INside the OUTcomes: A Rehabilitation Research Podcast

Episode 30: The Occupational Therapy & Disability Studies Network
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On this episode of INside the OUTcomes, my guests are two of the founding members of the [Occupational Therapy and Disability Studies Network](https://www.otdsnetwork.org/). The network's mission is to provide a community that creates and disseminates knowledge, integrating contributions from disability studies into the field of occupational therapy. [Dr. Danbi Lee](https://rehab.washington.edu/faculty/danbi-lee-phd-otd-otr-l) is an associate professor in the division of occupational therapy and a core faculty member of the Disability Studies Program at the University of Washington, Seattle. [Dr. Alisa Sheth](https://www.pacificu.edu/about/directory/people/alisa-jordan-sheth-phd-otrl) is an assistant professor of occupational therapy at Pacific University in Hillsboro, Oregon.

Welcome to the podcast, Dr. Lee and Dr. Sheth.

Dr. Lee, can you tell us a little bit more about the Occupational Therapy and Disability Studies Network and why it was established?

DR. LEE:

Sure. Yeah. So it's been ten years already, I just realized that this is the 10th anniversary of our establishing this network. But it was really six OTs who at the time were pursuing a Ph.D. in disability studies at University of Illinois at Chicago, one of the first disability studies program in the US. And, you know, as part of the program, there were a lot of conversations happening that were about challenging how society views disability and reframing it. And, you know, we saw a lot of gaps and issues and concerns in our field, especially, you know, as a field being that as part of the health care system.

So historically, what has been informed by the medical model, which really sees disability as a deficit abnormality and, you know, disability as medicalized and OTs have seen ourselves as those experts who know that’s not best for the people with disabilities. So we are all really motivated and ready to shake things up in our field and challenge the status quo. And so that's when we just like, you know, let's take some actions. And we got together over a bottle of wine and we're still laughing about it because that speaks to who we are. But we decided the name of our group and like you know, the around big ideas about what our vision and mission would be as a group. And really our vision is to foster critically reflective and socially responsive profession. And we think the way we can promote that is by infusing disability studies perspectives throughout our fields and education and practice and scholarship. And we really hope to promote this by, you know, helping clinicians, educators and researchers reframe how they see disability.

So disability is not an individual problem, but that it is a social construct, that the idea that people with disabilities are disabled by our society or the system or ableism, right? And that is designed for people without disabilities and also seeing disability as part of a diversity and human variation and as identity and not just as a deficit. Again, we know the way people see disability influences how they work, and in a field that means that changes all aspects of education, research and practice. And really our goal is to help our profession to see disability in a different way and yeah, change ultimately the practice you're doing.

SHARON:
Dr. Sheth, can you talk a little bit more about the importance of including disability studies in occupational therapy?

DR. SHETH:

Yeah, absolutely. This is a really great question and I think a really important one.

You know, Danbi was talking a little bit about what we as the, you know, disability studies and occupational therapy we're seeing kind of in our own practice and our own experiences. And I think the question around integrating the two in curricula has been something we've looked at in a number of different research projects we've done as a group.

One of our early projects was looking at disability simulations, which are actually a really common thing that's used in OT and other health professions curriculum. And those are sort of those activities where like students simulate what it's like to have a visual impairment by wearing like fogged up like Vaseline goggles. Or they may simulate what it's like to have a mobility impairment by using a wheelchair for a day like those sorts of activities. And so we really took a look at the literature and found that particularly from, you know, people in the disability studies world, we really had some significant and important critiques of these practices and actually found that these sorts of activities don't have the learning outcomes that that we think they may and they actually perpetuate stereotypes and negative perceptions around disability. And so I think that's one just good example of how a disability studies lens can really help us as educators kind of better reflect, you know, the self-identified needs and priorities of disabled people and disability communities.

And as, as Danbi also mentioned, be more critically reflective in our in our practices, right? We've also done some research where we talked with OT practitioners about disability studies and really saw that a lot of practitioners see the connections, right, around navigating systemic barriers around all these things that really impact the people we work with. That may be traditional frames of reference of practice just don't address, right.

But I think that we also found that there's often a lack of knowledge about disability studies and that there really is some value in that educational exposure to disability studies, both like when students are going through their OT education program, but also afterwards and like continuing education or other sort of practice. So again, around like really helping people navigate those systemic barriers to improve quality of life and outcomes, I think just really studies this is a really valuable, you know, framework and has a lot of important ideas that we can work with.

One other, you know, a couple other projects that we've been working on kind of around this is there was a special issue on disability studies in the American Journal of Occupational Therapy in 2005, and we were actually able to track down a lot of those researchers and authors. And we interviewed them a few years ago to kind of see their perspectives around, you know, what value does disability have, disability studies have for occupational therapy.

And, you know, those authors really highlighted that display size helps us think about non medicalized views of disability and the lived experience and community-based services. And that can be really valuable for an OT curriculum and that there's been some really good movement sort of in that direction. But there's still a lot of work to be done in terms of really being more accessible and inclusive and in our kind of education practices.

I think that, you know, linking this back to some of the ideas that that Danbi was talking about, that I think disability studies really helps us look at how our educational practices might be ableist or biased in in other ways and can really help provide a lot of good tools for students and practitioners to work with more collaboratively with disabled people and communities.

I think more recently, we've also started looking at how we can use a disability size lens to help create a more inclusive and accessible profession. Meaning how can we support disabled students and how we can support disabled practitioners to flourish in our profession and to really value the contributions of disabled students and practitioners and researchers to really push the field forward. And I think that speaks to our group as well.

We are a group that some of our members identify as disabled and others identify as non-disabled. And so we're really trying to bring in, you know, kind of those varied perspectives to really see, again, how we can promote a more a more inclusive profession, really, to put it to put it simply.

I think in my own kind of practice experience, I've worked for a number of years with people with intellectual and developmental disabilities or IDD from, you know, early childhood services through adult services. And I think I was lucky to be able to work on some research projects that looked at institutional care. So people who are in more skilled nursing facilities or larger institutions or even like large group homes and some of those other places where we're particularly adults with disabilities, often kind of end up.

And I think it really made me consider the impact that those sorts of settings that can be very restrictive are often very medicalized in their focus and not very empowering or supporting of like self-advocacy. How then, you know, now kind of in my, in my career, both as an educator and someone who supervises students in in the field, how can I help build partnerships with community based services for folks with ADHD that are more inclusive, that really want to support people to be a part of their communities and not kind of be in these more segregated settings, which unfortunately are still very common places where a lot of OTs work. So that really helped me, I think, shift how I was thinking about where OTs can be, can be right, and the types of supports that we can really help provide.

SHARON:

What is the typical occupational therapy curriculum?

DR. SHETH:

The OT curriculum is really regulated by a body called the Accrediting Council of Occupational Therapy Education. And there's very specific standards that every occupational therapy education program has to meet. And they run a wide gamut from, you know, learning about different conditions and, you know, functional skills through research skills, advocacy skills, that sort of thing. And actually something that the OT and Disability Studies Network has done in the past is we've actually written letters to this accrediting body promoting some more explicit standards that specifically talk about disability and really promote students learning more about disability in their own curriculum. And we haven't been super successful, although I will say there has been some shift where I think the standards are talking more about like social determinants of health, some of those bigger kind of systemic factors.

But I think to kind of go back to your question, Sharon, I think practitioners see the connections between disability studies and OT, but a lot of education is still really focused on more of like an individual.

You know, someone has this diagnosis or these sort of functional impairments and it still can feel very medicalized in a lot of ways. And as I think to really kind of what, you know, some of the stuff Danbi was talking about was that like we often bring in our own stereotypes and ideas about the goals that people should have about the things that, like you were saying, right? OTs help people with things they want or need to do. But often we bring our own biases to what those things should be. Whereas often, you know, maybe a disabled person might have a very different idea about what they want and need to do during the day versus what we think they should want or need to do during the day or how they do it. That's another one.

I think a good example would be like OTs sometimes can get very focused on independence and helping someone be independent. And that actually is not often a priority for a lot of disabled people. And the disabled community at large often really talks about interdependence. So this idea that we're all connected and then we all kind of help each other. And so it's not a priority to be able to do something on your own. More of the priority is do you have the resources and are you able to connect to other people to help you get those things done? And I think that's a good example of sometimes the disconnect between more traditional OT education and disability studies. DR. RIMMER:

It is, it’s eight weeks. So it's five hours a week, an hour a day, two hours of exercise, one hour mindfulness and one hour nutrition. We're looking currently at maybe restructuring some of that to make it less intensive for people who are more interested in doing things on their own more of a self-management program.

Today, it's pretty intensive in terms of the number of hours per week. But at the end of it, what we've been hearing from participants, is that they've learned a lot about holistic health versus one dimension. And you know, very often what we used to do is provide them with one aspect, typically exercise you know, everything is out there. For people with disabilities. It's all about exercise. And we realize that there are many dimensions of emotional, spiritual health, and really mindfulness and things that can improve their mental health that we've been missing in the community of people. So that's why we began MENTOR.

SHARON:

Danbi, you were going to add something?

DR. LEE:

Yeah, just thinking about OT and how a disability studies prospectus can inform.

I mean, one thing that comes to my mind, a lot of coaches really focus on the individual as a problem, so they try to, you know, focus on functional improvement. And what we less talk about is the barriers that they face when they go home right there in the hospital setting.

Of course, there should be a focus on the individual and the body so that the body, like the improvement, will start over, but that, you know, improving body function. But, you know, when they go home, they face a whole lot of societal, systemic barriers, attitudinal barriers. And we don't necessarily talk about them. And that's why there's why it needs to be part of education.

So it is part of our discussion, everyday discussion with our clients and we prepare them because that's going to be part of their life, right? So I think that expansion of like looking at disability not only on individual level but also societal level.

SHARON:

I wanted to get back to the network and talk specifically about some of the products that you've worked on and are working on. Can you talk a little bit about that?

DR. SHETH:

Yeah, absolutely. So in addition to some of those research projects that we've been really fortunate to publish, we also, you know, present pretty frequently at a number of different conferences. We've done workshops and posters with the American Occupational Therapy Association, the World Federation of Occupational Therapy, and then and then some state occupational therapy conferences. And we've also done some work with the Society for Applied Anthropology, which does some interesting work around medical anthropology and bringing home disabilities and OY and other health care professions together. So that's been one way we've really tried to kind of get the work we're doing out there.

As I mentioned, you know, there was a special issue on disability studies in the American Journal of Occupational Therapy in 2005. And then we helped guest edit a kind of updated version of that in 2021. And so we really tried to bring different research from really all over the world around, you know, disability studies. And it was a really great collection of, of research in different practice areas with different communities, some more like around education, other around more practice and that sort of thing.

We've also worked on some book chapters. We have an upcoming chapter that will be in text called Occupational Therapy Without Borders, which really tries to kind of challenge the, you know, traditional narratives in the profession. So it was really great to be able to be a part of that kind of outside the more traditional, you know, academic publishing.

We've also tried to have periodic like webinars or online conversations where we've brought in authors that we worked with in the special issue so that they were able to talk about their work and a little bit more of an accessible way, you know, answer questions folks might have about their research. And we've also had some, you know, discussions online where we bring folks together to talk about, you know, disability related topics in the field and just kind of provide n avenue for people to talk and get some, you know, insights into what other people are thinking about these sorts of topics.

We also have some social media. You know, we have a YouTube channel where we store a lot of the conversations and webinars that we've had and a Facebook page where we're able to share, you know, some of the other things that we've been working on.

Danbi is going to talk a little bit more about our new public facing website, but that's been a really exciting project we've worked on for the last, you know, almost a year and a half now that was funded by the University of Washington, Harland Hahn Endowed Fund. So that's a really exciting development.

SHARON:

Can you talk a little bit more about the website and what people can find there?

DR. LEE:

Yeah, sure. So we the website has been our dream for a while and we finally got funding to make it work, make it happen. And so we had so many resources and knowledge that we gained over the years that we wanted to share and disseminate and make it easy to access right to a lot of people.

And so one of the focus we had for the website or a starting point was to create modules for educators. We created these modules that educators could easily integrate into their teaching. And so far we created three modules. There is one ethics case that gets at ethical reasoning. They're using the Tim Bowers case, which was the assisted suicide case with someone who acquired spinal cord injury. This case kind of gets at how ableism influences people's choice. And our practice and the importance of it also highlights the importance of understanding lived experiences of people with disabilities and the importance of connecting with the disability community and really understanding what it means to have a disability and what you know that life is worth living with a disability and really combating that notion that disability is a bad thing, that you should not be living.

Another module focusing on Medicare and the social models of disabilities, which really gives a basic understanding of what those models are and how they can inform occupational therapy practice. And then lastly, there is a disability culture module. And so these modules really offer they have all their own structure in the same way. So they offer we have a brief introduction and presentation that is recorded that students can watch.

And then we have guides for instructors that include discussion questions, ways, different ways to use the materials that we offer, our list of resources that they can use and integrate. So and provides a fairly comprehensive guide for instructors to use. We also have a page dedicated to resources, and some of the topics are some of the categories of the resources include literature that are specific to OT, but informed by disability studies, disability rights and legislation, disability networks and advocacy, disability arts and culture.

There's also a section where you can find disability narratives because it's so important to listen to stories and lived experiences of people who have that experience. You know, as a non-disabled scholar, I'm, you know, an outsider experience. And there's so much value in reading the stories that and the narratives that people with lived experience provide. There's a section where we post all our events. We have, we post all our publications there, and there's a practice section that that's yet to be developed.

SHARON:

And what is the web address?

DR. LEE:

It's [otdsnetwork.org](https://www.otdsnetwork.org/).

SHARON:

Thank you both for being on the podcast. This has been very informative and I'm looking forward to what's next.

This has been INside the OUTcomes: A Rehabilitation Research Podcast. This podcast is supported by the National Institute on Disability, Independent Living and Rehabilitation Research. This is your host, Sharon Parmet signing off.