

Amy Camilleri-Zahra Podcast Transcription

Interviewer: Hello and welcome to the Trauma and Mental Health Report's podcast series. We aim to share stories and knowledge on topics related to trauma and mental health with the community. My name is Chiara Gianvito, and I'd like to welcome our guest for today's episode Amy Camilleri-Zahra. Today we will be discussing Amy's recent research on counsellors' perceptions of disability as well as diving into her own personal experiences. Let's get into today's conversation.

Interviewer: Hi Amy, it's so nice to have you on, today.

Amy: Thank you. It's an honour and a pleasure for me to be here.

Interviewer: [Laugh]

Interviewer: Yes, it's absolutely an honor. To begin, I kind of wanted to give our audience a definition of the terms disability and impairment as well as kind of an overall understanding of the social model of disability.

Amy: The social model of disability stemmed from mainly the UK disability movement. In the 70s, we had this group of people, the majority of them had a physical impairment, so of a physical nature. They came together—again the majority of them had been living in an institution so you know they were kind of experiencing being ostracized from the rest of society, being told what to do and you know when to get up and when they could have their lunch and dinner etc. They came together—they started by, if I remember correctly, it was Paul Hunt who had written a letter in *The Guardian* and asked others to kind of join him. It was done a bit in a away—not in secret, but since they were living in a residential institution being run by a big NGO they are kind of you know a bit—everything had to be done over letters, obviously there was no Internet, there was no emails. Anyway, they then later formed an organization called UPIAS which is the Union of the Physically Impaired Against Segregation and they were the ones who actually came up with the social model of disability. It's—basically the social model, for a number of years you know institutions and policies were run on what we know as the medical model of disability. Disability is perceived as something from a medical perspective, as something which is wrong, that disabled people need to be fixed, to be made normal and they were kind of all against it. They said you know let's come up with something which turns that on its head kind of and they came up with the social model of disability and two key points that came out of the social model of disability is the distinction between disability and impairment, so they make this specific distinction in the way we understand both terms. They said impairment is the biological reality. In my case, I have a mobility impairment, a physical impairment. It could be a visual impairment; it could be a hearing impairment, that is the biological aspect of it so

society can't really do anything on that OK. However, they define disability as the social aspect of it, that we are made disabled because society does not cater for the needs of persons with disability. When I'm lecturing about this I tell my students if all Malta, or all Europe, or all Canada were accessible, we would still have people with impairments but we would not necessarily have disabled people. Disability is a social construct. We encounter disability because we encounter obstacles in our daily lives, which are very often created by how society is planned, is, you know works. Disability is not something which is inherent, it's not something that I have, but that society creates for me. Again, I give the example, in my apartment it's all accessible I go down to my—to the garage I have a car which is—I can drive, I go to my office at university which is accessible. At no point do I feel disabled, you know from then, but if I had to go to Valletta which is the capital city of Malta, and I wanted to go to a coffee shop and they have stairs and there's no lift, then it is at that point that I feel disabled. This is the distinction that the social model makes, so the impairment is the biological reality which is there and it will always be there but disability is something that is created by society because it does not take into consideration the needs of people with different impairments. I want to add as well, it's not obviously just physical impairments but the fact that for example most, I don't know, programs on television might not have subtitles, so that is creating disability for people with a visual—with a hearing impairment sorry. It could be, you know— or for people with an intellectual **[5:00]** impairment not having access to the right—to the inform—to the right information that is accessible to them. Taking into—COVID, into consideration for example. Not making the information available to people with a visual impairment, with a hearing impairment, with an intellectual impairment. Those are kind of the examples of disability as put forward by the social model of disability.

Interviewer: Thank you so much for sharing with us. I think it's important to have the distinction and to kind of use language to properly define what we mean and use that in our life.

Amy: Yes, and if I can add this distinction then has—didn't stop there, but eventually IDA, which is the International Disability Alliance, which is a huge international organization, also adopted these definitions in their statute and then later on the social model of disability is considered to be kind of the foundation on what most of our legislation in Malta is based on. Also, the Americans with Disabilities Act for example and eventually the United Nations Convention on the Rights of Persons with Disabilities which has been ratified by a number of countries including Malta.

Interviewer: These themes are things that you've talked about in your recent paper on the social construction of disability amongst Maltese counselors, so these are all prevalent. Could you tell us a bit about the paper and your findings?

Amy: Yes of course. In my paper the aim was basically to try and understand how Maltese counselors, or counseling psychologists, define disability and how they perceive their disabled clients. My interest came because my undergraduate degree is in Psychology and then I did a masters in Disability Studies. I kind of tried to put the two together. I also have an interest in the area because I feel that therapy is important and should be accessible to everyone. I held a number of interviews with a group of counselling psychologists here in Malta, most of them had been practicing for some time. Basically, that is what I asked them, I wanted to know what they understood by the term disability and how they perceived their clients and the results that emerged from the study were mainly three. The first one is that they seemed to have—to be struggling with the politics usually associated with disability. For a number of years, disability has been—we have—tries to view it from a political aspect, you know, that it's not only the personal story of the individual but unless we try and see it from a political point of view in order to bring about change then we're not really going to make any changes. However, the counselling psychologists that I interviewed seemed to be struggling with this idea OK, that disability can be viewed from a politics aspect. They were also struggling with what we might term, politically correct terms. At one point, they did understa- they did claim that yes, disability is created by society for individuals because we don't create accessible spaces etc. Then they also were kind of contradicting themselves and they went back to “But is it the individual who is limiting themselves?” They were kind of going back and forth with this struggle. Then the second theme that emerged was—I named it “The Deserving and the Undeserving.” This is a very particular theme which was, which emerged in the 1930s in the UK when there were a lot of debates on what was then known as the Poor Law. It was used to refer to poor people, so those poor people who are kind of deserving of help from the government and those who maybe did not want to work and so were deemed as undeserving. I adopted this because my—well the participants in my research seemed to kind of use this also to disabled people. To them, there were disabled people who were deserving of help whereas there were those who they thought you know, “They're rude and they don't deserve the help.” I remember one was recounting about how [10:00], “You know, we give them the ramps, we give them the wheelchair and then they keep asking for more, that disabled people keep asking for more. Can't they be happy with the ramp and the wheelchair?” Again, there was this struggle, this contradiction between those disabled people who they deemed were deserving of help and those who they thought we shouldn't really help because they're just being—asking for too much. Then the third theme was that—what emerged or what I saw that was prevalent was that they were clinging to their professional ideology. The majority of them said that they practiced their counseling practice from a humanistic approach so their teachings were based on Carl Rogers. Again, they were struggling with this idea that we shouldn't be labelling disabled people as *disabled*, but then they were telling me that everyone has a disability, which can be considered a bit offensive to persons with disability who actually have a disability. We can't say—you know I get into these debates sometimes because— that wearing specs is a disability. It is not, I mean wearing a specs is accepted, it's not a disability because you can go about your life as you please. Whereas the real

obstacles that disabled people encounter are enormous compared to that. Again, they were struggling. However, it also emerged that all the participants felt that they wanted to know more and they felt that this aspect of—was not part of their training. They felt that they needed more training to be able to give a better service to persons with disabilities. They acknowledge the fact that what we call Disability Equality Training was not part of their training and that they were thirsty to know more about how they could go about giving a better service to persons with disabilities.

Interviewer: Thank you, it was so interesting for me to read it and I feel like I learned so much. What implications do you feel your research has for the counseling profession more broadly?

Amy: I think the main aspect is probably this, that we need to, we need to include Disability Equality Training, or else a study unit on how to offer counseling services to persons with disability in the training courses at universities or wherever these are being taught, because very often this is either sidelined or treated as a speciality or—and we can't go on with that because disabled people still have other problems. That's another thing for example, when I was conducting the literature reviews of the research, the background research for this paper, a number of studies have spoken about how very often persons with disability might want to go to counseling for other issues that they encounter which is not necessarily related to their disability. I mean, I am a disabled woman myself and I do have relationship problems, I might have marital problems, I might want to go to counselling for *a number* of other issues and they don't necessarily have to be related to my disability. Accessibility is another—physical access is another issue that for example unfortunately, a number of clinics are housed in buildings which are not accessible to persons with a physical impairment. Again, when I was interviewing my participants they were a bit—I told them “What if you had a person with a visual impairment or with a hearing impairment? How would you go about doing the sessions with them?” They struggled with that and that obviously leads to—then leads us to being a gap in these services for persons with disabilities.

Interviewer: Mhm absolutely. What do you feel in the counseling context speci—specifically, needs to be done to create that environment to support [15:00] disabled people?

Amy: As I said, the training—

Interviewer: Mhm

Amy: —is very important because unless you would have had training from—in your formative years or when, in the years that you are studying to become a counselor, this needs to be tackled. I know other grounds for example, issues with sexuality, or with gender, or with race, you know the majority of those are tackled in training but disability unfortunately has not—is not

considered at par with all the other, with all those other grounds or minority issues. Unless disability is given the amount of time it needs in the training process then we're not going to have counselor—then we're always going to have counselors who are going to stay away from giving their services to persons with disabilities because they're going to think “Ah, I'm not specialized in that,” because again, they think that you need to do a particular course in order to be able to give your services to persons with disabilities so unless it's going to start being considered as any other minority issue then we're not going to make any strides. I think it's very very important that at universities a study unit is dedicated to disability.

Interviewer: Absolutely making it in the standard to—

Amy: Exactly

Interviewer: To have it talked about openly and not be—

Amy: Exactly

Interviewer: afraid to approach it in—

Amy: And it will also help if, should any counselors in training have any biases because we all know that we all have our own, you know maybe misconceptions or perceptions or biases and I know for sure that these are treated when it comes to again sexuality or race or religion. However, it's not tackled when it comes to disability, so if it's tackled within one—whilst one is doing one is their training, their professional training, then we can really—counsellors can really be open to offering their services to everyone, including persons with disability.

Interviewer: Absolutely. Kind of shifting gears a bit, but I was wondering if you'd want to 8tell us a bit about your story and kind of how you got into the field.

Amy: [laughs]

Interviewer: [laughs]

Amy: Yes of course, it's been a very interesting journey so to say. [laughs]

Interviewer: [laughs]

Amy: I mean I was a mechanical engineering student which had nothing to do with what I'm doing at the moment.

Interviewer: [laughs]

Amy: I was 21 at the time and I contracted meningitis, I was very very unwell, very sick, and in order for me to survive basically I was told that both my legs would need to be amputated as well as my fingers. I obviously told the doctors to go ahead with it. I then did go back to my engineering course at university however, [clears throat] I wasn't feeling you know like kind of satisfied with what I was doing and I wanted to do—I wanted to work with people I then got into—got involved in activism work when it comes to disability rights. I had decided to change courses and started reading for a degree in Psychology. At the time I also, we also discovered that I had kidney failure as an effect of the meningitis, so I've been living with my father's kidney for the past 14 years now. So yeah, then I did my degree in Psychology. I later went on to do a masters in Disability Studies at the University of Leeds in the UK, I'm now an assistant lecturer at the University of Malta and I'm hopefully in my final years of my PhD—

Interviewer: [laughs]

Amy: [laughs]—and I'm looking at the social presentations of disabled women in Malta, so how society perceives disabled women in our society.

Interviewer: Could you tell us a bit about the challenges disabled women specifically face and kind of the experiences of disabled women specifically.

Amy: Yes there's obviously a lot of research about this, but across a number of countries and across a number of society it always boils down to the notion that disabled women encounter a specific kind of discrimination which is different to that that is experienced by women in general and disabled men. So even if we look at you know, simple statistics **[20:00]** and this is not just in Malta or in Europe but very often it's all over the world unfortunately, disabled women tend to fare worse when compared to non-disabled women and when compared to disabled men across a number of areas. Whether it's education, whether it's employment, whether it's even relationships. Their experiences are very nuanced, they have a particular experience which makes them very different from their counterparts. They encounter issue—negative issues I would say when it comes to employment again because you know, we all know that there are discriminatory practices towards women in general but even more so when you are a disabled woman, and even in education. Then there are also issues when it comes to domestic violence for example, so disabled women are four times more susceptible to experiencing domestic violence in comparison to non-disabled women and then there are issues when it comes to reporting domestic violence for example. Sometimes they are not taken seriously because there's still this idea that they can't be married or they can't be in a relationship if they are disabled. If they have a speech impairment it makes it very difficult for them obviously to report. Then there are the issues with regards to how hostels that house women who are victims of domestic

violence, how accessible these hostels are. Whereas it's difficult for any women to just you know get up and leave the house with her kids if she's going through domestic violence, but it's even more difficult for someone with a disability especially if you depend on a wheelchair, or depend on a lift, or you know you can't just drop your bags and run away, that is obviously much more difficult for disabled woman. There's also very specific abuse, especially when it comes to domestic violence, so it's not just the hitting or the fighting but it could be very very specific. Not—I don't know—not being—the wheelchairs kind of kept away from the bed for example when you wake up in the morning. There are very subtle ways of how disabled women experience domestic violence which makes it even more difficult for them to get out of the vicious cycle. There are also other experiences and obstacles related to motherhood for example, OK, how accessible are health care services for disabled women, how accessible are activities that you usually expect parents to do with their children. I've just recently published a very small article on the—on our university's newspaper about this, about how accessibility for parents, is it really a fact or a fantasy? Even from my own experience, I have a four year old boy and when it comes to attending these parent and baby clubs at the beginning, the majority of them were held in places which were inaccessible or as I would have to stay calling before and planning ahead. These are all obstacles that unfort—I mean it's very open so the impairment itself that makes itself—that makes life difficult but it's these obstacles that we're constantly encountering that makes life a bit difficult.

Interviewer: How do you feel we should go about tackling these kind of social—socially made obstacles on I guess the personal levels and larger levels to kind of make societies more equitable?

Amy: On a larger level, obviously it's the legislation which makes the difference I mean unless we have anti-discrimination legislation then there's not going to be any changes and even then the enforcement of the legislation because you could have the legislation which has been passed by parliament and it's there sitting on a shelf and not doing any good so we need enforcement. However, together with that we need to have education, so we need to be educating our societies, our youths, our children that [25:00] you know what disabled people want is not charity but what they want is their right to be able to enjoy their life at par with others basically. Very often unfortunately society is—feels more content with donating money towards a charitable organization rather than making the effort to not create obstacles for disabled people. I think the legislative aspect and the education aspect go hand in hand, we can't have just the legislation or just the education but it needs to be a combination of both so we use—we can also use the legislation to educate the people. From experience I found also that Disability Equality Training to organizations, to corporate organizations, organizations that offer us services like banks and schools etc., goes a long way because very—and Disability Equality Training is training which is very often done by a disabled person. It's a very particular training, I've been doing it for a number of years now. Both when I used to work with the Commission, but also now—nowadays

on a private level so I do a lot of training with a number of companies here in Malta and I feel that connection somehow does bring about change because as soon as you put a face to the cause or to the problem then people are more willing to make the necessary changes, not just to accommodate that person but then obviously to accommodate the rest of the community. So I feel, and as you know works with everything else. Very often you know you have a negative misconception when it comes to, I don't know, race or religion and that is why we have racism and disablism. However, once we get to know a person and we put a face to that problem then somehow people are more willing to make the necessary changes in order to have an equitable life as you said for everyone.

Interviewer: Well, thank you so much we're just about done today, I just wanted to ask if there's anything else you'd like to share or anything else you feel like we didn't cover today.

Amy: No, no.

Interviewer: [laughs]

Amy: [laughs] I mean it's been really interesting and I hope that your—whoever is going to be listening to the podcast will also enjoy the discussion so I look forward to I don't know I guess getting to know more listeners basically or getting to know more people who have listened to the conversation.

Interviewer: Yes, thank you so much.

Amy: Thank you for the opportunity anyway. [laughs]

Interviewer: Yes—so grateful to have you on and to have these conversations are so important so I thank you so much.

Amy: Thank you.

Interviewer: You've reached the end of this episode with the Trauma and Mental Health Report podcast. Thanks for joining us! Connect with us at trauma.blog.yorku.ca. You can also find us on Facebook, Twitter, Instagram or LinkedIn. Don't forget to subscribe to our podcast and newsletter to see our latest content. See you at the next episode!