Introduction

Prenatal diagnostic testing has entered a new realm. In the past decade it has ceased to be defined and delimited by amniocentesis, an invasive procedure offered only to women considered to be at particular risk for bearing a child with a birth defect. Instead, with the advent of population-based, rather than risk-based screening, prenatal testing for the detection of birth defects has joined the routine modes of scrutiny to which women's pregnancies are increasingly subjected. This has occurred with little explicit comment on the profound change it represents. Yet today, in many areas of the United States and Europe, every pregnant woman is considered eligible for prenatal diagnostic screening. This not only effectively marks every pregnancy as potentially "at risk," but places in the path of every pregnant woman the possibility of facing a decision about the continuation or termination of her pregnancy based on the presence of a birth anomaly. What this large group of "low risk" pregnant women think about such population-based screening and how they make decisions about participating in or opting out of it has been little investigated. The purpose of this chapter is to explore those questions. In doing so, we will also attempt to discover how this major development in the management of pregnancy has been effected with such silence and such ease.
The paradigmatic case in the development and expansion of population-based prenatal screening is the maternal serum alpha-fetoprotein (AFP) test. It was originally designed to screen a pregnant woman's blood for indications in the fetus of neural tube defects, which are serious malformations of the brain and spine. Currently this technology is being expanded to include further analyses from the same maternal blood sample. This “triple marker” analysis will make the test nearly as effective a screen for chromosomal abnormalities, including Down syndrome, as it is for neural tube defects. Throughout the United States today approximately 65% of women enrolled in prenatal care are already being screened for AFP levels (Meaney, Riggle, & Cunningham, 1993), and the Department of Health and Human Services recently made it a goal of their Healthy People 2000 initiative to “increase to at least 90 percent the proportion of women . . . who are offered screening and counseling on prenatal detection of fetal abnormalities” (USDHHS, 1991). In California that goal is closest to realization, since there is a legal mandate in the state that health care providers offer AFP screening to all pregnant women as part of routine prenatal care. The California State program, therefore, provides an excellent opportunity to examine how the institutionalization of AFP screening is perceived and reacted to by the women who are its consumers.

The research on which this chapter is based was undertaken in part to assess the role of cultural differences in women's decisions about whether or not to participate in the California AFP program. We interviewed women with different ethnic and social-class backgrounds and degrees of religiosity because we believed that these characteristics would influence test acceptance. Contrary to our expectations, not only did the overwhelming majority agree to be tested, but they showed marked similarities in the reasoning behind their decisions.

We believe this unanticipated result occurred because women's understandings about the AFP test were shaped primarily by the way the test was described to them by their health care providers and in a booklet prepared by the state's AFP program. We suggest that the structure and content of this information increased test acceptability far more than it succeeded in increas-
ing knowledge about the test. The strength of this effect may even explain the absence in our sample of the class and ethnic differences suggested by previous literature on women's use of reproductive genetic testing (Rapp, 1988).

It would be wrong, however, to conclude that this absence of variation along class and ethnic lines demonstrates the insignificance of cultural factors in decisions about the AFP test. Rather, we believe it demonstrates that there exist a set of cultural beliefs, understandings, and values, shared by those who offered and those who accepted AFP screening, which enhanced the acceptability of the test. Central among these is a fundamental faith in the power and value of scientific knowledge and the solutions science provides. In pregnancy, this view is expressed in the belief that undergoing routine prenatal care will help lead to a healthy birth. Yet in the arena of prenatal diagnostic testing, this optimistic faith must coexist with the more ominous themes of serious birth anomalies, selective abortion, and eugenic selection that prenatal diagnostic testing by definition entails. These contradictions create a tension which makes health care professionals uncomfortable discussing, and women uncomfortable contemplating, the realities of AFP screening. Our data suggest that this tension is reduced through the creation of a collective fiction: the presentation of AFP screening as a simple and routine part of prenatal care. We will demonstrate that this fiction is effective because it serves the interests of all parties involved. It serves the state public health program's purpose of trying to reduce the incidence of neural tube defects, health care providers' desire to limit their legal liability, and women's complex needs to be reassured about the outcome of their pregnancy and to leave open but unconsidered the option of terminating an affected pregnancy.

**Research Design**

This analysis is based on data collected from the pilot phase of a longer-term study. The pilot sample comprised 40 Catholic, pregnant women, between the ages of 20 and 34, all of whom had begun prenatal medical care before their 20th week of pregnancy. We chose to work only with women raised Catholic for
the pilot study. We speculated that, because of their church's objection to abortion, these women might be more likely than others to hold developed opinions on the subject of prenatal diagnostic testing.

One-half of the total sample was Mexican-American and one-half non-Hispanic white; one-half were from middle-class and one-half from lower-class backgrounds. All were patients at one of three sites of a single health maintenance organization (HMO) in Southern California. All had either received a negative AFP result \( n = 36 \) or had refused the screening test \( n = 4 \).

Data were obtained during semi-structured interviews and by observing the prenatal intake in which women were told about the AFP program by nursing staff. Interviews with informants took place at approximately their 24th week of pregnancy, when all prenatal diagnostic test results would have been received and all decisions based on those results made. For most informants this was about two months after being given information about the AFP program.

We also interviewed the clinic administrators and the nursing staff who conducted prenatal intakes at each of the three field sites, as well as an opportunistic sample of Southern Californian physicians and other health care providers, on issues surrounding AFP screening and prenatal diagnostic testing in general.

**The Medicolegal Context of the California AFP Program**

When the State of California created an AFP program, it included an elaborate informed consent and refusal process in keeping with the view of bioethicists that "participants in prenatal screening programs should understand the nature and purpose of the screening" (Faden et al., 1985). Ironically, in making this test standard-of-care for pregnant women, a legal liability was created for providers which may work against the very goals of informed consent outlined by bioethicists. The possibility of lost paperwork or later claims of inadequate test explanation present great legal and financial risk for providers. In contrast, the test procedure—a blood draw from the preg-
nant woman's arm—carries virtually no physical risk for the patient. Therefore, in weighing the costs and benefits of AFP screening for their patients and themselves, providers may conclude that the most expedient route is to encourage women to accept the test.

In fact, many providers we interviewed, both at the HMO and elsewhere, raised concerns about legal liability in discussing AFP screening, stating that their fear of legal ramifications influenced what they told their patients about the AFP program. Several claimed that the State's mandate to offer AFP screening was, in medicolegal terms, tantamount to a requirement that they test all their pregnant patients. Some even admitted that they make it difficult for a woman to refuse testing. One said, "I just tell them, 'Take it.'" Even physicians who are more willing to accept no for an answer may feel a need to bring the topic up several times simply to be able to chart a patient's repeated refusals. Women, who most likely have no idea what is motivating their health care provider, may as a result perceive this test as something very important.

The same concerns led those in charge at the HMO where we worked to create careful protocols to ensure staff cooperation in meeting the State's requirement that all pregnant women be informed about the AFP program. At one site, memos stamped with the slogan "Think AFP" urged providers to develop "an AFP consciousness"; at another, the lab technician had a special calendar file which alerted him when a patient was nearing the end of the time when she was eligible for the screening test. The third site employed a special monitor among whose functions it was to phone women who had missed scheduled AFP appointments in order to address any reservations they might have about the test. Thus, for example, women who expressed reservations about the test because they would not terminate a pregnancy for any reason were categorized as having misinformation and told about other reasons to undergo AFP screening, such as advance delivery room preparation, were a problem to be uncovered. In cases such as these, the distinction between informing women and persuading them seemed blurred, and is likely to have contributed to the high rates of AFP acceptance we observed.10
What Women Were Told about the AFP Test by Their Health Care Providers

A content analysis of the 40 prenatal intakes we observed strongly reinforced the view that the HMO’s de facto definition of AFP “compliance” was the obtaining of agreement to be tested, not simply the provision of information to aid decision-making.

While, as a rule, the prenatal intakes lasted from 15 to 30 minutes, no more than two minutes was ever devoted to discussion of the AFP test. Nearly all the information provided concerned the test procedure itself and what a woman had to do to obtain testing. Consent was thereby implicitly assumed unless a patient explicitly indicated that her wishes were to the contrary. Moreover, AFP screening was generally introduced in the part of the intake in which other blood work was scheduled. Since these other blood tests were presented as routine, but not voluntary, the effect was to routinize the AFP test as part of the HMO’s standard prenatal care package.

The specific language used by nursing staff to introduce and describe AFP could also be seen to further the goal of test acceptance by means of routinization. Thus, the frequent use of phrases such as, “It’s just a simple blood test,” “It’s only a prick in your arm,” or “It won’t hurt you or the baby” seemed intended to diminish test apprehension. In contrast, statements such as, “This is our AFP program, the government screening here in California,” “We do recommend the test for everyone, though you have the option not to have it done,” and “It’s not mandatory, but it is recommended” seemed geared more toward direct persuasion. Women were sometimes asked if they had any questions. They almost never did. Nothing was done to help them formulate such questions, and the prior conversational flow, in which the nurse had asked the questions while the patient answered, may have led our informants to feel that a question would be an imposition. The rushed nurses never probed past an initial patient response of “I have no questions.”

Perhaps even more striking than the form and content of the information women received about the AFP program is what they were not told. The conditions for which AFP screens, for
example, were at best defined vaguely as "misgrowths of the brain or spine" or merely glossed by phrases such as "the test looks for some birth defects in the baby" or "the test shows how your baby is developing." In no intake was a woman given information about the physiological, emotional, or familial effects of any of these conditions, nor were the kinds of decisions a woman would face in the event of a positive diagnosis ever discussed; the words "abortion" or "pregnancy termination" were mentioned only twice during all 40 intakes. Our view that this was not an accidental omission is supported by the following comment from a nurse who had important health education responsibilities at one site:

Once . . . I said that if there was a problem [with the AFP] it was then up to the woman to decide whether to continue the pregnancy or not. Later [my supervisor] told me never to talk about that because . . . [she has seen that] when she says anything about pregnancy termination, the women stiffen. So now I’m real careful and never mention pregnancy termination when I’m telling them about the AFP test.

In sum, in our provider interviews and prenatal observations we found both that a tension existed between the ethical objective that pregnant women be permitted to fully consider the implications of prenatal testing and the legal injunction that providers offer women the test, and that providers responded to this tension by blurring the line between informing and persuading. We would also suggest, however, that providers could rest assured in the belief that women did not want to hear more, a belief that could be supported by the observation that women neither asked many questions nor seemed resistant to the idea of being tested. Health care providers also knew that all these women would have another source of information about the AFP test.

The AFP Booklet—Another Source of Information

All health care providers are required to give their prenatal patients a booklet prepared by the State of California that de-
scribes the AFP program. The "California Alpha-Fetoprotein Screening Program" booklet (State of California, 1988) was written to be comprehensible to anyone reading at a tenth-grade level (Lustig, Linda, personal communication, 1991). In our view, however, the text is quite dense and difficult, often providing both more and less information than would seem necessary. In this regard, the booklet's discussion of the meaning of positive test results is instructive in the light of data we will present below on our informants' particularly poor understanding of this point.

One-half of page two of the booklet is devoted to a detailed chart of the various reasons why a woman might receive a positive AFP test result. Yet the booklet never defines a positive test result as a negative event, and it requires some sophistication in medical language to be aware of this counterintuitive usage of the word "positive."

In addition, descriptions of some of the situations that might lead to a positive test result are accurate without being particularly informative. For instance, "normal variation of the AFP level" is listed as the second most likely cause of a positive result raising, for some informants, questions about how test results could be definitively interpreted.

Moreover, in describing the conditions for which the test was designed to screen, the wording is surprisingly vague. Compare, for example, the straightforward syntax of "there may be twins" to the complex and hedging quality of "additional tests may be needed to find out if this [result] is due to birth defects such as neural tube defects or abdominal wall defects." Since additional tests are also needed to ascertain the presence of twins, the most reasonable explanation for this syntactic change is a desire to divert attention from the realm of possible birth anomalies and the choices they might entail to the more routine domain of "further testing."

But, should one conclude that the AFP booklet is simply an example of poorly written patient information materials, consider that nowhere in its pages is there a clear statement that this is a test to find out if a baby will be born with medical problems of so severe a nature that a parent might consider them incompatible with a decent life; neither is it mentioned that there is no
treatment for the great majority of these conditions other than ending the pregnancy. In fact, it is not until the very last page of text that one finds a small section entitled "What happens if the tests show that the fetus has a birth defect?" The reply is that further information would be provided on the defect and its effects, that "different options will be discussed," and that services are available to "support whatever decision the woman makes." "Option" and "decision," therefore, appear to be code words for abortion, while "special services" and "support" are the only indications that this decision may be painful or morally difficult. We contend that the obscurity of this language, and the out-of-the-way placement of the paragraph, are in keeping with the tone of the entire booklet. Thus while the AFP test raises alarming possibilities and disturbing solutions, the booklet is written in a way that obscures and reassures rather than informs. In the section below, we will examine the consequences of these various silences and omissions in the process of informing women about AFP testing.

**What Women Knew about the AFP Test**

The flaws in the procedures for informing pregnant women about the AFP screening test were best revealed when we assessed women's level of AFP knowledge after they had accepted or refused the screening test. We did this by developing a series of questions based on the AFP informed consent/refusal form. The points which women aver to have understood in signing the form are as follows: (1) the names of conditions AFP screening can detect; (2) the effects of those conditions on children and adults; (3) what next steps would be suggested if they received a positive result; (4) that the test is voluntary.

Ninety percent of our informants stated that they remembered getting this booklet and 75% said that they had read and understood it. We found, however, that they remembered little of the information it contained. Most notably, not one could explain adequately what were the various conditions that might yield a positive test result. Only 30% of informants recognized the term neural tube defect and of those who did, two-thirds had no accurate idea of what a neural tube defect was, several
confusing it with an ectopic or “tubal” pregnancy. The term spina bifida had a 60% name recognition but only about one-half of those informants felt they could define the condition. The majority who did so seemed to be taking a guess based on the name, such as, “Wouldn’t it be a spinal disease?” Only 10% had any idea about the symptoms and consequences of spina bifida and all who did had personal knowledge of someone with the condition. Fewer than one-half knew what their doctor would want to do next if their test result proved positive. Finally, more than one-third incorrectly thought or suspected that pregnant women were required by the state to take the AFP test.

What Our Informants Want to Know

Yet neither the way women were told about the test by their health care providers, nor the manner in which the official state booklet is written, provides a full explanation of our informants’ simultaneously high rates of test acceptance and low levels of test comprehension. To these factors must be added what the women themselves said they wanted to know about the test. For if the state and the health care providers have reasons for wishing to present AFP screening within an idiom of routine prenatal care, our data reveal that our informants share this preference and were able, therefore, to accept this “simple” blood test without feeling the need to understand very much about it or ponder its implications. Thus, even after women’s lack of AFP knowledge was revealed to them through our questioning, they overwhelmingly professed satisfaction with the amount of AFP information they had been given.

Informants’ responses were notably brief and stereotypical to all interview questions which concerned either the moral aspects of prenatal diagnostic testing, their reasons for test acceptance, or what they might do following a hypothetical positive result. This contrasted with their lengthy and detailed replies to questions during the rest of the interview. We also found that the words “abortion” or “pregnancy termination” were rarely uttered by a woman in answering these questions unless and until the interviewer used them. This suggested to us something
close to a cultural taboo on open discussion and careful considera-
tion of just those issues bioethicists see as most germane to de-
cisions and understandings about prenatal testing.

Precisely because women appeared to have difficulty articu-
lating their own views about the ethics of prenatal diagnostic
testing, we developed three short scenarios that represented ma-
jor bioethical stances on the subject. The “Disabilities Rights”
scenario used the voice of a handicapped woman who expressed
the fear that had the AFP test existed when her own mother was
pregnant, she might not be alive today. The “Religious Funda-
mentalist” scenario expressed an objection to prenatal tests be-
cause they can tempt humans into making Godlike decisions
about who is “entitled” to life. Placed between the two was a
“Pro-Testing” scenario told from the perspective of the parents
of a handicapped child. They discussed the difficulties and stress
of life for a handicapped child and its family and expressed
wholehearted approval of prenatal diagnostic testing because it
can help avert such births and allow couples to “try again.”

We anticipated that women would find two of the three po-
sitions mutually exclusive, and that most would identify at least
one as reflecting their own point of view. We were surprised,
therefore, to find that the great majority (80%) could endorse
none of these positions. The reason appeared to be that most
informants simultaneously supported testing while opposing
abortion. Thus, while the assumption underlying all three sce-
narios was that a positive test result would lead to terminating
the pregnancy, our informants did not appear to see a necessary
link between these two events. Many informants, for example,
agreed with the Religious Fundamentalist position that parents
should let God decide who would and would not be born and
which stated that a negative aspect of prenatal diagnostic tests
was that they could “tempt” some parents to intervene. But
they did not regard this temptation as a sufficient reason not to
make the tests available. In explanation they stated that al-
though others might use test results as a basis for pregnancy
termination, they themselves would never do so.

The majority of our informants seemed impatient with the
question about the moral correctness of offering prenatal diag-
nostic testing with which we ended each scenario. In fact,
hardly a single informant could endorse any suggestion that offering prenatal diagnostic testing was negative, or even problematic. Yet they consistently framed their scenario responses to answer a question we had not asked: How should one judge a woman who terminated a pregnancy following a positive prenatal test result? Often informants' responses to all three scenarios constituted a single, connected consideration of this unasked question. They emphasized the necessity for individual choice and refused to criticize a woman faced with this difficult decision. Thus, the most frequently repeated statements were, "It's her decision," "It's up to the individual," "You can't say for someone else.

It is plausible that these responses are an artifact of our all-Catholic study population. However, we find it more likely that they reflect deep contradictions within these women's belief systems regarding the selective abortion of anomalous fetuses, and that those contradictions are shared by much of the general population. This view is supported by our informants' responses to a standardized measure we devised to elicit hypothetical willingness to terminate a pregnancy for certain congenital conditions. Analysis of these data reveal that close to 70% of our informants believed that they would definitely or probably terminate a pregnancy for at least some of these conditions. Significantly, the most frequently selected conditions were those for which AFP screens. This is not out of line with California state statistics which indicate that approximately 80% of all California women who receive a confirmed positive AFP test result for nonremediable conditions choose to terminate their pregnancies (Genetic Disease Branch, 1990).

Why Women Want the AFP Screening Test

When asked what they liked about the AFP test and why they had agreed to be tested, the possibility of being able to end a pregnancy was mentioned extremely rarely. The most frequent response was that the test could offer reassurance that their pregnancy was going well. We have written elsewhere that many women consider prenatal medical care to be a "ritual of reassurance" (Browner & Press, 1991) rather than an opportu-
nity to receive specific services or safeguards. Studies of other prenatal diagnostic tests have found that reassurance is also a prime reason women seek such testing (Marteau et al., 1989; Green, 1990; Nielsen, 1981; Rothman, 1986). However, specific statements made by informants also suggest that many believed that the AFP test would not only assure but also ensure their baby's health. Thus, women frequently stated that they had accepted the AFP test "Just to be safe." Others stated that they took the test "because I wanted to make sure my baby would be the healthiest that it could be," or "I wanted to do anything that could help me or my baby." This last response expresses with particular clarity the ambiguity involved in a screening program, offered as a routine part of maternal prenatal health care, that can diagnose but for the most part not cure the conditions it detects.

The second most common reason women said they took the test was that it would provide them with "knowledge." Much has been written about the extreme salience of scientific knowledge in Western society. Some of that literature suggests that information which cannot prevent harm or provide an acceptable path for action might not constitute valuable knowledge. But such views were not shared by our informants who appeared to believe that scientific information offered to them could not, or should not, be refused. Rather they repeatedly expressed the belief that "the more you know about your child the better off you are" and wondered "how could it hurt to know?" This was true even though the majority of informants knew or feared that nothing could be done medically if the fetus were found to have a problem and, as we have stated above, in the main denied that they would use knowledge derived from prenatal testing as a basis for action.

Conclusion

Both the California state AFP program and health care providers present AFP screening as an uncomplicated and routine part of prenatal care. In doing so, they place it firmly under the rubric of broadly shared, contemporary American cultural beliefs about the value of scientific knowledge and medical care.
At the same time, this presentation enables all concerned in offering and accepting AFP testing to remain silent about issues on which there is no societal consensus—such as the appropriateness of aborting fetal anomalies and the eugenic implications of the practice.

This selective perception of what issues constitute the arena of prenatal testing is not imposed upon women. Rather, it fits within their own understandings and serves their own desire to avoid the discussion, if not the use, of pregnancy termination. It is precisely for these reasons that these silences and fictions should be seen as collective. The question that remains is whether this is an appropriate way to create policy and action in a society faced with increasingly acrimonious legislative and societal debate over abortion, growing pressure to make medical decisions deemed “cost-effective,” and the rapidly accelerating capacity to discover medical problems in fetuses long before their birth.

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NOTES

1. The most common neural tube defects are anencephaly, an absence of skull and brain, which is always fatal, and spina bifida, a failure of the spinal column to close, which produces symptoms of widely varying severity. Neural tube defects are among the most common birth defects. In California the prevalence rate is approximately 1:1,000 live births (Greenberg, James, & Oakley, 1983).

2. AFP screening alone detects close to 90% of cases of anencephaly and somewhat over two-thirds of open and closed spina bifida. Through the addition of analyses of unconjugated estriol and chorionic gonadotropin, the other two components of the triple marker screening, about 60% of Down syndrome can be detected.

3. Please note that our intent here is not to critique the California AFP program per se. Rather, we offer this analysis in the hope that it pro-
vides insight into both the implementation of one particular prenatal screening program and the broader issues surrounding the implementation of programs of this type.

4. Because the results reported here are based on data obtained from a relatively small number of women, any generalizations should, of course, be made with caution. However, preliminary analysis of the 125 additional cases from our main study, which includes a broader range of demographics, appears to support the analysis presented here.

5. Blood must be drawn for the AFP test between the 15th and 20th weeks of gestation. Thus, women who present themselves for their first prenatal medical appointment after their 20th week cannot be offered the test.

6. A woman was considered non-Hispanic white if she and her parents had been born in the United States and none of her grandparents had been born in any Latin American country. She was considered Mexican-American if she, either of her parents, or any of her grandparents had been born in Mexico, as long as the informant herself had come to the United States before the age of ten. The criteria for those two categories, therefore, are not strictly parallel. They imply a longer and more vigorous connection with the country of family origin for Mexican Americans than for other immigrant groups, and are based on the observations of researchers familiar with the Los Angeles Mexican-American community (Gilbert, Jean, personal communication, 1989; Hayes-Bautista, David, personal communication, 1990). Informants' self-ascribed ethnicity was consistent with these definitions.

7. We used mode of payment for medical services as a heuristic device to define our middle-class and lower-class samples. Thus, those women whose medical services at the HMO were paid for by MediCal (the California Medicaid system) were considered lower class; those whose services were subsidized by their employers were considered middle class. During the interview, we collected additional sociodemographic information, including income and educational level. We found that our heuristic did produce two distinct groups: Household income was just over $11,000 for the MediCal group and $43,000 for the middle-class group. Close to 60% of the MediCal recipients had not graduated high school; in contrast, just one middle-class informant had not graduated high school and over 40% had received at least some post-high school training.

8. Because this HMO has a MediCal contract with the State of California, we were able to recruit women from both SES groups from the same facilities. We believe that this has important methodological advantages. We believe that it is often impossible to separate reported class differences in, for example, patient compliance, from the differences in health care delivery provided lower-class and middle-class patients. In this case, however, we could observe that all women received identical services.
9. Three women in the sample received an initial positive test result that was reinterpreted as negative after ultrasound corrected the gestational age of the fetus.

10. Rates of AFP acceptance in California vary sharply by patient population and health care setting. Aggregate statewide statistics indicate a 60% acceptance rate. However, an early study by Richwald (1989) found that only 34% of low SES patients in seven Los Angeles County clinics agreed to the procedure when they had to pay for it themselves. (MediCal now covers the costs of the test.) In contrast, some private physicians report that close to 100% of their patients undergo AFP screening. Our own informal survey of other HMOs in Southern California yielded acceptance rates of around 85%, which is similar to those at our field sites.

11. HMO policy dictated that Down syndrome not be mentioned by staff in regard to AFP testing because HMO management was skeptical about the accuracy of AFP test results for this disorder.

12. The political motivations for this type of presentation are not hard to find. According to sources close to the creation of the California program, legislative approval was constantly in doubt. Eventual success has been attributed to a strategy that kept the program's profile as low as possible by splitting the bill into regulations approved in committee and funding included in the state's annual budget. Even so, this author was told that "the legislation got through by the skin of its teeth . . . [because] anything today that involves the 'A' word is hot."

13. Few studies have been done to assess participants' level of knowledge about AFP screening (but see Faden et al. [1985], Marteau et al. [1989], and Green [1988]), and only work by Faden et al. (1989) represents a detailed study of how well women understood the information that they received about the test. Although Faden's data are not completely comparable with ours, she also found "substantial gaps in the knowledge base of women" who had undergone AFP testing (p. 1382).

14. Attitudes concerning various handicaps and developmental disabilities were assessed through the Developmental Disabilities Attitudes Measure (DDAM), a ranking device developed by the researchers. This four-point Likert Scale comprised two sorting tasks. The symptoms of 18 conditions that are genetically transmitted were listed on cards. Informants were first asked to sort the cards according to their degree of concern about the birth of a child with each symptom. They were then asked to re-sort the cards according to how likely they thought they would be to terminate a pregnancy for each symptom.


BIBLIOGRAPHY

Collective Silences, Collective Fictions


