

***Adrienne Asch: A Career at the Intersection of Bioethics and Disability Studies***

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The first time I heard Adrienne Asch speak, she had assumed her role as a respected and influential member of the Disability Studies field. Later, as a student of Bioethics, I discovered that she was also a respected and influential Bioethicist. Who was this scholar with such expertise in two fields, and why did her contribution to each field have to be discovered separately? Asch passed away in November of 2013. Widely missed and memorialized in these two fields, I realized that there must be a third form of recognition for her pioneering work at the intersection of Disability Studies and Bioethics.

Asch was born in New York in 1946. Born premature, she developed retinopathy from too much oxygen in her incubator, thus losing her vision (Roberts 2013). Asch's own difficulty in finding employment after graduating from Swarthmore College with a Bachelor's degree in Philosophy made her keenly aware of disability as a civil rights issue (Fox 2013). She went on to study Social Work and Social Psychology at Columbia University and in 2005, she was recruited to direct the Center for Ethics at Yeshiva University in New York. A great deal of her work crossed disciplinary boundaries; bridging Bioethics, Disability Studies, Feminist Studies, Public Health, and Human Rights. Her most influential work opposed genetic testing and abortion to select against children predicted to have disabilities.

Asch was known for her straightforward and often blunt nature, but what struck me most was her profound intellectual patience with other people and their entrenched assumptions. On more than one occasion, I attended lectures and meetings on the topic of reproduction in Bioethics or Health Policy contexts, at which Asch was present. Sometimes, at these events, the discussion would turn to a consideration of what to do in case a fetal genetic test predicted disability (a narrative still broadly overshadowed by suggestions of burden and tragedy). She would listen to the conversation unfold. After a while, she would interject, reminding everyone that speaking of disability as tragedy

reflects mistaken assumptions about the value and quality of human life and the reality of human families. How many times must she have repeated this type of statement? I can only imagine how frustrating it must be to have spent a career battling such tenacious social attitudes about disability and the imaginary ideal of the “perfect” child. Underlying her persistence was a commitment to say what needed to be said, time after time. I have a profound respect for Asch and the dedication and passion that she brought to the world.

The pieces that follow were written by three individuals who knew her both professionally and personally. I think that, by seeing her through the eyes of friends and colleagues, we can begin to fully appreciate the great and lasting impact that Asch has had in Bioethics and beyond.

#### References:

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#### **Corinne Kirchner, PhD, Columbia Mailman School of Public Health**

Adrienne Asch’s recent death was premature in ways not yet fully acknowledged in the wide public recognition of the great loss it will have for our society. This brief article will focus on one sphere of intellectual creativity that engaged Asch for much of her professional development. (I did not write “professional career” because it is so artificial to separate activities that constituted Asch’s life in general from the more formal category we call “career”). I refer to her efforts to knead together the fields of Disability Studies and of Bioethics, for the expansive effects their blending would have on the thousands of individuals involved.

It was a persistent frustration to Asch that many of her admirers classified her first and foremost as a pioneering voice in clarifying disability rights and tended to overlook or diminish her identity as a Bioethicist. They often

based their prioritization on her lifelong blindness, thereby seeming to overlook her training and production in the philosophical analytic basis for work in Bioethics. As Asch's professional colleague and friend, I, too, was somewhat misinformed about the significance of this particular interdisciplinary effort. I did not understand the difficulty in promoting this combination of intellectual foci. To me, and presumably many others in Disability Studies, it seemed a logical linkage, and therefore an easy task. To me, it seemed that both fields expressed preeminent concern with social justice which had engaged Asch from her earliest professional entrée. Thus, I thought that promoting those two fields to work together would be a natural development. But no!

As Asch spelled out in her early writing on the topic, there was a serious barrier between the two fields. As her chapter in the influential *Handbook of Disability Studies* (Albrecht et al., 2001), explained Bioethics assumed the traditional and still lingering "medical model" view of disability. That view has been countered with the "social model," an alternative analysis of disability with multidimensional consequences. Those who take the medical perspective tend to view the wide ranging social consequences as a direct result of physiological difference, rather than as separately-generated sociocultural practices that can be addressed in their own terms to eliminate or minimize functional limitations and related attitudes of pity and rejection. To those observers, among them many Bioethicists of the 1970s and beyond, disability was a 'tragedy', necessitating reduced quality of life and hence exclusion from typical pleasures of valued community roles. Writers on the critical life-and-death and health resource allocation issues central to Bioethics, generally applied paternalistic, overly protective attitudes in making their judgments about by whom and how decision-making should proceed for the benefit of people with disabilities, including those with cognitive impairments.

Thanks in part to Asch's prolixity in writing and lecturing about the intersections of Bioethics and Disability Studies, and also to the many other leading thinkers whose writings she stimulated or partnered with over the last decade and more, much progress was made toward the initial vision of a robust interdisciplinarity. As recently as the past Spring, a lengthy entry in the Stanford online encyclopedia of philosophy (the SEP) coauthored by Asch, Wasserman, Blustein, and Putnam on "Disability and Justice", reveals that much of the original problematic view of disability continues to undermine Bioethicists' ability to accord full acceptance to people with disabilities.

However, that gap is likely to persist. As long as disability entails, both of the two types of injustice recognized by philosophers of justice – 1) physiological impairments, and 2) related disadvantageous societal outcomes – the challenge exists for analysts to identify the precise nature of the societal problem along with realistic aims and means for solutions. In other words, the challenge for Bioethics is to reach and study consensus on how justice for all members of society can be achieved or at least maximized, taking into adequate account that not all members have the same bodily capacities, i.e. the facts of the distribution of disabilities.

Comparing the 2001 and the 2013 chapters reveals that Asch had moved spectacularly into the complexities of relevant philosophical scholarly treatises on social justice. Her closing comment as of 2013 called for even more work

by the Philosophers. As in all her intellectual and personal ventures, she maintained clarity of focus throughout the period on disability as a cultural phenomenon, which offers variegated opportunities and difficulties for individuals to manage creatively.

Sadly, and ironically, the two fields whose linkage she tackled may come closest together in recognizing the vital loss of Asch's intellectual, moral, and emotional leadership.

References:

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**Rachel Adams, Columbia University**

At a workshop a few years ago, Adrienne Asch asked me to accompany her when we moved from one room to another. As I took her arm, tentatively attempting to steer her in the right direction, she barked, "don't clutch at me!" Making no effort to hide her irritation, she repositioned my hand where she wanted it. That may have been the first time Asch snapped at me; it would certainly happen again. Anyone who knew Asch is aware that she could be prickly, irascible, and blunt. She did not suffer fools gladly, and would tell you in no uncertain terms when she thought you were wrong.

Asch was also kind, generous, and brilliant. She took life experiences, like our clumsy encounter at the workshop, as opportunities for reflection, thinking deeply about the ignorance, fear, and misunderstanding that continue to inform prevailing attitudes toward bodily difference, as well as the possibilities of transforming beliefs, customs, and policies to make the world a better place for people with disabilities. She loved to meet people, to collaborate, and to debate. I was especially struck by how she made herself available to graduate students and younger

scholars. She was a generous advisor and mentor, but she was also open to learning from new ideas and perspectives. Every so often I could expect an email from Adrienne with the name and address of a colleague she thought would share my interests. I treasure those contacts and mourn the lost possibility of future connections.

When I learned that my second child had Down syndrome, Asch's writing about genetics, prenatal testing, and reproductive ethics became an invaluable source of wisdom. In the months after my son's birth, I was dismayed by the information about prenatal testing and genetic disability in the advice manuals I had accumulated during my pregnancy. So much was underdeveloped, inaccurate, and biased. These books seemed to assume a genetically perfect fetus, giving minimal or no information at all about the meaning of a positive diagnosis (one that disclosed a genetic disability). I have always believed strongly in women's reproductive freedom, including the right to abort a pregnancy for any reason. In becoming an advocate for my son, I realized I had to think further about the status of a disabled fetus in an otherwise wanted pregnancy. I still believed women should have control over their own bodies, but I wondered how free they were in the context of so much misinformation and prejudice?

How refreshing to find Adrienne's co-authored chapter in the *Our Bodies Ourselves Pregnancy and Birth Book*. There, she managed to distill the complex ideas about reproductive ethics developed in her academic work into language that would be accessible to many different kinds of readers. Unlike the standard pregnancy guides, which tend to say nothing about what happens after a positive diagnosis, this chapter addressed the option of abortion frankly, including the personal story of a woman who chose to end her pregnancy after discovering the fetus had Down syndrome. Even more remarkably, it addressed the option of continuing a pregnancy with a disabled fetus. It featured a second personal story written by the mother of an eight-year-old girl with Down syndrome. While giving plenty of information about possible developmental and medical complications, the chapter also insisted that a diagnosis of Down syndrome or another genetic disability would be only one aspect of a child's identity. Here was a chapter that walked a fine line between respect for the woman's right to make choices about her own body and the person the disabled fetus might become.

I take this chapter as a model of Asch's accomplishment. While fiercely independent, Asch also frequently asked for help. Many who knew Asch had the occasion to guide her from one place to another. As thinkers, we are also privileged to have had the opportunity to be guided by her passionate convictions, fierce loyalties, and strong ethical sensibility.

**Susie A. Han, Deputy Director and Principal Policy Analyst, New York State Task Force on Life and the Law**

I met Adrienne Asch through her participation as a member of the New York State Task Force on Life and the Law. The Task Force functions as New York State's Bioethics commission, charged with developing public policy on

issues arising at the intersection of Medicine, Law, and Ethics. Asch was appointed to the Task Force by Governor Spitzer in 2007, and since I became a staff member in 2009, I had the pleasure of getting to know her both professionally and personally.

As a member of the Task Force, Asch offered strong and thoughtful opinions, which were shaped by her personal experiences and prolific academic career in Bioethics as well as feminist and disability rights studies. Asch recognized the importance of diverse perspectives, and despite her strongly held beliefs, she worked with others to reach a compromise and/or consensus. If she expressed a dissenting opinion, she expressed them in a thoughtful, reasoned manner that made those in the majority reconsider their position. She reminded us that the responsibility of changing society's perception on various "vulnerable" (a word she hated!) populations should not be the sole burden of these individuals. Instead, all members of a civil society need to be more inclusive and embrace those with disabilities to further the goals of respect, social justice, and equality for all.

Asch was particularly attuned to terminology; she understood how terms used to describe people and groups influence social attitudes and help to shape policy. She consistently affirmed in her academic work and at the Task Force that the term "disability" was simply a label that should not diminish expectations for one's capabilities or future. Yet, as accomplished as she was, Asch never claimed to be a role model for those with disabilities, she simply wanted to be known as a Bioethicist and feminist.

Although I worked with Asch for several years, it wasn't until this past year that I got to know her outside of the Task Force. As many people have noted, Asch was feisty, blunt, and fiercely independent. She once told me that some found her personality to be off-putting, demonstrating a great deal of self-awareness. Asch actively chose to express who she was without allowing external factors to force her to change. These same qualities made her a good friend and confidante. One could not mince words with Adrienne; she kept you honest with yourself and in return she was honest with you. Adrienne did not believe in sugarcoating the details, and she got straight to the point and one had to keep up. She may have been tricky to get to know initially, but she was a loyal and protective friend to me, and as I have learned, to many others as well. Asch treasured her friends, and she was definitely someone you wanted in your corner.

Asch's passing is a great loss for many, both professionally and personally. The Task Force and I will miss her greatly, and her opinions and perspective will continue to resonate in Bioethics.