What We Really Know About Autism

A controversial agenda for resetting priorities related to autism.

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Review of *The Politics of Autism*. By Bryna Siegel. Oxford University Press. 344 pp. $29.95

In 1943, Leo Kanner gave autism its name. In an academic paper, Dr. Kanner described “the autistic disturbances of affective contact,” a malady in which children continue to behave like infants, focusing on their own needs instead of responding to the social signals of other people.

Three-quarters of a century later, a virtual consensus that genetic abnormalities (exacerbated, at times, by parental responses) “cause” the disorder has replaced the claim that autistic children reject others because their “refrigerator mothers” rejected them. But without bio-markers providing a diagnostic roadmap, and frequently changing DSM classifications, Bryna Siegel maintains, autism remains a moving target for genetic researchers and clinicians seeking effective treatment.

In *The Politics of Autism*, Dr. Siegel, a professor emeritus of child and adolescent psychology at the University of California, San Francisco, and the Founder and Executive Director of the
Autism Center of Northern California, examines an array of issues related to awareness, diagnosis, and treatment across the autism spectrum. Siegel tries – and often succeeds – in debunking “political correctness,” sensational media reports, exaggerated or false claims about Applied Behavioral Analysis, alternative medicine and vaccines, and unrealistic parental expectations. *The Politics of Autism* also sets out a comprehensive and controversial agenda for resetting priorities in special education, social services, adult housing, and research.

Siegel, alas, does not write well. Repetitious and excessively self-referential, her book is riddled with misplaced modifiers, errors of pronoun agreement, and other grammatical mistakes. Siegel’s prose is clumsy and cumbersome.

That said, *The Politics of Autism* is worth reading. Determined to “tell it like it is” and make radical arguments about what children need in order to achieve as much independence as possible to parents who prefer to hope against hope, Siegel challenges the contradiction she believes is embedded in autism culture: “cure is much more valued than ‘palliation’ – though palliation is what most get most of the time.” Schools, she writes, “provide a smoke screen,” enabling parents to “ignore adaptive and vocational limitations until the day after high school graduation.”

*The Politics of Autism* begins with a cogent explanation of the dramatic increase in autism diagnoses in recent years. Aided and abetted by expansive “soft science” DSM criteria, a diagnosis of autism, she points out, opens the door to services paid for by schools, insurance, and the government, and makes Big Pharma “Autism Stakeholder No. 1.” The greatest downside, she maintains, is that autism services are not always “best fitted to the child’s learning needs.”

Siegel believes that primary assignment to a classroom designed for students of the same chronological age (an approach once called “mainstreaming”) isn’t always better for individuals with moderate to severe learning impairments than a segregated special education classroom. She recommends that schools administer broad cognitive tests to autistic and non-autistic children at age ten. Youngsters (autistic or not) found to have severe developmental disabilities should then be assigned to a “daily living skills track,” with a curriculum that does not emphasize reading, writing and arithmetic. School administrators should assign those with moderate disabilities to a “functional academic-vocational track,” which should be extended through high school. Given a 90% unemployment or underemployment rate for higher and lower functioning autistic adults, Siegel insists that parents need someone to tell them what their children really need to maximize their autonomy and fulfillment.
Given widespread concerns about the “soft science” of behavioral and cognitive testing, many readers, along with parents, school administrators, and clinicians may find “tracking” inappropriate or dangerous. They may also dismiss Siegel’s recommendations about vocational education, using panels of experts instead of judges to decide disputes over treatment standards, and autism health economics as impractical or wrong-headed.

I suspect, however, that they will agree with Siegel that there is an urgent need for evidence-based special education planning – and for parents to receive ongoing and well-informed advice from professionals about the benefits of different therapies, the near-term impact of intervention, and how to factor in individual strengths and weaknesses. They may also agree that the government should reprioritize funding to support studies of symptoms (as well as biomarkers), early diagnoses, parent training, educational strategies, and viable adult community models.

As Siegel makes clear, these initiatives will require fundamental changes in the politics of autism.

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