



Representing the Autism Spectrum

Robert Chapman & Walter Veit

To cite this article: Robert Chapman & Walter Veit (2020) Representing the Autism Spectrum, The American Journal of Bioethics, 20:4, 46-48, DOI: [10.1080/15265161.2020.1730495](https://doi.org/10.1080/15265161.2020.1730495)

To link to this article: <https://doi.org/10.1080/15265161.2020.1730495>



Published online: 24 Mar 2020.



Submit your article to this journal [↗](#)



Article views: 259



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 2 View citing articles [↗](#)

OPEN PEER COMMENTARIES



Representing the Autism Spectrum

Robert Chapman^a and Walter Veit^{b,c}^aUniversity of Bristol; ^bCarnegie Mellon University; ^cUniversity of Sydney

The discussion by McCoy and colleagues (2020) of partial representation in the autism community offers rich insights into the difficult question of how we can best represent the entire autism spectrum. Many of their general conclusions about partial representation are also pertinent. They make a glaring mistake, however, that may undermine part of their original goal: We contend that the way they frame the autism cure/acceptance debate is misleading in such a way as to potentially stifle voices that should be center stage. Here we attempt to offer a correction that seeks to re-center these overlooked voices.

In order to represent the entire autism spectrum, care must be taken in how the cure/acceptance debate about autism is set up. The binary way McCoy and colleagues set up the issue mainly focuses on two extremes that we shall refer to as “self-representing autistics” and “nonrepresenting autistics.” By “self-representing autistics” we refer specifically to verbal self-advocates without further intersecting cognitive disabilities, who see autism as a natural manifestation of human neurodiversity, rather than as a disorder to be cured. By contrast, “nonrepresenting autistics” refers specifically to nonverbal autistics with further cognitive disabilities, who have high support needs and who have so far been unable to independently communicate.¹ Importantly, since nonrepresenting autistics cannot currently self-represent when it comes to autism policy, their pro-cure carers take themselves to act as surrogate representatives.

Based on this framing, McCoy and colleagues provide examples of organizations that represent mostly self-representing autistics or pro-cure autism carers, yet that only partially represent the whole spectrum.

The impression given is that both sides are equally guilty of partial representation. This leads McCoy and colleagues to indicate that we should acknowledge both the legitimacy of pro-cure surrogate representation from nonrepresenting autism carers, and the anti-cure self-advocacy of autistics—albeit each for their specific subsection of the autism spectrum.

We agree with McCoy and colleagues that it would be wrong for those with one specific disability to claim to straightforwardly represent those with multiple intersecting disabilities. Indeed, one of this article’s authors has made a similar argument previously, as we return to in the following. Still, we contest the way the debate is set up, namely, the binary framing via the focus of the two extremes of self-representing autistics versus autism carers. In fact, the way McCoy and colleagues frame the debate is familiar to us: It is rather straightforwardly adopted from autism carer critics of neurodiversity. McCoy and colleagues do not consider that many neurodiversity proponents would take this way framing itself to contribute to the sidelining of voices that should be at center stage.

The core issue with McCoy and colleagues’ binary framing is that they thereby overlook how most individuals on the autism spectrum sit somewhere in between the two extremes they focus on. This is important here because there are many examples of individuals who are much closer to nonrepresenting autistics than to self-representing autistics, who (despite still being deemed “low-functioning” in medical-deficit terms) nonetheless can represent themselves. Most relevantly, we are thinking here of cases where an individual who is nonverbal, and who was thought for years or decades to be wholly unable to communicate, later learns to independently

CONTACT Robert Chapman  kn18198@bristol.ac.uk  University of Bristol, Bristol, UK

¹In terms of support needs, this distinction maps onto the mild/severe or highfunctioning/lowfunctioning labels often used to describe different parts of the spectrum. We try to avoid these labels, as many autistics find them misleading and offensive.

type. We'll distinguish this group from nonrepresenting autistics by referring to them as "nonverbal self-representatives." These individuals might also be thought of as ex-nonrepresenting autistics. They precisely lived as such for years or decades, right up until the moment they were able to type. Crucially, if there's anyone who can tell us what being a nonrepresenting autistic is like, it is a nonverbal self-representative. Furthermore, they are still close to being nonrepresenting autistics on the spectrum we present, despite no longer being identical. A partial analogy here might be made with someone from a working-class background who has worked their way into a lower-middle-class lifestyle: While they may no longer be fully working class, they will surely understand being so more than anyone who has never been so. However, these voices are overlooked in the analysis of McCoy and colleagues. Indeed, it is striking that they do not quote a single nonverbal self-representative voice.

Also thereby overlooked is the fact that many nonverbal self-representatives are in fact anti-cure. Consider the words of Naoki Higashida (2013), who still cannot speak and who needs full-time care, but who purportedly learned to type independently later on (much to the surprise of those around him):

What would we do if there was some way that we could be "normal"? Well, I bet the people around us—our parents and teachers—would be ecstatic with joy and say, "Hallelujah! We'll change them back to normal right now!" [But] even if somebody developed a medicine to cure autism, I might well choose to stay as I am. (72)

Such views are further corroborated by other nonverbal self-representatives. For instance, Tito Rajarshi Mukhopadhyay, in his book *How Can I Talk If My Lips Don't Move? Inside My Autistic Mind* (2008), is highly critical of the "sickening ... belief system" that frames autism as "a disease that needs a cure" (178). Of course, we don't know how many nonverbal self-representatives share similar views, since this hasn't been empirically studied. But they are not hard to find. And as can be seen from these examples, we cannot simply assume that all nonrepresenting autistics would tell us they were pro-cure if they did learn to communicate successfully. We therefore remain skeptical of the level of epistemic credibility McCoy and colleagues afford to pro-cure autism carers when it comes to the cure/acceptance debate.

Furthermore, although we cannot justify this in detail here, we would like to highlight how epistemic injustice may influence the debate. Arguably, one of the reasons nonverbal self-representatives so often go unheard is that their voices have been consistently undermined by pro-cure autism carers. For instance, autism carer Lutz (2013)

has made considerable efforts to discredit the voices of nonverbal self-representatives given the "severe" label who are pro-neurodiversity and anti-cure. This reflects a wider problem whereby whenever those given the "severe" label do learn to type, prejudiced systemic stereotypes relating to autism stop others from believing their testimonies. As one of the current authors has noted, "The prejudiced belief that no 'severely' autistic people can think or communicate is used to dismiss all those who clearly can do so" (Chapman 2019c). Similarly, our issue with the framing adopted by McCoy and colleagues is that in focusing on the extreme ends of the spectrum, those who are closest to the more disabled end yet can speak are more likely to be overlooked. It is not just that the complexity of the spectrum is lost through the binary framing. Arguably, adopting a framing that may function to bias our focus away from nonverbal self-representatives is an issue of epistemic injustice.

Indeed, it is owing to concerns over the harms of both partial representation and epistemic injustice that neurodiversity proponents have already made points similar to those developed by McCoy and colleagues. For instance, a similar argument was forwarded by one of us (Chapman 2017, 2019b) and has been met with approval by others sympathetic to the neurodiversity perspective (e.g., Timimi et al. 2019). The key point of what Chapman (2019b) termed the *intersectional social model* was that it was "booby-trapped against autistic people (such as myself) talking over those autistic people with intersecting disabilities. For on this model, the only people who should be taken as the voice of any given intersectional identity are those that fall within their intersection." The main difference between Chapman's and McCoy and colleagues' analyses is that in Chapman's, which is also more sensitive to the possibility of epistemic injustice, nonverbal self-representative voices are positioned at center stage as a matter of principle. Moreover, there is a higher level of skepticism regarding both autism carers and self-representing autistics (rather than just the latter) when it comes to representing nonrepresenting autistics in the cure/acceptance debate.²

In offering this alternative analysis, we do not mean to dismiss the many positive more general

²Importantly, we do not mean to say that the neurodiversity movement should only be considered a movement to right past injustices. By ignoring or misrepresenting the autism spectrum, epistemic injustice can also undermine the very science on autism itself. Recent work in the philosophy of science on "model pluralism" (Veit 2019) suggests that alternative ways of framing debates and a diversity of models should be considered necessary steps toward a better representation of reality, and hence progress in science.

insights about partial representation from McCoy and colleagues, or indeed the voices and input of autism carers. The cure/acceptance issue is far from settled, (Chapman 2019a) and we acknowledge that our analysis may raise more questions than it answers. In the meantime, we urge that future contributions follow us in putting the voices of nonverbal self-representatives at center stage.

ACKNOWLEDGMENTS

Thanks to Heather Browning and David Batho for their feedback on earlier drafts.

FUNDING

This research was produced in part due to funding from the University of Bristol, as well as the Australian Laureate Fellowship project “A Philosophy of Medicine for the 21st Century” [Ref: FL170100160].

REFERENCES

- Chapman, R. 2017. Autism and intersectional theory. Paper presented at the Autism and Society Seminar II: Autistic wellbeing, UCL Institute of Education, London, March 1, 2017.
- Chapman, R. 2019a. Neurodiversity and its discontents: Autism, schizophrenia, and the social model. In *The*

- Bloomsbury companion to the philosophy of psychiatry*, ed. S. Tekin and R. Bluhm, 371–389. London: Bloomsbury.
- Chapman, R. 2019b. Autism and intersectional feminism: Representing voices across the spectrum. *Psychology Today* (blog). <https://www.psychologytoday.com/gb/blog/neurodiverse-age/201909/multiply-disabled-autism-and-intersectional-feminism>
- Chapman, R. 2019c. Are the voices of the “severely” autistic being silenced? How the medical deficit framing stifles autistic voices. *Psychology Today* (blog). <https://www.psychologytoday.com/gb/blog/neurodiverse-age/201909/are-the-voices-the-severely-autistic-being-silenced>
- Higashida, N. 2013. *The reason I jump: The inner voice of a thirteen-year-old boy with autism*. Toronto: Knopf Canada.
- Lutz, A. 2013. Is the neurodiversity movement misrepresenting autism? The curious case histories of some of autism’s biggest celebrities. *Slate*. <https://slate.com/technology/2013/01/autism-neurodiversity-does-facilitated-communication-work-and-who-speaks-for-the-severely-autistic.html>
- McCoy, M., E. Y. Liu, A. S. F. Lutz, and D. Sisti. 2020. Ethical advocacy across the autism spectrum: Beyond partial representation. *The American Journal of Bioethics* 20(4): 13–24.
- Mukhopadhyay, T. R. 2008. *How can I talk if my lips don’t move? Inside my autistic mind*. New York, NY: Arcade Publishing, Inc.
- Timimi, S., D. Milton, V. Bovell, S. Kapp, and G. Russell. 2019. Deconstructing diagnosis: Four commentaries on a diagnostic tool to assess individuals for autism spectrum disorders. *Autonomy (Birmingham, England)* 1(6): AR26.
- Veit, W. 2019. Model pluralism. *Philosophy of the Social Sciences*. Online First. doi: [10.1177/0048393119894897](https://doi.org/10.1177/0048393119894897).

THE AMERICAN JOURNAL OF BIOETHICS
2020, VOL. 20, NO. 4, 48–50
<https://doi.org/10.1080/15265161.2020.1730506>



Taylor & Francis
Taylor & Francis Group

OPEN PEER COMMENTARIES



Autism Advocacy Before and After DSM-5

Ryan H. Nelson

Baylor College of Medicine

In “Ethical Advocacy Across the Autism Spectrum: Beyond Partial Representation,” McCoy et al. (2020) compellingly describe the phenomenon of partial representation in autism advocacy and outline practical strategies for addressing it. This commentary seeks to provide additional context in which to situate their discussion by summarizing autism’s nebulous history

in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), and the ways in which disability advocacy has evolved alongside developments in the field of psychiatry. Building upon the authors’ analysis, I conclude by suggesting that there is reason for autism advocates to outline their constituencies in ways that depart from the contours of DSM-5.

CONTACT Ryan H. Nelson  ryan.nelson@bcm.edu  Center for Medical Ethics and Health Policy, Baylor College of Medicine, Houston, TX 77030-3411, USA.

© 2020 Taylor & Francis Group, LLC