

## Association of Maternal & Child Health Programs (AMCHP) Testimony Senate Committee on Appropriations Hearing on Driving Innovation through Federal Investment April 29, 2014

The Association of Maternal and Child Health Programs (AMCHP) is pleased to submit testimony regarding innovation driven by federal research investments in maternal and child health programs. With roots going back to the Children's Bureau established in 1912, the Title V Maternal and Child Health Services (MCH) Block Grant is a long-standing incubator and conductor of research and innovation, grounded in the understanding that "the health of the child is the power of the nation." Our future depends on making sure that children and families across the country have the tools and resources they need not just to survive but to thrive. Federal investments have driven innovation in state and local maternal and child health programs for decades, with one of the greatest outcomes being an over 90 percent decline in infant mortality since the federal Title V MCH program was begun in 1935.

The Title V MCH Block Grant today provides the foundation for core public health programs dedicated to improving the lives of families in every state, the District of Columbia, and eight territories. In 2013, the \$634 million Title V MCH Block Grant provided health education, support and services to over 40 million women, infants and children, including children with special health care needs. It is a proven, cost effective, accountable, and flexible funding source used to identify and assess the most critical, pressing and unique MCH needs of each state and community. States and their partners then use these assessments to drive public health policy and program innovations that improve health.

States also represent the crossroads where federal research is translated into effective local practice. Although specific initiatives may vary among the states and jurisdictions, all of them work with local, state, and national partners to accomplish the mission of improving the health of all mothers and children, with a requirement that at least 30 percent of resources be devoted to children with special health care needs.

The source of many historic innovations and a key component of the Title V MCH Block Grant is the Special Projects of Regional and National Significance (SPRANS). SPRANS funding complements and helps ensure the success of State Title V, Medicaid and CHIP programs by driving innovation, training young professionals and building capacity to create integrated systems of care for mothers and children. Projects often demonstrate how "new knowledge is put to work."

Examples of innovative projects funded through Title V SPRANS include guidelines for nutrition care during pregnancy and lactation; recommended standards for prenatal care; successful strategies for the prevention of childhood injuries; and health safety standards for

out of home childcare facilities. SPRANS also supports Bright Futures, which is a national health promotion and disease prevention initiative that addresses children's health needs in the context of family and community. In addition to use in pediatric practice, many states implement Bright Futures principles, guidelines and tools to strengthen the connections between state and local programs, pediatric primary care, families, and local communities.

Title V SPRANS funding has also been essential in developing and testing the innovative medical home model of care for children with special needs, which is now widely used as the model of care for all children and adults. The medical home provides care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective to all children and youth, including children and youth with special health care needs. The Maternal and Child Health Bureau's (MCHB) early and ongoing support to the American Academy of Pediatrics, state Title V agencies, and Family Voices has allowed these organizations to define clinical recommendations, build leadership, educate and train their members, offer clinical and consumer resources, and carefully measure the extent to which children and families are actually receiving recommended medical home services.

In addition, Title V SPRANS support is the only major federal health effort supporting transition from pediatric to adult health care. With that funding, MCHB has invested in the development of a clinical report on health care transition jointly developed by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians. Based on this clinical foundation, SPRANS dollars then went into the development and testing of a quality improvement approach to transition in pediatric and adult practices. These are called the Six Core Elements of Health Care Transition, and they are now being implemented and evaluated in clinical sites and health plans across the country.

## Additional examples of successful, federally-supported MCH innovations include:

*Improving Birth Outcomes* - The massive reduction in infant and maternal mortality has been one of the great public health achievements of the 20<sup>th</sup> and early 21<sup>st</sup> centuries. Title V is one of the main federal programs responsible for promoting preconception and prenatal care, and infant mortality reduction programs in the United States. Consider that in 1963, Patrick Bouvier Kennedy - the newborn son of Jacqueline and President John F. Kennedy - born 5 and a half weeks premature and weighing 4 pounds 10 1/2 ounces died two days after his birth from infant respiratory distress syndrome. Research heavily funded by the National Heart, Lung and Blood Institute and the National Institute of Child Health and Human Development (NICHD) led to the development of surfactant, which reduced deaths of premature infants from respiratory distress syndrome. Today over 99% of all babies born this premature in the United States survive

Using Title V MCH Block Grant funds, states help women and families understand the importance of utilizing early and comprehensive preconception, prenatal and interconception care. State MCH program also assist families in reaching the providers they need, whether for prenatal care or specialized maternity services, assure safe and quality obstetric and neonatal care practices, and help maintain access to regionalized perinatal care systems for premature births.

*Newborn Screening* - Today, Title V supports newborn screening programs in all states to detect life threatening or disabling inherited disorders. Each year nearly all of the 4 million babies born in the United States benefit from newborn screening for inherited genetic or metabolic conditions. In 1962, it was a Title V funded research trial that led to the adoption of universal newborn screening in every state. The original research focused on PKU (phenylketonuria) screening, a test to check whether a baby has the enzyme needed to properly digest food. Without the proper enzyme, a child can develop brain damage, seizures, and mental retardation. With treatment – the simple practice of avoiding certain foods – the child can lead a normal life. Today, all states screen for PKU. About one in 14,000 children has this disorder, and each year, PKU is detected in about 250 U.S. children. Since 1960, more than 200,000 individuals and their families have been spared mental retardation and given the chance to live a normal life.

With the support of the Title V MCH Block Grant, every state now offers parents newborn screening tests, and with today's technology these tests can detect up to 60 potentially life threatening or disabling disorders. One out of every 333 babies has a genetic or congenital condition detected. Of the more than four million babies born in the U.S. each year, newborn screening saves the lives of more than 12,000—from death or from a lifetime of intellectual or physical disability, and parents gain information about how to treat their child's condition.

Sudden and Unexpected Infant Death (SUID) and Sudden Infant Death Syndrome (SIDS) - Sleep-related deaths represent the leading cause of death among infants between one month and one year of age. Attributed to Sudden Unexpected Infant Deaths (SUID) / Sudden Infant Death Syndrome (SIDS), unsafe sleep practices associated with accidental suffocation and/or unknown cause of death contribute to the largest post-neonatal cause of infant mortality, defined as the death of a baby before his or her first birthday.

Based on research studies, many of which were funded by the National Institute for Child Health and Human Development, the American Academy of Pediatrics recommended that babies be placed on their backs or side to sleep. This was followed by the launch of the Back to Sleep campaign in 1994. Between 1994, when the Safe to Sleep<sup>®</sup> campaign (formerly known as the Back to Sleep campaign) started, and 1999, the overall SIDS rate in the United States dropped by more than 50%. During that same time period, the rates of back sleeping more than doubled.

*Immunizations* - According to the Centers for Disease Control and Prevention (CDC), vaccination is another one of the greatest public health achievements of the 20<sup>th</sup> Century and substantial declines in cases, hospitalizations, deaths, and health-care costs associated with vaccine-preventable diseases were evident in the first decade of the 21<sup>st</sup> Century. These improved outcomes would have been impossible in absence of national efforts to promote vaccine use among all children, which began with the appropriation of federal funds for polio vaccination after introduction of the vaccine in 1955.

*Home Visiting* – Supported in part by the Maternal and Child Health Bureau, research conducted by David Olds provided the foundation of evidence-based nurse home-visitation models for at-risk first time mothers in order to improve outcomes for themselves and their children. Over 190,000 families have been served since 1996 through what has become the Nurse-Family Partnership with proven results of improved prenatal health, fewer childhood injuries, fewer subsequent pregnancies, increased intervals between births, increased

maternal employment, and improved school readiness. Title V funding continues to support this and other home visiting programs with positive outcomes.

*Family Planning-* Roughly half of all pregnancies in the United States are unplanned. While pregnancy intendedness is not the only factor that determines healthy outcomes for moms and babies, unintended and unwanted pregnancies do have important health, economic and social consequences. Unplanned pregnancies tend to result in lower birth weights, premature births, and higher rates of infant illness and death. Federal investments in Title X and other programs help states and communities apply this science so women and families can avoid the potential negative consequences of unintended pregnancies.

*Motor Vehicle Safety* - According to the CDC, more than 12,000 children from age 0 to 19 years of age die from unintentional injuries and more than 9.2 million are treated in emergency departments for nonfatal injuries every year. The good news is that childhood injury prevention programs work, and the CDC estimates that 240,000 lives were saved between 1966 and 1990 because of improved motor vehicle and highway design; increased use of safety belts, child safety seats, and motorcycle helmets; and enforcement of laws regarding drinking and driving and speeding. The CDC continues to conduct research and advance science around what is known to work to prevent motor vehicle injuries and death, and through the National Center for Injury Prevention and Control, promotes practices such as safety belt use.

*Conclusion-* The above examples are just a few important ways in which federal investments are working to improve maternal and child health outcomes in the United States through innovative approaches, many of which are low-tech and inexpensive. By continuing this smart investment in the Title V MCH Block Grant, we can ensure that the program continues to make services work for children and families by:

- Serving as an incubator for innovative ideas and solutions to address pressing maternal and child health need;
- Identifying the best solutions and helping to bring these to scale across the states;
- Giving states and other partners the opportunity to further refine strategies and models first developed by Title V;
- Developing services and systems of care that benefit all children and families; and
- Developing special services and systems of care for children and families with complex health needs.

Despite this track record of success, federal funding for the Title V MCH Block Grant has declined nearly \$100 million since 2003. To sustain and accelerate efforts to improve maternal and child health, AMCHP calls on Congress to reverse this erosion in funding and provide adequate resources to drive innovation.

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AMCHP's mission is to support state maternal and child health programs and provide national leadership on issues affecting women and children. For more information on this statement, or other AMCHP policy work, please contact Amy Haddad, Associate Director for Government Affairs at 202-775-0436 or <u>ahaddad@amchp.org</u>.