

Episode: *Author Interview: "Asylums and Harm Embodiment"*

Guest: Sara M. Bergstresser, PhD, MPH, MS

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[bright theme music]

TIM HOFF: Welcome to another episode of the *Author Interview series* from the *American Medical Association Journal of Ethics*. I'm your host, Tim Hoff. This series provides an alternative format for accessing the interesting and important work being done by Journal contributors each month. Joining me on this episode is Dr Sara Bergstresser, a lecturer in the Masters of Bioethics program at Columbia University in New York City. She's here to discuss her article, *Asylums and Harm Embodiment*, in the August 2022 issue of the Journal, [Inequity and Iatrogenic Harm](#). Dr Bergstresser, thank you so much for being on the podcast with me today. [music fades]

DR SARA BERGSTRESSER: Thanks for having me here.

HOFF: So, what is the main ethics point of your article?

BERGSTRESSER: So, for me, the key point of this article is that poor policy decisions can lead to long-standing and actually irreversible harm for people. And these things can actually persist for many years after the policy itself has been changed. In this way, I look at 19th and 20th-century systems of psychiatric institutionalization, and these depended on locked, remote facilities where people were sent away to spend years or even lifetimes. A lot of these people, after deinstitutionalization, had no way to adapt to community living because in these impoverished environments, they really were not able to interact with others or to learn how to socially interact in culturally appropriate ways.

HOFF: Mm.

BERGSTRESSER: And so, I did ethnographic anthropological research in Italy in a community mental health center. And in this article, I talk about Paulino, which is a pseudonym, and he was a resident of the community mental health center earlier in the 20th century. At this point, he was about in his 60s, and he was somebody who rarely spoke. And if he did, it was pretty much one-word things or a-few-word phrases. He had a lot of difficulty dressing himself. He had trouble avoiding traffic in the road. He, you know, if he was going to drink some coffee, somebody had to dilute it with cold water, or he'd burn his mouth. So, he had very substantial trouble with not just speaking, but with everyday life. And I found out later that this was because he was most likely abandoned in an adult psychiatric hospital as an infant.

HOFF: Hmm.

BERGSTRESSER: So, an adult hospital: no treatment plan for children, no education, really, no way to develop the social skills that we all do in childhood. And he lived there until he was about 60 years old. So, that's where iatrogenesis, so, the theme of this issue comes in. I argue that the state that he's in, that he has difficulties emotionally, physically, with communication, etc., it's not evidence of some sort of hypothetical disorder that

would've put him there, even if they could've known that when he was an infant. What it was, was something that was produced by the hospitalization.

HOFF: Hmm.

BERGSTRESSER: So, the hospital itself deprived him so much of stimulus, of learning opportunities, of engagement with the real world that he just never learned how to do it. And by the time deinstitutionalization occurred when he was about 60, it wasn't possible anymore. So, even though this policy that kept him isolated wasn't in effect anymore, the damage had been done.

HOFF: Mm.

BERGSTRESSER: And that's one of the main points, again, is that policy, just trying it out isn't necessarily innocent. It can cause damage, even if it's reversed later.

HOFF: Hmm. And so, what do you see as the most important thing for health professions students and trainees to take from this article specifically?

BERGSTRESSER: For me that I think it's important for students to realize that oftentimes, there'll be a lot of pressure to keep silent about things that you see which you might think are wrong. You might see people around you keeping silent, or you might feel as though you're going to be chastised by speaking out. But I want to say that ethics in some ways requires us to speak out sometimes, even if it is uncomfortable for us or we think that we might be chastised for it. And the reason is, first of all, because with these sort of agreements about silence, there's no way for critiques to come out, and so there's really less way for people to understand what needs to be changed. Also, if everybody is normalized into being silent, they don't know if their colleagues actually agree with them or not. There's not discussion, and there's not really a way to productively move forward and figure out if the policy you have could be improved or if it's actually something that's harmful to the people that you're treating.

HOFF: And finally, if you could add a point to this article that you either didn't have the time or space to explore, what would that be?

BERGSTRESSER: So, I didn't really explore in much depth the idea that in the U.S., we can actually learn a lot from international health systems. So, this article is technically about Italy, but institutions and deinstitutionalization are something we had in the U.S. as well.

HOFF: Mmhmm.

BERGSTRESSER: And in fact, I think we actually have a responsibility to learn from relevant information at the global scope, because there are a lot of things that we can learn without having to test them out and potentially do harm by paying attention and understanding experiences elsewhere. It might take some effort to find or to translate it to our own context, but it is in some ways irresponsible to ignore information that could allow us to develop better policies without causing harm to people in a sort of trial-and-error phase. [theme music returns]

HOFF: Dr Bergstresser, thank you so much for being on the podcast with me today and for your contribution to the Journal this month.

BERGSTRESSER: Great. Thank you.

HOFF: To read the full article, as well as the rest of the August 2022 issue for free, visit our site, [JournalofEthics.org](https://www.journalofethics.org). We'll be back soon with more *Ethics Talk* from the *American Medical Association Journal of Ethics*.