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File:
Maternal +
child Health

JUN 21 1995



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Catherine A. Hess, M.S.W.

Carol H. Rasco
Assistant to the President
for Domestic Policy
The White House
1600 Pennsylvania Ave., N.W.
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June 16, 1995

Dear Ms. Rasco:

On Wednesday, I attended the budget briefing at which you spoke about President Clinton's priorities. The Association of Maternal and Child Health Programs (AMCHP) greatly appreciates the President's and your continuing commitment to children and to improving access to health services.

As we discussed with you in our January and March meetings, when you so graciously spent time with our Executive Council, the Title V Maternal and Child Health Block Grant is a relatively small but critically important program to addressing both of these priorities. It is the only federal program devoted exclusively to maternal and child health; it provides flexibility while assuring accountability; it supports the infrastructure for coordinated service systems, including those for children with special needs; and it complements Medicaid. The MCH Program will be even more critical if Medicaid changes result in loss of coverage for children, and as states move to managed care delivery systems. The MCH Program covers children and services not covered by Medicaid, and provides the expertise to help Medicaid develop managed care that works for families.

We understand that decisions have not yet been made about all of the priorities to be identified within domestic discretionary programs in the budget document the President will send to Congress. We would like to again request your consideration and assistance in explicitly identifying the MCH Block Grant as a program that should be protected from reductions. As you know, the House has proposed a 50% cut in the program, and the Senate proposes to fold it into a larger block grant with adult oriented programs. While we are getting optimistic

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signals from some House and Senate Democratic and Republican members that these budget assumptions will not be followed in the committees of jurisdiction, an affirmation of the President's priority on MCH would greatly assist in assuring that this 60 year old program survives.

Enclosed are briefs further explaining why the House and Senate Budget Proposals for Title V do not make sense for the nation, the states, or for our children. Also included are three briefs documenting that the Title V program works for infants and pregnant women, for all children, and especially for children with special health care needs. Please contact me if you need more information or have questions. We greatly appreciate any assistance you can provide.

Sincerely,

A handwritten signature in cursive script, appearing to read "Catherine A. Hess".

Catherine A. Hess, M.S.W.
Executive Director



THE NEED TO PRESERVE THE NATION'S COMMITMENT TO THE HEALTH OF MOTHERS AND CHILDREN: A RESPONSE TO THE SENATE BUDGET PROPOSAL TO CONSOLIDATE MCH INTO A STATE HEALTH BLOCK GRANT

The Senate Budget Resolution proposes folding the Title V Maternal and Child Health (MCH) Services Block Grant into a larger state health block with 18 other largely unrelated programs administered by the Health Resources and Services Administration (HRSA). No rationale is provided for the proposal. The following points illustrate why this proposal would not well serve the nation's, the states' and most importantly, children's interests.

The Senate proposal is not consistent with principles adopted by the nation's Governors, especially in protecting children. On January 31, 1995, the nation's Governors adopted "Principles to Guide the Restructuring of the Federal-State Partnership". In the preamble laying out general principles, the "Governors urge Congress . . . to maximize state flexibility in areas of shared responsibility. However, the Governors believe that children must be protected throughout this process . . . Governors recognize the special responsibility of government at all levels in meeting the needs of children and families." By combining the Title V MCH Block Grant with a range of programs focused on adults and even the elderly, the Senate Budget Proposal would eliminate the only federal program focused broadly but exclusively on the health of children and their families.

Without specific authority and accountability, maternal and child health services easily get lost. The vulnerability of pregnant women and of children and youth during critical formative periods of growth and development underscore the unique and important differences between the types of services needed by children and families and those needed by adults. Children and youth are dependent on families as well as on community and social institutions for meeting their interrelated health, educational and social development needs. Without special attention and public accountability, preventive maternal and child health services can easily be overlooked when more powerful constituencies and more costly services demand attention and resources. The value and efficacy of prevention and early intervention services have been demonstrated, yielding long term benefits in family preservation, adult productivity, and hence, the national economy, as well as cost savings for remedial services.

The programs that would be consolidated by the Senate are not united by a clear national purpose. The Governors' January policy position included eight principles to guide consolidation of discretionary grant programs. While the lack of explanation for the Senate proposal precludes assessing it against all of these principles, it clearly fails on three. In addition to failing on the principle to "recognize the national interest in protecting and serving children", the Senate proposal does not meet the principle of including "a clear definition of national purpose and national objectives". The programs proposed for consolidation include those focused on specific diseases (e.g. Hansen's Disease), on specific geographic areas (e.g. Pacific Basin) and on other populations besides children (e.g. Alzheimer's Projects). An April 1995 report on "Rethinking Block Grants", prepared for the Finance Project, also suggests that based on the nation's prior experience, "Block Grants must define clear purposes, program goals and objectives." The report notes that if national policymakers' goal is to reduce total federal funding to states, "fuzzing the sense of purpose . . . may be a deliberate strategy for diffusing political support . . . but the experience of the past decade suggests that over the long term this may be counter productive." Constituency groups successfully lobbied to create new, more narrow categorical programs over the past decade. Structuring block grants based on clear purposes, common goals and target groups, along with adequate accountability measures, can diminish constituent pressures to create new categorical programs in future.

States lack experience and existing structures to manage many of the programs proposed for consolidation. The Governors also believe in the principle that program consolidation must "be consistent with the way in which state government delivers services to its citizens". Aside from the MCH Block Grant, most of the other programs proposed for consolidation by the Senate have been administered directly by the federal government, with little state involvement or experience in their administration. In a February 1995 report on "Block Grants: Characteristics, Experience and Lessons Learned", the General Accounting Office (GAO) found that where states previously had operated programs consolidated into Block Grants, that program experience allowed states "to rely on existing management and service delivery systems". The transition to block grants, therefore, was relatively smooth, with states able to incorporate programs into plans to achieve broader state goals and priorities. This was the case with the MCH Block Grant, where state health agencies either administered or had substantial involvement with most programs that were consolidated into Title V in 1981. However, in the case of some other 1981 block grants that consolidated categorical programs that related primarily to the federal government, the programs were not well integrated with overall state planning processes. In the case of one of these block grants, states actually had to develop new administrative structures. The block grant proposed by the Senate could actually increase, rather than ease, administrative burdens on the states.

The MCH Block Grant already achieves the benefits of state flexibility and administrative simplification. The 1981 amendments creating the MCH Services Block Grant increased the longstanding flexibility and adaptability of Title V to meet family and community needs. Six other related categorical programs were consolidated with basic state run programs for maternal and child health. The block grant expanded state authority to determine how to best use resources to improve maternal and child health and foster health and development of children with special needs due to chronic and disabling conditions. Many states took advantage of this increased flexibility to develop innovative MCH programs that came to serve as national models -- in preventing low birthweight, in helping teenagers assume responsibility for their health, and in supporting families in caring for children with disabilities. Administrative costs are capped at 10%, and the efficiencies of state flexibility have already been realized. The Senate proposal would provide no additional benefits or savings in administering State MCH programs.

Over sixty years of change in society and government, our nation has maintained its commitment to its special responsibility for maternal and child health through Title V of the Social Security Act. Just as the nation made a commitment to its elderly citizens, it recognized and made special provisions for the vulnerable population at the other end of the age spectrum - children. Title V of the Social Security Act has been a dynamic program over those years, responding to the most pressing maternal and child health problems at the time -- from the health effects of child labor early in the century, to emergency maternal and infant care in wartime, to problems including prevention of violence today. Over the last five years, a strong emphasis has been placed on a family-centered approach that supports parental responsibility in assuring the healthy development of children. Throughout these sixty years the Title V Maternal and Child Health Program has assured a focus and public accountability for maternal and child health at federal and state levels.

Policymakers should consider building on the Title V MCH Block Grant, not reversing the progress made over the past 14 years. While adjustments in Title V could further improve its success, the basic block grant framework is working well. With 1989 amendments, the federal-state partnership is more appropriately balanced, and accountability to taxpayers improved. State flexibility to design programs to meet community and family specific needs and the important focus on maternal and child health have been maintained. Merge into a larger block grant risks losing this integrated focus on maternal and child health. Moreover, it could set back the progress made and ignore the lessons learned in the past 14 years about how to make a block grant work well. As they did in 1981, policymakers instead should consider building on Title V and further enhancing national and state focus on maternal and child health. Title V's broad unifying national mission and state MCH programs' experience in administering and coordinating an array of related federal and state programs provide a sound base for structuring a more comprehensive, family-centered approach to the health and development of our nation's children and youth.

May, 1995



WHY THE MATERNAL AND CHILD HEALTH BLOCK GRANT IS ESSENTIAL: A RESPONSE TO THE HOUSE BUDGET RESOLUTION

On May 18 the House passed a budget resolution which included a recommendation for a 50% cut in both the *Maternal and Child Health Services Block Grant* and the *Preventive Health Services Block Grant*. The explanation given for the proposed cuts was "Because the federal commitment to other programs directed towards maternal and child health and preventive health services has increased substantially in recent years, these block grants are not essential."

The House proposal clearly reflects a lack of understanding of the *essential* role Title V plays in supporting the infrastructure of state and community-based services to women and children. The proposal also fails to recognize the critical role the MCH Block Grant plays in helping states deliver services to children and families not eligible for Medicaid and/or services not provided by Medicaid.

The majority of MCH Block Grant funds are spent on essential preventive public health services—services designed to protect and improve the health of all children and families within the State. According to the Federal Department of Health and Human Services, only 25% of MCH Block Grant funds are spent on basic medical care. The other 75% are spent on services to improve the health care system, prevent health problems, and maximize resources. These services include monitoring and reporting on the health of children, including such measures as low birthweight, infant mortality, preventable injuries, and teen pregnancies, and developing and implementing strategies to reduce the level of these health problems. Public information and parent education, provider training and technical assistance, and support for community-based planning efforts and innovative demonstration projects are other means by which MCH Programs benefit all children. The MCH Block Grant also supports services that help families appropriately use the health system. These services include, among others, outreach and transportation.

The MCH Block Grant assists States in assuring that health care providers are available for all families in rural and other underserved areas, regardless of their insurance status. In many areas of the country, there are not enough health care providers available. The MCH Block Grant provides funds to organize health clinics and provides staff or funding to support traveling teams of health care providers, including pediatricians, obstetricians, and specialty providers, to make health care available to all families.

The MCH Block Grant enables States to improve access to health care for the growing number of uninsured children. The number of uninsured Americans rose by over one million in 1993. Four out of five of the newly uninsured were children. The MCH Block Grant subsidizes access to public and private providers for infants and children, including those with chronic illness and disabilities, as well as pregnant women.

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Over 14 million women and children rely on the MCH Block Grant. Medicaid expansions have not reached all poor children and there are many low and middle income working families that are uninsured and underinsured. The MCH Block Grant helps these families obtain access to needed care, including families whose children have a chronic illness or disability.

The MCH Block Grant and the Medicaid program are mandated to work together to assure complementary services. They do not *duplicate* services. MCH Block Grant funds are used to pay for services for children and pregnant women not covered by Medicaid. In addition, MCH programs assist Medicaid by recruiting and training providers, facilitating the reimbursement process, developing and monitoring standards, and providing technical assistance for service delivery.

The MCH Block Grant forms the essential framework upon which States have built and maintained their systems of care for women and children. MCH funds are *flexible* and form the *glue* that brings together multiple agencies and services for children by coordinating, integrating and filling gaps. State MCH programs administer a number of related federal and state funded services and the flexibility of the block grant enables states and communities to put the various funding streams and programs together in a way that makes sense for families. The MCH Block Grant assists in the delivery of services for programs offered by local health departments, community and migrant health centers, the Part H Early Intervention Initiative, the WIC program, and HIV prevention and treatment programs, including Ryan White Title IV services, among others.

In an environment of cost containment and increased state responsibility, the MCH Block Grant becomes more, not less, essential to the health of children. The need to contain costs in the Medicaid program may result in increased numbers of uninsured children. In addition, our country has not yet found a way to stem the growing numbers of uninsured. Potential cuts in other public health grant programs, such as rural outreach, will also put increased demands on the gap filling role of the MCH Block Grant. Further, with states taking on more responsibility for designing programs, developing standards and monitoring quality, the expertise and resources of the state MCH Block Grant programs will be needed to assure that state systems are appropriately designed to meet children's needs and improve their health. And, as the private and public sectors move to managed care MCH Block Grant services such as outreach and consumer and provider education will remain critical to assuring these systems work well for families.



**The Title V Maternal and Child Health Services Block Grant
Works For Children with Special Health Care Needs and Their Families**

Under Title V we have confirmed the value of a Federal and State partnership to promote health and improve access to care. Through...timely clinical intervention, recognition of the benefits of health promotion and disease prevention strategies, and improved access to comprehensive services for disabled, handicapped, and chronically ill children, many Americans enjoy more productive and fulfilling lives.

Senator Robert Dole (R-KS)

Maternal and Child Health [Title V of the Social Security Act], celebrating its 60 year partnership with the States, is an essential program that...forms the infrastructure for provision of family-centered, community-based, comprehensive, coordinated care to children with special health care needs and their families.

C. Everret Koop, M.D., Sc.D.

Early intervention services are critical if we want to ensure that children with disabilities are able to reach first grade ready to learn. Such services may reduce the need for and cost of special education later for children who receive services early.

Rep. Bill Goodling (R-PA)

Obviously, the federal deficit is a major barrier to expanding the Maternal and Child Health Care Block Grant and other programs...but as study after study, experience after experience demonstrates, the cost of not spending more and improving services to help in the development of the first stages of life multiplies into the expense of addressing far more serious problems later on...

Senator Jay Rockefeller (D-WV)

Title V Care Coordination and Case Management Programs Help Keep Children with Special Needs Healthier: By law, all State Title V Programs dedicate at least 30% of their budgets to children with special health care needs, undertaking a wide range of activities to serve this population. Among the critical services supported by Title V are care coordination and case management, which help promote optimal functioning, reduce preventable complications or deterioration of long term conditions, avoid hospitalization or institutionalization and save public funds.

- In *Spokane, Washington* the *State Title V Program* supports *nutrition services* for children with special health care needs, including nutrition screening, counseling and case management for special needs children upon discharge from the hospital. Program efforts result in decreased hospitalizations, better resistance to infections and fuller participation in therapies which benefit the long-term outcomes for success and productivity of these high risk children.
- The *Massachusetts Title V Program* is responsible for care coordination and case management in the State Medicaid Home and Community-Based Waiver Program. Serving 150 children with disabilities, The Title V Program develops saves the state \$15 million per year in institutional costs by developing a service plan for each child that enables families to keep their children at home.

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Title V Early intervention Programs Promote Optimal Functioning: Title V early identification and early intervention activities include programs such as newborn screening; home visiting to families with at-risk children such as low birth weight or HIV positive babies; and multidisciplinary interventions such as those under Part H of the Individuals with Disabilities Education Act (IDEA). These efforts help promote optimal functioning and reduce health care, special education and other service costs for families and for taxpayers.

- *Florida's Title-V Program* supports a pediatric AIDS early intervention program which combines home visits, therapies and developmental intervention for HIV positive children. A one-year evaluation of the program showed 98% of participating children remained stable or gained in cognitive skills, 81% remained stable or gained in motor skills and 79% showed either improvement or no decline in communication abilities. Given the degenerative nature of this disease, stability for this population is interpreted as a significant contribution.
- While all *State Title V Programs* participate in some way in early intervention activities under Part H of the Individuals with Disabilities Act (IDEA), the Title V program is the *lead agency* for Part H in 18 states. Early intervention efforts provide family-centered, multidisciplinary early intervention services to young children through age 5, who have or are at risk of chronic and disabling conditions. States report that these type of services improve child development and social adjustment, reduce parental stress and help families make the best choices for their children.
- Early intervention services like those supported by State Title V programs have been shown to be highly cost-effective. *Massachusetts* reports savings of \$2,705 per child per year, after deducting the cost of early intervention services. *Montana* reports savings of \$2 for every \$1 spent on early intervention by the time the child is age 7 and projects \$4 saved for every \$1 spent by age 18. *Florida* projects costs savings of nearly \$21,000 per child over a 20 year period.

Title V Programs Help Children with Special Health Care Needs Get Community-Based Preventive and Primary Care Services: Title V Programs work with families and providers to develop community-based systems of care for children with special health care needs, thus, helping children stay with their families and reducing the need for institutional care and related costs.

- The *Massachusetts Title V Program's* partnership between tertiary providers and primary care providers enables children with HIV to receive their care in their community from their primary provider, thereby saving the costs of hospitalization or specialty care. The Massachusetts program has enabled 70% of these children's medical visits to take place in a community health center rather than in the hospital.
- *Florida's Title V Program* supports the *Medical Foster Program*, a 4-agency collaborative effort, providing a family-based medical home for medically complex and fragile children who require long-term care. The program enables children to leave hospital or institutional care by placing them in a family environment with foster parents trained in specialty care. This program has proven to be highly cost-effective, costing on average \$40 - \$70 per day, as compared to hospital board rates of \$650 - \$1,000 per day. One State district reported annual savings of \$378,000 for a single child, a 94% reduction in cost. Another impact study found savings of nearly \$1.1 million annually in care for 62 children (78% reduction in cost) and a third review found annual savings of nearly \$800,000 on care for 33 children (86% reduction in costs).



The Title V Maternal and Child Health Services Block Grant Works for Children and Youth

...Many of this nation's citizens have literally grown up under the benefits of this multicomponent program. Title V [MCH Block Grant] has proven to be both adaptive and creative over the past 50 years. It has taken on many challenges within its overall mandate to protect and preserve the health and welfare of mothers and children.

Robert Dole (R-KS)

We sometimes have difficulty grasping the concept behind long-term cost effectiveness programs like MCH...the MCH Block Grant is the only health care program explicitly for children...It is one of the best federal programs we have.

Dale Bumpers (D-AR)

Thousands of local health departments and other programs across the nation receive funding through the Title V Maternal and Child Health Block Grant to provide basic and specialized health care to low-income pregnant women and children, including children who are severely ill and have special health needs and those living in areas where health services are limited.

National Commission on Children

It is essential that we invest more resources now in these programs [including the MCH Block Grant] if we are to make any substantial progress in reducing the cost of acute care in this country...How do you quantify today the savings that will surely be achieved tomorrow from future generations of children that are truly educated in a range of health-related subjects...

Arlen Specter (R-PA)

Title V Prevention and Primary Care Programs Improve Health and Other Outcomes for Children and Youth: Throughout the country, State Title V Programs provide the means to get preventive and primary health services to children and youth. These efforts result in reductions in disease, prevention of hospitalization, more consistent use of non-emergency services and savings in the cost of care.

- **Missouri's State Title V Program** funds were used to start *LINK* (Let's Invest in Kids Now), a primary care clinic in Springfield for Medicaid-eligible children with no regular health care provider. A cost effectiveness study found that for every dollar spent at *LINK* the cost of the same illness at a hospital emergency room was \$7.
- **South Carolina's Title V Program's Child Health Initiative** combined outreach and case management efforts by local public health nurses with services from private physicians to assure that Medicaid-eligible children receive preventive and primary care. Data from Lancaster county, one of three sites, show a decrease in missed appointments, with "no-show" rates comparable among Medicaid and non-Medicaid children. In addition, 95% of Medicaid clients in the program were up to date on immunization, helping to raise the county-wide rate from 60% in 1992 to 90% by late 1994.
- **New York State's MCH Block Grant** funds are used to provide preventive dental care to more than 150,000 children. It is estimated that each \$1 spent on preventive dental services saves at least \$3 in costs that would have been associated with treating dental caries. A diseased tooth can cost \$50 to \$1000 dollars for subsequent treatment.

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Title V Injury Prevention Programs Save Children's Lives and Reduce Disabilities: Two-thirds of State Title V Programs support injury prevention activities, including public and provider education campaigns, poison control centers, programs to purchase and distribute safety products such as car safety seats and bicycle helmets, and the development of injury surveillance systems to track trends and target resources. Research shows both that Title V injury control efforts do make a difference and that the kinds of injury prevention efforts supported by Title V Programs are highly effective and save money as well. A recent study revealed that Title V funding of injury control is associated with lower childhood death rates from unintentional injury, and that states with greater Title V program commitment to injury prevention have fewer child deaths due to unintentional injury.

- **Poison control centers** such as those supported by Title V funds save lives and dollars by directing true emergencies to prompt medical treatment and by screening and counseling non-emergency cases. Approximately 70% of calls coming to poison control centers are resolved by phone. Without these centers, some 600,000 additional poisoning victims would seek direct medical treatment, leading to increased medical expenditures and inappropriate emergency room use. It is estimated that an additional \$545 million would be saved annually if all Americans had access to a poison control center.
- **By purchasing child safety seats, bicycle helmets and other safety equipment and distributing them to low-income families,** Title V programs save lives and provide families with the means to prevent injuries in their children. Studies show that the use of child safety seats cuts the risk of death or injury by 50% to 70%, and that every dollar spent on a child safety seat saves society \$32. Economic savings include, among others, reduced Medicaid payments; decreased police, fire and ambulance costs; and reductions in overall welfare expenditures for the permanently disabled. Studies of the cost-effectiveness of bicycle helmets show that for children aged 4 to 15, every dollar spent on bicycle helmets saves society up to \$31 in avoidable, injury related costs.

Title V Programs Help Prevent Lead Poisoning in Children: Since 1982, the MCH Block Grant has had a major administrative responsibility for the prevention of lead poisoning in children -- a condition that can result in delayed development, severe anemia, sensory and motor problems, mental retardation, and even death. Together with the Environmental Protection Agency and the Centers for Disease Control (CDC), Title V programs form the system of lead poisoning prevention efforts nationwide. In 1991, Title V Programs supported lead screening services in 35 states, medical follow-up management in 22 states, environmental follow-up management in 30 states, community education in 31 states and consultation to other agencies providing lead screening services in 31 states. These programs reduce disabilities, save lives and reduce costs to society. The CDC estimates that preventing high blood lead levels (above 24 μ g/dL) saves \$1,300 per child in medical costs and \$3,331 per child in special education costs.

Title V Programs Help Immunize the Nation's Children: State Title V programs nationwide work to improve immunization rates among America's children. In approximately 40% of the states, more than half of all children statewide who were fully immunized received some or all of their immunization services through Title V support. All Title V programs work collaboratively with State Immunization and Medicaid Programs to reach those most in need. Title V programs also work with WIC, Community Health Centers, Local Health Departments and private providers to promote immunization. Title V efforts include, among others: funding of vaccine administration; outreach to low-income families; helping families and providers keep track of immunization status; provider education and development of immunization standards and policies for providers.

Immunization services are among the most cost-effective health services. The American Academy of Pediatrics estimates that every dollar spent on measles, mumps and rubella vaccine saves \$21, every dollar spent on diphtheria-pertussis-tetanus vaccine saves \$30, and that each dollar spent on polio vaccine saves \$6.



The Title V Maternal and Child Health Services Block Grant Works for Pregnant Women and Infants

Maternal and Child Health...is an essential program that provides preventive care for populations of pregnant women ...

C. Everret Koop, M.D., Sc.D.

MCH Block Grant funds have played a significant role in expanding health care to underserved pregnant women ... in communities nationwide. Therefore we urge continued and expanded support of this program.

National Commission on Children

I would like to speak from the successful experience that the State of Utah has in the administration of its Maternal and Child Health Program. Utah has successfully developed programs aimed at reducing infant mortality...Utah leaders have used the opportunities present to better coordinate services and more effectively meet the health needs of our people.

Orrin Hatch (R-UT)

...[support for combating infant mortality] recognizes the value of the Maternal and Child Health Block Grants...in providing dependable health care to a most vulnerable, yet extremely valuable, segment of this great Nation--pregnant women and children.

Bill Bradley (D-NJ)

Title V Programs Reduce Infant Mortality and Low Birth Weight

The MCH Block Grant forms the essential framework upon which States have built and maintained their systems of care for pregnant women and infants. State Title V programs develop model services for low-income, pregnant women; jointly administer programs with Medicaid that improve care and lower costs; provide technical assistance in maternity and newborn care; and provide funding and other support to local health departments and other community-based providers of services to pregnant women and their infants. Evaluations show that Title V supported programs for pregnant women and infants result in improved health outcomes and save public funds as well:

- Evaluations of *Florida's Improved Pregnancy Outcome Program* -- administered by the State Title V agency -- demonstrate reductions in low birth weight, very low birth weight and neonatal deaths, along with a positive net benefit in costs related to neonatal deaths.
- The *Massachusetts Healthy Start Program*, developed by the State Title V Program with the State's Department of Welfare, has demonstrated a reduction of low birth weight and prematurity among babies born to Healthy Start mothers as compared to infants born to women covered by Medicaid and to women with no insurance coverage.
- In *North Carolina and Kentucky*, studies show that among babies born to mothers on Medicaid--those whose mothers received comprehensive care through Title-V supported public health clinics--were significantly less likely to be born low birth weight than those whose mothers received Medicaid-supported care through private providers.

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- **Utah's Baby Your Baby Program** -- spearheaded by the State Title V Program -- combines outreach and enhanced Medicaid eligibility for comprehensive prenatal services. Evaluations show earlier receipt of prenatal care, a dramatic drop in infant mortality and low birth weight, and significant savings to Medicaid.

Title V Supported Newborn Screening Programs Prevent Death and Disabilities, Severe Mental Retardation, and Lifelong Institutionalization

For over 30 years, Title V Programs have had major responsibility for assuring newborn screening services, including detection, diagnosis and treatment. Today, these services reach virtually all of the 4.1 million infants born in the U.S. each year, screening for diseases such as PKU (phenylketonuria), hypothyroidism and sickle cell anemia. Newborn screening with follow-up care have made it possible to avert many of the tragic health consequences of these and other disorders. An analysis by the Office of Technology Assessment indicates that newborn screening services are cost effective and cites the importance of high volume, State programs in keeping costs down and effectiveness high.

- Without early detection and treatment, nearly all children born with PKU and hypothyroidism become severely retarded and require lifelong institutional care. Now, with universal newborn screening in every state, studies show that virtually all affected children detected at birth and given proper follow-up care develop to their full potential.
- Prior to the development of newborn screening programs for sickle cell anemia approximately 25% of children with this disorder died before reaching age 2. Now, among affected children who are identified at birth and receive proper follow-up care, there are virtually no deaths during the high risk period of birth through age 2.
- Prior to the development of *Maryland's Title V* administered newborn screening program for hearing impairment, the average of diagnosis of Maryland's hearing impaired children was 2 1/2 - 3 years. By 1995, eight years after the program's initiation, the average age of diagnosis has been significantly lowered to less than 12 months, thus ensuring that hearing impaired infants can achieve greater developmental potential because of much earlier intervention.

Title V Programs Help Prevent Transmission of HIV in Babies Born to Infected Women

Serving nearly 4.2 million women annually, State Title V Programs are in a key position to reach high-risk, low-income women with HIV counseling, testing and treatment programs. Across the country, but particularly in those states with the highest incidence of AIDS in women and children, State Title V Programs have responded to the epidemic with a range of interventions, such as: incorporating HIV counseling and testing into prenatal care services; developing guidelines and provider education for universal HIV counseling, voluntary testing, and use of the drug Zidovudine (ZDV) in pregnancy; and arranging for emergency coverage of ZDV costs for newborns not yet eligible for Medicaid.

These kinds of Title V services have become even more central to the effort to save lives since the results of a recent National Institute of Health Study indicated that administering ZDV to pregnant HIV-infected women reduces transmission of HIV to infants by as much as two-thirds. It is critical that women be provided effective education and counseling to enable them to make informed decisions about their care and the care of their infants.