

Episode: Author Interview: When Disability is Defined by Behavior, Outcome Measures Should Not promote “Passing”

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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 now is Ari Ne’eman, a PhD candidate in Health Policy at Harvard University in Cambridge, Massachusetts and co-founder of the Autistic Self Advocacy Network. He’s with me to discuss his article, *When Disability is Defined by Behavior, Outcome Measures Should Not promote “Passing,”* in the July 2021 issue of [The Journal](#), *Visibility and Measurability in Health Care*. Ari, thank you very much for joining me on the podcast. [music fades out]

ARI NE’EMAN: Thank you for having me.

HOFF: To begin with, what is the main ethics point of your article?

NE’EMAN So, there are a wide variety of interventions focused on disabilities or diagnoses that are primarily or exclusively defined by behavior. And when talking about diagnoses defined by behavior, it becomes very important to grapple with this question of how do you define clinical progress? Because that’s really a area that is tied up with values in some very intense ways. Often there’s a implicit or explicit assumption on the part of providers that progress should be defined as the establishment of typical behavior, essentially making someone look or act normal.

HOFF: Mmhmm.

NE’EMAN And that’s actually something we should be very concerned about. There’s a lot of evidence, both from people’s lived experience, but also a growing body of research showing that demands to try and pass as normal, to pass as non-disabled, can in fact impose some very serious harms on people with a wide variety of disabilities. These kinds of clinical passing demands really should be avoided as a default, and there should be a relatively high bar before providers are willing or should consider it ethical to impose such clinical passing demands in their work and in service provision to people with disabilities. So, I discuss that, and I talk a little bit about how we really need to reevaluate many of the outcome measures that are presently being used. I use autism as a case study—but it’s certainly not the only place in which this is the case—in order to address these concerns regarding clinical passing demands and the harm they cause.

HOFF: Great. Thank you. And what do you see as the most important thing for health professions students or trainees to take from your article?

NE’EMAN Well, I think one of the key things here is that you really are not in the business, or should not be in the business, of trying to make people seem as normal as possible.

HOFF: Mmhmm.

NE'EMAN: And there has to be some recognition that there is a really unfortunate history in many diagnoses of interventions designed to promote what in the autism world is sometimes referred to as "indistinguishability from peers."

That's a phrase that comes from behaviorist interventions in autism that really have been a source of great concern for autistic adults and a growing number of families that have really discussed the ways in which those kinds of demands to promote things like eye contact or discouraging rocking or flapping or other things, other stims that autistic people engage in that are totally appropriate and natural for autistic people to engage in, even though they may appear unusual, how the efforts to suppress those things in the past have been associated with tremendous harm.

And so, I think a really important point for clinicians and providers to be aware of is that, frankly, when you pick a target for intervention, you are making a decision that is tremendously value-laden, especially when you are intervening in a diagnosis that is defined by behavior. There is no clear, bright line between saying we are going to select an intervention target in order to ameliorate the symptoms of this disability, and we are going to make you look normal. And I think when you phrase those things, each of those things, each of those sentences comes with very different connotations. I think we implicitly understand that the demand that people look and act normal is not really an appropriate province of medicine or clinical care.

But in behaviorally defined diagnoses like autism, often, attempts to ameliorate symptoms, in clinical parlance, are experienced as a demand to promote typical appearance. And that speaks to problems in how we have approached autism intervention in the past and in the present.

HOFF: Sure. And if you could add a point to your article either that you were thinking of while writing or that you've received as feedback since publishing, what would that be?

NE'EMAN: You know, I talk a little bit about the idea that this is relevant across a broad range of diagnoses. And one thing I've been giving a little bit of thought to is the ways in which this shows up even in diagnoses that are not predominantly defined by behavior. Something I've heard from a number of folks in various disability communities since publishing is that this is actually relevant even in diagnoses that are entirely defined by biomarkers or functional impairment in ways that are very, very clear. There are ethical issues, for example, in blindness, where there's often a demand on the part of blindness professionals that blind people learn how to appear sighted, often through simulating eye contact or discouraging blindisms, forms of sensory seeking behavior that are very similar to stimming on the part of autistic people. And those kinds of clinical passing demands also impose really unnecessary stress and harm some blind people.

I've heard from many people with physical disabilities, ranging from people with cerebral palsy and another developmental disabilities, to many older people with polio talking about how the demand, that sort of implicit demand, from providers and sometimes from family members, that they use modes of transportation that are as close as possible to walking really can interfere with their lives. I've heard from folks whose experiences moving from using crutches to using a power wheelchair reflected an experience of tremendous liberation, of being freed from pain, but also, really struggling with the ways in which

providers and family members construct this experience that improved their quality of life so much as an experience of failure.

So, I do think, you know, something I didn't really speak to so much in the article is the extent to which this is actually, this topic of clinical passing demands and this, really, need for us to justify why we are targeting something as an intervention outcome is in fact relevant far beyond diagnoses that are defined by behavior. [theme music returns]

HOFF: Well, Ari, thank you very much for your powerful contribution to this conversation in the Journal and for being on the podcast today.

NE'EMAN Thank you so much. I'm really glad to be joining you.

HOFF: To read the full article and the rest of the July 2021 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*.