Implications of Reproductive Technologies

The recent development of new reproductive technologies has dramatically altered the experience of conceiving, carrying to term, and giving birth. At first glance, the new technologies appear to offer women greatly expanded choices regarding whether they conceive, how they conceive, and the health of the child they produce. While reproductive technology may have a positive and desirable impact on some individuals, the implications for society as a whole, however, are mixed.

For example, the very availability of prenatal diagnosis in combination with the availability of abortion may place pressure on parents to use prenatal technologies (Andrews, 1987)—particularly those parents who think they lack the resources to raise a child with special needs. A possible devaluation and stigmatization of people with genetic defects may follow. The availability of prenatal knowledge of genetic “problems” assumes that such conditions can be avoided. The growth of prenatal screening technology, therefore, could foster an environment in which society no longer feels responsible for disabled people.

The ways in which societal questions concerning reproductive issues are framed further complicate matters. Especially troublesome is the assumption that individuals are privately responsible for “solving” genetic problems. Andrews argues that
new reproductive technologies focus upon genetic causes while de-emphasizing environmental causes of illness (1987). Rothman criticizes the effect of procedures such as amniocentesis as privatizing a public health problem. She believes that a health care system that stresses prenatal diagnosis and subsequent abortion of "defective" fetuses will place less emphasis on research into the causes and treatment of genetic diseases (1986).

Although the new reproductive technologies affect all women and parents to some degree, the extent of those ramifications will vary according to class position and racial and ethnic identity. Taken from a historical perspective, it is conceivable that in the future poor people might be coerced to abort due to the perceived economic burden on society of having a disabled child. It is also conceivable that in the future poor people might be denied full access to those technologies. As a result, their children would disproportionately represent the population of those with special needs.

To further explore the implications of reproductive genetic technology on low-income women and women of color, the following areas will be discussed: (1) access and barriers to general prenatal care and reproductive genetic services; (2) the availability of reproductive genetic services through public programs and funding; (3) sociocultural issues involved in genetic counseling; and (4) conclusions and recommendations for improving the quality of access to reproductive genetic services.

Access to Prenatal and Reproductive Genetic Services for the Poor: Financial and Systems Barriers

The Uninsured

Many poor women do not utilize prenatal care because they are uninsured. A study by Brown in 1988 showed that of an estimated 9 million women of childbearing age, 1,530,000 (17%) were uninsured altogether, while an additional 5 million were uninsured for prenatal care. Among women of childbearing age, the following statistics were documented for the uninsured women, by demographic status: 23% were unmarried; 22% were 15–19 years old; 27% were 20–24 years old; 21%
were black and 28% were Hispanic; 35% were below the pov­
erty level and 33% had incomes at 100 to 149% of the poverty
level; 25% had fewer than 12 years of education; 20% were
from the South; and 29% were from the West. Studies point out
that privately insured women are more likely to obtain adequate
prenatal care, including specialized care, than are those who are
uninsured or on Medicaid (Brown, 1988).

Acceptance of Medicaid Patients

Many Medicaid recipients lack access to prenatal care because
a large number of obstetricians will not accept Medicaid as a
form of payment. In 1983 a national survey of private physi­
cians who provided obstetric care found that 44% did not ac­
cept Medicaid. Although states have made efforts to address this
issue over the years, the situation has not changed significantly.
In large part, the problem is due to the fact that physicians do
not receive full reimbursement for their services through Medi­
caid. Many physicians, however, feel that high-risk Medicaid
patients are more apt than non-Medicaid patients to sue their
providers (Rosenbaum, Hughes, & Johnson, 1988). According
to a 1992 American College of Obstetrics and Gynecology sur­
vey, rising malpractice rates have led more than 23% of all re­
sponding physicians to reduce their high-risk caseloads. Many
physicians have stopped treating high-risk mothers and babies
on their premises to avoid legal liability (Rosenbaum et al.,
1988).

Waiting Periods in Minority Clinics

The length of the waiting period for obtaining prenatal care
in federally funded Maternal and Child Health (MCH) pro­
grams greatly influences the feasibility of obtaining prenatal
screening. The average waiting period for new patients is about
three weeks, but the average length varies from state to state. In
1986, six states had an average waiting period of one week or
less, but in 12 states it was four weeks or more. The average
waiting period in Vermont was 14 weeks, clearly precluding
early entry into prenatal care (AGI, 1987). A long waiting pe­
riod affects the practicality of utilizing certain prenatal proce­
dures, and this is compounded if low-income women seek pre­
nential care late in their pregnancies. Women receiving prenatal care late may be rushed through the counseling and screening process; as a result, they may be unable to absorb the information or psychologically prepare for tests, increasing the likelihood of unwise decisions being made.

Long waiting periods for access to prenatal screening particularly affect women who enter prenatal care late in their pregnancies. Compared to white women, a high percentage of black women receive inadequate care or do not have the recommended number of visits (Children's Defense Fund, 1991), decreasing their chances for counseling at an early stage. Women who enter prenatal care late may request screening as far as 20 weeks into their pregnancies which, in many instances, makes it impossible to schedule counseling, undergo the procedure, obtain the results and, if needed, obtain further counseling.

**Provision of Services through Public Programs and Funding**

Maternal and Child Health Block Grants (which usually include services for children with special needs), community and migrant health centers (AGI, 1987), state-funded regional genetic centers, and funding through Medicaid all provide some level of reproductive genetic services and prenatal care for low-income patients (AGI, 1987). The federal government also funds genetics programs through demonstration projects, through the Bureau of Maternal and Child Health, for Special Programs of Regional and National Significance (NCEMCH, 1991). Some government programs have been contracting with health maintenance organizations (HMOs) to provide services to low- and moderate-income populations. In addition, the federal government provides some services itself. The Public Health Service, for example, is directed to provide voluntary genetic testing, diagnosis, counseling, and treatment of individuals; some members of the armed services and their families can obtain services through CHAMPUS; and some states provide services on a piecemeal basis for categorical problems such as Tay-Sachs disease. Services can also be obtained through Sup-
plemental Social Security Income (Greenstein, 1987). States ensure access to genetic services by acting as direct providers, paying for services outright in programs that are specifically directed at genetics, in addition to requiring others to pay for testing when it is provided by health professionals in the private sector (Clayton, 1994).

The cost of reproductive genetic screening, however, often makes it inaccessible to low-income women and their families. Services for the poor are generally available through the above-mentioned programs. Most of those programs, though, limit access to reproductive genetic services and impose eligibility requirements. These limitations shape availability according to political and organizational biases and agendas underlying social policy programs and their funding.

**Funding through Medicaid**

The Medicaid program, Title XIX of the Social Security Act, is the nation's major vehicle for financing health care for low-income persons who receive cash assistance under Aid to Families with Dependent Children or Supplemental Social Security Income. With the introduction of COBRA legislation, a patient no longer has to be eligible for cash assistance to be eligible for Medicaid. Medicaid works through a system of reimbursement to participating private physicians, hospitals, clinics, laboratories, pharmacies, and other health care providers for designated services. It is administered within broad federal guidelines, but individual states decide the categories of persons eligible, income eligibility levels, and the services covered. Therefore, the medical services available to low-income persons vary from state to state (AGI, 1987).

**Limitations on Clinic Visits**

Medicaid patients who have medical indications for reproductive genetic testing require a higher than average number of visits in order to receive the recommended ultrasound, amniocentesis, counseling, or other services. In 1986, however, only 14 states would reimburse for further visits; in addition, in many of those states the provider must petition for such reimbursement on a case-by-case basis and must have a medical di-
agnosis. For example, in Colorado and North Carolina additional reimbursement is available when a woman has toxemia, cardiac or neurological problems, or a similar condition. In Florida additional reimbursement is available in cases such as preeclampsia (AGI, 1987). In most instances, visits will already have been rendered by the time reimbursement is requested, meaning that the physician takes a financial risk by proceeding. It is conceivable that a physician may indeed refuse to treat a client once the allotted number of visits have been exhausted.

**Access to Screening Procedures**

There are a variety of reproductive genetic tests available. For the purposes of this discussion, I will outline a few techniques: Amniocentesis involves inserting a needle through the abdomen of a pregnant woman into the uterus to remove a small amount of amniotic fluid that is tested to determine fetal abnormalities. Ultrasound screening determines fetal position and age and may identify certain fetal abnormalities. Alpha-fetoprotein (AFP) tests are performed to detect abnormalities from a blood sample. Chorionic villi sampling (CVS) is an early diagnostic test that removes from the uterus a piece of chorion, the outer tissue of the sac surrounding the embryo. The chorionic tissue is analyzed to determine the genetic makeup of the fetus. This procedure can test for most of the same chromosomal, metabolic, and other genetic disorders as amniocentesis, but it cannot identify the presence of neural tube defects (Blatt, 1988).

The majority of states provide Medicaid reimbursement for amniocentesis, ultrasound, and AFP. As a general rule, all the procedures required for these particular screening techniques are funded. Connecticut and Kansas provide only partial coverage of amniocentesis, reimbursing the physician fee for the procedure, but failing to reimburse laboratory fees for examining the amniotic fluids (AGI, 1987). In a 50-state analysis of Medicaid reimbursement for medical genetics, it was found that in six states determination for reimbursement for CVS procedures was based on individual consideration on a per-test basis by medical review (Greenstein, 1987). Prenatal testing procedures tend to be expensive. For example, estimates of the costs of amniocentesis (including ultrasound) range from $600
to $2,000 depending upon the institution and the condition for which the testing is being done. However, the mean reimbursement for amniocentesis by Medicaid is significantly less, often not even covering one-half of the cost of the procedure. The low reimbursement rates for these procedures from the Medicaid program reduce the number of physicians willing to provide particular prenatal screening services to low-income women.

Even if low-income women can find private physicians willing to accept Medicaid, they are often faced with qualifying restrictions that act as barriers to obtaining quality prenatal screening service. Some states stipulate restrictions, often based on prior authorization by a physician, the age of the woman, the type of medical complication, or the number of tests previously completed. For example, a low-income woman can obtain ultrasound screening via Medicaid funding in all states except California. However, in New Hampshire she is subject to prior authorization, and in three states (Georgia, Minnesota, and Texas) she is subject to restrictions by age and by particular medical complication, and reimbursed only in those cases in which the procedure is defined as "medically necessary." Other states leave the definition of medical necessity to the discretion of the physician. The variability in definition means that some low-income women may not be able to obtain a particular screening technique in the areas in which they live, despite the fact that the procedure is funded in their state and that they qualify for it in neighboring states.

In Greenstein's 50-state study, between four and six states (depending on the type of counseling provided), did not cover genetic counseling costs, and between three and five provided reimbursement based on individual consideration by medical review (1987). This implies that a woman may have access to one procedure, but not to the counseling that may be necessary to accompany the test. Genetic procedures and results from laboratory tests are only valuable when preceded or accompanied by genetic counseling. The counseling helps couples interpret and think through the results of the test—a difficult and sensitive task.

It should also be noted that in order for genetic counseling to be reimbursed it must be carried out by a physician or a geneti-
cist with a Ph.D. In many instances, these individuals are too overwhelmed with other medical duties to be able to adequately provide counseling services. Many physicians have a genetics counselor, who is part of their practice, provide this care in order that the service be reimbursed. However, recent studies show that the average Medicaid reimbursement for counseling was approximately only one-third of the amount private insurers would reimburse for the same service (Greenstein, 1987).

The lower rate of Medicaid reimbursement and the restrictions on the provision of services contribute to creating a two-tiered medical system that influences access and quality of care for low-income women. Although some restrictions may be medically appropriate (such as considering the age of women) and others may protect poor women and women of color from unwarranted overuse of prenatal screening procedures, overall the restrictions do not allow equal access to high-quality health services. Even in places where prenatal screening is available in terms of geographic location, poor women have less control over the quality of care they receive because only some physicians and clinics choose to participate. Thus, the ability of Medicaid patients to obtain prenatal screening is markedly different from that of middle-class women.

**Funding through MCH Programs and Community and Migrant Health Centers**

The Maternal and Child Health program has very broad goals, including the promotion of maternal and child health through the provision of basic prenatal care and specialized care to children with disabling conditions. When Congress enacted the MCH Block Grant in 1981, prenatal care and genetic services were two of the programs covered; therefore, reproductive genetic services can be provided from MCH Block Grant funding through maternal and child health and genetic services programs. The income eligibility levels for free or subsidized care vary considerably from state to state, ranging from incomes at 100 to 250% of the poverty level. Three states have no income restrictions whatsoever (AGI, 1987).

Community health centers (CHCs) and migrant health centers (MHCs) provide services to underserved, disadvantaged populations. Several hundred agencies in urban and rural areas
of 49 states receive federal funds for reproductive genetic services (NCPCI, 1986). Two-thirds of the clients belong to minority groups and six out of ten have incomes below the federal poverty level. An additional 25% have incomes between 100 and 200% of the federal poverty level. Perinatal care services are included in the authorizing legislation that defines the primary care services that must be provided by CHCs and MHCs. Physician, laboratory, and other services relevant to maternity care must also be provided.

While CHCs generally provide a broad range of services including education, counseling, and social services, the medical care related to pregnancy appears to be fairly basic. Thirty-four percent of those agencies that do provide prenatal care do not serve high-risk patients on-site. Twenty-two percent of the CHCs and MHCs that only service low-risk patients on-site offer paid referrals for high-risk patients (AGI, 1987).

An examination of the funding of prenatal screening techniques through MCH programs and CHC and MHC services reveals two patterns that hamper equal access for low-income women. First, prenatal screening procedures are generally available in fewer states through MCH programs, CHCs, and MHCs than the number of states that provide specific services through Medicaid funding. For instance, only 48% of CHCs and MHCs and 80% of the country's MCH programs fund or provide ultrasound as compared to the 96% of states that fund the procedure through Medicaid (although as mentioned above, two states only provide partial coverage). The pattern is similar for coverage for amniocentesis and other related procedures (AGI, 1987).

The second pattern relates to the difference in the services offered through the MCH programs and the CHCs and MHCs. Overall, fewer states fund prenatal screening techniques through CHCs and MHCs than through MCH programs. For example, 72% of the states provide or pay for amniocentesis in MCH programs, while only 48% of the states provide or pay for this procedure in CHCs or MHCs (AGI, 1987). Furthermore, some clients are asked to pay a small fee.

It is important to note that women who have access to Medicaid but receive their services through these clinics also face
limited coverage, unless referred to a facility that accepts Medicaid. Such women should be made aware of the fact that if they are referred elsewhere additional procedures may be covered (although many women with Medicaid only have access to clinic services).

Overall it is clear that low-income women or women of color who use these clinics have more restricted access to prenatal screening techniques than women who utilize Medicaid services, and far more restricted access than women who have other forms of third-party coverage.

Special Programs for Pregnant Women

Some states have special maternity programs for women who are eligible for Medicaid and/or public assistance. There are also programs available for women who have low incomes, but incomes that are above the eligibility requirements for Medicaid. The first type of program has special provisions to determine eligibility in a short period of time and to provide a more comprehensive package of services for pregnant women. Most of these programs provide presumptive eligibility for women, allowing them to receive prenatal care services while actual eligibility for Medicaid is determined (Brown, 1988). Such programs allow women to enter prenatal care earlier in their pregnancies than would be the case if they applied for Medicaid without the benefit of this special program, and they also allow women to be evaluated for high-risk conditions including those that would require prenatal screening and testing. However, although these programs do offer the services of a nutritionist, health educator, case manager, and other specialists, most do not provide the services of a genetics assistant or genetics education on-site. Such provision could greatly increase referral and follow-up for potential genetic problems that affect some low-income populations—problems indicated by factors such as hemoglobin variants, being older than 35, HIV-positive status, and teratogen exposure from working in a dangerous environment, or substance abuse. Nevertheless, these programs do provide much-needed early prenatal care and screening services.

The second type of special program provides services to
women whose incomes are too high for Medicaid but too low to comfortably afford private insurance. One such program is the Healthy Start Program in Massachusetts. In 1985 the program accommodated women who were not currently enrolled in Medicaid, had no private insurance, and had a family income at or below 200% (originally 185%) of the federal poverty level. Healthy Start also underwrote the initial cost of the women's eligibility for Medicaid. All necessary medical care to maintain health during pregnancy is covered, including prenatal screenings, plus one pediatric visit. Providers are reimbursed at Medicaid rates for physicians at CHCs and at non-Medicaid public assistance rates for hospitals (Brown, 1988). It is up to the individual states to determine what types of procedures will be covered by such programs. In most cases, to control program costs (as with all public programs), there are some financial constraints and limitations put on the services provided to clients. Program evaluators have shown that this initiative has increased the number of low-income women able to access prenatal care (Brown, 1988) and should consequently have increased the number of women accessing reproductive genetic services at some level.

Reproductive Genetics Offered through HMOs

Some people with low incomes receive their care through HMOs, either through employment-based services or through state case management. For instance, in recent years an increasing number of states have begun to contract on a prepaid basis with providers of comprehensive health services, such as HMOs. Under these plans a local health care provider agrees to provide all or most of the needed health services to a patient for a fixed fee paid monthly or annually in advance. This kind of plan, called capitation, enables states to control costs by shifting the financial risk associated with paying for unexpected major medical problems from the state to the local provider.

The provision of care through HMOs is not, however, well matched to the realities of reproductive genetics. Because HMO policy discourages using specialists, HMO providers may not refer patients as often as they should for services or procedures (Pyeritz, 1990; Kenney, Torres, Dittes, & Mocias, 1986). In ad-
dition, HMOs normally contract with one laboratory. If the medical center to which a patient is referred for testing uses a different laboratory than the one contracted by the HMO, laboratory procedures may not be reimbursed. This situation may force the medical center to absorb the cost for low- or moderate-income patients.

Although HMOs have achieved considerable presence in a short time, with a few exceptions, they have not resolved how to deliver genetic services. At the present time, few HMOs believe they are large enough to support a full-time geneticist and genetics laboratory. Referrals outside the plan are expensive and are often viewed as a drain on potential profits (Pyeritz, 1990). Nevertheless, HMOs are beginning to address access to genetic services. Blake conducted a statewide assessment of financial access to genetic services in New York State and found that some form of coverage was provided for genetic services. Claims for genetic services in New York are paid if ordered by a patient's physician, the patient being referred if she has a history of miscarriage, has previously given birth to a child with a genetic disorder, or is in a high-risk group. In addition, it was found that genetic services were provided both by in-house HMO group members and by referrals to outside consultants or genetic service centers (Blake, 1987). The number and type of services referred to outside providers varied with each HMO. Eleven of the 17 HMOs surveyed indicated that referrals were sometimes made to non-HMO providers currently recognized as part of the statewide genetic services program (Blake, 1987). Although this is the case in New York State, additional research needs to be conducted on the role of HMOs in the provision of genetic services throughout the country.

Whether services are provided through an HMO or through other programs, the costs of providing care to low-income or culturally different populations are relatively higher than are the costs of providing services to the general population, and reimbursements are proportionately less. For instance, reimbursement is rare for nonphysician services that may be involved in the care of low-income or foreign-born patients, such as interpreters, additional social service referrals, nursing services, or genetics counselors or assistants (March of Dimes, 1990).
Access to Abortion

Abortion following prenatal diagnosis is fully available through Medicaid in just 13 states. Ten states fund abortion through Medicaid only in instances in which the woman's life is endangered, while other states impose varying restrictions, such as providing funding only when the pregnancy is a result of a rape or incest (Daley & Benson-Gold, 1993). Federal employees, recipients of services from the Indian Health Services (IHS), and federal inmates are also subject to such restrictions. For example, during fiscal year 1987, the Bureau of Prisons paid for an abortion only when the life of the mother would have been endangered if the fetus were carried to term or if the pregnancy was a result of rape. Most of these limitations do not allow a woman who has a "defective" fetus to have an abortion with public funding. For federal inmates, their sole source of medical care is through the prison, and for Native Americans who are geographically isolated from towns and cities, the IHS may in reality be their only source of health care. For those populations, then, access to abortion is very limited.

In instances where a woman chooses to terminate her pregnancy after an undesirable test result, the financial costs may be prohibitive—particularly in the case of a late-term abortion, which usually costs about $900. Poor women, thus, have very few options unless the abortions are performed at low or no cost. Public hospitals are a major source of health care for the poor, yet only 17% of all public hospitals report having performed abortions in 1985 (Henshaw, Forrest, & VanVort, 1987). Poor women also have limited access to facilities that provide abortions after the first trimester. Because so few providers perform late-term abortions, locating a facility, scheduling the procedure, and arranging travel can all impose serious burdens (Boston Women's Health Book Collective, 1986).

Professional and Public Education and Referral Systems

Because reproductive genetics is a relatively new and constantly changing field, public and medical providers require current, up-to-date information on procedures and services. Primary health care providers, too, need to have a basic knowl-
edge of the various genetic diseases, the related tests, and their implications. They need to know how to conduct the prescreening in order to identify patients at potential risk, and they need to be able to convey this information to low-income clients in a comprehensive manner in order to educate them on their full range of options (Paul & Kavanaugh, 1990). Ways in which to effectively educate the public should be further explored.

Referral systems should also be examined to ensure an effective system that takes into consideration the special needs of low-income patients. As is the case with other medical services, programs serving low-income patients may need increased mechanisms to facilitate follow-up, including telephone follow-up and pre-referral services (Paul & Kavanaugh, 1990). An active relationship between genetic services units and community clinics can involve those clinics in providing ongoing education about the referral process.

**Geographic Access**

In many states, genetic testing and counseling centers are located at major medical centers; depending on the state, there may be one or several sites. Most centers utilize a sliding-fee scale to assist families who have few resources for payment. In most of these programs, all services offered to more affluent patients are available to low-income clients, regardless of their ability to pay.

Some low-income women, however, may not be able to utilize services available in their state because the prenatal services are unevenly distributed geographically and are targeted to urban women. Research shows that women are more likely to use amniocentesis if they live in metropolitan rather than rural areas and if they have higher education levels (AGI, 1987). These findings hold regardless of race. It has also been found that women living in the South are less likely to have an amniocentesis. The subgroup utilizing the highest proportion of amniocentesis services tend to be white women older than 35 residing in areas other than the South (AGI, 1987). These findings seem to indicate that black women residing in the rural South may have especially limited access to reproductive genetic services.

Some studies, in addition, show that women who live in ru-
ral areas and are less educated are more likely to be subjected to prenatal screening using x-rays (AGI, 1987). According to a 1987 study, x-ray screening was performed on some women despite the fact that exposure to x-rays during pregnancy poses an unnecessary, albeit small, risk to the fetus, and that "it has been estimated that one-third of [the] individuals that had x-rays could have had an ultrasound for the same purposes (determining fetal position, fetal age, and multiple pregnancy)" (AGI, 1987). The higher rate of x-ray screening for rural women and for less educated women may be due to several factors: ultrasound technology and personnel may not always be available, clients may be less informed about the danger of x-rays to fetal health, or physicians may have less regard for their clients' health. Regardless of the cause, the more frequent use of x-ray screening may produce negative consequences for certain populations (AGI, 1987).

Other prohibitive factors related to geographic access include parking costs, travel time, time taken off from work, and babysitting fees. Many people do not own cars or cannot afford public transportation (Paul & Kavanaugh, 1990); thus, low-income people who live in suburban and rural populations may be hampered in their access to genetic services and so may use them less. In order to improve the availability of genetic services to geographically isolated populations, it is necessary to establish satellite clinics that utilize local resources, to demand adequate financial support for regional medical genetic centers to provide necessary transportation, and to utilize local resources to develop self-help strategies to address unmet needs.

Sociocultural Barriers and Diversity Issues

The goal of genetic counseling is to educate people about possible etiology, prognosis, management, recurrence, risks, options, and resources relating to genetic diseases (Vargas & Wilkerson, 1987). As with any decision-making process, the meanings attached to whatever is being communicated—in this case the results of the screening and the options available—depend upon the individuals involved and their sociocultural environments (Sue, 1981). When the topics being discussed are
as emotionally charged and controversial as issues of reproduction and possible abortion, the individual's core values, while too often unexamined or taken for granted, are likely to be tapped.

Among clients, genetic providers, and counselors, a great diversity is created through the multitude of differences in income level, language, culture, religion, and philosophy (Paul & Kavanaugh, 1990). While such variance in our culture is often a source of enrichment, the differences can also create impediments not easily overcome. There are the overt barriers of communication problems caused by language differences between Hispanics, Asians, and other immigrants, and English-speaking Americans. Less overt, however, are the ethnocultural differences, which are perhaps the greatest barrier to receiving care. Basic philosophies, life experiences, values, and histories vary. The emotions and desires of people may be similar from culture to culture, but their expression is often quite different. An inability to interpret nonverbal language or to understand the social pressures or gender roles in the context of another culture may blind caregivers to the psychosocial needs of their clients (Paul & Kavanaugh, 1990).

In addition, when the counselor and the client hold different class, racial, or ethnic positions in society, the interaction is likely to highlight differences in power and even attempts at social control. Low-income women and women of color, coming from communities whose worldviews often differ from the worldviews of the dominant culture and the medical profession, may experience a greater disjunction between their views and the views of the counselors than may white middle-class women. Luker, for example, documents the impact of different class-based worldviews on reproductive issues in her study of activists for and against abortion rights (1984). Hall and Ferree discuss the different structures of abortion attitudes by race (1986).

The new prenatal technologies frame the entire issue of reproduction for all women in terms of the dominant worldview. These technologies embody a definition of a reproductive problem that focuses on the fetus almost to the exclusion of the mother. Both Rothman and Petchevsky graphically depict the
way ultrasound procedures foster the definition of the mother as a "habitat" for the fetus, which becomes a "man-in-space" entity falsely assumed to be capable of independent existence (Petchevsky, 1987; Rothman, 1986). The "eclipsing of the pregnant woman's part in childbearing" is evident in the language used to name the new technologies. The phrase "test-tube baby" ignores the nurturing womb; the term "artificial insemination" disguises the "normal" process of conception, pregnancy, and birth once sperm are present; and "surrogacy" discredits the act of pregnancy as part of mothering (Petchevsky, 1987).

But another aspect of the dominant worldview is the historical association between eugenics and most social policy programs addressing the reproductive activities of poor women and women of color. Davis and Gordon both document how the contraceptive movement shifted from birth control to population control for state purposes in the nineteenth century (Gordon, 1977; Davis, 1983). Initially advocated by progressive thinkers, the birth control movement was an attempt to provide women with more reproductive choices. However, by the 1930s the "birth control movement was increasingly absorbed into programs aimed not at self-determination but at social control by the elite" (Gordon, 1977). Policies were promoted to maintain the dominance of the native-born white population while restricting the reproductive activities of other segments such as immigrants, blacks, and Native Americans. Davis points out the political tone of the birth control movement when she notes the class-bias and racism that crept into the movement early on. More and more, it was assumed that poor women, black and immigrant alike, have a "moral obligation to restrict the size of their families." What was demanded as a "right" for the privileged came to be interpreted as a "duty" for the poor (Davis, 1983).

This "duty" of the poor to have fewer children who might need welfare or other governmental services has become an underlying theme of many federally funded programs. One of the most blatant expressions of the population control directive is the involuntary sterilization of women of color. Dreifus documents how medical residents developed their surgical skills by
Services for Low-Income Women

performing tubal ligations on Hispanic women who were uninformed or misinformed of the operation they were undergoing (1977). Davis describes several cases in which black teenagers were sterilized through various governmental agencies including publicly funded birth control clinics (1983). Other studies have indicated high sterilization rates for Native American and Puerto Rican women.

Given the increasing feasibility of “selecting good genes,” those who are concerned about the new reproductive technologies should also be concerned that we may be entering a new eugenic era (Bowman, 1977). As was the case in the 1920s, an enthusiasm for using genetic makeup to make judgments about social worth has surfaced. Decisions on who has access to the new technologies will continue to be influenced by age and race; and subtle (and not so subtle) pressures will continue to be put on women who are being counseled, according to their socioeconomic status.

The use of reproductive technologies is often perceived by poor women and women of color within this tradition of eugenics and population control. The meanings and values associated with abortion and having children are often played out between a white, educated genetics counselor and a low-income black or Hispanic client against a historical background of distrust, control, and unequal power.

Within this historical context, three dimensions of conflict in worldview are likely to occur for low-income and minority women. First, in many cultures people see themselves as having little control over their fate, feeling as though they should not interfere with the will of God. For example, many Southeast Asians believe that amniocentesis interferes with the natural selection of the population, which is considered sacred (Asian Health Project, 1986). Devout Roman Catholics often view disability as God’s will. Instead of assuming that all cultures share the same attitudes, it is important to recognize cultural diversity, even within the seeming unity of, say, the predominantly Catholic Latino culture (Almquist, 1984). Given the uniqueness of their historical treatments by governmentally funded health services, it is likely that Cuban, Chicano, and Puerto Rican women have different attitudes toward reproductive technology.
Second, culture will affect ideas about how to interact with authority figures and who should be included in the decision-making process within the family structure. Harwood found that some Puerto Rican patients are unwilling to show that they did not understand or agree with an authority figure such as a physician (1981). The medical model assumes that the individual patient is the paramount decision maker for testing and treatment. But for many women of color, other family members—even extended family members—may be of prime significance in the decision-making process (Farfel & Holtzman, 1984).

Third, as discussed in Rayna Rapp’s chapter in this book, different individuals and cultural groups have varying perceptions of the levels of disability they can cope with and what it might be like to live with a disability (Rapp, 1994, 1987). These and other dimensions of the worldview will heavily influence the dynamics of the counseling process.

In order to help alleviate potential cultural misunderstandings, some valuable community resources can be drawn upon. For instance, in terms of language problems, the training and employment of capable and sensitive interpreters is crucial; the use of mere translators is not sufficient. Indeed, some languages used in the United States today do not even have a genetics vocabulary (Paul & Kavanaugh, 1990). Bilingual care is the most desirable, and efforts should be made to train minority workers in professional capacities. In addition, an understanding of more than the community’s most basic value system is essential. It would do health professionals well to learn about their community’s orthodoxy and interpretation without stereotyping. The local clergy can be useful sources in this respect. While at times being unaware or even suspicious of genetic care providers, their knowledge is useful; and they can themselves benefit from an opportunity to learn about genetics, thereby being able to counsel and comfort more effectively (Paul & Kavanaugh, 1990).

**Informed Consent**

The legal principle that competent adult patients should have autonomy over their bodies is firmly grounded in case law and
state statutes (Andrews, 1987). Patient decision-making is protected under the doctrine of informed consent, which requires that a patient's authorization for the diagnostic or treatment option be intentional, substantially noncontrolled, and based on substantial understanding (Faden & Beauchamp, 1986). Informed consent is impaired when clients are not given information (Farfel & Holtzman, 1984) or when the information given is unintelligible or is interpreted through different cultural filters.

Rapp describes how cultural factors can hamper informed consent on at least three levels (Rapp, 1994, 1987). First, certain medical information may not be salient within the sociocultural context of low-income clients. Second, some low-income clients cannot understand the medical terminology being used to interpret the medical information being given. Third, the client may prioritize the medical problems differently from the physician or genetics counselor. Again, given the great impact that decisions relating to informed consent can have on a woman's life, the various sociocultural issues need to be specifically addressed to this question.

Confidentiality

Confidentiality in the prenatal screening process is an extremely important issue for women of color who, historically, have experienced adverse consequences when intimate information has been revealed to third parties. Prenatal screening increases the amount and type of information included in medical files which, if revealed, could harm the patient's reputation, increase family conflict, or restrict education or employment opportunities (Winslade, 1982). Negative consequences have been documented for sickle-cell trait carriers when information was made available to third parties: employers refused to hire, promote, or even retain identified workers, and insurance companies either refused health and life insurance coverage or inflated the cost of coverage despite the fact that the sickle-cell trait has not been linked to shortened life spans (Hubbard & Henifin, 1984).

People with low incomes tend to be at higher risk of having their confidentiality rights abused. Many belonging to the low-
income population, such as unwed mothers, adolescent parents, and people at risk of contracting AIDS, have been categorized as being socially "deviant." The disclosure of personal information about them, because they have not adhered to society's moral codes, can have an especially negative impact on their lives. Unwed adolescent women, for example, may fear that the knowledge of their sexual activity or pregnancy will be revealed to their parents, while unwed male partners may fear that their identity will be revealed to public officials pursuing child support payments (Bowman, 1977). A woman may herself avoid prenatal care if she fears that she will be required to involve her male partner in genetic screening.

**Conclusions and Recommendations**

Although most prenatal screening techniques may be partially funded and available, poor women do not have equal access to them. To provide all women with the option of using reproductive genetic techniques and to make it a personal choice to utilize these techniques, it is imperative that all families have financial, geographic, and social access to prenatal diagnostic procedures.

Funding is a key, but not the only ingredient in this recommendation; information about the availability and purpose of these technologies should be effectively communicated to the public, and the existing qualifying restrictions should be evaluated and removed or modified should they be found to function as barriers to access. Funding should extend to more than only the poorest women who qualify for Medicaid. As has already been done in many states, the state and community should be funders of last resort for the poor who are ineligible for Medicaid or private insurance.

In genetic counseling involving poor women and women of color, it is important that differing worldviews and other potential barriers be considered by health care providers. One solution is that informed consent forms be required and written in simple understandable terms, in languages appropriate to the communities in which they are distributed. In addition, test results, particularly those involving sensitive areas, should be
Services for Low-Income Women

kept confidential and not as part of the patient’s medical record. Legal provisions guaranteeing confidentiality should be strengthened.

Furthermore, the negative influence of cultural factors in the counseling process should be addressed specifically. First, minority genetics counselors should be recruited: Black, Latino, and Asian health professionals, including social workers, physicians, counselors, nurses, and auxiliary health workers, should be encouraged to pursue some level of training in genetic counseling to increase the availability of counselors who are familiar with the culture, religion, and language of the community being served and who may understand or share that community’s attitudes toward death, disease, disability, and abortion. This approach has been successfully implemented in a number of genetics projects throughout the country.

Second, graduate genetic counseling curricula should include courses on counseling culturally diverse populations, and graduates of past programs should be informed of the availability of continuing education in this area. Where such courses are not available, they should be instituted, and licensing agencies should emphasize the need for such courses. Representatives of the minority groups to be served should be involved in the design, development, and operation of graduate education as well as in the actual medical provision of services.

Instead of merely identifying certain medical or utilization-related characteristics of population groups and service providers, it is important to identify clearly the barriers and gaps in services, and to analyze nationwide what constitute successful strategies. Once this information is gathered it is imperative that it is disseminated to service providers, advocacy groups, and state and local professional and government services to be reviewed and utilized for policy and program development. Additionally, if we are ever going to identify the underserved and document where they live and how well programs designed to serve them are succeeding, we will have to build a minimal base of data, working with the regional and state data coordinators to do special data collection and analysis.

The basic purpose of reproductive genetic technologies ought to be to provide a woman with as much relevant infor-
mation as possible so that she can make an informed and responsible decision. Between the theory and the actual practice of this ideal, however, there exists an enormous gap. Only by questioning our faith in technological progress, by illuminating the larger framework of medical care and reproduction, can the needs of low-income women and women of color be met. Placing their needs and experiences at the center of any analysis of reproductive technologies brings to the light the operation of ideological as well as structural factors that act as impediments to effective health care delivery. So much emphasis currently lies on the furthering of high technology when low-income women need better public health service in general and basic prenatal care in particular, including equal access to available technologies.

If we begin from the perspective of low-income women and women of color, we see that reproductive technology is just one small piece of a health care system that is neither structurally nor ideologically prepared to meet women’s needs. Changing this will require more than creating access to any particular technology or developing new technology. Even the most useful technology is only a means, not an end in itself. The social, economic, medical, and legal context in which women’s reproductive health concerns are addressed affects all women, and the perspective of low-income women and women of color may help us to recognize this essential truth.

NOTES

1. Information from Greenstein’s 1987 study and from the Alan Guttmacher Institute has not been updated because no more recent studies are known that are of a similar or as comprehensive a nature.
2. Greenstein (1987) describes seven levels of genetic counseling, including initial extended, initial intermediate, initial brief, follow-up extended, follow-up intermediate, follow-up brief, and pre-amniocentesis.

BIBLIOGRAPHY


NATIONAL Clearinghouse for Primary Care Information. (1986, Fall). *Community health centers: A quality system for the changing health care market* [Pamphlet]. McLean, VA: National Clearinghouse for Primary Care Information.


