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Stigma, Incommensurability, or Both? Pathology-First, Person-First, and Identity-First Language and the Challenges of Discourse in Divided Autism Communities

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There is an intense debate in the autism world between supporters of person-first language (PFL: e.g., “person with autism”) and identity-first language (IFL: e.g., “autistic” and “autistic person”). This controversy can engender intense passion and bitter disagreement, reflected in fiery comments on social media.¹ Polarization is high: In one study, people on the spectrum were most likely to rate “autistic” the *least* offensive of various terms, yet “autistic” was also nearly the most likely to be rated *most* offensive.²

However, PFL and IFL are not the only ways of describing autism. They were preceded by what might be best described as “pathology-first language” (PathFL). In PathFL, disability labels such as “autistic” are, without reflection on the implications of such language use, allowed to define disabled people as afflicted by pathology and as defective. For example, one 1968 study informs us that the “autistic child” has “a *severe* disorder” (emphasis in original) that, among other features, is characterized by “a lack of sympathy or empathy”; we are also told that such children are usually “mentally subnormal.”³ Unfortunately, although it is hard to find any principled argument supporting PathFL, some autism studies still seem to use PathFL today.^{4–6}

Person-first language emerged in reaction to PathFL. Advocates of PFL argued that disability should not be allowed to define a person in this negative, stigmatizing way: that instead, terms such as “person with autism” should be used to emphasize individuals’ personhood and humanity while relegating their disabilities to being merely one of many personal attributes.^{7,8}

However, IFL advocates such as Sinclair⁹ found PFL unsatisfactory. From the perspective of these advocates, PFL completely dodged the real problem: the stigmatization of disability itself. As these advocates saw it, PFL,

by distancing the person from their disability, was accepting that autism and disabilities were inherently negative: that they could not define someone in a positive way or even that they were inconsistent with personhood.⁹ IFL advocates also emphasize that PFL is seldom used to refer to nonstigmatized groups.^{9,10}

Superficially, an IFL approach uses the same words used by PathFL—e.g., “autistic”—but their underlying meaning and connotation are entirely different. “Autistic” in PathFL describes a negative pathology; PathFL users seem indifferent to the effects of such discourse on identity. By contrast, “autistic” in IFL suggests that autism should be a positive part of someone’s identity, coexisting with other identities (e.g., “a Chinese-Canadian autistic woman”). This does not mean that autism has no existence outside the realm of identity,¹¹ merely that in the IFL approach, autistic people are encouraged to accept, be proud of, and identify with their neurodivergence.

This is far from the only autism-related term meaning different things to different people. Another example is “disabled.” Arnhart et al.¹² suggest that “disabled” should be viewed as a stigmatizing term. This is perhaps because, for many people, the term “disability” refers to what a *person* cannot do.^{8,13} However, in the social model of disability, “disability” has little to do with the person: It refers to the barriers and challenges imposed on people by the *society*’s failure to be accessible and inclusive.¹⁴ Still other approaches, such as social-relational and social-ecological models, take intermediate positions.^{15–17} Thus, there are many meanings of “disabled,” and it is far from clear that they are all inherently stigmatizing.

These differences of meaning seem to give rise to *incommensurability*: a lack of a common standard for comparison or measurement. Major approaches to autism, such as neurodiversity approaches and pathology approaches, are often referred to as Kuhnian “paradigms.”^{18,19} Owing to the greater heterogeneity of approaches to autism and disability compared with the more monolithic Kuhnian scientific paradigms, I prefer to speak of a multiplicity of “approaches,” but I agree these approaches share several crucial features of paradigms: They are used by more or less distinct communities of people, they dictate a “proper” approach that should be taken by their respective adherents, and—crucially for the topic of this commentary—they involve different ways of

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defining concepts and of viewing the world.²⁰ Owing to this last point, they are to some degree incommensurable: It is often impossible to match a concept in one approach with an exact equivalent in another approach.

This incommensurability problem greatly complicates quantitative measurement of stigma in autism terminology. When the same words have multiple meanings and connotations to different communities, how can researchers classify words as inherently stigmatizing or nonstigmatizing or use these classifications to measure stigma in language use? Indeed, there is a danger that classification of words as inherently stigmatizing or nonstigmatizing could lead to circular reasoning. If researchers based such classifications on their own community's approach to language use, they could conclude that other communities following different approaches use terminology in a stigmatizing way simply because people in these communities follow different approaches than the researchers' own. This may be a limitation of the study conducted by Arnhart et al.¹²

Fortunately, the challenge of incommensurability need not reduce us to relativism. Kuhnian incommensurability has not prevented science from being generally progressive, nor has it prevented historians of science from understanding outdated paradigms.^{20,21}

Greater engagement can help us overcome incommensurability. Through dialogue and collaboration, people following different approaches can come to appreciate and understand the differences in their lexicons and worldviews. This sort of engagement should involve not only interdisciplinary partnerships among academics from different communities of researchers but also participatory collaboration between researchers and community members. Recommendations regarding participatory research are available.²²

Participatory groups of academics and community members would be excellently positioned to conduct further empirical investigation of stigma in autism terminology. The diversity of these research teams would allow them to articulate sophisticated hypotheses informed by multiple approaches to terminology. Studies could ask participants to provide quantitative measurements of stigma in terminology, such as explicit ratings of terms, implicit association tests on terms, or even ratings of people (in vignettes or real-life interactions) described using different terms. Moreover, participants could be asked to define terms; these qualitative definitions could be coded to describe, and perhaps assign participants to groups based on, the multiple meanings of terms.

However, the rich data that would be provided by these sorts of studies would only be correlational; it would not allow for causal conclusions. Simply because a community of people tends to use some term alongside a number of stigmatizing terms, it does not logically follow that the first term *caused* members of that community to use the other stigmatizing terms.

Indeed, it seems more plausible that people's terminology choices would reflect their overall approaches to

autism and disability and their membership in communities associated with these approaches. For example, the assumptions, beliefs, and commitments underlying neurodiversity approaches might lead a neurodiversity advocate both to use IFL and to resist medicalizing and pathologizing language. Instead of determining choices to use other terms, the advocate's choice to use IFL, PathFL, or PFL might be more important as one signal of their wider political affiliations.

Therefore, it may be wise to be wary of focusing too much on IFL and PFL alone. PFL and IFL are of course important dimensions of identity that should be respected, but there are numerous other serious terminology issues in the autism world, including functioning labels, disorder labels, deficit language, language of risk and red flags, patronizing language, and dehumanization, to name only a few.²³⁻²⁵ These sorts of negative terminology choices are not "objective," and alternative terms are—far from being Pollyannish—often more nuanced and less value-laden.²⁴ Crucially, insofar as autism acceptance is related to mental health,²⁶ it seems reasonable to fear that the stigma and prejudice conveyed by these negative language choices are harming autistic people. We must therefore apply a critical lens toward autism-related terminology in general.

This can help us address the challenge posed by PathFL. In light of the findings of Arnhart et al.,¹² it seems possible that the increasing adoption of IFL inadvertently helped reopen the door to PathFL because many researchers outside the autistic community and the neurodiversity movement may struggle to distinguish IFL from PathFL. Fortunately, a solution to this problem exists: Adopting stronger policies against pathologizing language would prevent PathFL usage. The journal *Autism in Adulthood* has not only implemented such policies but has also recruited autistic adults to help implement them, thereby adding the community's expertise to that of academic reviewers.

What other actions can we take in the PFL-IFL debate?

At the individual level, we should always respect a person on the spectrum's preference to use IFL or PFL.²⁵

The issue of how to refer to autistic people as a collective group is more complex. In principle, the opinions of people on the spectrum should still be the ultimate decision maker: Nonautistic people should defer to the consensus of people who are autistic. Investigations such as those of Gernsbacher¹⁰ and Arnhart et al.¹² might help persuade people on the spectrum to take one view or another, but the collective view of people on the spectrum should always be the deciding factor. Researchers should therefore frame research-based terminology recommendations as suggestions for people on the spectrum.

I am autistic and I support IFL. I find the pro-IFL arguments advanced by Sinclair,⁹ Gernsbacher,¹⁰ and others compelling.

Furthermore, I would argue that support for IFL is already high²⁷ and that it is probably increasing. I also

suspect (although studies have yet to investigate this) that some people on the spectrum who support PFL may lack knowledge of pro-IFL arguments: Given the higher support for PFL phrases such as “has autism” and “with autism” among parents and professionals,²⁷ parents and professionals might introduce people on the spectrum to PFL, but if people on the spectrum do not seek out communities of autistic adults, they may not be exposed to IFL. However, I acknowledge that it is not yet entirely clear that a consensus exists in favor of IFL or PFL. Opinion remains somewhat mixed,^{2,27} and more research is needed to explore the views of nonspeaking and minimally verbal people who do not type.^{28,29}

Thus, although I personally encourage researchers to use IFL when collectively describing autistic people, I acknowledge the current lack of consensus and that it is likely appropriate at this point for researchers to use PFL if they feel there are good reasons for doing so. Alternatively, there exist compromise positions: mixing PFL and IFL, using “person on the spectrum” or—as proposed by Arnhart et al.¹²—saying “person who is autistic.”

Perhaps most importantly, though, we must try to understand one another’s approaches, worldviews, and terminology. Instead of assuming that terminology choices we do not understand are reflections of stigma and prejudice, we should listen to one another and grasp the nuances in one another’s views. Instead of dismissing someone as a member of an adversarial outgroup when they use terminology we reject, let us assume good intent, engage in dialogue, and educate one another.

Of course, the burden of this sort of engagement should not be shared equally. In particular, autistic people should not be forced to subject themselves to genuinely stigmatizing or offensive discourse for the sake of understanding it. Instead, because of the power held by researchers and professionals and our fields’ legacies of harm toward autistic people, the onus is on researchers and professionals to regain community members’ trust and build the partnerships that will lead us toward mutual understanding.

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