Healthy Babies: Efforts to Improve Birth Outcomes and Reduce High Risk Births

Summary
While most families have healthy child births, poor birth outcomes are emotionally and financially devastating for families. Poor birth outcomes are also costly for state and federal financing programs. For example, Medicaid, which finances 40 percent of the four million annual births in the United States, pays for 50 percent of hospital stays for premature and low birth weight infants. \(^1\,2\,3\)

Hospital charges for babies with a primary diagnosis of low birth weight/premature delivery average $75,000 per child. The lifetime cost for children born with one of 17 common birth defects and/or cerebral palsy is $8 billion (in just one year in the United States).

States and Governors have a vital interest in improving birth outcomes, and states have been involved in several efforts known to help improve birth outcomes. Specifically, states can implement initiatives that:

- Improve Access to Medical Care and Health Care Services. Early and adequate prenatal care provides a means of identifying mothers at risk of delivering a premature or low birth weight infant and provides an array of medical, nutritional, and educational interventions. Early medical care can also identify medical conditions and medical risk factors that affect pregnancy, as well as assure that treatment is provided and the health of the mother and baby is monitored;

- Encourage Good Nutrition and Healthy Lifestyles. Research confirms that eating healthy foods; taking folic acid; treating HIV; abstaining from smoking, drinking alcohol, or using harmful drugs; and living without violence will improve birth outcomes;

- Reduce Use of Harmful Substances. Smoking, drinking alcohol, and using illicit drugs while pregnant can have severe and long lasting health affects for both mother and baby, and have clearly been linked to poor birth outcomes. Treatment has proven effective for women who have been unable to stop smoking, drinking alcohol and using drugs on their own.

What is a Poor Pregnancy Outcome?
The goal of every pregnancy is to have a healthy baby. However, not all pregnancies and deliveries avoid complications. For example, some recent statistics show that:

Pregnancy and Birth Outcomes in the United States
- Over four million babies are born every year in the United States.
- Poor Birth Outcomes:
  - Infant mortality (7 deaths per 1,000 live births – 2002 saw the first increase since 1958)
  - Premature birth (12.1% in 2002 – 29% increase in the rate of premature births since 1981)
  - Low birth weight (7.8% of births were low birth weight in 2002, the highest level in more than 30 years)
  - Birth defects (3-4% of babies – 120,000 to 150,000 babies a year — are born with birth defects)
  - Maternal mortality (2-3 women die each day of pregnancy-related complications – this rate has not decreased since 1982)

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• Infant mortality (death in the first year of life) increased from a rate of 6.8 infant deaths per 1,000 live births in 2001 to a rate of 7.0 per 1,000 births in 2002, according to preliminary data released by the National Center for Health Statistics. This was the first increase in the United States since 1958. Infants were 12.1 percent of all births in 2002. Overall, there has been a 29 percent increase in the rate of premature (prior to the 37th week of pregnancy) births since 1981.6 Premature births were 12.1 percent of all births in 2002. Overall, there has been a 29 percent increase in the rate of premature (prior to the 37th week of pregnancy) births since 1981.7 The percent of babies born too small (weighing less than 5.5 pounds) in 2002 was 7.8, the highest level in more than 30 years.8 Between 3-4 percent of babies (120,000 – 150,000 per year) are born with birth defects.9 10

The recent increase in infant mortality occurred for deaths in the first month of life, mostly in the first week, and was offset by a decrease in late fetal deaths.11 Infant deaths after the first month remained unchanged. The perinatal mortality rate—which describes the rate of death near the end of pregnancy and right after birth—remained steady.

Most pregnancies that are at risk for a poor birth outcome are traced to a number of factors. Certain behaviors and lifestyle factors, such as smoking, drinking alcohol, using illegal drugs, experiencing soon after a previous delivery, put a woman at greater risk for a poor pregnancy outcome. A mother’s medical condition also influences birth weight, prematurity, and the health of the baby, especially if she has high blood pressure; certain infections; heart, kidney or lung problems; diabetes; HIV/AIDS; or is obese.

**Birth Defects**

Birth defects are the leading cause of infant mortality, causing more than 138 infant deaths per 100,000 live births.12 One of every 33 babies is born with a birth defect.13 A birth defect is an abnormality of structure, function, or metabolism (body chemistry) present at birth that results in physical or mental disability or is fatal.

The causes of about 75 percent of birth defects are unknown.14 However, both genetic and environmental factors can result in birth defects. Many deaths appear caused by a combination of one or more genetic and environmental factors. Birth defects are known to be the result of: a woman drinking while she is pregnant, a lack of sufficient folic acid in a woman’s diet before and during pregnancy, and exposure during pregnancy to some medications, chemicals, and infections.

**Low Birth Weight and Premature Birth**

Low birth weight and premature birth are the second leading causes of infant mortality.15 Low birth weight infants are at heightened risk for chronic health and developmental problems such as cerebral palsy, brain damage, chronic lung and liver disease, deafness, blindness, epilepsy, learning disabilities, and attention deficit disorder. Women under 17 or over 35 and women who have had a previous premature birth are at increased risk of having low birth weight babies.

Birth weight and premature birth are linked. More than 60 percent of low birth weight babies are premature.16 Premature birth is the leading cause of neonatal mortality (death in the first month of life) in the United States. Premature birth accounts for 35 percent of all health care spending for infants, and 10 percent of all health care spending for children.17

The causes of prematurity are unknown for 50 percent of premature births.18 The earlier a child is born, the less developed his or her organs will be, and the more complications the child is likely to face. Very
premature babies have the highest risk of death and lasting disabilities, such as mental retardation, cerebral palsy, lung and gastrointestinal problems, and vision and hearing loss. Low birth weight and premature babies often require care in a neonatal intensive care unit (NICU), which has specialized medical staff and equipment that can deal with the multiple problems such infants face.

**Maternal Mortality**
Maternal mortality is defined as death during pregnancy or within 42 days of giving birth and caused by pregnancy-related complications. Maternal mortality ratios in the United States are higher than those of many other industrialized nations. Each day in the United States two to three women die of pregnancy complications. This rate has not changed in the past 20 years, and large racial disparities persist in measures of both maternal mortality and morbidity (the relative incidence of disease).

The racial and ethnic disparities in the rates of low birth weight, prematurity, and infant deaths is significant. Women of color are at greater risk of delivering a low birth weight baby and/or a premature baby than white women. Infants of color are more likely to die within the first year of life than their white counterparts.

**What do Poor Pregnancy Outcomes Cost?**
The average hospital charge for infants with a principal diagnosis of low birth weight/prematurity was $75,000 compared to hospital charges of newborns without complications, which averaged $1,300 in 2001. Hospital charges related to premature births were estimated at $13.6 billion in 2001.

In 1990, health care for insured mothers and infants with poor birth outcomes cost United States businesses and workers $5.6 billion, or about 3 percent of after-tax profits. It has been estimated that $8 billion is the lifetime cost for children born annually in the United States with any of 17 common birth defects and/or cerebral palsy.

A woman’s smoking, alcohol, and drug use while pregnant can have severe and long lasting health affects on mother and baby as well as considerable cost implications. The first year health care costs for babies whose low birth weight was attributed to their mothers' smoking during pregnancy are estimated to be $1 billion to $1.5 billion. CDC estimates $367 million in health care costs for excess neonatal direct health care costs due to maternal smoking in 1996. Costs are estimated at $1,142-$1,358 per smoking pregnant woman (90 percent of it for treating infants for smoking-related illnesses such as asthma.) A pregnant woman who smokes is between 1.5 and 3.5 times more likely than a nonsmoker to have a low birth weight baby. Infants whose mothers smoked during pregnancy have 2.3 times the risk of Sudden Infant Death Syndrome (SIDS) than infants of non-smoking mothers.
Babies born to women who drank alcohol during pregnancy are at risk for birth defects, mental retardation and peripheral nerve damage. Alcohol consumption during pregnancy, especially heavy drinking, is also associated with a cluster of congenital birth defects called Fetal Alcohol Syndrome (FAS), which are estimated to cost as much as $1.6 billion a year.

Nationally, the medical expenses for infants exposed to cocaine in utero are estimated at $504 million a year. The costs for special health and educational services for each drug-exposed child from birth through age 18 are estimated at $750,000. In addition to direct costs of care, an estimated 30 percent of drug-exposed infants need foster care. Annual costs of basic foster care range from $3,600 to $5,000 per infant and are higher when specialized services are provided.

IMPROVING POOR PREGNANCY OUTCOMES AND REDUCING COSTS ASSOCIATED WITH HIGH RISK BIRTHS
States can improve access to medical care, encourage healthy maternal behavior and prevent risky behavior, and increase access to smoking cessation and substance abuse treatment. States are pursuing several strategies known to help improve birth outcomes, such as:

- **Improving Access to Medical Care and Health Care Services.** Early and adequate prenatal care provides a means to identify mothers at risk of delivering a premature or low birth weight infant and provides an array of medical, nutritional, and educational interventions. Early medical care also can identify medical conditions and medical risk factors that affect pregnancy, as well as assure that treatment is provided and the health of the mother and baby is monitored.

- **Encourage Good Nutrition and Healthy Lifestyles.** Research has confirmed that eating healthy foods; taking folic acid; treating HIV; abstaining from smoking, drinking alcohol, or using drugs; and living without violence will improve birth outcomes.

- **Reducing Use of Harmful Substances.** Smoking, drinking alcohol, and using illicit drugs while pregnant can have severe and long lasting health affects for both mother and baby and clearly have been linked to poor birth outcomes. Treatment has proven effective for women unable to stop smoking, drinking alcohol and using drugs on their own.

Improving Access to Medical Care and Health Care Services
In order to provide early and continuous care to pregnant women, mothers, and young children, states may employ and, if fiscally possible, expand Medicaid programs. States also can utilize prevention and early intervention initiatives to provide services. Some avenues that states can explore include:

- **Increasing Medicaid Eligibility.** Medicaid is one of the largest providers of prenatal care, covering almost 40 percent of the nation’s births. Over the last 20 years, Congress gradually increased the mandated federal minimum level of coverage under Medicaid for pregnant women, infants, and children. Today states are mandated to cover pregnant women at or below 133 percent of the Federal Poverty Level (FPL) under Medicaid. Although states are experiencing budgetary constraints in light of current fiscal conditions, many states have expanded coverage beyond the federal mandate, some as high as 300 percent of the FPL. In October 2002, 12 states had expanded Medicaid coverage above the federal minimum to 200 percent of the FPL or higher.

- **Providing Presumptive Eligibility.** Presumptive eligibility allows a state to provide immediate access to
prenatal care for pregnant women currently not receiving Medicaid benefits. Presumptive eligibility grants temporary Medicaid coverage, typically at a provider site, until a formal Medicaid eligibility determination can be made. This allows a pregnant woman to receive health services as soon as she seeks care. As of October 2002, 32 states provided presumptive eligibility for pregnant women.

Adopting Continuous Eligibility. Pregnant women who meet income guidelines lose eligibility for Medicaid 60 days postpartum unless they become eligible through another pathway. However, states can provide pregnant women and infants up to age one continuous eligibility in Medicaid. This entitles pregnant women and infants to receive health services continuously regardless of fluctuations in income that might make them otherwise ineligible. As of October 2002, 15 states provided continuous eligibility to pregnant women enrolled in Medicaid beyond the federally mandated 60-day postpartum requirement, many for family planning services only.

Utilizing State Children’s Health Insurance Program (SCHIP) to Cover Pregnant Women. Five states have received a section 1115 Waiver to expand SCHIP to include pregnant women.

Applying for a Family Planning Waiver. Several states have used section 1115 Family Planning Waivers to extend family planning services to women (and men) who are ineligible for Medicaid. States may access federal Medicaid funds to expand coverage to include low-income single adults (who may have grown children), as well as children above Medicaid’s eligibility ceiling.

States have used Family Planning Waivers in seeking to reduce the number of unplanned pregnancies, to increase spacing between births, and to improve birth outcomes. These waivers assist states in improving birth outcomes by improving access to reproductive health services such as screening and treatment of HIV/AIDS, cervical cancer, and sexually transmitted diseases (STDs), which if left undetected can lead to poor birth outcomes. Waivers also assist states in improving birth outcomes by preventing pregnancies within nine months of a previous delivery, which can lead to low birth weight and infant mortality.

States with Family Planning Waivers are required to fund pregnancy-related care—including family planning services—for 60 days postpartum to women with incomes up to 133 percent of the FPL. Some states have obtained approval to continue Medicaid coverage for family planning for women who would otherwise lose Medicaid coverage after the 60-day postpartum period. Other states have granted coverage solely on the basis of income to women not covered previously under Medicaid. A recent study conducted on states with Family Planning Waivers shows that the cost savings to the states and federal government was significant.

The following details how states are using Medicaid to provide family planning services:

- Eighteen states have obtained federal approval to extend Medicaid eligibility for family planning services to individuals who would otherwise not be eligible;
- Six states have extended eligibility for family planning services to women losing Medicaid postpartum;
- Two states provide family planning benefits for women losing Medicaid for any reason;
- Ten states provide family planning benefits to individuals based on income; most states set the income limit at or near 200 percent of poverty;
- Four states provide family planning benefits to men and women; and
- Two states limit their programs to women at least 19 years of age.
California’s Family Planning Waiver was approved in 1999. Prior to obtaining a waiver, California operated the California Family Planning, Access, Care, and Treatment Program (PACT), which was funded with state dollars. The California PACT program differs from family planning programs in other states in that eligibility is determined at the same site services are provided, and the delivery system includes private physicians and pharmacies. This maximizes access to services to families covered by the program. Every dollar spent through the Family PACT program saved an estimated $4.48 in public expenditures.49 A recent evaluation of California’s effort showed that services delivered through the Family Planning Waiver have been successful at increasing the use of effective contraceptive methods and improving access to screening and treatment of HIV and a number of STDs. In addition, the evaluation showed that prior to their first Family PACT visit, a third of contraceptive clients were either using an ineffective contraceptive method or no method at all, while after their visit, 95 percent were using an effective contraceptive method.

Data from Rhode Island’s Family Planning Waiver program has shown that in addition to being highly cost effective, the program is helping to reduce the number of women who become pregnant again shortly after giving birth. Since the program’s implementation, the proportion of women with Medicaid-funded deliveries becoming pregnant within nine months of a previous birth has been cut nearly in half. The program has almost eliminated the disparity between the proportion of privately insured women and Medicaid enrollees with short birth intervals.50

Providing Comprehensive and Coordinated Prenatal and Perinatal Services. Several states have expanded Medicaid benefits and the types of providers reimbursed through Medicaid and have implemented comprehensive strategies to improve birth outcomes.

Illinois passed legislation in 2003 that allows the state to expand Medicaid benefits to cover a wider array of prenatal and perinatal services to prevent low birth weight and premature infants and to promote perinatal health. This legislation requires the Department of Public Aid to develop a plan for prenatal and perinatal preventive health care that will be updated every two years and to document the cost effectiveness of the services funded by this legislative change.51 Illinois has already modified its Family Planning Waiver to include coverage for multivitamins and folic acid, HIV testing, and also to expand the populations eligible. The state is now looking at dental services, smoking cessation counseling, and a wide array of other initiatives involving mental health, substance abuse, high risk pregnancy case management and outreach to “hard to find” women.52

Colorado operates Prenatal Plus, a Medicaid funded program that provides case management, nutrition, and psychosocial services to women assessed as high risk for delivering low birth weight babies. The program, which is operated jointly by the Medicaid agency and public health department, has assisted 650 healthy births at low birth weight risk since 1996.

New Jersey is providing comprehensive screening of pregnant women and referrals to an array of services to improve birth outcomes and child health through the Children’s Futures Initiative funded by the Robert Wood Johnson Foundation in collaboration with the City of Trenton, the Central Jersey Maternal and Child Health Coalition, Mercer Trenton Addiction Science Center, and the State Department of Health and Senior Services. Nurse case managers at prenatal clinics conduct screenings of pregnant women. Women with risk factors are linked to more comprehensive assessments, medical and behavioral health services, and home visiting programs. Women at prenatal clinics also complete a five-question screening tool called the 4P’s Plus—designed to identify their family history and household use of tobacco, alcohol, and drugs. On-site counseling sessions are provided when use of these substances is reported.
**Partnering with Managed Care Plans**

States are working with managed care plans to improve birth outcomes for Medicaid recipients by decreasing the time it takes to enroll pregnant women into managed care plans and get scheduled for an appointment, quickly identifying existing members who become pregnant, increasing provider use of comprehensive pregnancy risk assessment instruments, and referring pregnant women for additional services (i.e., case management, smoking cessation, behavioral health services) when necessary.

**Ohio’s** Medicaid program is working with health plans to improve birth outcomes. Data is tracked on women who begin prenatal care and on the number of prenatal visits women receive. Babies’ weight is monitored and best practices are highlighted at quarterly meetings of managed care plans.53

**Nebraska** has developed a Performance Monitoring Plan for Medicaid plans. Baseline measures and targets were developed for the ratio of the Medicaid eligible population, primary care physicians and obstetricians/gynecologists (OBGYNs), and the percent of low birth weight babies. These are tracked and efforts are made to improve outcomes.54

**Utilizing Home Visiting Programs.** Home visiting is a long-standing, well-known prevention strategy used by states and communities to improve the health and well-being of women, children, and families, particularly those who are at risk. Early investments in home visiting programs are shown to reduce costs associated with foster care placements, hospitalizations and emergency room visits, unintended pregnancies, and other more costly interventions.

Home visiting programs can help identify women at-risk of delivering a low birth weight or premature infant. The advantage of home visiting is that it gives the visitor an opportunity to understand a woman's health-related behaviors in the context of the rest of her life and surroundings. This enables the visitor to devise meaningful strategies to help reduce adverse behaviors and to improve a woman's capacity to follow through with health recommendations.

Home visiting can also be used after a family brings home a premature or low birth weight infant, or an infant with severe birth defects. These programs are designed to enhance child development and teach parents ways to improve their child’s cognitive development and overall physical health.

The Nurse Family Partnership,55 an evidence-based home visiting program utilizing nurses, currently is being implemented in 21 states56 with good outcomes. Research shows that the program resulted in positive outcomes for women’s prenatal health including reduction in smoking and alcohol consumption during pregnancy and reductions in injuries to children and rates of subsequent pregnancies with four dollars saved for every dollar invested.57 Although some states use Medicaid to partially fund this program, **Louisiana** is the only state using Medicaid to fully fund this service through Targeted Case Management, an optional benefit that can be offered to specific populations of recipients.58 Research shows Louisiana has reduced premature births by 52 percent and low weight births by 22 percent for women receiving this service.59

**Instituting Birth Defect Surveillance, Monitoring, Early Intervention, and Prevention Programs.** Many states have instituted birth defect surveillance, monitoring, early intervention, and prevention programs. These programs seek to identify the causes of birth defects, prevent birth defects, and link affected children with services. Data is used to target resources better, provide services to affected families, and study the causes of birth defects and the risk factors involved. In 2002, The Trust for America’s Health, a non-profit organization dedicated to disease prevention, reviewed all state efforts to track and prevent birth defects
and graded each state. Only eight states received a grade of A. In 2003, the Trust for America reviewed state progress and saw improvement in 43 states. As of September 2003, the Centers for Disease Control and Prevention (CDC) had granted cooperative agreements in 28 states to fund birth defect programs for the development or expansion of their surveillance systems, prevention programs, and activities to improve the access of children with birth defects to health services and early intervention programs.

**Texas** utilizes active surveillance to identify more than 13,000 babies born with structural birth defects annually. Texas has a CDC-funded Center for Birth Defects Research and Prevention that participates in the National Birth Defects Prevention Study. This is a case controlled study of major birth defects involving extensive interviews and collection of biologic samples from parents and babies to identify the causes of birth defects. Texas also assists families in obtaining services by providing a brochure available in English and Spanish. The brochure describes programs available to provide help for children with special needs and provides contact information for a toll free referral line, a toll free number for the Early Childhood Intervention program (ECI), local phone numbers for Texas Department of Health social workers statewide, and an on-line Texas Assistance and Referral System (STARS). In **New Jersey and Colorado**, state registries notify local health departments of families with children born with birth defects for contact and linkage with services.

**New Mexico** collects birth records and hospital data for surveillance. Children are referred for services and receive care coordination and early intervention. Surveillance data is used in developing prevention programs and delivering services to women at-risk of birth defects in future pregnancies. The state developed a comprehensive prenatal education module that focuses on changing health behaviors of pregnant women, including vaccinating against rubella and chicken pox prior to planning a pregnancy; avoiding obesity and eating healthy; controlling diabetes; avoiding tobacco, alcohol, and illicit drugs; and consuming the proper amounts of folic acid. The module is available in English and Spanish, and there is a module for Navajo communities that is customized to be culturally appropriate.

**Encouraging Comprehensive Newborn Screening**. State newborn screening programs test all newborns for disorders that may have no immediate visible effects on a baby but, unless detected and treated early, can cause physical problems, mental retardation and, in some cases, death. Each year approximately 3,000 babies with severe disorders are detected by newborn screening programs. Comprehensive state newborn screening programs involve testing, follow-up, diagnosis, treatment, and evaluation. The number of genetic and metabolic disorders that states and the District of Columbia newborn screening programs test for range from four to 36 with most states screening for eight or fewer disorders. All states screen for at least two disorders—phenylketonuria (PKU) and congenital hypothyroidism. More than half the states screen for galactosemia, sickle cell disease or hearing loss.

**Encouraging Good Nutrition and Healthy Lifestyles**
To help reduce instances of infant birth defects and illnesses, states can encourage proper, healthy eating habits and safe, healthy behaviors. States can work to:

**Improve Nutrition.** All states operate Women Infants and Children (WIC) programs to safeguard the health of low-income women, infants, and children up to age five who are at nutritional risk, by providing nutritious foods to supplement diets, information on healthy eating, and referrals to health care. WIC serves 45 percent of all infants in the United States. Families eligible for WIC services must be at or below 185 percent of the FPL. States can effectively publicize their programs so that eligible families are aware of their availability.
**Prevent Birth Defects through Folic Acid Consumption Campaigns.** Folic acid, a B vitamin, helps prevent birth defects of the brain and spinal cord when taken daily prior to and during the early weeks of pregnancy. These neural tube defects (NTDs) cause a birth defect in the brain called anencephaly, which is fatal, and Spina bifida, which affects the spinal cord and can result in paralysis. (Preventing one case of Spina bifida saves $421,900, the average lifetime cost of treatment).

Research has shown that 75 percent of NTDs can be prevented through adequate folic acid consumption. States have been working to prevent NTDs through folic acid consumption campaigns that include provider education, community education, radio and television advertising, and vitamin distribution. Since 1998, the U.S. Food and Drug Administration (FDA) has required that folic acid be added to foods containing wheat that are labeled “enriched.” Fortification and folic acid campaigns have lowered by 23 percent the number of babies born in the United States with NTDs. In addition, increases in folic acid intake in the general population since fortification have led to a reduction of strokes and heart disease.

States continue to educate health care providers and consumers that all women of childbearing age need to take the recommended amount of folic acid daily since it is most effective before a woman is pregnant and in the early stages of pregnancy, and since 50 percent of pregnancies are unplanned. States also are working to prevent NTD recurrence by encouraging women at high risk to take the higher amounts of folic acid recommended.

**Illinois** passed a law in 2003 requiring the Department of Human Services to conduct a folic acid public information campaign.

In general, the southeastern states and parts of the U.S.-Mexico border have higher NTD rates than other areas of the country because of a high number of women with known NTD risk factors including maternal diabetes and obesity, lower socioeconomic status, and Hispanic ancestry. North Carolina, in particular, has had levels of NTDs that are higher than the national average with 200 pregnancies affected each year. The state has implemented a number of successful programs that have led to a reduction in NTD rates. Activities include an innovative community peer education program and an Office Champion program that offers short in-service workshops to health care provider offices, then recruits a point person from that office to serve as an ongoing contact and folic acid supporter. The campaign has a comprehensive college outreach program, a wealth of educational materials and a Web site. In addition, radio and television spots in Spanish and English have reached hundreds of thousands of households. The rate of NTDs has dropped dramatically in the Western Region of the state in response to the folic acid campaign. In 1995, the prevalence was over 14.64 per 10,000 births, but fell to 2.5 per 10,000 births in 2000, which represents an 83 percent decrease. The North Carolina campaign has recurring fiscal support from the North Carolina General Assembly and has received a one time donation of $3 million for use in future folic acid campaigns from the VitaGrant Settlement, a lawsuit case against vitamin manufacturers.

**Prevent Perinatal HIV/AIDS Transmission.** In 2003, the CDC recommended prenatal HIV testing for all pregnant women, as a pregnant woman’s use of zidovudine (an HIV drug known as ZDV, and previously as AZT) during pregnancy and labor reduces transmission of HIV from mothers to infants. There are now approximately 300 cases of perinatal transmission annually, down from a peak incidence of 907 cases in 1992. States have adopted different strategies for HIV testing of pregnant women. The CDC found that the HIV testing rate varied depending on the type of approach utilized. The percentage of women who report they received an HIV test during pregnancy is measured through a CDC surveillance project called the Pregnancy Risk Assessment Monitoring System (PRAMS), operational in 32 states and New York City.
**Michigan** has had success with prenatal HIV testing and has spent time and energy educating providers on the need to test pregnant women at the first pre-natal visit and at the later stages of pregnancy unless a woman does not consent to be tested or it is medically inadvisable. Hospitals are required to test a pregnant woman who is delivering if there is no documentation of her HIV status. Michigan has an active HIV surveillance program, and case files are reviewed when a baby is born with HIV. The state works with the hospital where the baby was born to develop and to implement corrective action measures when this occurs.  

**Florida** has had success with an opt-in testing system and also requires the offering of HIV testing at the initial prenatal visit and again at 28-32 weeks, and at hospital labor and delivery for women of unknown HIV status. PRAMS data show Florida to have the highest percentage of pregnant women reported taking an HIV test in 1999. Since 1999, the state has operated the Targeted Outreach for Pregnant Women Act (TOPWA) Program. Through this program, community outreach is provided to women at high risk of delivering an HIV-infected or substance-exposed infant. These women are offered on-site pregnancy and HIV tests. At-risk women not receiving adequate prenatal care are actively referred to needed services. Between 1999 and June of 2003, 14,000 on-site pregnancy tests identified over 2,500 of the close to 12,000 pregnant women enrolled in the program, and over 9,000 on-site HIV tests were given. More than two percent of women tested HIV positive. Thirty percent of these women were pregnant at the time of testing. Over 20 percent of enrolled pregnant women and 40 percent of screened women had not previously been tested for HIV.

**Prevent Violence.** Domestic violence affects up to 300,000 pregnant women in the United States. (The prevalence ranges from 2.4 percent to 6.6 percent.) Violence is more common among pregnant women than many conditions that are screened routinely. Physical violence during pregnancy is significantly associated with fetal death and low birth weight. The American College of Obstetricians and Gynecologists (ACOG) recommends that physicians screen all patients for violence throughout pregnancy. Factors that studies found to be related to violence during pregnancy include violence before pregnancy, younger age of the victim, and unintended pregnancy. Four states, Illinois, Oregon, North Carolina and Pennsylvania, received funding from HRSA in 2002 to screen and provide services to pregnant women experiencing violence.

**Reducing Use of Harmful Substances**

With the understanding that smoking, drinking, and drug use contribute to poor birth outcomes, states can educate pregnant women on the positive outcomes associated with abstinence. States can increase public awareness of the detrimental effects of unhealthy behaviors and can:

**Encourage Abstinence from Smoking, Drinking, and Drug Use.** States have been conducting public and provider education campaigns to alert pregnant women that they should not smoke, drink alcohol, or take illicit drugs while they are pregnant. Alaska has been actively developing strategies to reduce Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) and to improve service delivery to babies affected by alcohol during pregnancy. Alaska is one of five states that comprise the Fetal Alcohol Syndrome Surveillance Network (FASSNet) funded by CDC. The other states are Arizona, Colorado, New York, and Wisconsin. Alaska has the highest rate of FAS among these states. Alaska’s strategy includes public and provider education, outreach, training, and technical assistance to prevent drinking during pregnancy.

**Improve Access to Smoking Cessation.** A meta-analysis of 18 studies found that a brief 5-15 minute counseling session by a trained provider, combined with pregnancy-specific messages and self-help
materials, can increase the rate of quitting among pregnant women who are light to moderate smokers by 30-70 percent.  

Adopting new clinical guidelines is a challenge for most clinicians and health care delivery systems. National data shows that 81 percent of OBGYNs ask pregnant women about their tobacco use, but that only 22 percent proceed to counsel those women who smoke. To address how best to implement smoking cessation interventions, three states are conducting demonstration programs funded by the Robert Wood Johnson Foundation and administered by the Smoke-Free Families National Dissemination Office.

The Oregon Smoke-Free Mothers and Babies project has recruited 10 counties to participate in their initiative, which is based on the project’s maternity case management model. Smoke Free Mothers and Babies is creating a coordinated system of care between case managers and prenatal providers, and are establishing a quit line through outreach and training, standardized documentation procedures, and a fax referral system.

The Maine Prenatal Collaborative is recruiting physicians whose practices are members of the Maine Health System. The Collaborative is using a group learning process among provider practices to raise clinician self-efficacy, promote a team approach, and incorporate patient self-management tools.

The Oklahoma Smoke-Free Beginnings project is recruiting practices that participate in the Oklahoma Physician’s Research Network. The project is adapting an academic detailing model by assigning physician enhancement assistants to train providers on-site and develop new office systems.

**Provide Medicaid Reimbursement for Smoking Cessation.** It is estimated that 38.5 percent of women who receive Medicaid-funded services smoke during pregnancy. A 2002 study showed that 36 states cover some tobacco-cessation treatments for all Medicaid recipients. Of these states, four cover pregnant women only. In addition, four states of the 36 states providing services to all Medicaid recipients had expanded their existing coverage to include more treatments, 16 states provide coverage for counseling, 10 states reported using the Public Health Services Clinical Practice Guideline when developing their program, and 11 states reported informing Medicaid recipients of the coverage.

**Increase Access to Substance Abuse Treatment.** Illicit drug use while pregnant clearly has been linked to poor birth outcomes. In addition, lifestyle factors of an addict such as malnutrition, STDs, and poly-substance abuse also are closely linked to poor birth outcomes. It is estimated that each year between 100,000 and 300,000 infants are born who have been exposed to illicit drugs in utero. One California study found that 5.2 percent of mothers in the state tested positive for illicit drug use just prior to delivery.

A national survey conducted in 1994 by the National Institute on Drug Abuse (NIDA) suggests that up to 221,000 children are born each year having been exposed to illicit drugs during gestation. Furthermore, findings from the NIDA survey indicated that the number of children prenatally exposed to alcohol far exceeds the number exposed to illicit drugs, thereby placing the total number of children born each year exposed to alcohol and illicit drugs at over 1 million. Studies have long been thought to underestimate the numbers of affected infants because mothers may deny drug use, medical personnel may not ask certain groups of women about drug use, doctors may not recognize the signs of drug use, or the results of toxicological screens may be incorrect.

Nineteen states have either created or funded drug treatment programs specifically targeted to pregnant
women and seven states\textsuperscript{121} provide pregnant women with priority access to state-funded drug treatment programs. Nine states\textsuperscript{122} require health professionals to report suspected prenatal drug abuse and four states\textsuperscript{123} require them to test for prenatal drug exposure if they suspect abuse.\textsuperscript{124}

**Colorado** operates the Special Connections program through a partnership between the Colorado Medicaid program, the Colorado Prenatal Plus program, and the Colorado Child Welfare Division. This program has provided substance abuse treatment to pregnant women since 1992. The program seeks to prevent babies from being born premature, or with birth defects or low birth weight, by reducing or stopping the substance using behavior of the pregnant women receiving services during and after the program. The program has been extremely successful. For fiscal year 2002, of the 158 babies born for which outcomes data was collected, 90 percent were of normal birth weight and tested negative for all substances at birth.\textsuperscript{125}

**Kentucky** is reducing drug and alcohol use during pregnancy through the KIDS NOW initiative. Outreach is conducted through 14 regional mental health/mental retardation boards, local health departments, private physician offices and district and circuit court judges. Physicians are encouraged to screen pregnant women and refer them for substance abuse prevention and treatment when necessary. During fiscal year 2000-2001, the program assisted 360 pregnant women with substance abuse problems.\textsuperscript{126}

**Washington** State provides substance abuse treatment to pregnant women through the MOMS program. Research has shown that women who received treatment had much better birth outcomes than women who did not. Women without treatment were over three times more likely to deliver a baby prematurely and showed a higher frequency of fetal or infant deaths than women receiving treatment.\textsuperscript{127}

**Conclusion**
States have a vital interest in improving birth outcomes and reducing such adverse outcomes as birth defects, low birth weight, premature birth, and maternal mortality. These immediate negative results can also lead to long-term issues such as chronic illnesses and, in certain cases of high-risk families or severely ill children, foster care placement.

There are a number of ways that states can save and improve lives while cutting health care costs. States can improve access to medical care by taking another look at Medicaid eligibility and utilizing Family Planning Waivers. They can encourage healthy maternal behavior and work to prevent risky behavior through programs focused on prenatal responsibility (such as good nutrition and safe behaviors). States can also increase access to programs for smoking cessation, alcohol use, and drug treatment. Governors can play a fundamental role by creatively utilizing funding mechanisms, as well as through expansion of prevention and monitoring, education, and outreach initiatives.
Resources for Improving Birth Outcomes

- March of Dimes www.marchofdimes.com
- Improving Birth Outcome Toolkit, Center for Health Care Strategies Web site www.chcs.org/ManagedCare/birthToolkit.htm or call (609) 895-8101
- New Jersey Blue Ribbon Panel on Black Infant Mortality Reduction www.state.nj.us/health/fhs/bim.htm
- For information on the Nurse Family Partnership see the National Center for Children, Families, and Communities www.nccfc.org
- Health Resources and Services Administration www.hrsa.gov
- Centers for Disease Control and Prevention www.cdc.gov

Encouraging Healthy Behavior and Preventing Risky Behaviors

- National Birth Defects Prevention Network www.nbdpn.org
- Spina Bifida Association of America www.sbaa.org
- National Council on Folic Acid www.folicacidinfo.org/
- North Carolina Folic Acid Council www.getfollic.com
- New Mexico prenatal education materials in English, Spanish, and Navajo. Contact: Susan Nalder, Ph.D. (505) 476-8889 or Jean Higgins (505) 476-8859
- For information on the 4P’s screening tool see the Children’s Research Triangle www.test.childstudy.org/crt/

Violence Prevention


Smoking Prevention and Cessation

- The Robert Wood Johnson Foundation Smoke Free Families Program www.smokefreefamilies.org
- A technical assistance manual on implementation of pregnancy-specific guidelines for smoking cessation by the San Diego Partnership for Smoke Free Families is available at www.smokefreefamilies.org/documents/PSFManual.pdf
- Center for Tobacco Cessation www.ctcinfo.org -- Invest in a Healthy State: Covering Tobacco Cessation Services under Medicaid Toolkit.
- Campaign for Tobacco Free Kids www.tobaccofreekids.org
- National Partnership to Help Pregnant Smokers Quit www.helppregnantsmokersquit.org and info@helppregnantsmokersquit.org

Fetal Alcohol Syndrome and Substance Abuse Treatment

- National Organization on Fetal Alcohol Syndrome www.nofas.org
- FAS Community Resource Center http://come-over.to/FASCRC/
- Substance Abuse and Mental Health Services Administration www.samhsa.gov/
- Legal Action Center www.lac.org/
- One Sky Center National Resource Center for prevention and treatment of substance abuse among Native people www.oneskycenter.org
This Issue Brief was written and researched by Cassandra O’Neill, an independent contractor, for the NGA Center for Best Practices.

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14 CDC Programs In Brief Birth Defects and Developmental Disabilities www.cdc.gov/programs/defects.htm
15 March of Dimes Perinatal Data Center, 2002 “Ten Leading Causes of Infant Mortality United States, 1999”
16 March of Dimes quick reference low birthweight
18 Interview with March of Dimes staff March 8, 2004.
19 Safe Motherhood: Promoting Health for Women Before, During, and After Pregnancy; CDC; 2003.
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21 March of Dimes Perinatal Data Center “Hospital Charges for Prematurity – 2001 Data” August, 2003
22 Ibid
23 Chollet DJ, and others. 1996. The Cost of Poor Outcomes in Employer-Sponsored Health Plans.” Medical Care 34, pp. 1219-34.
25 Healthy Start in Pittsburgh/Allegheny County, PA, “Cost Savings of Preventing Low Birth Weight Births”
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30 Healthy Start in Pittsburgh/Allegheny County, PA, “Cost Savings of Preventing Low Birth Weight Births”
32 California provides coverage up to 300% of FPL.
Healhy Babies: Efforts to Improve Birth Outcomes and Reduce High Risk Births

33 Alaska, Arkansas, Delaware, Georgia, Illinois, Iowa, Maine, Maryland, Massachusetts, Minnesota, New York, Vermont
34 Cornell, op cit.
36 Cornell, op cit.
37 Alabama, Arizona, Arkansas, District of Columbia, Florida, Iowa, Maryland, New Jersey, New Mexico, New York, Tennessee, Texas, Utah, Virginia, Washington
38 Cornell, op cit.
39 Colorado, District of Columbia, New Jersey, Rhode Island, Wisconsin
40 Section 1115 Waivers and Budget Neutrality: Using Medicaid Funds to Expand Coverage; State Coverage Initiatives Issue Brief; A national Initiative of the Robert Wood Johnson Foundation; May 2001.
41 www.agi-usa.org/pubs/memo012604.pdf
42 Alabama, Arizona, Arkansas, California, Delaware, Florida, Illinois, Maryland, Mississippi, Missouri, New Mexico, New York, Oregon, Rhode Island, South Carolina, Virginia, Washington, Wisconsin
43 Arizona, Florida, Maryland, Missouri, Rhode Island, Virginia
44 Delaware, Illinois
45 Alabama, Arkansas, California, Mississippi, New Mexico, New York, Oregon, South Carolina, Washington, and Wisconsin
46 California, New York, Oregon, and Washington
47 Alabama, Illinois
48 State Policies in Brief, Medicaid Family Planning Waivers; Alan Guttmacher Institute; February 1, 2004; www.guttmacher.org
49 The Guttmacher Report on Public Policy Volume 3, Number 5, October 2000
California Program Shows Benefits of Expanding Family Planning Eligibility
50 Ibid.
51 Illinois Public Act 93-0536.
52 Comments from Anne Marie Murphy, Director of Medicaid, Illinois.
53 Interview with Michael Wilson Ohio Department of Job and Family Services, March, 2004
54 Interview with Center for Health Care Strategies staff, March, 2004
55 The Nurse-Family Partnership is one of the Blueprints for Violence Prevention
56 California, Colorado, Georgia, Illinois, Kentucky, Louisiana, Maryland, Michigan, Minnesota, Missouri, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, South Dakota, Washington, and Wyoming
57 www.nccfc.org
58 Interview with Nurse Family Partnership staff member, March 2004.
59 Preliminary Year End Report July 2003
60 Arkansas, California, Georgia, Hawaii, Iowa, Massachusetts, Oklahoma, and Texas
61 Trust for America’s Health, Birth Defects Tracking and Prevention: Too Many States Are Not Making the Grade, 2002.
65 Other states participating in this study are Arkansas, California, Iowa, Massachusetts, New Jersey, New York, North Carolina, and Utah with a tenth site in Atlanta, Georgia.
66 Interview with CDC staff, April 13, 2004.
Does your child have special needs? Brochure Texas Birth Defects Monitoring Division, Texas Department of Health, 12/2002.

Interview with Amy Case, Texas Department of Health, March, 2004

Interview with Cara Mai, Centers for Disease Control, March, 2004


Iowa screens for 36 disorders, all newborns are screened for six and screenings for an additional 30 are performed on selected populations, as a pilot program, or by request

GAO Newborn Screening Characteristics of State Programs, March 2003.

There is no uniform national policy for the selection of screening tests so there is variation between state programs.

Oliver, op cit.

GAO Newborn Screening Characteristics of State Programs, March 2003.

Women at higher risk of having a baby with a neural tube defect should take a larger dose of folic acid daily (4 milligrams). Women with diabetes or epilepsy are also at increased risk and should consult their doctors to determine if they should take a larger dosage. Hispanic women have a risk 1.5-3 times higher than non-Hispanic white women for having a child affected by neural tube defects and have lower blood folate levels and are less likely to consume foods fortified with folic acid. Centers for Disease Control

Trust for America’s Health, Birth Defects Tracking and Prevention: Too Many States Are Not Making the Grade, 2002.


Russel, S “Folate may curb heart attacks, strokes” San Francisco Chronicle, March 6, 2004

CDC, Folic Acid Prevention Activities, www.cdc.gov

Section 10-35 of the Illinois Department of Human Services Act


B-Line Express, Volume 3 Issue 1 Winter 2003, NC Folic Acid Council

North Carolina Birth Defects Monitoring Program

Interview with Anna Bess Brown, North Carolina Folic Acid Council, March 12, 2004


Under Secretary For Health’s Information Letter HIV Testing to Prevent Perinatal Transmission, July 3, 2003

PRAMS data is collected in Alabama, Alaska, Arkansas, Colorado, Florida, Georgia, Hawaii, Illinois, Louisiana, Maine, Maryland, Michigan, Minnesota, Mississippi, Montana, Nebraska, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Texas, Rhode Island, South Carolina, Utah, Vermont, Washington, West Virginia. (Previously California, Delaware, District of Columbia, and Indiana participated.) www.cdc.gov/reproductivehealth/pramstates.htm


Interview with Loretta Davis-Satterla and Debra Szwejda, Michigan Department of Community Health, March, 2004.


Preventing Perinatal HIV Transmission: An Update on the TOPWA Program, October 2003, Florida Bureau of HIV/AIDS.

Violence Against Women: Data on Pregnant Victims and Effectiveness of Prevention Strategies Are Limited, GAO, May 2002


Studies have shown that the numbers of physicians screening for violence at the first prenatal visit range from 17-39 percent - GAO report.

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104 www.smokefreefamilies.org
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107 Ibid.
111 Kentucky, Nebraska, Utah, Washington
112 Hawaii, New Jersey, North Dakota, Oklahoma
114 Arizona, California, Delaware, Florida, Georgia, Indiana, Maine, Massachusetts, Michigan, Minnesota, Mississippi, Nebraska, Nevada, New Jersey, New York, North Carolina, Oregon, Pennsylvania, Rhode Island, Texas, Utah, West Virginia, Wisconsin
116 California, Florida, Maine, Michigan, Mississippi, Nevada, Oregon, Pennsylvania, Texas, Utah, and West Virginia
119 Pregnancy and Drug Use Trends, NIDA www.drugabuse.gov/Infofax/pregnancytrends.html
121 Arizona, Georgia, Kansas, Missouri, Oklahoma, Texas, Wisconsin
122 Arizona, Illinois, Iowa, Massachusetts, Michigan, Minnesota, North Dakota, Rhode Island, Utah
123 Iowa, Minnesota, North Dakota, Virginia
125 Special Connections Annual Report July 1, 2001-June 30, 2002, March 27, 2003
127 Public Alcohol/Drug Treatment Improves Birth Outcomes in Washington State Fact Sheet