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Review of *Prenatal Testing and Disability Rights* edited by Erik Parens and Adrienne Asch

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Prenatal Testing and Disability Rights

Erik Parens and Adrienne Asch, eds.

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IS PRENATAL TESTING REALLY A PART OF good prenatal care? As the work of the Human Genome Project (HGP) progresses, and genetic tests for more conditions and variations become available, this will become a more difficult question for clinicians, health care institutions, and families. Many within the disability rights community have increasingly challenged the unexamined assumption that prenatal testing for genetic disability is an unqualified good. The disability rights critique, however, has received little acknowledgment from the mainstream bioethics or medical community. In order to bridge this gap, the Hastings Center sponsored a two-year-long project that brought together members of the disability rights, bioethics, and medical communities. This book is the result of these efforts.

The editors open the volume with a chapter that summarizes the main contours of the conversation—outlining the disability critique of prenatal testing for genetic disability, posing the counterarguments offered by bioethicists, and ending with the recommendations on which the working group could agree. Tellingly, the editors note that the project participants could not reach agreement on any substantive questions (e.g., the meaning of parenthood, demarcating genetic conditions for which it might be reasonable to test from those which it might be unreasonable to test). The only point on which participants could agree was that of informed consent. This in itself is a window into the difficulties of this book.

After Part One, which includes the editors' summary and Cynthia Powell's overview of the practice of prenatal genetic testing in the United States, the book is subdivided into three additional sections. The six essays in Part Two examine the question of prenatal genetic testing in light of different understandings of the meaning of parenthood. The five essays in Part Three grapple with what is known in this conversation as the "expressivist argument." Disabilities rights critics oppose prenatal testing for genetic disability in part because it "sends a message" to persons with disabilities that they and their ilk are of less value than other members of society. Prenatal genetic testing thereby "expresses" and actualizes this belief. Throughout this volume and particularly in this section, various bioethicists challenge this argument. The final section, Part Four, addresses questions of policy-making, although only one of its five essays—that by Jeffrey Botkin—actually moves toward concrete policy recommendations.

A discussion and evaluation of all eighteen essays is clearly beyond the scope of this review. I would therefore like to focus on four essays (beyond Parens and Asch's opening chapter) that I found most important and insightful. The first, Philip M. Ferguson, Alan Gartner, and Dorothy K. Lipsky's essay, "The Experience of Disability in Families: A Synthesis of Research and Parent Narratives," is essential reading for anyone working in perinatal medicine and genetic counseling. It not only helpfully traces historic shifts in familial understandings of disability. It more importantly reviews recent research findings on family adaptation to raising a child with a developmental disability. This research unequivocally challenges standard cultural assumptions that children with disabilities are unduly burdensome on families. The authors find that families with disabled children fare on average no better or worse than families in general.

Two of the most insightful chapters in the volume are those offered by Bruce Jennings and Nancy Press. Jennings and Press, in separate essays, challenge the fundamental misunderstanding that shapes most of the discussion in this book. As mentioned above, the disabilities rights critique opposes prenatal genetic testing because of "the message it sends" about the worth of disabled people. Too many authors in this volume misconstrue this argument. They reduce it to the straw argument that *individual* women or parents, by using prenatal diagnostic technologies, are "sending a message" to disabled persons. Too much ink is spilt attempting to show how this is not the case.

Jennings, in his essay, "Technology and the Genetic Imaginary: Prenatal Testing and the Construction of Disability," rightly reframes the expressivist critique and argues that it is not *individuals* that "send a message" to persons with disabilities but the entire infrastructure of genetic testing itself. Recognizing "the reality-constituting power of the technology itself" and "the illusion of freedom" that it can give, Jennings argues that seeing these questions from an individualist perspective is naïve. His fundamental argument illuminates the context in which individual decisions occur: "It is easy to lose sight of the enormous public apparatus of scientific research and testing facilities, to say nothing of the enormous public (whether governmental or corporate) investment and expense that genetic testing technology represents. It is breathtakingly implausible to characterize the use of genetic testing in obstetric practice in our society as 'private' in any sense" (p. 131).

Press, in her essay "Assessing the Expressive Character of Prenatal Genetic Testing: The Choices Made or the Choices Made Available," continues Jennings' argument. Like Jennings, Press finds the individualistic construction of prenatal testing to be naïve or, worse, intentionally masking the purpose of prenatal testing as a tool of social policy. She reframes the discussion at a more fundamental level than most of the rest of the essays recognize. "What is the message," she asks, "in the case of prenatal testing and who are the senders and receivers?" (p. 216). Press's chapter is rooted in her own anthropological research with women undergoing the MSAFP (maternal serum alpha fetoprotein) test. Her findings on how the actual meaning and purpose of this test became encoded and obscured in professional literature and patient understanding provide a devastating critique of the

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"Collaboration" has real meaning in Baton Rouge.

75 percent of the applicants come seeking dental help. Finding affordable dental care has always been difficult in the greater Baton Rouge area. General dentists are needed to serve as initial providers. Even so, because patients are a marginalized population that tends to neglect its oral health, every one of the "clinic"'s dental specialties is over utilized.

Surveys have shown that people in Louisiana have a history of accessing their medical care through emergency rooms of the statewide "charity hospital" system (community hospitals, including LSU–Earl K. Long, under the direction of the LSU Medical School). The virtual clinic is working to change those patterns by encouraging people to go to primary care physicians for preventive and educational health care. Program organizers know that people who have regular medical care are less likely to ignore symptoms until they become so severe that they require a trip to the emergency room.

Today, for the first time in their lives, thanks to the Greater Baton Rouge Community Clinic, many area residents have charts on file in physicians' and dentists' offices. Because they do, they are able to seek medical and dental care without the loss of income that often occurs when one is forced to take time to seek treatment. Preventive care is now a reality for them.

"Collaboration" is a word that gets thrown around a lot these days, but in the Baton Rouge area it has real meaning. The Greater Baton Rouge Community Clinic is a case of good people helping good people. □

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routinized practice of prenatal testing. As with the essay by Ferguson and his colleagues, it's amazing what a difference data makes.

The final essay worth reading is that by Jeffrey Botkin, entitled "Line Drawing: Developing Professional Standards for Prenatal Diagnostic Services." Elsewhere Botkin has attempted to outline criteria for how society or the medical profession might reasonably distinguish between genetic tests that ought properly be offered and those that ought not. Here he takes a different approach. He works through the process of clinical decision making, as it works in other areas of medicine, to provide the beginning of a template for how medicine might work toward developing reasonable limits for the application of prenatal tests, especially as the outcomes of the HGP make tests for more genetic variations available.

In closing, I would like to raise three additional points that indicate the deeply troubled framework within which this particular conversation occurred. First, as is made clear from the outset and reiterated in too many of the essays, the discussion is constrained by its allegiance to pro-choice orthodoxy. An absolutist pro-choice position is adhered to dogmatically, even by those who wish to criticize this particular choice against individuals with disabilities. But their insights into the humanity of the fetus and the social ramifications of genetic testing followed by selective abortion are not allowed to raise questions for the practice of abortion more broadly construed. This introduces a fundamental incoherence into the project.

Moreover, this eliminates from the conversation those with significant religious, especially Catholic, perspectives. What one finds here is strictly a secular exchange. It remains amazing to this author to find a book on disabilities—published by Georgetown University Press, no less—in which no reference to the work of Jean Vanier and the communities of L'Arche* appears.

A second incoherence emerges from an obvious omission from the structure of the project. While Part Two focuses on the meaning of parenthood, no essays treat the meaning of children themselves. Clearly these are related, but the essays on parenthood focus almost exclusively on what it means to or for *the parents* to have a child. There is little if any attention paid to the meaning and value of children in and of themselves, the societal value of children, or the religious or cultural understandings of children, among other things. In a project on prenatal testing, this remains a puzzling omission. Questions concerning children are, of course, substantive questions, and this omission, no doubt, reflects the inability of the project to engage substantive issues.

Finally, one does not get a sense from the essays that anyone who participated in the project came away from the two-year conversation fundamentally changed. It does not bode well for the social embodiment of this debate that so much time, money, effort, and intellectual engagement resulted in so little persuasion of interlocutors on fundamental, substantive points.

All in all, both the weaknesses of the volume and the contributions of the five essays outlined above make this an important book for health care professionals who work in the areas of genetics and prenatal care, for institutional leaders who must discern how to appropriate genetic technologies into the infrastructure of their institutions, and all others concerned about how technologies increasingly constrain choice and silently achieve social ends.

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*L'Arche, founded by Jean Lanier, is an international federation of communities of people with learning disabilities. Information concerning its U.S. affiliate is available at www.larcheusa.org/about1.htm.