the framework that you've outlined in the article. So, if folks haven't read the article yet, I would highly encourage you to go check it out and reach out to the team here, Hannah Sahana and Shelly, if you have questions or want more information. Okay, that is all for our conversation. Today, we'd like to thank Hannah, Sahana and Shelly for joining us again. I hope that you learned something through this conversation. I think that the work that they are doing, and really, some of the insights that I've gained through this podcast are going to be incredibly helpful in the work that I'm doing right in my day-to-day job. I kind of do this podcast for fun, and I hope it's helpful for you, too, and I would encourage you to reach out to the Mailman Center anyway. They're doing remarkable work. They're trying to address these issues of health equity that are so important. So here, at the end, as always, I'd like to thank DDNJ Managing Editor and Author Insight Podcast Producer Alex Schiwal, for her hard work to edit and get this podcast in the journal out. She carries the bulk of the burden in making sure that the journal and the podcast continue humming along, and she's just a remarkable collaborator, and we're glad to have her on board. So, thanks, Alex. We'd also like to thank the Utah State University Institute for Disability Research, Policy & Practice for their financial and in-kind support for this podcast in the journal, and the journal also receives support from the Utah State University Libraries and Digital Commons, and we are grateful for their ongoing efforts to support our work. So, as I mentioned earlier, please be sure to subscribe. Please share this podcast on social media, email. However, you share things. Share it with your friends, your family, your colleagues. Help us get the word out. Your ratings and reviews also on the different podcast platforms make a difference and help raise the visibility of this podcast. You can learn more about the Developmental Disabilities Network Journal at our website, which is digitalcommons.usu.edu/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 & Practice website, which is idrpp.usu.edu, go to the About tab, and underneath that, you'll see Developmental Disabilities Network journal. And under that link, you will find all of the information about our podcast guests, transcripts, links, everything else you might want to know. So, thanks so much for listening. Keep up the good work. You're making a difference, and we want you to know that what you do matters and stay tuned for our next episode. Thanks all. We'll talk to you later.