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Fady - Hi. This is Disability Saves the World with Fady Shanouda. I am Fady Shanouda. This podcast brings you insights from leading experts in disability and mad studies from around the world. You'll hear about the research and work of disabled artists, scholars activists, and our allies you'll also get some insight into their lives - their favorite non-DS activities, their hobbies and the adventures they've taken. Most importantly you'll hear how they think disability can save the world. My name again is Fady Shanouda (he/him pronouns) I have a PhD in Public Health Sciences. I am a postdoc in London in the UK and I identify as a fat, disabled, cis- man of color. If you don't know me hopefully you'll get to know me a little bit more over the course of the next few episodes. On today's show we are joined by Anna Chowaniec. Anna is a PhD Candidate at the Institute of Ethnology and Cultural Anthropology at the University of Warsaw in Poland. She recently completed a 3-month research visit to London UK to conduct research, participate in seminars, and overall learn from some of the leading experts in her field. It's also where we met. I am so excited to speak with her about her research - (Anna - diversity is something that makes people more aware of others) and her life outside of academia (Anna - he was playing on the guitar and singing blues for us) ask her, of course, how she thinks disability can save the world. (Music Ends).

Fady - Hi Anna, how you doing?

Anna - Hi,  
good thank you.

Fady - Thank you again for coming on the podcast it's great to have you here. I'm really excited to have this conversation with you internationally this time.

Anna - Yeah, I was so excited as well thank you, thank you.

Fady - Sorry?

Anna - Thank you for inviting me.

Fady - Absolutely, really glad to have you on. We are both still in quarantine having just traveled internationally, less than two weeks ago, so what better way to spend our time than talking about, you know, our research, disability, and kind of catching up.

Anna - You know so it's like an occasion just to speak to other person, it's just...

Fady - ...wonderful to talk to another person. So let's start with Segment 1. I call this inside the project/research/ work/art and I'd like you to tell me a little bit about your project... So we'll start off by asking maybe a question about why disability studies.. why did you get involved in that area or that discipline?

Anna - Sure, so the thing is I didn't start my project as a disability studies project. It just.. it became obvious at some point that it's something that I should pursue; something that's a part of my research. So I started actually... it's done with my Master's because I was doing research about the about the families, or more specifically, mothers of children with Down Syndrome in Poland and when I finished my master's I applied, because they were looking for a researcher in a bigger project, which was about the rare disorders in Poland. So I started working there as an anthropologist and after let's say two or three interviews I've done with my participants it became so obvious that the question of ability is one that I should like follow. It's something that's the most one of the most important elements in those people's lives. That's how it happened. It didn't start that way but it ended up this way.

Fady - And so when you started researching disability like what were the kind of first things... that you like what's the first thing... like did you go to the library, did you put disability or did you go to speak to somebody or you know like what was... how did you get to disability studies?

Anna - Great question. It started when I was doing my masters of course and funny enough it started with a special education. So I was looking for literature about the special education the understanding of disability and I was so disappointed because everything I found it like if you didn't answer any of my questions.

So I knew it's not, you know, like I shouldn't follow this and I started looking more into like Social Sciences understanding of disability, which was much more eye-opening actually because the abilities that I encounter now in my fieldwork are so specific that I had to like follow very particular ways of understanding what the disability is. Which means that, for example, most of the people that I was doing research with, they have invisible disability which of course is something very much different than let's say have been impaired mobility or something like this. So I have to like try to follow something else. I try to find the answers. I'm not yet satisfied, let's say, yeah because...

Fady - You're also dealing with rare disorders right? You were saying, you're dealing with people who have... like your project is around people who have very specific like food allergies, or very specific... or sorry rare disorders that require a specific diet a specific...Tell us a little bit that about that project?

Anna - Yes.

Fady -.... and how disability studies interacts with that. Yeah so the groups that I'm doing research with are groups of Polish patients with two metabolic disorders. So LCAD (long-chain Acyl-CoA dehydrogenase) and PKU (phenylketonuria). Both of those disorders are like, the errors of metabolism which means that the the things that you get from food cannot be properly...your body cannot properly produce substances from the food. So in LCAD that's energy so you cannot produce energy from fats and in the case of PKU you cannot produce some proteins from the proteins in your food. So in both of those cases if you do not follow very restrictive diet, so either very high in calories, in case of LCAD or which without the proteins in the case of PKU you can either die or became very much intellectually disabled, with Parkinson's, and other neurological problems in the PKU. So you do not follow the diet, which is like the only treatment that works for the Polish patients for many different reasons. But it's the only thing that works if you do not follow the diet you can either die or become severely disabled. The problem is that because you know the treatment is the diet and those people, are those children - the families - they "look normal."

Fady - Right.

Anna - It's not visible. They are not treated as people with any kind of disability. It's not recognized as disability. It's more like a potential of disability. The problem is that they caregivers, so usually mothers, you know, they have to follow the requirements of the diet so they have to make every meal, count calories, count proteins, and everything it's like the full-time job. And they are not getting paid.

Fady - Those issues around like like who, sorry, I guess there's issues around the in terms of like getting funding in order to kind of stay at home full-time in order to care for their young children that doesn't actually get recognized by the state.

Anna - Yes exactly. So if those children were recognized as having a disability then it would be much less of a problem, because there are, you know, there is welfare there are funds for caregivers. But then the person who you're paying for has to be recognized as having a disability and it's really hard to, you know, like prove to the system but my child is having a disability because it's not showing. You know, it's... some of the doctors that I've interviewed they say, "like it's only a diet." Which is partially true, it's just it's not seen in the way that it's, you know, it's helpful for anyone.

Fady - Yeah, so have you have they done anything like have their parents done anything in particular to try to get their kids recognized... as having a disability? Had there any been like interesting stories or interesting methods that they've used?

Anna - Oh sure because they most of those parents, in case of LCAD, I know almost every single patient's parent is on the Facebook group for this you know for this group of patients. So what is happening if one of the families is having problem with getting their benefits, other parents are helping them. So for example they're sending them their documentation; everything just to prove that you know they their child got the benefits. So this child is the same should, you know, should have the same support and everything. So it's more like grassroots movement, so they can do anything on the like the higher level, sure, it's really hard. There are plans to change it, although no one really knows if those changes are good... those changes are gonna be for good or you know, yeah - but changes no one knows. Yeah so for now, it's more like aggressive movements to you know like to help each other sending documents sending their own you know paperwork for for those other parents to to use in front of a court, let's say. So, yeah so that's what's been what's been happening. The problem is that those welfare committees they're like different in different cities. There are hundreds of them if not thousands in Poland. So every single committee can make you know their own choice. So that's the problem and if you are showing that other children are treated this way, there is a chance that your child will be treated the same. Yeah, so it's like very, for me it was very inspiring to see like this kind of parental activism in that forum which was like on the, like internet platform. They've never met in person but they know what they need and they know how to help...

Fady - And like they know that it's important - because they're setting a precedent, right? So they know it's important - like if one child gets it or if one one, one of them is recognized as having a disability, that it's more likely for more and more and more other people to get recognized, which is yeah...which is great. I mean they were are really building like a like an network online.

Anna - Yes, yes that's exactly what it is. So I know that in case of the PKU it works pretty much the same. So they're just that those parents are fighting for their children to be recognized as disabled which may sound you know strange. You don't want your child to be seen as disabled but in that case it's you know for their own benefit. So that's, you know, it was when I was doing research it was kind of a tough question because you're asking those parents like is your child disabled? How do you think? And they were like, "In some instances, yes, yeah but generally, not.

Fady - Yeah that's true... like it's not I think... that idea of like disability

is true for lots of different groups, right? It's not just like people with like rare disorders. Like the problem with the state right is they require disability to look and act one way, right? When in fact like we know that disability comes and goes, that disability is not always around us like as disabled people. We don't experience it all the time, the same way, and so it's interesting how like the the threshold you have to pass in order to get support is sometimes too high, right? And what your research I feel like is demonstrating is like you know that we that the definition of disability actually might need to be consulted, right? Like actually considered... Maybe that it's too stringent.

Anna - Yeah, yeah, absolutely I mean it's very contextual because if you look at the situation of those families, for example, when they are at home with their families even having dinner which is like very - you know - specific time... let's say yeah they are not disciplined - you know - they do not have any kind of this ability but when it comes to let's say education or the welfare they are very much you know disadvantaged. So I think that it shows that the the current understanding, let's say legal understanding of disabilities is very disappointing.

Fady - Yeah so I want to know like what are what kind of theory or what kind of approach are you taking besides disability studies? Like are you reading anyone that is helping you with your analysis?

Anna - Mm-hmm it's a great question.

The answer to that is I'm not following any particular theory only. Because what I've done is I let those families like show me whatever they feel is important in their experience. So I've been just following this experience and whatever showed up, showed up. So I I will just, you know, I let them do whatever they wish to you know they just they introduced me to their lives. So aside of the disability studies, there are of course of course childhood studies - because most of the people that I've met with those disorders are children.

Fady - Yeah, so how does that inform your work?

Anna - That's you know you have of course a big question about the methodology. If you want to do research with children, how do you approach it? How do you know make the children, you know, as you know as a participant? What kind of other methods other than the interview you can use? So I decided that I didn't at that time I didn't feel equipped. However, I never like in those situations of of research in the interviews, which happened mostly at home, children were always present, so if they wanted to add anything they could. They were very much welcomed. I just didn't, I just didn't do my research only with children because of the methodological issues that concern doing research with children. So I didn't do that, however, they were welcomed and they could, you know, add whatever they wanted. I was speaking with them, I was playing with

them, you know, we had walks, we had like playdates and so on. Just.. just.. we, I mean, they were not the main...

Fady - They weren't the main participants.

Anna - They weren't the main participants because I I just didn't feel that, I'm you know, I can do that at that time. Now, I'm maybe a bit more wise. I could do that but at the time. Now however... It's something that I might do at some point in the future because I find it really interesting. Very exciting. Oh maybe next time.

Fady - Yeah for your postdoc, it's like the next step, right? You did the family and now you need you know you can now do the specific individuals. I know you did you did once tell me that you did do participant observation for weeks with an older, with an older person.

Anna - Yes so... With some of those families that I've met, I stayed for a few days so even weeks, as you say, because I wanted to see how they are experiencing the disease in everyday life. So you can imagine preparing meals it's like everyday struggle and I also wanted to see the dynamics at the table so I was spending at least a few hours in each household. And in some cases even days or in one case, as you say, a few weeks. So that was the the the person that you are talking about I actually became friends with her and she allowed me to spend two weeks with her. So we were living together, we are cooking together, and we were working together for those two weeks so I could see how it's, you know, what does it take to well stay healthy and stay alive.

Fady - Yeah this is really immersive like methodologically like really immersive experience into you know someone's life. Sure you got lots of information from doing that.

Anna - Yes, yes so we were you know, not only like living together, I was eating the same as she was, of course because we were cooking together, so I also for those two weeks I was also following her diet which was very like high in calories and without any fats so that was interesting.

Fady - Was it hard, was it hard changing your diet like that?

Anna - Umm, not really not that much, because on this diet you can eat... you can eat rice and pasta and lean meat and let's say zero percent fat yogurts and milk and so on. So you can make most of the things that you probably usually eat, right? Just changing it slightly the bigger problem was that you know we were eating constantly or at least drinking very sweet tea.

Fady - So it was the amount of food that was really difficult.

Anna - Yeah, yes so that was that that's when I understood... because you know I just I found out at some point that those people they do not truly feel hunger because if you have to eat constantly you never really experienced hunger. So that was that was very interesting because I I didn't feel hungry for like two weeks.

Fady - So other... I want to ask about like now I know you're writing your research now so you're like coming up with like your analysis and your ideas. I'm wondering like are... is there any really interesting thing that you can share with us? Like your results or outcomes? Things that you think you know are kind of really important that you learned about disability from doing this work?

Anna - Yeah, so I think what I found for what was interesting to me was that there's a lot of disabilities that you cannot see. And that was something very interesting, because I didn't only follow those patients but I also, you know, I - it was going to the conferences about rare disorders and so on so on. So I've met a lot of people with other types of disorders, rare disorders. Most of them... in most cases you couldn't tell that there's anything different about them. You couldn't say that, you know, they have some problems in their everyday life. They just look like everyone else. So that's really eye-opening for me, that you, because you know I've been I - the issue of disability was present in my life for many years because my sister has a disability. And so that was, so you know of this for me that there are some cases when it's just so obvious you can look and tell. And here in that case you - just just - cannot and there... are there are estimates that there are like two and a half million, three million people with rare disorders in Poland. Which means there is a huge group of people with invisible disabilities in our country. So that was something that I've learned during my research.

Fady - Yeah, two and a half three million people who may not be getting the support or help that they need because their disability isn't kind of recognized.

Anna - Yes it's not recognized and what's no it's more important probably it's not visible. So it's not all problem, in let's say welfare system, it's also a problem in their everyday life because they are not know easily recognized as having a disability. That's a huge group and I didn't realize that before.

Fady - Well your research sounds so exciting and so fascinating I can't wait - I know it's gonna be written up in Polish - for most of it but I'm so glad that's you know an English audience will get to hear about some of it through this podcast. And who knows, maybe you'll translate it someday into English or other languages so that you know we in the in the I guess majority world can can cite it and work with it. But I did want to move to Segment number two. Now I call segment number two, "In the Middle (The Liminal)" And I'd like to ask you who's your current academic crush? Who are you reading or who are you listening to or watching that you just absolutely are in love with?

Anna - That is a great question because I don't have it currently. I don't have any academic crush. Maybe you could say that I have because my partner is an academic

Fady - Oh, I love that answer, so sweet.

Anna - Yeah but you know what I have a really soft spot for something really let's say unusual.

Fady - Yeah?

Anna - I really love ethnographic work, polish ethnographic work from before the Second World War. So from nineteen thirties. I really really do love it. I mean it's piece of really great literature, yeah. So there's a lot of you know... they were they were doing their their studies about the folk culture in Poland in the 1930s. A piece of really good literature. It's so easy and also very poetic sometimes and with all the methodological issues... I mean really really lovely. Just to read about the rural lives of folks at the time.

Fady - That's so wonderful. Also like before, you know, things changed forever in Poland. That's so cool I think that qualifies definitely as an academic crush. So who, if you...if you, could give advice - you are currently still a candidate - but you've been through quite a bit now and I wondered if you had any advice for other students or young academics who may be listening and who wondered about you know what if you had any kind of piece of wisdom you could give them?

Anna - Yeah so I guess the main advice I could give them is follow your passion. Because I knew since I was 12 years old that I want to be an anthropologist and you know I did that.

Fady - Right!

Anna - You finish your studies but you love what you're doing you find a way to pursue it one way or the other. But if you do love it, if you're good at it, and you probably are if you love it, then you should pursue it. And it will work out, somehow in some way, at some point... so just follow it.

Fady - That's great. That's great. Okay we're on to segment three. Segment three is called "Outside the project/research/work/art. I'd like to ask you about your most famous interaction. So who's the most famous person you've met and what was the story?"

Anna - Okay so that's a funny question because in my private life, my family works in show business here, in Poland.

Fady - No way!

Anna - Yes, so you know I've met a lot of people in show business here - actors, musicians, and so on. But I don't think you know any of those people... When I grew up my father was working in the theater so I spent a lot of time in theater when I was a child and I really love this smell of the stage in theater it's lovely. So I cannot really tell you but I can tell you that I've met...you

probably know Thomas Csordas - at the academic. He's very famous from his from... his work about the embodiment from the 1990s. And I've met him at the conference. He asked me about the situation...he was playing on the guitar and singing blues for us. He's such a great musician. He was singing songs - blues songs - about the anthropology. Yes, so that's was the encounter that's so funny.

Fady - That's so great. Okay, uh so um I want to know what obscure fact or idea do you carry around with you? Like what.. what piece of information, the thing that you pull up, you know, at a social gathering when things are awkward.

Anna - That is a funny question. I was thinking about it and maybe I would say in case of disability that people with Down syndrome usually have straight hair.

Fady - Oh really?

Anna - Yes they cannot .. they very, very, very. rarely have curly hair. Even if they're like African-American. Yes they have straight, thin hair.

Fady - And so I guess the context is that your sister has Down Syndrome and this is like why you, well you have this piece of information.

Anna - Yeah exactly and her hair is very straight.

Fady - Right. That is an obscure fact. I did not know that.

Anna - Your welcome!

Fady - So besides reading besides reading 1930s polish anthropology what are you currently reading that you feel like other people should be reading?

Anna - Oh I don't know if they should be reading but in those hard times of quarantine I really like some, you know, if you're sure that's easy to read so I've been reading do you know the Netflix series "The Witcher?"

Fady - Ya!

Anna - So it was written by a Polish author. His name is Sapkowski, Andrzej Sapkowski and so I've been reading those books lately. Because it's like a really good fantasy. Yeah I like them. I like them. I never thought that I would like fantasy books but I do.

Fady - Okay I'm gonna have to pick those up then. I really like fantasy so... I didn't like the Netflix show, I have to admit. Not that this is a podcast about you know critiquing Netflix shows. But I was not a fan of the Netflix show, so maybe the book will be better.

Anna - Yeah it's much better than the Netflix series.

Fady - And do you have a current hobby besides you know petting your cat who's named "the cat" in Polish? What kind of hobbies are you enjoying and how did you get started in them?

Ann - Okay so hmm I really...I'm really into the history of fashion so I've been reading a lot about the subject and I'm also following like every single account above this on the Instagram like crazy. So I'm not sure how it started. I think it has something to do with the theater. I guess so yeah I'm not only like it's not only like you read about it or follow my Instagram account but also once a year we are organizing this huge 1920s party. So for three days we are dressing in the 1920s style.

Fady - Cool!

Anna - Yeah so that's that's really great and I like vintage - vintage hairstyles which is really hard to do. But I can...

Fady - That's so cool. That sounds like so much fun. So why three days? Do you guys like do other things besides just dress up?

Anna - Yeah so we have on the first date it's like gangsters and flappers party. The next day there's like a swimming pool from the 1920s or thirties, in the next city. So we are up there in full like nineteen twenties gear - swimsuits you know and all those things and then we have like a huge ball. So that's why three days.

Fady - What a weekend. That sounds like a fun weekend.

Anna - It is! And a lot of champagne.

Fady - Of course, of course. So we'll end as we always do with me asking. And finally, how do you think disability can save the world?

Anna - Oh I think it's very important to have diversity in our society. It's something that makes...Diversity is something that makes people more aware of others and now, in times of the epidemic and pandemic I think we we are looking at the vulnerables much more often. Because of the people with different types of you know pre-existing conditions and disabilities. Everything that we are doing... most of the things that we've been doing - as not the healthy part of the society - is to protect them so in my opinion not only it makes us aware of others but also makes our work more diverse. Which is a, you know, really important beautiful thing.

Fady - Yeah. Absolutely. Well, Anna it was absolutely wonderful to speak with you. I'm so excited about your work. I'm disappointed that we had to end our time together in London

early, but hopefully we'll meet again and I'm glad that we got to catch up again here today. (Music starts). So thank you, so much for coming on.

Anna - Thank you for inviting me. It was lovely to talk to you.

Fady - Thanks again to Anna Chowanec for coming on the show today. Next week, we'll be joined by Danielle Landry from York University. Excited to have her on the show. This podcast is hosted, produced, and edited by me, Dr. Fady Shanouda. Thank you for listening and if you have any questions or would like to send me an email you can do that now on the email connected to this podcast which is [disabilitysavestheworld@gmail.com](mailto:disabilitysavestheworld@gmail.com). You can also check out my work if you're interested at [fadyshanouda.com](http://fadyshanouda.com). Thank you again for listening and we'll see you next time on Disability Saves the World. (Music Ends).