2

Public Health Screening Programs

Disease screening is one of the most basic tools of modern public health and preventive medicine. Screening programs have a long and distinguished history in efforts to control epidemics of infectious diseases and targeting treatment for chronic diseases. Women in prenatal care routinely receive tests for complete blood count and blood type, diabetes, syphilis, and other conditions. Newborn children are routinely tested for errors of inborn metabolism and other problems. Although most of these outcomes are rare, a positive test result triggers interventions that benefit both mother and child, and these efforts have been responsible for substantial improvements in health and well-being.

As these screening programs have been implemented over the years, a substantial body of experience has been gained. In practice, when screening is conducted in contexts of gender inequality, racial discrimination, sexual taboos, and poverty, these conditions shape the attitudes and beliefs of health system and public health decision makers as well as patients, including those who have lost confidence that the health care system will treat them fairly. Thus, if screening programs are poorly conceived, organized, or implemented, they may lead to interventions of questionable merit and enhance the vulnerability of groups and individuals.

This chapter was prepared to provide background information on the terminology and generally accepted principles that should guide public health screening efforts, and to provide a historical and social context for implementation of HIV screening programs. The chapter begins with a discussion of screening as a public health paradigm, reviews a series of historical examples of perinatal screening programs in this context, and summarizes some of the issues associated with HIV testing in the United States.

SCREENING PROGRAMS: A PUBLIC HEALTH PARADIGM

In the public health paradigm, "testing," "screening," "case finding," "surveillance," and "counseling" are relevant to understanding what constitutes a screening program. In the context of this report, *testing* is the application of a test or measurement to selected individuals for the purpose of identifying a disease or medical condition. The individuals might be selected for testing because there is a clinical reason or risk factors that suggest the presence of the condition. *Screening* generally refers to the application of a test to all individuals in a defined population. Screening is commonly instituted for the purpose of *case finding*—identifying a previously unknown or unrecognized condition in apparently healthy or asymptomatic persons and offering presymptomatic treatment to those so identified. Screening is also sometimes done for *surveillance* purposes: to monitor the incidence or prevalence of a disease in a defined population over time, or to compare the incidence or prevalence among different populations. Surveillance is an important public health activity, and is necessary for monitoring the impact of, and allocating resources to, prevention programs. *Counseling* is the communication process by which individuals and their family members are given information about the nature, risks, burden, and benefits of testing, and the meaning of test results.

This report concentrates on HIV screening for the purpose of identifying and treating individual pregnant women for their own health and preventing transmission of HIV to their infants, that is, case finding. Testing of selected individuals and screening for surveillance purposes are important efforts, but not directly related to the committee's charge.

Principles of Public Health Screening

Through the experience with public health screening programs, a series of characteristics of well-organized public health screening programs has evolved (Wilson and Jungner, 1968). The committee's summary of the relevant characteristics is as follows:

1. The goals of the screening program should be clearly specified and shown to be achievable.
2. The natural history of the condition should be adequately understood, and treatment or intervention for those found positive widely accepted by the scientific and medical community, with evidence that early intervention improves health outcomes.
3. The screening test or measurement should distinguish those individuals who are likely to have the condition from those who are unlikely to have it. Tests can be judged in terms of their sensitivity (proportion of actual cases found by the test to be positive), specificity (proportion of non-cases found to be negative),

and positive predictive value (proportion of positive test results that are actual cases). Serious social, political, and economic problems tend to arise when screening tests fail to identify most of the people with the disease (false negatives), or identify far more people than actually have the disease (false positives).

4. There should be adequate facilities for diagnosis and resources for treatment for all who are found to have the condition, as well as agreement as to who will treat them. Psychological trauma and social disruption are most likely to result when screening programs identify people with a disease but fail to provide treatment.

5. The test and possible interventions should be acceptable to the affected population. For instance, a screening program that required a spinal tap of all participants, or had pregnancy termination as the only option, might not be acceptable to some groups. Programs in which there are concerns about the use of patient information or even the primary motives (using the test as a means of discrimination designed to deny civil rights, for instance) might also be judged unacceptable.

6. The cost of case finding, diagnosis, and treatment or intervention should be economically balanced in relation to the medical cost savings that might result from the screening program. Screening programs need not be cost-saving, but their costs must be reasonable in relation to the anticipated benefits, and to other opportunities for public health programs.

Various legal and ethical principles should also apply to public health screening programs (Faden et al., 1991). As a general principle, the least burdensome approach (from a legal and ethical viewpoint) that meets public health goals should always be preferred.

Programs must conform, first of all, to the requirements of the United States and state constitutions, common law, and statutory provisions. Targeted screening programs, for instance, must avoid problems of denial of equal protection inherent in focusing upon particular groups for testing. Moreover, the means to achieve otherwise acceptable social objectives must be narrowly tailored to avoid interference with the exercise of other important liberties, such as privacy. Screening programs must also comply with existing legal requirements concerning informed consent and confidentiality, duties to treat, and standards of professional negligence (Faden et al., 1991).

Moral considerations not protected by laws must also be taken into account. Three broad principles—beneficence, autonomy, and social justice—guide these considerations. Beneficence relates to the need to balance the benefits of public health measures (chiefly the protection from disease) against the harms (which could be physical or involve the loss of privacy or autonomy). Respect for autonomy emphasizes the importance of individual freedom and choice, both for political life and for personal decisions. Justice relates to the fair distribution of benefits and burdens of a public health program. None of these principles can be

seen as consistently more important than the others, but the degree to which they are satisfied must be balanced in every instance (Faden et al., 1991).

Spectrum of Screening Programs

Although screening programs are commonly thought of as either voluntary or mandatory, there is in fact a continuum of approaches that can be taken. Faden and colleagues (1991) characterize five types of programs: (1) completely mandatory, (2) conditionally mandatory, (3) routine without notification, (4) routine with notification, and (5) non-directive patient choice.[1]

In a *completely mandatory* program, a government agency requires citizens to undergo a screening test and sanctions those who do not comply. In public health screening programs, either providers or patients can be compelled to take action and suffer the consequences of not doing so. In addition, mandatory programs differ in the degree to which they are enforced, and the nature of the sanction for not complying. Enforcement and sanctions typically vary according to the agency upon which the mandate falls. State health departments can more easily enforce a policy requiring hospitals to test individuals than one requiring individuals to be tested because hospitals are subject to regulation, receive government funding, and regularly report a variety of performance measures.

In a *conditionally mandatory* program, either government or a private institution makes access to a designated service or opportunity contingent upon participation in the screening program. A prenatal care provider, for instance, could require women to undergo certain tests as a condition of receiving prenatal care.

Individuals in a *routine without notification* program are routinely and automatically tested unless they expressly ask that the test not be done.

Participants in a *routine with notification* program are informed that a certain test is a standard part of prenatal care, and that they have the right to refuse before the testing is done. Most women will be tested unless they explicitly opt out. Written informed consent is not necessary, but providers might want to document patient refusals in order to protect themselves from malpractice liability.

In a *non-directive patient choice* program individuals are provided information about the test, and the choice about whether to be tested is left to them. Patients actively must choose to be tested, and if they do not opt to be tested, the default is that no testing will occur. This type of program is the model typically employed in the context of genetic counseling where it is labeled "non-directive counseling." This also is the model used by HIV anonymous test sites.

While routine with notification and routine without notification programs,

[1]Faden and colleagues (1991) called the last option "voluntary," but the committee chose to call it "non-directive patient choice" to stress the more active role of the patient inherent in this type of program.

like the patient choice model, are voluntary, in that women have the right to choose not to be tested, women are much more likely to be tested under either of the "routine" models. In routine programs, the default is that all women will be tested, implying that the health care team believes that the test is an important part of good medical care. In the routine without notification program, women are not likely to know that they are being tested. In a routine with notification program, the woman must be explicitly informed of the test, and that she has the opportunity to opt out.

This list of categories is not mutually exclusive, nor a strict rank ordering, and some policies can reflect a combination of these approaches. As documented in Chapter 6, the current law in California and New Jersey, for instance, requires prenatal care providers to offer an HIV test to all women, but leaves it to the women to decide whether they want to be tested. In Texas, providers are required to test all women in prenatal care and their newborns unless a woman objects in writing, and to notify them about the testing and their right to refuse.

EXPERIENCE WITH SELECTED PUBLIC HEALTH SCREENING PROGRAMS[2]

Pregnant women are routinely tested for many conditions. The American Academy of Pediatrics and the American College of Obstetricians and Gynecologists, for instance, recommend that the following tests be performed early in pregnancy: hematocrit or hemoglobin, urinalysis, urine testing to detect asymptomatic bacteriuria, determination of blood groups and CDS (Rh) type, antibody screen, determination of immunity to rubella virus, syphilis screen, cervical cytology (as needed), antibodies to hepatitis B virus surface antigen, and HIV (with the women's consent) (AAP and ACOG, 1997). Newborns are routinely tested for phenylketonuria (PKU), a condition that can lead to mental retardation without dietary interventions, and other inborn errors of metabolism (Acuff and Faden, 1991). These tests are well accepted, and seen to clearly benefit the women and her child. Some prenatal and postnatal testing programs, however, have been more controversial.

The first prenatal screening program mandated by law was for syphilis in the 1930s and 1940s. In early 1960s, many states mandated newborn screening for PKU. Screening for other inborn errors of metabolism (congenital hypothyroidism, galactosemia, homocystinuria, histidenemia, maple syrup urine disease, and tyrosinemia) followed in the 1970s. In the early 1970s, many states initiated mandatory screening for sickle cell disease, a disease that had limited treatment options, in a variety of populations. Later in the same decade, maternal serum

[2]This section is drawn largely on the work of Acuff and Faden (1991).

alpha-fetoprotein tests were introduced, on a voluntary basis, to help detect neural tube defects. Today, specific tests mandated or recommended as standards of practice vary substantially across state lines. Mandatory prenatal and newborn testing for substance abuse is increasingly common.

In order to understand the context and appreciate the issues and challenges involved in making policy recommendations for HIV screening of pregnant women, the committee has focused on the historical experience with five selected conditions: (1) syphilis, (2) phenylketonuria, (3) sickle cell disease, (4) neural tube defects, and (5) substance abuse. These examples were chosen because they illustrate issues relevant to the perinatal transmission of HIV: they involve maternal and child health issues, infectious diseases, a variety of risks and benefits, and minority populations.

Syphilis

Early in the twentieth century, syphilis was more common than all other sexually transmitted diseases (STDs), and congenital syphilis was the leading cause of spontaneous abortions and stillbirth. Approximately one million women of childbearing age had syphilis. As a result 25,000 fetuses per year died before birth and 60,000 were born with syphilis (U.S. PHS, 1940). Prenatal syphilis testing was available as early as 1906, but was not mandated by law due to "onerous treatment options and the stigma of being shown to have the disease" (Acuff and Faden, 1991). Indeed, even being tested for syphilis was stigmatizing, and many physicians were reluctant to embarrass women in their care by suggesting it.

In 1936, Thomas Parran, the U.S. Surgeon General, established a program for controlling syphilis that included mandatory premarital and prenatal blood tests. Two years later, a *New York Post* editorial entitled "13,000 Babies" described stillborn and affected babies in New York (*New York Post*, 1938**)**. *Post* staff reported that "although public prenatal clinics were requiring blood tests for syphilis, only half of New York City's practicing obstetricians were routinely testing their private patients." By the end of 1945, as a result of this campaign, 36 states had passed prenatal syphilis screening laws. Under these laws, birth certificates had to record whether the test had been done prenatally and to explain why those who were not tested were not—women and physicians could refuse on religious or other grounds. Although these laws were passed before the introduction of antibiotic treatment, they resulted in a rapid decline in congenital transmission through case finding (Acuff and Faden, 1991), contract tracing, and the difficult and less effective therapies available at the time. Perhaps the most important aspect of these screening programs was that by making testing routine, they overcame the resistance of physicians to risk offending patients by suggesting a test for syphilis.

Phenylketonuria

Phenylketonuria (PKU) is a hereditary metabolic disorder, in which a deficiency of an enzyme results in the accumulation of the amino acid phenylalanine, resulting in severe mental retardation. It occurs in approximately 1 per 12,000 to 15,000 live births. In most infants diagnosed with PKU, mental retardation can be prevented by restricting dietary phenylalanine, starting before four weeks of age. In 1961, a simple heel-stick test for the condition was developed, and voluntary screening in conjunction with educational programs was initiated soon after in Massachusetts. By 1963, all Massachusetts maternity hospitals had voluntarily enrolled in PKU screening programs and were screening all newborns for PKU. Later that year, Massachusetts became the first state to enact a mandatory screening law.

Although the American Academy of Pediatrics and other professional groups opposed a legislative approach, 43 states have enacted mandatory screening laws, and the rest have set up active testing programs without statutory support. The existing statutes do not punish noncompliant parents. PKU screening is thus an example of a mandatory screening program, with the onus of compliance on maternity hospitals. In 1975, Maryland repealed its compulsory PKU screening law, replacing it with a statute and regulations requiring parental informed consent (Holtzman, 1984). After this change, 99.9% of parents offered newborn screening accepted it (Faden et al., 1982).

Although the PKU program has prevented retardation in thousands of infants, it has been argued that it was introduced prematurely from a medical point of view. Critics of the programs say that the public was led to believe that there was a higher degree of certainty about the results of PKU tests than was the case (NAS, 1975). As a result, some, but probably only a small percentage, of infants identified by the test were incorrectly identified and treated as having PKU. Others have criticized the statutes for not providing either adequate quality assurance mechanisms or adequate funding to care for infants identified as having PKU. The concerns about PKU testing, therefore, are in terms of the third and fourth principle of public health screening described above.

Sickle Cell Disease

Sickle cell disease (SCD) is an autosomal recessive hemolytic anemia occurring most frequently in African Americans, but also in persons of Mediterranean origin and others. Sickle cell disease, the homozygous condition, is estimated to occur in as many as one in 400 African-American newborns, and approximately 8% of African Americans are carriers of the sickle cell trait, the heterozygous condition. At least 10% of SCD cases in the United States occur in non-African Americans.

Little attention was given to sickle cell screening until the 1970s, when Dr. Roland Scott, in a letter to the *New England Journal of Medicine*, called for mass premarital carrier screening (Scott, 1970). Scott argued that although it was more prevalent in African Americans than cystic fibrosis, PKU, and other conditions of concern, little public health effort was directed at SCD. Scott noted that there was no cure for SCD, but suggested that it could be the first hereditary illness to be controlled by genetic counseling (that is, by encouraging carriers not to marry or have children). Scott's appeal was echoed in a public awareness campaign, and in 1971, President Nixon singled out SCD for special attention in a health message to Congress, calling for an increase in federal spending on sickle cell research, education, and screening.

Also in 1971, Connecticut passed the first sickle cell screening legislation, which other states quickly followed. These laws were typically introduced by African-American legislators and passed by unanimous vote. Screening was typically mandatory for some groups, but the legislation did not always specify which populations should be targeted; some included newborns, preschool children, individuals seeking marriage licenses, or inmates. Some laws called for carrier screening and some for disease screening.

Initial supporters of SCD screening were spurred on by the success of PKU screening, but the clear difference between SCD and PKU was not fully appreciated until later. There was no intervention for SCD at this time other than counseling to avoid marriage or pregnancy (prenatal SCD screening was not feasible). In addition, questions about whether and how programs should be targeted led to the potential for stigmatization. Some states explicitly targeted only African Americans. The New York statute required urban schoolchildren to be screened, but not rural children. The lack of attention to the eugenic implications of informing someone that he carries sickle cell trait led to charges of racism and growing opposition to screening programs. Most of the laws that were passed in the 1970s lacked confidentiality provisions, and, as a result, there were many documented cases of job discrimination, especially in the military, even for those having asymptomatic sickle cell trait. Eventually, the National Sickle Cell Anemia Control Act, passed in 1972**,** said federal funds could be used for screening only if programs were voluntary.

Studies published in the 1980s demonstrated that a prophylactic regimen of penicillin in infants significantly reduced the morbidity and mortality of SCD, and in 1987 a National Institutes of Health (NIH) consensus conference called for universal (not targeted) newborn screening for hemoglobinopathies (NIH, 1987). As a result of this recommendation and increased federal funding, 29 states have reinstituted non-targeted newborn screening programs.

The experience with SCD screening in the 1970s illustrates the difficulties that can arise when the goals of screening programs are not clearly specified, when there is no treatment that improves health outcomes, and when the intervention is not acceptable to the target population because of stigma and discrimina-

tion. Current screening efforts, consistent with the NIH consensus statement, have addressed each of these problems and, as a result, are more acceptable on public health and ethical grounds. The change in approach to SCD screening over time, as new facts and treatment opportunities emerge, illustrates that programs must have the flexibility to change over time, as the situation changes.

Neural Tube Defects

Neural tube defects (NTDs) are major birth defects affecting the brain and spinal column. These defects range from uniformly fatal to severely disabling conditions, and include spina bifida. In 1973, it was reported that maternal serum alpha-fetoprotein (MSAFP) levels are elevated in pregnancies where the fetus is affected with an open neural tube. Alpha-fetoprotein (AFP) is a normal fetal protein that is usually present in maternal serum, so a higher than normal level indicates that the fetus is leaking fetal protein, usually, but not always, from an open neural tube. Follow-up tests such as amniocentesis and ultrasonography are required to confirm the diagnosis. By 1977, several companies had developed MSAFP kits, but the American College of Obstetricians and Gynecologists (ACOG) and other groups opposed their use because of the test's inherently high false positive rate. Others opposed the program because, since there is no identifiable high-risk groups for NTDs, all pregnant women would have to be screened. In addition, some individuals find the screening program unacceptable because the only option for preventing the birth of a child with an NTD is to terminate the pregnancy. Another concern was that some areas did not have the amniocentesis and ultrasonography facilities necessary to follow up a positive MSAFP test result. There are concerns, therefore, relating to the third, fourth, and fifth public health screening principles.

In 1985, ACOG, apparently driven by a concern about malpractice litigation, issued a strongly worded alert to its members advising them to investigate the availability of the tests in their area, familiarize themselves with the procedure and follow-up tests, advise every prenatal patient of the availability of the test, and document this discussion and the patient's decision. ACOG did not, at this time, change its recommendation that the test not be used routinely. Two years later, ACOG, citing greater understanding of MSAFP and improvement in follow-up tests, and new findings about the association of MSAFP with Down's syndrome, concluded:

> MSAFP screening for neural tube defects detection should now be undertaken in United States communities having expertise in ultrasound, genetic counseling, and amniocentesis. In communities in which these facilities are limited, it is still prudent to inform pregnant women of the availability of MSAFP screening. . . . Those communities not having appropriate facilities should attempt to

> develop a full scale MSAFP program, collaboration with an existing program, at a regional level [Simpson and Nadler, 1987].

MSAFP is thus a non-directive patient choice screening program, with strong incentives to providers to inform women about its availability.

Prenatal and Newborn Screening for Substance Abuse

State policies on prenatal and newborn screening for substance abuse are evolving rapidly in the context of a discussion of changing state policies regarding drug use (Chavkin et al., 1998). Overall, states are moving away from a therapeutic approach focusing on treatment and oversight to criminal prosecution. Between 1992 and 1995, the number of states with mandatory drug or alcohol testing of pregnant women increased from one to six, and the number of states with mandatory drug or alcohol testing of neonates increased from zero to four.[3] An increasing number of states have a practice of reporting positive toxicology results. The number of states with such practices for pregnant women increased from 7 to 31, and for neonates from 18 to 33, over the same period. Furthermore, in 1995, 12 states mandated treatment for pregnant women found to be using drugs, and 13 mandated treatment for women with children. No states had mandatory treatment policies in 1992.

Many of these screening programs are being introduced in prenatal care as a result of substance abuse laws and policies, without clear public health goals and without providing treatment to improve health outcomes. In addition, the common intervention, removal of the child from the mother's care, is not acceptable to the affected population. Some of these programs are targeted to minority groups, and thus are stigmatizing. More basically, perinatal substance abuse screening programs illustrate the problems that arise when a screening program is set up to deal with a problem that all agree about (e.g., "crack babies") but the implications are not carefully thought through (Jos et al., 1995).

To date there has been little outcry about prenatal and newborn substance abuse screening programs, perhaps because the interests of the affected women are not well reflected in policy decisions, but the history of other screening programs suggests that this approach may not serve public health goals well.

HIV TESTING AND SCREENING IN THE UNITED STATES

As described in Chapter 4, the primary HIV/AIDS screening tests used in the United States identify antibodies to the HIV virus, indicating that an individual has been exposed to the virus and has mounted an immune response. As such,

[3]The District of Columbia is counted as a "state" in this paragraph.

HIV tests do not indicate whether "seropositive" individuals (those who test positive for HIV) have AIDS, a later stage in HIV disease. Also, infected individuals may not test positive for HIV for a period of weeks after infection. Thus there is a distinction between "HIV-infected," "seropositive," and "AIDS." When applied to newborns, standard HIV tests react to maternal antibodies, which are present in all children of HIV-infected mothers, up to 18 months after birth, whether the child is HIV-infected or not. Newborns who test positive for HIV antibodies are said to be "HIV-affected."

Serum HIV tests first became available in the United States in 1985 and were originally used to protect the safety of the blood supply by excluding blood from HIV-positive donors (IOM, 1995c). At the time, there was great concern about the safety of the blood supply, so the improved ability to accurately detect infected individuals (especially compared to the surrogate measures that were the best tools before this time) made serum HIV tests attractive public health measures. Tests also became available at this time for individuals, but stigma and discrimination associated with homosexuality, drug use, and AIDS itself, coupled with the fact that there were no measures available to alter the disease process in HIV-infected individuals, limited their acceptability. Some assumed that the primary purpose of testing was to facilitate the adoption of risk reduction behaviors. Over time, however, it became clear that knowledge of HIV status was insufficient to stimulate behavior change in all affected persons, and that many other factors contribute to decisions about risk reduction behaviors (Coates et al., 1988).

It was not until the discovery of effective interventions such as ZDV and *Pneumocystis carinii* pneumonia (PCP) prophylaxis in the late 1980s that HIV testing carried medical benefits for the individuals tested. Soon afterwards, some professionals advocated moving beyond testing solely as a means to stop the spread of HIV. Rhame and Maki (1989), for instance, reported that HIV testing had benefits for infected persons and the general public health. As an example, they noted that early detection of HIV status was one means to counteract denial, facilitate early treatment, and ultimately improve the health status of people infected with HIV. More generally, Rhame and Maki (1989) note that more general HIV testing would

1. reduce the reluctance of those at risk to pursue testing;
2. undermine the existence of the we/they mentality and stigma associated with HIV disease;
3. motivate risk reduction behaviors;
4. serve as the basis for partner notification programs; and
5. facilitate the identification of candidates for clinical research.

In a review of the factors associated with the acceptability of voluntary HIV testing in the United States, Irwin and colleagues (1996) concluded that the factors associated with high acceptance rates include (1) the person's perception

of HIV risk; (2) acknowledging risk behaviors; (3) confidentiality protections; (4) presenting counseling and testing as "routine" rather than optional; and (5) the provider's belief that counseling and testing will benefit the client. Factors associated with low acceptance rates included prior HIV testing, fears about coping with results, and explicit informed consent.

While the benefits of testing appear clear and relevant to the current situation where effective treatment is available, serious cautions must be acknowledged. According to Quinn (1998), testing could have a paradoxical effect on public health. For example, tremendous fear about AIDS, its existence within stigmatized groups, and the perception that AIDS was a death sentence contributed to discrimination against those with AIDS or even those perceived to be at risk for HIV infection. Being tested per se was viewed as a sign that one was at risk. Additionally, among ethnic and racial minority populations, there were concerns that the benefits of early detection might have resulted in further stigma and discrimination (see below), outweighing the benefits of treatment. Thus, recommendations for broader testing might serve to drive those at highest risk underground.

When HIV testing programs were first instituted, HIV-positive individuals were subject to discrimination, and in some cases, even those known to have been *tested* for HIV were assumed to be at high risk. Presently, most HIV testing is voluntary and intended to benefit the person being tested, yet there is mandatory testing in certain situations such as the armed forces and prisons. Both the Congress and state legislatures continue to consider legislation mandating HIV testing for other defined populations. Considering these events, the affected communities have lingering concerns about HIV testing. This history explains why HIV testing was, and still is, thought by many to differ from other clinical testing and public health screening programs, part of a phenomenon often labeled "AIDS exceptionalism" (Bayer, 1991).

As this report was being prepared in 1998, an increasing number of states are requiring positive HIV test results to be reported to state health departments with names or other personal identifiers (Gostin et al., in press). The purpose of most of these requirements is to improve surveillance, as people with HIV infection are living longer and AIDS cases per se have become increasingly less informative about the HIV epidemic (Gostin et al., 1997). Legislation enacted in New York in June 1998, however, includes a provision that would require that HIV-positive individuals be asked about their sexual partners so that health department officials could trace contacts. AIDS activists have expressed concern about the potential loss of privacy that would come from linking surveillance and contact tracing activities, and suggested that these provisions would discourage people from being tested and seeking treatment (Perez-Pena, 1998).

Meeting in January 1998, AIDS activists, public health officials, and others considered the important changes that had occurred in recent years in terms of new diagnostic tests, improved treatment opportunities, and progress in behav-

ioral science and the prevention of HIV risk behaviors, and concluded that their thoughts about HIV testing had not kept pace. The group's consensus is that knowledge of HIV status is desirable because it allows individuals to make informed treatment and prevention decisions. From this starting point, the group agreed on three themes that should guide current HIV testing activities:

1. HIV testing is a tool that should be linked to both prevention and care;
2. HIV testing should be expanded in a variety of settings, guided by public health principles; and
3. Testing strategies must address issues of stigma and social risk.

Although not stated in these terms, the consensus report essentially calls for an end to AIDS exceptionalism, balanced with efforts to reduce the need for a special approach in the first place (Kaiser Family Foundation, 1998b). Making testing more routine, in itself, can also help to reduce the stigma associated with testing per se.

Newborn HIV Screening

Newborn HIV screening was introduced in the late 1980s for the purpose of surveillance, not case finding, when public health officials in some states and at the Centers for Disease Control and Prevention (CDC) realized that blood samples routinely taken from all newborns for PKU testing also could be tested for HIV. Because these tests detected maternal antibodies, they revealed the mothers' and not the babies' HIV status. Since no known treatment for HIV-positive children or means to prevent transmission existed at that time, anonymous or "blind" testing was considered acceptable, and, since it was blind, women would not refuse to be tested based on known or perceived HIV risks, so prevalence data would be unbiased. This survey, known as the Survey of Childbearing Women (Davis et al., 1995), was thus extremely valuable for surveillance purposes, and indeed was the only truly reliable national surveillance data on HIV prevalence in any defined population (NRC, 1989).

In the mid-1990s New York State legislators and others argued, in the interest of the HIV-positive children whose status was not known to their parents or guardians, that the results should be "unblinded," as described in Appendix L, and CDC soon discontinued the Survey of Childbearing Women nationally. New York statutes now require notification of parents and health care providers of all infants with positive HIV tests, so what was a surveillance activity became a case finding program. As described in Chapter 1, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Amendments of 1996 could, under certain conditions, obligate other states to institute similar programs. Such mandatory newborn screening approaches have been criticized as providing only limited benefits to the children found to be positive (compared to prenatal diag-

nosis of the mother), unable to prevent transmission from mother to child, and seriously intruding on the privacy and autonomy of the mothers, whose HIV status is actually being determined.

New York's "Baby AIDS" law illustrates the need for flexible policies that can accommodate new scientific and clinical information. According to Appendix L, by the early 1990s, PCP prophylaxis had been shown to be effective in preventing pneumonia in HIV-infected newborns. The New York City Child Welfare Administration's policy, however, made it difficult to test children in foster care for HIV, even if it was suspected that they were infected. Given these circumstances, and the lack of evidence at that time that transmission could be prevented, "unblinding" the results made sense, as a response the foster care situation in New York City. By the time that the idea of unblinding the heel-stick test results overcame political opposition and became law, the AIDS Clinical Trials Group protocol number 76 (ACTG 076) results had already shown transmission could be prevented. The law, thus, may have been an appropriate response to the situation before 1994, when it was first conceptualized. With its focus on newborn rather than prenatal testing, however, the law does not reflect current public health and clinical preventive approaches.

Community Response to HIV Testing

The advocacy of articulate, politically sophisticated organizations in the gay community has had a tremendous impact on AIDS policies. With the shift in the epidemic toward African-American and Hispanic populations in recent years, current support for protections against discrimination and voluntary measures to control the epidemic may be seriously eroded. These minority groups have limited advocacy organizations and resources needed to protect their rights. As the epidemic continues to affect people living in poverty and people who have historically been disenfranchised, there is an increased risk that testing can and will be used to discriminate against people infected with, or even thought to be infected with, HIV and will further isolate people with AIDS. Thus, policy decisions must incorporate strong protections for those who are already suffering from discrimination.

The potential for such regressive policies is underscored by the epidemiology of perinatal HIV transmission, characterized by its disproportionate impact on African-American and Hispanic women, and the devastation to their lives, their families, and their communities. These women must be the focus of increased prevention and treatment efforts. The interaction of race, gender, and social class will continue to be critical factors to be addressed as new policies are developed, implemented, and evaluated.

Much of the voiced African-American opposition to HIV testing programs must be understood in the context of historical perceptions of mistrust and fear toward the public health and medical research establishment. This underlying

distrust and fear is grounded in a history of medical neglect and significant violations of human subjects in research, especially in the Tuskegee Study of Untreated Syphilis in the Negro Male (Jones, 1993; Gamble, 1993, 1997). A formal apology for this treatment, issued by President Clinton in 1997, should help to create a new, more favorable atmosphere on these issues (Thomas and Quinn, 1997).

Without adequate protection such as anonymous testing, case reporting without name identifiers, voluntary partner notification, and strong confidentiality regulations, those people at greatest risk who already feel significant distrust of the public health/government system may not seek HIV testing services. Consequently, there may continue to be a growth in numbers of unknowingly infected individuals, higher mortality rates than among those whose infection is detected early, tremendous budgetary strains on the health care delivery system, and more HIV-infected babies. This situation could spark public support for repressive policies against those suspected to be HIV-infected (Stoddard and Reiman, 1990; Lovvorn and Quinn, 1997).

CONCLUSIONS

Public health screening programs have helped to control epidemics of infectious disease and to target treatment for chronic diseases. The examples in this section, especially congenital syphilis and MSAFP, illustrate the tangible public health benefits of perinatal screening efforts. In practice, however, when screening is conducted in contexts of prevalent gender inequality, racial discrimination, sexual taboos, and poverty, these conditions shape the attitudes and beliefs of health system and public health decision makers as well as patients, including those who have lost confidence that the health care system will treat them fairly. Thus, if screening programs are poorly conceived, organized, or implemented, they may lead to interventions of questionable merit and enhance the vulnerability of groups and individuals.