

Knowing autism: The place of experiential expertise

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Authors' Note: Liz Pellicano is a psychological scientist who does not identify as autistic; Jacqueline den Houting is an autistic research psychologist; Lee du Plooy is an autistic researcher; and Rozanna Lilley is an anthropologist and education researcher who has a son on the autism spectrum. We comment in particular on the social and ethical issues raised by this target article.

Abstract

Jaswal & Akhtar challenge the notion that autistic people have diminished social motivation, prompted in part by a desire to take autistic testimony seriously. We applaud their analysis and go further to suggest that future research could be enhanced by involving autistic people directly in the research process.

Jaswal & Akhtar (J&A)'s compelling target article leaves us in no doubt that autism scientists need to reconsider their explanation of autistic sociality. Previous studies that consistently showed low rates of social contact for young autistic people and adults (e.g., Orsmond et al.

2013; Shattuck et al. 2011), together with parents, clinicians, and educators' anxieties about autistic people's apparent lack of motivation and/or difficulties initiating and sustaining friendships (e.g., Calder et al. 2013; Cribb et al. in press), have reinforced a widespread belief that autistic people cannot – and more important to the current discussion, do not *want* to – form friendships and social relationships. These studies and sentiments, however, have almost exclusively focused on the number of friends a person has, not on the *quality* of those connections. J&A make us think again.

In doing so, they are not entirely alone. Some of our own qualitative work with autistic children and young people – those who are cognitively able *and* those with additional intellectual disabilities and/or limited spoken communication – has repeatedly suggested that they value deep and trusting relationships with others, including friends, family members, and those who support them, even when it might be difficult to maintain those relationships (Cribb et al. in press; Pellicano et al. 2014b; Sedgewick et al. in press). But as J&A highlight, these qualitative, subjective reports have for the most part been eschewed by scientists, who often perceive them as contributing no more than anecdotal evidence – despite the fact that this evidence often flies in the face of popular theoretical accounts of autism.

By their example, J&A instead appeal for psychological scientists to take “autistic testimony seriously,” both to avoid the kinds of misinterpretations that these authors describe and “to contribute to a more accurate, humane, and useful science of autism” (TA abstract). Such a view builds upon a growing acknowledgment within the scientific community that autistic people possess insight into autism that has been too frequently overlooked. Scientists' knowledge claims are generally built on empirical observation, theoretical argumentation, and, ultimately, objective “truths”; parents and primary caregivers have unique experience

about their child's development and the types of support from which they might benefit most; autistic people, in contrast, have direct experience of what it is like to be autistic and how they negotiate their everyday lives. Lay members of the autism community, and autistic people in particular, therefore have what Collins and Evans (2002) have called "experience-based expertise," which as Milton (2014) and Milton and Bracher (2013) describe, can be crucial in "knowing autism" better.

The value of experience-based expertise has been highlighted beyond the field of autism. Jack and Roepstorff (2002), for example, note that in psychological science, "[subjective] experience is still regarded as a problem, rather than a resource ready to be tapped" (p. 334). They have called for a rethink of psychological paradigms, arguing that our standard methods of experimentation need to be "subject to a methodological triangulation in which objective behavioral measurement, recordings of brain activity and introspective evidence can be related to each other" (p. 337). We believe this must be a crucial component of psychological science in the future.

Returning to autism, the lessons here are clear. A fuller understanding of autism must give due attention to the crucial subjective experiences of autism – the experiential particularities of autism – as well as the objective, scientific facts (Taylor, 1977). But we would go even further than that. We contend that the best way to ensure that analysis of autism includes such experiences is by changing the way research itself is conducted. Getting autistic people involved in the research process, not just as participants but also in the design, implementation, analysis, interpretation, and dissemination phases of research, is the surest way of ensuring that our work is attentive to the autistic experience (Fletcher-Watson et al. 2018; Pellicano & Stears, 2011; Pellicano et al. 2014a).

Traditionally, research priorities have been set almost exclusively by scientific funders and academics. Autistic people have therefore rarely been involved in the decision-making processes that shape research or its application. They have been excluded from the very research that directly concerns them. In the past few years, an increasing number of researchers have been working with autistic people as partners and engaging autistic people in all stages of the research process to address issues that are prioritized by the autistic community and to ensure that research is conducted in a way that is sensitive to their needs and values (see Fletcher-Watson et al. 2018; Nicolaidis et al. 2011; Pellicano et al. 2014a). Participatory autism research still makes up only a fraction of the plethora of autism research conducted across the globe, but it represents the best possibility of ensuring research that incorporates the breadth of autistic experience.

J&A enable us to think anew about autistic social motivation, doing so in part by drawing upon autistic testimony. The task now is to see how many other orthodoxies of autism science could be challenged by greater attention to the autistic experience.

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