Autism and Society is a Special Issue devoted to quantitative and qualitative research and perspectives on the autism spectrum. A more accurate description of this issue’s content might be ‘Autism in Society’. Autism, both as diagnosis and as lived experience, does not sit outside society; the condition is embedded within and interwoven with the social materiality of persons, families, institutions and communities. Over time, this social materiality will have a profound impact on those living with autism. One of the key messages in this Special Issue is that high-quality research into the social dimensions of autism is as necessary and as valuable as basic scientific research into autism. Access to services, availability of treatments, evidence-based interventions, stigma, costs and educational resources – this is a well-known list of concerns, to be sure. Nevertheless, it is notable, even astonishing, that alongside significant gains in scientific understanding of autism ‘under the skin’, these social needs are still so widely unmet and still so much in the foreground of the struggle to ensure a good life for individuals living with autism.

Of course, the apparent gap between the needs of autism communities and the funding priorities of scientific research represents a more general problem of resource allocation to, and in, mental health. There is increasing recognition of this disconnect, albeit still motivated by the same narrow framework. Early this year, the Director of the US National Institute of Mental Health (NIMH), Tom Insel, blogged with excitement about the star turn that mental health was making at this year’s Davos retreat for global economic leaders. Mental health, he said, was poised to be ‘the new AIDS’ in global economic priority setting. Furthermore, Insel said,

> [O]ne of the recurrent comments in sessions at Davos was the importance of including social factors in both research and treatments for brain disorders. In addition to ‘no health without mental health’, we can add from Davos ‘no wealth without mental health’.

There can be no doubt that global attention and resources would make an enormous difference to the pace of research and knowledge translation in mental health, and that acknowledgement of mental health as an economic concern as well as a health concern provides significant motivation for sustained global resource allocation in this area.

But what of these important ‘social factors’? Within NIMH’s research agenda in the coming years, ‘the social’ is significant in so far as it is conceptualized as a potential factor in mediating or moderating biological mechanisms and networks. Davos’s conceptualization of ‘the social’ is based on economic priorities; a nation’s mental capital depends on its collective brain health – this is one key way economists tend to see the problem of mental health.

The emphasis on understanding genetic and neural underpinnings of mental illness (and thereby to potentially revolutionize psychiatric diagnosis and treatments) is a significant shift, even if the fruits of this scientific agenda are likely to be some way off. The problem arises if the narrow interpretation of ‘social factors’ in an economically driven justification, combined with the particular account of ‘the social’ inherent in biomarker research, trumps spending on research into basic social factors that matter in tangible ways to the autism community and to the everyday lives of people on the spectrum. For example, participation in the workforce and support for independent living are important for people with autism and other mental health conditions; but these should be viewed as long-term outcomes of interventions that initiate support much earlier in the developmental course of a life with autism.

What reasons are there for the existing gap in equitable, accessible, respectful, high-quality and effective service provision for people with autism, as compared to other mental health conditions? We would argue that a major cause is the lack of a coherent, longitudinal research funding agenda in this area. This both creates and maintains a set of corollary problems; we outline three of these below (this is not meant to be an exhaustive list):

1. **Lack of generally agreed, evidence-based service provision**. Research in any area benefits from a well-defined problem and a research design that uses well-validated methods so that findings can be compared across other, similar studies. The autism spectrum is, by definition, not a well-defined problem. At the phenotypic level, autism is a heterogeneous condition with symptoms and degrees of impairment that vary widely from one individual to the next and within the lifespan of a single individual. As a consequence, research into autism service
provision tends to incorporate people with a wide range of capabilities. At the same time (and not unrelated to the problem of phenotypic diversity), service provision varies across local and global geographies, with varying levels of financial provision, different quality standards, and diverse identification, intervention and education programmes. Under these conditions, it is almost impossible to construct a robust, evidence-based general baseline for autism service provision across states and global territories, and many studies focus on local best practice models. A coherent overarching funding agenda could initiate and evaluate systematic comparisons where appropriate, enabling scaling up and international extensions of evidence-based practice.

2. Research into social factors in autism is frequently opportunistic, isolated and not of sufficiently high quality. Over the years, we have observed scientific research into autism grow into an international consortia-based enterprise, attracting long-term, high-level public and industry funding. We are not suggesting that this model represents research utopia; however, it has generated increased attention to and elaboration of quality dimensions in research, alongside an emerging focus on data sharing and transparency driven by funders and high-level scientific journals. In contrast, there have been few efforts to clarify basic quality indicators in social science research in autism (or in other mental health disorders). For example, research into social factors in autism often entails qualitative methodologies; those best placed to conduct studies on, for example, experience with services, pathways to treatment, stigma are clinical researchers who lack training in the requisite qualitative methods. The results are shallow questionnaire-driven approaches to the investigation of complex social problems or poorly executed qualitative research with no follow-up or evaluation. A funding agenda to significantly increase research into the social factors that most matter to the autism community must ensure that methodological training and capacity building are part of a sustained programmatic model. Otherwise, it will be easy to minimize the value and impact of such research.

3. Theoretical and empirical approaches to autism in society are not accepted as a stand-alone worthy endeavour within the mainstream research community. The complexity of autism in real-world settings does not lend itself well to constrained laboratory investigation. However, research attempting to address this complexity outside the laboratory is often viewed as an add-on or an adjunct to mainstream research. As a result, these approaches are rarely integrated into ‘the science’ and therefore begin too late, and often after research is completed and results are available. Once research has already been disseminated or applied, then it is considered appropriate to evaluate its ethical and social implications. It is fortunate, and important, that this simplistic, linear view is slowly being replaced with an interest in substantive partnerships that bring to the same table researchers from diverse disciplines to continually deliberate these real-world issues and to view them as an integral component of scientific discovery. With this Special Issue, we hope to stimulate more of this kind of collaborative research.

We need to respect the fact that priority setting in autism research will inevitably intersect with the contentious debates in and around prevention and efforts to socialize (some would say to ‘normalize’) the neurodiverse. Whatever position one takes in the ‘neurodiversity’ debates around autism, there can surely be general agreement that public funding should be used to identify and to overcome those basic factors that get in the way of flourishing for people on the autistic spectrum.

The kind of research discussed in this Special Issue, on participatory approaches, on knowledge translation, access to quality services and social inclusion, can teach us a lot here. Ironically, despite the intensity of this debate, research in these areas is still largely underdeveloped in autism. Given a research climate that emphasizes impact, translation and responsible research and innovation, studies that model, test and incorporate inclusive approaches and knowledge translation strategies should be obvious low-hanging fruit, particularly for public funding agencies. Moreover, research priorities need to expand to reflect the complexity and lived experiences of those affected by autism, their families and their communities. The progress made in understanding the underlying biology of autism should become integrated with more comprehensive trans-disciplinary frameworks.

*Autism and Society* showcases how much we can gain as a research field when complex social and real-world debates and perspectives are considered seriously, empirically and collaboratively. We thank Sven Bolte and Liz Pellicano for inviting us to be guest editors and for helping us put together a terrific issue.

**Note**


Ilina Singh and Mayada Elsabbag
Editors