Taking the Initiative

Multiple programs have been developed or enhanced over the past several decades to address the issue of infant mortality, both at the national and state levels. The U.S. Department of Health and Human Services (HHS) supports a wide range of programs designed to prevent infant mortality. These efforts include programs to improve access to prenatal and newborn care. The HHS also supports public health campaigns to promote healthy habits among new or expecting parents to prevent child malnutrition, as well as medical research to better understand and prevent birth defects, premature births, and sudden infant death syndrome and to promote healthier growth and development.

There are several national programs and system plans, projects, and initiatives that were created by the HHS and its Health Resources and Services Administration's Maternal and Child Health Bureau and subsequently passed into law by Congress in attempts to improve maternal and infant health and to reduce and prevent infant mortality. Many of these national programs are intertwined with those at the state level and provide enhanced healthcare opportunities for many of the population at risk. A sampling of these programs includes the following:

The **National Healthy Mothers, Healthy Babies Coalition**: begun in 1981, prompted by the U.S. Surgeon General's conference on infant mortality. Six lead organizations–the American College of Obstetricians and Gynecologists, March of Dimes, American Academy of Pediatrics, American Nurses Association, National Congress of Parents and Teachers, and the U.S. Public Health Service–established the informal coalition to improve the quality and reach of public and professional education related to prenatal and infant care.

Universal Newborn Screening Program: a preventative public health program which exists in all 50 states and the District of Columbia for early identification of disorders in newborns that can affect their long-term health. Newborn screening programs in the United States began with the work of Dr. Robert Guthrie, who in the 1960s developed a screening test for phenylketonuria (PKU). The panel of newborn disorders screened varies from state to state, and decisions for adding or deleting tests involve many complex social, ethical, and political issues. Generally, infants are screened for PKU, congenital hypothyroidism, galactosemia, maple syrup urine disease, homocystinuria, sickle cell disease, congenital adrenal hyperplasia, tyrosinemia, and hearing. Although state newborn screening programs vary in the number of disorders for which they screen, states generally follow similar practices and criteria in selecting disorders for their programs. The number of disorders included in state programs ranges from four to 36 (Table 9). Some states provide screening for certain disorders to selected populations, through pilot programs, or by request. Almost all state programs provide informa-

Genetic Newborn Screening by State 2002		
	Number of Disorders	
State	Screening Required for All Newborns	Screening Conducted for Selected Populations as Pilot Program or by Request
Alabama	5	0
Arkansas	4	0
Florida	5	0
Georgia	8	0
Kentucky	4	0
Louisiana	5	0
Maryland	9	0
Mississippi	5	0
Missouri	5	0
North Carolina	32	0
Oklahoma	4	0
South Carolina	6	0
Tennessee	5	0
Texas	5	0
Virginia	8	0
West Virginia	3	1

table 9

Source: National Newborn Screening and Genetics Resource Center,*http://genes-r-us.uthsca.edu/resources/newborn/screenstatus.htm*

tion for parents and conduct provider education, but less than one-fourth of all states provide information for parents on their option to test for additional disorders not included in the state's program.

Head Start and Early Head Start: comprehensive child development programs that serve children from birth to age 5, pregnant women, and their families. Beginning with a task force recommendation in 1964 for the development of a federally sponsored preschool program to meet the needs of disadvantaged children, Head Start and Early Head Start provide intervention programs to enhance children's physical, social, emotional, and cognitive development.

The Healthy Start Program: funded by the Health Resources and Services Administration (HRSA) of the Department of Health and Human Services, began as the Healthy Start Initiative in 1991 within 15 urban and rural communities with infant mortality rates 1.5 – 2.5 times the national average. The program began with a five-year demonstration phase to identify and develop community-based approaches to reducing infant mortality by 50 percent and to improve the health of women, infants, and children. Healthy Start was authorized by Congress as part of the Children's Health Act of 2000.

The **National SIDS/Infant Death Resource Center**: provides information services and technical assistance on Sudden Infant Death Syndrome (SIDS) and related topics. The goal of the program is to promote understanding of SIDS and provide comfort to those affected by SIDS through information sharing. State SIDS programs are funded through the Maternal and Child Health (MCH) Block Grant.

SIDS "Back to Sleep" Campaign: named for its recommendation to place healthy babies on their backs to sleep, the Campaign has been successful in promoting infant back sleeping to parents, family members, child care providers, health professionals, and other caregivers of infants. Placing babies on their backs to sleep reduces the risk of Sudden Infant Death Syndrome (SIDS), also known as "crib death." The "Back to Sleep" campaign, launched in June 1994, is sponsored by the National Institute of Child Health and Human Development, Maternal and Child Health Bureau, American Academy of Pediatrics, SIDS Alliance, and the Association of SIDS and Infant Mortality Programs.

Early Hearing Detection and Intervention Programs: designed to identify infants with hearing loss by universal screening. This allows identified infants to be enrolled in an early intervention program. These intervention programs help facilitate the development of visual and/or spoken language and the cognitive skills needed to succeed academically and socially. Various states have adopted the programs since it was first initiated in 1965. In 1999, the American Academy of Pediatrics endorsed a policy statement to implement a **Universal Newborn Hearing Screening** before a newborn is discharged from the hospital, diagnostic evaluation before three months of age, and initiation of appropriate intervention services by six months of age.

ZERO TO THREE: established in 1977 as joint project of the National Infant and Toddler Child Care Initiative and the Child Care Bureau, Administration for Children and Families of the Department of Health and Human Services designed to support state and territory Child Care Development Fund (CCDF) administrators in their efforts to effect system-wide improvements in infant and toddler

child care. This is a three-year project involving 10 states and territories per year.

WIC (Women, Infants, and Children): funded by the U.S. Department of Agriculture (USDA), WIC was established as a pilot program in 1972 and made permanent in 1974. WIC provides federal grants to states for supplemental foods, healthcare referrals, and nutrition education to low-income pregnant and postpartum women, and to infants and children who are found to be at nutritional risk. The current federal WIC regulations also contain provisions to encourage women to breastfeed and to provide appropriate nutritional support for breastfeeding participants.

WIC Farmers' Market Nutrition Program (FMNP): established by Congress in 1992, provides fresh, unprepared, locally grown fruits and vegetables to WIC recipients through the use of sales at farmers' markets. Women, children, and infants over four months old who have been certified to receive WIC program benefits or who are on a waiting list for WIC certification are eligible to participate in the FMNP. Each state agency may participate in some or all of these qualifications. Currently, 44 state agencies operate FMNP, of which 13 are within the Southern region: Alabama, Arkansas, Florida, Georgia, Kentucky, Maryland, Mississippi, Missouri, North Carolina, South Carolina, Tennessee, Texas, and West Virginia.

Child Care Food Program: established in 1968 to ensure children in licensed or approved daycare centers, settlement houses, and recreation centers were receiving nutritious meals. The program initially targeted needy areas that had large numbers of working mothers and provided limited reimbursement. In November 1978, Public Law 95-627 made the Child Care Food Program permanent, expanding it to cover all public or private nonprofit institutions or sponsored facilities, licensed or approved to care for children.

Pregnancy Risk Assessment Monitoring System (PRAMS): an ongoing project of the CDC with state health departments, PRAMS is a population-based risk factor surveillance system designed to identify and monitor selected maternal behaviors that occur before, during, and after pregnancy among women who deliver a live infant. Currently, 12 of 16 SLC states participate in PRAMS (Alabama, Arkansas, Florida, Georgia, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, Texas, South Carolina, and West Virginia).

Fetal and Infant Mortality Review (FIMR): established in 1990, it is a collaborative effort between the federal Maternal and Child Health Bureau and the American College of Obstetricians and Gynecologists. The FIMR is a resource center providing information and advice about implementing the fetal and infant mortality review method. The FIMR information complements local population-based fetal and infant mortality data. It identifies critical community strengths and weaknesses as well as unique health and social issues associated with poor outcomes. Based on the national model, each state conducts its own FIMR. Thirty-one states currently participate in the program. Of those, 11 are SLC states (Alabama, Arkansas, Florida, Georgia, Maryland, Mississippi, North Carolina, Oklahoma, Texas, South Carolina, and West Virginia).

Universal Childhood Vaccine Distribution Program (UCVDP): the result of national efforts to promote vaccine use among all children, it began with the appropriation of federal funds for polio vaccinations after introduction of the vaccine in 1955. Since that year, federal, state, and local governments and public and private healthcare providers have collaborated to develop and maintain an effective vaccine delivery system nationwide.

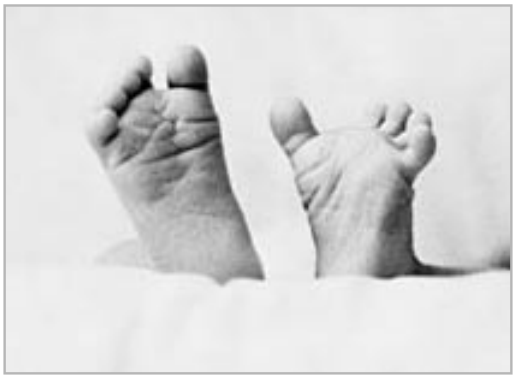
Newborn's and Mother's Health Protection Act of 1996 (NMHPA): a result of the Health Insurance Portability and Accountability Act (HIPAA) reform. It prohibits group health plans and health insurance issuers from restricting the length of hospital stay in connection with childbirth to less than 48 hours following a vaginal delivery or 96 hours following a delivery by cesarean section as determined by an attending provider who is an individual licensed under state law, responsible for providing direct maternal or pediatric care such as a nurse midwife, physician assistant, or nurse practitioner.

State Children's Health Insurance Program (SCHIP): also known as Title XXI, proposed by President Bill Clinton and passed as part of the historic, bipartisan Balanced Budget Act of 1997, SCHIP is the largest single expansion of health insurance coverage for children in more than 30 years. SCHIP is a health insurance program designed to bring quality healthcare to currently uninsured children up to the age of 19 and pregnant women of any age who meet income guidelines. SCHIP gives the states three options for devising a plan to cover uninsured children: designing a new children's health insurance program; expanding current Medicaid programs; or a combination of both strategies. The U.S. Department of Health and

Human Services must approve each state's plan before SCHIP funds become available.

Maternal and Child Health Block: authorized under Title V of the 1935 Social Security Act, this is the only federal program solely devoted to improving the health of all mothers and children, including those with special healthcare needs. Every state has a Title V program that provides services to children with special healthcare needs. The eligibility requirements and the name of the programs vary from state to state. Each state is required to submit an annual application, and grants are awarded to state health agencies to address community level needs, consistent with Title V regulations and guidelines. The Block Grant is administered by the federal Maternal and Child Health Bureau.

Federal Abstinence Education Grant Program: one of several provisions of the 1996 Welfare Reform Legislation, created to help reduce teen out-of-wedlock births. The grant's purpose is to enable each state to provide abstinence education where appropriate, mentoring, counseling, and adult supervision to promote abstinence from teenage sexual activity.



National Council on Folic Acid (NCFA): a partnership of more than 80 national organizations and associations, managed by the National Healthy Mothers, Healthy Babies Coalition through a cooperative agreement with the CDC. The National Council on Folic Acid works conjunctively with each state's folic acid council to improve infant health by preventing neural tube defects (NTDs) as a result of folic acid deficiency during pregnancy. Neural tube defects include spina bifida and anencephaly. Neural tube defects affect an estimated 4,000 pregnancies each year. Spina bifida, the most common NTD, is the leading cause of childhood paralysis. Anencephaly, another type of NTD that affects the brain, always is fatal. In 1992, the U.S. Public Health Service recommended that all women of childbearing years take 400 micrograms (or 0.4 mg) of folic acid daily to prevent having a pregnancy affected by a neural tube defect. In 1998, the FDA required the addition of folic acid to enriched breads, cereals, flours, pastas, rice, and other grain products in order to increase the amount of synthetic folic acid in the general population's diet. Currently, 14 of the 16 SLC states are participating members of the NCFA (Alabama, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia).

National Breastfeeding Awareness Campaign: funded and carried out by the U.S. Department of Health and Human Services Office on Women's Health (OWH), based on the recommendations of the *HHS Blueprint for Action on Breastfeeding (2000)* to promote breastfeeding among first-time mothers who would not normally breastfeed. The overall goal of the campaign is to increase the proportion of mothers who breastfeed their infants in the early postpartum period to 75 percent and those within six months postpartum to 50 percent by the year 2010. The campaign aims to empower women to commit to breastfeeding and to clearly illustrate the consequences of not breastfeeding (seen in infants) such as a higher likelihood of diabetes, weight problems, some childhood cancers, and other illnesses and conditions. The U.S. Surgeon General recommends that infants be fed with breast milk for the first six months of life.

National Abandoned Infants Assistance: developed as the result of the Abandoned Infants Assistance (AIA) Act passed by Congress in 1988 to address the "boarder baby" phenomenon (wherein infants, particularly those perinatally exposed to drugs or HIV, reside in hospitals indefinitely due to difficulties in locating appropriate living arrangements). Administered by the Children's Bureau, the AIA program provides grants to support service programs that help prevent the abandonment of children, particularly infants, who have been exposed to drugs, the human immunodeficiency virus (HIV), or the acquired immunodeficiency syndrome (AIDS). The Act also allows for those infants to reside in hospitals indefinitely due to difficulties in locating appropriate living arrangements. This legislation, reauthorized by PL 102-236 in 1991 and PL 104-235 in 1996, provides funding to support the National AIA Resource Center and directs service projects in participating states. On June 25, 2003, the Keeping Children and Families Safe Act of 2003 was signed by the president and became PL 108-36. This law reauthorized AIA, along with other programs, through fiscal year 2008. Currently, eight SLC states receive funding from the Children's Bureau for their AIA direct service programs and projects: *Great Starts* of Tennessee; *Oklahoma Infant Assistance Program* of Oklahoma; *Project Lagniappe*

of Louisiana; *Project Prevent* and *Project Healthy Grandparents* of Georgia; *Project SAFE* of Florida; *TIES Program* of Missouri; *Family Matters* of Maryland; and *Relatives as Parents Program* of West Virginia.

Child Care Development Fund (CCDF): provides funding to states for child care, the majority of which is spent on care for children ages 5 or younger. At least 4 percent of these funds must be spent on improving the quality of care. About 75 percent of CCDF funds are distributed through certificates or vouchers which parents can use to obtain child care services in a variety of settings. Fifty-six percent of children being served under CCDF in 2000 were cared for in a child care center; 31 percent in family child care homes; 4 percent in group homes; and 9 percent cared for in the child's own home. In FY 2002, CCDF was funded at $4.8 billion.

Special Education Grants for Infants and Families: a formula grant program that assists states in implementing a coordinated statewide system of early intervention services to all children with disabilities, from birth through 2 years old, and their families. In FY 2002, Special Education Grants for Infants and Toddlers were funded at $51 million. This program is administered by the U. S. Department of Education.

1-800-311-BABY: operated under the Maternal and Child Health Bureau, as a national toll-free telephone line initiated to link together information and referral services in all 50 states, the District of Columbia, and Puerto Rico, to help pregnant women obtain proper prenatal information and care. By calling 1-800-311-BABY from anywhere in the United States, pregnant women will be routed automatically to their state maternal and child health hotline or to one of the Healthy Start prenatal care hotlines at 22 sites nationwide. Callers will receive pregnancy and prenatal care information and, in most cases, referral to nearby clinics or healthcare providers.

The **National Adolescent Health Information Center**: established in 1993 with funding from the Maternal and Child Health Bureau. It is based within the University of California, San Francisco's Division of Adolescent Medicine, Department of Pediatrics and Institute for Health Policy Studies. The overall goal of the program is to improve the health of adolescents by serving as a national resource for adolescent health information and research and to assure the integration, synthesis, coordination, and dissemination of adolescent health-related information.

Special Projects of Regional and National Significance (SPRANS): Community-Based Abstinence Education: begun in 2001, provides support to public and private entities for the development and implementation of abstinence education programs for adolescents, ages 12 through 18. This program funds the planning and implementation of community-based, abstinence-only educational interventions designed to reduce the proportion of adolescents who have engaged in premarital sexual activity, including but not limited to sexual intercourse; reduce the incidence of out-of-wedlock pregnancies among adolescents; and reduce the incidence of sexually transmitted diseases among adolescents. The program is now in its third year and has 102 implementation grantees.

While there still are unanswered questions about the persistence of infant mortality in the United States and the divergence between black and white infant mortality rates, interventions including preventative care, access to Medicaid, and access to the public health system are succeeding in reducing infant deaths in this country. One of the most innovative approaches to reducing infant mortality rates in the South is the use of community health outreach workers, including the Project's Hold Out the Lifeline. Without such outreach and support, residents of low-income and rural communities would otherwise lack the benefits of the information and techniques that have become basic in modern medicine. The Project's Hold Out the Lifeline initiative served as the starting point for many current community outreach and faith-based community programs today.

One of the biggest challenges today is making sure low-income pregnant women, children, and families are insured and have full access to the public health system. Low-income women and children in the South face serious barriers to healthcare. In many communities, there are simply too few clinics and health providers (Table 10). Moreover, the crisis in medical practice litigation has exacerbated the situation, leaving poor, uninsured patients in many areas of the South with few options for obstetric care. In 2000, Louisiana had the highest percentage of uninsured children (16.4 percent) and also the lowest percentages of children with private insurance (54.5 percent). At the other end of the spectrum, Tennessee had the lowest percentage of uninsured children, at 5.4 percent.

In 2000, there were 11 million related children (Related children in a family include a householder's own children and all other children in the household who are related to the householder by blood,

marriage, or adoption.) under 18 years of age living in families with income below the federal poverty threshold (e.g., $17,603 for a family of four). Children living below the poverty level comprised 15.6 percent of all related children living in families. While 2000 brought the lowest childhood poverty rate since 1978, childhood poverty continues to exceed that of adults by 71 percent and the elderly by 58 percent. Very young children and black and Hispanic children are particularly vulnerable. Related children under age 6 had a poverty rate of nearly 17 percent. A much higher proportion of black (30.4 percent) and Hispanic (27.3 percent) related children under age 18 were poor compared to related white children (12.3 percent). Of the 11 million related children living in poverty, 55.5 percent lived in homes headed by a single mother; 38.3 percent lived in homes headed by married parents; and 6.2 percent lived in families headed by a single father.[32]

One of the four original goals of the Southern Regional Task Force on Infant Mortality was "to take steps to raise public awareness of the severe nature of infant mortality and low birth weight in the South and of the potential which exists for instituting effective preventative measures." Today, 20 years later, Southern states still are working toward those goals. The South has made tremendous strides in reducing infant mortality rates in the last two decades, but the problem continues to exist.

Another significant development in maternal and infant health is the Medicaid expansion and the establishment of the Maternal and Child Health (MCH) Title V Federal-State Block Grant. Central to the objectives of the Project was access to prenatal care by low-income women. The states' efforts to expand Medicaid eligibility was a critical step in providing this access. Since the expansion of Medicaid, the number of women and children receiving maternal and child healthcare services has dramatically increased, and Medicaid payments to prenatal care providers also have increased. This has allowed county health departments to provide some medical services to Medicaid-eligible recipients. The expansion also afforded many county health departments the opportunity to reinvest their efforts from primary care to population-based public health activities as other providers have assumed a greater role in the provision of Medicaid reimbursable health services.

Since the inception of the Title V Program, Southern states have benefited tremendously from the MCH grants and partnership funds. States and jurisdictions use Title V funds to design and implement a wide range of maternal and child health programs that meet national and state needs. Although specific initiatives may vary among the 16 states utilizing Title V funds, all programs work to reduce infant mortality and incidence of handicapping conditions among children; increase

Health Insurance Status of Children Birth Through Age 18 in 2000

State	Percent with Private / Employer-Based Insurance	Percent Enrolled in Medicaid/SCHIP	Percent Uninsured
Alabama	65.5	26.6	8.6
Arkansas	62.4	26.3	11.3
Florida	62.8	20.3	17.0
Georgia	74.0	17.3	8.7
Kentucky	72.7	19.2	8.1
Louisiana	54.5	29.0	16.4
Maryland	82.3	9.9	7.8
Mississippi	61.0	29.2	9.8
Missouri	71.5	19.3	9.2
North Carolina	68.9	20.9	10.2
Oklahoma	55.6	31.5	12.9
South Carolina	70.6	20.4	9.0
Tennessee	64.4	30.2	5.4
Texas	61.3	17.2	21.5
Virginia	78.7	8.7	12.6
West Virginia	57.9	31.0	11.1
United States	**67.6**	**20.6**	**11.8**

table 10

Source: *Child Health USA 2002*, *State-Specific Data,* Maternal and Child Health Bureau, U.S. Department of Health and Human Services.

the number of children appropriately immunized against disease; increase the number of children in low-income households who receive assessments and follow-up diagnostic and treatment services; and provide and ensure access to comprehensive perinatal care for women and for children with special healthcare needs (CSHCN). Table 11 illustrates these partnerships.

Solutions to improving maternal and infant health are not always medical. State legislatures in the South recognize that there are a variety of ways to ensure the health and welfare of their most vulnerable residents, and many of them have instituted measures to accomplish those goals. In addition to the national programs, there are various state-specific programs offered in each of the SLC states that were developed to help reduce infant mortality and to ensure positive health outcomes for pregnant women and their infants, especially those of low income. Many states are mounting new efforts to regain the momentum toward achieving the maternal and infant health objectives that the Project initially sought. To ensure the maximum use of limited resources, state and local health officials are working together in assessing current programs, evaluating new developments, and determining unmet needs. Infant mortality is a serious issue that requires serious efforts. Knowing that many families in the South remain poor and disadvantaged, many state public health systems have included strategies aimed at reducing poverty and improving social status in several programs.

The MCH Federal-State Partnerships in 16 Southern States 1998 and 2003

State	Year	Populations Served			Total MCH Partnership Funds
		Pregnant Women	Infants <1 year	CSHCN (Special Needs)	
Alabama	1998	26,850	58,668	22,300	$81,978,501
	2003	7,295	55,438	23,633	$72,158,736
Arkansas	1998	16,969	23,529	15,159	$23,179,515
	2003	14,549	37,961	18,092	$31,078,443
Florida	1998	80,841	75,637	47,581	$305,092,907
	2003	121,097	69,235	56,636	$272,805,206
Georgia	1998	81,102	113,986	15,105	$243,533,618
	2003	131,099	133,200	11,480	$279,766,502
Kentucky	1998	32,324	37,102	16,060	$51,424,392
	2003	12,957	24,508	9,913	$61,593,340
Louisiana	1998	55,205	65,947	8,466	$44,482,709
	2003	44,486	65,249	5,711	$42,699,623
Maryland	1998	70,151	69,214	14,125	$32,994,850
	2003	73,250	76,254	6,976	$21,406,247
Mississippi	1998	14,985	42,831	6,249	$18,666,637
	2003	30,667	41,511	3,141	$23,345,470
Missouri	1998	1,028	77,987	5,647	$29,790,422
	2003	1,004	77,456	6,147	$22,101,488
North Carolina	1998	72,103	125,227	64,787	$192,721,500
	2003	75,149	118,178	63,079	$154,265,704
Oklahoma	1998	6,025	48,160	16,727	$17,823,950
	2003	6,874	50,222	23,873	$15,076,546
South Carolina	1998	21,498	37,730	13,589	$82,184,490
	2003	19,212	26,632	10,944	$72,108,964
Tennessee	1998	24,153	50,632	4,695	$35,440,694
	2003	42,280	90,663	6,244	$31,328,518
Texas	1998	124,692	88,064	26,848	$108,010,200
	2003	78,348	381,088	47,202	$84,352,152
Virginia	1998	10,359	91,664	11,160	$36,382,597
	2003	8,412	99,235	7,349	$24,661,009
West Virginia	1998	20,735	20,735	5,126	$32,937,116
	2003	20,725	20,176	5,568	$40,306,379

table 11

Source: *"Title V: A Snapshot of Maternal and Child Health 2000," and "Data Summaries for Title V Expenditures and Individuals Served,"* Maternal and Child Health Bureau, U.S. Department of Health and Human Services.