Why I Haven’t Changed My Mind about Prenatal Diagnosis: Reflections and Refinements

The arguments raised by colleagues and friends during this Hastings Center project on the disability rights critique of prenatal genetic testing are important, serious, and sophisticated. They are made by scholars and health professionals with deep commitments to creating a more just, caring, and inclusive society for every child and family. The arguments raised against the disability rights critique and in support for the social practice of prenatal diagnosis are put forward by those who support the legal victories and societal changes that the disability rights movement has struggled to attain. In what follows I will try to explain why, despite the challenges to this critique, I and others still believe that support for prenatal diagnosis and selective abortion contravenes the goals of people with disabilities for full acceptance and inclusion in our society, and why it also threatens cherished values in the parent-child relationship. I continue to view the practice of prenatal diagnosis followed by selective abortion as both misinformed about the true nature of disability and as problematic in what it connotes about societal and parental willingness to appreciate the many forms of human variation.2

I will not here review in detail the components of the disability rights critique, discussed in the opening chapter and in several other contributions to this volume. I am aware that many of my views are shared by others who espouse similar critiques; I do not present what follows as endorsed by all those with disability-based objections to prenatal testing.3

Throughout this project, we have discussed the contentions that prenatal diagnosis is “morally problematic” and “misinformed.” I take up these arguments as they are discussed in the opening of this volume. Misinformation and misinterpretation about disability pervade the con-
struction of some moral arguments. Consequently, I address moral problems and misinterpretation throughout this discussion.

The “Message” of Prenatal Diagnosis and Selective Abortion

You are a professor in a philosophy department at a large urban university. In your class of fifty students, you notice that five students have pierced tongues and lips and that a few others have dyed their hair in unnatural colors. You have difficulty even looking at these students because of their style, and you ignore their raised hands when they want to participate in class discussion. Midway through the semester, a man with dyed hair comes to your office to raise questions about the work in the course, and you realize that he actually has some interesting observations to make about the class and find yourself chagrined at your avoidance of his raised hand, of which you were only half aware until he appears at your door. The characteristics of Down syndrome, spina bifida, cystic fibrosis, or hemophilia, you say, are not as trivial as piercings and dyed hair, and perhaps you are right, but recognize that prenatal testing gives only one piece of information about the embryo or fetus, that it carries a particular characteristic thought worthy of note by the medical profession. Prenatal testing is a clear case of first impression, and as with any such impression, it is an incomplete impression; when followed by selective abortion or by discarding an otherwise implantable embryo, that first impression includes a decision never to learn about the rest of who that embryo or fetus could become after its birth. Mary Johnson, the longtime editor of a major disability movement publication, writes in a similar vein when she says:

A decision to abort based on the fact that the child is going to have specific individual characteristics such as mental retardation, or in the case of cystic fibrosis, a build-up of mucus in the lungs, says that those characteristics take precedence over living itself, that they are so important and so negative, that they overpower any positive qualities there might be in being alive.  

Writing in 1987, another woman with a disability underscores how incomplete is the information provided by prenatal testing when she says:

I know that amniocentesis can’t tell any parents what kind of child they will have. It can only tell what disability might exist in that child. Amniocentesis could never have told my mother that I would have artistic
talent, a high intellectual capacity, a sharp wit and an outgoing personality. The last thing amniocentesis would tell her is that I could be physically attractive.\footnote{5}

No matter how much we may find the previous self-description immodest, it is the description of someone who feels that she must justify the right of people with her disability to exist because she recognizes that its presence alone makes others ignore everything else about her and could make future parents reject a child they wanted once they learned of this unexpected characteristic through a prenatal test.

Those who object to the "expressivist argument" contend that prospective parents who terminate a pregnancy after a diagnosis of a disability may do so for many reasons that are not overtly prejudiced or hostile to people with disabilities. The prospective mother and her partner may feel that they haven't the financial or emotional resources to "cope" with the "extra" demands that a child with a disability would entail. Or they may already have a child with the same or another disability and feel stretched to their limit and want a child whose needs and demands will not be "special." Or, it is argued, the prospective parent may herself have a disability identical to the one diagnosed and may feel that to transmit that disability is to pass along a harsh and painful part of life to her child. All these claims do not refute the view that this one characteristic of the embryo or fetus is the basis for the decision not to continue the pregnancy or to implant the embryo. That decision still concludes that one piece of information about a potential child suffices to predict whether the experience of raising that child will meet parental expectations. In most cases of preimplantation genetic diagnosis or prenatal diagnosis, the woman or couple desires to be pregnant at this time; the termination of the process only occurs because of something learned about this child.
Why I haven't changed my mind about prenatal diagnosis: Reflections and refinements. In E. Parens and A. Asch (Eds.). Prenatal testing and disability rights. Washington, DC: Georgetown University Press. Parens, E., & Asch, A. (2003). Disability rights critique of prenatal genetic testing: Reflections and recommendations. Mental Retardation and Developmental Disabilities Research Reviews, 9, 40-47. Patterson, A., & Satz, M. (2002). Why I Haven't Changed my Mind About Prenatal Diagnosis: Reflections and Refinements. Prenatal Testing and Disability Rights. Posted: 2000. See Karpin, I. Since it is clear that some account needs to be taken of the role that men must also play in determining who we may call kin, it might have been useful to talk of the not-yet pregnant pregnant couple. However, this route is not taken here because the only certainty at this technological moment is that women will be the ones gestating and developing the fetus. Why I haven’t changed my mind about prenatal diagnosis: reflections and refinements. A Asch. â€™s medical dictionary. Mosby. Preimplantation genetic diagnosis (PGD) for genetic prion disorder due to F1985 mutation in the PRNP gene.Â Importance: To describe the first case of preimplantation genetic diagnosis (PGD) and in vitro fertilization (IVF) performed for the prevention of genetic prion disease in the children of a 27-year-old asymptomatic woman with a family history of Gerstmann-Sträussler-Sheinker syndrome (GSS). Observations: PGD and fertilization cycles resulted in detection of 6 F198S mutation-free embryos. When we received our daughter’s prenatal diagnosis of Down syndrome, we cried. Our minds were clouded by statistics, worry and fear. We didn’t know a damn thing about Down syndrome. What did I know? My baby would be born with delays. That was all I knew. Thatâ€™s pretty limited knowledge for a teacher. My network consisted of those who had children without disabilities. I asked my OB to book us to terminate. I couldn’t do it. I couldn’t possibly be a good mom to a child with Down syndrome.Â Why would I want to end a life? The life that James and I made? She told me to go to that ultrasound appointment. She encouraged me to get to know this unborn baby.Â Change how you deliver the diagnosis. Get educated. Change your words.