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Author(s): Rayna Rapp
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Refusing Prenatal Diagnosis: The Meanings of Bioscience in a Multicultural World

Rayna Rapp
New School for Social Research

This article explores the reasons women of diverse class, racial ethnic, national, and religious backgrounds give for their decisions not to accept an amniocentesis or, having accepted one, not to pursue an abortion after diagnosis of serious fetal disability. The narratives of refusers reveal conflicts and tensions between the universalizing rationality of biomedical interventions into pregnancy and the wider heterogeneous social framework to which women respond in their decision-making processes.

This article presents an anthropological analysis of prenatal diagnosis, a cluster of technologies used for assessing the chromosomal and genetic normalcy of fetuses in utero. An ever-expanding list of these technologies includes ultrasound imaging, amniocentesis, chorionic villus sampling, percutaneous-umbilical chord sampling, and other evolving experimental interventions, all backed up by abortion technology, for those who receive bad news about the health of their fetuses and choose to end specific pregnancies.

AUTHOR'S NOTE: The research on which this article builds was conducted in New York City over the course of the decade 1984-1993. At various times, my research has been funded by the National Science Foundation, the National Endowment for the Humanities, the Rockefeller Foundation’s Changing Gender Roles Program, the Institute for Advanced Study, the Spencer Foundation, and a sabbatical leave from the New School for Social Research. I thank them all for their support and absolve them from any responsibility for what I have made of it. Above all, I thank the hundreds of pregnant women, mothers of young children, and their supporters, as well as the medical service providers, who believed in the importance of this work and participated in it. All names have been changed for reasons of confidentiality. A first draft of this article benefited from the insightful comments of Faye Ginsburg, to whom I owe my usual debt of gratitude for her extraordinary generosity as a friend and colleague. Three anonymous reviewers and Linda Layne, guest editor for this issue of Science, Technology, & Human Values, also provided comments that were very valuable in the revision of this article.
As an anthropologist committed to studying the social impact and cultural meaning of prenatal diagnosis, I have benefited greatly from scholarship in the history and sociology of science and technology, learning about developments in medical genetics, cytogenetics, and biomedical visualization technologies that have made the routinization of these interventions into pregnancy possible (e.g., Cowan 1992, 1994; Judson 1992; Yoxen 1990). But as a fieldworking ethnographer, I am committed to breaching the boundaries often set up in those fields. My training orients me toward tracking what happens not only inside but also outside of laboratories and hospitals, as the technologies of prenatal diagnosis make themselves felt among their downstream users, audiences, or consumers: those whom Adele Clarke and Theresa Montini (1993) recently labeled “invisible and implicated actors.” Like many others who work in science and technology studies, I long ago lost any belief in the potency of the inside/outside boundaries described by the science-speaking natives of the domains I study. Although my research includes time spent in laboratories and observing genetic service providers, I am particularly interested in finding multiple ways to query how women of diverse racial-ethnic, national, class, and religious backgrounds experience the offer of genetic testing in their pregnancies, what they do and do not want from technology, how they understand childhood disabilities, what a fetus is, and what might be worth an abortion. This new biomedical technology provides a context in which every pregnant woman is interpolated into the role of moral philosopher: one cannot confront the issue of the “quality control” of fetuses without wondering whose standards for entry into the human community will prevail and what the limits of voluntary parenthood might be.

In 1983, when I began to investigate the social impact and cultural meaning of amniocentesis (and related prenatal diagnostic technologies), the voices of experts in medicine, bioethics, health planning, and law dominated the published literature. These experts were mostly male, overwhelmingly white, and highly professional. As a feminist researcher and health activist, and as a woman trying to understand the complex consequences of having used amniocentesis in my own pregnancies, I thought I could help to wrest the discourse on new reproductive technologies from the hands of medical experts, turning it over to the women who used, might use, or might refuse to use them. My first pilot interviews were conducted with pregnant women who had received what is so antiseptically described in medicine as a “positive diagnosis”—that is, the news that something was seriously wrong with their fetuses, forcing them to make a decision to end or continue the
pregnancy. In those interviews, I was struck by the difficulties women had in working in a communicative system whose vocabulary was almost exclusively medical, whose grammar was technological, and whose syntax was as-yet unnegotiated. Trying to discover a method to study one reproductive technology, I attempted to identify and query as many constituencies with interests in amniocentesis as I could imagine. As an anthropologist, I was committed to using participant observation to learn my way around this problem. It is, of course, a messy methodology because it encourages its practitioners to expand their work as far into a research topic as their own subjectivity and scholarly resources allow.

I began in the cytogenetics lab run by the Health Department of New York City, learning how diagnoses are constructed—laboratory life, to borrow a famous and felicitous phrase. I learned to spin samples, turn test tubes, and cut karyotypes. I also followed the lab’s counselors through their peripatetic rounds at many hospitals in the city, dividing my time among “city” hospitals that serve the working poor; “middle” hospitals with robust mixes of working class and middle class patients; and “elite” facilities with wealthy clientele. I observed hundreds of intake interviews in which they explained prenatal testing to women of diverse race, class, ethnic, national, and religious backgrounds in all three hospital types. I interviewed scores of women who had had the test or who had refused it. And I hung out in a support group for parents whose children have Down syndrome, the most common condition picked up by the test, as well as in an early intervention program in which infants and toddlers with other chromosomal and genetically caused disabilities were enrolled. I also became fascinated with genetics as a field that provides powerful and proliferating discourses on the state of being human. I spoke with geneticists and genetic counselors about how they saw the implications of their practical work. And I started to worry about the multiple intersections of popular media representations of all the related issues (genetics, prenatal testing, abortion, childhood disability, and disability rights) on which my study touched.

In constructing a kind of Venn diagram of these intersecting layers, it is evident that pregnancy and the modern technologies that intervene to regulate it are not vested simply within the world of biomedicine and reproductive technology. (Indeed, when I went to interview women and their supporters about a new pregnancy technology, we often ended up spending much of our time discussing religion, but that is another chapter). Pregnancy and its technologies both occupy multiple and convergent spaces in the social life of individual women and their supporters; in the lives of diverse medical,
educational, religious, and activist constituencies; in modern globally proliferating media technologies; and, of course, in the politics of representation.

Like historians, anthropologists are obsessed with following all the scraps and edges of their problems, often preferring to view a central issue from multiple and oblique angles. Here, I take the women who refuse to use amniocentesis as a pivot around which to view a cascade of problems concerning the impact of a new scientific technology. Just as a film negative can be used to print a positive image, so, too, the negative assessments of those who reject this technology can be used to reveal its positive, productive powers and to uncover how pregnant women and their supports contextualize the choices they must make.

Like many other feminist analysts of science and technology, I do not assume the unproblematic sovereignty of methodological individualism or that science in action begins or ends with the actions of scientists (e.g., MacNeil 1987; Morgall 1993; Wajcman 1991). Rather, consumers (or, in this case, nonconsumers) of a biomedical technology can be seen as experts capable of analyzing its burdens and benefits and casting a rather different light on contests for meaning and rationality. By working through the narratives of pregnant women who opt not to use a technology increasingly described as “safe” and “rational” throughout the world of prenatal care in the contemporary United States, I hope to show what insights may be gained when a highly diverse group of women is taken as knowledgeable commentators on the social dimensions of science.

**The Complex Terrain of Technological Refusal**

I wanted to take the test, but then he said no. At the hospital, I was all gung-ho, but on the way home, he expressed his feelings. That whole night, he expressed his feelings. We went back and forth. The next day, I called up so many people. I have this religious aunt. She’s the one that made me see—Down syndrome, no need to take the test for Down syndrome. It’s not necessary. Everything my husband said, she said, too. So I went, “OK, I won’t take it.” And I didn’t take it. (Catherine Judd, age thirty-six, African American legal secretary)

When I first met Catherine Judd and her husband at a counseling session at a middle hospital, I was sure from her reactions and questions that she intended to use the test. But a few weeks later, when I called to see how she was feeling after an amniocentesis and to schedule an interview appointment, she told me that she had changed her mind. We met for lunch that week, and tape recorder in hand, I learned that Catherine’s decision not to use amniocentesis was made in the context of opposition from her close kin. At first,
her choice appeared entirely personal, mediated by the strength of her kinship community. But later in the same interview, she also said,

My husband didn’t say much there [at the hospital], but he sure read those forms carefully. He didn’t much like the parts about experimentation.

At first, I intervened to say,

You mean the consent form for the laboratory? What they mean by experimentation doesn’t have anything to do with you or your husband or your baby’s body. It’s about using the leftover amniotic fluid to check for other chromosome patterns, to compare it with other fluid, instead of just looking at it for a diagnosis for you. That’s the way they find out about general patterns, by comparing lots of leftover fluid. . . . And you can say “no” to the experimental use and still have the test for your own use, if you want that.

As we talked, I realized the narrow, science-focused preoccupations of my own interpretation. Her husband was expressing strong feelings about experiments in a much wider context: his perception of the role of Black people and medicine. And Catherine herself went on to say,

Because I read something . . . I don’t remember what magazine I read it out of, but I remember reading that the reason why we have AIDS was to kill off the Blacks and the gays. . . . I don’t know how true it is, but supposedly over in Africa what they did was they shot the children. They shot something into the immunization shots, into the people over in Africa, and that’s how it started.

The Green Monkey experimental theory of AIDS in Africa purports to explain how a malevolent experiment ran amuck and spread a killer disease first throughout that continent and then to the New World. In the late 1980s and early 1990s, it was much discussed in certain Black-focused tabloids and talk shows. While scientists have denounced such theories as “disinformation” or even as “paranoia,” their staying power needs to be evaluated in light of a long history of indifferent, or even menacing, experimental medical interventions for which Black communities have historically served as guinea pigs: the infamous Tuskegee syphilis experiment and the chaotic conditions attending early sickle-cell anemia carrier trait screening have both been widely reported in Black-focused media. African American consciousness of biomedical experimentation may thus be filtered through realistic if incompletely remembered, and, sometimes, media-orchestrated, views of prior medical interventions. It is not then so surprising that Catherine’s husband read the informed consent form for laboratory work on the amniotic fluid sample with a cynical eye. Might we interpret this suspicion as a response to
a structural position that Black communities have historically occupied vis-à-vis medical experimentation in the United States?

Catherine Judd's change of heart thus raises an important theoretical issue for me: it was both the product of individual choice contextualized by kin and community pressure and a response to racially differentiated histories and sentiments concerning medical intervention and experimentation. Indeed, the imbrication of social history and individual volition, collective position and personal choice—or the intertwined and negotiated workings of structure and agency—continually perplexed me as I attempted to find out how people came to accept or to refuse prenatal testing.

Although amniocentesis has rapidly diffused and become part of routine prenatal care for some sectors of the population, some choose not to accept its complicated benefits and burdens. Their narratives may enable us to understand why a routinizing technology does not always stay en route. Are some groups more likely to opt against the technology than others? Do some reject it categorically, while others accept only some of the assumptions, values, and practices embedded in the technology? A woman may step off the conveyor belt of a routinizing technology at many points in its trajectory; but not all exits are used equally, nor are those who exit at specific points a random group. These patterns provoked my interest in refusers. Initially, I wondered if refusers were "resisters"—that is, people who consciously opposed routinization. Or was their refusal based on a lack of access to information and discomfort with biomedical discourse, thus also reproducing prior hierarchies between patients and providers? But my search for resistance and reproduction was, of course, too simple: the reasons for refusing to use amniocentesis are diverse and complex.

In prior articles, I have argued that the communicative practices on the basis of which women accept prenatal testing are themselves highly structured: comfort with the etiquette, protocol, and procedures of biomedicine surely varies with educational and occupational location (Rapp 1988, 1993, 1994, 1995, forthcoming). At counseling sessions, women give a variety of reasons for their decisions not to use amniocentesis. These include fear of miscarriage, disbelief in the accuracy of statistics and testing, discomfort with unbalancing the imagined forces sustaining a pregnancy, and religious beliefs. A refusal may also be based on a report of male opposition, a subject to which I return below. Yet, each individual refusal exhibits a complex interplay between personal intention and social forces; after all, male dominance or scientific literacy or religious observance or prior reproductive history all express both individual and social characteristics. Moreover, the timing of an acceptance or a refusal may be structural as well.
The Influence of Class Background and Ethnicity on Refusal

Among the structural reasons for rejecting prenatal testing, class-associated differences loom large. It is an axiom of genetic counseling that middle-class patients (disproportionately White) usually accept the test, while poorer women (disproportionately from ethnic-racial minorities) are more likely to refuse it. But that generalization needs interrogation. Private patients (that is, middle-class ones) usually do not come for genetic counseling (to learn about amniocentesis) unless they are already determined to have the test. They are likely to have prior knowledge about it gleaned from books, friends, and private physicians, whom they inform about their disinterest or opposition to the test. They never schedule an appointment with a genetic counselor; thus, refusers in this class rarely get counted.

This was surely true for a well-known economist with whom I spoke who opted against prenatal diagnosis when pregnant for a third time in her late thirties. She felt entirely confident about refusing amniocentesis based on her own reading of health statistics. In perusing the medical literature, she discovered that cytogenetic tests in midtrimester amniotic samples produced a detection rate for Down syndrome fetuses that was 25 percent higher than the live-born rate for children with the same condition. Reasoning that the test was inaccurate, she opted out. What her reading failed to disclose was, however, the reason for the differences of rates given within biomedicine: fetuses with atypical chromosomes remain highly vulnerable to miscarriage throughout the pregnancy and stillbirth and death in the neonatal period. The difference is not one of laboratory error but reflects life-threatening physiological circumstances. Likewise, an educational consultant who had suffered through several years of infertility before her first successful pregnancy at age thirty-four rejected amniocentesis during her second pregnancy, at age thirty-seven. She was more frightened of the miscarriage rate than she was of the rate of detection of fetal chromosome problems. It should be stressed that both these cases involve scientifically confident middle-class women who felt empowered to make a decision against the grain of their immediate peer group to forego amniocentesis, while situating themselves comfortably within statistical, scientific thinking.

Some middle-class women and their partners also reject the test on the basis of philosophical, ethical, or religious reasoning. For example, a nurse married to an epidemiologist in the New York City Health Department decided against amniocentesis after she and her husband had investigated the potential adoption of a "special needs" (disabled) child. When the couple could not conceive after the birth of their first child, their Protestant church
had directed them toward an agency that specialized in hard-to-adopt children. By the time a second, successful pregnancy was established, they felt quite open to the possibility of raising a child with a disability and decided not to use prenatal testing. Another male physician whom I met through the health department wistfully described himself as a virtual conscript to my study: his wife, raised a devout Catholic, would not consider amniocentesis, despite his own professional interests in the test. But these stories—which mirror class-refracted versions of concerns also offered by clinic patients who reject amniocentesis—came to me through personal networks of friendship and work; they were never entered into the medical ledger, for the rejections occurred in the context of private medicine.

Among clinic patients, an appointment with the genetic counselor may be the first opportunity they have to ponder the significance, risks, and benefits of prenatal testing. All hospitals keep registers of pregnant women's appointments and their outcomes; in some hospitals, those who refuse amniocentesis are also asked to sign an "informed consent" document attesting to their decision. These patients make up their minds in a context in which their choices become part of hospital statistics.

Moreover, many women from working-class and working-poor backgrounds, including African American and Hispanic women, do accept the test. Their rates of acceptance and refusal as recorded in hospital records vary dramatically from facility to facility. At one clinic that serves primarily a Spanish-speaking low-income population, for example, acceptance rates are high: 70 to 80 percent. At another clinic with an Afro-Caribbean and Spanish-speaking population, acceptance rates are low: 30 to 40 percent (Hsu 1989). We could go fishing for a cultural explanation about pregnancy beliefs, medical attitudes, and so forth. But the explanation might be simpler: the first prenatal clinic is a stable and welcoming environment in which women tend to feel comfortable and to trust the nurses. It has a lower rate of nurse turnover than many other hospitals. Clinic patients, therefore, have the opportunity to develop an ongoing relationship with a health care provider whom they are likely to see through the course of one or more pregnancies. By the time they arrive for an appointment with a genetic counselor, pregnant women have usually talked with a favorite nurse, often in Spanish, and feel competent to accept or reject the test.

The prenatal clinic with a low rate of acceptance, by contrast, has been a site of struggle over services for many years, and it is a difficult environment in which to receive health care. Women (and often their young children) feel imprisoned in uncomfortable waiting rooms where they routinely spend two to three hours before being seen. By that time, the level of anger and frustration, as well as the lack of professional-patient communication, makes
it much more likely that a woman will break a counseling appointment or sit through it in a state of distrust. Far more than simply “ethnic differences” are at stake here. Rather, acceptance rates are conditioned by the microsociology of access to respectful medical services. The ecology of prenatal clinics depends on the stability of residential neighborhoods; on city, state, and federal health care funding and politics; on hospital labor contract negotiations; and on issues of community control.

More complicated to evaluate structurally are the cases of women who arrive too late in their pregnancies to be offered the test. In some city hospitals, a woman’s tardy entry into the prenatal care system is based on her prior experiences with pregnancy. Experienced mothers from some pronomalist, highly fertile ethnic communities do not seek much prenatal medical care. Hasidic women, for example, often do not register for maternity beds until the sixth month of their pregnancies, knowing full well that this is a hospital requirement. Prior to that point, many feel entirely competent to monitor their own progress, contacting doctors or nurses only if the present pregnancy feels different from their many prior ones. They are thus unlikely to visit a prenatal clinic in time to be offered an amniocentesis. Moreover, genetic screening in their communities is somewhat demedicalized and linked to marriage arrangements, rather than to prenatal care. Among Hasids and traditional Orthodox Jews, a grassroots genetic screening program for those diseases that run at elevated rates in Ashkenazi-derived communities (initially, Tay-Sachs disease; now, increasingly, other conditions like Gaucher’s disease for which prenatal screens have become available) works directly in the community, screening potential spouses before they meet one another, rather than relying on the screening of already-established pregnancies. Marriages among those deemed “incompatible” by the screening program are then avoided as families plan for their adolescents’ futures. So members of the Hasidic community are thus not likely to use the same entry point to genetic screening, nor to include it in prenatal care, except under emergency conditions.

But in a city where more than 20,000 women give birth annually without ever having received any prenatal care at all, there are other problems endemic to the health care system that condition the likelihood that a woman will enter too late to be offered an amniocentesis. Non-English speakers, especially if they are recent immigrants, may not know their entitlements: Medicaid will cover prenatal care, including prenatal diagnosis, but the paperwork necessary to get into the system is intimidating. A crowded, busy clinic may discourage women attempting to make an appointment, even though in principle, obstetrics nurses are prepared to help anyone identified as of “advanced maternal age” or as having had a serious problem in a
previous pregnancy to jump the cue and receive prompt attention. But unless they have the confidence and ability to speak with the intake nurses, such women may well be dismayed by long waits for service and complex paperwork.

In some city hospital clinics serving the working poor, up to one third of all the genetic counseling interviews I observed involved women who had arrived at the end of their second trimester of pregnancy, too late for prenatal testing. Some were quite willing to sit through the counseling sessions to learn about chromosomes, birth defects, and amniocentesis “for the next pregnancy” or to “spread the word” to friends and kin. Others were disconsolate to discover that they could no longer have what they considered to be an important test of which they had no previous knowledge. Observing low-income women frequently entering prenatal care too late for amniocentesis made me wonder in each case if the woman would have used or rejected the test. My problem is moot: despite the best efforts of many individual health care providers, the health care system had already structurally rejected her through its inability to make prenatal clinics adequately accessible.

In addition to late entry into the prenatal health care system, there are other ways to exit the conveyor belt of amniocentesis. Some women, especially in city hospitals, refused the test indirectly, by missing one or more counseling appointments. “No shows” are a highly variable lot: among private patients, the rate of those referred for counseling who do not keep their appointments is low, under 10 percent. But their numbers run toward one-third of all clinic patients referred for counseling in some city hospitals; in others, good communication between nurses and patients means that a pregnant woman can refuse the test directly and no appointment will be made for her, in respect of her wishes. Episodically, I would attempt to follow up no shows with a phone call. The reasons women gave for missing appointments were diverse. Sometimes, they would explain that the stresses of daily life—cancellation of baby-sitters, broken plumbing, bad weather, and lack of an adequate coat—had kept them from an appointment. Sometimes, a woman had had a miscarriage before she was scheduled for counseling. But often, fear of the test was reason enough to skip an appointment and to avoid talking about it.

**Doubts, Fears, and Communities of Origin**

Most refusals, however, happen during or directly after a counseling session. In such cases, I was able to observe women making a decision based on the information at hand, to which they responded with the resources of their personal and cultural background. The most common reason that
women from many social sectors and cultural traditions gave for refusing amniocentesis was fear of miscarriage. For them, any risk of causing the loss of the pregnancy, no matter how small, was unacceptable. While concern about miscarriage rates was the single most common issue raised in counseling, this fear was especially prevalent among women who had suffered prior miscarriages or bouts of infertility.

Reproductive history entered strongly into most, perhaps all, of women's decision making. This is undoubtedly as true for women who accepted the test as for those who rejected it. Moreover, reproductive history was strongly intertwined with sources of knowledge that might be medical or more broadly social. For example, one mother of a child with Down syndrome refused amniocentesis in a subsequent pregnancy because she had learned too much: "Down's is only the tip of the iceberg," she told me. "There's hundreds of birth defects; this test can only pick up a few. What's the point in getting false assurances?" Her fear of "lightning striking twice" could not be allayed by the incomplete information testing offered. Another mother whose second child had died of hydrocephalus wanted no part of testing: "Doesn't matter. I can't go home empty-handed again!" she exclaimed. As all genetic counselors know, individual reproductive history figures large in the decisions women and their supporters make about using or refusing testing.

And reproductive histories are not simply individual; they are woven into family and community life. For example, Mercy Aguilar, an advertising executive, was sent for genetic counseling because of prior miscarriages and because, at age thirty-four, she was "borderline A.M.A." as well. Mercy had also been exposed to medical uterine radiation in the early weeks of this pregnancy, before she realized she was pregnant. She entered group counseling with a bias against amniocentesis: as a member of a large, close-knit, and practicing Catholic Filipina family, she had participated in raising a brother with Down syndrome.

We are eight in my family, and we all know the joy he [the brother with Down syndrome] brought to us. When my mother gave birth to him, she blamed herself, but gradually, we learned you don't cause this. It's just part of nature. Now, my mother is only concerned with the danger to me of all this testing. She isn't concerned if I have a normal child. Of course, we all want a normal child. But if the child is retarded, well, my whole family will be behind me. They will help me; it's different than for most people in America.

Mercy went on to speak eloquently about the solidarity of large families, even when separated by migration. She also said that the prior miscarriages had made her even more determined to carry the present pregnancy to term. And
she added, almost as an afterthought, a liberal response when I asked about her Catholic background:

I would never have an abortion. It’s OK for people who believe in it, but I don’t believe. My husband agrees: we want this child, we don’t want to endanger it. If there is something wrong, we accept that.

Here, reproductive history is family history as well: the stability of a large family that raised a disabled child successfully and familial and religious acceptance of Down syndrome all condition the meanings of prior miscarriages and form a context within which a decision not to use prenatal testing was made.

Sometimes, reproductive history refers back to a community or culture from which immigrants have come, encompassing a fund of social information that is at odds with medical practices in their new host country. Katya Janos, a Hungarian painter, refused amniocentesis at age thirty-four, insisting with confidence that her family had no genetic problems and that testing was not offered before the age of forty in her native country. If she would not do it there, then why do it here, she reasoned. Wilhemina Jordan, age forty, told me she briefly considered having an amniocentesis when we met at a city hospital. But nothing in her Liberian background supported the test:

My sister, she hollered at me, "We never did this back home," and she got a healthy boy when she was thirty-six. She hollered and she hollered and she hollered. She made me remember about her births and our family’s births. Here, everything is different: the babies get born here in the early morning. I never heard of such a birth at home. Perhaps they need the testing here, but not there. [At the hospital] they want me to come back to discuss it. I know they mean to help me, but I was brought up one way, and not another. I’m afraid of complications. I’ve been through a lot of pain to have my children; that is how we do it at home. I never did this; we never did this. What do I need this for now?

Other immigrants say,

I don’t want to know about the future. That’s not how we think in my country.
(Rose Clarion, age thirty-nine, Haitian garment worker)

Miscommunication between science speakers and the multiple Englishes of clinical life is always a possibility. When I interviewed Marcya Milton, a Jamaican home health attendant, age forty-four, after she refused prenatal testing at a city hospital, she spoke eloquently at length about her belief that
a female deity had given her a healthy baby girl the year before and would protect her present pregnancy. As we were about to part, she added, almost as an afterthought,

Milton: Oh, and another thing. Now, before you go, there's one thing I really must tell you. When I went to counseling last year, it was a nice lady that counseled me, and the figure was one-half. On the desk, she wrote that figure. It's a 50-50 chance the test will harm my baby.

Rapp: She must have misunderstood your question: it's less than a *point* 50 percent chance of causing a miscarriage: 50-50 is a very big number, and I'm sure she intended a very small one.

Milton: I didn't ask any questions. I just sat and listened, and then I discussed it with my husband, and what with the chances so high, well, we were against it. Now, this time, she said that the chances of having a baby that's retarded was 900. Do you know what I mean when I say 900?

Rapp: Do you mean 1 in 900? At 45, the counselors usually say the risk of having a baby with a chromosome problem is 1 in 19.

Milton: Yes, it was only 900, so you know what I mean now. We couldn't take a 50-50 chance of harming that baby.

This refusal of testing intertwines a doubled discourse: at the beginning of our conversation, Marcya expressed a strong personal faith as the reason for her confidence in a healthy outcome; this was experientially the most significant reason she gave for choosing not to have the test. But at the end of our conversation, she also revealed a profound misunderstanding of both miscarriage rates and the risk of carrying a chromosomally atypical fetus. The numbers given were not the numbers received; this problem haunts medical decisions based on statistical thinking, especially when multiple and intersecting probabilities are being explained to someone without a privileged scientific education.

Many women without a high degree of scientific literacy have developed a practical sense of community epidemiology. Enfolding their own reproductive health into that of kin and friends, they say,

I don’t smoke, I don’t drink, I don’t do drugs. My mother had my sister when she was forty. My sisters, they all had late babies, healthy babies. My friends, they’re all fine. I’m healthy. I don’t need this test. (Veronica Landry, age thirty-six, Trinidad-born factory worker)

A geneticist at a city hospital replied,

It doesn’t depend on how you feel, on how you live. The only way to know for sure if your fetus has these problems is to have the test.
But Veronica had made up her mind, and she had the last word: “I like surprises,” she said.

Sometimes, pregnant women and their partners refuse amniocentesis because the test cannot pick up the problems about which they are concerned and because they do not find the conditions it can detect sufficiently disturbing to merit testing. Women frequently sought counseling because of exposure to pharmaceuticals, street drugs, or other potentially toxic substances early in pregnancy only to learn that damage caused by such agents would not show up in amniocentesis. The discourse of genetic counseling speaks of added and diminished risks, offering a test “for reassurance,” which did not cover the conditions about which they were concerned. They opted against it, since it could not allay their anxieties.

Some people also express a disbelief in the accuracy of testing. Those without privileged educational backgrounds are most likely to utter statements like “I don’t believe they can really know all that stuff” or “Isn’t that just baby’s pee they’re lookin’ at?” or “No wonder they say it’s ‘99 percent accurate.’ That’s for when they make their mistakes. Then you can’t hold them to it.” But occasionally, highly educated professionals express similar skepticism or misgivings. A close social science colleague who was attempting to get pregnant once told me she did not believe in chromosomes: she thought that modern genetics had taken a wrong tack and was insufficiently focused on the interaction of environment and organism. While sympathetic toward her abstract philosophical position, I pushed hard to find out what she thought chromosomes might be (or not be):

That squiggly stuff in the microscope? It’s cellular material, I’m sure, but I don’t believe it does half of what they think it does. I wouldn’t trust what they say is in it all that much.

Misunderstandings or disbeliefs concerning scientific discourse and findings account for some decisions to forego testing, especially, but not exclusively, among women without advanced scientific education. But the incorrect “numbers crunching” of the White professional economist mentioned earlier should remind us that this interpretive tendency is not exclusive to those who come from working-class and working-poor backgrounds.

Religion, Personal Responsibility, and “Choice”

And not all rejection of amniocentesis comes from skepticism about scientifically based information. Religious beliefs provide another set of
powerful resources from which a refusal may be drawn. Some women, like Marcya Milton, hold a personal or denominational faith in the health of their fetuses. Others, like Mercy Aguilar, meld religion and family history into their acceptance of Down syndrome as a possibility with which they could comfortably live. And some use religion as a way to make a clear, if difficult, decision. Pat Carlson, for example, was raised as a Mormon in the South West. Living in New York and working as the head of a secretarial department in one of the city's largest and most high powered law firms, she had not attended temple in decades. At age thirty-seven, with one grown child and one divorce behind her, Pat found herself pregnant after a casual liaison. She was extremely pleased, despite the complex conditions involved in undertaking late, single motherhood. She accepted an amniocentesis at the suggestion of her obstetrician without much concern. But when her fetus was diagnosed as having Down syndrome, she was shocked. At that point, Pat beat a beeline to her Mormon roots:

Maybe if I was married, maybe if I had another shot at it. But this was it: take it or leave it. So I took it. I called the Mormons back. Oh, I hadn't been to temple for years. But I knew in my heart of hearts they'd convince me not to have an abortion. And they did. One man, he just came and prayed with me; he still comes. Stevie [her son with Down syndrome] gets a lot of colds; I can't always make it to temple. But when we don't make it, he comes over and prays with us.

In this case, the Mormons have consistently provided personally tailored shut-in prayer service and tremendous social support for a woman who left their fold to swim against the current but returned when she needed their help. Religious beliefs and practices and the concrete social resources churches provide are thus central to many pregnant women's orientation. And while many denominations, in principle, accept genetic testing and even abortion, others are vociferously opposed. In either case, the women with whom I have spoken rarely "toed the line" of any particular church; they were much more likely to describe the complex accommodations through which they tested and negotiated their faith. Religious orientation is a complex matter when viewed from a pregnant woman's point of view: she is both the producer of a child and guardian of its future moral education and a bearer of a religious tradition that wields cosmological power over her own actions and intentions. The liminality of pregnancy sets these multiple and intersecting responsibilities into high relief. In their conversations with me, women did not so much reflect theological or doctrinal positions as exhibit the working out of an experiential trajectory through which profound existential dilemmas could best be understood and internalized. This is no less true for the mainline
Protestant medical professionals who decided not to use amniocentesis after exploring the possibility of adopting a special needs child with the help of their church than it is for the factory-working Adventist clinic patients who thought that they would be rewarded for their faith and clean living with healthy pregnancies.

**Ambivalence**

Sometimes, a woman who initially signs on for an amniocentesis changes her mind in the period between genetic counseling and the appointment for the tap. Many factors may influence a change of heart, as Catherine Judd’s dilemma, which opens this article, makes clear. In the “first yes, then no” stories that I collected, two processes stand out with particular clarity. One has to do with the lateness of the test; the other, with the role of men. Both strongly influence the ambivalence that women exhibit when they refuse prenatal testing after first accepting the idea of the test.

Because amniocentesis is conventionally offered between the sixteenth and twentieth week of gestation, it comes at a time in which a commitment to a pregnancy has already been made. As feminist sociologist Barbara Katz Rothman (1986) pointed out with both anger and poignancy a decade ago, the timing of this test forces women into a “tentative pregnancy.” Technologies for earlier intervention are under continuous development and testing, but that is another chapter of the story I am telling. They are not yet widely and safely available, nor are they likely to become so in the near future. For some women, the tardiness of the test looms larger and larger as they confront their scheduled appointments:

I signed the forms, and then I said to myself, “Let me think about it.” I decided not to have it. I didn’t want to know now, no way; it’s too late. In the beginning, I almost had an abortion, but then I decided to keep it. Once I decided, that’s it. If anything’s wrong, it makes no difference now. I’m not going through no abortion at this stage. I just have to deal with it, whatever happens. I discussed it with my fiancé. He said it was up to me, but I don’t want no abortion this late. The lady showed it to me [on sonogram]. I seen it; it’s really a baby there. It’s hard to know what will happen, but I’m not having no test, not now. If it had been earlier, well, yes, especially when I was making up my mind [to keep or end the pregnancy]. But not now; it’s too late. (Charlene Gray, age thirty-eight, African American bookkeeper)

A second reason for converting a “yes” into a “no” is also structural but is not connected directly to the technology itself. I have come to think of this reason as “The Man Question.” It was particularly difficult to interview men
directly about their responses to the offer of an amniocentesis for their pregnant mates during my fieldwork. I was able to complete only fifteen home interviews with men and learned much of what I know about their responses as filtered through the interpretations of the women who were their partners. But I came to believe that men strongly influenced women’s choices, despite their often-apparent absence from the parts of the process that were visible to me. They did so in many ways, in part according to the gendered roles appropriate to their class and cultural backgrounds: by forbidding the use of the test or pushing it; by picturing pregnancy as an exclusively female realm in which they had no decision-making interests; and, sometimes, by “boundary-keeping” conversations between their partners, health care providers, and nosy anthropologists. In these gendered scripts, confrontation, manipulation, and resistance might flow in either direction. What was revealed was not so much a single pattern of male dominance and female subordination, or male insistence on female difference, but the disruption of not-quite-conscious gendered assumptions that the offer of a new, morally fraught technology brought to the surface. Nonetheless, it was striking to me how often women said, “My husband won’t let me” in response to the query “Why did you decide not to have this test?”

Lucile Edwards offered one classic version of this narrative, a few weeks after our meeting at a city hospital at a genetic counseling group. Although she said she was initially very interested in having an amniocentesis, she had eventually decided against it and went on to elaborate:

I was thinkin’ of doin’ it as my husband has diabetes in his family, and what with genetic problems, you never know. But then, he don’t approve.... I don’t quite know why. When they explained it at the hospital, it was so interesting to me.... But he insist. My husband, he has seen people older than us havin’ kids and nothin’ happen. I explain to him, most of the times, it’s all right, it all works out. But then sometimes, just sometimes, it don’t. In England, I know this lady, she had twins: one came out fine, the other came out a mongol. Because of her age. I don’t know what I’d do, how I’d raise it. But my husband, he don’t believe in it; no abortions—he don’t believe in that, either.... I have a friend, she asks me, “What do you think about all this, about your husband and you?” I say, “My ideas are not similar to his ideas. But we have to live together, to raise our children.” We’ve got three kids. It’s time to plan for their futures, to sacrifice for their futures. I need to get back to work, not havin’ any more babies, and certainly, no sick babies. But he won’t permit it. (Lucile Edwards, age thirty-seven, Afro-Caribbean cook)

Contained in this story is a personal history of male privileged decision making and female peacekeeping across gendered values. Likewise, Catherine Judd, whose story opens this article, was persuaded, but not commanded, to
forego an amniocentesis by her husband’s racial-historical and religious concerns. These cases, and many others, suggest that women’s refusal is deeply responsive to their partners’ opinions.

Thus ambivalence about the test—whether due to its looming lateness or to objections raised by partners—may be manifest in a change of heart. When a pregnant woman finds herself caught between a desire for scientific knowledge and control and attentiveness to timetables and agendas of intimate bonds with a growing fetus or a partner, she may choose against the technological option. In these cases, social and psychological rhythms come to dominate over the powerful technoscientific choreography mandated by prenatal testing.

**Against the Technological Grain**

I have argued that the imbrication of class and ethnic backgrounds, religious influences, and intra- and interpersonal agendas all organize the possibilities that women evaluate as they decide to use or not to use amniocentesis. Those who refuse the test, no less than those who accept it, are, therefore, responding to a complex, highly structured social nexus within which they negotiate and exercise personal choice. The structure of choices of another group of refusers also bears analysis: some women accept an amniocentesis and, learning of “bad” or “positive” results, decide to continue their pregnancies. It is to the decision-making processes of such women who employ the technology but do not pursue the consequences for which it was initially developed that I now turn.

But first, two caveats are in order: no records are kept either federally or by state on the outcomes of amniocentesis. According to epidemiologists, biostatisticians, and genetic counselors with whom I have spoken, the decision to keep a pregnancy after receiving the diagnosis of a serious condition is relatively rare. But it is not really possible to evaluate precisely how rare (Drugan et al. 1990; Meaney, Riggle, and Cunningham 1993; Palmer et al. 1993). A second and related point is this: the decision rests in large measure on the diagnosed condition. Most people hold firm opinions about Down syndrome long before they encounter amniocentesis; they thus feel entirely competent to make a decision to continue or end a pregnancy in which this condition has been diagnosed. When Down syndrome is diagnosed, abortion rates run high—90 to 95 percent. But most of the other conditions for which the test can provide diagnoses—other chromosome problems ranging from the severe and deadly, like trisomy 13, to the ambiguous, like the sex chromosome anomalies, Turner’s or Klinefelter’s syndromes—are usually
unknown before a pregnant woman and her supporters receive the news that their fetus "has something seriously wrong." Response to disability news, couched at first in entirely biomedical discourse, is thus a complicated affair, engaging a lot of hard work toward understanding and evaluation on the part of both genetic counselors and their pregnant patients.

Pat Carlson, who returned to her Mormon roots when she wanted to keep a pregnancy after a positive diagnosis of Down syndrome, is unusual. But she was not exceptional in the way in which both prior reproductive history and religious resources entered into her decision-making process. Before coming to resolution, Pat did a lot of work. Her obstetrician suggested an abortion as he delivered the bad news, but Pat stalled for time. She visited a neighborhood home for retarded adults and said,

You know, it was kind of nice. They looked pretty happy, they had jobs, they went bowling. It really made me think about it. Maybe if I was married, maybe if I had another shot at it. But this was it: take it or leave it. So I took it. And I called the Mormons back.

An unmarried divorcee with a grown child, Pat had survived two miscarriages and the death of a premature baby who lived only three days; her reproductive history made her value this pregnancy as a "miracle." She used the Mormon church to sustain her decision to keep the pregnancy in the face of her obstetrician's objections.

Migdalia Torres-Ramirez's story also contains elements that are both usual and unusual. Sent for genetic counseling and an amniocentesis at the tender and unusual age of nineteen, Migdalia was a devout Puerto Rican Catholic who considered abortion to be "killing." But she was also the older sister of a girl with spina bifida whose disabilities had made a profound impression on Migdalia and her mother. As Migdalia described it,

My sister, she can't walk, she can't see, they left her blind at [the city hospital]. My mother is still in a law suit. When I got pregnant the first time, I was very young—fifteen, sixteen when I had my baby. I talked with my mother; she really wanted me to have the tests. I wanted it, too. She had such a cross to bear. God gave it to her, but it's a lot of work. . . . I was only concerned if my own baby couldn't walk or talk. . . . I just didn't want my baby to be like my sister. I don't know what I would have done if it had been like my sister. I think I would have had an abortion. My mother and me, we're against abortion, so maybe I would have carried that cross, like my mother did. But then again, it's a case where I think I would have had an abortion.

Migdalia's fetus didn't have spina bifida, for which she had requested prenatal diagnosis. It did, however, have Klinefelter's syndrome, one of the
sex chromosome anomalies involving growth problems, sterility, and, possibly, learning disabilities and mild mental retardation. Migdalia's reaction to the news is instructive:

I wasn't too concerned when they said he'd be normal. Just that he might be slow-minded, but he'd look normal in appearance. I have faith in God. I'll be there for my son. And I have my mother helping me all the way. He's gonna be normal; he'll see and walk. That's all I care about. As long as he looked normal, acted normal, I'll be there for him. And I didn't mind if he maybe was a bit slow. And as it turns out, he isn't; he's quick to pick up everything. Back then, I talked it over with my mother; she thought so too—what's the use of killing it if he'll be normal, he'll walk?

Like many other women for whom religion provided orienting metaphors and beacons, Migdalia's narrative is richly embroidered with her Catholicism; it also highlights her close relationship with her mother. In deciding to keep her pregnancy after Klinefelter's syndrome had been diagnosed in her fetus, Migdalia was somewhat unusual; counselors estimate that more than 65 percent of women receiving this diagnosis choose terminations. But her unusual decision has a very strong context: intimate knowledge of one disabling and worrisome physical condition in her sister could be contrasted with a disability that “didn’t show.” It was the relative invisibility of the consequences of her son's atypical chromosomes that made them normal in her estimation. For Migdalia, both spina bifida (her sister's condition) and Klinefelter's syndrome (her son's condition) have concrete, specific meanings.

In one case, I was present as a positive diagnosis was produced. I observed a technician as he found something ambiguous on the number 9 chromosomes of the sample he was scoping. The head geneticist agreed: there was additional chromosomal material on the top, short arm of the number 9 chromosomes. She called it “9P+”—9 for the pair of chromosomes on which it was located, P to designate the short arm, and plus to indicate additional chromosomal material. First, she scanned the literature for an interpretation, assimilating it to some rare clinical reports on “trisomy 9,” the closest known condition. In all those cases, babies born with trisomy 9 had physical anomalies and were mentally retarded. Armed with a provisional diagnosis, the geneticist met with the genetic counselor who then counseled the mother. The mother was firm in her decision to keep the pregnancy.

A month after the baby's birth, the mother visited the genetics laboratory for a consultation. The “trisomy 9” turned out to be a six-week-old Haitian boy named Etienne St-Croix. His mother, Veronique, spoke reasonable English and good French. His grandmother, Marie-Lucie, who carried the child, spoke Creole and some French. The two geneticists spoke English,
Polish, Hebrew, and Chinese between them. I translated into French, ostensibly for the grandmother and mother. Here is what happened:

The geneticist was gracious with Veronique but, after a moment’s chitchat, asked to examine the baby. She and a second geneticist, both trained in pediatrics, handled the newborn with confidence and interest. The counselor took notes as the geneticists measured and discussed the baby. “Note the oblique palpebral fissure and micrognathia,” one called out. “Yes,” answered Veronique in perfect time to the conversation, “he has the nose of my Uncle Hervé and the ears of Aunt Mathilde.” As the geneticists pathologized, the mother genealogized, the genetic counselor remained silent, furiously taking notes, and the anthropologist tried to keep score. When the examination was over, the geneticists apologized to the baby for any discomfort they had caused him and asked the mother one direct question. “I notice you haven’t circumcised your baby. Are you planning to?” “Yes,” Veronique replied. “We’ll do it in about another week.” “May we have the foreskin?” the geneticist queried. “With the foreskin, we can keep growing trisomy 9 cells for research and study the tissue as your baby develops.” Veronique gave her a firm and determined “yes,” and the consultation was over.

Later, I asked Veronique and Marie-Lucie what they had thought about the amniocentesis, the diagnosis, and the genetic consultation. The mother replied,

At first, I was very frightened. I am thirty-seven, I wanted a baby, it is my husband’s second marriage, my mother-in-law is for me, not the first wife, [and] she wanted me to have a baby, too. If it had been Down’s, maybe, just maybe, I would have had an abortion. Once, I had an abortion, but now I am a Seventh Day Adventist, and I don’t believe in abortion anymore. Maybe for Down’s, just maybe. But when they told me this, who knows? I was so scared, but the more they talked, the less they said. They do not know what this is. And I do not know, either. So now, it’s my baby. We’ll just have to wait and see what happens. And so will they.

Here, marital and kinship relations clearly influence the decision to continue a pregnancy after positive diagnosis; so does religious conversion. But at the center of this narrative lies another important theme: diagnostic ambiguity. Biomedical scientists work from precedent, matching new findings with old. When presented with an atypical case, they build a diagnosis in the same fashion, comparing the present case with the closest available prior knowledge in clinical archives.4 While the geneticists are confident that this child will share the developmental pattern reported in the literature for other children with very similar chromosomal patterns, the mother was quite aware of the idiosyncratic nature of the case, its lack of clear-cut label and known
syndrome. She, therefore, decided that the contest for meaning was still an open one. This is a dramatic instance of interpretive standoff between representatives of biomedical discourse and representatives of family life.

But in some sense, all positive diagnoses appear ambiguous to pregnant women. An extra chromosome spells out the diagnosis of Down syndrome, but it does not distinguish mildly from severely retarded children, nor does it indicate whether this particular fetus will need open-heart surgery. A missing X-chromosome indicates a Turner's syndrome female but cannot speak to the meaning of fertility in the particular family into which she may be born. Homozygous status for the sickle-cell gene cannot predict the severity of anemia a particular child will develop. All such diagnoses are interpreted in light of prior reproductive histories, community values, and aspirations that particular women and their families hold for the pregnancy being examined.

This problem of ambiguity—inside of biomedicine and inside of family life—is one encountered by genetic counselors with a fair degree of frequency. Virtually all counselors I interviewed mentioned mosaic conditions when I asked about difficult cases. In mosaic diagnoses, cells are both normal and atypical in varying proportions. Roughly speaking, the greater the density of atypical cells, the greater the likelihood of disabling conditions that are known to geneticists and can be described to potential parents. But some conditions—for example, trisomy 22—exhibit mosaicism at the cellular level, without profound clinical expression at the level of the whole organism—that is, the child later born from a diagnosed fetus. And sometimes, a known condition—for example, Down syndrome—may be present in mosaic patterns on the cellular level, producing a child who is “slow” but still coded by the relevant caretakers in her life as “normal.” Mosaic diagnoses are thus hard to explain and harder to interpret. Their inherent ambiguity leads many women to continue pregnancies in which they have been diagnosed, especially if the number of atypical cells is relatively small or the genetic counselor can say of a particular condition with some degree of confidence, “It rarely has profound clinical significance.” Women receiving mosaic diagnoses are among the most likely to stop the technological conveyor belt, preserving their pregnancy and preparing for the birth of a child whose cellular “fortune” has been read but whose clinical future they understand to be truly unpredictable.

Existentially speaking, of course, we all live with truly unpredictable clinical futures; the existence of prenatal diagnosis has simply added a new twist to that impasse in the human condition. Now, it is possible, indeed, necessary for those who would have the chromosomes of their fetuses “read,”
to know something about possible problems and limits a coming child may face in vitro without having encountered those problems and limits as they unfold in vivo. The difference between a biologically described organism and a socially integrated child is, of course, enormous. And it is within this gap—between laboratory-generated descriptions of disabilities and potential disabilities, and their consequences for family life as a child develops—that some women receiving positive diagnoses choose to operate. Those who opt to continue a pregnancy after any positive diagnosis must consciously face what the rest of us only confront episodically: the hard work of redescribing and reinscribing a powerful biomedical definition into the more complex and variegated aspects of personhood, childhood dependency, and family life. In this situation, the structure of chromosomes initially looms large as a defining characteristic of what a child's future may bring. Women who continue pregnancies after positive diagnoses thus expend considerable agency reducing the significance of chromosomes to welcome a child on other grounds than biomedical normalcy.

By Way of Conclusion

As I have tried to show throughout this article, women with potent religious affiliations, strong kinship or other communitarian social support, or powerful reasons anchored in their reproductive histories are most likely to decide against the biomedical information amniocentesis brings as a basis for accepting or rejecting a particular pregnancy. These patterns hold true across differences of income, lifestyle, and job description, which provide rough measures of class. But other patterns of amniocentesis use and rejection are highly class structured: access to information and respectful health care surely condition how prenatal testing is perceived and valued. With better access, middle-class women are also less able to achieve any distance from the biomedical discourse within which their own rationality is forged. Those without much privileged scientific education are most likely to reject testing altogether, although many women from working-class and working-poor backgrounds also choose to be tested. And the problem of male privilege, or even male dominance, in decision making also intersects these patterns of use. Such socially structured heterogeneous processes thus do not reduce to a reflexive response to any particular diagnosis; in other words, they hold no automatic or predictable intersection with the biomedical diagnoses available through prenatal testing.
My use of the terms “in vitro” and “in vivo” in the preceding paragraphs and my musings about the gap between biomedical diagnoses and the integration of diagnosed babies into family life have an intention that is far from innocent. Here, I have been speaking about knowledge gained in conversation and observation of an essentially discursive set of practices: counselors, pregnant women, and anthropologists all communicate and reflect on their communication as the central focus of their mutual interactions. But we are not the only ones who do so. To this analysis must be added many things: chapters on the history of the technology itself, discussions of how professional service providers construct the legitimacy of their practices, and analyses of cytogenetic laboratory work in action. But the “invisible and implicated actors” whose social subjectivity guards the passage points into and exits from this technology surely have much to teach us about its social construction.

Operating at the intersection of reproductive technology, genetic discourses, and gender relations as they refract and enact other forms of social hierarchy, pregnant women in America have increasingly become “moral pioneers.” They are recruited as judges of standards for entry into the human community. Women in all their social and cultural diversity have long been exquisitely and differentially consigned to matters of the body and domesticity in North American culture. Their symbolic association with “private life” now offers material vantage points illuminating some of the implications of contemporary biomedical discourses and practices. Scientific practices seep unevenly through the crossroads and chasms at which biotechnology and family life conjoin. When we begin with the amniocentesis stories of diverse women, we gain an important commentary on the difference between a scientific message of obligatory universality and the concrete, local contradictory particularities of applied technology as an aspect of a lived dilemma. That dilemma encompasses the social inscription in pregnant bodies of realms as seemingly distant as shifts from academic to commercial genetics. It includes papal politics at UN conferences on women and population. And it is deeply influenced by municipal, state, and federal struggles over health care budgets and clinic hours. Pregnant women are thus positioned as ethical gatekeepers vis-à-vis this technology. They are at once moral pioneers and cultural conscripts in a social drama played out on an uneven and shifting terrain on which reproductive technologies are routinized in a multicultural class- and gender-stratified world. The confident dominion of biomedicine here encounters a refusal through which some of the fault lines of science in social context may be mapped and investigated.
Notes

1. Moral pioneers: fetuses, families, and amniocentesis (Rapp forthcoming), from Routledge, takes up these religious and philosophical narratives.

2. Throughout this article, all names are pseudonyms.

3. Satmar Hasids, in particular, are extremely sophisticated about medical technology and services. During the period of my second pregnancy in 1991-92, my obstetrician also served members of the Hasidic community; intrigued by my never-ending research questions, he told me many stories as a "provider informant" about their prenatal care practices. Although known carriers try not to become pregnant after having lost children to Tay-Sacks disease, Halasik law can be interpreted to permit testing and even abortion under certain circumstances. But both must be accomplished before the pregnancy is forty days old, the last moment at which the life of a male fetus may be ended. U.S. medical protocols offered chorionic villus sampling at nine to eleven weeks, too late in the pregnancy to accommodate religious teachings. The obstetrician thus told of sending Hasidic "accidental" pregnancies to England, where a cutting-edge experimental program was using chorionic villus sampling for prenatal diagnosis far earlier than it was available here. When I retold this story to a representative from Dor Yeshurin in 1994, he laughed and said, "That was yesterday's news. Today, we send them to Philadelphia, where there's a terrific doctor who will do it for us even earlier." In his estimation, the newest of reproductive technologies could be successfully used to sustain religious practice. To accomplish this goal, his organization was highly networked into the interstices of medical experimentation.

4. This problem of stabilizing diagnoses is not dissimilar to other problems of uncertainty in the development of diverse technologies described in the essays included in Clarke and Fujimura (1992).

5. The point is made throughout Rothman (1986). It was also pointed out to me separately by Shirley Lindenbaum and Emily Martin.

References


Rayna Rapp is Professor of Anthropology and Chair of the Graduate Program in Gender Studies and Feminist Theory, New School for Social Research, in New York City (65 Fifth Avenue, New York, NY 10003). Her edited and coedited volumes include Toward an Anthropology of Women; Promissory Notes: Women in the Transition to Socialism; Articulating Hidden Histories; and Conceiving the New World Order: The Global Politics of Reproduction. She is currently completing a book on the social impact and cultural meaning of prenatal diagnosis from which this article is drawn. She has been active in the movements for reproductive rights and for building women's studies in the United States for twenty-five years.