

## A new era for autism research, and for our journal

Autism  
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Autism research is changing. There is more of it than ever before. In August 2017, the Interagency Autism Coordinating Committee (IACC), the advisory committee that coordinates federal efforts and provides advice to the US government on issues related to autism, recommended that autism-related research funding in the United States should increase further still, doubling by 2020. If this recommendation were successful, US lawmakers would commit an unprecedented amount of funding to autism research. But it is not just the amount of research being commissioned that is being transformed, it is also the *kind* of research. The IACC now calls for research to address the diagnosis, biology and causes of autism and, critically, efforts to improve services across the lifespan. This latter focus is especially notable. While most current autism research addresses the underlying biology and causes of autism (Pellicano et al., 2013, 2014), which arguably ‘leads to significant future advances and opportunities’, the IACC (2017) has called for a ‘paradigm shift in how we approach autism’ (p. vi), to include research that will have a more immediate and direct impact on the daily lives of autistic people and their families, especially related to services and supports, and with underserved populations.

This revised approach to autism – to acknowledge the need to address the everyday realities of autism – is very much welcomed. It is the result, in part, of increased engagement with autistic people and their allies, who have repeatedly called for research that recognises the needs of autistic people<sup>1</sup> living in the here-and-now (Pellicano et al., 2013, 2014). Indeed, it is increasingly acknowledged that for autism research to adequately address the issues facing autistic people and their allies, the nature of research agendas must be shaped together by researchers and community members (e.g. Bølte, 2017; Cusack, 2017; Krahn and Fenton, 2012; Pellicano et al., 2014).

This community engagement in research extends – and *should* extend – beyond identifying research priorities. The design, delivery and dissemination of autism research (funded or unfunded) never rely on the efforts of researchers and funders alone. It critically depends also on the participation<sup>2</sup> of autistic children, young people and adults

and their families, as well as the assistance of clinicians and educators, and the training of up-and-coming (autistic and non-autistic) researchers. In this way, autism research is a shared endeavour. Precisely because it is a common endeavour, autism research requires the participation of that broad community on fair terms. It is not right that one group holds all of the influence and power. If any group, or collection of groups is unattended or their opinions discounted, then they are being treated unfairly and in a way that does damage to autism research itself. The core ethos of this journal must include ensuring that everyone who participates in autism research has their views taken into account.

This takes us, of course, to the symbol that used to occupy the cover of this journal – the puzzle piece. Others have written at length about the history of that symbol, how it was initially deployed by the UK’s National Autistic Society (NAS) in 1963, and how it has become increasingly controversial as the years have progressed (Grinker and Mandell, 2015; see also Gernsbacher et al., 2017). But what has become much clearer recently is that autistic self-advocates and many who support them have not only felt that the puzzle piece does not capture their view of autism itself, but that the failure of organisations such as this journal to act in response constitutes a core disrespect, as if their voices and opinions did not matter equally to other people’s (Brook, 2016).

It is interesting to consider some of the objections to the puzzle piece, as these highlight how views about autism are changing, and that this is partly driven by autistic self-advocates and their allies. One criticism of the puzzle piece is its implication that autistic people are a problem requiring a solution. This widely-held idea is increasingly contested in mainstream debates about autism, even if no-one disputes that autism is very often accompanied by real difficulties that can be detrimental to well-being. A related point is that the puzzle piece implies that autistic people are somehow incomplete and need to be made whole. This links to the question of whether it is desirable, or ethical, to seek a ‘cure’ for autism. A generation ago, among non-autistic clinicians and researchers, such a question barely seemed worth asking; now it is the focus of intense debate (e.g. Bagatell, 2010).

Some autistic self-advocates also point out that jigsaw puzzles are usually for children and therefore, as a symbol, they serve to embody – and perhaps even perpetuate – the myth that autism is essentially a childhood condition. Here, again, contemporary views of autism are at odds with the puzzle piece’s meaning: autistic people spend most of their lives as adults, and the research agenda needs to reflect this better (IACC, 2017).

The puzzle piece is therefore no longer an apt, or even adequate, symbol for autism as we currently understand it. In the face of this, and after much prolonged deliberation, the editors of *Autism* decided to act. Over the last year, we have talked to people of a range of backgrounds about the puzzle piece on the cover of our journal and what could replace it. We have discussed with autism researchers, autistic and non-autistic alike, with activists and campaigners and with professional designers (at no additional cost to the journal itself). Autistic input was essential to this process. Agreement was not immediately easy to reach – the symbolism around autism has a long and contentious history – but by listening, trying things out and then listening again, we nonetheless found a way forward. It was clear, quite soon, that the time of the puzzle piece itself had passed, however blameless the intentions of those who had designed it in the past had been. And it was clear too that what should replace it should be free of the negative stereotypes that have blighted the lives of autistic people for far too long (see Gernsbacher et al., 2017, on the puzzle piece specifically). Finally, we settled on a design that met the approval of all involved in the consultation and we hope very much will meet with all of our readers’ approval too.

We realise that some will think that an argument about symbols and the covers of journals is trivial, a distraction from what really matters. We disagree. Instead, we believe that we are entering a new era of autism research, an era characterised by a new commitment to equality of participation, an era in which the voices of those who participate in research in all kinds of ways will be listened to and taken seriously at every stage of the research process. The move away from the puzzle piece here and towards our new design is not only about how we choose to represent autism, but it is also about proving that we represent that broader change itself.

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### Notes

1. Identity-first language (i.e. autistic person), opposed to person-first language (i.e. person with autism), is preferred by many autistic people and their allies. Therefore,

in this article, the authors use predominantly identity-first language (see Gernsbacher, 2017; Kenny et al., 2016; Sinclair, 1999).

2. By ‘participation’, we mean taking part at any or all parts of the research process – from being a research participant in the orthodox sense to being actively involved in the design, implementation, interpretation and dissemination of the research itself.

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