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Authors

Dinishak, Janette

Akhtar, Nameera

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Integrating autistic perspectives into autism science: A role for autistic autobiographies

Janette Dinishak

Nameera Akhtar

University of California, Santa Cruz

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Abstract

Autism science faces several conceptual and ethical challenges. These include fundamental issues such as how to characterize autism and the fact that research findings and how they are interpreted sometimes contribute to negative perceptions of autistic people. We argue that some of these challenges can be addressed by centering the perspectives of autistic people and focus on one way to accomplish this: having non-autistic researchers critically engage with personal accounts of autistic experience. We discuss some of the advantages and challenges of engaging with these accounts and argue that they can play a role in the reform of autism science.

Keywords: autism, autistic perspectives, epistemic justice, first-person accounts, autism science reform

Lay Abstract

Autism science faces challenges in how to think about autism and what questions to focus on, and sometimes contributes to stigma against autistic people. We examine one way that non-autistic researchers may start to combat these challenges: by reading and reflecting on autistic people's descriptions of their personal experiences (e.g., autobiographies) of what it is like to be autistic. In this paper, we review some of the advantages and challenges of this approach and how it may help combat some of the challenges currently facing autism science by focusing studies on the questions autistic people find most important, counteracting stereotypes, and increasing understanding of autistic experiences.

Integrating autistic perspectives into autism science: A role for autistic autobiographies

“The novel reader’s experience... becomes a training in the honoring of Otherness...a crucial pre-condition for positive social change.” (Hale, 2007, p. 189)¹

Autism science faces several interrelated conceptual and ethical challenges (Milton, 2020). The conceptual challenges arise from very different perspectives on what autism is and lead to ethical issues concerning how it is studied and how autistic people are treated. One dominant perspective frames autism in terms of deficits in need of correction and views specific behaviors as “symptoms” (Dinishak, 2016). A contrasting view conceptualizes autism as a form of human diversity that requires accommodation by society and the environment (Singer, 1999), much like being Deaf or hard-of-hearing requires accommodation in the form of video captioning and locomoting via wheelchair requires elevators and curb cuts (Gernsbacher, 2015). These conflicting perspectives create a disconnect between what (some) non-autistic researchers and (some) autistic people view as appropriate topics for research and targets for “intervention” (Pellicano & den Houting, 2022; Pellicano et al., 2014). Indeed, interventions often presuppose concepts of well-being modeled on non-autistic experience, but these concepts may not provide good guidance on what constitutes autistic flourishing (Chapman & Carel, 2022; Rodogno et al., 2016). For example, stereotyped repetitive behaviors are viewed by some researchers as “problem behaviors” that interfere with optimal functioning (Loftin et al., 2008), but many autistic people say they play an important role in self-regulation, and therefore should not be stigmatized and should not be targeted for elimination (Kapp et al., 2019).

¹ Although Hale is referring to the effect of reading novels in particular, we believe her point also applies to autobiographical accounts.

In the last decade or so there has been a lively and productive discussion about how autism science reinforces the marginalization of autistic people and how to address this (Ashworth et al., 2021; Cascio et al., 2020a, 2020b; Fletcher-Watson, et al., 2021; Pellicano & Stears, 2011). One major problem is that much of autism research does not capture the research priorities of autistic people themselves. As such, there is “...an urgent need to produce more effective basic autism science that is capable of generating tangible benefits for the wider community” (Pellicano, 2020, p. 233). Another problem is that the goal of many (non-autistic) researchers seems to be to make autistic people simply appear less autistic and often no distinction is made between behaviors autistic people find useful versus harmful (Ne’eman et al., 2020). As an antidote to research practices that reinforce stigma, it is necessary to include autistic perspectives in autism research (Autistic Self Advocacy Network; Benevides et al., 2020; Milton & Bracher, 2013); failing to do so can lead to active harm (Holt et al., 2021; Milton, 2014).

Participatory research is bringing autistic perspectives to autism science in a very direct and necessary way to address these issues. Both (non-autistic and autistic) researchers (den Houting et al., 2020) and autistic research participants (Pellicano et al., 2021) have generally favorable attitudes towards it, while acknowledging its challenges (Pickard et al., 2021). It seems likely that interacting with autistic researchers and community members on research teams plays an important role in challenging non-autistic researchers’ perceptions of autism. In this paper we focus on another potentially powerful way of influencing non-autistic researchers’ views of autism: reading autobiographical accounts of autistic experience. We ask: what role(s) can autobiographical accounts of autism play in autism science? This question concerns not just the role the autobiographical accounts could play, but also, and, perhaps more importantly, should

play? Jaswal and Akhtar (2019) recently argued for the importance of taking autistic testimony seriously, especially when it contradicts prevailing wisdom, but did not go into detail on the ways autistic testimony can be useful. Our general aim is to assess the promise and challenges associated with engaging with these accounts of autistic experience.

In Section I, we explore various interrelated roles autobiographical accounts can play in improving autism science. We also examine if attention to these accounts can counter epistemic injustice (Fricker, 2007), any unfair treatment related to knowledge, understanding or participation in communicative practices (Kidd et al., 2017); e.g., when someone is denied the opportunity to contribute to knowledge production because they are not respected as credible or is denied education or other epistemic resources that would allow them to interpret their experiences. In Section II, we discuss challenges to using these accounts, and consider whether, despite the concerns brought out by these challenges, autobiographical accounts of autistic experience have an important role to play in addressing the conceptual and ethical issues facing autism science. To preview the conclusions, we believe that autobiographical accounts can be used in a variety of ways for the betterment of autism science, including the following: to challenge existing hypotheses (to see if they are consistent with first-person accounts),² to prompt new research questions and hypotheses, and to identify and challenge assumptions. Autobiographical accounts can also help address some of the forms of epistemic injustice autistic people are often subject to (Chapman & Carel, 2022; Dinishak, 2021). More broadly, we think the primary benefit of autobiographical accounts is in shifting perspectives of non-autistic researchers to consider and develop alternative explanations of the behaviors and experiences associated with being autistic.

² In what follows we will use “autobiographical” and “first-person” interchangeably.

Positionality Statement

We are both non-autistic and have both experienced profound changes in our views of autism as a result of reading autobiographies written by autistic individuals. One of us (Nameera) learned to conceptualize autism from the medical perspective and was led to believe (by all of the research purportedly demonstrating deficits in theory of mind in autistic individuals) that autistic persons were unable to take others' perspectives. John Elder Robison's *Look Me In The Eye* (2007) led her to begin questioning this view. Robison's examples of being misunderstood by non-autistic people drive home Milton's (2012) point that communication is bidirectional and that putting all the blame for misunderstandings on autistic people is unfair. The other author (Janette) found that autistic people were regularly portrayed as unable to understand metaphor in the philosophy and linguistics research she encountered on autism. Reading Tito Rajarshi Mukhopadhyay's *The Mind Tree* (2003) and experiencing his use of metaphor cast serious doubt on this portrayal and helped her begin to develop a skeptical attitude toward deficit views of autism more generally. These and other critical engagements with autism memoirs informed the authors' first collaboration (Dinishak & Akhtar, 2013).

Cautionary Notes

Before proceeding, three notes are in order to help orient the reader. First, there are multiple ways to integrate autistic perspectives into autism science. One way involves asking autistic research participants to report on their experiences via surveys and interviews. An even more powerful way is participatory research as it incorporates autistic perspectives on "both *what* research is done and how it is conducted" (Poulsen et al., 2022, p. 3). In this paper, we focus on autobiographical accounts (e.g., written memoirs, blogs, social media posts, videos) which are first-person narratives describing what it is like to be autistic that are often produced

and published for the public, not for the purposes of asking and answering research questions. More specifically, we focus on (non-fiction) written narratives. (In future work on this topic it would be interesting to explore whether different modes of sharing first-hand accounts (e.g., blogs, videos, social media) are associated with different benefits and challenges and whether they require different kinds of techniques for engaging with them.)

Second, researchers can use autobiographical accounts of autism in a variety of ways. Two include: (i) treating these accounts as a source of data that one systematically analyzes, synthesizes, and/or quantifies (e.g., performing content analyses of multiple published autistic autobiographies); and (ii) reading and reflecting on a number of autistic autobiographies. We focus primarily on (ii) as it is an under-explored topic. While we pay special attention to the potential roles and benefits of reading and reflection for non-autistic researchers in particular (though of course non-autistic non-researchers, and autistic researchers and non-researchers could also benefit), we address both (i) and (ii) in our discussion of challenges to using autobiographical accounts in autism science in Section II. Third, autism is highly heterogeneous and is experienced differently by different individuals and within the same individual across their lifespan and across contexts. As such, autistic people confront a wide range of sensory, motor, perceptual, and cognitive experiences that can vary over time (Tavassoli et al., 2014). For example, some autistic people have hyper-sensitivities in a sensory modality while others have hypo-sensitivities in the same modality. These variations in sensory sensitivity can result in reacting differently to the same stimuli. Some autistic people find social interaction motivating while others do not (Fletcher-Watson & Crompton, 2019). One autistic individual may find social interaction in one context motivating but not in another. Some autistic people make little or no eye contact while others do. Some do not speak or have limited speech, and among non-

speaking autistics some communicate through typing while others do not. Some autistic people might camouflage their autistic differences (e.g., suppress repetitive hand movements) as a way of adapting to and coping within the non-autistic world but not camouflage those differences when in the company of other autistic individuals or when they are alone. The enormous variability and complexity of autistic experiences should encourage caution concerning how far one can generalize from any one example of autistic experience or particular autobiographical account of the experience of autism. This variability and complexity should encourage us to read a wide range of autistic autobiography.

I. Potential Roles for Autobiographical Accounts in Autism Science

First, autobiographical accounts can be used to evaluate existing hypotheses. For example, one might hold that a candidate hypothesis must be *consistent* with first-person accounts of experience. Call this “the consistency constraint.” Suppose there are two hypotheses, H1 and H2, to explain phenomenon x, but only H1 is consistent with (some) first-person accounts of experiences of x. All else being equal, H1 would meet the consistency constraint while H2 would not. The nature and strength of the consistency constraint can vary. It can function merely as a recommendation or, more strictly, as a requirement on a theory. Likewise, the consequences for theory in the event that a hypothesis fails to meet the constraint can vary. For example, should a theory that does not meet the constraint be discarded, or can such a theory still be retained, for reasons that outweigh meeting this constraint? How strictly one construes the consistency constraint depends, in part, on one’s views of the relation between theory and experience and whether and how to respond when the two are conflicting or even contradictory.

Now let’s examine how the consistency constraint might be used to evaluate hypotheses about autism given the variability of autistic experience. The research literature currently

features two contrasting hypotheses proposed to explain reduced (relative to non-autistic people) eye contact: gaze aversion and gaze indifference. The first states that autistic people actively avoid eye contact because they find it aversive (Dalton et al., 2005; Kylliäinen & Hietanen, 2006). The second states that low frequencies of mutual gaze indicate a passive indifference to gaze, one of a number of social insensitivities believed to be associated with autism (Chevallier et al., 2012; Moriuchi et al., 2017). Suppose that both of these hypotheses are consistent with observed behavior, but only one is consistent with autobiographical accounts of experiencing eye contact. In this case, the hypothesis that is consistent with autistic experience meets the consistency constraint while the other does not. However, as noted above, there is considerable variability in accounts of autistic experience, including experiences of eye contact. While many autistic people report experiencing eye contact as uncomfortable, even painful (e.g., Kedar, 2012; Lawson, 1998), others report eye contact experiences (e.g., being told that they are staring relentlessly) that suggest the absence of hyperarousal (Trevisan et al., 2017). In this case, the consistency constraint should prompt researchers to refine their hypotheses. In particular, it should function as a check on the scope of the generalizations made. Given the complex and variable qualities of autistics' reported subjective experiences of eye contact experience, the scope of the generalizations will need to be limited to reflect that they cover only a subset of autistic individuals.

Second, accounts of the lived experience of autism can prompt new research questions, suggest new hypotheses, and help researchers identify and/or conceptualize new forms of a phenomenon (e.g., social interest, intersubjective engagement and experience) that have not been sufficiently acknowledged and studied. One way to generate new research questions is by refining existing models. For example, discovering variability in autistics' experiences of eye

contact in autobiographical accounts could be followed up with an interview or survey to study factors that might contribute to the variability (e.g., eye contact with a stranger versus eye contact with a close friend), and this discovery could help researchers further specify their hypotheses. The revised hypothesis might explain and predict only a subset of the phenomena the initial hypothesis purported to explain and predict, but it would be consistent with autobiographical accounts of autistic experience and would better capture the complexity and variability of this experience. Another way to generate new research questions is by motivating entirely new lines of inquiry.

For example, autistic burnout, often described by autistic adults as involving long-lasting, pervasive exhaustion, loss of skills, and reduced tolerance to stimulation (Raymaker et al., 2020), has been largely neglected in the academic and clinical literature. As Kieran Rose (2018), an autistic adult, writes, “Autistic Burnout is an integral part of the life of an Autistic person that affects us pretty much from the moment we’re born to the day we die, yet nobody, apart from Autistic people really seem to know about it.” Autistic adults’ accounts of autistic burnout have helped others, including non-autistic autism researchers, to become aware of it, characterize it, and better understand how it differs from other forms of burnout (e.g., occupational burnout), clinical depression, and other conditions (Higgins et al. 2021; Raymaker et al., 2020).

Third, consulting first-person accounts of autistic experience can help identify and challenge deeply embedded, pernicious assumptions and biases, and in this way “knock off its pedestal our received and often armchair view about what things must be like for others” (Misak, 2010, p. 396). For example, autistic accounts of repetitive behaviors challenge the belief that such behaviors are functionless or harmful (Charlton et al., 2021; Kapp et al., 2019). Many autistic individuals report experiencing these behaviors as having cognitive, communicative,

and/or self-regulatory value.³ The title of a collection of first-person accounts of non-speaking and speaking autistics, *Loud hands: Autistic people, speaking* (Bascom, 2012), suggests that hand flapping, for example, has communicative value. These accounts also identify unconventional (and perhaps idiosyncratic) ways autistic people engage with others and the world around them, broadening non-autistic researchers' notions of "communication," "interaction," "response," and "voice." To take another example, Jaswal and Akhtar (2019) used autistic testimony (largely from autobiographical accounts) to dispute the idea that autistic people lack social motivation. Autistic adults' descriptions of being misunderstood by non-autistic people (as seen in many autobiographical accounts) can similarly be used to challenge the widespread idea that autistic people are responsible for their social difficulties.

Drawing on autistic scholar Milton's (2012) concept of double empathy, several studies have demonstrated that the social difficulties experienced by autistic people are partly a consequence of the attitudes and behaviors of non-autistic people: non-autistic people are not very good at reading autistic facial expressions (Brewer et al., 2016) nor at identifying autistics' mental states (Edey et al., 2016), and they tend to make prejudiced assessments of autistic individuals based on first impressions (Sasson et al., 2017). These important studies have inspired recent interventions designed to improve both autistic and non-autistic individuals' understandings of each other. One such successful intervention involved autistic and non-autistic individuals discussing a novel together (Chapple et al., 2021; 2022). We hypothesize that reading and reflecting on autistic autobiographies in particular, by exposing non-autistic readers to autistic perspectives, may lead to even greater reductions in the double empathy problem.

³ See Doan and Fenton (2013) for a detailed critique of the common view of repetitive behaviors that draws on first-person accounts of autism in illuminating ways, and Kapp et al. (2019) and Charlton et al. (2021) for autistic adults' reports of the calming effects of stimming.

Finally, reading and reflecting on first-person accounts of autistic experience may help prevent and treat epistemic injustice. Fricker (2007) distinguishes two main kinds of epistemic injustice: testimonial and hermeneutical. Hermeneutical injustice occurs when aspects of one's social experience are obscured or are difficult to articulate and understand because of gaps in collective interpretive resources for understanding those experiences. Testimonial injustice occurs when someone gives a person's testimony less (or more) credibility than deserved because of prejudice. Here we focus on testimonial injustice as it is most directly relevant to challenges to using first-person accounts that we discuss in Section II (see Dohmen (2016) and Dinishak (2021) for discussions of hermeneutical injustices autistic people face with respect to their first-person accounts of their experiences of autism).

Some non-autistic researchers question the credibility of autistic authors who because of identity prejudices they hold about autistic people (e.g., the erroneous assumption that autistic people are unable to understand mental states; see Gernsbacher & Yergeau, 2019). In contrast, when non-autistic researchers regard autistics' experiential reports as reliable testimony, they are taking the accounts to have evidential value. Treating personal accounts as a good source of evidence on the lived experience of being autistic recognizes autistic individuals as reliable knowers of (and, indeed, experts on) their experiences, and thereby corrects for testimonial injustice. And examples found in those accounts of, for example, perspective-taking (Robison, 2007) and use of metaphor (Mukopadhyay, 2003) also counter misconceptions about the cognitive skills autistic individuals are often said to lack.

This section has shown that autobiographical accounts of autistic experience can play a variety of roles in theorizing about autism. Some roles are theory-constraining while others are theory-broadening. Moreover, these accounts do not play (merely) descriptive roles; they play

substantive and evaluative roles as well (e.g., by serving as evidence, constraining theory choice, overturning embedded assumptions, and revealing neglected topics). There are, however, challenges to fruitfully engaging with first-person accounts of autism and incorporating them into autism science, challenges we examine in the following section.

II. Challenges to Using Autobiographical Accounts in Autism Science

Three issues need to be examined when considering the benefits of incorporating first-person accounts of autistic experience into autism science: 1) whether the accounts should be taken at face value or engaged with critically; 2) whether they meet the standards of scientific evidence; and 3) even if they do not, can they still be of value?

Regarding the first, what sorts of considerations motivate the idea that first-person accounts should be taken at face value? One might reason that not only do accounts of the first-person experience of x give one insider knowledge of or insight into x , but further, that their authors have special authority and experiential expertise (Milton, 2014; Pellicano et al., 2019), making them good sources of evidence on the experience of x . And one might reason further that to prevent testimonial injustice we *must* recognize autistic individuals as reliable knowers of the lived experience of being autistic, and to do this we must take their autobiographical accounts at face value.

At first blush it might seem that taking personal accounts at face value is how one recognizes those accounts as sources of knowledge and recognizes their authors' epistemic agency and authority. But is failing to take these accounts at face value equivalent to a failure to recognize them as sources of knowledge and autistics' epistemic authority? On the contrary, sometimes taking first-person accounts at face value can impede progress in gaining knowledge (Misak, 2010) and in treating/preventing epistemic injustice (Gosselin, 2019) by discouraging

scrutiny. That reflection and critical scrutiny promote productive discourse and deepen knowledge is a familiar insight. However, the idea that taking a speaker's first-person account at face value can *contribute* to, rather than help correct, epistemic injustice, is less familiar and perhaps more surprising.

To help get traction on this idea, we turn to Gosselin's (2019) compelling work on the conditions that ensure epistemic justice when first-person accounts are shared and those that undermine it. Gosselin argues that taking first-person accounts of autism at face value can sometimes lead to first-person credibility excess (disproportionately valuing someone's first-person testimony), which ultimately undermines epistemic agency rather than supporting its development. One way it does so is by perpetuating a problematic distinction between a first-person experiencer and a third-person theorizer of experience whereby the experiencer is treated as a mere witness and/or passive source of data rather than as an active participant in epistemic practices; for example, through raising ideas, asking questions, and engaging in a back-and-forth dialogue about their experiences (Gosselin, 2019). The person sharing their experience of autism is regarded as having authority to describe their experience from a first-person perspective but is not regarded as having the authority to weigh in on the implications of those experiences from a third-person theoretical perspective. The interpretation and analysis of the "data" is left to the (non-autistic) "experts" (Gosselin, 2019), thereby undermining the autistic person's epistemic agency.

For autobiographical accounts to improve autism science, it may be necessary for writers and readers of these accounts to participate in dialogue and critical reflection on them. Misak (2010) proposes a variety of ways to engage critically with first-person narratives in medicine to encourage productive discourse and deepen knowledge; e.g., asking questions such as "Does the

narrator seem focused on wanting to tell a good (perhaps lively, entertaining or scary) story as opposed to wanting to tell an accurate story?” and “Does my own ideology get in the way of my evaluation?” (p. 396). Additional questions readers of autistic autobiographies might ask include, “Are the narrator’s descriptions of their experiences and interpretations of them consistent/inconsistent with descriptions of autism provided elsewhere, for instance, in the DSM-V?,” “Does anything in the account surprise me? Does anything contradict or challenge my current understanding,” “Does anything in the account fulfill an expectation I had before reading it?” These methods can be fruitfully applied in critically engaging with autistic autobiographies. But we must also proceed with caution in applying our critical practices to the analysis and interpretation of first-person accounts of marginalized people. Above all, non-autistic people need to scrutinize their own evaluations of these accounts, as it is probably more common to misapply critical practices in ways that lead to epistemic injustice, such as discounting or downplaying the testimony of autistic people simply because they are autistic.

Another, more general, challenge that arises when interpreting first-person accounts, especially autobiographies written for a general audience, and one that bears on the question of whether they should be taken at face value, involves navigating the interplay between fact and fiction. One must confront ambiguities such as whether the accounts are aptly characterized as sources of rich description of experiences or particular texts representing a literary genre (Radden & Varga, 2013). These interpretive challenges can cast doubt on first-person accounts as literal descriptions of experience.

This brings us to the second issue: whether first-person accounts meet the standards of evidence in science. Some have argued that autistic accounts may be unreliable because of a deficit in understanding mental states (Frith & Happé, 1999), but this claim is itself empirically

questionable (Gernsbacher & Yergeau, 2019). Other researchers may accept that the accounts are literal descriptions of experience but still argue that they are “unsystematic and prone to various biases” (Mitchell et al., 2019, p. 34). For example, not everyone is able to write about their experiences and so the accounts end up representing “the experiences of cognitively able autistic people and those motivated to share their stories with others” (Fletcher-Watson & Crompton, 2019, p. 20) and those who are “more invested in reframing conventional accounts of autism than others” (Silverman, 2019, p. 46). However, some forms of bias can be beneficial in some contexts and for some purposes. For example, one might claim that autistic people who have had negative experiences with Applied Behavioral Analysis (ABA) might be (legitimately) biased against this approach. But it is precisely this type of bias that has inspired studies documenting reports of negative experiences with ABA (e.g., McGill & Robinson, 2020) and can uncover and counteract other forms of bias; e.g., conflicts of interest in research examining the effectiveness of autism interventions (Bottema-Beutel & Crowley, 2021; Bottema-Beutel et al., 2020).

Still, concerns about bias suggest that if autobiographical accounts are to play evidential roles in autism science, reliance on informal exposure to a few select autistic autobiographies, while a helpful starting point, is an inadequate method to rely on for mapping variability. Systematic evidence is necessary to map the variability in the lived experiences of autistic individuals (Fletcher-Watson & Crompton, 2019). Content analyses of a large number of autobiographies and eliciting first-person accounts from interviews and surveys can begin to capture the extensive variability in autistic individuals’ lived experiences. Yet whether informal exposure or formal and systematic methods for attending to first-person accounts are used, there remains a need to exercise caution in drawing general conclusions about the nature of “autistic

experience” from the accounts of a subset of autistic individuals (those with the motivation and ability to write about or narrate their experiences).

Even if first-person accounts of autistic experience do not meet the standards of scientific evidence,⁴ they can play roles in improving autism science that do not require treating them as evidence. And some of these roles of first-person accounts can be fulfilled through reading and reflecting on autistic autobiographies. As discussed above, first-person accounts of autistic experience are a rich source of inspiration for identifying neglected phenomena and hypotheses. However, many questions remain concerning the value of first-person accounts of autistic experience and how to learn from them. What might be learned through reading autistic autobiographies that could not be learned as well (or at all) through other research methods? First-person narratives may have distinctive (cognitive and epistemic) value, partly by virtue of being stories and having narrative form. It has been argued that stories open us to non-propositional modes of knowing, such as knowing what it is like to be someone other than oneself (perspective-taking) and learning how to reconceptualize situations (Rowe, 2009). While this is generally argued in the context of fictional narratives, it is no great stretch to make the same argument for autobiographical accounts: that “[b]eing absorbed in a narrative can stimulate empathic imagination” (Koopman & Hakemulder, 2015, p. 79).⁵ Supposing this is true, are (any of) these modes of knowing ones that scientists should seek out to generate knowledge about autism and autistic people? Autism science is a domain of scientific inquiry that concerns particular kinds of human diversity. Hence, two kinds of non-propositional knowledge, understanding what it is like to be someone other than oneself and learning how to

⁴ Misak (2010) argues that first-person narratives can have the status of evidence, but they must be subject to critical scrutiny.

⁵ Interestingly, in a recent effective intervention designed to reduce stigma against autism among non-autistic adults, researchers included “engaging, first-person narratives” (Jones et al., 2021) in the video training.

reconceptualize situations, seem especially valuable for broadening theorizing beyond conventional categories of understanding behavior and experience.

But how should autism scientists go about taking these modes of knowing into account as part of knowledge production in autism science? What capacities, dispositions, and other features or traits might facilitate non-autistic researchers gaining a better understanding of the subjective experiences of autistic people and becoming more open-minded from reading and reflecting on first-person narratives of autistic experience? We think it is likely that a number of factors contribute to these outcomes, including approaching first-person narratives with intellectual humility, curiosity, and a willingness to be surprised and challenged (Krumrei-Mancuso et al., 2020). Reading autistic autobiographies may lead to better perspective-taking, which is integral to honoring Otherness (i.e., acknowledging and respecting an individual's or group's differences) and improving autism science in the ways we have been discussing. Of course this is not to say that exposure to first-person narratives of experiences of being autistic is sufficient to overturn deeply entrenched prejudicial beliefs. Researchers with ableist prejudices, for example, may be more reluctant to read first-person narratives and more resistant to absorbing insights they offer, while researchers who are familiar with the double empathy problem and who already regard lived experience as a form of expertise may have more initial motivation to do so. Educating the former about the benefits of reading and reflecting on first-person narratives through more formal training (similar to the training in “close reading” done in narrative medicine programs; Charon, 2006) might help to address barriers to their engagement with autobiographical accounts.

These concerns about how to motivate those reluctant to engage with first-person accounts bring into view additional challenges to enacting our recommendations for how to

fruitfully engage with first-person narratives. Here are two. First, fully articulating the distinctive value of first-person narratives is not easy, which makes it difficult to alleviate skepticism about their value, especially for scientific study. This value may not be translatable or reducible to the value of phenomenological data gathered more systematically through surveys or structured interviews. Second, autobiographical accounts help us attend to the meanings of individual experiences of particular persons. Since these accounts are about particulars, whatever insights they convey resist generalization whereas scientific research usually seeks to discover and establish generalizations. How then can autism scientists incorporate insights gained from their engagement with autobiographical accounts effectively? Should they treat them as data sources and use systematic methods to code and analyze them or should they read them as stories, attending to their narrative structure, appreciating their particularity, and resisting generalizations? We suggest that the two approaches need not compete. It might be best to read the accounts as particular stories (much like case studies) for roles such as shifting perspectives and challenging preconceived notions, but systematic content analyses of them may be better for the purpose of constraining theory.

Conclusion

We have argued for a variety of roles for autobiographical accounts in helping to address some of the fundamental conceptual and ethical issues confronting autism science: descriptive and evaluative, evidential and non-evidential, theory-constraining and theory-broadening. Including them in knowledge production about autism can combat stereotypes and promote epistemic justice for autistic people. In conjunction with participatory research, reading autobiographical accounts of autistic experience may help non-autistic researchers combat stereotypes, question received wisdom, and focus their research programs on questions of

interest to those who will be most affected by it. In these ways, the aims of autism science reform are similar to the aims of feminist epistemology and philosophy of science, which seek to identify and reform dominant conceptions and practices to serve the interests of women and other subordinated groups disadvantaged by these conceptions and practices (Anderson, 2020).

We have also suggested that stories, by virtue of their narrative form, may promote understanding of autistic experiences and other non-propositional modes of knowing that have distinctive value for the non-autistic people who read/view them (Chapple et al., 2021; Jones et al., 2021). One important next step would be to conduct surveys and/or interviews with non-autistic researchers who have read several such accounts to obtain empirical data on their perceptions of whether and how they (and their research programs) have been affected by these accounts.

References

- Anderson, E. (2020). Feminist epistemology and philosophy of science. In E. N. Zalta (Ed.), *The Stanford encyclopedia of philosophy*.
<https://plato.stanford.edu/archives/spr2020/entries/feminism-epistemology>.
- Ashworth, M., Crane, L., Steward, R., Bovis, M., & Pellicano, E. (2021). Towards empathetic autism research: Developing an autism-specific Research Passport. *Autism in Adulthood*.
<https://doi.org/10.1089/aut.2020.0026>
- Autistic Self Advocacy Network Position Statement: Autism Research and Therapies.
<https://autisticadvocacy.org/about-asan/position-statements/>
- Bascom, J. (2012). Quiet hands. In J. Bascom (Ed.), *Loud hands: Autistic people, speaking* (pp. 119-123). Washington, DC: The Autistic Press.
- Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M.-L., . . . & Coughlin, S. C. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism*, 24(4), 822–833. doi:10.1177/1362361320908410
- Bottema-Beutel, K., & Crowley, S. (2021). Pervasive undisclosed conflicts of interest in Applied Behavior Analysis literature. *Frontiers in Psychology*, 12, Article 676303.
<https://doi.org/10.3389/fpsyg.2021.676303>
- Bottema-Beutel, K., Crowley, S., Sandbank, M., & Woynaroski, T. G. (2020). Conflicts of interest (COIs) in autism early intervention research: A meta-analysis of COI influences on intervention effects. *Journal of Child Psychology and Psychiatry*, 62, 5-15.
<https://doi.org/10.1111/jcpp.13249>

- Brewer, R., Biotti, F., Catmur, C., Press, C., Happe, F., Cook, R., & Bird, G. (2016). Can neurotypical individuals read autistic facial expressions in autism spectrum disorders? *Autism Research, 9*, 262-271. doi:10.1002/aur.1508
- Cascio, M. A., Weiss, J. A., & Racine, E. (2020a). Making autism research inclusive by attending to intersectionality: A review of the research ethics literature. *Review Journal of Autism and Developmental Disorders, 8*, 22-36. <https://doi.org/10.1007/s40489-020-00204-z>
- Cascio, M. A., Weiss, J. A., & Racine, E. (2020b). Person-oriented ethics for autism research: Creating best practices through engagement with autism and autistic communities. *Autism, 24*, 1676-1690. doi:[10.1177/1362361320918763](https://doi.org/10.1177/1362361320918763)
- Chapman, R., & Carel, H. (2022). Neurodiversity, epistemic injustice, and the good human life. *Journal of Social Philosophy. <https://doi.org/10.1111/josp.12456>*
- Chapple, M., Davis, P., Billington, J., Myrick, J. A., Ruddock, C., & Corcoran, R. (2021). Overcoming the double empathy problem within pairs of autistic and non-autistic adults through the contemplation of serious literature. *Frontiers in Psychology, 12*, Article 708375. <https://doi.org/10.3389/fpsyg.2021.708375>
- Chapple, M., Davis, P., Billington, J., Williams, S., & Corcoran, R. (2022). Challenging empathic deficit models of autism through responses to serious literature. *Frontiers in Psychology, 13*, Article 828603. <https://doi.org/10.3389/fpsyg.2022.828603>
- Charon, R. (2006). *Narrative medicine: Honoring the stories of illness*. Oxford, UK: Oxford University Press.
- Charlton, R. A., Entecott, T., Belova, E., & Nwaordu, G. (2021). “It feels like holding back something you need to say”: Autistic and non-autistic adults’ accounts of sensory

- experiences and stimming. *Research in Autism Spectrum Disorders*, 89, 101864.
<https://doi.org/10.1016/j.rasd.2021.101864>
- Chevallier, C., Kohls, G., Troiani, V., Brodtkin, & E.S., Schultz, RT. (2012). The social motivation theory of autism. *Trends in Cognitive Sciences*, 16(4), 231-239.
<https://doi.org/10.1016/j.tics.2012.02.007>
- Dalton, K., Nacewicz, B., Johnstone, T., Schaefer, H.S., Gernsbacher, M.A., Goldsmith, H.H.,... & Davidson, R.J. (2005). Gaze fixation and the neural circuitry of face processing in autism. *Nature Neuroscience*, 8, 519–526. <https://doi.org/10.1038/nn1421>
- den Houting, J., Higgins, J., Isaacs, K., Mahony, J., & Pellicano, E. (2020). “I’m not just a guinea pig”: Academic and community perceptions of participatory autism research. *Autism*, 25(1), 148-163. <https://doi.org/10.1177/1362361320951696>
- Dinishak, J. (2016). The deficit view and its critics. *Disability Studies Quarterly*, 36.
<https://doi.org/10.18061/dsq.V36i4.5236>
- Dinishak, J. (2021). Autistic autobiography and hermeneutical injustice. *Metaphilosophy*, 52(5), 556-569. <https://doi.org/10.1111/meta.12514>
- Doan, M., & Fenton, A. (2013). Embodying autistic cognition: Towards reconceiving certain “autism-related” behavioural atypicalities as functional. In J. L. Anderson & S. Cushing (Eds.), *The philosophy of autism* (pp. 47-71). New York, NY: Rowman and Littlefield Publishers, Inc.
- Dohmen, J. (2016). ‘A little of her language’: Epistemic injustice and mental disability. *Res Philosophica*, 93(4), 669-691.

- Edey, R., Cook, J., Brewer, R., Johnson, M. H., Bird, G., & Press, C. (2016). Interaction takes two: Typical adults exhibit mind-blindness towards those with autism spectrum disorder. *Journal of Abnormal Psychology, 125*(7), 879-885. Doi:10.1037/ABN0000199
- Fletcher-Watson, S., Bolte, S., Crompton, C. J., Jones, D., Lai, M.-C., Mandy, W., . . . Mandell, D. (2021). Publishing standards for promoting excellence in autism research. *Autism, 25*(6), 1501-1504. <https://doi.org/10.1177/13623613211019830>
- Fletcher-Watson, S., & Crompton, C. (2019). Autistic people may lack social motivation, without being any less human. *Behavioral and Brain Sciences, 42*:E88.
- Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. New York, NY: Oxford University Press.
- Frith, U., & Happé, F. (1999). Theory of mind and self-consciousness: What is it like to be autistic? *Mind and Language, 14*, 82-89. <https://doi.org/10.1111/1468-0017.00100>
- Gernsbacher, M. A. (2015). Video captions benefit everyone. *Policy Insights from the Behavioral and Brain Sciences, 2*(1), 195-202. <https://doi.org/10.1177/2372732215602130>
- Gernsbacher, M. A., & Yergeau, M. (2019). Empirical failures of the claim that autistic people lack a theory of mind. *Archives of Scientific Psychology, 7*(1), 102–118. <https://doi.org/10.1037/arc0000067>
- Gosselin, A. (2019). Philosophizing from experience: First-person accounts and epistemic justice. *Journal of Social Philosophy, 50*(1), 45–68.
- Hale, D. (2007). Fiction as restriction: Self-binding in new ethical theories of the novel. *Narrative, 15*(2), 187-206. <https://www.jstor.org/stable/30219250>

- Higgins, J. M., Arnolds, S. R., Weise, J., Pellicano, E., & Trollor, J. N. (2021). Defining autistic burnout through experts by lived experience: Grounded Delphi method investigating #AutisticBurnout. *Autism*, 25(8), 2356-2369.
<https://doi.org/10.1177/13623613211019858>
- Holt, A., Bounekhla, K., Welch, C., & Polatjko, H. (2021). “Unheard minds, again and again”: Autistic insider perspectives and theory of mind. *Disability & Rehabilitation*,
doi: 10.1080/09638288.2021.1949052
- Jaswal, V. K., & Akhtar, N. (2019). Being versus appearing socially uninterested: Challenging assumptions about social motivation in autism. *Behavioral and Brain Sciences*, 42, E82.
doi:10.1017/S0140525X18001826
- Jones, D. R., DeBrabander, K. M., & Sasson, N. J. (2021). Effects of autism acceptance training on explicit and implicit biases toward autism. *Autism*, 25(5), 1246-1261.
<https://doi.org/10.1177/1362361320984896>
- Kapp, S. K., Steward, R., Crane, L., Elliott, D. Elphick, C., Pellicano, E., & Russell, G. (2019). “People should be allowed to do what they like”: Autistic adults’ views and experiences of stimming. *Autism*, 23, 1782-1792. <https://doi.org/10.1177/1362361319829628>
- Kedar, I. (2012). *Ido in autismland: Climbing out of autism’s silent prison*. Sharon Kedar.
- Kidd, I. J., Medina, J., & Pohlhaus, G. (Eds.) (2017). *The routledge handbook of epistemic injustice*. New York, NY: Routledge.
- Koopman, E. M., & Hakemulder, F. (2015). Effects of literature on empathy and self-reflection: A theoretical-empirical framework. *Journal of Literary Theory*, 9(1), 79-111.
<https://doi.org/10.1515/jlt-2015-0005>

- Krumrei-Mancuso, E. J., Haggard, M. C., LaBouff, J. P., & Rowatt, W. C. (2020). Links between intellectual humility and acquiring knowledge. *The Journal of Positive Psychology*, 15(2), 155-170. doi:10.1080/17439760.2019.1579359
- Kylliäinen, A., & Hietanen, J. K. (2006). Skin conductance responses to another person's gaze in children with autism. *Journal of Autism and Developmental Disorders*, 36(4), 517-525. <https://doi.org/10.1007/s10803-006-0091-4>
- Lawson, W. (1998). *Life behind glass: A personal account of Autism Spectrum Disorder*. Lismore, Australia: Southern Cross University Press.
- Loftin, R. L., Odom, S. L., & Lantz, J. F. (2008). Social interaction and repetitive motor behaviors. *Journal of Autism and Developmental Disorders*, 38, 1124-1135. <https://doi.org/10.1007/s10803-007-0499-5>
- McGill, O., & Robinson, A. (2020). "Recalling hidden harms": Autistic experiences of childhood applied behavioural analysis (ABA). *Advances in Autism*. <https://www.emerald.com/insight/content/doi/10.1108/AIA-04-2020-0025/full/html?skipTracking=true>
- Milton, D. E. M. (2012). On the ontological status of autism: The "double empathy" problem. *Disability and Society*, 27(6), 883-887. <https://doi.org/10.1080/09687599.2012.710008>
- Milton, D. E. M. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*, 18, 794-802. <https://doi.org/10.1177/1362361314525281>
- Milton, D. E. M. (2020). From tokenism to full participation: Autistic involvement in research and the delivery of services. In H. McLaughlin, P. Beresford, C. Cameron, H. Casey, J. Duffy & (Eds.,) *The Routledge handbook of service user involvement in human services research and education* (pp. 440-445). London, UK: Routledge.

- Milton, D. E. M., & Bracher, M. (2013). Autistics speak but are they heard? *Medical Sociology Online*, 7, 61–69.
- Mitchell, P., Cassidy, S., & Sheppard, E. (2019). The double empathy problem, camouflage, and the value of expertise from experience. *Behavioral and Brain Sciences*, 42, E100.
- Misak, C. (2010). Narrative evidence and evidence-based medicine. *Journal of Evaluation in Clinical Practice*, 16, 392-397.
- Moriuchi, J. M., Klin, A., & Jones, W. (2017). Mechanisms of diminished attention to eyes in autism. *American Journal of Psychiatry*, 174, 26–35.
<https://doi.org/10.1176/appi.ajp.2016.15091222>
- Mukhopadhyay, T.R. (2003). *The mind tree: An extraordinary child breaks the silence of autism*. New York, NY: Arcade.
- Ne’eman, A., Albrecht, K., & Kapp, S. K. (2020). Obsessive-compulsive behaviors in autism. *Journal of the American Medical Association*, 323(8), 790. doi:10.1001/jama.2019.21991
- Pellicano, E. (2020). Broadening the research remit of participatory methods in autism science: A commentary on Happé and Frith (2020). *The Journal of Child Psychology and Psychiatry*, 61, 233-235. doi:10.1111/jcpp.131212
- Pellicano, E. & den Houting, J. (2022). Annual research review: Shifting from ‘normal science’ to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, 63(4), 381-396. <https://doi.org/10.1111/jcpp.13534>
- Pellicano, E., den Houting, J., du Plooy, L., & Lilley, R. (2019). Knowing autism: The place of experiential expertise. *Behavioral and Brain Sciences*, 42:E107.

- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism, 18*(7), 756-770.
<https://doi.org/10.1177%2F1362361314529627>
- Pellicano, E., Lawson, W., Hall, G., Mahony, J., Lilley, R., Heyworth, M.,...& Udell, M. (2021). “I knew she’d get it, and get me”: Participants’ perspectives of a participatory autism research project. *Autism in Adulthood*, <https://doi.org/10.1089/aut.2021.0039>
- Pellicano, E., & Stears, M. (2011). Bridging autism, science and society: Moving toward an ethically informed approach to autism research. *Autism Research, 4*(4), 271-282.
doi:[10.1002/aur.201](https://doi.org/10.1002/aur.201)
- Pickard, H., Pellicano, E., den Houting, J., & Crane, L. (2021). Participatory action research: Early career and established researchers’ views and experiences. *Autism, 26*(1), 75-87.
<https://doi.org/10.1177/13623613211019594>
- Poulsen, R., Brownlow, C., Lawson, W., & Pellicano, E. (2022). Meaningful research for autistic people? Ask autistics! *Autism, 26*(1), 3-5.
<https://doi.org/10.1177/13623613211064421>
- Radden, J., & Varga, S. (2013). The epistemological value of depression memoirs: A meta-analysis. In K.W.M Fulford, M. Davies, R. G. T. Gipps, G. Graham, J. Z. Stadler, G. Stanghellini, & T. Thornton (Eds.), *The Oxford handbook of philosophy and psychiatry* (pp. 99-115). Oxford, UK: Oxford University Press.
doi:10.1093/oxfordhb/9780199579563.013.0009
- Raymaker, D., Teo, A.R., Steckler, N.A., Lentz, B., Scharer, M. Santos, A.D., . . . & Nicolaidis, C. (2020). “Having all of your internal resources exhausted beyond measure and being

- left with no clean-up crew”: Defining autistic burnout. *Autism in Adulthood*, 2(2), 132-143. doi: 10.1089/aut.2019.0079
- Robison, J. E. (2007). *Look me in the eye: My life with Asperger's*. New York, NY: Random House.
- Rodogno, R., Krause-Jensen, K., & Ashcroft, R. E. (2016). “Autism and the good life”: A new approach to the study of well-being. *Journal of Medical Ethics*, 42, 401-408. doi:10.1136/medethics-2016-103595
- Rose, K. (2018). An autistic burnout. *The Autistic Advocate: Autistic People Have a Voice*. <https://theautisticadvocate.com/2018/05/an-autistic-burnout/>
- Rowe, M. W. (2009). Literature, knowledge, and the aesthetic attitude. *Ratio*, 22(4), 375–97.
- Sasson, N. J., Faso, D. J., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman. R. B. (2017). Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Scientific Reports*, 7, Article No. 40700. <https://doi.org/10.1038/srep40700>
- Silverman, C. (2019). What do autistic people want from autism research?” *Behavioral and Brain Sciences*, 42, E111.
- Singer, J. (1999). “Why can’t you be normal for once in your life?” From a “problem with no name” to the emergence of a new category of difference. In M. Corker & S. French (Eds.), *Disability discourse* (pp. 59-67). Buckingham, UK: Open University Press.
- Tavassoli, T., Hoekstra, R. A., & Baron-Cohen, S. (2014). The Sensory Perception Quotient (SPQ): Development and validation of a new sensory questionnaire for adults with and without autism. *Molecular Autism*, 5(1), Article 29. <https://doi.org/10.1186/2040-2392-5-29>

Trevisan, D. A., Roberts, N., Lin, C., & Birmingham, E. (2017). How do adults and teens with self-declared Autism Spectrum Disorder experience eye contact? A qualitative analysis of first-hand accounts. *PLoS One*, *12*(11): e0188446.

<https://doi.org/10.1371/journal.pone.0188446>