

Autism

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Autism

A Social and Medical History

Mitzi Waltz

Sheffield Hallam University, UK

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Mitzi Waltz © 2013

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Preface: Autism, and How We Got Here

In May 2009, as I began work in earnest on this book, my inbox filled up with a flurry of emails from adults with autism and from researchers who work closely with them. All were concerned with being heard in the ongoing process to revamp the autism diagnostic guidelines for the upcoming fifth version of the *Diagnostic and Statistical Manual of Mental Disorders*. Better known as the *DSM*, this is the Bible for diagnosis and billing used by psychologists and psychiatrists in the US, and has a worldwide impact as well.

The past four versions had featured no input from those whom the *DSM* describes as ‘autistic.’ However, the sociocultural context of autism is changing, and one measure of that is the increased importance of people with autism in debates about diagnosis and other issues.

Currently, to be diagnosed with mental disorder no. 299, ‘Autistic Disorder,’ a person must exhibit ‘qualitative impairment in social interaction... qualitative impairments in communication... [and] restricted repetitive and stereotyped patterns of behavior, interests and activities’ (American Psychiatric Association, 1994). Some further specifics are included under the descriptions of each of these criteria. Compared to the diagnosis of Down syndrome, with its characteristic chromosomal and physical differences, deciding whether a person is on what we now call the autism spectrum is not at all straightforward. Nor is diagnosis in childhood a reliable predictor of adult outcomes, or even what kinds of special education methods, medical treatments, or behaviour management schemes, if any at all, are most likely to be of use.

In the *DSM V*, for the first time sensory-perceptual issues will appear as something that may affect people with autism and might be considered when making a diagnosis, though not yet as a diagnostic criterion. It is remarkable that it has taken so long for the internal experience of autism, rather than aspects of autism that may puzzle or bother non-autistic people, to become a part of how it is officially defined.

As Laurence Arnold, an adult with autism, puts it:

Autism is a *word*, with a history and connotations. It is a semi-otic pointer [and] what it signifies is governed not by any natural laws, but by the rules of communication theory, whereby the originator of the message may not be completely understood by the receiver because of a variety of cultural, neurological, environmental and simply accidental and incidental interference . . . [Autism] is not inherently wrong, just different, but that difference and the varying degrees of that difference are heavily negatively nuanced in a society and environment to which we are not maximally adapted.

(Arnold, L., 2009, personal communication, 15 May)

This condition that has existed throughout human history did not even gain a name until 1943, and the process of attaching any depth of understanding to that name has been beset by controversy, conflict, and even fraud. Over 65 years after the word 'autism' was first made shorthand for a pattern of child development and behaviour, no agreement has been reached about even the most basic issues, such as causation. How we got here, and what that process has meant for autistic people, their families, and the professionals tasked with teaching and supporting them, is the topic of this book.

It is not a straightforward story of medical progress or increasing social acceptance, but a convoluted tale in which ideas seem to return again and again regardless of the evidence base, and in which a disparate chorus of voices from history emerge with much to tell us. It weaves in and out of the histories of medicine and psychiatry, as well as those of social exclusion and inclusion, eugenics, special education, and the disability rights movement.

I have attempted throughout to relate this history through its impact on the lives of people with autism as well as through facts and statistics, though in the case of historical events some necessary licence has been taken with imagining what might have been. In describing the short life of Ralph Sedgwick in Chapter 1, for example, I needed to add colour from accounts of everyday activities in his London neighbourhood to turn a set of case notes into something more like a real boy.

It is also by no means the whole story. Entire volumes will need to be written to illuminate what happened outside the US and Europe, where the diagnostic category first emerged. New evidence is continually being gathered. In addition, each person ever diagnosed with autism has an individual history that, while it intersects with the story told here, also has its own trajectory.

Mitzi Waltz

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Finally, the inspiration to keep working on this project has come from the very important people on the autism spectrum in my life. Knowing and listening to you has changed my life, and my ideas about autism. The next chapter of this history will be written by you.