

Making Sense of Autism or Making Sense of Individuals with Autism?

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> Abstract • I argue that the importance of self-illness ambiguity for the social perception of autism is not sufficiently acknowledged, and offer some suggestions for follow-up research.

Handling Editor • Alexander Riegler

« 1 » In their target article, Maciej Wodziński and Paulina Gołaska-Ciesielska provide an important contribution to our understanding of the social perception of autism – a topic with significant societal relevance. Their main finding, that there is a discrepancy between the conscious reflective knowledge and the unconscious background knowledge concerning autism, has important ethical ramifications and may serve as an important starting point for follow-up research.

« 2 » In my commentary, I intend to pick up on a collection of topics in the target article that are touched upon but not (sufficiently) elaborated. On a charitable reading of this commentary, this discussion could be seen as precisely a “starting point for follow-up research.” On a less charitable reading, it could be read as a criticism of the employed methodology and conceptualizations. The two topics that I have in mind are

- the importance of language (addressed primarily in §39); and
- the phenomenon of self-illness ambiguity (addressed primarily in §38).

« 3 » These topics may jointly give rise to the idea that the construction process concerning autism, which Wodziński and Gołaska-Ciesielska aim to bring into focus, is essentially driven by the more fundamental construction of self-illness relations (either of people with autism or of people with mental illness more generally). Let me clarify this point by means of an analogy. The studies on linguistic preferences in relation to autism, cited by Wodziński and Gołaska-Ciesielska in §39, highlight that those preferences tend to be the result of how people

see the person in relation to their autism. Roughly, preference for “autistic person” is informed by the construal of person and autism as inseparable, whereas “person with autism” is informed by the construal of person and autism as, in principle, separable. In a similar fashion, it might be argued that how people think about the nature of autism, its causes, and the traits associated with it, follows from their more general constructive processes on self-illness relations (e.g., about people as overlapping with an illness or being separate, Sadler 2007; or as the illness being internal or external to the agent, Sass 2007). Such self-illness relations are notoriously complex and clarifying them is hindered by various conceptual and epistemological obstacles (Dings & Glas 2020). For instance, mental disorders are sometimes construed by lay people in terms of biological “things” that are detached from the person, exerting control and making the person less predictable. This has social ramifications, as people tend to avoid unpredictable people. Such mechanisms have been found with regard to people who suffer from depression (Deacon & Baird 2009) and ADHD (Singh 2013) and it may also be the case for autism. Thus, to what extent may the data found in this study be understood as being the result of the participants’ understanding of the self-illness relation in autism (or self-illness relations more generally)? « 11 » Note that this may tie in directly with the aim of Wodziński and Gołaska-Ciesielska to investigate the role of reflective versus background knowledge. For instance, it might be that the way in which people *unconsciously* construe self-illness relations has an impact on their background knowledge concerning autism but not on their reflective knowledge. Thus, construction processes concerning self-illness relations in general might differentially impact construction processes concerning autism in particular. These matters could either be read as empirical questions, to be addressed in subsequent research, or as interpretative questions with possible ramifications for the data of this study.

« 4 » A related methodological question follows from the conceptual difficulties in separating people from illnesses: How to set up a (qualitative) study that is sensitive to this possibility, i.e., that people’s con-

structive processes concerning autism is inextricable from their constructive processes on self-illness relations more generally? « 12 »

In the current study, these seem to be sometimes targeted separately. For instance, in the first part of the survey, some questions clearly target autism (such as its nature and causes) but other questions seem to target the relation between autism and the individuals diagnosed with autism (including traits associated with autism). In this respect, it is worthwhile to consider whether there would be a difference in whether a study targets

- “autism” as a general diagnosis;
- “people with autism” in general; or
- more specific cases that reflect individual variety.

More concretely, it might be that a vignette study yields different results from the ones obtained via the questionnaires in the study by Wodziński and Gołaska-Ciesielska (see, e.g., Bröer & Besseling 2017 for an example of a vignette study targeting the self-illness relation in the context of depression).

« 5 » At any rate, there is a dynamic and recursive interplay between, on the one hand, how diagnosed individuals think about themselves in relation to their illness, and, on the other, the way in which this self-illness relation is construed by friends, family, the media and society at large (Dings & Glas 2020; Glas & Dings 2020). The precise impact of lay understandings of self-illness relations on how people understand themselves and others is, as yet, unclear and requires further investigation.¹ The study by Wodziński and Gołaska-Ciesielska certainly contributes to this complex issue but my point so far has been that including the self-illness relation (as an explicit target of investigation) might lead to a more nuanced interpretation of the obtained data.

« 6 » As a way of opening up avenues for future research I wish to briefly discuss some research from another field which may be directly related to the issues I have highlighted so far. What I have in mind is so-called “experimental philosophy,” which tries to elucidate lay intuitions concerning

1 | See my paper “What is special about ‘not feeling like oneself’? A deflationary account of self(-illness) ambiguity,” co-authored with Leon De Bruin, which is currently under review.

identity and personhood in the context of illness. Such research is not extensive, but a study by Nina Strohming and Shaun Nichols (2015) offers a great example. Strohming and Nichols use both hypothetical and non-hypothetical case studies to investigate how laypeople think about the “self” in the context of neurodegenerative illnesses such as Alzheimer’s. What they find is that laypeople, in the process of trying to make sense of whether an individual is still the same person, structurally emphasize (changes in) the moral character of the person, rather than, e.g., perceptual or memory capacities of that person. For that reason, Strohming and Nichols (2014) talk about the “essential moral self.” Coming from a slightly different angle, Strohming, Joshua Knobe and George Newman (2017) delineate the concept of a “true self.” In short, this concept highlights that laypeople have various intuitions about who someone “really” is, where someone’s “self” might differ from their “true self.” In relation to the study by Wodziński and Gołaska-Ciesielska, it would be worthwhile to investigate the constructive processes of laypeople when it comes to the self-illness relation of autism, and whether those laypeople also highlight the importance of moral features in evaluating people with autism (as suggested by Strohming & Nichols 2014) and whether they employ concepts similar to that of a “true self” (as suggested in Strohming, Knobe & Newman 2017).

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- Funding:** Gefördert durch die Deutsche Forschungsgemeinschaft (DFG) – 419046236 (DFG Forschungsgruppe FOR2812 “Szenarien der Vergangenheit”); Funded by the Deutsche Forschungsgemeinschaft (DFG, German Research Foundation) – 419046236 (DFG Research Unit FOR2812 “Constructing scenarios of the past”).
- Competing interests:** The author declares that he has no competing interests.

RECEIVED: 7 SEPTEMBER 2021

REVISED: 4 OCTOBER 2021

ACCEPTED: 5 OCTOBER 2021

Is Heidegger’s Fundamental Ontology an Antidote to Dominant Social Constructions of Autism?

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> Abstract • I argue that Wodziński & Gołaska-Ciesielska’s target article appears undecided in its normative core. On the one hand, the authors speak of autism as a construct and propose a diversity perspective as an alternative and less diminishing construction than the dominant social one. At the same time, they succumb to some version of ontology in which there is genuine neurodiversity that could normatively speak against either biomedical or social constructions of autism.

Handling Editor • Alexander Riegler

Being-in-the-world

« 1 » The title of this commentary is obviously somewhat provocative. After all, neither Martin Heidegger nor fundamental ontology is mentioned in the original contribution in Maciej Wodziński and Paulina Gołaska-Ciesielska’s target article. However, in §§4, 9, and 27, the authors use the phrase being-in-the-world, a literal translation of the German *in-der-Welt-sein* from Heidegger’s *Being and Time* (Heidegger 1962). Whether or not this choice of terminology is intended, I consider it a key term for the present topic. It is because the concept of being-in-the-world points towards the issue of the ontological status of diversity. And diversity, in the authors’ argument, has potentially subversive potential against the largely unjustified, but prevalent social constructions of autism.

« 2 » Being-in-the-world is essentially synonymous with *Dasein* (or human existence), a term that indicates the uniqueness of each being that cares for its own being. It is a uniqueness framed within the existential structure common to all. In Wodziński & Gołaska-Ciesielska’s article, being-in-the-world appears in the context of discussing