by Gil Eyal et al.

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This ambitious survey of autism studies and therapies by a team from Columbia and George Mason Universities in New York functions both as history and sociological analysis. It assumes the reader has some familiarity with the clinical symptoms of autism, but is not overly technical, so is suitable for undergraduates, caring professionals, and a general audience with an interest in autism. Its analysis is painstakingly argued to demonstrate that the current ‘autism epidemic’ is not the result of altered populations with new clinical symptoms but, instead, is a consequence of altered clinical understandings of what constitutes the condition. The thesis of this book therefore makes sense only when it is understood as a sociological account not only of how diagnostic substitution has led to the enormous rise in diagnoses in the late 20th and early 21st centuries, but also why this happened.

Chapter one, ‘The Puzzle of Variation in Autism Rates’, makes a strong case for the linking of autism diagnosis to a specific societal development: namely, the deinstitutionalisation of care for the learning-disabled. This is
demonstrated through an interesting international comparison of autism
diagnosis statistics from the developed and developing world. Although the data
could possibly have been better presented at times (for example, by providing
graphs to correlate different data sets, rather than providing separate charts for
separate variables), it does convincingly support the authors’ argument that
diagnosis rates increase not as a spontaneous ‘epidemic’ of autism related to
affluence or development, but geographically as a function of the societal
changes accompanying and emerging from deinstitutionalisation. Of particular
interest is the political correlation of autism prevalence depending on the
Republican or Democratic representation of US states which the authors
attribute, with some statistical evidence, to the attitudes and resultant care
provisions of different social groups according to a ‘supply’ model of autism
perception. The implication is that better awareness and resources, in keeping
with deinstitutionalisation, tends to be politically led by a Democratic agenda.

From here onwards, chapters two to eleven chart a carefully researched
cultural history of autism interwoven with a persuasive argument of how
shifting attitudes and paradigms are generated mainly by deinstitutionalisation.

Economies of ‘supply’ (therapies offered) and ‘demand’ (public awareness
and the seeking for diagnosis) are, the authors claim, transcended by their
enveloping model of the ‘matrix’ of more complex historical contingencies. The
metaphors employed here are of ‘interstitial spaces’ filled by ‘networks of
expertise’, both created by an array of societal factors.

This is a subtle distinction to maintain and at times the argument slips back into a more straightforward economy of supply and demand. To be fair, the authors do not claim to negate this model, but to refine it. A striking demonstration of this economy of supply and demand is the undeniable logic of the claim in chapter nine that a fact of medical history is, inevitably, that the personal bias and presupposition of the clinician largely leads the process of diagnosis. Looking back, the theories of past clinicians do, with hindsight, seem alarmingly crude and naïve: the authors apologise for their use of the political incorrectness of past legislators and clinicians, but also point out that a history drawing on the general context of learning disability issues without citing this authentic language would be of little value.

The narrative does progress towards the aspiration of person-centred diagnosis and care, but the object is not to create a happy ending of neat resolution after the chaos of complex clinical and societal trends. There is an optimistic note in the conclusion, but it does feel slightly as if this has been tacked on without a serious analysis of the challenges still ahead.

More positively, however, the emphasis on the move away from custody and cure towards concepts of social change and prosthetic environment, and current slogans from the self-advocacy movement like *Work with autism, not against it*, underline the trend towards empowerment and inclusion. In the
introduction, and again in the conclusion, genetic etiologies are sidelined as almost an irrelevance in view of the practicalities of a highly diverse spectrum of needs which, largely due to the work of Wing and other pragmatic campaigner-researchers, currently impinges on or even merges with a diverse range of intellectual and communication impairments. The MMR vaccine and similar controversies of biological causation are given short shrift in the face of the more pressing need of finding strategies within a ‘social destiny’ model of care: rightly, in this reviewer’s opinion.

Much of the narrative of the matrix negotiated out of deinstitutionalisation centres justifiably on the inter-disciplinarity of research and therapy, and the rise of parent advocacy. Sadly, but perhaps as a reflection of the history it narrates, there is almost no reference to the needs of adults with autism, and the parents of autistic children dominate until relatively late on, when the self-advocacy of adults with higher-functioning autism comes into play. The authors do comment that a further volume focusing on self-advocacy and current trends is both needed and planned by them, and this would be welcomed.

Later chapters implicitly critique the deregulated array of therapies currently available, certainly in the USA (and, one might add, increasingly in the UK). The rise of the whole ‘network of expertise’ charted here leads inevitably to a non-hierarchical matrix of care. Its strength is in flexibility,
empowerment and creativity. Inevitably, its corresponding weakness is the erosion of the real or perceived safety-net of professional hierarchy.

If the review of past errors horrifies the contemporary reader, one might hope that one result of this unravelling of socio-medical mechanisms might be an equally chastened wariness towards any definitive ending of the saga of how autism is understood.

The historical perspective is long, and ambitiously so, starting with the early pioneers Bleuler, Kanner and Asperger and covering the 1950s and ‘60s in depth. This at first sight seems an annoying deferral of the arrival in the 1970s of Lorna Wing’s ‘autistic spectrum’ model. However, the choice is justified by the way it shows the epistemic mutations necessary for the evolution of clinical constructs. Indeed, the lengthy post-1940s negotiation of a new matrix of theory and care which undercuts the psychiatric hegemony is central to the narrative. The frequent use of the term ‘blurring’ accentuates the relativistic nature of this process, and alerts the reader to develop critical scrutiny of the range of contemporary therapies and models. This is uncomfortable, unsettling, but necessary reading. It is also, incidentally, an excellent reference source on the history of autism. It provides a challenging and useful resource for understanding and evaluating current practice in autism care.

The entire notion of an autistic spectrum, with its now-commonplace designation of a ‘triad of impairments’ as presented by Wing in the 1970s, is
shown to have emerged not as the obvious phenomenon it may seem. The basic purpose of this book is to unearth the genealogy of this model, and to reveal it not as a cleanly revealed phenomenon which may now seem to have previously required only to be discovered by clinical research. The development of the autistic spectrum is laid bare as a cultural construct still in evolutionary process, and the elucidation of this morphing phenomenon is the crowning achievement of this book.

Bibliography