

[Music by Molly Joyce 00:00 - 00:15]

Bonnie: Welcome to *Included: The Disability Equity Podcast*, brought to you by the Johns Hopkins University Disability Health Research Center. This podcast challenges stereotypes of disability by sharing stories, data, and news. Each season digs deep into topics, offering multiple perspectives, and will expand your view of disability. We are your hosts. I am Bonnielin Swenor, director of the Johns Hopkins Disability Health Research Center.

Nick: I'm Nick Reed, assistant professor at Johns Hopkins University Bloomberg School of Public Health. On this episode of *Included*, we're talking with Dr. Doron Dorfman about his work in the emerging field of disability legal studies. Doron Dorfman is an associate professor of law at Syracuse University College of Law. His research is at the intersection of disability and health law and explores how stigma informs the legal treatment of people with disabilities among other marginalized groups.

Dr. Dorfman's work has been published in the *Boston College Law Review*, *Illinois Law Review*, *UC Irvine Law Review*, and leading peer-review journals at the intersection of law and social sciences, such as *Law and Society Review* and *Law and Social Inquiry*. His work has been cited by federal courts and the Israeli supreme court and has been featured on national media outlets, including *The New York Times*, *Washington Post*, *LA Times*, and *USA Today*. He's received multiple awards for his work, including the National Burton Law360 Distinguished Legal Writing Award, the Steven M Block Civil Liberties Award. Dr. Dorfman was recently selected as the 2021 Health Law Scholar by the American Association of Law, Medicine, and Ethics and St. Louis University's Center for Law and Health Studies.

Prior to academia, Dr. Dorfman was a litigator in Israel where he gave legal advice to disadvantaged workers and asylum seekers. He then completed his JSD, which is a PhD in law, at Stanford University before joining the faculty at Syracuse.

[Music by Molly Joyce 02:19 - 02:28]

Nick: Dr. Dorfman, thank you so much for making time to join us today.

Dr. Doron Dorfman: It's a pleasure. Thank you for having me.

Bonnie: Dr. Dorfman, your work has really shaped multiple important discussions during the pandemic. Let's start with one of your

landmark papers that you published with Dr. Mical Raz in *JAMA Health Forum* titled “Mask Exceptions During the COVID-19 Pandemic: A New Frontier for Clinicians.” This was one of the most widely read *JAMA Health Forum* commentaries to date.

To provide our audience some background, the summary reads, “While masking remains contentious, there is bipartisan agreement among policymakers that medical exemptions for masking are necessary and appropriate. Yet, there’s a dearth of guidance for clinicians on how to approach a request for an exemption.” This paper really, as you and I have discussed previously, struck a lot of chords with me. I would love for you to share with our audience a summary of the argument or some more insight on the conclusions of this really important article.

Dr. Doron Dorfman: Thank you. At the beginning of the pandemic, the CDC has recommended a few exemption categories for mask mandates. Those included children under two, people with difficulty breathing, and anyone unable to place or remove a mask on their face. At the same time, though, there were a lot of reports of individuals, who are anti-maskers, who objected to these mandates and started displaying all those falsified IDs and certificates to indicate that they are, themselves, exempted from wearing a mask in public.

There was this vacuum for physicians who were torn between the public health goals of the mask mandates and the need to accommodate people with disabilities. What Dr. Raz and I say in this piece is that there are a few categories that should get exemptions, like people who have sensory processing disorders that usually appear with people who are autistic or are on the autistic spectrum or people with intellectual or developmental disabilities or with people who have face deformities where they’re not able to put the mask on their face and it will hold on. There’s other situations of people with other conditions and other disabilities, like people with pulmonary illnesses, who might actually get life-threatening complications because of COVID. They also tend to cough and maybe spread the disease even further, and so an exemption for them might not be that great of an idea.

We, in our piece, encouraged doctors to sit down with their patients and think about other accommodations that would work for them, like curbside service or remote work or placement in non-public-facing positions at the workplace. We basically wanted to show physicians that this whole idea needs to be an interactive

process between the physician and the patient. We really wanted to bring this idea of an interactive process into the relationship between a doctor and a patient. The interactive process is a little known artifact of the ADA, usually between employer and employee. I think that's what we tried to say in this piece.

Bonnie: Yes, should be a well-known [laughter] part of the ADA, I would say. You also conclude, in evaluating an individual patient, clinicians should seek to balance appropriate accommodations with public health. I loved that sentence so much, I have to say, in this paper. I'm just so curious if your view on this has changed at all as the pandemic really has moved forward. You wrote this paper—this paper was at least published a year ago, July 2020.

Dr. Doron Dorfman: I think, nowadays, we're, obviously, in another stage of the pandemic where the vaccination rollout has been moving along. While we have a majority of the population that were vaccinated, we now still have many who are not. The new question is what to do with all those people who are immune compromised, who might not have developed enough antibodies from the vaccine, and who are now at risk of contracting COVID in spaces where masks are no longer required. Dr. Raz and I, actually, we're going to publish another article in the *JAMA Health Forum* next month when we are looking at masking as a reasonable accommodation, which is now a little bit different than our first piece.

We show and explore how an employee, like a professor or a teacher, could ask others to mask up in their office or in the meetings they attend, and that would be considered a disability accommodation, or more specifically, it will be considered a modification to the current policy that does not require or even prohibit masking. We saw that in Iowa and Texas and Utah, where there were executive orders by the governors or bills prohibiting mask requirement in school, colleges, and universities, which is very concerning, I think.

I think, now, we do reconsider this idea of masking to actually protect people with disabilities and make sure the ones who really could not tolerate masks get vaccinated so they won't pose a threat to fellow people with disabilities who are immune compromised. I think, as we go along with this pandemic, our views on those issues change. I think it's nice to be able to look back a little bit and reconsider your work. I'm very happy that we're able to publish another paper on this.

Bonnie: Thank you. I think that is so timely. These conversations about returning to work, obviously, are what everyone is talking about, returning to the classroom, so important. Fascinating. I really, really appreciate that.

Dr. Doron Dorfman: I have another piece *[laughter]* that is also coming up in the *Journal of Law Medicine & Ethics* where I talk about the pandemic and also the topic of disability *[unintelligible 08:44]*, which we'll talk about in a minute. I really show there how all the arguments against teachers who weren't willing to go back in person because they are either caregivers of other people with disabilities or are people who are immune compromised or people with disabilities themselves actually really corresponded with other ideas about anti-union ideology, and how those teachers actually, and the teachers' unions who supported them, how dare they not wanting to go back to work. I really think there's a lot to unpack in those situations. We see how ideologies and stigmas and stereotypes really come together at this moment in time. I think it will be a really fascinating thing to see in the future.

Nick: That's a really interesting intersection of work, *[laughter]* Doron. As you were talking, I was thinking about this layer of ideology. I'll be honest with you, as an academic myself, I was actually wondering, I wonder how many times a week Dr. Dorfman gets an email from somebody angry at his work? *[Laughter]* This is ideologically charged, the basis for how some people feel. Do you mind? Do you get a lot of emails?

Dr. Doron Dorfman: I don't get a lot of hate email, actually, to be completely honest. Well, I hope it doesn't happen now, Nick. Let's not give anyone any ideas.

Bonnie: If you do, sir, I can give you advice.

[Laughter]

Bonnie: I get my share.

Dr. Doron Dorfman: Yeah, I'll get back. I do get a lot of emails from people where the research really impacted them, mostly physicians and also patients. That always strike a chord with me, and it's always exciting. I'm this law professor who doesn't write about those big constitutional law theories. I write about the law in the everyday life of people. I'm a first-generation student myself. I'm a son of immigrants. I'm non-American. I think I have a point of view of looking at everyday life and finding how law really creates those situations

and how it reacts to those situations. That's what I like to write about. I like that there's so much reaction to my work, and people tell me how much it really affected their lives or how it resonated with them. It really makes everything I do worthwhile.

Nick:

One, it's so nice to hear that. It is nice to have good feedback. Two, what a positive outlook, and what an indication of meaning that your work is necessary. People are emailing you and letting you know it's not just work that's going out to those academic circles. We send it out into the academic stratosphere, and who knows who reads it? Actual people in the trenches are emailing you to tell you that this is necessary and needed. I think, as a theme for this podcast, there's more visibility necessary around the inclusion of disabilities into these bigger-picture conversations. Thank you for doing that.

I would love to talk about another one of your papers, "The Treatment of Disability Under Crisis Standards of Care: An Empirical and Normative Analysis of Change Over Time During COVID-19." This was published in the *Journal of Health, Politics, Policy, and Law*. You and your co-authors examine crisis standards of care in 35 states and compared states that revised their plans to those that have not. Do you mind sharing with our audience what you found?

Dr. Doron Dorfman:

Sure. I'll just say that this work is co-written with Ari Ne'eman and Michael Stein from Harvard and with Zack Berger from Johns Hopkins. I think there were so many papers written about crisis standards of care plans, which basically instruct healthcare professionals on triage, and how disability, in many of those plans, was basically a reason to relegate people with disabilities to the bottom of the list for care when there is a situation of scarcity of ventilators or other life-saving equipment. I think many scholars have written in opposition to that, highlighting the history of ableism and of eugenics in medicine. Some even looked to case law and tried to extrapolate from that to this situation.

It wasn't only scholars who paid attention to this. By the way, this was a global phenomenon. I'm originally from Israel, and this was a huge issue in Israel as well, all those triage plans as well. It wasn't scholars only, but disability rights organizations who worked with the Health and Human Services Office for Civil Rights, which is the agency in charge of enforcing federal anti-discrimination law in healthcare, in health policy. They were working together, those organization in HHS, the Office of Civil Rights at HHS, to amend those plans so that disability would no

longer be a reason to assess a person's deservingness to receive life-saving care. That the lives of people with disabilities are actually worth the while. They're worth saving.

What we did, I think, which is unique, I think, among this—many papers that have written about this from many directions is that we examined and coded those crisis standards of care plans from 35 states throughout the pandemic, meaning across time and how it changed across time during the pandemic. We were able to show that 18 states that actually revised their plans later on in the pandemic were more aligned with the priorities that disability advocates had in mind. Meaning that the Disability Rights Movement was actually able to influence policy in real time. They were able to change those crisis standards of care to not have disability as a reason to prevent or to put someone on the bottom of the list for life-saving care.

That was, I think, really exciting and intriguing collaborations with real civil society organizations and the federal government that really yielded results in so many states that revised the plans. I think it's really—I think that this paper really, empirically, shows another avenue for law and social change that is different than what we knew so far in disability and justice advocacy.

Bonnie:

It has been so interesting, during the pandemic, to see the conversations between policymakers and disability rights and disability advocates open up in really important ways and hopeful ways, *[laughter]* in some cases. I think this paper really highlighted that, which has been fantastic. One of the positive, in my mind, outcomes of the pandemic for the disability community. Hopefully, that traction will continue. I think, to me, that was so well showcased in this work in this paper. I hope that continues. I'm curious if you think, across your span of work, if there is opportunities for that to continue, if there is space for that, if there is traction for that. It seems like that has not been moveable for so long.

Dr. Doron Dorfman:

I think there has been a history of contention between the federal government and the Disability Rights Movement for many years. Whether it was the 1977 sit in at the offices of the Health and Human Services in San Francisco. We protested of not passing the regulation to important Section 504 of the Rehabilitation Act, which is a pre-cursor to the ADA. That's a historical event that a lot of people know about. The Capital Crawl in DC in 1990 to encourage congress to pass the ADA, or more recently, protests against the repeal of the Affordable Care Act in 2017. Here, we

see, as I said, a new model promoting disability rights and creating social change through negotiation and collaboration. I have to say that, really, I think like you, Bonnie, it makes me optimistic in some way.

Just recently, on July 6th, the DC Circuit has overturned the FDA decision to prohibit electric shock treatment for “behavioral issues” of autistic people, people who are neurodiverse, and people who have intellectual and developmental disabilities or mental disabilities at the notorious Judge Rotenberg Educational Center in Massachusetts that hosts mostly, by the way, children and adolescents who are black or brown. There is an intersection between race and disability in this instance, like in many instances. The reasoning for overturning this ban on electric shock, which seems very important and elementary in some way, the reason was that it was beyond the scope of the FDA to prohibit shock treatment because it intervenes with the regulation of the practice of medicine. The FDA can only regulate medical devices in this instance and not the actual administration of the shock.

It wasn't, basically, the FDA's role to do that. That's what the DC Circuit decided. I see potential here for another collaboration between disability rights advocates and the federal government, the Health and Human Services, HHS, to, again, regulate this issue and prohibit electric shock once and for all. I think what we saw here with the crisis standard of care can replicate itself in other issues, and hopefully, it will and create, I think, a better environment and a better way of treating people with disabilities.

Nick: This is super interesting. I wanna dig in a little bit. In your piece that I read where you look at 35 states, and you do see some change, there's a crisis going on. I see the parallels between the application, for example, of the shock therapy and where you could make a difference. Is there a certain piece to this puzzle where there has to be a crisis ongoing? COVID is the crisis. Does that facilitate the conversation, allow us to make sudden changes because of public health interventions that are necessary for life at this moment in time? Do you think that that piece of the moment in time and environment is less of a consideration?

Dr. Doron Dorfman: I think you're right, that there needs to be a crisis, or there can be a more of awareness and a more of public awareness of a situation. We can look at that #FreeBritney issue and how it really affects supported decision-making and conservatorship for people with disabilities, an issue that used to be a very niche topic. Now, everybody saw the documentary on Netflix. Everybody is an

expert on this. When I was thinking about this question, it really hit me that how popular culture or the way our society works, social media, *et cetera*, can really raise awareness to a specific topic. Then, hopefully, we can maybe make it—we can maybe make progress on something like that. I do think there is—we're gonna see more of the model of supported decision-making being done more extensively now in different states. My colleague, by the way, Nina Kohn at the College of Law, has a great paper about that that she's been writing way before Britney Spears exploded.

To come back to your question, I do think, if we need more—what we really need more is telling people that there's this hospital or this facility that shocks children [*laughter*] in Massachusetts right under our noses for many, many years. I don't think there's gonna be a lot of people who think that will be okay. That's actually an extreme case. I'm optimistic that that would actually change. I think it's actually even—in some ways, it's even an easier case than the crisis standards of care, which involves all those ethical considerations and all those stereotypes about the worthiness of disabled lives, and where we are when we have a scarcity of resources. I, actually, am optimistic about this. I do think we don't only need the crisis. We just need a little bit more of a push from the public against it.

Bonnie: Perhaps some data to help push. [*Laughter*]

Dr. Doron Dorfman: Yes, yes.

Bonnie: It's something we always talk about on this podcast is the need for better disability data to push, to highlight these gaps, to highlight these issues.

Dr. Doron Dorfman: My work is mostly empirical. That's unusual for a law professor, especially a law professor with no disability, without disability rights. I don't really know a lot of people who actually do that. What I try to do is not only look at case law data. I'm trying not to only count cases but to actually look at real-world application of disability law on the ground and see how they reflect in cases—in court cases I mean, and how they really are mirrored in court cases as well. Yes, I'm a big believer in data. I think that it is something that needs to be done more rigorously, I think. I'm very thankful for a lot of colleagues here, at Syracuse University, where I work, and in Johns Hopkins and in other places who do really great work on this, like Scott Landes, which was on your show, too, who's a great friend and someone I really look up to.

Nick: There's a lot of synergies here on all the different sides. I'm blanking on a good analogy, but it takes a team to move all of this forward. It's not gonna happen in any one silo.

Dr. Doron Dorfman: Yeah. I think more and more people think—

Nick: This is a new area for the *Included Podcast*, but we decided to break up Dr. Dorfman's interview into two parts because it was so fascinating. Bonnie and I could not stop talking to him. We're gonna conclude for this episode, and we'll see you on the next episode of the *Included Podcast*.

Bonnie: You have been listening to *Included: The Disability Equity Podcast* brought to you by the Johns Hopkins Disability Health Research Center.

Nick: Thank you to our *Included Podcast* team and everyone that made this podcast possible, especially Prateek Gajwani, Curtis Nishimoto, and our guests. Music is by Molly Joyce. This podcast is supported by a Johns Hopkins Ten by Twenty Challenge Grant.

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