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The Benefits of Experience Greatly Exceed the Liabilities

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INTRODUCTION

Nelson et al. (2023) argue that the inclusion of personal experience in bioethical debates has significant benefits and liabilities, illustrating their claim with two examples: unproven medical treatments and disability bioethics. We believe that the benefits of including personal experience in disability bioethics far exceed its liabilities. The absence of participants with relevant experience impoverishes and biases bioethical debates, while the biases risked by their inclusion are hardly unique to personal experiences and are readily mitigated.

The two liabilities Nelson et al. emphasize are conflicts of interest and partial representation. In both cases, their concerns, while reasonable, are exaggerated. In the former case, the conflicts created by personal experience are no greater than those created by other material and psychological stakes and need no special correction. This is especially so for the disability experience since non-disabled bioethicists already tend to discount the self-reports of disabled people as Pollyannaish, ill-informed, and defensive. Partial representation does present a challenge, especially for a group as heterogeneous as people with disabilities. But, to adapt Justice Brandeis' famous line, the remedy for partial representation is more representation, not exclusion. Before questioning the liabilities, however, we want to emphasize the benefits of including disabled people in bioethical debates and giving their self-reports substantial weight in contexts where personal experience is relevant.

EPISTEMIC ADVANTAGE AND EPISTEMIC (IN)JUSTICE

Nelson et al. say, "A strong argument for prioritizing the experiences of those living with disability is that those experiences are a byproduct of injustice" (*XX*). They do not argue for this claim, but we believe its justification is two-fold: failing to include disabled people in debates, particularly those that concern or affect their well-being, (a) commits epistemic injustice and (b) risks perpetuating other forms of injustice. First, failing to give a significant role to disabled individuals in these debates exhibits testimonial injustice, because disabled individuals have a privileged understanding of their experiences. Second, excluding them risks repeating the injustices that disabled people have long faced. Historical abuses of disabled people often rested on the assumption that non-disabled people knew what was best for them. Giving a central role to disabled people in discussions of their welfare would challenge that assumption and reduce the occurrence of such abuses.

For example, Applied Behavior Analysis (ABA) is a common form of treatment for autistic people, especially children. ABA uses methods from behavioral psychology to eliminate undesired behaviors and encourage desired ones. What counts as desired or undesired, however, depends on who is asked, and autism advocates have criticized behavior analysts for not asking patients for *their* goals (Leaf et al. 2022). It is a clear violation of autonomy to subject patients to "treatment" they do not, or cannot, assent to, aimed not at relieving their distress but at eliminating behaviors the therapist considers undesirable (Wilkenfeld and McCarthy 2020).

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Resolving this autonomy violation is complicated by several features of ABA patients. Autism often limits a person's ability to communicate their treatment goals, it is often comorbid with other disabilities that may impair a person's medical decision-making capacity (DMC), and ABA is typically practiced on children too young to consent. For those who lack DMC, we can look to the testimony of autistic adults, both those who have experienced ABA and those who have not. Their testimony could inform debates about what (if any) behaviors associated with autism warrant modification when the patient cannot consent. For instance, if autistic adults generally report that self-stimulating behavior (stimming) helps rather than hinders them, it would be presumptuous to attempt to eliminate similar stimming in autistic children. If there is any way to practice ABA ethically, it requires the inclusion of autistic voices, both at the clinical level and in academic bioethics.

MITIGATING BIAS

Although recognizing the importance of considering the personal experience of disabled people, Nelson et al. discuss several forms of bias that can distort the reasoning of those with a vested interest in the outcome of a debate. They propose a "grain of salt norm," which calls for additional skepticism about the arguments of someone with a vested interest. While the biases they discuss are problematic, we suggest that each of them either (a) affects everyone's reasoning regardless of conflicts of interest or (b) can be mitigated.

Post-hoc reasoning—making a quick intuitive judgment, then rationalizing it—is a frequent feature of bioethical debates, and is itself a subject of intense debate. Personal experience is one source of such reasoning but hardly a major one, compared to, e.g., family or religious upbringing. Moreover, as Nelson et al. recognize, "biased reasoning is not necessarily poor reasoning" (XX). A rationalization can be a good argument; it merely warrants closer scrutiny because of its source. Similarly, confirmation bias affects all of us in nearly every judgment we make. While we may recall evidence better when it coheres with our views, we can mitigate this bias by deliberately seeking out conflicting evidence.

Three other biases—motivated reasoning, emotional reasoning, and availability bias—are likely to impact those with a vested interest in a debate more than disinterested participants. Again, however, they need not result in bad reasoning and can be mitigated. Participants can carefully review each other's arguments in light of these potential biases. Availability, for example, may well be a source of bias for those who draw on intense, vivid experiences. Being autistic, one of us (E.B.) finds it helpful to illustrate arguments in disability ethics by reference to examples relating to autism. That need not be a problem, so long as he keeps in mind that his experiences are only examples that, however powerful, are not proof, and may not represent the views of other autistics. A concern about representativeness leads us to the second claimed liability in taking personal experience into account.

ADDRESSING PARTIAL REPRESENTATION

People with disabilities have diverse experiences, needs, and values. As a result, Nelson et al. argue that the testimony of disabled individuals runs the risk of being unduly generalized. One person's experience may be taken as representative of all people with their condition, or even of all disabled people. Before addressing this problem of partial representation, it is important to consider its source.

In *How to Be an Antiracist*, Ibram Kendi writes "When we believe that an individual's seeming success or failure redounds to an entire group, we've accepted a racist idea" (Kendi 2019, 93). Similarly, when we believe that an individual's views represent those of an entire group, we've accepted a racist (or ableist, sexist, homophobic, etc.) idea. Most disabled people—at least those engaged enough to take part in bioethical debates—are well aware of how internally diverse they are. Overgeneralization does not arise from disabled speakers offering their personal experiences as representing the community. It arises from listeners assuming that these speakers are acting as representatives, however emphatically they reject that role.

So how do we address partial representation? First, anyone hearing testimony from a disabled person should assume that they speak only for themselves, or if in doubt, ask them. Second, partial representation can be mitigated by *more* inclusion. Perhaps the best way to prevent the misconception that one disabled person speaks on behalf of the "disabled community" is for another disabled person to say, "They don't speak for me." While there are challenges in broadening representation, they are similar to those regularly faced, and usually overcome, by bioethicists seeking to obtain representative samples of relevant groups.

CONCLUSION

We have argued that in the case of disability, the liability side of the "paradox of experience" is overstated. First, the biases arising from a vested interest in the outcome of a debate are familiar ones. They require no special measures to mitigate, especially in the case of disability bioethics, where there is little danger that the first-person testimony of disabled people will receive excessive deference. Second, the problem of partial representation arises from a history of exclusion and is reinforced by the attitudes of nondisabled listeners. The primary responsibility for correcting it should rest with the bioethics community, not with those previously excluded.

We cannot have satisfactory debates on disability ethics without respectfully considering the personal experiences of disabled people. The "liabilities" associated with their personal experience not only *can* be mitigated but *must* be, to secure space for their neglected critical perspectives.

DISCLAIMER

The view presented in this commentary is solely the authors'. They do not represent the position or policy of NIH or any part of the Federal Government.

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Assisted Dying: More Attention Should Be Paid to the Epistemic Asset of Personal Experience

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The target article (Nelson et al. 2023) offers a valuable contribution to the "paradox of experience," which was illustrated by using examples about access to unproven medical products and disability bioethics. As the authors noted, the paradox extends well beyond these particular issues, and appeals to experience are seen throughout bioethics. In this commentary, we will argue how the personal experience of patients serves as an epistemic asset and a liability in the debate around assisted dying. By weighing both

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