

H-Net Reviews

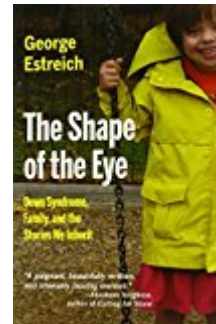
in the Humanities & Social Sciences

George Estreich. *The Shape of the Eye: Down Syndrome, Family, and the Stories We Inherit*. Dallas: Southern Methodist University Press, 2011. xiii + 284 pp. \$23.95 (cloth), ISBN 978-0-87074-567-6.

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There is now a small, but distinct literary genre of caregiver narratives involving Down Syndrome children, books that interweave personal reflections, practical advice, and informal activism. George Estreich, an American author living in Oregon, covers many of these themes, from the shock of the neonatal diagnosis of his daughter, Laura, to the vertiginous experience of multiple medical problems and teams of professionals intruding into his family's most personal moments. The medical complications that Laura confronts are numerous—infant cardiac anomalies requiring urgent surgery, protracted feeding issues, pneumonia, hearing impairment, and the extraction of tonsils and adenoids. For Estreich, the unexpected journey is one of setbacks, confusion, multiple medical interventions, and rapid acquaintance with the patois of helping professions. It is also, for the author, a journey of self-discovery and reflection on the nature of disability. As he admits, “Down Syndrome did not transform our lives, so much as expose its basic terms” (p. 226).

Estreich incorporates findings from the fields of genetics, history, and educational psychology within chapters largely devoted to his daughter's early years. He returns repeatedly to the “original meiotic error” that generated the trisomy 21 and transformed not only his life but also that of his wider, extended family. As the title implies, the book is self-consciously about *family*—including the impact of Laura on him, his wife, and their other daughter, as well as meditations on his wider fam-

ily, especially his Japanese-born mother and recently deceased Jewish American father. His daily observations are punctuated by insights and dry wit. Commenting on the awkwardness of responses by neighbors and friends to his daughter's diagnosis, he writes: “They struggled to say something appropriate. That struggle, and not unkindness, characterized most of our interactions, and it seemed appropriate that a disorder so specifically affecting language should bring people to the edge of words” (p. 23). Indeed, words are very much the centerpiece of *Shape of the Eye*, for what makes the book stand out is that, in addition to being a stay-at-home father, the author is also an award-winning poet. As a consequence, the language that he uses to articulate his emotional world is rich, vivid, and arresting. He self-consciously avoids what he refers to as the “treacly sweetness” of many self-reflections that dominate parenting books and, more recently, social networking sites. Instead, he seeks to convey the raw and competing emotions of love, resentment, confusion, and admiration as he goes about his daily caring for his daughter.

Within this framework, the book has a few constraints. Since it ends with Laura entering preschool, the author's insights are limited to the early years of her life. The challenges involving parenting a child with Down Syndrome through adolescence and into adulthood lie in the future. *The Shape of the Eye*, like similar works, contains a lot of personal history—such as house renovations, romantic encounters, and bereavement over a

parent. Some arc back cleverly to the central narrative; others seem to trail off. The history of his mother's childhood in wartime Japan, in particular, though fascinating, seems like an excerpt from another, different work altogether.

Despite these minor quibbles, this is a marvelous book. There is an unmistakable air of honesty, authenticity, and humility that underpins the author's writing. For those of us with family members born with Down Syndrome, many of Estreich's observations have an unerring

veracity. And at times, his poetic inclinations lead to passages of haunting beauty. "Her [Laura's] speech is a landscape before dawn: indistinct shapes, a darkness textured by the eye. It brightens towards an imagined, articulate noon" (p. 226). Stripped of the too-common overcompensating, maudlin accounts that one so often reads of Down Syndrome (and disability in general), this book is a breath of fresh air. It is these personal narratives that can provide a nuanced, genuine, and humanizing portrayal of individuals with Down Syndrome for new parents and the public alike.

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