Like Autism, Representation Falls on a Spectrum

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We live in a representative democracy. We presumably have the franchise to elect who will represent our interests. Moreover, we live in a society with a range of organizations that advocate for certain causes and represent the interests of a variety of stakeholders. The autism “community” is no different. Yet, no monolithic set of interests represents all the members of the autism community. A great deal of heterogeneity exists, among stakeholders and among representatives of those interests. Not surprisingly, tensions exist. The range of peer commentaries in response to McCoy et al.’s (2020) target article, “Ethical Advocacy across the Autism Spectrum: Beyond Partial Representation” makes clear the divisiveness in the autism community. Disagreement exists over whether autism is a disorder or disease necessitating treatment or cure, a disability that requires a civil rights approach, or whether it is a difference—a form of neurodiversity. This debate over categorization goes beyond mere taxonomy, as this will determine whether autism should be addressed through a biomedical model or a social/holistic model. While these views may seem completely apposite, they can be viewed as illustrative of the spectrum of autism itself.

One commonality among these viewpoints is that in the autism community, if not the entire ID/D community, partial representation is a reality. Whether partial representation is truly a deficit and whether or how to resolve it is at the heart of the divisiveness. Identifying any advocacy group that reflects the view of all it purports to represent seems impossible.

McCoy et al. should be commended for sparking such an important dialogue about who should speak for autistic persons. In reading their analysis and those of the many peer commentators, the answer to the question is much like most answers in ethics—it depends. No advocate or advocacy group can be all things to all persons on whose behalf they purport to speak. Therefore, even a federated model as proposed in their target article may not yield complete representation. The fact that multiple autism advocacy groups already exist suggests that a unified agenda has not been developed. The stakeholders are as diverse as autistic individuals—parents/caregivers have interests not just in advocating for those for whom they care but for themselves as well; those without ID/D have considerations distinct from those with ID/D; employers of autistic employees have their interests and the list goes on. As Jongsma and Shicktanz state “Not only is autism a spectrum, meaning that people may vary with regard to the ‘severity of symptoms,’ but there is also a difference between the interests of autistic children and those of autistic adults” (Jongsma and Shicktanz 2020, 28). A recognition that all have valid concerns is a starting point, but then begs the question of whether the totality of partial representation or representatives may aggregate to a sufficient albeit incomplete representation, as is the case in any democracy.

In “Neurodiversity and Autism Advocacy: Who fits Under the Tent?” Richman makes an important point about who has a voice in a federated approach, asking “what duties a federation of autism advocates might have toward those who consider themselves part of the autism community and engage in ‘alternative’ treatments or practices that are ill-founded, even dangerous” (Richman 2020, 33). While a federated approach might be a starting point, consideration of evidence-based policymaking and advocacy can be of assistance in determining who should or should not be “under the tent.” Advocating for treatment, services, and accommodations that are unfounded or identified as potentially harmful cannot and should not be part of the discourse; it may, in fact, impede or dilute other advocacy efforts. Taking a utilitarian approach wherein the greatest good is sought for the greatest number of individuals being represented may also determine who belongs under the tent.
Day et al. in their commentary stress that for these divergent perspectives to come together, trust is necessary arguing that, “[h]ighlighting the shared lived experiences of members across the spectrum may serve as a first step in building this trust” (Day et al. 2020, 35). They go on to state that “Using the lived experiences of all members of the autism community to highlight the commonality that all members are ‘affected by’ ASD may help reconcile competing interests through developing a mutual understanding that those living with ASD do so collectively and individually” (Day et al. 2020, 35). Where a federated approach may be helpful is in unifying some messages and avoiding conflict on others. One can be an advocate for services while still advocating for recognition of neurodiversity so long as agreement exists that autism presents on a spectrum and therefore advocacy efforts must occur along a spectrum as well. Those who can self-advocate have more opportunities available to them to do so than those who lack capacity, but they may not be the most representative voice for all. For example, in the commentary, “Additional Challenges to Fair Representation in Autistic Advocacy,” Fellowes recognizes that autistic advocates “may struggle to see the point of view of others … To the degree to which any particular autistic person struggles to see the view of others, there will be significant challenge to successful fair representation…. difficulties in seeing the perspective of other might partially explain why there is so much hostility between pro-neurodiversity and anti-neurodiversity advocates” (Fellowes 2020, 44).

Like autism itself, the organizations that purport to represent autistic individuals do not have firm boundaries of representation. As Ne’eman and Bascom state: “The authors frame a firm divide between Autistic self-advocates and those incapable of expressing their opinions. But this line is more blurry than they acknowledge” (Ne’eman 2020, 25). These porous boundaries exist within autism itself. There are no sharp boundaries between disability, disorder, and difference. As Simon Baron Cohen states:

there is a case for all of the terms “disorder,” “disability,” “difference” and “disease” being applicable to different forms of autism or to the co-occurring conditions. Neurodiversity is a fact of nature; our brains are all different. So there is no point in being a neurodiversity denier, any more than being a biodiversity denier. But by taking a fine-grained look at the heterogeneity within autism we can see how sometimes the neurodiversity model fits autism very well, and that sometimes the disorder/medical model is a better explanation. (Baron Cohen 2019)

Taking an evidence-based approach will help in determining who can self-advocate and who needs the support of others to advocate; it will also help to define what should or should not be the subject of advocacy. Such a nuanced approach will appreciate that our nosological categories of autism have profound implications for a variety of issues. A diagnosis of autism for a child will trigger a whole host of legal entitlements. An autistic adult who requires guardianship or a power of attorney for health care is only eligible for various supports. How will this current debate support autistic adults who are not able to self-advocate and may need additional support? Who will speak for them? How? And when?

REFERENCES


