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Cultures of Testing Reflections

For the past few weeks, this class has been focusing on philosophical arguments concerning reproductive technologies by looking at *Donum Vitae* and Kahn's *Reproducing Jews*. The topic shifts this week to the impacts of a growing culture of prenatal testing. As a student, I am very interested in genetics as a field and want to go into a professional career where I have the chance to work with these ideas every day, though I acknowledge that there are countless ethical implications, as explored in the pre-work for class.

In the article "Shouldering Moral Responsibility: The Division of Moral Labor among Pregnant Women, Rabbis, and Doctors" by Tsipy Ivry and Elly Teman, the authors explore the moral complexities in the Jewish community, specifically with orthodox Jews. In Judaism, my understanding is that termination of pregnancy is permitted, especially when saving the life of the mother as saving a life takes precedence over everything else. The authors go through how many couples, when faced with distress over a prenatal diagnosis, will go to their rabbi or the Fertility in Light of Halacha (FLOH) group to help with their decision. To me, it seems like the authors describe the role of the rabbi as a judge in some ways—passing his decision onto the couple as an amalgamation of expert opinions from *halacha* and other medical professionals. Moral judgment is essentially decentralized in this system. Rather than have this monumental decision fall on the couple alone, the rabbi takes that responsibility, spreading it out among his

own backup advisors so that no one person is at fault. I find this quite interesting—this idea of responsibility and fault—because no one is guilty of causing a tragedy like the ones described in the article. With genetics, it is easy to blame one's genes or blame the parents for passing on a mutation some would call a defect, but we all have mutations—that is what makes each person unique.

When one of these mutations is lethal or detrimentally affects a newborn's way of life, that is when society has found ways of intervening. In Rayna Rapp's book, *Testing Mothers, Testing the Fetus: the Social Impact on Amniocentesis in America*, she discusses the social, cultural, religious, and ethical implications of prenatal testing technologies, specifically amniocentesis. An amniocentesis takes amniotic fluid from the mother's belly where the fetus is growing to test for genetic, specifically chromosomal, abnormalities. She uses a participant observation method, where Rapp was able to interview and get directly involved in the process by working alongside activists and, in her words, forcing an internship on testing centers. The book discusses how technologies impact disabled communities and explores a connection with eugenics because of the artificial narrowing of the population based on what is defined as "normal." One common theme in the book involves how scientific terminology is increasingly different from common vernacular. This is true of almost all subjects. I have found multiple times in science and humanities that academic resources are incredibly difficult to understand, and the only way to truly comprehend everything, is to continue reading complicated papers you do not get until one day, you suddenly know all the terms. That being said, it seems like Rapp offers a middleman between the two: genetic counselors.

Personally, I work directly with genetic counselors and see this firsthand. The scientific and academic languages are incredibly complex. The average American may not know what a chromosome is or how it is involved in the development of life. In the office, as a volunteer, I get to see all the acronyms and the multitude of possible tests and the varied testing forms for each test. It amazes me how genetic counselors and geneticists keep all of these rare genetic diseases straight as new variants/types of mutations are uncovered for new diseases. To be completely honest, I do not understand half of what I see because I simply do not have the exposure yet to understand the shorthand. On the other side, when I have the opportunity to shadow, I see why Rapp calls genetic counselors “moral pioneers” (Rapp 307). Genetics is incredibly complex, and genetic counselors have found a way to explain it plainly in common speech so patients can understand while removing their bias from the situation so whatever decision is made is from the patient, not the counselor. Yes, there are suggestions from the medical team on what they would do or how they would proceed, but at the end of the day, genetic counselors do their best to equip patients with the knowledge they need to make an informed decision.

The very nature of prenatal testing is complicated, even if we have trained genetic counselors to help us through the process. In the documentary *The Burden of Knowledge*, many women describe their mixed feelings toward testing. To me, the documentary took a very hesitant stance on testing, showing some women who were grateful for the testing and others who expressed very serious doubts and concerns about it. For example, one woman early in the movie talked about how the very existence of these tests incites anxiety and brings out doubts in women that something is wrong with their child. However, very soon after, one man with his wife expressed that he would be offended if they hadn't been offered a prenatal screen. In

acknowledging that the movie was made and produced in the mid-90s, I can understand the hesitance as testing was still very new to medicine. It is still considered new now; however, I am the kind of person who would want to know if something was wrong. There is a great deal of emotional, physical, fiscal, and mental load when you have a child with a severe disability. You have to be able to carry the weight of a child who will likely always be dependent on you and your family while also making enough money to support medical expenses. Of course, this always depends on the severity of the disability and on the parent. There are many disability groups, namely from the deaf community and from those with Down Syndrome, who advocate for carrying the baby to term—that these characteristics are not disabilities and are not inherently negative. But, in truth, those decisions remain with the parents and what they can handle as people.

In summary, the issue of prenatal testing and screening is an incredibly complex one. It does not have a simple solution because there are multiple ways to approach it. In fact, I hesitate to call it an “issue,” because that implies that a solution can be found somewhere in the multitude of approaches that exist. Development is complicated, and I remember a professor of mine saying that, because of its complexity, human gestation is incredibly difficult to complete compared to other animals. For some, prenatal testing offers a sense of security in knowing what was once unknown, but for others, it poses a huge problem that needs fixing. It is a complicated ethical issue that cannot be solved in these few short pages of summary, but I implore you to think about it: is knowledge really better or does it just cause complications?