

Adrienne Asch

(1946–2013)

Bioethicist who fought for disability rights in reproductive technologies.

Adrienne Asch was a brilliant, feisty bioethicist and feminist who grappled with the impacts of human reproductive technologies on disability rights and social inequality. A groundbreaking scholar, teacher and activist, Asch questioned the practice of parents using prenatal testing and selective abortion to choose their children's traits and exclude those predicted to have disabilities.

Asch, who died from cancer on 19 November, was born in New York City in 1946. Premature at birth, she developed retinopathy as a result of too much oxygen in her incubator, and soon lost her vision. She later attended public schools and sat in the same classrooms as sighted children in Ramsey, New Jersey. In 1969, after graduating from Swarthmore College in Pennsylvania with a bachelor's degree in philosophy, Asch had trouble getting hired because she was blind — and this inspired her interests in disability rights. She received a master's degree in social work from Columbia University in New York in 1973, and in 1981 she earned a certificate from the Institute for Contemporary Psychotherapy, where she trained as a family therapist.

Asch's career as a bioethicist began in the early 1980s, when she was investigating employment-discrimination cases for the New York State Division of Human Rights and conducting a private psychotherapy practice. At a bioethics meeting at the New York City Bar Association, she objected to the absence of speakers with disabilities participating in a debate about withholding life-saving treatment for babies born with spina bifida or Down's syndrome.

Her comments led to conference invitations and her involvement in a project on the care of imperilled newborns at the Hastings Center, a bioethics think tank in Garrison, New York. Two decades later, Asch was part of the working group that developed the Hastings Center guidelines for end-of-life care. At her urging, the guidelines were informed by consultation with representatives from disabilities communities. It is thanks in large part to Asch that bioethicists and researchers have begun to engage people with disabilities as valued, peer participants.

In 1988, as a doctoral student in social psychology at Columbia, she published *Women with Disabilities: Essays in Psychology,*

Culture and Politics, co-edited with Michelle Fine, a social psychologist now at the City University of New York. It represented key features of her work — the intersection of



feminism and disability rights, attention to the experiences of women with disabilities and resistance to demeaning stereotypes.

In 1994, two years after receiving her PhD, Asch became a professor of women's studies and biology, ethics, and the politics of human reproduction at Wellesley College in Massachusetts. In 2005, she was recruited by Yeshiva University in New York to direct its Center for Ethics. She also taught courses in epidemiology and population health and in family and social medicine at Albert Einstein College of Medicine in New York.

In addition to writing many scholarly articles and book chapters, Asch co-edited two influential books: *Prenatal Testing and Disability Rights* (2000) and *The Double-Edged Helix: Social Implications of Genetics in a Diverse Society* (2002). Her scholarship and advocacy were fuelled by a deep conviction that people with disabilities are as valuable as those with able bodies, their lives as worthwhile and their rights equal in every respect.

A just society, she argued, must eliminate pervasive discrimination, not children with disabling traits. Asch was a staunch supporter of a woman's right to abortion,

but distinguished between abortions to avoid having any child and those to avoid having a child with particular features. She pushed for parental decisions, social policies and bioethics debates to be based on genuine experiences rather than tragic myths and fears. Asch was especially instrumental in shifting genetic counselling away from a prevention-based model, which steers prospective parents to select against disabling traits, towards a social model, which provides information about life with a disabling condition.

Asch had an endearing ability to be at once gracious and confrontational, passionate and prickly. She was always open to differing views, but she never compromised her insistence on absolute respect for the lives and perspectives of people with disabilities. She was known for asking probing questions to identify common values and expose disagreements that needed to be hashed out.

As feminist scholars who wrote about the bioethics of reproduction and inequality, Adrienne and I crossed paths frequently beginning in the late 1980s. Her cogent arguments helped me to incorporate disability studies in my own writing on genetic selection and the devaluation of black women's childbearing. In 2008, we participated in a workshop for an issue of *Signs: Journal of Women in Culture and Society* on reproductive and genetic technologies. Adrienne asked why scholars who write about disability rights fail to cite scholars who have disabilities. Her questions made me think more seriously about the experts I relied on and more deeply about the role of disability in my own work and life.

In many bioethics meetings, Adrienne was the only person with a visible disability. Her unmistakable voice compelled the rest of us to confront how disability-rights arguments affected our commitment to social justice and human equality. Yet, Adrienne wanted mainly for us to see her and others with disabilities as unremarkable. As she put it in a 2006 interview: "I'm neither unhappy nor proud. I just am." ■

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