



**Season 1 Episode 10:  
How to be an Able-Bodied Advocate: Intellectual Disabilities?**

Transcription possible by Wreally. [Transcribe.wreally.com](https://www.transcribe.wreally.com)

[www.disarmingdisability.com](http://www.disarmingdisability.com)

[Upbeat intro music]

Nicole:

Hey.

Sarah:

Hey!

Nicole:

Hey! Dona nana nana, nana. Nana, I don't know the next words that I never know the words to songs though.

Sarah:

I don't either I just sing and I don't even sing along them right people are like what are you thinking? I was like, I know you know the song it goes. No, it's like the easiest thing to saying and writing but what look, you know, what can't you sing bye-bye, right cool?

Sarah:

So here we are. We are in episode 10- 10 this has been quite an adventure. How you how you feel about Nikki?

Nicole:

Oh man, Sarah. I mean first of all like selfishly getting to spend a lot of time with you has been fantastic because for those of you who don't know like Sarah and I like we knew each other but we've really had to get into know each other. We took like personality profiles before we started working together laid a bunch of groundwork and we set rules and expectations and we did our strengths and our weaknesses and we did all of this huge amount of homework before we ever even really agreed to do a podcast and then we got to a point where we just like had to push the baby bird off the cliff and that was Disarming Disability that we push off this clip. Yeah, and after we pushed it off the cliff, we've just been kind of trying to fly and it is Been, deep breath. It has been super rewarding. / so exhausting. Would you agree with that?

Sarah:

Absolutely exhausting and it's like every week there is this all of these little details and because we want to produce good content and it's not just recording. It's not just

calling someone and having a 45-minute conversation with them. It's all of the legwork building the relationship in order to be able to even ask that person if they want to come on and and and talk to us and then developing all the questions and and how we want to outline the conversation with them. But then it's also like transcribing episodes, that takes a long time and and coming up with discussion questions and making sure that we're being really intentional about what we are producing and that it's not, like yes, it is a podcast but it's larger than actually recording and putting that out because it's not just that. And learning what are those little details that need to be taken and and done sort of in between. So I'm learning a lot totally.

Nicole:

Yeah, it's been really really fun and scary and just like you said like both the thing that we have in common is we both. Well, there's a couple things we do way too much. Yes, we do way too much because we feel so passionately about the message that we have and the words that we want to share. So we're just juggling lots of personal projects, but that's great because we're both investing and a lot of our different identities and I think we need to in order to be balanced human beings,

Sarah:

right right

Nicole:

You know, we're fighting with with full-time actual full time jobs or full-time school or whatever it is. So it's been it's been amazing. And I know that we'll talk more about this once we get to our final episode and we actually are deconstructing and talking about what season 2 will look like and and already already in this season. There are so many things that were like great in season 2 we're going to do it this way. Like that's such a common talk to each other now, which is fun to it's fun to be in a space where we're close enough to the like the finished the first Finish Line where we'll be able to like regroup make things better and like fly again or like a pushed off the different Cliff, right? Yeah, so it's good but it's exhausting and real life happens man realize how it goes in. Yeah, so I don't know. That's how I'm feeling.

Sarah:

What about you? How are you feeling? I feel this I mean, I feel very similarly. I also want to reflect back on. I think it was in our first couple of episodes where we were really talking about what we want to do with this and why we're doing it and what we believe in and there was a moment where you're like, this is what Sarah and I have been doing where we this is what we've been spending our free time on and I think that's really important that like all of this is our free time and again all of our personal projects like this isn't the only thing that I'm doing and and I'm sure you've had messages like this to I had a friend text me. She's like, "oh my God, you did this and you did this and you did this and your field where I can you're living in a new city and she's like do you ever sleep?" and "I was like, no!" like I don't know and then trying to remember to like actually take time for myself to take care of my body and and like do fun things with friends that has no other like larger, impact, meaning, for society other than just enjoying time alone and doing peep time with people that I love and not feeling so stressed out with all my little to-do lists because those are all my projects like yes, I'm sure yeah,

Nicole:

I definitely feel that sense of it's weird because yet again this like fire that we keep talking about that we've let this life that's turned on in both of us, it gives you this huge sense of responsibility. Like I feel like I have this responsibility to be doing something like that and think about wasn't a podcast. It would be some other version of what we're doing. And so that responsibility is a really real feeling to me and it and it's hard it's hard because you want to like fulfill that responsibility or find ways that you're feeling like you're connecting to the community while also, you know, like having a beer with your friends on Friday night and not feeling guilty because you're not transcribing episodes, you know, yes.

Sarah:

Yes. Yes and I think yeah and I really think that that's what helps helps all those late nights and all those early mornings is that we just believe in this so much so that helps kind of drive and push us forward, which is fun.

Nicole:

It's really it's been a ride man. It has been a ride. We're not done yet. So we're out there quite yet,

Sarah:

But we're getting close and I think it's important to take moments of like look at where we've come and I think that self-reflection is really important through all stages of this. I think self-reflection and general is really important and also, Just about all of this. So it's important to take a moment moment and be appreciative of where we come and appreciative of what we created and knowing how we can do it differently for next time but not getting hung up on like well if we just done this or this is just happened because I think it's really easy to get stuck in those circles and those sort of like cycles or one of my those scripts in our minds. So it's good to come over at so yes, we are doing it's also summer's coming. So I'm just really excited to be out of the winter and and sort of just really looking forward to what summer brings and just places of joy and happiness in total each a totally totally and change life is changing.

Nicole:

Yeah. Yeah so cool. Well should we move on and introduce Our Guest?

Sarah:

Yes!

Nicole:

All right. Let's hop into it. Let's waste no more time. Here we go. Luca Badetti is a doctor in disability studies with a background in Clinical Psychology and theology Luca promotes individual and Community growth holistically and inclusively. He teaches at Loyola University in Chicago has Institute of pastoral studies and DePaul University's peace Justice and conflict study programs. He's involved with L'arche communities of shared life between people with and without intellectual disabilities and he is given a TED Talk based on his community "experience called embrace" your inabilities more info on Lucas background may be found at [Luccabadetti.com](http://Luccabadetti.com)

Sarah

Okay, wonderful. Well Luca how has your week been?

Luca:

Hello. I'm the week has been going pretty well. I'm currently in Rome. I came back here in January. I was in Chicago just before so it's been a good week so far.

Sarah:

That's fabulous. I'm very jealous. I wish I was in Rome right now. That's okay. We've got stuff for today. You're going to talk to us about through the relationship in being an ally so let's just open up and go right into it. What does it mean to be an ally for people with disabilities?

Luca:

Well, to me I've discovered the disability world through meeting individuals with disabilities and becoming a friend so entering into mutual friendships. And from there I got to know the disability culture the disability population the needs of the disability world. So to be an ally I think is too, at least that's one way of understanding it, is to recognize the needs of people with disabilities and too advocate for them and to Journey alongside people with disabilities.

Sarah:

Mmm, I love that. I know in one of the TED Talks that I watch of you which will put that link on our website too, so you can see it there. I know in the Ted Talk you'd spoken about this our inabilities and that everyone has an inability that there are things that we are unable to do and require help for doing can you talk a little bit about that sort of in your experience and being an ally?

Luca:

Yeah. Well, first of all, you know, the the choice of inabilities was I think relevant because it's something that we can all relate to basically we all have abilities and we all have in abilities. There is some disagreement as to whether we're all disabled or not. Some people say no absolutely not because you know, we don't want to diminish the experience of people with specific physical and intellectual disabilities if we start saying they were all disabled. Why some people are more towards the well, we all have disabilities, but they often seem to actually mean inabilities when they say that although it's also true that disability. I think it's becoming more and more of a fluid identity in some ways many of us can identify as disabled maybe you know as we age or as different as we experience different things. So I think the the term disability now is using a more fluid way. But anyway in living in community with people with intellectual disabilities, I really sort of saw with my own eyes, how we all need one another so it's not just people with disabilities needing the help of people without disabilities or vice versa. It's about mutual relationships, you know. So to me meeting people with disabilities was about entering into friendship when I first started living in L'arche, which is a community in which people with and without intellectual disabilities live together in a spirit of belonging and that is impacted me deeply and I've learned a lot from that experience both about being a friend and being an ally.

Sarah:

yes, when I think it's really important this concept of being a friend and that you are in this, words that I heard were like "Mutual relationship" with someone that you were "equals" in that relationship and that it's not someone who is like here. I'm

going to be your ally I have all the answers. I have all these capabilities. I'm going to help you person with a disability because you're sort of this like under person in our society. So like look, I'm wonderful and I'm giving you these things and I need to be praised on how wonderful I am. Because that's not the narrative that we want and that's that's not the power differential that were seeking either and I think that what you're saying about that Mutual friendship that equality that it's like these are two people and these friendships exist and they're beautiful where you do have that that equality there.

Luca:

Also because you know when we say, ally to you know, the people with disabilities there is a profound Beauty there in regards to awareness and sensitivity and joining with but we don't want to just, how should I put it? It can be easy to stay outside of the group if we just say, "Well, I care about disability issues" Okay? But I think when we become friends, there is an actual involvement. And a relationship that happens in which it's not just a people, a group, but it's also individuals with their own specific needs and their own stories and their own desires and needs and wants um so yes, I'm an ally of people with disabilities, but I'm also a friend of Tom, Jimmy, Sarah etc, etc.

Sarah:

Can you speak a little bit more about some of these relationships that you've had?

Luca:

Yeah. So I discovered about L'Arche which is a French word for "the arc" because the this movement of community was started in France. They are all over the world. I felt I needed I wanted community and there was something special about this community in which Day-to-day life, you know was lived in like very simple way. And so I went and the first in the I remember the first my first visit. I just went with one of the core members, That's how people with disabilities are called enlarged in the English-speaking World, core because they're at the heart of community. I mean the first time I went to visit I went with a core member and a house coordinator, you know grocery shopping. And you know, many people might have other organizations might have different types of orientations, so to speak when new people arrive. Well, I was just visiting but you know going to the supermarket, you know, it's such a simple thing, but you're doing it together and that's really important, you know, it changes the experience. So even going grocery shopping, you know was something that can be shared. I've learned a lot from people with intellectual disabilities, about what it means to be human. I think we are such a society that is a bit obsessed with intellectual power and it excludes people that it deems not smart enough or not quick enough or not productive enough, etc, etc. and we see this a lot in our with older people with dementia, etc, etc. That they're not really the kind of outside of of the social social cultural milieu, you know. And I think at the heart of being human is not just you know reason but the heart living in relationship with people and I think with people we need to like some people with intellectual disabilities have helped me say this. I still remember one day I was away for a, I was away for vacation and I came back to the house where I was living in.

And the core member and a core member who is a friend of mine and who has Down syndrome, you know, as soon as I came in he welcomed me. Give me a hug and he looked at me in the eyes, and he said did you miss me? You know, did I miss him when I was gone. And it was such a vulnerability and honesty in that statement. There is just one example of how living in community can really sort of bring us together and make us feel that we are part where an important part of of a bigger whole, you know, in which both people with intellectual disabilities and without are important.

Sarah:

Right. So right when I know things that we I'm in school to be an Occupational Therapist as well. So I know things that we talk about all the time in occupational therapy is people engaging in their meaningful activities and going back to grocery shopping like that is a daily tasks that people need to do and want to do and enjoy doing or don't like doing regardless that's an aspect of daily living and not all people, you know have have rights to enjoy and and engage in all those parts of daily living whatever that looks like and to whatever degree people are able and want to be able to engage in those type of types of things. And I think that it's easy to see and I know even in my own life and you know, when people see my hand and then they start asking a lot of questions and they're like, oh well, how do you do your hair? How do you do this? I need this and you're like well like I do them. I don't just sit in my room and like wait for people to do them for me and like yes, sometimes I drops off or sometimes it's clunky or sometimes I need to you know, do 10 extra steps to do things. But it just is this interesting.

But I think because we don't see a lot of disability in our media and and we don't know the social scripts around it overall as a society that we sort of assume because we're not seeing it. We can't imagine what it can look like and and that we think that people are sort of just this recipients of care sort of unable to do a lot of things and and that's so not true and that yes people with disabilities are going grocery shopping and they are playing games with their friends and they are sitting around and eating dinner and helping to make dinner and that these are all opportunities that people can meaningfully engaged in things in their lives and then that helps develop those meaningful relationships and those real friendships that all of us want to do and can do and are capable of doing and that like capacity for love isn't limited to people who are able-bodied if you will, but it doesn't those are things that we all have access to do and it can look different amongst different people, but we still have the ability to do so.

Luca:

You mentioned an important word which is enjoyment, you know, like often people with disability uh, people have often tried to change people with disabilities people with intellectual disabilities. Why you should learn more is to do these days where you act that way. You should be hit that with proper. Yeah, and yes, we want people to grow in their skills to help people, you know achieve, you know what they want, etc. Etc. And I think friendship brings that element of also enjoying time together. I remember one of the common between going out to drive. I mean I used to drive and

we just used to go on a ride and listen to music, you know, because it's something that we enjoy doing together.

Sarah:

Based on that that component of friendship and I think even the word friendship similarly to the word partner shares that equality and mutual respect and understanding for the other person and that level and again just sort of reiterating that aspect of equality to which I think is important and that these relationships are real and exist and are important

Luca:

but we also have to become that we also have to be honest and aware of power dynamics and differences you bring in the issue of power is really important. Yeah, so like sometimes when we use the word, well, you know when people use the words like, you know, "we're like a family" or "we're all friend" etc. Etc. Hopefully yes, as long as that doesn't hide what can be or what are you know, power imbalances, you know? Yeah. Yeah.

Sarah:

Do you have ways to sort of appropriately navigate power imbalances? Well, I think the first step is really important.

Luca:

Yeah, it first happened. It really important step is to be aware of those. You know when people say that "awareness can bring about change" you know, first some people are not aware of them. They don't see them for some people. It's like they're so steeped in power dynamics that they cannot see a whole lot from you know from the outside source of thing or kind of, you know, distance himself from it from them a little bit. I think once we become aware of them and are even able to talk about them, you know, I think change change can happen there, but often you might need training or someone to help you see that because if people are too immersed in them, they might not be able to see them right away.

Sarah:

Yeah, that reminds me of a book that I'm reading right now. It's called Counseling People with Disfigurement that was written by Eileen Bradbury. I think and she talks a lot about this aspect of helping and sort of who the helper is and what the helper role is and it's not the responsibility of the helper to come in and solve things and it's the responsibility of the helper and the person who is receiving help to join in this mutual agreement of what help is needed that's derived from the individual who's who wants the help and the individual who's able to provide the help but it's this mutual relationship. They talk about like scaffolding and structuring their relationship. So that expectations are managed on both ends and they know what that looks like and the helper is there to help the person achieve the components that they want to achieve. So the helper is not finding all the answers. The helper is not telling the person how to do XY and Z and that if you need this done while you have to do this way and these are the things that you need to do to resolve whatever situation but more so there to help guide that person so that they can find the answers on their own within themselves as much as possible and then you know sort of like when that relationship ends then than understanding that yes, we received the

help and we gave the help and it's over versus someone becoming really dependent on the helper and that helper then gaining the sort of power dynamics where the helpers is the only person that's able to do or help with this certain tasks and then the person becomes dependent on the helper and then the relationship sort of gets exploited in that way. So I just thought that was really interesting that it was both people are entering with this mutual agreement and then understanding what that is and then ultimately the person who wants to help is working to try to find those answers on their own versus being told what they needed to do they

Luca:

it kind of brings up to I mean the importance of the disability rights movement and the advocacy movement how far we've gone because years at least if I think about the population of people with intellectual disabilities. I mean the era of institutionalization it's not a long ago, you know, so a lot has been changed not everything. I mean there is still some mentality which is quite institutional, but there is been quite some change happening. I also want to sort of go back just briefly to the when you asked about ally.

Sarah:

Yes

Luca:

I really really am interested in learning more and more. How do we learn or how do we how can we hear the needs of people with profound intellectual disabilities? People might not be able to speak move etcetera. And in that sense that the ally being an ally so important because many people. I mean people can communicate in different ways, right? I think also someone who cannot move cannot speak can still communicate and be a presence. I'd like to learn more and more doll how to better here cuz it's not always an easy thing, but it's an important thing, you know. And I think being an ally for people with profound intellectual disability people that cannot speak for themselves. It's it's really important and often that not really talked about. That kind of Forgotten which is a pity, you know.

Sarah:

Right. It is absolutely and they're humans and they exist in their people and they have wants and desires and feelings that people have because we are human Yeah. No, yes, and they experiencing and having that be very difficult to communicate people to people, you know, sort of what those needs and desires are. cool. I'm also thinking sort of in this relationship that we have and when we are working on being an ally sort of exploring other things that are important to really understand about ourselves as we're taking on being an ally role. I know one of them was sort of understanding the power differential dynamic that could exist in being really mindful of that. Are there other types of things that are important to know within ourselves in order to be effective allies.

Luca:

Hmm, something to think here. This is a good question. I think see there are so many different ways of being an ally so it's a bit difficult to for example, somebody might have a friend with a disability and their friend tells them that you know, the city is not accessible. So they might join into being an ally for accessibility, which is great some other people might know even more about disability issues in general so

they might actually study them and they might actually inform themselves about all different kinds of issues. So I think there can be different ways of becoming an ally that it's alright not to just think of, you know one advice for Orala, so to speak for everybody.

Sarah:

Oh, yeah.

Luca:

I think it's important too always here the experience of people with disabilities. And to give space to that and not imposing one's understanding on it. But to really make space or look what is your experience to try to understand it to hear what the needs are. So that you can be you know an informed ally, you know, that's really important.

Sarah:

Yes. Yes absolutely hearing and giving the space in order to listen and I love that aspect of not interjecting. I think that goes back to that helping model to I was I was trying to explain to her that that not just providing answers but really helping to hear and understand and give space for someone to share what their needs are and maybe their needs aren't an ally thinks that their needs should be. So I think that that's really important to also can you explain a little bit more of different roles of ally? So I know the one that you had mentioned was helping to advocate for a more accessible City whether that be like bus stops that are more accessible or t-stops that are more, you know Metro train stops that are more accessible things that way what are what are other ways that people can be allies?

Luca:

Well well, Just some that come to mind, Standing up against, you know. How do you call when bullets mm bullying?

Sarah:

Bullying? Yes, Bullying

Luca:

Yes, standing up against bullying when people with intellectual disabilities, you know are being bullied to stand up and speak out for people with disabilities, you know against the bullying I think also for example of bringing disability issues and disability discourses into everyday conversations disability issues are really in some way, They are about us all in different ways in one way. I was saying before how disability can be a fluid identity, words anyone might experience a physical disability or an intellectual or whatever at some point in their lives. So disability issues are not just about them, you know the group of employees of it, but they can actually they affect us all at the same time. They're about us all because at least the social model of disability, which is a sort of way of looking at disability that emphasizes the social and structural barriers that people with impairments face. Well, the social model says that this ability in some ways created by oppressive social and structural barriers and therefore we are all we should all ask ourselves that question or how can we change our social structures and contexts so that they become more enabling so really bringing disabilities as into many conversations is a way of being an ally right, you know, it's like this issues matter, you know. Yeah, I then there is I mean many other ways you can just you know speaking about friendships of experiences that people

might have had with disability with people with disabilities. Sometimes it can be as simple as that. So of course participating in disability causes, politics Etc so many different levels. mmm

Sarah:

And the politics also makes me think about be aiming again. We should be mindful and all things related to politics especially with those and policies that are being written but really understanding how laws right now, especially with healthcare because that's something that's always a dynamic here in the United States and that looking at how those policies whether that's granting access or limiting access or sort of capping reimbursements or things like that how that really is impacting people with disabilities in the services that they're able to access and then also knowing that if people at any point like you had said could encounter disability and their own lives and then those policies are then impacting them to so it really is all of us and I think that's something to be really mindful of to really understanding what reimbursement looks like

Luca:

hmm

Sarah:

Well, wonderful. We also want to be mindful of your time to is there anything that's we didn't talk about that is really important to talk about or that you'd like to share.

Luca:

Mmm Can I say now? Okay.

Sarah:

Yes, please. Well, it's really interesting how to also engage into Intercultural dialogue in regards to disability. I just saw the course on Theology of disability this one and I started one disability studies and introduction any way to have students from all over the world And the their unique cultural experience of disability is quite interesting. I think sometimes at least you know, I have a doctor in disability studies, which is a discipline. That is developed quite a bit in the western world. And I mean, I don't have an answer. It's a question, you know, and in teaching this course has helped me sort of, become aware of it more. Yeah, how do we how do we engage in Multicultural dialogue? I mean we can but when people might have very different cultural, understandings of disability and becoming an ally, you know, the people with disabilities and recognizing our own cultural framework that we operate in you know, it's more of a question. I don't think it's just a question that maybe for another conversation or to explore more deeply.

Sarah:

You're an academic!

Luca:

Well, these are all questions questions are so important.

Sarah:

Are they are!

Luca:

Who what is it? Maria Rilke or something? Someone? Yeah, Maria Rico. I think who if I'm not mistaken is mentioned that you can believe that no problem. You know like she like perfect. Okay, where was it being in touch with the questions? Sometimes may lead you into the answer. Yeah, yeah. Yeah, you know just already because often we think we have to solve or find the answer but sometimes just knowing what the question is moves as in the direction, you know, so yes.

Sarah:

Yes. Yes, it does when I think about that in a cultural context to and different courses that I've taken it's important to not sort of try to go in and implement things that are going to change a culture right and in that we are appreciating respecting the cultures that we all are living in but then how can we also ensure that the culture is supportive and respectful of all people within the culture. I think it's hard to to sort of piece through all of that and and that disability looks very different in lots of different cultures with saying culture or five times its and knowing that a different sort of groups. Explain disability differently and and correlate different things to disability as well. And and whether that's a heavily religious component or whether that's a heavily sort of like guilt component or whether that's a pride component and that that looks differently. So so looking at someone who is in a western culture studying disability and trying to really be promote and prideful of people with disability to then feel, you know to help find others in other cultures access their pride to that's a big question.

Luca:

It's quite something to see how, when like in speaking about empowerment it speaking about helping remove disabling barriers how there can be such a "yes, that makes sense" kind of thing across cultures, you know, so I think yes, there are cultural differences, but also there is like I think a human, how should I put it, like a in a human sense. About what is past and what is not you know, and then you know it yes cultures are different. But at the same time we're all human, you know, so I think if we can connect at that level. Yeah, how can we leave more humanely and how can we help people leave more humanely,

Sarah:

Right?

Luca:

I think we can connect across cultures, you know.

Sarah:

Yes. Yes. Yeah that reminds me of something I wrote in my journal when I was on my exchange didn't trip and I know that Italy and the United States are both sort of Western cultures. But one thing I wrote was that like people are like laughing and crying here right now at the same time that I'm laughing and crying and that I don't speak Italian and I don't know the movie that they're talking about but I can still connect with people on a very human level and laugh and cry with people even though I don't know the larger context of what's happening, but I still feel it. I still feel that this is a really excited moment and someone is really happy so I can still connect on that level of being happy with someone and on the flip side to being angry with someone being sad with someone, you know, being excited or any of these other emotions, we're still humans and people feel them across cultures cross

disabilities cross, you know, yes all of them things and that we can connect on that humans.

Luca:

There is a beauty about presence heart beyond words beyond ideas, you know, I'm reminded. I mean this really I stayed in in my mind. I've actually just written a book called *I Believe In You* and this was this I stayed with me so much that I've included as the sort of and at the end of the book is sort of you know in the epilogue. I was in a large home and the certain point. I was watching a cartoon with a core member because he liked that cartoon. And you know, so that was nice. What's the cartoon Etc? And then I see books by my side. You know, there was a bookshelf or something. I pick up a book. I started reading it and he touches the book and closes it. You know beyond yes words and ideas and one more book and you know, it's like watching the cartoon together. It's fine enough, you know present.

Sarah:

Presence in that Human Experience and listening and hearing and opening them that space. Those are all really beautiful thing.

Luca:

Maybe that helps. I mean being an ally, you know, like being able to connect to people's experiences and their needs this is really valuable now.

Sarah:

Yes, it was wonderful. Look great. Okay. Wonderful. Thank you so much for your time Lucaa. I really appreciate it. It's been a really wonderful conversation. I'm so excited

Luca:

We could talk like this for hours. We can go hours. It's nice space for share some of the experience. I'm glad you wanted to hear it and thank you for doing this needed.

We want to give special thanks to our Network Public House Media for our intro beats Jason Barnes at cybrntx for a logo art Patrice, you can find them at normal person's.com and Matt Meldrum and Ryan Louis are two handed technical team subscribe on Apple podcasts or a PublicHouseMedia.org follow us on Twitter at disarm disabled follow us on Instagram and Facebook at disarming disability and check out our website disarming disability.com. See you next week. Bye.