



## Episode 12: Medical Model: What did we learn from the experts?

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### Audio commercial: Selena

This is Selena Evet host of stories from planet Earth. Thanks for listening to the following show on Public House Media

[Upbeat intro music] Disarming Disability

### Sarah:

Well hello and welcome back and we are really excited to really sort of process the last three speakers that we had. We just have concluded the medical model. So we heard from Sally Martens to the Nurse Practitioner and is working our PhD work and really looking at pure relationships scores that kids with visible differences are having and sort of how those relationships scores change throughout their lives.

Then we spoke with Dr. James who is an orthopedic hand surgeon who has really been a tremendous and really foundational leader in Pediatric Hand surgery and then we spoke with myself who just completed my doctorate project in occupational therapy and sort of shared a parent resource that I did for my thesis project and sort of just shared- what occupational therapy is.

And and so now it's really the time to sort of process what three what these three specific roles have within Healthcare, but then larger just what medicine is looking like today, and I know that all of this is sort of relation- related to hands and that is purely because this is the world that we exist in a lot of the things that we talked about isn't specific to hands the themes can translate to other different professions. So I just want you to know that you're still a part of the conversation like these themes still apply.

And as far as what's happening medicine today, I know things have a little bit different flavor depending on you know, what branch of medicine, you know, you could be interacting with but I do feel that it's important to note that we recognize that everyone that we had talked had some type of relationship to hands. But know that that's not exclusive to this conversation either.

### Nicole:

Real. I mean, I feel like when we were talking about guests to have like we wanted the most expert of the experts that we could have and yeah because of the world that we're in I mean like Dr. James is is a when it comes to our community and when it comes to you hand surgeries, so to nab her specifically of course is such an honor and and yeah again that comes back to to the fact that that's our experience and we always want yeah like Sarah- want to acknowledge that but also I think let's let's talk maybe a little bit.

Maybe that's a good space to start from what what parallels do we feel like or maybe what universal themes did we pull from the conversations that were had that kind of in looking at the medical world, which when you live with disability in some way shape or form you're going to be spending time in hospitals. You just are Um, what-what universal kind of themes. Did you did you latch onto in our conversation Sarah? Dr. Sarah expert Sarah?

**Sarah:**

Ah!oh, okay. I was really I was really thankful to hear that because I know that when we sort of talked about the medical model there is this hmm like that it's sort of like the medical model or the social model or you know, these different models of understanding disability. It's a point where they're real- a clash and I feel like there's almost this crusade against the medical model and the like "don't think that we're broken. Don't try to fix this with your microscopes!" or whatever.

And and so I think it was just really helpful to hear from experts in the medical field today and know that like the climates that were existing in today recognizing that medicine is a space that can help if it's helpful, and I really just appreciated talking both with a Sally and with Dr. James that it was at the child and again they were Children's hospital- so it's at the child is at the center of care and that they can really you know, what are the different types of supports that they can give to that child to help that child live a meaningful life.

And and that that could be a whole variety of answers and that medicine can help provide a different variety of answers and but it doesn't need it doesn't need to like it doesn't have to be an end-all be-all. It doesn't have to be like, okay because you were born with this condition you have to have this thing and that's it and I really that feel that hearing from the medical model that is almost sort of a different perspective than maybe what the medical model used to be or maybe how we viewed sort of like doctors and surgeons and things like that in the past.

But I feel like present day. There's a lot more like who is the person and how can we really help the person do the things that they need to do and and are the supports that can be accessed in medicine and and and whether that's like, you know, traditional medicine or like therapies or different types of supports or interventions that can really help the person do what they want to do, which I feel like kind of helps shift that in my head.

**Nicole:**

Totally. Yeah for me. It was really good to hear Sarah of the two of us- yes is definitely the scientific mind and I mean science is okay, but like, you know, like definitely, you know, it was good to hear from somebody who is not thinking about scientific things a lot. And who only knows about the experiences specifically that I've had when it comes to being on the hospitals- that it seems the conversations we had were more of a holistic approach- I felt like.

It really the conversations we had were about addressing. Yes the child at the center of the care, but what's going on around them, you know specifically what are they feeling emotionally? How do we address those things? Emotionally what supports can we put in place? What understanding can we give and I think I think that is the step that when the medical model is talked about in a negative way. I think that's the step that's missing is just like there's more than that to a person than just, you know, like put the bone back together person walk outside person better, you know?

Like, you know, there's there's just yes so much more complexities happening and I feel like in all three episodes- that's what we were talking about is just like holistically how how it's so much more complicated and that's okay.

Would you have to I thought was really really cool. And yeah, and I would like to think that that is mirrored in all all of the kind of doctoring that is is happening in the 21st century now. I would love to believe that.

**Sarah:**

Yeah, and I know and I know that that is a huge part of occupational therapy, right? I took two and a half years of classrooms where we spoke a lot about who is the person what are the barriers that this person is facing? Like how is this not only like who is the person but we talk about one of the big parts of Occupational Therapy. You could look into the PEO model. So we're looking at who the person is like what are the features of the person what's with our personalities? You know, what are the different parts of their body that maybe are working or not working or whatever like those types of things then we're looking at the environment that their existing in and then environment is both like the physical environment, it's a social environment and then also you can extend it to like temporal. So like where is this person at that stage in their life because things that this person needs at 8 are different than the things that this person needs at 25 are different than the first things that this person needs at 60, right? So it's like looking at that temporal context context as well and then looking at the occupation they want to do right.

So like, you know children their main occupation is play and play exploration and then you know, we sort of assume that adults are doing more like self care tasks and may be engaging in different types of employment or maybe finding relationships or you know,

sort of like building that self and then when we're older, you know roles in occupations change a little bit.

So we sort of like look at that model and so much stressed with in occupational therapy is not the diagnosis because they're like everybody who has a T3 Spinal Cord Injury is a different person. They are all different people. They all have unique challenges like and not every T3 spinal cord injury is the same, you know, sometimes it's a complete sometimes it's partial. Sometimes people are able to get function back faster than others or like there's everything is so unique and so specific that we we didn't talk about diagnosis a lot almost to the point of frustration to some of us because we're like, we just need to know more about Alzheimer's disease, you know, because we think that that would really help our ability to care and really go through different things with the you know different people that we work with but really like that part of it doesn't matter like yes, it adds a little bit of course, like knowing how neurons work is important, but it's not like okay. So when we have this type of injury, then we provide this type of care like it really is- how do we look at this whole person? What are the barriers that this person is facing and how can we help them?

And I also understand that like, yes, like hospitals exist and insurance exists and there's things that would be amazing that we could do that is within our scope of practice that were not able to do because there are you know, sort of systematic limitations and problems. Problems and there's a lot of problems with access to care.

So I feel like that is entirely different conversation. But I feel it's really important looking at who are care providers are and sort of extracting the sort of like complications of insurance reimbursement type things and like what qualifies for insurance like that is so if we just extracted that from the equation and extract that from the medical model and really looking at who are the professionals what is in their scope of practice and how can we look at that to be able to provide the best care for people who may need it. I think it's really helpful to and an on a second note.

That's like one thought on a second thought something that was really helpful in liberating and for me in my occupational therapy practice is that like people get to make decisions on their medical care, right? And they should and if people ever feel like they're not in a space where they're making decisions or they feel that their medical providers are saying that they need to have this type of blah blah blah because or I'll swallow balh blah will happen. Like people are always have the right to second opinion and people always have the right to consent to care. So just because somebody strongly recommends that something needs to happen people still get to make that decision. So I feel like that's a really important thing to highlight and again, every person is unique every circumstance is unique and obviously if I'm unconscious and I need immediate Medical Care in order to keep my life alive then like, you know, that's that's a different type of space.

I get that but largely people have the right to have the right and the ownership of making their own medical decisions and that's something to really take into consideration, you know, and and that if medicine is going to be beneficial for person's life and function then you know, you have the right to choose that if that works.

**Nicole:**

Yeah, totally to everything that you just said and I feel like it particularly in the conversation with Dr. James. It was interesting to me that she really- they've done enough research to know kind of what where you should be doing surgery versus a I think it was between what did she say the ages of four and nine eight or nine where you shouldn't mess with a mean in in the case. She was talking about it was specifically with body image and changing changing a way in which a body looks because that's when the child is forming the first opinions and it's so foundational that that unless it is something that is you know needed and is me For function in needed to stay alive and you know kind of like those Extreme Measures- She doesn't like to even do surgery on children.

And I think that's that is a beautiful example of of what we're talking about looking at the person as a person and understanding that, you know, we know scientifically now that between these ages identity is formed and let's not touch it if we know that that is too important to mess with and yeah it was I thought that That was really really very beautiful thing that she talked about and I you know, of course she's said it in a very doctor-esque way where it was just like these the facts but that that's beautiful that she they understand and realize in practice it in that way, you know.

And also I feel lucky in the sense that that particularly the conversations we were having at that point. We're talking about elective surgery. So we understand that that's not always the case and sometimes there's not choice involved there. Well, yes it yet again, like you said I guess consent to care but I also feel like the part of disability- I guess what I'm trying to to cover or cover my bases on is the fact that so many of us do rely on you know, that that branch of of doctoring and going to see a doctor and and yes, whereas we do have choice of maybe who were going to see still some of us have to be going to get certain treatments or have to be receiving some sort of care- so like so the care and the the relationship with the doctoring part of the world - we don't get to choose almost does that make sense kind of where I'm going with that like it's yes, but also not a choice, I guess. maybe it's what I'm saying that yes?

**Sarah:**

Yes. Yes. I think that comes into that like you and I know that like it's Is a really easy thing to say and and I also acknowledge that it's a really easy thing to say, but I just think really helpful to know or I suppose at the same time really helpful to know that you have rights as a human. And that you have the right to do research on a particular type of operation that you have the rights to advocate for yourself and and really make sure that whatever type of intervention whether it be, you know, like a different type of like a medication or it being an operation. And or it being a type of therapeutic practice like

and I understand of course, there's there's outliers in every situation and I get that and I know that every circumstance and situation is different and I know that a lot of people don't have the most positive experiences with the Healthcare System. I totally acknowledge that and own that not trying to gloss over that by any means.

And I think knowing that that you do have have choice and and oh just trying to exercise the the type of choice you have and and being able to research whether you are able to yourself for the people who are here supporting you can research what type of intervention is and really sort of keep up those those protocols if that makes sense and really ask and write notes and you can ask Healthcare Providers questions and you can make notes on things that they say and and sometimes have to healthcare providers of you're seeing multiple of them- they may seem thing say things that seem contradictory so you can really ask those specific questions like, okay. "Well I heard this from this person. I just wanna make sure that that's also following up in this care to"

And I know that that puts a lot of pressure on a navigating the healthcare system and that sense to and and I share this in that last summer. I had a hernia so I had a hernia operation and I was offered two different surgical interventions for that and it was really interesting like me being in healthcare and how I needed to advocate for myself in that space to. And even just finding out how long the operations are going to be what the recovery periods like what type of medications I will be on and those are things I had hoped that my healthcare provider would have just given to me, but he did not. So these are things that I had to ask on my own and it was very frustrating even somebody who is like at has a graduate-level education whose English is a primary language like and I have access to resources right?

So and I know that that was a little bit of a frustrating process and but even with that like I still was able to ask the questions and have them answered and I really I hope that people feel empowered to do that as they are navigating their care and and that medicine in it's like best form is to help provide, you know to help provide access to our lives in its best form its here to help allow us to or help be the bridge to have us engage in the things that we want to in need to do throughout our lives right? Like that that is sort of like the role the like best like space was right words. I'm trying to say that's like it in its purest form-

**Nicole:**

Its like Ideal form?

**Sarah:**

Yes, ideal form and it's ideal for him. That's why and what our medical professionals are here.

**Nicole:**

Yeah. Well, I think they work the nail on the head when you were talking about. It can be overwhelming to understand or know what your options are right? Like I am somebody who absolutely feels that way and it takes it takes time and it takes energy and I think that's kind of a reoccurring theme within the disability experience is that - because we're adapting and doing things in a little bit of a different way it takes so much emotional time and so much emotional energy and so much literal time and literal energy to to become the experts and all of these different spaces, right?

How do I become an expert truly in the way in which the world is treating me and what micro aggressions mean and how do I how do I deal with these scripts of conversations that I'm constantly having with people in my everyday life, right?

These are things that that nobody really is bringing us those answers and I feel like the medical world is its own Silo of that form of energy that you have to almost like drink your Red Bull and be like, okay, let's go. I like worked my way up into understanding that this is going to take time. This is going to take energy. This is going to - I might have to disagree with a doctor. I might have to fight with an insurance company. I might have to you know, like it's there's there's extra- There's just *extra*. That goes into it.

And I and yeah, and I think this is another area where where yeah that is happening. And I think it's okay to acknowledge that and I think that we can only be encouraged by the conversations that we did just have with our three experts including Dr. Sarah you did messaging of truly caring for the person as a person is is what I took away from them right?

Like that is I took away so so building yourself into being ready to kind of like dive in and become your own expert. I feel like it's worth it. Maybe that's my idea. My ideal is brain talking but I think it's fair to acknowledge the fact that that's a lot of time and energy and resource that people are spending, right?

**Sarah:**

Yeah, and I think that's more that's more of the system that we have set up in place. Right? And I think it's very easy to get caught in the system and get stuck in the system and could you get angry with the system but I think to if we can extract the system from the healthcare providers themselves and really know that this it takes a lot of time. Well, I suppose it takes a lot of time either way, but people are committing large parts of their lives and their careers for these professions and it's not an easy adventure for them either.

So I feel like that helps provide the context that they really want to do this because they're really believe in it and they really care and they really want to help us like and us being people not just people with disabilities but really wanting to help ourselves live happy and healthy lives, right? So but knowing that there are like large systemic barriers that are can be pretty debilitating that are really frustrating to navigate so really

working to it to extrapolate that and it's not that there are people who are living and working in the medical model that are really on our side and an our side being on the side of people who are living with disabilities. In that they want to help provide, you know a good lives for all of us.

And so I just I feel like to help to help add that to our understanding of the medical model and helping to to give life to our Healthcare professionals and see them as people because I think it's also really easy to be like, "right and then the blah blah blah and the blah blahs are like this"

So it's just I really appreciated that I heard that in both the conversations with Sally and Dr. James that it's like these are just really incredible women who are trying to trying their best with the tools that they've learned in order to help the lives of kiddos living with them differences right now?

**Nicole:**

Yeah. Yeah. And again, I feel like I just like on the tail end of this specific part of our conversation. I feel like I just want to reiterate the fact that we acknowledge the fact that specifically kind of the world that we live in and what specifically we were talking about were not specifically like life-endangering life-altering surgeries, and there are people with disabilities who are going through that and that is a part of the experience and I think that's in that's a slice of the pie that we have extra privilege in you know, where where yeah where we have privilege there and I think I just want to acknowledge that. Okay. What what do we want to talk about next?

**Sarah:**

We in school. We talked about self-determination and that being sort of in the space. I think it's worth came from the space of individuals who Different types of intellectual differences or different different disabilities and that people still get choice to determine what they want to do in their lives and I think particularly as individuals enter adulthood and being a therapist and you know, like perhaps living in a group home or some ways to help best support individuals who are existing in this space and and somebody wants to engage in alcohol or somebody wants to engage in different types of sexual activities.

Like at what point do you let at that or not like that happen, like where our ethics play in like people still have the right to self-determination to do what they want to do. But then are we just imposing on them what we think they understand or what we understand of a situation or just because we find a situation is too risky- does that mean that individuals are not allowed to be involved in it, or how can we best support individuals who may know who may or may not I mean really, what is our determination to see if they if they understand how risky situation is or you know me as an individual like I have the right choose to be engaged in Risky situations, but it just wasn't brought up really interesting conversations and my OT program in that sort of how can we best



support individuals and where do ethics play and is that me internalizing things is that me superimposing or us as Healthcare professionals superimposing roles on top of it. It just it led to an interesting conversation.

I mean, we didn't necessarily for find answers, but it was like, you know if these things come up like how do you respond and it's import to think through these things and to really of course we want everyone to be safe but allowing that space for mistakes to happen. But how big how big of a space do you let them write? Like, how can you support people and how can I be supported to in life to by giving them like an appropriate threshold to make mistakes before intervening before they like crash and burn type of thing to right?

**Nicole:**

That is interesting because because I feel like you know as the healthcare professional he was Are to provide service and who is there to help bridge the gap of Independence or bring Independence? Right?

Yeah that ethical ethics conversation is fascinating because I parallel it in my brain to to the microaggression when somebody you know, this happens to me probably once a year, I'll have somebody literally like try to give me money or gift me with something who's a complete stranger and then who will be like oh "Oh bless you God Made You So Special you're such a gift to this earth" who's totally talking down to me, right and with no understanding of the fact that that the things that they are saying are totally condescending and and in their world they are doing something so kind and so nice

And yet of course, it's not so in paralleling it to that kind of feeling obviously, it's not the same thing that that feeling. Obviously it not the same thing, but almost condescension of choices and and who does get to make your choices and should should that healthcare provider or or person who is helping you be a part of those- do you have to welcome them? Do you have to- how does that play back and forth and certainly they have more play in our lives than a lot of other communities.

So they are a strong voice that is in in our brain right? Like so many a pattern of societal thought that is not even spoken but that I can tell you is felt within you know, the specifically one-handed Community is is what do we do about Prosthetics? And Depending on who you talk about you can pull common themes about what is talked about and what works and what doesn't work and that's totally just people having opinions and talking and inserting what they think and feel.

Does that not make sense where I'm going with this like it is it is really kind of weaved into our culture. And so what what it's a powerful position to be in when you can be be a service provider to a community right? It's almost this this um, power that is held it is. So I don't know if any of that rambling made sense, but that in real time was what I would you know about?

**Sarah:**

You know what it's kind of funny this maybe an entirely different segue but we're just going to come here- so come with it. It makes me think of -I just because yes Health Care Professionals are in a level of authority- I don't know if that's the right word to use. But yes, like do have an impact on our lives, right?

And I think it's important to help shift that that in the sense that we still have choice in that right like Health it like I can't just walk up to a prosthetics office and be like, hey, I'd like a prosthetics arm like, there's there's a system that I need to be a part of then I need to meet with certain people in order to approve those things for me to have that appointment. Right like I can't just walk into an operating room be like hey, can you do this thing on me?

Like no, there's like you have to meet with people people have to make decisions people have to you know, but I feel like each one of those should really be a conversation and I really feel like fighting for that conversation as important-- which makes me think of I am living with a really good friend of mine for this interm while I am figuring out my life in Philadelphia and they're really lovely and fun.

And now I noticed that I'm singing about everything that I do in my life because we always think about everything which is cute but we've watched Frozen 2 this week and it was really exciting and I hadn't seen Frozen 2 before so the first time and neither moment. Okay, great, so I'm not going to ruin it for you. But there's this moment where Anna is like out adventuring doing the things on is doing she has a plan. She's facing some barriers in the plan that she's trying to do. She's not able to do it on her own she ends up being like sort of swept up off of this thing from Christoff right?

And they're sort of traditional, you know male female roles in Disney's sort of like there's this Damsel in Distress and the prince comes in and saves them and then everything's great?

But here Christoff like picks her up puts her on their their horse, which is name is somebody - that I forget so don't judge me on that. But so she – Spheh? is that the horse's name is or is a reindeer? Or is it a deer?

**Nicole:**

Yeah Spheh and it's a raindeer.

What is it like to be a reindeer? Yes. Yeah. It's a

**Sarah:**

Oh reindeer my bad. I was is it a horse? What its is name? Maybe it's Stephen. I don't know anyway, ok she she picks. He Scoops Anna up on a puts her on spend and he says "I'm here. What do you need?"

And I just I feel like that's what the medical professional is here is sort of like I see that there's things that you need to do in your life like I you know, and I feel I see you know, whatever like there's these barriers this person is facing there's these things that this person needs to be able to do and the medical role in that space of authority and power if you will they're able to have the resources to pick up that person, you know, and sort of put them on there on there, but then be able to ask like im here- what do you need

versus like? Okay, I know what's happening. I think that the best thing to do is XY and Z you clearly haven't done the right things be or else you wouldn't be in the space of disaster. Right?

Like because there's two different ways that that conversation could happen and I just I feel like the conversations that we're having with with Sally and with Dr. James and I like to think with myself to - was sort of that that way of like, okay like here are the tools that I have here are the resources that I can provide you access to like. What do you need to do? and how can we best support you and maybe this needs to be a mutual thing like maybe like the what Independence looks like for us is is sort of being in this together in a sense and together could be having this ongoing relationship with multiple Healthcare professionals, you know, and even you know health care workers in the sense of you know, if we have if we want to include like aids and you know, whatever rehab and caregivers and things like that in that space too.

But that I think I just really I just really love that imagery. "I was like, okay, like here I am and here to help give these resources and I can be extra layers of supports like what you need and how can we help you get there?" and it's really like that.

**Nicole:**

I mean that's I feel like that's the cherry on top of the conversation. Yeah, I think that's yeah, that's beautiful and I and I'm thankful that the people that we talk to I feel like really understand that and yeah, and it's good to be reminded that again the healthcare providers are there to be a resource to us.

And even I think about how we were talking about them being translators, right? Especially with kids, kids are coming in and speaking and say they're saying their verbalizing lots of things, but maybe there's a meaning behind what they're saying, you know, maybe you know, they're asking for a Barbie hands prosthetic that doesn't move or doesn't do anything functional.

Well, maybe it's a time in their life when it's extra- It's extra emotion and they're trying to Navigate actually socially what it means and and trying to blend more and you know, like actually translating what those kids need and having the tools to be able to help them when they're in those moments.

So yeah, I think that's great. And I'm so I'm so thankful. Again, if you want to check out the conversations that we were talking about all about the medical model. You can check out our website with links to all at links and resources to all of the guests that we had and all the conversations that we had together. They were amazing. Please go back and listen if you didn't and yeah anything anything else you want to wrap up with Sarah. Dr. Sarah expert Sarah?

**Sarah:**

Oh check out nursing check out being surgeon. Like what I have Healthcare is is somewhere that you want to be like fine ways that you can and in a sense something that's it's interesting for you that there are way is that you can be a health care provider regardless of of what difference are disability looks like which I think is really important.

**Nicole:**

Hazzah cool? We'll see you next week. Same time. Same place where we will have amazing conversations. We can't wait for you to join us and always make sure your Disarming Disability.

**Sarah:**

Thank you for spending part of your day with us. We want to give thanks to our Network Public House media. And for intro beats Jason Barnes with cybernetics for logo art. We want to remember Patrice. You can find his work at normal person's.com.

**Nicole:**

Be sure to follow disarming disability on Facebook and Instagram. and lastly be sure to check out our website [disarmingdisability.com](http://disarmingdisability.com) where you can find all 13 Episodes of Season 1, links to resources, transcriptions, and discussion questions for each episode. Check out our blog where we feature amazing Disability Advocates.