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New Modes of Understanding and Acting on Human Difference in Autism Research, Advocacy, and Care -- A special issue of BioSocieties

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By Aaron Seaman



The current issue of [BioSocieties](#) is a special issue, entitled “[New Modes of Understanding and Acting on Human Difference in Autism Research, Advocacy, and Care](#)” and edited by Gil Eyal, Des Fitzgerald, Eva Gillis-Buck, Brendan Hart, Martine D. Lappé, Daniel Navon and Sarah S. Richardson. Abstracts and links to the articles are below....

[New modes of understanding and acting on human difference in autism research, advocacy and care: Introduction to a Special Issue of BioSocieties](#)

Gil Eyal, Des Fitzgerald, Eva Gillis-Buck, Brendan Hart, Martine D. Lappé, Daniel Navon, and Sarah S. Richardson

The papers collected in this special issue examine specific instances of autism research, treatment and advocacy. Their shared aim is to explore not the causes, but the manifold biosocial consequences and theoretical implications of the recent expansion of the autism spectrum. Three such implications are singled out in the introduction as common threads running through all the papers. First, the extent to which developments in the field of autism research, treatment and advocacy pose a challenge to theories of ‘biomedicalization’ and ‘geneticization’. Second, the intimate connection between autism’s recalcitrance to be pinned

down and explained and its enormous biosocial productivity. Third, the need to broaden Hacking's (1998, 2006) concept of 'looping' to make sense of the 'moving target' that is autism.

[The trouble with brain imaging: Hope, uncertainty and ambivalence in the neuroscience of autism](#)

Des Fitzgerald

This article is about ambivalent dynamics of hope and uncertainty within neurobiological autism research. While much literature has commented on the positive hopes and expectations that surround technoscientific projects, fewer have focused on less promissory visions – and, in particular, on the presence of uncertainty and ambiguity among working scientists. This article shows how autism neuroscientists actually talk about their research in ambivalent, entangled registers of both promising hope and deflated uncertainty. The article locates the dynamic between these in an 'intermediate terrain' of autism research – in which autism is both 'present' as an epidemiological and social force, but also 'ambiguous' as a (not yet) well-defined clinical and scientific object. It argues that neuroscientists work through this terrain by drawing not only on a discourse of unalloyed hope and promise, but by entangling their research within a more complex register of 'structured ambivalence', which includes languages of uncertainty, deflation and low expectation. As well as showing the novelty of research within autism's 'intermediate terrain', this adds to a growing literature on the 'sociology of low expectations', and analyses the presence of such feelings among scientific researchers particularly.

[Autism as a biomedical platform for sex differences research](#)

Eva M. Gillis-Buck and Sarah S. Richardson

Autism has become a 'biomedical platform' for sex differences research in fields such as genetics, endocrinology and neuroscience. Increasingly, researchers in these fields pose the male prevalence of autism as a model for investigating sex differences in the brain, and offer basic research on sex differences in the brain as a resource for understanding the etiology of autism. The use of autism as a biomedical platform for sex differences research obscures empirical and interpretive contestations surrounding claims about the male prevalence of autism. We argue that the uncritical use of this research platform across many fields stands to distort scientific research on autism

and contribute to harmful gender stereotypes.

[Autism parents & neurodiversity: Radical translation, joint embodiment and the prosthetic environment](#)

Brendan Hart

It has become increasingly common to view and discuss autism as a form of difference, rather than a disorder. Moreover, the autism spectrum has generated new possibilities for personhood and social inclusion. These developments have typically been ascribed to the recent work of autistic autobiographers and autistic self-advocates associated with the neurodiversity movement, who are providing a sort of linguistic infrastructure to support autistic personhood. Drawing on historical and ethnographic research, this article makes the complementary and analogous claim that parents of autistic children have used autism therapies to create a technical infrastructure to support autistic personhood. The article follows an earlier genealogical thread to argue that parents have used the techniques and technologies of behavioral therapies (sometimes said to be incommensurable with neurodiversity's philosophy) in ways that have actually helped establish this autism-as-difference view. They have done so by translating their child's behaviors and utterances and engaging in forms of 'joint embodiment' with her to create enabling 'prosthetic environments' where her unique personhood can be recognized. Through an ethnographic focus on 'prosaic technologies' and the politics of everyday practice, the article also provides a thicker and more grounded account of what Ian Hacking calls the "looping effect of human kinds".

[Taking care: Anticipation, extraction and the politics of temporality in autism science](#)

Martine D. Lappé

Research on autism has increased significantly over the past several decades. This upsurge parallels the steep rise in autism diagnoses. Together, these conditions have increased the number of people occupying the social role of research participants, including investigators, analysts and subjects. Simultaneously, addressing scientific questions about autism now involves new research efforts including prospective enriched-risk cohort studies exploring the environmental and genetic causes of autism during pregnancy and early child development. Rather than one-time donations, these studies require extended commitments on the

part of all those involved in the research. This article draws on ethnographic observations of research practices and interviews with investigators, study staff and participants to examine the emergent relationships between research and care in this area of autism science. I introduce the notion of 'taking care' to describe the forms of anticipatory labor and mutual extraction involved in longitudinal research. Through tracing three modes of taking care across practices of study design, data collection and participation, I argue that research and care become intimately intertwined and mutually constructed during the research process. These findings reflect how processes of taking and giving are constitutive of research participation for all those engaged in the research enterprise. This article considers the relationships between these practices and new forms of community and sociality related to biomedical science.

[The trading zone of autism genetics: Examining the intersection of genomic and psychiatric classification](#)

Daniel Navon and Gil Eyal

This article argues that the impact of genetics on psychiatry, and on our understanding of human difference more generally, will be mediated by the threefold social role of diagnostic categories as (i) coordinating devices; (ii) identities; (iii) sites of looping processes. This argument is explored by examining the intersection of a rare genetic disorder – 22q13 Deletion/Phelan-McDermid Syndrome (PMS) – with the much broader but genetically heterogeneous category of autism. We show that a 'genomically designated' classification such as PMS thrives as an object of research and social mobilization by virtue of its capacity to interface with, rather than supplant, the existing psychiatric diagnosis of autism. Autism genetics thus functions as a 'trading zone' (Galison, 1997) that allows for the exchange of knowledge, biomedical objects and resources despite incommensurable ends and frameworks of understanding.

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