Schmidt on Löwy, 'Imperfect Pregnancies: A History of Birth Defects and Prenatal Diagnosis'

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The following book review from H-Disability may be of interest to some H-Women list members.

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Ilana Löwy. *Imperfect Pregnancies: A History of Birth Defects and Prenatal Diagnosis.* Baltimore, MD: Johns Hopkins University Press, 2017. pp. (hardcover), ISBN 978-1-4214-2363-0.

Reviewed by Marion Schmidt (Georg August Universität, Göttingen) **Published on** H-Disability (November, 2018) **Commissioned by** Iain C. Hutchison (University of Glasgow)

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Prenatal diagnosis, historian of science Ilana Löwy explains at the beginning of *Imperfect Pregnancies: A History of Birth Defects and Prenatal Diagnosis*, "is a highly atypical diagnostic approach" (p. viii). Usually, diagnosis is followed by some attempt at treatment. Yet with anomalies diagnosed, the only "therapy" available is "therapeutic abortion." It brings up the question of who is the patient, in the first place—the mother or the fetus—and how to separate the (potential) rights and interests of the one from the other. Because of these difficult definitions, Löwy suggests that prenatal diagnosis has been treated as "as an unclassifiable, sui generis phenomenon" (p. viii) and has been studied mostly as a bioethical or moral issue. Instead, *Imperfect Pregnancies* treats it as a biomedical technology, aiming to explain "how a search for fetal anomalies was transformed into a routine component of the standard medical care" (p. xi). This supposed lack of research is a bit of a puzzling overstatement, given that prenatal diagnosis is a frequent subject of discussion among historians of science, medicine, and disability, and that different parts of its history have been covered elsewhere.[1]

Nevertheless, Löwy offers a good survey of these developments and attitudes in different Western industrialized countries, although it remains unclear which "industrialized" countries are included, and why. She focuses mostly on the United Kingdom, the United States, and France, but also includes studies in English and French from Israel, the Scandinavian countries, the Netherlands, and Poland. That such a wide survey must necessarily remain somewhat superficial is clear, but it nevertheless provides a useful first impression. Particularly interesting is her juxtapositioning of the diffusion of various prenatal tests and methods in various national and cultural contexts and beliefs about responsible motherhood.

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Löwy's perspective is influenced by her scholarly background in the history of cancer research. Looking at prenatal diagnosis, she notes the similarities between the "surgical excision of nonvital body parts to eliminate the risk of cancer and an abortion to prevent the birth of an impaired child" (p. viii). Consequently, her analysis is strongest when she follows the development and diffusion of diagnostic technologies such as amniocentesis or fetal ultrasound pushed by different professional groups and biomedical companies. (These commercial interests, unfortunately, are mostly mentioned only in passing.)

Chapter 1 offers an overview of birth defects before the advent of prenatal diagnosis. This includes a short history of embryology and teratology in the UK and France in the late nineteenth and first half of the twentieth centuries, including different theories about maternal behavior and pregnancy outcomes, and early theories to explain and prevent congenital intellectual disabilities such as Down Syndrome.

Chapter 2 focuses on the history of karyotyping, which marks the beginning of modern prenatal diagnosis. When, in the late 1950s, scientists determined the exact number of human chromosomes, this opened the path to defining a rapidly growing number of chromosomal abnormalities and tying them to a range of clinical symptoms. In the 1960s, physicians began to routinely perform amniocentesis to culture and karotype fetal cells to detect fetal anomalies. Amniocentesis, however, was a risky procedure, and only suggested to women with at-risk pregnancies. These women, Löwy writes, needed to "balance the risk of giving birth to an impaired child with the risk of miscarrying a healthy fetus, and by the paucity of alternative solutions" (p. 64).

In chapter 3, Löwy looks at the roles of the 1964-65 rubella epidemic and thalidomide scandal in bringing about the legalization of abortion, pointing out how public debates about the birth of visibly disabled children "created a new legal entity: the 'unacceptable' fetus" (p. 78). Here and elsewhere, Löwy returns to the importance of visible otherness in pushing the development, application, and acceptance of prenatal testing, without, however, drawing from seminal texts in disability studies that problematize this othering gaze.[2]

Chapter 4 follows the move from prenatal diagnosis for a limited group of at-risk pregnancies to the prenatal screening of a much larger population. As Löwy puts it, "prenatal diagnosis of fetal malformations became prenatal screening for the risk of such malformations" (p. 6). In the 1970s, the development of serum markers in maternal blood offered a risk-free way of screening for neural tube defects or chromosomal syndromes. By the 1980s, testing for a serum marker could be combined with higher-resolution ultrasound to achieve a more accurate picture of fetal status. Using the example of Down Syndrome screening, Löwy shows how different attitudes towards risk and maternal responsibility, the right (not) to know, and, not least, physicians' liability for pregnancy outcomes affected the dissemination of testing. Screening, she writes, is meant to reassure women, but can also have the opposite effect, pushing women on to a medicalized and insecure trajectory, and in some countries with strict abortion legislation, leaving them without any recourse.

Chapter 5 examines prenatal diagnosis for sex chromosome anomalies, for example, for the "dissociation between genetic diagnosis and its concrete meaning" (p. 144). Turner syndrome (XXY), for example, is correlated with highly variable, "relatively minor but not insignificant developmental problems" (p. 122). Nevertheless, the abortion rate for fetuses diagnosed with Turner syndrome

ranges from 70 to 90 percent across Europe. Chapter 6 offers a detailed analysis of new genomic approaches, such as fluorescence in situ hybridization (FISH) or comparative genomic hybridization (CGH), that allow for screening of the entire genome for abnormalities. These technologies, which originated in the search for cancer cells, are increasingly also used for screening parental or fetal cells for genetic anomalies. Sometimes this has unintended consequences. CGH can identify hereditary conditions in parents who previously considered themselves healthy, transforming them into carriers and/or patients. This situation produces a particularly stressful insecurity when geneticists find variants of unknown significance; that is, small variations in DNA that might or might not have some pathological relevance. Here we have the old dilemma of genetics: our diagnostic technologies are far ahead of our abilities to make sense of genetic information, much less to find therapeutics.

Dissecting such complicated technologies and the resulting insecurities are the strong points throughout *Imperfect Pregnancies*. Elsewhere, I would have wished for a more critical analysis of current genetic research, such as recent claims of links between congenital heart anomalies and intellectual impairments, or the higher prevalence of autism diagnosed in children with Prader-Willi or Rett Syndrome. Yet, as for example Jennifer Singh's study of genetic research of autism has shown, such genetic causation and linkage studies are often little more than speculation about the role of the above mentioned variants of unknown significance.[3] Moreover, as long as we lack better understanding of genetic causation, any claims that condition *X*actually causes intellectual delay should always be treated with skepticism. There has been a long history of linking various physical differences or disabilities with intellectual delay or mental health issues, an assumption that closer examination has revealed to be based, more often than not, on bias and discrimination. Here and elsewhere, a critical look at the medical-clinical model of disability would have added a useful dimension to Löwy's analysis.

Overall, Löwy gives a very useful overview of the growth of prenatal diagnostic technologies and the expansion of prenatal diagnosis from a small group of women with at-risk pregnancies to ever wider circles, if not, in some countries, a majority of women. This expansion corresponds with an ever-growing number of abnormalities that can be discovered, and an ever-tighter medicalization of pregnancy and the fetus. In this, prenatal diagnosis is not an expectation, but part of a larger trend in modern biomedicine, which increasingly considers everyone a potential at-risk patient. Löwy deals empathetically with the maternal stress produced by prenatal diagnosis, which often results in as much insecurity as reassurance.

Yet, *Imperfect Pregnancies* would have profited from an engagement with disability history and disability studies, not least in its rather black-and-white portrayal of disability activism that suggests a false and harmful dichotomy between disability and women's rights. Following Kirstin Luker, Löwy claims that debates over prenatal diagnosis are "less about disability rights or human diversity" and more about a conflict between seeing women as primarily mothers or caretakers, or as autonomous and diverse beings (p. 122).[4] It is, without a doubt, true that the "debate on abortion rights cannot be dissociated from the debate on women's role in society" (p. 122). It is also true that women still carry the main burden of childcare, including caring for children with disabilities. Yet presenting disability care as solely women's work, and completely excluding the emotions, attitudes, and perspectives of their (mostly) male partners, reifies those very gender norms and glosses over past and present realities and family realizations. Portraying, in 2017, disability rights as a straw man

hiding the real issues, while failing to take into account the insights produced in the last two decades by disability history/studies on the intersection with gender and women's rights, seems rather anachronistic.

Notes

[1]. For example, see S. M. Lindee, *Moments of Truth in Genetic Medicine* (Baltimore, MD: Johns Hopkins University Press, 2005); Alexandra M. Stern, *Telling Genes: the Story of Genetic Counseling in America* (Baltimore, MD: Johns Hopkins University Press, 2012); and Andrew J. Hogan, *Life Histories of Genetic Disease: Patterns and Prevention in Postwar Medical Genetics* (Baltimore: Johns Hopkins University Press, 2016).

[2]. See Rosemary Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997).

[3]. Jennifer Singh, *Multiple Autisms: Spectrums of Advocacy and Genomic Science* (Minneapolis: University of Minnesota Press, 2015).

[4]. Kristin Luker, *Abortion and Politics of Motherhood* (Berkeley, CA: University of California Press, 1984).

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