

H-Net Reviews

in the Humanities & Social Sciences

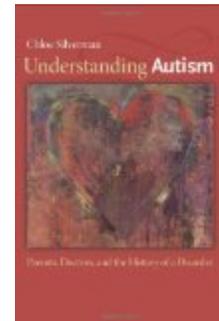


Chloe Silverman. *Understanding Autism: Parents, Doctors, and the History of a Disorder*. Princeton: Princeton University Press, 2011. x + 340 pp. \$35.00 (cloth), ISBN 978-0-691-15046-8.

Reviewed by Carolyn Ogburn (UNC-TEACCH)

Published on H-Disability (April, 2014)

Commissioned by Iain C. Hutchison



What's Love Got to Do with It? A History of Autism and Affect

Chloe Silverman's book, *Understanding Autism*, which grew out of her dissertation work at the University of Pennsylvania, explores the diagnosis of autism through the lens of social history and ethnography of the biology of affect. "Autism refers to a symptom, a disorder, and a syndrome," Silverman writes (p. 2). Initially the word 'autism' was used to provide a concept for negative affect, the apparent lack of social engagement found in a subset of individuals diagnosed with schizophrenia during the first years of the twentieth century. Examining autism through the lens of affect, Silverman contends, has characterized the study of autism from that time.

Silverman's premise is to understand autism by using love as a central analytical tool. Her argument is that "theories of affect, and love in particular, shape the discourses of developmental psychology, psychiatry, and, more recently, biology" (p. 1). These theories of affect she briefly alludes to are so wide-ranging as to render Silverman's statement meaningless; she quickly tamps down any heightened expectation, noting that these theories "work as 'good enough' analytic tools for interpreting contemporary biomedicine" (p. 1). Defensively, she observes that "our analytical categories need only be up to the task of illuminating key themes and conflicts in the material" (p. 2). Love works, she says, "pretty well" (p. 2). She states time and again that her primary focus will be on autistic children and their parents, rather than on autistic adults, though, as she rightly notes, "to focus on children is to ignore entire lifetimes of membership spent in families and communities" (p. 2). She also chooses

to base her work entirely upon widely published texts, rather than engage in interpersonal research. However, she identifies the biomedical practitioner Martha Herbert as a great influence with whom she has co-written an article; Herbert is cited first among her acknowledgments. Silverman attends biomedical conferences, and quotes people she meets at these events. In this way, her research is partial: the affect she claims to read in the history of autism as a disorder influences her own work.

Understanding Autism is extensively researched through secondary literature, is well written, and is a valuable addition to the critical studies work being undertaken in the field of autism. Like Majia Holmer Nadesan's *Constructing Autism: Unraveling the 'Truth' and Understanding the Social* (2005), Silverman examines the positioning of autism within the psychological landscape of the mid-twentieth-century United States. In particular, she looks upon the shift from the diagnosis as strictly psychological toward, increasingly, a biomedical one, by which she means "the particular complex of social and technical practices that emerged after World War II at the intersection of molecular biology, genetics, immunology and clinical applications derived from the laboratory-based knowledge" (p. 13). She rightly places the rise of biomedical diagnosis squarely within research developed to promote biomedical interventions, which in turn generated the need for specificity of diagnosis, which works within the framework of insurance coverage and reimbursement schedules to promote the concept of diagnosis as a standardized measurement. The interdisciplinary

perspective she brings to this history is engaging and thoughtful.

Silverman points out that the line between biological difference and emotional response has long been blurred in autism's history. She shares Leo Kanner's (1896-1981) description of autism as examples of "*inborn autistic disturbances of affective contact*" (emphasis Silverman's, p. 32). Kanner's interest in autism seems to have been spurred by his desire to develop effective measures of emotional qualities, similar to quantitative measurements of intellectual abilities. One incentive for this goal would be to differentiate autistic children from those who were born "feeble-minded," considered a life-long condition, and unlike those whose condition was emotional and could be treated by psychodynamic process as it was then understood. Indeed, not one of the initial eleven children in Kanner's study was considered to have intellectual disability; the central shared quality noted by Kanner was the children's "*inability to relate themselves* in the ordinary way to people and situations from the beginning of life" (emphasis Silverman's, p. 35). Hans Asperger (1906-80), working at the University Children's Hospital in Vienna, also used Bleuler's term, autism, to describe a set of children he saw as having a biologically based personality disorder, noting, as Kanner did not, a tendency of parents to demonstrate similar interpersonal qualities as their children. Rather, Kanner observed an "emotional frigidity" in the parents, an observation which was to have a dramatic impact on the history of the disorder.

Bruno Bettelheim (1903-90) is largely reviled today, but in the 1950s and 1960s was considered a leading expert, one of many researchers who believed the cause of autism lay in the family dynamic. Silverman devotes an entire chapter to Bettelheim's influence, which she claims "once rivaled Montessori, Piaget, and Anna Freud" (p. 61). His experience with children began in Vienna when he and his first wife shared their home with an American girl whom he believed to be autistic. Bettelheim, then employed at his father's lumber business, patiently played children's games with the girl, allowing her to entirely control her own proximity and level of engagement. After nearly eighteen months with Bettelheim and his wife, the girl spoke her first words, a complete sentence "in perfect English" (p. 64). This experience, Silverman writes, spurred him into a career working with "troubled children" (p. 64). Bettelheim's internment in a Nazi concentration camp would inform his milieu therapy, his belief that a complete change in personality could result from creation of a "total environment"

(p. 66). As director of the University of Chicago's Orthogenic School from 1944 until his retirement in 1973, he developed a course of treatment that attempted to foster emotional connection. Unlike the prevailing residential model of the time, the environment at the Orthogenic School was more of a home than a hospital; its most important workers were counselors and teachers who spent their daily hours with the children, while psychologists served in a consultative capacity. Treatment was individualized to the child. And yet, it was less the treatment itself which would characterize Bettelheim's legacy, Silverman observes, than his refusal to alter his approach over time. For Bettelheim, to concede any possibility that autism was a neurological condition was a direct refutation of his milieu treatment.

Kanner would eventually regret his earlier characterization of autism as a result of parental coldness, and he wrote an introduction to Bernard Rimland's (1928-2006) *Infantile Autism* (1964) detailing evidence in support of autism as a neurological condition. By this time, many leading clinicians were already refuting autism as a psychodynamic condition, but the disorder was still considered so rare that few had ever encountered it. The first epidemiological study, published by Victor Lotter (d. 1988) in 1966, found a prevalence rate of 4.5 per 10,000. Those who did encounter these children had little to go by in terms of diagnostic guidelines, relying instead on Kanner's description of "extremely aloof behavior, repetitive and circumscribed activities, and near-typical intelligence" (p. 49). Kanner, together with Leon Eisenburg (1922-2009), created the first formal diagnostic criteria in 1956, identifying "extreme self-isolation" and "obsessive insistence on the preservation of sameness" (p. 49). It wasn't until 1978 that differences in language and communication were included as a third diagnostic criterion, through the work of Michael Rutter, Lorna Wing, and Judith Gould. Including language development as a core criterion of the disorder changed the way in which clinicians thought about autism, for by including disordered speech among the core criteria for diagnosis, autistic language itself was now considered devoid of applied meaning. Unlike earlier psychoanalytical interpretations, in which every action and word came laden with unconscious meaning and intention, no such interpretation of behaviors and word usage characterized autism. Thus, common language patterns among children with the diagnosis, e.g., reversal of pronouns, were no longer thought to be reflective of psychological meaning.

Ivar Lovaas (1927-2010) believed that treatment could

be applied regardless of cause; that the underlying catalyst for the observable behavioral patterns could be disregarded in favor of addressing the behavior itself. Like Bettelheim, he promoted the use of total environment in his treatment; however, Lovaas proposed to bring parents into the treatment as “explicitly trained cotherapists” (p. 113). Treatment in what was to become Applied Behavioral Analysis was to be delivered for a standard forty hours per week, despite Lovaas’s own warning that the treatment model had been based on a research facility with many more resources available to it than the typical household. In 1965, a *Life* magazine article, “Screams, Slaps, and Love,” brought widespread parental attention to his behavioral approach, both positive and negative, for, as the article’s title makes clear, aversive techniques were considered a component of the behavioral intervention at that time.

The role of parents in the history of autism cannot be understated. Of early researchers, many—including Lorna Wing, Michael Rutter, and Bernard Rimland—were also parents of autistic children. Many of the behavioral intervention practices of the time—including both work done in Applied Behavioral Analysis and the TEACCH program—incorporated the skills, knowledge, and attention of parents as co-therapists, granting them the role of “expert amateurs” (p. 93). At a time when parents and experts often met on antagonistic territory, Eric Schopler (1927-2006), at the University of North Carolina, pioneered the use of the one-way mirror to further encourage shared understanding between professionals and parents regarding treatment of children. In addition, in Schopler’s model parents themselves directed the priorities of the therapist’s interventions based on priorities unique to that child or family, and developed their own home teaching programs based on what they had learned in the therapy sessions. Parents then served as natural advocates for continuation of treatment programs that they found to be effective. In organizations like the newly developed National Society for Autistic Children (NSAC, now Autism Society of America), founded in 1965 by Bernard Rimland and other parents, including Amy Lettick, they worked towards developing better school and education programs for their children. Unlike similar organizations, such as the United Kingdom’s National Autism Society (NAS), the goal of the NSAC was less to provide quality-of-life services for its families than to generate greater awareness of the condition. Parents thus become expert in new ways, as co-therapists for their children, as advocates for them in educational settings, and as lobbyists for better treatment options.

Behavioral therapies, according to Silverman, have thus shaped the role of parents within a context of increased surveillance of parenting and childhood.

“Love is a form of expertise,” Silverman writes (p. 97). Beginning in 1974, “Parents Speak” was a column that ran in the leading academic journal, *Journal of Autism and Childhood Schizophrenia*, later renamed *Journal of Autism and Developmental Disorders*. Parents were “aware that they had data that clinicians and researchers didn’t possess,” which included careful observation of their children in daily life (p. 134). The role of parents as expert observers of their own children has meant that treatment of autism has been, in practice, usually taken from multiple treatment models, an approach perhaps “irrational to experts who proceed from theory to treatment,” Silverman observes, “but [which] reflect[s] a pragmatic logic rooted in caregiving and defined by practice” (p. 135). This poses ethical considerations, such as the right of a parent to choose care for his or her child, or adult son or daughter, based on principles grounded in affection, or love—what Silverman calls the “good parenting that constitutes a type of ‘moral imperative’” (p. 225). These ethical considerations are noted, but not, I feel, fully explored in this text. The large role that parents have played in developing understanding and treatment of autism, however, is rarely documented with this degree of attention; it is this which may be of primary interest to the historian.

I would question Silverman’s statement that children with autism have their most “effective representatives among the hundreds of thousands of parents, practitioners, and researchers devoted to autism” (p. 11). This assumption is based on her rationalization that not every child or adult with autism has access to fluent verbal language, or indeed verbal language at all. “Even those considered ‘high-functioning’ or mildly affected may have difficulty serving as advocates for their own cause,” she writes, without further clarification (p. 11). Having difficulty advocating for one’s cause, however, does not imply that one’s interests are better served by another. The argument for self-representation has been made repeatedly by self-advocacy organizations, such as the Autism Self-Advocacy Network (ASAN) which takes its motto from the disability rights movement: “Nothing about us, without us.” While Silverman admits the strength of the self-advocacy movement, she discounts the ethical right of autistic adults to “speak for” those who “are not speaking,” including “children, adults in institutions, parents who feel that the state and the medical industry disregard their complaints, and researchers excluded from main-

stream biomedical research [who] are all silenced in one way or another” (p. 11). What she neglects to note is that unlike these other “silenced” groups, autistic adults (of all “functioning” levels) have often themselves *been* institutionalized; they often share significant similarities of functioning and experience with other autistic people, both verbal and non-verbal; and without exception, they all have been children with autism.

Silverman may have intended to write a book about the passion which spurs the biomedical movement within the autism community, but what she has written instead is far richer and fuller, an absorbing and coherent history of the ways in which autism has been viewed since the particular constellation of characteristics which we now refer to as Autism Spectrum Disorder was first identified as a unique diagnosis.

If there is additional discussion of this review, you may access it through the network, at:

<https://networks.h-net.org/h-disability>

Citation: Carolyn Ogburn. Review of Silverman, Chloe, *Understanding Autism: Parents, Doctors, and the History of a Disorder*. H-Disability, H-Net Reviews. April, 2014.

URL: <http://www.h-net.org/reviews/showrev.php?id=40150>



This work is licensed under a Creative Commons Attribution-Noncommercial-No Derivative Works 3.0 United States License.