
Chapter 1

Summary and Policy Options

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Summary and Policy Options

INTRODUCTION

A nation's future lies with its children. Thus, the health of children is a matter of fundamental importance to all societies. In highly industrialized countries like the United States, the vast majority of children are healthy,¹ but preventing disease and reducing injuries among the young holds promise for even further improvements in their well-being.

Substantial improvements in children's health have been registered in the United States within the recent past. The U.S. infant mortality rate, for example, declined from 14.1 per 1,000 live births in 1977 to 10.8 in 1984, and the mortality rate of children between 1 and 14 years declined from 42.3 per 1,000 in 1977 to 34.1 per 1,000 in 1984.

Without dismissing the importance of such gains, one can cite at least three compelling reasons for an assessment of strategies for further improving American children's health. First, the evidence suggests that the United States is not doing as well as it could in preventing health problems in children, despite the improvements to date. Second, prevention or treatment of health care problems in early childhood can benefit a child for a lifetime, and, conversely, failure to prevent such problems can be costly to the child, the child's family, and the Nation. Finally, the burdens of illness, disability, and death are not borne evenly. Some American children are at particularly high risk for poor health, and many of them have only limited access to medical services.

The high cost of poor health in infants and children suggests that some preventive strategies, even those approaches that are initially expensive,



Photo credit: March of Dimes Birth Defects Foundation

Prevention or treatment of health care problems in infancy or early childhood creates a lifetime of benefits for the child, the child's family, and society.

may have payoffs in improved health, lower medical care costs, or both, that make them well worth their expense. The principal objective of this OTA assessment was to identify preventive strategies with high payoffs in relation to their initial costs.

¹As used in this assessment, health refers to physical, not emotional or mental health. As many as 12 to 15 percent of the Nation's children may suffer from mental or emotional problems. For a discussion of issues involving children's mental health, see OTA's background paper *Children's Mental Health: Problems and Services* (663).

²A preventive strategy is any action taken by individuals, professionals, or governments to alter the environment, change the be-

havior of a child or the family, or provide effective health care with the intention of preventing disease or injury (364). A strategy includes not only specific preventive technologies (e. g., vaccines or childproof safety caps for medicines) but also the means of financing, organizing, and delivering such technologies (e. g., mandatory school immunization programs).

STUDY BOUNDARIES

Given the wide range of potential issues in children's health, boundaries were needed for OTA's study. OTA focused on preventive strategies applicable to preadolescent children, because the major health problems of adolescence have their origins in emotional and behavioral problems rather than in problems of physical health.

Furthermore, the assessment focused largely on strategies involving personal health care services, not on strategies involving, for example, the educational sector or the larger environment in which children are raised. Some authorities claim that American children's health problems can be effectively addressed only in the context of a comprehensive national strategy that considers the implications of changes in the structure of the American family, the increasing percentage of mothers who work outside the home, and the increasing percentage of children in poverty (248,396,639). Although a good case can be made for a comprehensive national strategy on children, and some elements of such a strategy are already in place, there is still good reason to search for more limited actions that can be implemented and that can benefit children today.

This assessment of preventive strategies placed heavy emphasis on the importance of reducing the

U.S. infant mortality rate, which is almost double the rate in Japan and higher than the rates in 15 other developed countries (733). One of the primary causes of infant mortality is low birthweight (under 2,500 grams or 5 lbs. 8 oz.). Two personal health care strategies for preventing low birthweight are examined in this assessment:

- providing better access to family planning services for high-risk women, particularly adolescents; and
- improving prenatal care for pregnant women at high risk of giving birth to low birthweight babies.

OTA also focused on four other health problems of young children:

- congenital disorders detectable by newborn screening techniques;
- diseases and conditions preventable through well-child care;
- accidental injuries; and
- maltreatment (child abuse and neglect).

Each of these health problems accounts for a substantial burden of illness, disability, and death in U.S. children. Table 1-1 summarizes some pertinent facts about each area chosen for study.

TRENDS IN U.S. INFANT MORTALITY

Infant mortality is a matter of widespread concern in this country. The infant mortality rate for any year is defined as the number of infant deaths under 1 year of age per 1,000 live births in the same year. About 1 percent of all babies born in the United States—40,030 in 1985—die in the first year of life (709). Almost two-thirds of these infant deaths occur in the neonatal period (the first 28 days of life); the others occur in the postneonatal period (28 days to 1 year).

The infant mortality rate has long been a primary indicator of the overall health status of nations for two reasons. First, it tends to be closely associated with access to food, shelter, education, sanitation, and health care; and second, it is rela-

tively easy to monitor with basic vital statistics collected in most countries.

The United States ranks 17th among industrialized countries in infant mortality, and its position has not improved since 1980 (733). If the U.S. infant mortality rate in 1985 had been equal to that achieved by the country with the lowest rate (Japan, with a rate of 5.5 deaths per 1,000 live births in 1985), there would have been 19,350 fewer infant deaths in the United States that year—a sum greater than the number of deaths of all U.S. children 1 to 15 years of age in 1985.

The high U.S. infant mortality rate is brought about largely by the high low birthweight rate in this country. Low birthweight so overwhelms

Table 1-1.—Burden of Illness in U.S. Children

Problem	Burden of illness or cost
Infant mortality and low birthweight	<ul style="list-style-type: none"> • Almost 40,000 babies (1 percent of all U.S. births) die in the first year of life each year. • The United States ranks 17th among industrialized countries in infant mortality. • 6.7 percent of all U.S. newborns are low birthweight babies (under 2,500 grams, about 5 lbs. 8 oz.). • 16 percent of all very low birthweight babies (i.e., those weighing under 1,500 grams, about 3 lbs. 5 oz.) are moderately or severely handicapped.
Congenital disorders detectable by newborn screening	<ul style="list-style-type: none"> • About 4,500 cases of detectable diseases causing death or mental retardation occur each year.
Conditions preventable through well-child care	<ul style="list-style-type: none"> • 37 percent of U.S. infants were fully immunized against diphtheria, tetanus, and pertussis (whooping cough) in 1983. • 78 percent of white children and 62 percent of nonwhite children from 1 to 4 years old were fully immunized against polio in 1985. • Almost 8,000 cases of measles occurred in the United States in 1986.
Accidental childhood injuries	<ul style="list-style-type: none"> • 7,850 deaths were caused by accidental injuries in children under 15 years old in 1984. • 1 in every 9 children is hospitalized for accidental or other injuries before age 15. • 10 million emergency room visits per year are made for accidental or other injuries.
Child maltreatment	<ul style="list-style-type: none"> • At least 1,200 children's deaths in 1986 occurred as a result of child abuse. • 24,000 children sustained serious physical injury due to child abuse in 1983. • 1.9 million cases of suspected child abuse and neglect were reported in 1985. • 150,000 to 200,000 cases of sexual abuse occur in the United States each year.

SOURCE: Office of Technology Assessment, 1988

other health problems of early childhood that it cannot be ignored. The prevention of low birthweight and infant mortality has been a recent concern of many groups in this country (296,604); in 1979, the U.S. Surgeon General's Report on Health Promotion identified the reduction of infant mortality as a fundamental goal of the Nation (715).

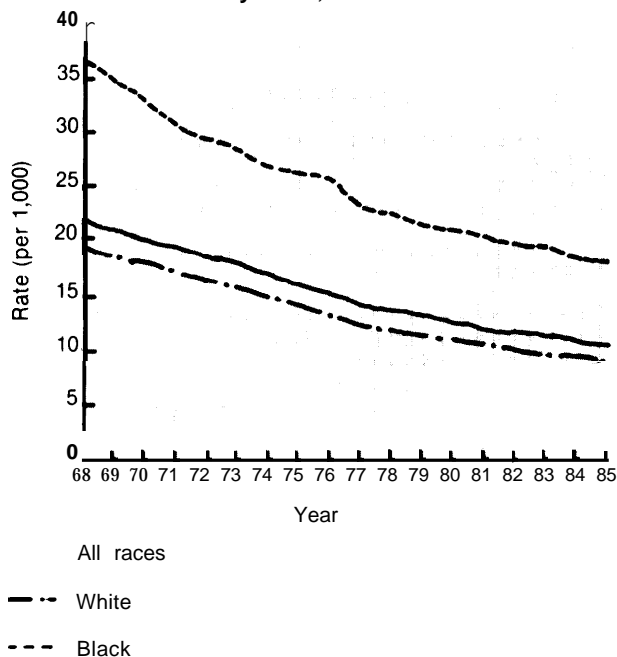
Until the early 1980s, the United States made remarkable progress in reducing infant mortality. During the 17-year period from 1968 to 1985, the U.S. infant mortality rate declined by about 50 percent for both whites and blacks—from 21.8 deaths per 1,000 live births in 1968 to 10.6 per 1,000 births in 1985 (see figure 1-1). The average annual compound rate of decline during this period was 4.2 percent. The infant mortality rate for blacks remained equal to about twice the white rate throughout the 17-year period.

In the early 1980s, the pace of the decline in the U.S. infant mortality rate slowed apprecia-

bly. In the 3-year period from 1981 to 1984, the annual average of rate of decline was 3.3 percent, down by about 20 percent from the 4.1-percent average experienced in the 4-year period from 1977 to 1981. And provisional U.S. infant mortality data extending into 1987 indicate continued deterioration in the pace of decline.

Year-to-year fluctuations in reported infant mortality rates are to be expected, but the recent slowdown in improvement of the U.S. infant mortality rate cannot be dismissed as a random variation around the trend. At OTA's request, the National Center for Health Statistics (NCHS) predicted U.S. infant mortality rates for the 3-year period from 1982 to 1985 on the basis of trends in final U.S. infant mortality rates from 1968 to 1981. The U.S. infant mortality rate in 1985 was 10.6 infant deaths per 1,000 live births, significantly higher than the rate predicted for that year on the basis of the NCHS analysis (9.9 deaths per 1,000 births). Had the U.S. infant mortality rate

Figure 1-1.—U.S. Infant Mortality Rates by Race, 1968-85



SOURCE Office of Technology Assessment, 1988, based on U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics, Hyattsville, MD, unpublished data from U.S. vital statistics, 1986

continued to decline after 1981 at the rate predicted by NCHS on the basis of previous trends, the United States would have suffered about 2,630 fewer infant deaths in 1985 than were actually reported.

No single explanation is sufficient for why the U.S. infant mortality rate began to level off in the early 1980s and continues to do so into the present. But the key to the slowdown puzzle appears to be the deteriorating U.S. birthweight distribution—especially the increase in the number of live births recorded in the lowest birthweight categories. In 1980, low birthweight infants represented less than 7 percent of all newborns in the United States but accounted for 60 percent of all babies who died in infancy (687).

Progress in reducing infant mortality rates can come through two routes:

1. changes in birthweight-specific infant mortality rates, and
2. changes in the distribution of birthweights toward heavier babies.

Historically, most of the progress in the United States since 1960 has been via the first route. In fact, between 1960 and 1980, about 91 percent of the improvement in the U.S. infant mortality rate was due to changes in birthweight-specific mortality rates (80). In recent years, U.S. birthweight-specific mortality rates have continued to improve, in large measure as a result of rapid advances in the technology of neonatal intensive care (665). Neonatal intensive care units (NICUs) offer sophisticated monitoring and therapy to premature infants whose undeveloped lungs do not function properly. The 1970s saw rapid advances in respiratory therapy techniques and improvements in mechanical ventilation, which had a major impact on the survival of premature infants with respiratory distress syndrome. In the 1980s, continued improvements in outcomes have occurred in very low birthweight infants (those under 1,500 grams or 3 lbs. 5 oz.), with the greatest improvement in the 750- to 1,000-gram birthweight group (665).

While U.S. birthweight-specific mortality rates have improved in the 1980s, the reported birthweight distribution in this country has actually deteriorated. Between 1977 and 1984, the percentage of live births at normal birthweights (greater than 2,500 grams) increased slightly, but the distribution of low birthweight infants shifted toward the lowest birthweight intervals (those under 1,000 grams or 2 lbs. 3 oz.). Had U.S. birthweight-specific mortality rates not improved in this period, the deteriorating birthweight distribution would have resulted in an *increase* in the overall U.S. infant mortality rate (339).

Ironically, the success of NICUs in improving outcomes of the larger very low birthweight babies may be partly responsible for the reported deterioration of the birthweight distribution. As the frontier of viability has been pushed back to smaller and smaller babies, obstetricians and neonatologists may be more frequently resuscitating the very tiniest newborns, even those under 500 grams, despite the fact that very few of these infants will survive. The increased concentration of high-risk births in sophisticated regional perinatal centers and ethical concerns arising from the

“Baby Doe” controversy may also be contributing to higher rates of resuscitation.

In addition to more aggressively resuscitating the tiniest newborns, U.S. hospitals today may be more careful to report **as** live births what in the past might have been reported as fetal deaths or have gone unreported altogether. Greater awareness of State birth reporting requirements and legal and economic considerations may be influencing reporting practices (210,755).

Whatever the reasons, the number of reported live births under 500 grams in this country increased much more rapidly in the 1980s than did live births at all other birthweights (699,704,709). The vast majority of newborns under 500 grams die in infancy; thus, an increase in the reported number of live births in this category would have the effect of pushing up U.S. infant mortality rates.

In fact, OTA calculated that if the number of live births under 500 grams had increased between 1977 and 1984 only as fast as the number in the other low birthweight categories, the U.S. infant mortality rate in 1984 would have been 10.4 rather than the reported rate of 10.8 per 1,000 live births.³ The slowdown in the rate of change in U.S. infant mortality would have been much less apparent without the excess births in the under-500-gram category: the average annual rate of decline in U.S. infant mortality rate would have been 4.4 percent (rather than the reported rate of 4.1 percent) from 1977 to 1981 and 4.1 percent (rather than the reported rate of 3.3 percent) from 1981 to 1984. Thus, a large part of the slowdown in improvement in the U.S. infant mortality rate in the early 1980s may be a reflection of changing management and reporting of very premature deliveries rather than a real deterioration in the health of pregnant women.

³Following the birth of Baby Jane Doe (an infant born with multiple birth defects) Federal regulations were written to require that hospitals treat severely handicapped infants over the objections of their parents. Those regulations were later declared unconstitutional by the Supreme Court.

⁴OTA assumed for this analysis that all under-500-gram live births died in infancy. Only a few such babies have survived to date.

Other factors may also have contributed to the slowdown in improvement, although available evidence suggests that their impact would be modest. Such factors include the natural maturation of technologies for neonatal intensive care that diffused widely in the mid-1970s and that are now improving outcomes of the smallest birthweight babies; the completion of the process of diffusion of abortion services in the late 1970s that may have differentially reduced birth rates in women at high risk for infant mortality, such as very young teenagers and unmarried women (610); the increase in the percentage of infants living in poverty; and deterioration in real dollars in the availability of subsidized health care services for pregnant women and children.

The coincidence of increasing poverty among infants in the early 1980s and decreased real spending on publicly subsidized health services in this country is particularly disturbing. From 1978 to 1984, the percentage of infants residing in poor families rose from about 18 to 24 percent. During this period, Medicaid expenditures in constant dollars per child recipient declined by 13 percent (278) and Federal funding for three important sources of primary health care for poor women and children—maternal and child health services, community health centers, and migrant health centers—declined in constant dollars by 32 percent (40,117,394).

Together, these trends suggest that more pregnant women and infants encountered severe financial obstacles to obtaining timely health care services in the early 1980s than in the late 1970s. Any resulting deprivation would be expected to have only a modest effect on the overall U.S. infant mortality rate, because relatively few women and infants would have been newly affected by the poverty and cutbacks and infant mortality is still a rare event. Yet, for a particular infant, being born to a mother in poverty with limited access to prenatal and infant care substantially raises the risk of dying in the first year. Thus, cutting back on funding for health care services at the same time that infant poverty rates in this country were increasing raised the risks of infant mortality for these babies.

PREVENTING LOW BIRTHWEIGHT

The United States invests a great deal in the treatment of low birthweight babies and realizes considerable success. Neonatal intensive care has played a major and definitive role in the improved survival of low birthweight and premature infants since its introduction in the 1960s.⁵ Each year, about 150,000 to 200,000 infants (from 4 to 6 percent of all U.S. newborns) are admitted to NICUs. At least one-half of these infants are low birthweight babies. Without question, neonatal intensive care is effective and becoming more effective over time. In 1960, 72 percent of all very low birthweight infants (1,500 grams or less) born in hospitals with sophisticated NICUs died in the first 28 days of life; by the early 1970s, the percentage had dropped to 54, and by the early 1980s, it had declined to 27 percent (665).

Although NICU care is effective, it is **also** expensive, ranking among the most costly of all hospital care. The effort to reduce the dependence of low birthweight babies on this expensive technology adds urgency to the search for strategies to prevent the need for NICU care in the first place.

Prenatal Care

Prenatal care encompasses a wide range of preventive, diagnostic, and therapeutic services delivered throughout the course of pregnancy, with the goal of both a healthy baby and a healthy mother. Preventive components of prenatal care include screening for potentially harmful conditions in the mother and fetus, education and counseling, and sometimes nutritional supplements. Diagnostic and therapeutic interventions represent responses to and followup of problems identified either through symptoms or screening.

Because prenatal care includes not only preventive interventions such as screening and counseling but also treatment when needed, it is bound to be effective in altering the health of some mothers and infants. Treatment of gestational diabetes or hemolytic disorders, for example, is crit-



Photo credit: Yale University and March of Dimes Birth Defects Foundation

Questions remain about exactly which preventive measures in prenatal care are effective and at what intervals in the course of a normal pregnancy they are most effectively applied. Ultrasound examination is not currently recommended by the American College of Obstetricians and Gynecologists for routine use during pregnancy.

ical to healthy outcomes for both mother and infant. The real question of effectiveness is not whether prenatal care makes any difference to child health, but exactly which preventive measures—monitoring, screening, education and counseling, or nutritional supplements—are effective and at what intervals in the course of a normal pregnancy they are most effectively applied.

Various new techniques of prenatal care are being developed, and evidence needs to be gathered to ensure their appropriate use in the care of pregnant women. One technique for which evidence is only now accumulating, for example, is called “ambulatory tocodynamometry.” Its place in monitoring women at high risk for premature delivery is still undetermined.

Effectiveness

The earlier that prenatal care is initiated, the more frequent the number of scheduled visits, and the more screening procedures that are performed, the more expensive prenatal care becomes. If frequent routine visits and procedures do not offer any advantages in terms of lowering risks of premature labor, allowing more effective treatment

⁵For detailed information on the effectiveness and costs of neonatal intensive care, see OTA's 1987 case study *Neonatal Intensive Care for Low Birthweight Infants: Costs and Effectiveness* (665).

or better management of labor and delivery than does seeking care when symptoms develop, the value of such preventive care would be dubious.

OTA examined the evidence on the effectiveness of early initiation of and more frequent prenatal care visits in reducing the rate of low birthweight and neonatal mortality. Despite serious shortcomings in almost all studies of prenatal care, the weight of the evidence from more than 55 studies of the effectiveness of earlier, more frequent, or enriched prenatal care services supports the contention that two key birth outcomes—low birthweight and neonatal mortality—can be improved with earlier and more comprehensive prenatal care, especially in high-risk groups such as adolescents and poor women. Although the evidence clearly supports the effectiveness of prenatal care, it is less revealing about the size of the effect that should be expected from increasing the quality or quantity of prenatal care received by any segment of the population.

Cost-Effectiveness of Expanded Prenatal Care for Poor Women

If prenatal care can improve birth outcomes, the logical next question is whether a specific strategy to increase access to effective services is worth its costs. The Omnibus Budget Reconciliation Act of 1986 (Public Law 99-509) gave States the authority to make a new group of previously ineligible pregnant women eligible for Medicaid—those whose incomes fall above the State's standards for Aid to Families With Dependent Children (AFDC) but below the Federal poverty level. Since April 1987, States have had the option of selecting any income standard for extending Medicaid eligibility to pregnant women, provided the standard is below the Federal poverty line.⁷ By January 1988, 26 States had exercised their option to expand Medicaid eligibility to include more pregnant women in poverty.

OTA performed a cost-effectiveness analysis to determine how costs to the U.S. health care system (not just to Medicaid) would be affected by

⁷The Omnibus Budget Reconciliation Act of 1987 (OBRA-87) passed by Congress in December 1987 (Public Law 100-203) gave States even greater freedom to expand eligibility for Medicaid to pregnant women with incomes up to 185 percent of the Federal poverty line.

a policy of universal eligibility for Medicaid of all pregnant women in poverty. Under such a policy, approximately 194,000 pregnant women would be newly eligible for Medicaid coverage, but almost 60 percent of these women already have some form of private health insurance coverage. Overall, OTA estimated that offering Medicaid eligibility to all pregnant women in poverty would cause an additional 18.5 percent of women in this category to initiate early prenatal care (i. e., care in the first trimester of pregnancy). Nationally, the extra prenatal care would cost about \$4 million per year.⁷

OTA estimated that for every low birthweight birth averted by earlier or more frequent prenatal care, the U.S. health care system saves between \$14,000 and \$30,000 in newborn hospitalization, rehospitalization in the first year, and long-term health care costs associated with low birthweight (see table 1-2).

How effective would earlier prenatal care have to be for the extra prenatal care costs among newly eligible women—estimated at \$4 million—to be outweighed by the societal savings resulting from a reduction in the rate of low birth-

⁷Note that these extra costs of prenatal care *do not* represent the additional costs to Medicaid of providing eligibility, nor do they represent the full costs of prenatal care for the newly eligible women. They represent the additional costs associated with the new care initiated as a result of enhanced eligibility. The extra costs to Medicaid might be much higher, since Medicaid would probably be paying for care that previously had been paid for by patients and their families or been donated by other government agencies, providers, or philanthropic groups.

Table 1-2.—Net Incremental Health Care Costs of a Low Birthweight Birth

	Low-cost estimate	High-cost estimate
Initial hospitalization cost:		
• Hospital costs	\$ 3,763	\$ 5,236
• Physician costs	475	1,487
Total	\$ 4,238	\$6,723
Rehospitalization costs in first year (hospital costs only)	\$ 802	\$ 802
Long-term costs of treating low birthweight	\$ 9,000	\$23,000
Total net incremental costs	\$14,040	\$30,525

SOURCE: Office of Technology Assessment 1988

weight? OTA estimated that the expansion of eligibility for prenatal care benefits under Medicaid would have to prevent between 133 and 286 low birthweight births among the 194,000 new eligibles for the societal health care savings to outweigh the costs. If these women began with a low birthweight rate of 10.2 percent,⁸ the low birthweight rate in the target population would have to decline by between 0.07 and 0.20 percentage points for health care costs to break even.

The reduction in low birthweight births would be concentrated in the group of poor women whose use of prenatal care changed as a result of the expanded eligibility for Medicaid. Among these new users, the low birthweight rate would have to decline by between 0.4 and 0.8 percentage points to between 9.4 and 9.8 percent.

Is it reasonable to expect reductions of this magnitude in the low birthweight rate? The evidence on the impact of earlier prenatal care on birthweight suggests that such reductions are quite feasible. The quantitative results of several reasonably well-designed studies of the effect of earlier prenatal care on birthweight showed effects that were at least twice as great as the effects required for the expansion of Medicaid eligibility to pay for itself in reduced health care costs (149,311,569, 600). That early prenatal care can also be expected to prevent some infant deaths (though the number cannot be predicted with certainty) further enhances the strategy's cost-effectiveness. Encouraging poor women to obtain early prenatal care through expanded Medicaid benefits is a good investment for the Nation.

Comprehensive School-Based Clinics for Teenagers

One approach to reducing the U.S. infant mortality rate and low birthweight would be to give women at high risk of poor birth outcomes better opportunities to avoid unintended pregnancies (296). Teenagers and women age 35 and above have a higher risk than other women of having babies that die in the first 28 days of life and that weigh 2,500 grams (5 lbs. 8 oz.) or less

at birth.⁹ Similarly, women who have not graduated from high school are at greater risk of experiencing these poor birth outcomes than women with at least a high school education.

In 1984, over 1 million teenagers in the United States became pregnant. About 40 percent of these pregnancies ended in abortion and 13 percent ended in miscarriage (443), so the number of births to teenage mothers in this country in 1984 was about 470,000 (443). The vast majority of teenage pregnancies are not only unintended but unwanted once they occur. In 1979, 82 percent of unmarried teenagers who became pregnant in the United States reported that the pregnancy was unwanted, but of unmarried teenagers who did not want their pregnancy, only 32 percent used contraception (443).

Strategies for preventing teenage pregnancy span a wide range of philosophies, from programs that are intended to influence teenagers' attitudes about sexual behavior and relationships to programs that prescribe or dispense contraceptive services (443,652a). There is tentative evidence that comprehensive school-based clinics that offer contraceptive services (as well as other kinds of health care) can lower teenage pregnancy rates and avoid unwanted births. Not all school-based clinics located in high schools and junior high schools offer family planning services. Of those that do, only a few actually dispense contraceptives. Some clinics prescribe contraceptives, and many others refer students to other providers.

The effectiveness of school-based clinics in preventing pregnancies and births among adolescents has been examined at two programs to date, one with three sites in St. Paul, Minnesota (147,333), and the other located in Baltimore, Maryland (777). Studies of the St. Paul school-based clinic program suggested that the program was successful in reducing birth rates among female students (147,333). The Baltimore school-based clinic program appears to have prevented pregnancies and reduced levels of sexual activity among students receiving services (777).

⁸The low birthweight rate is defined as the percentage of live births with a birthweight of less than 2,500 grams.

⁹Except for very young teenagers (those under 15 years of age), the relationship between age and neonatal mortality is a reflection of other factors, such as poverty, poor health care, or risky behaviors, that tend to cluster in adolescent mothers.

Although it is premature to draw conclusions about the effectiveness of school-based clinics in reducing high-risk unwanted pregnancies in adolescents, the evidence accumulated to date does look promising. The costs of providing comprehensive school-based health services is about \$125

per year per student (443). As more evidence on the effectiveness of school-based clinics in reducing rates of teenage pregnancies and births accumulates, study of whether such clinics can yield net savings to the U.S. health care system will be warranted.

PREVENTING HEALTH PROBLEMS IN EARLY CHILDHOOD

Once a baby is born, various preventive strategies are available to promote his or her health during infancy and beyond. OTA assessed the effectiveness or cost-effectiveness of interventions in four general categories: newborn screening for congenital disorders, well-child care, prevention of accidental injuries, and prevention of child maltreatment.

Newborn Screening for Congenital Disorders

The screening of large populations of newborns for congenital disorders began as a public health activity in 1961 with screening for phenylketonuria (PKU). PKU, an inherited disorder of metabolism, occurs in about 1 in 10,000 to 1 in 15,000 infants. The development of a newborn screening test permitted its detection in the first week of life, so that treatment could begin before 2 to 4 weeks of age, thus avoiding the irreversible mental retardation that would otherwise occur.

Today, newborn screening for PKU and congenital hypothyroidism is conducted in all 50 States and the District of Columbia. Tests for various other congenital disorders are also offered in some States, including tests for homocystinuria, galactosemia, maple syrup urine disease, sickle-cell anemia, cystic fibrosis, biotinidase deficiency, and congenital adrenal hyperplasia.

In general, the disorders included in routine newborn screening programs are diseases that are present throughout the life of an affected individual, do not get better (and often worsen) with time, and can result in severe mental retardation, physical disabilities, and even sudden death if untreated in the first days or weeks after birth. Al-

though only a few disorders are in this category, and those are relatively rare, newborn screening followed by early and sustained treatment can make the crucial difference in affected infants.

Effectiveness

The effectiveness of newborn screening in identifying affected infants depends in part on the accuracy of the test itself; it also depends on the ability of the screening program to collect blood specimens from all infants and to perform the tests properly and in time to initiate treatment. Thus, the organization and management of newborn screening services, the timing and number of newborn blood specimens, and laboratory performance have major bearing on the effectiveness of newborn screening.

The United States and Canada are the only developed countries offering newborn screening that do not have a national screening program. In the absence of a national newborn screening program or national set of minimum standards, each State has taken a slightly different approach to providing screening services. A few States have joined with neighboring States to form regional programs (279). Most States have their own newborn screening programs; State programs usually do have a centralized screening laboratory, but many do not have an organized program of services linking the laboratory with followup, treatment, and monitoring. A few States operate without a central laboratory or a centrally organized program. These States rely on an informal network of individual families, physicians, and a combination of public and private laboratories to provide screening and followup.

In some areas, the lack of a coordinated network of newborn screening services may reduce

the overall effectiveness of newborn screening by putting infants at risk for not being screened or for not receiving appropriate treatment. There are no national data on the number of infants at risk, however, because there is no central system for collecting comprehensive data with which to monitor and compare the outcomes of newborn screening in the State and regional programs.

Cost-Effectiveness of Newborn Screening

Although the value of newborn testing in the hospital for PKU and congenital hypothyroidism is now widely accepted, there is substantial question about the appropriateness of testing for other conditions and about the need for a routine second blood specimen at around the third week of life to pick up cases that might have been missed on the first screen. The second specimen issue has gained importance in recent years as the trend toward early hospital discharge of newborns has increased the probability that some affected infants will be missed. (In 1985, about 42 percent of all newborns were discharged before 3 days, up from 31 percent in 1980, and the optimal age for PKU testing is 3 to 5 days after birth.) Concern over the adequacy of the test in blood specimens taken within 24 hours of birth (282,283,409) led the American Academy of Pediatrics (AAP) Committee on Genetics to recommend that all infants whose first sample was collected before 24 hours after birth have a second blood sample taken by the third week of life.

OTA performed a cost-effectiveness analysis comparing a basic screening strategy—one specimen taken in the hospital to test for PKU and congenital hypothyroidism—to no screening and to six expanded strategies. The six expanded strategies involve a second specimen or additional tests on a single specimen.

Newborn screening for PKU and congenital hypothyroidism using one specimen reflects the minimum situation common to all U.S. newborn screening programs. Compared to no screening, this basic screening strategy not only saves many infants (about 1,291 per year) from lifetimes of severe disability but also yields net savings for the U.S. health care system of about \$120 million per year. Each of the six expanded screening strate-

gies would save more babies from deadly or disabling diseases than the basic strategy (ranging from 50 to 160 infants nationwide per year, depending on the strategy), but the incremental costs of achieving those extra successes are high (see table 1-3).

The net health care costs per case detected by any of the expanded newborn screening strategies remain high even under the “best case” assumptions applied in a sensitivity analysis. OTA found, however, that under the best case assumptions, the cost of detecting an extra case via an expanded one-specimen strategy—to test for PKU, congenital hypothyroidism, galactosemia, and maple syrup urine disease—is about \$85,000. This amount would buy an entire lifetime for a child with one of these disorders and is low compared to the cost of many therapies currently considered accepted medical procedure. The cost (in 1986 dollars) per year of life gained from heart transplantation for congestive heart failure, for example, is about \$28,000 (162) to \$40,000 (98), and for a year gained from hemodialysis for end-stage renal disease is about \$36,500 (530).

Four congenital disorders not included in the screening strategies examined in OTA’s cost-effectiveness analysis—sickle cell anemia, cystic fibrosis, biotinidase deficiency, and congenital adrenal hyperplasia—are being considered for inclusion in an increasing number of newborn screening programs. Newborn screening for sickle cell anemia, in particular, is gaining widespread support as a result of recent evidence linking early detection and treatment of the disease with reduced mortality in the first few years of life (198).

OTA did not evaluate tests for these four disorders in its cost-effectiveness analysis, because reliable data on the long-term value of screening for these disorders do not exist. Few evaluations of the sensitivity and specificity of the screening tests and of the long-term value of early detection and treatment of sickle cell anemia, cystic fibrosis, biotinidase deficiency, or congenital adrenal hyperplasia have been conducted. In the absence of more data on effectiveness, estimates of the cost of screening and treatment, not to mention costs averted by screening, would be incomplete at best.

Table 1-3.— Incremental Effectiveness and Health Care Costs of Six Expanded Newborn Screening Strategies Compared to a Basic One-Specimen, Two-Test Strategy^a (1986 dollars)

Expanded strategy	Number of extra cases detected in the United States	Net incremental cost per extra case detected and treated
Two specimens: on first specimen, test for PKU and CH; on second specimen, repeat test for PKU and CH in all infants . . .	75	\$466,000
Two specimens: on first specimen, test for PKU and CH; on second specimen, test for PKU and CH only in infants with first specimen collected less than 72 hours after birth	49	\$253,000
Two specimens: on first specimen, test for PKU and CH; on second specimen, test for CH only in all infants	64	\$432,000
Two specimens: on first specimen, test for PKU and CH; on second specimen, test for PKU, CH, and HC in all infants	94	\$421,000
One specimen: test for PKU, CH, GA, and MSUD	68	\$173,000
Two specimens: on first specimen, test for PKU, CH, GA, and MSUD; on second specimen, test for PKU, CH, and HC in all infants	162	\$317,000

Abbreviations: PKU = phenylketonuria; CH = congenital hypothyroidism; HC = homocystinuria; GA = galactosemia; MSUD = maple syrup urine disease. ^aThe basic newborn screening strategy to which the expanded strategies in this table are compared is a one-specimen strategy with tests for phenylketonuria (pKU) and congenital hypothyroidism (CH).

SOURCE: Office of Technology Assessment, 1988.

Well-Child Care

Well-child care refers to a variety of preventive health services offered by physicians or other health professionals at defined points in a child's life, beginning as early as the second or third week after birth and extending into adulthood (227). The goal of well-child care is ultimately to improve the physical, cognitive, and psychological health of children both in childhood and adulthood.

Well-child care encompasses two main aspects of prevention:

- immunization; and
- health supervision, consisting of physical examinations and other tests that screen for illness or developmental problems, health education, and parental guidance.

Immunization

Immunization provides the starkest example of the power of prevention to save or prolong lives, prevent significant disability, and lower medical care costs. It represents the ideal of medical progress—prevention rather than cure or relief of symptoms (642). Today, children in the United States are routinely vaccinated against eight dis-

eases: diphtheria, tetanus, pertussis (whooping cough), polio, measles, mumps, rubella (German measles), and, most recently, *Haemophilus influenzae b* (Hib).

The cost-effectiveness of the childhood vaccines is well established in the literature—indeed, such vaccines not only confer medical benefits but are cost-saving. The diphtheria, tetanus, and pertussis (DTP) vaccine—the most controversial vaccine—continues to be cost-saving, despite a rapid rise in vaccine prices due to the recent vaccine liability crises. As vaccine prices increase, however, costs saved with childhood immunization programs diminish. Thus, developments with regard to the current vaccine liability crisis will have an impact on whether childhood immunizations continue to be cost-saving.

New technologies on the horizon also will have an impact on the cost-effectiveness of childhood immunizations. Two new DTP vaccines developed by the U.S. National Institutes of Health and Japanese researchers could substantially reduce the number and seriousness of adverse reactions to the pertussis component of the DTP vaccine. A reduction in adverse reactions could decrease the amount of corresponding litigation and ultimately reduce vaccine prices.



Photo credit: Children Hospital National Medical Center

Well-child care comprises physical examinations and tests that screen for illness or developmental problems, immunization against polio and other diseases, health education, and counseling of a child's parents.

Health Supervision

Evidence on the effectiveness of components of well-child care other than immunization is more remarkable for its limitations than for its findings. No evidence supports the contention that well-child care other than immunization significantly influences mortality or morbidity among children or that it enhances the development of a child's social competence. On the other hand, sample sizes have been uniformly too small and followup too brief to identify mortality changes; the available measures of childhood morbidity have been inadequate, and most investigators have not even looked at children's developmental outcomes. The

particular importance of the outcome measures examined to date and their duration of impact have not been evaluated. For these reasons, expert opinion and good intentions rather than scientific data currently guide the provision of well-child care. Participation in well-child care does seem to provide substantial satisfaction to both parents and providers, and the value of their satisfaction should not be overlooked.

Of the components of well-child care examined by OTA, childhood immunization for eight diseases is the only one shown to be cost-effective and cost-saving. A schedule of well-child care visits that corresponds to the AAP's and Immunization Practices Advisory Committee's recommended schedule for childhood immunization, therefore, is cost-saving. Such a schedule would include seven well-child care visits for normal infants and children in the first 6 years of life. The schedule for well-child care visits recommended by AAP calls for 13 visits in the first 6 years of life. Whether more well-child care visits than the seven required for childhood immunizations would be cost-effective is unknown, because researchers have yet to be able to document the effectiveness of the health supervision aspects of well-child care in terms of improved health outcomes. In formulating recommended schedules for well-child care visits, AAP and other recommending bodies have relied on expert opinion regarding the effectiveness of the components of well-child care other than immunization (284).

Preventing Accidental Childhood Injuries

Accidental injuries are the leading cause of death in American children after the first few months of life.¹⁰ In 1984, 7,850 U.S. children under age 15 died as a result of such injuries (713). Nationally, approximately 353,000 hospitalizations and nearly 10 million emergency treatments

¹⁰To describe accidental injuries, many people prefer the label "unintentional injuries" because they believe that the term "accidental" implies unavoidability. OTA has chosen to use the term accidental injuries for two reasons. One is that it is the term more commonly used by the general public. The other is that many researchers in the field of child abuse argue that the term unintentional injuries does not in fact exclude all injuries due to child abuse, because some child abuse is unintentional.

annually are due to childhood injuries. Approximately 4,700 children under age 17 experience bed-disabling injuries each year (705).

Childhood accidents are very costly to American society, even after the tremendous social and emotional costs of death and disability are excluded. NCHS estimated that in 1980, injuries and poisonings (accidental and nonaccidental) accounted for 13.3 percent of acute medical care costs for U.S. children under age 17, or nearly \$2 billion (479). Most of this cost, which does not include long-term care costs or nonmedical costs, is probably due to accidental injuries. As a group, accidental and other injuries are the leading cause of potential years of life lost before age 65 (685). In infants under age 1, injuries are the second leading cause of death (after death due to conditions present at birth); and in all other children under age 15, they are the leading cause of death (451).

In 1984, the greatest number (43 percent) of the accidental fatalities in children under age 15 resulted from vehicle-related accidents. Drowning and fires/burns were also prominent causes of death among children in this age group.

There are three broad strategies for preventing accidental childhood injuries:

- *Persuasion/education*: persuading people to increase their self-protection (e. g., through education or reminders to use seatbelts).
- *Regulation of behavior*: requiring people to increase their self-protection (e. g., by passing laws requiring the use of seatbelts).
- *Automatic protection*: providing automatic protection from injury through product or environmental design (e. g., by designing automobiles so that a person is automatically seatbelted when in the vehicle) (451,531).

For motor-vehicle-related injuries in children, both regulation and automatic protection have been very effective in reducing deaths (and, presumably, serious injuries as well). In 1977, Tennessee passed the first State law requiring children to be restrained in an infant or child seat. By 1984, all 50 States had enacted laws requiring the use of safety restraints for children in automobiles (29). These laws contributed to the 36-percent de-

cline in motor-vehicle occupant deaths among children under age 5 between 1980 and 1984 (234,713).

Still, there is considerable room for improving child safety restraint laws. Many States require safety restraints in automobiles only for very young children. Altogether, 38 States have no restraint requirements for children over age 5 (and many States do not require restraints for children over 3 or 4) (719). Laws covering only certain ages and exempting certain vehicles may fail to prevent a substantial number of avoidable deaths. One analysis of motor-vehicle occupant fatalities in very young children (ages 0 to 5) concluded that in some States, up to 43 percent of deaths occurred in children who would not have been covered under restraint laws as of 1984 (636).

The evidence regarding the role of enforcement in improving the effectiveness of safety restraint use is somewhat conflicting. A few studies of specific enforcement efforts have found that such efforts had little additional effect (535). One study of seatbelt use found, however, that Texas had the highest rate of compliance in the Nation, a rate which Texas authorities attributed to vigorous enforcement efforts (518).

Automatic protection has also played an important role in the reduction of motor-vehicle-related childhood injuries. Attempts to reduce automobile injuries have included both product and environmental changes. The Motor Vehicle Safety Act of 1966 (Public Law 89-563) required automakers to include certain safety features in 1968 and subsequent model cars, such as shoulder belts, energy-absorbing steering assemblies, and interior padding. Reductions in automobile-associated deaths observed into the 1980s can probably be attributed in part to the continued attrition of old vehicles that did not meet the standards. The effect of the standards on death rates of children alone has not been estimated.

Other possibilities for improvement also remain. For example, many vehicles still have protrusions such as knobs and tapered dashboards that can cause injury to the faces, heads, and chests of individuals during crashes or sudden braking (752). One study found that 12 percent

of children's injuries in motor vehicles occurred in noncrash braking or swerving (4).

Although education programs designed to encourage families to use child safety restraints in automobiles have met with only modest success (522,523), education may be an important component of regulatory strategies, both in encouraging the legislative process and as a necessary background to acceptance and proper use of required technologies (177).

For accidental childhood injuries not involving motor vehicles, similar conclusions can be drawn. Automatic protection is most effective and regulation is often effective in reducing accidental injury rates, especially when accompanied by educational campaigns. Examples of actions that could together substantially reduce children's deaths due to accidental injuries include:

- helmets for bicyclists,
- barriers around swimming pools,
- universal use of smoke detectors,
- window bars in windows above the first floor,
- hot water heater temperatures of no more than 120 degrees Fahrenheit,
- stringent limits on the sales and use of all-terrain vehicles, and
- "no-right-turn-on-red" laws,

It must be remembered, however, that many of these preventive interventions involve additional costs to society or substantial loss of personal choice, issues that need to be taken into account when considering accident prevention policies.

Preventing Child Maltreatment

Child maltreatment—including physical, psychological, and sexual abuse and neglect—is an especially troubling children's health problem because it is caused primarily by adult behavior, not by accidents or natural disease processes. In the past two decades, there has been an explosion of concern in professional and lay communities about the problem, but policy debates regarding appropriate responses are hindered by the lack of consensus about what constitutes maltreatment, what causes it, how frequently it occurs, and, most important, how it can be prevented.

All 50 States and the District of Columbia have laws defining child maltreatment and mandating that professionals working with children report suspected cases. Typically these laws are vague, leaving a good deal open to interpretation. State child protection agencies, which are designated by law to respond to reports of alleged child maltreatment, typically have a higher threshold for identifying a case as abuse or neglect than health care professionals have (143). For example, a pediatrician might consider corporal punishment of a child to be abusive and decide to counsel a child's parents about alternative disciplinary strategies. A social worker for a State child protective service agency, on the other hand, might require scattered bruising to substantiate a case report.

The lack of clear definitions of child maltreatment complicates attempts to estimate the frequency with which maltreatment occurs, but even clear definitions would not make measurement of the size of the problem easy. The unacceptability of child maltreatment and its potential legal consequences makes conventional methods of estimating incidence and prevalence (e. g., population-based surveys or incident reporting) unreliable. The more serious the maltreatment, however, the more likely are reporting systems to identify incidents. In 1985, 1.9 million cases of child maltreatment were reported to child protective services agencies in the United States (657). A 1986 survey of child protection agencies estimated that at least 1,200 children died of child abuse in that year (448).

Few child maltreatment prevention programs have been rigorously evaluated to ascertain their short-term and long-term outcomes. Between 1979 and 1981, the National Center on Child Abuse and Neglect (NCCAN) sponsored a national evaluation by Berkeley Planning Associates of 19 NCCAN-funded clinical demonstration projects (56). The 19 federally funded projects were intended to demonstrate the effects of specialized clinical treatments in five abuse and neglect subpopulations (sexual abuse, adolescent maltreatment, substance-abuse-related maltreatment, child neglect, and remedial services to maltreated children). The evaluation methodology was critically flawed, lacking in comparison groups or in ob-

rates of participation, and their participation rates increased slightly in the period between 1978 and 1984. The increase may be due to factors unrelated to payment, in particular, the increase in the supply of pediatricians during the period. Despite these trends, continued stringency in Medicaid payment rates can only put more pressure on children's access to private physicians in the future.

Finally, administrative red tape and payment delays not only slow down the Medicaid enrollment process but also discourage private providers from participating in the program. The net result is that in many areas, children eligible for Medicaid must seek care at clinics that specialize in care for the indigent or at hospital emergency rooms.

CONCLUSIONS

Fortunately, most children in the United States enjoy excellent health, but this assessment demonstrates that greater strides toward improvement in their well-being are still possible if more emphasis is placed on cost-effective prevention strategies. As the same time, a reality must be recognized in any effort to employ such strategies. Every inch of ground gained is won with greater

difficulty and usually at higher costs than the last because the remaining problems, by definition, are more intractable. It is the familiar phenomenon of diminishing returns, with one vital difference: virtually no new gain can be dismissed as unimportant if it promises some real reduction of infant mortality and other forms of suffering.

OPTIONS FOR FEDERAL POLICY

OTA has identified several preventive strategies for improving American children's health, some of which would be clearly cost-saving to the U.S. health care system, some of which are effective (though not cost-saving), and some of which hold promise of having important impacts on children's health:

- . improved access to early prenatal care for poor women (cost-saving);
- comprehensive school-based clinics for adolescents at high risk of unwanted pregnancy (promising);
- newborn screening using a single blood specimen to identify four congenital disorders (PKU, congenital hypothyroidism, maple syrup urine disease, and galactosemia) (effective);
- . well-child care as often as required for full immunization of young children (seven visits in first 6 years of life) (cost-saving);
- . use of child safety restraints in automobiles (effective, probably cost-saving);
- . nurse home visitor programs for pregnant

women and infants in families potentially at high risk for low birthweight, childhood accidents, or child maltreatment (promising); and

- Ž improved access to physicians' services for children living at or near the poverty level (effective).

Specific policies for bringing about these improvements are discussed below.

Expanding Access to Prenatal Care for Poor Women

Option 1: Congress could mandate that eligibility for Medicaid be extended to all pregnant women with incomes below the Federal poverty line.

In the Omnibus Budget Reconciliation Act passed in December 1987 (OBRA-87) (Public Law 100-203), Congress gave States the power to extend Medicaid coverage to pregnant women with family incomes up to 185 percent of the Federal

poverty line.¹² States vary widely in Medicaid eligibility and benefit standards, however, and there is no reason to think that the variation will be reduced under a program in which participation is voluntary. So far, only 26 States have elected to expand Medicaid benefits to all pregnant women in poverty. States may be reluctant to undertake responsibility for a new eligibility group, because expanding Medicaid to pregnant women in poverty will increase Medicaid costs as Medicaid pays for prenatal care that formerly was paid for by other State programs with more Federal matching dollars (e.g., the Maternal and Child Health services block grant), paid for by the patients' families, or provided by physicians and hospitals without compensation.

Requiring Medicaid coverage of all women with incomes below the poverty line would ensure equity in eligibility for Medicaid across the States. This option would raise Medicaid costs, although it could free some Maternal and Child Health services (MCH) block grant money to be used for other health needs of children and pregnant women. In States reluctant to implement this option, its effectiveness could be undermined through enrollment procedures that delay or make difficult the determination of Medicaid eligibility.

Option 2: Congress could require States to shorten the period for determining Medicaid eligibility for pregnant women and could direct the Federal Medicaid authorities to promulgate simplified eligibility forms and procedures for such women.

In some States, pregnant women who are eligible for Medicaid find it difficult to receive early prenatal care because of delays in the Medicaid enrollment process. States have 45 days to process an application for Medicaid, but women may encounter additional delays when their applications are incomplete or when other problems arise. Congress could require States to make Medicaid eligibility determinations for pregnant women a priority and to require less documentation for approval.

¹² The 1987 Federal poverty level is \$11,203 for a family of four (382).



Photo credit: March of Dimes Birth Defects Foundation

Early prenatal care can reduce the incidence of low birthweight and the high costs of neonatal intensive care.

Some providers have been reluctant to offer care to pregnant women in anticipation of their eligibility for Medicaid because of the fear of retroactive denial of eligibility and nonpayment for the services rendered (185). Under OBRA-86 (Public Law 99-509), a "qualified provider" can provide services to a woman presumed to be eligible and be guaranteed Medicaid reimbursement for that care even if eligibility is ultimately denied. Qualified providers include health departments, hospitals, and clinics, but not private physicians' practices. Thus, the presumptive eligibility clause of OBRA-86 appears to channel pregnant women who are probably eligible for Medicaid into sources of prenatal care other than private physicians. Relaxing the definition of a "qualified provider" would assure private physicians of some Medicaid reimbursement even if a woman's eligibility for Medicaid is ultimately denied; thus, this change would encourage private physicians to accept poor women for prenatal care.

Encouraging the Development of Comprehensive School-Based Clinics for Adolescents

Option 3: The Federal Medicaid program could direct the States to expand funding for comprehensive school-based health clinics through Medicaid and its Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program.

jective measures of effectiveness. Consequently, this evaluation provides little information regarding the usefulness of the approaches undertaken by the demonstration programs,

The use of home health visitors to families at high-risk for child maltreatment has been studied more than any other preventive approach. Five programs, each of which provided a wide array of services to clients including visits in the home, have been evaluated (33,34,225,391,471,586). Although the specific home care services differed among the studies, four of the five studies found that home care services were effective in reducing actual rates of child maltreatment.

Taken together, available evaluations of home health visitor programs suggest that such pro-

grams may be successful in preventing child abuse and neglect.¹¹ Although it is difficult to specify at this point what program elements are most important in producing the positive outcomes, the home visitor model appears to have a number of practical advantages that enhance its effectiveness, including reaching parents who lack self-confidence and trust in formal service providers, obtaining a more accurate and direct assessment of the home environment, linking parents with other support services, and reminding parents that excessive punishment or neglect of children are not condoned in our society (470).

¹¹ Visiting nurses may also be effective in increasing birthweight and lowering infant mortality (94,169).

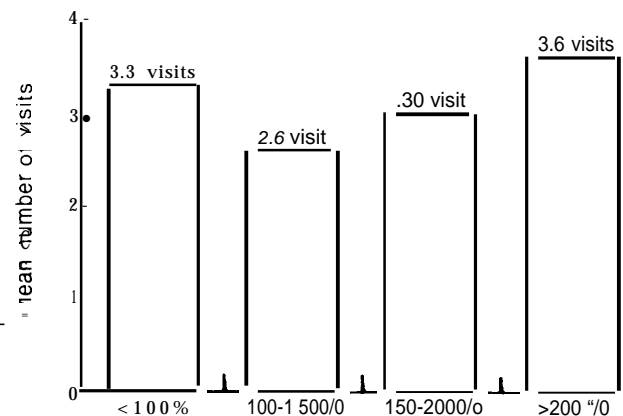
IMPROVING CHILDREN'S ACCESS TO EFFECTIVE HEALTH SERVICES

Although this assessment focused largely on preventive strategies for promoting or maintaining children's health, a fundamental question raised in any discussion of children's health is whether systematic differences exist in American children's access to needed health care services.

OTA's review of the available data revealed a consistent relationship between family income and children's use of health care services. Not surprisingly, the higher the family income, the more services a child uses. This relationship appears to be stronger the sicker the child. Very healthy children do not differ widely by income group—they all see physicians infrequently—but the frequency with which American children who are sick see a physician depends very much on their income.

The relationship between family income and children's use of health care services is softened by the availability of health insurance coverage, so that very poor children, who have access to Medicaid, are more similar to middle-income children in the frequency of use of medical care than are other poor or low-income children (see figure 1-2). Indeed, children on Medicaid appear to have as many general checkups and immunization visits as middle-income privately insured chil-

Figure 1-2.—U.S. Children's Medical Visits: Mean Number of Visits by Family Income, 1980



Family income as percentage of Federal poverty level

SOURCE: Office of Technology Assessment 1988 based on data from J. A. Butler, W. D. Winter, J. D. Singer, et al. "Medical Care Use and Expenditure Among Children and Youth in the United States: Analysis of a National Probability Sample." *Pediatrics* 76(4):495-507, 1985.

dren (except for those enrolled in health maintenance organizations) (45). As might be expected, having a generous health insurance plan has a greater effect on the use of medical care for children in poverty than it does for other children. Poor children whose families pay a large amount out of their own pockets use much less care than

do those who receive free care (383). Parents do not appear to be particularly good at discriminating between visits that are likely to be highly effective and those that are not (383). When parents cut back on visits, they don't just cut back on care that is not likely to make much difference to the course of illness; they reduce in equal measure visits for conditions for which medical care is highly effective.

Family income and health insurance status influence not only the amount of health care U.S. children receive but also the site in which they receive it. Poor children—both those with Medicaid eligibility and those without—are much more likely to receive care in a health clinic, a hospital emergency room, or outpatient department than are middle-income children.

The result of these systematic differences in the frequency of use of services and the site of care suggests that poor children are treated very differently from nonpoor children by the U.S. health care system. For poor children, the availability of adequate health insurance makes a big difference in whether they get care they need; however, Medicaid eligibility means that poor children are more likely to obtain medical care at a hospital or public clinic than in a private physician's practice.

OTA estimates that in 1986, between 14 and 19 percent of all American children under 13 years of age had no health insurance eligibility whatsoever. Children without health insurance are heavily concentrated among the poor and the near poor (family incomes between 100 and 150 percent of poverty): 61 percent of all children reported to be uninsured in 1986 were poor or near poor.

Almost 40 percent of poor children in intact families have no health insurance. In fact, poor children in two-parent families are much less likely to have health insurance than are poor children living with never married mothers, whose rate of uninsuredness is at most 16 percent. This difference can be explained by the fact that children in intact families in poverty have somewhat higher incomes on average than do those in households headed by single mothers, making fewer of them eligible for Medicaid on the basis of income.

The existence of Medicaid is clearly a great benefit for eligible children. As a federally aided, State-administered program of medical assistance for low-income people, Medicaid enhances access to health care for the poor. Because each State designs and administers its own program within Federal guidelines, however, the adequacy of Medicaid in meeting the needs of children varies widely across the States.

Federal legislation has been expanding Medicaid eligibility for children since 1984. By July 1988, all children through age 6 who meet the income and resource requirements of the AFDC program, regardless of whether they are actually eligible for AFDC, will be eligible for Medicaid. Because the AFDC income standards are State-specific, however, the eligibility criteria are still varied and, in many States, stringent. In 1986, less than one-half of all American children under 13 years of age in poverty were covered by Medicaid (672).

The Omnibus Budget Reconciliation Act of 1986 (OBRA-86) (Public Law 99-509) gave States the right to extend Medicaid on a phased-in basis to all children under 5 years of age whose incomes and resources put them below the Federal poverty line. As of January 1988, only 26 States had extended eligibility. More recently, the Omnibus Budget Reconciliation Act of 1987 (OBRA-87) (Public Law 100-203) permitted States to offer Medicaid to infants whose family incomes are below 185 percent of the Federal poverty level and to children up through age 8 with family incomes below the poverty level.

Physicians who care for Medicaid patients encounter severe restrictions on the payments they receive. In general, Medicaid fees lie well below the fees paid by Medicare, which are in turn lower than those paid by the private sector. The disparity grows with every year. Between 1982 and 1984, for example, private physicians' fees increased by 13.2 percent, while the median Medicaid fee for a brief office visit remained virtually unchanged (278). As a consequence of low Medicaid fees, physicians' willingness to participate in Medicaid is limited. Nationally, pediatricians are about average among all specialties in their

School-based health clinics that offer family planning services are promising as an effective way to reduce pregnancy rates among high-risk teenagers. Teenagers have special needs when it comes to family planning services. Because of their need for confidentiality, a caring attitude on the part of staff, and proximity, the usefulness of the existing network of family planning services for teenagers is limited (515a,776a).

At present, 64 percent of the total funding for school-based clinics is provided by public sources; the remaining 36 percent is provided by private sources (e. g., foundations, corporations, private fees). Of the public funding for school-based clinics, the bulk is provided by States through the MCH block grant or State-only funds (333a). Medicaid's EPSDT program provides about 14 percent of the total funds for school-based clinics. Other Federal programs, including Title XX (Social Services), Title X (Family Planning), and the community health centers program, provide about 6 percent of the total funds.

As a comprehensive program of preventive care for Medicaid-eligible children under 21 years of age, EPSDT is potentially available to fund a greater proportion of the services provided by school-based clinics offering family planning services. In some States, however, school-based clinics are not recognized as Medicaid providers because they do not have a physician on staff. Furthermore, States can restrict payment to school-based clinics by stipulating very few screening visits for adolescents under the EPSDT periodicity schedule. To address these problems, Federal EPSDT regulations could be changed to require States to certify as EPSDT providers clinics that serve schools and to mandate a minimum number of EPSDT screening visits for adolescents.

Implementing this option would still leave to local jurisdictions the decisions about what kinds of services to provide and in what schools. This option would merely enable localities that want to offer family planning and other health services to high-risk adolescents through school-based clinics to make greater use of Medicaid funds,

Promoting Effective Newborn Screening Programs

Option 4: The Federal Government, acting through the Division of Maternal and Child Health, could use newborn screening grant funds to encourage States to develop coordinated newborn screening programs.

The effectiveness and costs of newborn screening depend on the accurate identification of infants with the target disorders and coordination of screening with followup and treatment services. Experts have long agreed that the quality and efficiency of newborn screening programs could be enhanced by the development of regional screening programs, particularly where small State populations and low budgets restrict access to high quality screening services (e.g., 442). Currently, however, there is no ongoing system in place to assist States in developing regional programs.

At present, there are only three regional newborn screening programs in the United States, together accounting for about 20 percent of births (281). A majority of births (about 71 percent) are covered by State screening programs, most of which have a centralized laboratory, but only some of which have an organized program of services linking the laboratory to followup, treatment, and monitoring. A few States, accounting for about 9 percent of all births, operate without either a central laboratory or a centrally organized program, thus relying on an informal network of families, physicians, and a combination of public and private laboratories to provide screening and followup. In some areas, the lack of a coordinated network of services may be putting infants at risk of not being screened or of not receiving appropriate treatment.

The importance of program organization and management in achieving the theoretically feasible levels of effectiveness and efficiency of newborn screening argues for an aggressive Federal posture in encouraging the development of high-quality, low-cost newborn screening programs.

The Centers for Disease Control's monitoring of the accuracy and precision of screening tests through its laboratory proficiency testing program addresses part, but not all, of the problem. The

U.S. Department of Health and Human Services, acting through the Division of Maternal and Child Health in the Public Health Service, could take an active role in encouraging and coordinating the development of regionalized newborn screening programs through its already existing oversight authority and its discretionary funds.

Option 5: The Federal Government could increase funding for research on the effectiveness of newly developed tests designed for routine newborn screening.

A number of States are considering inclusion in their screening programs of newly developed tests for cystic fibrosis, sickle cell anemia, biotinidase deficiency, and congenital adrenal hyperplasia. Adequate funding of research on the effectiveness of screening and treatment for these four disorders before the new tests diffuse widely into routine screening is needed to ensure the appropriate use of resources.

The value of newborn screening for cystic fibrosis, the most common of the disorders currently under consideration for inclusion in screening programs, is currently unknown. Carefully designed research studies of both accuracy of detection and effectiveness of early treatment are needed to make good judgments about the appropriate place of tests for cystic fibrosis in newborn screening programs. One such study of cystic fibrosis, funded by the National Institutes of Health, is already underway (166).

A federally funded study of one aspect of early treatment for sickle cell anemia was recently conducted (198). That study found that the use of prophylactic antibiotics in affected infants was successful in reducing the risk of sudden death due to overwhelming infection early in life (198). Other issues in the screening and treatment aspects of newborn screening for sickle cell anemia have not yet been resolved. Such issues include problems in counseling and followup of sickle cell carriers.

Tests for biotinidase deficiency and congenital adrenal hyperplasia are already being included in many State screening programs. No adequate long-term studies to determine the value of screening for these two disorders have yet been done.

Encouraging Appropriate Well-Child Care

Option 6: The Federal Government could encourage States to develop EPSDT screening protocols that combine fewer well-child care visits than are recommended in the American Academy of Pediatrics (AAP) guidelines with real increases in physician fees.

For the poorest children who are eligible for Medicaid, access to well-child care needs to be dealt with either through the regular Medicaid program or through the Medicaid's EPSDT program. States have established EPSDT screening protocols that typically include fewer well-child visits than the 13 recommended in AAP guidelines but more than the 7 visits recommended for childhood immunizations in the first 6 years of life. But as the EPSDT program has been implemented by the States, only a minority of eligible Medicaid children actually do have EPSDT visits in any year.

There are several potential explanations for this situation. First, 32 States explicitly allow Medicaid providers to bill for routine checkups for children under the regular Medicaid program, so many children may be receiving well-child services through this source. Second, the EPSDT program in many States is not well integrated with



Photo credit: Children Hospital National Medical Center

A schedule of well-child care visits that corresponds to the recommended schedule for childhood immunizations is both effective and cost-saving to the U.S. health care system.

the primary health care system; EPSDT screening sites are separate from children's usual sources of medical care. Third, States have not aggressively recruited providers to the EPSDT programs, and private providers may be reluctant to undertake the reporting commitments required by EPSDT. Finally, rates of payment for EPSDT screens are generally low.

To increase recruitment of providers to EPSDT, one of the key incentives is the level of payment offered by Medicaid for EPSDT services. The evidence supporting the provision of more well-child care visits than the number required for complete immunization is very limited. Thus, States could limit the number of well-child care visits under EPSDT to the seven required for immunizations and would be able to provide higher rates of payment to EPSDT providers without incurring additional program costs.

Whether this option would actually be cost-neutral to Medicaid programs is uncertain, because Medicaid children do not now receive the full complement of well-child care visits, and higher enrollments in EPSDT could actually increase the number of visits as well as the reimbursements per visit. Nevertheless, OTA's analysis indicates that improved adherence to clearly effective and cost-effective well-child care could be worth the immediate outlays.

Such a strategy would be counterproductive if only one part were implemented by the States. That is, if the States were to limit the EPSDT periodicity schedule without substantially increasing rates of payment for EPSDT screenings offered by private physicians, children might not receive the basic number of well-child care visits that are so clearly cost-saving to the U.S. health care system.

Reductions in the number of well-child care visits should not be confused with reductions in the scope and availability of followup services. Once problems are identified in Medicaid eligible children, the availability of diagnostic and treatment services is critical to these children's health status.

Option 7: Congress could require States to offer children required followup services identified in EPSDT screens, regardless of whether the services are covered in the State's Medicaid plan.

Once a child has entered the EPSDT screening system, the State is mandated to provide vision, hearing, and dental services but is not required to offer other followup care as needed above and beyond the services outlined in the State's Medicaid plan. This option would increase the probability that children's health problems identified by EPSDT screens are actually dealt with by Medicaid.

In States that contract with private providers for EPSDT screens, this option would encourage providers to enroll children in EPSDT. The option might discourage States from expanding Medicaid children's access to EPSDT services, however, because the State would lose control over covered services.

Encouraging the Use of Child Safety Restraints in Automobiles

Option 8: The Federal Government, operating through its highway funding authority, could encourage those States whose child safety restraint laws are not very stringent to adopt more rigorous standards.

Child motor-vehicle safety-restraint laws have indisputably reduced serious injuries in very young children, and all States currently have laws requiring the use of infant or child restraints. The details of these State laws differ (636). To enhance the safety of children in States with less effective laws, the Federal Government could promulgate a model child safety restraint law whose adoption could be required for the receipt of Federal highway funds.

Encouraging the Development of Nurse Home Visitor Programs

Option 9: Congress could mandate that the U.S. Department of Health and Human Services fund experiments and evaluations of home visitor programs in populations at high

risk for low birthweight or child maltreatment and other injuries.

Home visitor programs are labor intensive and therefore costly, and the evidence on their effectiveness is based on a small number of programs run by dedicated, enthusiastic, and particularly skilled people, so it is premature to conclude that the home visitor approach should be broadly applied. Nevertheless, the evidence is certainly strong enough to warrant more widespread experimentation with the home visitor concept as a method of improving the outcome of pregnancy and the health of young children. Possible funding and coordinating agencies include the National Center on Child Abuse and Neglect (NCCAN), the Division of Maternal and Child Health in the Public Health Service, and the Centers for Disease Control, all of which have jurisdiction over child health problems for which home visitor programs may be effective.

Funding for experimental programs needs to be directed to those with the strongest evaluation designs if useful information on effectiveness is to be achieved. The performance of NCCAN in funding valid research has been disappointing. Peer review of proposals for demonstration and evaluation grants or contracts is one way of directing funds to the programs with the strongest evaluation designs.

The U.S. Department of Health and Human Services already has the power to issue waivers under the Medicaid program to States that offer additional services (such as home visitors) to selected subgroups of Medicaid eligibles as an inducement to participate in case-management systems where the freedom to choose a provider is restricted (Sec. 1915(b) of the Social Security Act). To obtain a waiver, however, a State must show that the proposed program will as a whole reduce costs or slow the rate of increase in Medicaid program costs. It may be difficult to justify an expensive program such as home visitors on the basis of cost-savings to Medicaid. More flexibility on the part of the Health Care Financing Administration in approving waivers containing these services would enhance the development of such programs.

Improving Poor Children's Access to Physicians' Care

Option 10: Congress could mandate that eligibility for Medicaid be extended to all children under 9 years of age in families with incomes below the Federal poverty line.

OBRA-87 gave States the option to expand Medicaid to cover all poor children under 9 years of age and offer Medicaid to infants in families with incomes up to 185 percent of the Federal poverty line. Making Medicaid eligibility for all poor children under age 9 mandatory would eliminate the inevitable disparity among States in eligibility that will result from the optional provisions of OBRA-87 and would improve access to care for such children.

The available evidence suggests that this option would be likely to improve the health status of newly eligible Medicaid children because it would increase their use of effective health care. It would also be costly to Medicaid because free care would bring about more use of medical care by these children.

Option 11: Congress could require States to increase the fees paid to physicians when they care for Medicaid children.

For children who are eligible, the Medicaid program offers a comprehensive array of health services. The key problem, however, is finding adequate sources of care. Physician participation in the Medicaid program varies from place to place, but it is clear that there are administrative and payment barriers that discourage Medicaid families from using private practices.

The low levels of Medicaid fees in comparison to private fees in many States is of particular concern. By mandating increased fee levels for physicians who treat Medicaid children, Congress could arrest the tendency for Medicaid children to seek primary care in sites different from those used by non-Medicaid children. Increased fee levels would also raise Medicaid program costs, however, and could encourage some unnecessary use of health services by Medicaid patients.

Option 12: Congress could increase direct Federal subsidies of health care providers—through community health centers, maternal and child health projects, and other programs administered by State and local governments—to provide primary health care for poor families.

An alternative to expanding Medicaid eligibility would be for the Federal Government to increase its commitment to funding publicly subsidized providers of health care for the poor. The erosion of real Federal funding of programs that provide health care services for poor children and pregnant women in the last 9 years—a period when the population of poor and uninsured children grew—has caused an increasing strain on these services.

Increasing funding for direct provision of health services to the poor would have the advantage of permitting States or localities to target serv-

ices to areas of greatest need and to tailor programs to the needs of poor women and children. Programs of enriched prenatal care, for example, can be more easily coordinated through State or local governments or community health centers than through physicians' private practices.

By definition, however, the funding of public or publicly subsidized clinics for the poor tends to separate provision of care for poor children and pregnant women from care given to the nonpoor. The implications of separate streams of medical care are unclear. Although targeted programs can offer enhanced services tailored to the multiple needs of poor children and their families, their quality and effectiveness are likely to vary widely across areas. Without freedom to use other settings of care made possible by access to public or private health insurance, some poor women and children could ultimately receive lower quality care.