



State Title V Block Grant Narrative

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Sections 5.4 – 5.7, containing standard forms and detailed descriptions of national and State performance and outcome measures, are not included in this PDF. Data from these sections can be viewed in interactive formats on the Title V Information System Web site (<http://www.mchdata.net>).

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1.4 Overview of the State

Pennsylvania's central role was recognized from this nation's inception as evidenced by its *Keystone State* nickname and continues today, as reflected in Governor Tom Ridge's goal for Pennsylvania "to be a leader among states and a competitor among nations".

Geographically, Pennsylvania is bordered by six states: New York, New Jersey, Delaware, Maryland, West Virginia, and Ohio. Its 46,068 square miles are divided into 67 counties with three major cities. Philadelphia, Pennsylvania's largest city, is also among the largest (fourth) in the United States and a major Atlantic port. Pittsburgh, Pennsylvania's second largest city, is among the nation's leaders in iron and steel production. Erie, the third largest, is Pennsylvania's great port and is located on Lake Erie. Allentown follows in size and is an industrial center on the Lehigh River. Harrisburg, Pennsylvania's state capital, is located at Pennsylvania's center.

Pennsylvania leads the nation as its most rural state. Although much of its land is mountainous, Pennsylvania has many fertile valleys suitable for farming. Its 56,000 farms are mostly small, independent, family-owned operations, which average about 150 acres in size and together comprise nearly nine million acres.

Public Health Implications: Assuring the provision of quality, available, accessible and affordable health care services across Pennsylvania's most rural communities presents a formidable challenge. This is especially true in light of the continued roll out of *HealthChoices* (Pennsylvania's mandated Medicaid managed care initiative) into rural counties across the state, most of which lack public transportation systems and proximal access to tertiary hospitals. The Bureau collaborates with the Office of Medical Assistance (MA) and Pennsylvania's *Children's Health Insurance Program (CHIP)* in outreach efforts to grassroots communities. This unique interagency partnership involves the Departments of Public Welfare, Insurance, and Health. In July 2000, the plan is to intensify efforts to enlist grassroots organizations across the state with demonstrated relationships and needed expertise to enroll children in the MA and *CHIP*. Special consideration is being given to outreaching rural populations across the state.

This year, the Department is reviewing health issues that may be unique to rural Pennsylvania. Almost one third of the state's population reside in areas defined as rural by the Census Bureau (42 of 67 counties). The Rural Health Plan will address, by Category of Health Action, population-based health status indicators and underlying causes which may be more prevalent in rural communities. This document may be used by rural communities to identify health improvement priorities, and its findings will encourage the development of a coordinated system of preventive, social and personal health services in local health improvement systems.

Only California, New York, and Texas exceed Pennsylvania in population. Pennsylvania's total population is expected to grow by 1.9%, boosting it over 12.25 million by the year 2005. More than twice as high as the growth

rate of the previous decade, this projection is largely attributed to the expected immigration of Hispanics, Asians and other minority groups. The largest shift in population is expected among middle age groups as baby boomers move into their 40's and 50's. The 'birth dearth' evidenced in the mid-1960's to mid-1980's will result in a sizeable decline among those 25 to 39 years of age. Growth in the elderly (80+) will also substantially increase.

Public Health Implications: These population shifts will challenge the State's ability to maintain adequate levels of health insurance coverage and will result in an increased demand for residential, home and community-based elder care, adult health promotion and disease prevention services, as well as, direct health care and social services. Recognizing this trend, Pennsylvania's Governor Tom Ridge has proposed use of its tobacco settlement monies for free to low cost insurance for underinsured adults, a home and community-based initiative to help Pennsylvanians 'age-in-place', and insurance for Pennsylvania's disabled to aid them in their efforts to become viable contributors to Pennsylvania's workforce.

A state's population is the most important factor governing the size and composition of its labor force and the availability and subsequent utilization of its public and private health care resources. While the growth rate of Pennsylvania's labor force will slow due to the large decline in its youth population reaching working age, its labor force is projected to grow overall to 6,397,000 (6.8% growth) by 2005. As the baby-boomers age, the average age of the labor force will increase; freshly trained youth will enter the labor force; older workers will need retraining; and dislocated workers will become more critical to meet the demands of changing technology. Women's share of the labor force is projected to exceed the current 47%, as a larger proportion look for jobs aided by welfare-to-work efforts.

Public Health Implications: This will increase the need for respite and child day care, non-traditional schedules and business hours, job sharing and other family-centered considerations and promotional programs (e.g., promoting responsible fatherhood and male responsibility) both in the workforce and in Pennsylvania's public-private health services delivery systems. These considerations are especially important in improving the quality of life for families caring for individuals with disabilities and children with special health care needs, mothers of breastfeeding infants and pre-school children. In recognition of this trend, the Bureau will identify strategies and develop incentives to increase the availability of affordable childcare services with the capacity to care for children with special health care needs.

Diversity among Pennsylvania's workers will increase as minorities increase their share of the labor force. While in 1994, Blacks, Asians, and others races represented 9.4% of Pennsylvania's labor force, it is likely by 2005, this will grow to 10.5%. The highest growth is expected among Hispanics whose share of the labor force will increase from 2.3% to 3.4% over the same period.

Public Health Implications: As diversity increases so will the demand for culturally competent, linguistically sensitive services from Pennsylvania's private and public health and social service systems. Eliminating racial and ethnic disparities in health outcomes will continue as a public health priority in Pennsylvania. The Bureau will continue to systematically examine Pennsylvania's maternal and child health status indicators to identify racial/ethnic disparities and develop strategies and programs by which to eliminate these.

Technological changes, foreign competition and shifts in consumer tastes and preferences will cause an employment shift from a goods to a service-producing workforce. By year 2005, four of five jobs in Pennsylvania will be in service-producing industries. Employment growth will be concentrated in health, business, and social services. Together these will make up almost three-fourths of the service-producing job growth. Pennsylvania's health service industry will experience the largest growth, followed by business, social and educational services. Social services, the third largest services growth industry, is expected to employ 211,300 Pennsylvania workers in 2005. This represents a blistering gain of 62.5% from 1994. Residential care will be responsible for 36% of the total social services growth of 81,300. While numerically smaller, child day care employment will increase by 25,700, nearly doubling Pennsylvania's 1994 child day care employment of 27,400. This reflects the increase in working mothers that will take place as welfare eligibility tightens and the number of non-traditional families continues to grow. Consequently, job opportunities for health care and social services professionals will increase substantially along with concurrent advances in technology resulting in the need to enhance workforce competency. Unemployment rates in Pennsylvania already reflect a tightening job market. As of December 1999, Pennsylvania's seasonally adjusted unemployment rate equaled the national rate of 4.1%. This signaled a decrease of 0.2% and the second lowest rate in more than a quarter century. Fifty of 67 counties produced lower unadjusted unemployment rates in December, the lowest at 1.8% and the highest at 9.3%. Of significance, for Pennsylvania is that the highest unemployment rates are almost exclusively found in rural counties, the highest three being Forest, Huntington, and Clearfield.

Closely tied to unemployment are poverty levels. In 1995, (most recent data) the percent of children, ages 5 to 17, below the poverty level in Pennsylvania was 15.7% compared to 18.7% nationally. Philadelphia, Fayette and Greene Counties ranked highest with rates of 36.1%, 27.7%, and 25.1%, respectively. For all children less than 18 years of age, the Pennsylvania rate was 17.3% compared to 20.8% nationally [-42.08 μ (95%)]. Philadelphia, Fayette and Greene Counties again, ranked highest with rates of 37.4%, 30.8% and 27.1%, respectively.

Public Health Implications: It is estimated that 15% of Pennsylvania's MA-eligible children and 40% of its CHIP-eligible children are not enrolled. For both programs, when these percentages are broken out by percent of poverty, the highest proportion of these eligible, unenrolled children are among those at the very lowest end of this socioeconomic continuum. Since poverty is positively correlated to high unemployment rates, it is safe to theorize that many of Pennsylvania's unenrolled MA/CHIP-eligible children will be

found in rural counties where the highest unemployment rates and the highest levels of poverty are found. A unique three-agency outreach partnership involving the Departments of Public Welfare, Insurance, and Health has been formed. The Bureau is collaborating with the Office of Medical Assistance and Pennsylvania's *Children's Health Insurance Program (CHIP)* to promote outreach through grassroots organizations. In July 2000, the partnership will intensify its efforts to enlist grassroots organizations that demonstrate strong community connections to disenfranchised populations and the needed capacity to enroll children in the MA and *CHIP*. Special attention is being given to ensuring appropriate outreach to Pennsylvania's rural communities. In addition, Governor Tom Ridge has proposed the use of tobacco settlement dollars for the provision of health insurance to Pennsylvania's uninsured and underinsured adult population.

In Pennsylvania, the highest school dropout rates are among Hispanics, who will also be the fastest growing segment of the labor force. Public-private efforts to reduce youth risk behaviors associated with high rates of school failure and drop outs will need intensified across the state, as future jobs will require workers with education and training beyond high school. To the extent this phenomenon disproportionately befalls minorities, it will serve to widen existing disparities currently demonstrated by Pennsylvania's education, socioeconomic and health status indicators. In addition, these trends signal the potential for health care and social services professional shortages, and threaten to drive up the cost of health care while concurrently diminishing the availability of competent community-based services in rural areas where unemployment rates are highest and wages lower than in metropolitan areas across the state. A shortage of educators would increase the cost of education and the size of the classroom, and simultaneously reduce the availability of affordable education, and potential for student success, creating a vicious cycle for those minorities most impacted by these trends. Maintaining diversity among Pennsylvania's workforce in the Health and Social Services professions will become a heightened challenge just when the population they serve is expected to reflect the highest diversity in the history of the State.

Recognizing the need to enhance the present and future competency of Pennsylvania's private and public health workforce, in April 2000, the Department launched its University-affiliated *Public Health Institutes*. These regional institutes will provide affordable, training opportunities statewide, to Pennsylvania's private and public health work force in an on-going effort to enhance workforce competency in the face of an ever-changing health care environment. To attract individuals to health care related fields and concurrently draw qualified professionals to health care professional shortages identified across the state, the Department's Bureau of Health Planning has developed and implemented a comprehensive initiative affecting supply, recruitment and retention of primary health care practitioners in order to improve access to primary health care services for residents of medically under-served areas in the Commonwealth. The program has fostered the development of partnerships with and between communities, health care facilities

and educational institutions so that the process of recruitment and retention may occur as part of a continuum, beginning in high school; continuing through college, professional school and residency; and culminating with the decision to locate and remain in an under-served area. To maximize the statewide benefits of these community-based partnerships, the program encourages and expects entities that receive funds, or another type of support under one of its programs, to participate in and support other programs in a mutual effort. It has also led to innovative linkages such as between the Governor's School for Health Care, medical and nursing schools, Federally Qualified Health Centers (FQHCs) and the Statewide Area Health Education Centers to foster primary care careers and support the educational needs of practitioners in rural areas.

In addition, the Bureau of Health Planning serves as the Primary Care Office (PCO) for the Commonwealth. In 1991, the Department obtained a Federal/State Primary Care Cooperative Agreement Grant from the United States (U.S.) Public Health Service. This grant has been renewed on an annual basis. The primary objectives of this grant are planning and coordination of primary care strategies between State and Federal government, liaison and linkage with community-based primary providers in order to enhance the availability of primary care services for medically under-served citizens in Pennsylvania. The grant provides support to assist in the development and delivery of comprehensive primary health care service in areas that lack adequate numbers of health professionals or have populations lacking access to primary care services, and technical and non-financial assistance to primary care delivery sites, FQHCs and National Health Service Corporations practice sites.

One of the main functions supported by this grant is the identification and development of requests for designation of areas as Health Professional Shortage Areas (HPSAs) and Medically Under-served Areas (MUAs). The HPSA designations are utilized to determine National Health Service Corporations assignments, participation in State and Federal loan repayment programs, federal funding of primary care centers, assignment of foreign physicians to Appalachian counties, and to provide increased reimbursement for Medicare providers. The MUA designations are necessary for the development of FQHCs and Rural Health Clinics (RHCs). Since grant support began, this program has led to the development of a Primary Care Assessment Index for Pennsylvania counties and cities, as well as the development of county-based primary care access data which have enabled the program to target areas of greatest need. In addition, staff has assisted 96 communities in obtaining HPSA or MUA designation for their areas. As of March 30, 2000, there are 85 areas which have received federal designation as a primary care health professional shortage area; 30 areas with such a dental designation and 21 mental health professional shortage area designations.

Pennsylvania is well on its way to meeting the United States Health Service Healthy People 2010 infrastructure-building objectives *"to increase to 100 percent the number of states which have a health improvement plan, and to increase to 80 percent the number of local jurisdictions that have a health*

improvement plan linked to the state plan these objectives.” The Pennsylvania Department of Health has embarked on a new direction for health planning. Since 1997, the Department has worked with its Health Policy Board and a broadly representative group of advisors to develop recommendations for a State Health Improvement Plan (SHIP). Through its SHIP the Department engages and facilitates local health improvement partnerships in developing self-directed action steps to address health disparities and access barriers within their individual communities. It provides greater flexibility in working together to develop creative solutions to local health problems through data collection, information sharing, and the coordination of health resources along the spectrum of prevention, acute care, and long term care with state and local partners committed to sharing risk, responsibility and resources. SHIP related activities focus on three priorities:

- 1) Working with community health improvement partnerships to establish a method for mutual identification of priorities, resources, roles and responsibilities, as well as outcomes and evaluation measures;
- 2) Emphasizing planning and prevention to address the root causes of diseases, death and disability. Studies have shown that modifiable behavioral risk factors may be the cause of as much as 50 percent of deaths in the United States. The SHIP groups root causes into six main Categories for Health Action: Communicable Disease, Chronic Disease, Family Health, Violence and Injury, Environmental Health, and Service Delivery Systems. The use of Categories for Health Action permits the use of a broad definition of health, and creates greater latitude for communities to address local problems. In addition, the root cause approach creates opportunities for program integration and interagency cooperation since the focus shifts from specific disease, which implies limited program interest, to underlying causes that create common ground for health improvement strategies; and
- 3) Improving access to data and sharing health status information with communities. Because of a survey of the data needs of community health improvement partnerships, the Department is developing a clearinghouse to provide a wide range of access to demographic, economic and health status information. Community health improvement partnerships may access this information to help identify health status indicators and health disparities in their communities, and how the community compares to statewide and national health indicators.

By changing the focus of health planning from a facility-oriented planning approach, SHIP encourages the development of public/private partnerships to develop and implement programs and share responsibility and accountability. SHIP implementation has four main health improvement priorities:

- 1) Integrate population-based health improvement principles into the local health and social services system.
- 2) Reduce fragmentation and increase coordination of programs.

- 3) Reflect national health improvement objectives such as “Healthy People 2000/2010 National Health Promotion and Disease Prevention Objectives.”
- 4) Support and encourage the linkage of preventive, social and personal health services into local health improvement systems.

As part of the effort to reduce fragmentation and duplication of services at the local level, and to consistently integrate SHIP principles, all Department contracts and grants include a requirement, where appropriate, that the grantee collaborate with the local health improvement partnership to address local health improvement practices.

Pennsylvania currently has 78 local health improvement partnerships. They are voluntary, community-based organizations that embrace a broad definition of health and have conducted assessments of local health status, citizen concerns and resources. The Department selected seven of these partnerships to participate in a demonstration project to design and test the new process. These seven partnerships were chosen based on a shared vision for health improvement with the Department, the degree of linkage of resources, the scope of participation of local organizations, and their overall willingness to assist in the development of a new planning process. The Department plans to expand the existing seven pilot community health improvement partnerships to include at least one state/local partnership in every one of its 67 counties by 2001.

SHIP will effectively serve as a vehicle for state government to partner with communities in an effort to address health disparities. In the spirit of that partnership, Primary Care Office (PCO) staff have recently conducted six public meetings in rural areas to give communities an opportunity to comment on local perceptions of health disparities. The PCO has recognized that access to dental care is a statewide problem; those recent public meetings in rural areas have reinforced the health disparity faced in uninsured and Medicaid recipients in obtaining adequate dental care. To begin to address this disparity, the Department of Health (DOH) is providing small grants designed to encourage communities to obtain a dental Health Professional Shortage Area (HPSA) designation; further activity in those under-served communities will be supported through dental workforce recruitment and collaboration with the Pennsylvania Department of Public Welfare around reimbursement issues.

The following table focuses on racial/ethnic disparities evidenced in Pennsylvania among selected Maternal and Child Health (MCH) indicators.

Indicator	District	Black	White	Hispanic	All	Comments
Average Annual Infant Death rates 1995-97	Southcentral	12.6	6.1	7.4	6.5	1995-97 average annual infant death rates among blacks are 2 to nearly 4 times the rate in the white population for all districts in Pennsylvania. District Hispanic rates were uniformly higher than Whites and lower than Blacks in all districts. Pennsylvania's Hispanic & Black rates exceed the nation's rate while the White rate is equal to it.
	Southeast	16.9	5.8	9.6	8.5	
	Southwest	18.7	5.9	13.7	7.3	
	Northcentral	15.9	6.3	10.6	6.5	
	Northeast	24.1	6.8	10.9	7.2	
	Northwest	17.5	7.1	6.8	7.6	
	PA	17.2	6.1	9.7	7.7	
USA	14.7	6.1	5.9	7.3		
Indicator	District	Black	White	Hispanic	All	Comments
Infant Deaths Rate 1997	Southcentral	8.4	4.7	4.4	5.0	1997 PA infant death rate for Blacks & Hispanics are higher than Whites and lower than Blacks in all districts except Southcentral and Northcentral respectively. Compared to the nation PA rates are higher in all categories except for 'Whites' which is lower. The *Reflects only 7 deaths.
	Southeast	17.4	6.0	9.3	8.7	
	Southwest	18.9	5.4	13.5	6.9	
	Northcentral	21.1	6.6	29.4*	6.9	
	Northeast	26.7	7.4	13.8	8.0	
	Northwest	17.3	6.4	7.2	6.9	
	PA	17.4	5.9	9.8	7.6	
USA	14.7	6.1	5.9	7.3		
Indicator	District	Black	White	Hispanic	All	Comments
Percent Low Birth Weight Live Births 1997	Southcentral	12.0	6.5	7.5	6.8	'97 Percent Low Birth Weight to Live Births for Pennsylvania exceeds the nation's rate for all categories except White, where rates are equal. In all districts, rates for Blacks & Hispanics are higher than Whites except in the Northwest district where the Hispanic rate is lower than White. In all instances, Black rates are highest.
	Southeast	14.2	6.2	9.3	8.2	
	Southwest	14.8	6.6	7.6	7.5	
	Northcentral	15.5	6.1	7.4	6.3	
	Northeast	13.6	7.3	11	7.6	
	Northwest	13.3	6.9	6.5	7.1	
	PA	14.1	6.5	9.2	7.6	
USA	13.0	6.5	6.4	7.5		
Indicator	District	Black	White	Hispanic	All	Comments
Percent No Prenatal Care, 1 st Trimester Live Births 1997	Southcentral	29.4	13.9	27.9	15.1	Pennsylvania's '97 Percent 'No Prenatal Care, 1 st Trimester' for Black & Hispanics exceed the nation's rate. Lack of 1st trimester care in PA is substantially higher than national rates in the Northwest & Southeast Districts. Only the Southwest district has lower Black rates than the national rate. *Reflects only 18 births.
	Southeast	32.7	13.0	29.5	18.0	
	Southwest	22.3	9.3	17.4	10.8	
	Northcentral	28.5	16.9	26.5*	17.3	
	Northeast	28.6	11.4	23.1	12.0	
	Northwest	36.1	16.3	32.8	17.3	
	PA	30.7	12.6	27.9	15.3	
USA	27.7	15.3	26.3	17.5		
Indicator	District	Black	White	Hispanic	All	Comments
Percent of Births to Mothers Under 18 Live Births 1997	Southcentral	11.1	3.2	11.3	3.7	PA's percent live births to mothers <18 exceeds the national rate for Black & Hispanics with the latter evidencing a significantly higher rate. For all districts, rates are substantially higher than the 'White' except in Northcentral where the Hispanic rate appears equal to the White rate, however, Northcentral rate *reflects 2 births.
	Southeast	9.9	2.6	11.3	4.3	
	Southwest	10.9	2.3	4.0	3.3	
	Northcentral	9.2	2.9	2.9*	3.0	
	Northeast	11.3	3.5	11.0	3.7	
	Northwest	11.8	3.5	13.7	3.9	
	PA	10.2	2.8	11.0	3.9	
USA	9.7	4.1	7.2	4.9		

Pennsylvania is geographically, demographically and politically diverse. This is reflected in its governmental systems. Governance is an often-confusing mix of town, city, county, and state jurisdictions. This is further complicated by the organization of the Commonwealth's educational, public health and human services systems. Pennsylvania is organized into 501 independent school districts, 10 city/county health departments, and a state-administered Department of Health with a direct presence in 61 of Pennsylvania's 67 counties. The Pennsylvania Departments of Health and Public Welfare divide the state into regional districts for ease of management, however, their respective regions encompass different geographic areas.

Public Health Implications: Multi-layered systems have potential for fragmentation. This challenge is being addressed on various levels via multiple strategies, including:

- The Governor's Policy Office is strategically charged to promote, and where necessary, guide interagency discussions on issues that impact multiple agency activities, outcomes and their common audiences.
- Governor's Executive Order 1996-1 defined Administrative Agency responsibility to engage in meaningful, formal, public/stakeholder discussions and incorporated these as an essential step in its efforts to promulgate regulations.
- Robert S. Zimmerman Jr., newly appointed Secretary of Health, has challenged Department staff to work collaboratively on an on-going basis with its sister agencies and affected community partners.
- The Department's State Health Improvement Plan (SHIP) promotes linkages and collaboration at all levels of government via an indicator-driven health planning process. Via its written agreements, the Department requires its contractor/grantees to link to community health improvement projects that have demonstrated participation in multi-agency collaborative boards at the community level.
- The Bureau's *Special Kids Network (SKN)*, an outreach, information and referral system for children with special health care needs (CSHCN) and their families, has a strong community systems development component. *SKN* staff analyze data which tracks its ability to match a caller with an available, appropriate service in the callers vicinity. When data demonstrates services are not available to meet expressed needs, Network staff request clearance to work on specific projects with local communities. Special Health Care Needs Consultants (SHCN-C) in each of the Department's six Community Health District Offices provide the leadership for CSHCN at the local level. Through their respective District Executive Director, SHCN-C's have direct connection to the local SHIP partnerships. The local SHIP partnership provides input on the appropriateness of the selected Network projects. Once approved, Network staff provide information to local community planning groups and facilitate local planning efforts to address the problem. When appropriate, this work is also facilitated in collaboration with Pennsylvania's 10 City/County Health Departments.

- Regularly scheduled quarterly meetings are held with City/County Health Departments and Health District Directors to which all bureaus in the Office of Public Health Programs regularly provide updates on current and proposed activities.

1.5 The State Title V Agency

1.5.1 State Agency Capacity

1.5.1.1 Organizational Structure

The Bureau of Family Health is housed organizationally within the Department of Health in the Deputate for Public Health Programs which houses four other Bureaus: Community Health Systems, Communicable Diseases, Drug and Alcohol Programs, and Chronic Disease and Injury Prevention. This structure facilitates ongoing dialogue and cross program collaboration on issues impacting common populations. It further promotes resource allocation efficiencies, enhances policy/programmatic consistency and coordination, and improves communication and collaboration across the public health services offered by the Department through its central and field operations. In this context, the Bureau funds positions within its sister bureaus and in other support units in the Department.

On April 28, 1999, Governor Tom Ridge appointed Robert S. Zimmerman Jr., Secretary of Health. He was confirmed by the Senate on June 14, 1999. Most of Mr. Zimmerman's professional career has been spent in the Department of Health, although, at the time of the nomination, Mr. Zimmerman was serving as Deputy Secretary for Medical Assistance Programs in the Department of Public Welfare. Relationships established during his tenure in the Office of Medical Assistance Programs, facilitate strategic cross-department communications and collaboration which are particularly important for the Bureau of Family Health which serves much of the same population. At the beginning of the Ridge Administration, Mr. Zimmerman served as Acting Secretary of Health, and from 1993 to 1995, he developed and directed the new Bureau of Primary Care Resources and Systems Development. Since 1981, he twice served as Acting Deputy Secretary for Public Health Programs; director of the Bureau of Epidemiology and Disease Prevention; Acting Deputy Secretary for Administration; director of the Bureau of Maternal and Child Preventive Programs; and director of the Bureau of Special Food Programs (WIC). Robert S. Zimmerman Jr. became the first appointee to the Commonwealth's Senior Management System as director of Special Food Programs and received recognition for quickly turning the once-troubled Women, Infants and Children (WIC) program into what continues to be a national model. As evidenced by his broad experience, Mr. Zimmerman has a unique understanding of the Pennsylvania's maternal and child health population and its Title V Maternal and Child Health Services Block Grant. Since his arrival, Mr. Zimmerman reorganized the Department by re-instating the Deputate for Administration and strategically realigning services across the Department. (See attached organization chart). To date, the only change made to the Bureau of Family Health ("The Bureau") is the appointment of its new Director, Ivonne C. Bucher de Gutiérrez, who replaced the former Acting Director, Daniel L. Brant.

The Bureau of Family Health is comprised of three Divisions: Supplemental Nutrition Programs (WIC), Maternal and Child Health (MCH), and Special Health Care Programs (SHCP). Direct responsibility for Title V Programs

resides in the latter two divisions. This organizational structure institutionalizes Title V goals and activities within the Department's cadre of related programs and provides a leadership and management focal point for maternal and child health. The Bureau has broadened its attention on population-based initiatives and continues to move away from a categorical focus.

The Pennsylvania Department of Health, along with its Bureau of Family Health, is headquartered in Harrisburg, Pennsylvania. The Bureau funds one MCH Consultant and one Children with Special Needs Consultant (field coordinators) in each the Department's six Community Health District Offices. These field consultants directly report to the Department's Bureau of Community Health Systems, which is the implementation arm of the Department. Staff from both Bureaus work closely through the Maternal and Child Health and Special Needs Consultants. At a minimum, they annually update written integration plans that delineate responsibility and define actions to accomplish annual objectives, which are linked to the national, state and community-based health status indicators and performance measures presented in this report. In August 1999, a database was implemented statewide to track progress towards desired goals and to improve intradepartmental and cross-program communications. The Bureau of Family Health communicates regularly with Pennsylvania's ten local Health Departments located in the state's major metropolitan areas, through regular, quarterly meetings of Pennsylvania's City/County Health Department Directors facilitated by the Bureau of Community Health Systems and through ongoing, direct communications stemming from its Title V contractual relationships.

Organizational charts of the Department of Health, the Bureau, and positions are attached.

1.5.1.2 Program Capacity

Program capacity is maintained and enhanced both through programs/services conceptualized and organized within the Title V agency, as well as a group of intra-and inter-agency initiatives. The purpose is to develop and structure program initiatives at the community level. The intent is to meet community needs.

The program capacity of the Bureau of Family Health falls under two categories: A) Preventive and Primary Care Services for Pregnant Women, Infants and Children, and B) Children with Special Health Care Needs (CSHCN) program activity areas. These components are described below:

A) Preventive and Primary Care Services Capacity Building for Mothers, Infants and Children:

Maternal and Child Health Outreach Program: Love 'em With a Check-up, initiated in 1993, continues to link pregnant women and their infants and children to sources of prenatal and well child care, services, information and assistance. Through the Interagency Outreach Campaign, expanded linkages with the Department of Public Welfare's (DPW) Medical Assistance (MA) Program, and the *Children's Health Insurance Program (CHIP)*, have facilitated enrollment for thousands of eligible women, infants and children into MA systems of care and the state's *CHIP*. For a more detailed description of the *Love 'em with a Check-up* Outreach Campaign, see Section 2.5 Progress on Outcome Measures, Enabling Services, page 33.

Healthy Start: Pennsylvania is fortunate to have six Federal *Healthy Start* Projects. Launched in 1991, *Healthy Start* was established to demonstrate innovative ways to reduce infant mortality in some of the areas with the highest infant mortality rates in the country.

Philadelphia and Allegheny Counties had two of the original fifteen project sites. Chester County and Chester City projects were added in the Fall of 1997. During the past year, Philadelphia *Healthy Start* received a grant award to start a new in north central Philadelphia. Allegheny County received funding to establish a project in Fayette County. These projects focus on improving local infant mortality rates through a variety of strategies selected by the respective projects. Along with our Title V-funded *Love 'em With a Checkup* Campaign and DPW's *Healthy Beginnings Plus Program*, these *Healthy Start* Projects are a major component in Pennsylvania's endeavor to improve pregnancy outcomes.

HealthChoices: As of July 1, 1997, all Medical Assistance recipients (including children with special health care needs) who live in Philadelphia, Bucks, Chester, Delaware, and Montgomery Counties were served through *HealthChoices*, DPW's mandated managed care program. They were enrolled in one of the four participating mandatory managed care plans (Health Partners of Philadelphia, Keystone Mercy Health Plan, Oak Tree Health Plan and Americhoice) and were required to have their care coordinated by a primary care physician.

Implementation of *HealthChoices* in Southwestern Pennsylvania began on January 1, 1999, expanding mandatory managed care for MA enrollees to the second largest health care market in the Commonwealth. MA recipients in a ten-county area of Southwestern Pennsylvania are now enrolled in one of three Managed Care Organizations (MCOs): Gateway Health Plan, Three Rivers Health Plans, and Best Health Care.

The next major *HealthChoices* expansion will be into the Lehigh/Capital Zone, which includes ten counties in the greater Harrisburg and Allentown areas. The targeted implementation date for expansion is Fall 2001. Target dates for expansion into the remaining counties across the state have not been established.

All MA-covered services that are provided under the fee-for-service program are being covered under *HealthChoices*. As of the end of SFY 1999, there are approximately 849,628 recipients enrolled in MA managed care plans, including *HealthChoices*. The statewide Medical Assistance eligibles for the same time period totaled approximately 1,330,000. The state's Department of Public Welfare, the designated Medicaid agency, is providing behavioral health services (drug and alcohol, as well as mental health) through separate capitated managed care contracts in each county.

State Health Improvement Planning (SHIP) Process: Refer to details in Section 1.4, State Overview, page 9.

Oral Health: Efforts to improve oral health and access to dental care are ongoing in several areas of the Department. First, the Bureau of Health Planning is supporting dental workforce recruitment in under-served areas. Secondly, the Bureau of Chronic Disease is attempting to encourage the fluoridation of more community water systems by providing small community grants. Finally, the Bureau of Chronic Disease is conducting dental health needs assessment to better determine the dental health status of Pennsylvania's children.

Project for Community Building (PCB): The Governor's state fiscal year 2000-01 budget includes funding for continuation of the eight PCB project components. This initiative emphasizes community-based and community driven strategies for community revitalization. It offers communities a broad range of new tools and resources to assist and stimulate local self-help initiatives. With the goal of reducing teen pregnancy, the Department's abstinence education program is one component of the Project for Community Building.

Child Death Review (CDR): The epidemiological review of state and local child deaths is vital to understanding and interpreting causes of death in childhood and developing strategies for prevention. Accordingly, the Department, in collaboration with the Pennsylvania's Department of Public Welfare (DPW) and the Pennsylvania Chapter, American Academy of Pediatrics (PA AAP), continued the process of expanding the State's *CDR* process during Federal Fiscal Year (FFY) 1999. A Memorandum of Agreement (MOA) was signed between the Departments of

Health and Public Welfare to facilitate ongoing, systematic multi-disciplinary review of how and why children (0 to 19 years of age) die in Pennsylvania. This MOA facilitates sharing of funds and information, and delineates the respective responsibilities of each Department. Through a contract with PA AAP and the expanded involvement of the Department's District staff, the Department is expanding statewide and local *CDR* activities and services, including a database development to facilitate the analysis of death certificate information, and the training and technical assistance for local child death review teams. The Department is now exploring the merit and feasibility of expanding upon *CDR* to include Fetal and Infant Mortality Review (FIMR).

Capacity-building Activities of the Regional Maternal and Child Health (MCH) Consultants: The MCH Consultants in each Health Department District function in a consultative role with MCH providers and agencies in their Districts. They identify the priority needs of counties through existing needs assessments and MCH data, then consult with other key community leaders to address these needs. The MCH Consultants consult routinely with staff in the Department of Health District Offices and State Health Centers regarding the scope, content, and effectiveness of MCH services and also to develop and monitor the implementation of the MCH component of the District Integration Plans.

Activities conducted by the MCH Consultants include: coalition and/or task force implementation and development; coordination of local MCH services; training and technical assistance to MCH providers regarding abstinence, lead poisoning prevention, smoking cessation initiatives, child death review teams, teen pregnancy prevention, *Sudden Infant Death Syndrome (SIDS)* follow-up, breastfeeding initiatives, services to the day care population, and to high risk infants, children and families. The Consultants collaborate with the Department of Public Welfare to provide support to local Family Service System Reform (FSSR) and Communities That Care (CTC) Collaborative Boards across the State.

Consultation and Education Regarding the Health and Safety of Children in Child Care Settings: In 1996, the *Early Childhood Education Linkage System (ECELS)* program joined the Federal "Healthy Child Care America" campaign, which emphasizes coordination across funding sources to improve the quality of child care. The campaign, spearheaded by the Health and Human Services (HHS) Administration for Children and Families, has national goals, consistent with *ECELS* program goals which are as follows: safe, healthy child care environments for all children, including those with special health needs; up-to-date and easily accessible immunizations for children in child care; access to quality health, dental, and developmental screening and comprehensive follow-up for children in child care; health and mental health consultation, support, and education for all families, children, and child care providers; and health, nutrition, and safety education for children in child care, their families, and child care providers. Since 1996, the partnering agencies, through the Contractor (PA AAP) have worked to implement these goals under the name of Healthy Child Care Pennsylvania. *ECELS* maintains a registry of largely volunteer or public health professionals (over 1,200) from various disciplines linked by the efforts of a small staff of health professionals based at the PA AAP to address these issues. *ECELS* supports access to curricula and materials for

training of child care workers, technical assistance to solve problems encountered through health consultation, as well as access to training on how to be a health care consultant for a child care facility. *ECELS* is now linking health consultants with DPW licensing staff to facilitate appropriate focus on issues important to the child care licensure process. *ECELS* is encouraging child care centers to take more children with special needs. In addition, the Bureau is exploring the feasibility of expanding the *ECELS* program to link consultants to non-traditional providers of child care, such as respite care providers, and providing incentives to child care providers to improve access to child care and respite care for children with special health care needs (CSHCN). The Contractor is also working with the six regional offices of the Department of Health's *Special Kids Network* to help serve children with special health care needs. Informational materials on seizures, diabetes, spina bifida, asthma, otitis media, hepatitis B, HIV-positive children, tube feedings, intermittent catheterization and other topics related to the care of children with special needs were developed and disseminated, along with a training curriculum on children with asthma in child care settings. The *ECELS* audiovisual library includes over 100 titles of which a total of 26 videos are on children with special health care needs. Having provided leadership for the development of a six-part video series demonstrating how to implement the National Out-of-Home Child Care Standards, *ECELS* now uses this video series and well-tested curricula, for training health consultants and child care providers. *ECELS* continues to build a library of self-learning modules for child care providers. At this time, there are 16 separate self-learning topics that child care providers can request for distance learning. To further improve out-of-home child care issues, *ECELS* has increased the use of electronic communication by joining the World Wide Web and 24-hour access to callers via voice mail. A variety of materials, including the audio-visual catalog, the quarterly newsletter, the fact sheets, and the Model Child Care Health Policies are showcased on the World Wide Web to encourage practices of early childhood programs in Pennsylvania.

B) Children with Special Health Care Needs (CSHCN):

To maximize program capacity, the Division of Special Health Care Programs (SHCP) maintains a very active role in developing a statewide service system for CSHCN. The Division is working in concert with providers and families who are directly impacted by services. The goal is to promote cooperation among key community stakeholders, including parents and health care professionals, to ensure comprehensive culturally sensitive services and to avoid duplication and address unmet needs across Pennsylvania. Emphasis is placed on family-centered and community-based programs while focusing on service coordination. Through its partnerships at the local level, the Division's capacity to reach the population in need has significantly improved. Examples include capacity-building efforts, such as the Division's *Special Kids Network (SKN)* Community Systems Development activities; the formation of Regional Action Teams statewide; community building through the Special Health Care Needs Consultants and Community Health Nurses in our District Offices; and the CSHCN consultant at the Philadelphia Department of Public Health. Consistent with the Department's State Health Improvement Plan (SHIP) philosophy, Division programs foster data collection and analysis to support community-driven programs.

The Division continues to maintain specific initiatives at the State level which have effectively responded to unmet needs. The Block Grant has supported services including the Special Needs Medical Programs; multi-disciplinary team clinics; the *Family Consultant Program*; *Parent-to-Parent of Pennsylvania*; and the *Special Kids Network*. In addition, state or alternative federal funds support the *Chronic Respiratory Disease*, *Head Injury*, and *Chronic Renal Disease Programs* which are an expansion of our capacity to serve additional Title V populations. State funds are also used to provide home services for children who are ventilator dependent; spina bifida, adult cystic fibrosis, Cooley's anemia, and hemophilia services; as well as outreach/education for individuals with epilepsy and Tourette syndrome.

The *Special Kids Network* provides the infrastructure and program capacity from which public and private agency linkages have been established in communities across the State. It helps families with CSHCN find services in two ways. Staff respond directly to callers of the Network's 800 number and utilize a database of over 8,000 service providers to assist families in making connections to needed services. The Network also helps families by improving access to services for CSHCN through community systems development activities. Gaps in services are identified by speaking with families and providers about their needs, gathering information from existing needs assessments, and obtaining data about the unmet needs of callers. Staff then work directly with communities to enhance or create services to meet the needs of special needs families. This is accomplished in collaboration with the Special Health Care Needs Consultants in the Department's six Districts and in line with the Department's SHIP process.

The Division is expanding its focus on CSHCN at the city/county level in other ways as well. Staff have been meeting with Pennsylvania's ten city/county health departments and assisting them to include CSHCN in their triennial needs assessments and work plans as required by the Bureau as a condition of their Maternal and Child Health (MCH) Services Block Grant process. CSHCN staff provides technical assistance and consultation in this regard. The Division intends to expand its support to city/county health departments that assess and prioritize the service needs of CSHCN and their families and submit work plans and objectives that focus on these needs at the local level. In addition to the Philadelphia Department of Health, which is already receiving support from the Division, both the Allentown and Montgomery County Health Departments have submitted CSHCN work plans for Block Grant support from the Division beginning in October 2000.

The Division also has improved the coordination of our programs with other programs of the Department, as well as with other public/private agencies. Division staff collaborates with the Department of Public Welfare's Office of Medical Assistance (MA); the Department of Insurance, *Children's Health Insurance Program (CHIP)*; the Supplemental Security Income (SSI) Workgroup; the Folic Acid Education Outreach Project; Shriner's Hospitals for Children and the Pennsylvania Academy of Pediatrics partnership; interagency partnerships with Early Intervention, local and state Interagency Coordinating Councils, and the local and state Child Death Review Teams.

In the meantime, the Division of SHCP has a referral process whereby applicants to the Title V Programs who appear to meet the SSI definition or appear to be income or condition eligible for Medical Assistance are referred to the county Medical Assistance Offices. This is indicative of the improved coordination between Title V programs and is evidenced by the decreasing number of children who need Title V direct medical services. In Pennsylvania, CSHCN who receive SSI automatically receive Medical Assistance (MA). There are 40,210 SSI beneficiaries under age 16 in Pennsylvania all of whom receive MA. Only 32 of them are also enrolled to receive services through Title V. With our current data system, we are unable to discern whether these children receive SSI disability benefits or whether they are simply receiving a Social Security death benefit. We will work to correct this flaw in our data collection. We are currently working with the Office of Medical Assistance Programs to match Title V recipients with MA recipients. The next step will be to better identify the demographics and characteristics of these children.

1.5.1.3 Other Capacity

Staff in the Divisions of Maternal and Child Health and Special Health Care Programs plan, administer, evaluate, and analyze program activities. Other staff within the Health Department provide consultation and technical assistance to the Bureau and assist in the development and monitoring of services. This includes a wide range of professionals, some of whom are not directly funded by the Block Grant, and include personnel who provide assistance with fiscal, legal, statistical, computer systems, injury prevention, and health promotion issues. (See Table 1.)

In addition, valuing the experience of family members, the Division of Special Health Care Programs (SHCP) continues to gather input from its most valued clients – children with special health care needs (CSHCN) and their families. This has been accomplished through various venues including staff within our Division who are parents and siblings of individuals with special health care needs. Title V funds also support the *Parent to Parent of Pennsylvania Network* which is a major source of input to the Division. *Parent to Parent* mentor-participants, as well as several of its Advisory Board members, are parents of CSHCN. The Division continually seeks innovative ways to assimilate input of family members in the design, development and implementation of its programs.

The capacity of the Division of SHCP to implement and improve services for CSHCN is exponentially increased through the employment of CSHCN family members in many of our programs. For example, as part of its *Family Consultant Program*, contracted hospitals employ family members of CSHCN. These parents support families of hospitalized CSHCN and educate hospital staff on the true meaning of family centered care. Because of this requirement, the Division's *Family Consultant Program* has been successful in conveying a greater understanding of family problems and issues to the medical staff. It is important to note that many of the employees of the *Special Kids Network* are family members of CSHCN. This has allowed the Network to be more sensitive to family needs and has led to the inclusion of family members in community groups as local problems and issues are discussed. Finally, as CSHCN are "children first," the Division of SHCP has maintained active involvement with other Department initiatives for children.

TABLE 1
DEPARTMENTAL STAFF BY FUNDING SOURCE

DOH OFFICES	BLOCK GRANT	OTHER	Location
Bureau of Family Health	4	2	Harrisburg
Division of MCH	22	5	Harrisburg
Division of SHCP	24	10	Harrisburg
Office of Legal Counsel	1		Harrisburg
Bureau of Financial Operations and Management Services	1		Harrisburg
Bureau of Chronic Diseases, Childhood Injury Program	1		Harrisburg
State Center for Health Statistics & Research	0		Harrisburg
Bureau of Community Health Systems, Division of School Health	2		Harrisburg
Bureau of Community Health, MCH and SHCN Consultants	13		Heath District Offices & Hbg.
TOTAL	68	17	

1.5.2 State Agency Coordination

Preventive and Primary Care Services for Pregnant Women, Infants and Children

The Department’s *Love ‘em With a Checkup* campaign is now coordinated in Pennsylvania with the outreach efforts for the *Children’s Health Insurance Program (CHIP)* and Medical Assistance (MA), creating one comprehensive outreach and referral system that assists thousands of low income women and families to get health insurance and to obtain prenatal and primary care. Outreach efforts are carried out through one interagency media service contract managed in the Department of Health. Workplans for each of three Departments – the Department of Health, the Department of Insurance (*CHIP*) and the Department of Public Welfare (MA) – are coordinated in semi-monthly meetings of an interagency workgroup. The Departments take turns coordinating the meetings of the workgroup, setting agendas and preparing minutes. Media outreach for all three programs directs callers to the Department’s *Healthy Babies and Healthy Kids Helplines*. In 1999, the Helplines responded to a total of 115,539 telephone calls requesting assistance with applications for health care coverage, and with locating health care providers and services.

The Departments of Health and Public Welfare contract with four regional councils to support family planning services provided at approximately 192 local clinics throughout Pennsylvania. Utilizing funding from four different sources, the state agencies pay for services through one integrated reimbursement system utilizing a common fee

schedule. The four funding sources include the Department of Health's Title V/Maternal and Child Health (MCH) funding for teens 17 years of age and under, the Department of Public Welfare's Title XIX and Title XX funding, and state funding for breast cancer screening and women's medical services. The United States Department of Health and Human Services Title X funding is provided directly to the family planning councils.

The Director of the Division of Maternal and Child Health represents the Department of Health on the Department of Public Welfare's State Collaborative Board for Family Service System Reform (FSSR). The purpose of FSSR is to empower local communities to coordinate local services and resources based on their determination of need.

Staff employed in the Division of Maternal and Child Health represent the Department in the interagency workgroup responsible for coordinating the Governor's Project for Community Building. Abstinence Education is one of eight initiatives that comprise the Governor's project.

Children with Special Health Care Needs

The Division of Special Health Care Programs (SHCP) has recognized the importance of coordinating the State's Title V activities with various agencies at both the public and private level. This is in keeping with the State Health Improvement Plan (SHIP). Several current initiatives illustrate this increasing ability of State Title V programs to respond to the needs of the children with special health care needs (CSHCN) population in a more comprehensive and coordinated manner.

Staff from the Division of SHCP maintain an ongoing advisory role and consultative relationship with the Department of Public Welfare (DPW) to assure that CSHCN, who are enrolled in managed care plans, have access to and receive services appropriate to their special needs. This interagency advisory role has become increasingly important as DPW expands its mandated Medicaid managed care statewide. Staff participate with DPW in quality assurance site visits to the Medical Assistance (MA) Managed Care Organizations to assure a focus on the specific needs of CSHCN. They also participate on the DPW Enrollment and Outreach Workgroup. The Workgroup developed a common application for MA and *Children's Health Insurance Program (CHIP)*, as well as enhancements to current outreach strategies that will increase enrollment of eligible children into MA and *CHIP*. While the Division has a process in place that assures its eligible clients are referred to MA and *CHIP*, it continues to work on a process to ensure that CSHCN found ineligible for MA and *CHIP* are referred to Title V for services as appropriate. The Division is electronically linked to DPW's MA patient enrollment system, which facilitates coordination of services and referrals. In addition, it works with DPW to maintain standard payments for inpatient services using the MA Diagnostic Related Grouping system. It maintains current and uniform fees for outpatient services by a regular comparison of its fees to MA, making updates as necessary.

Staff from the Bureau of Family Health, DPW's Office of Medical Assistance Programs (MA), and the Department of Insurance's *Children's Health Insurance Program (CHIP)* have developed a work group with the purpose of

identifying and coordinating common interests between Title V, MA, and *CHIP* Programs for CSHCN. This interagency work group has identified issues that impact CSHCN and that require coordination to achieve the desired outcomes for this population. These issues include defining the population served and the eligibility criteria used; sharing data and comparing services provided; clarifying the definition of CSHCN used by each agency; and sharing needs assessments and satisfaction surveys.

The Director of the Bureau of Family Health is the Department's designee to Pennsylvania's State Interagency Coordinating Council (SICC). Through her participation in this 15-member Governor-appointed advisory board, the Bureau Director ensures the Division of SHCP actively participates at the state and local levels. The role of the SICC is to advise and assist state agencies via recommendations to the Departments of Health, Education, and Public Welfare regarding the implementation and maintenance of the Statewide Early Intervention System; its sources of fiscal and other support from federal, state, local, and private sources; and personnel issues, including provision of in-service training. Division staff attends monthly SICC meetings to exchange information and Special Health Care Needs Consultants represent the Division at the Local Interagency Coordinating Council (LICC) meetings in their respective Districts. There are 50 LICCs in Pennsylvania that meet regularly to address local concerns and to share information with the SICC.

Division staff participate in monthly Early Intervention Technical Assistance (EITA) meetings to exchange information and to assure coordination among programs. EITA Consultants assist agencies to provide family-centered supports and services in natural environments and inclusive settings.

Division of Special Health Care Programs staff participate on the Assistive Technology Lending Library Management Board, an interagency committee comprised of representatives from the Pennsylvania Departments of Aging, Education, Health, Labor & Industry, and Public Welfare. The Assistive Technology Lending Library is a statewide program, funded by the Commonwealth of Pennsylvania, to enable people with disabilities and older Pennsylvanians to try out assistive technology devices and equipment in order to decide which best meets their needs and desires. The Commonwealth has contracted with the Institute on Disabilities, Pennsylvania's University Affiliated Program at Temple University, to establish and operate the program. The responsibilities of the Board are to oversee development and implementation of policies and procedures for efficient operation, to evaluate programs, to make recommendations for new equipment, and to oversee the program budget.

The Division has forged numerous relationships with other state and local agencies and programs. As a result of the collaborative relationship between the Division of Maternal and Child Health's (MCH's) *Healthy Baby/Healthy Kids Helpline* and the *Special Kids Network*, callers receive the benefit of having resources available to them through cross-referrals. A similar arrangement exists between the Network and the Department of Education's Connect Information Services and the Statewide Adoption Network. The Division coordinates funding with the Departments of Public Welfare and Education in issuing a grant to the *Parent to Parent of Pennsylvania* program

which matches parents of CSHCN with other similar parents. All three agencies participate on the board of directors in an advisory capacity. The toll-free line for the *Special Kids Network* also is an access point for callers to *Parent to Parent*. Both programs are housed together, and there are protocols for seamless referral of calls from one program to the other.

The Division participates on the Advisory Council for the Deaf and Hard of Hearing which is coordinated by the Office for the Deaf and Hard of Hearing in the Department of Labor and Industry. This relationship allows us to access technical assistance on issues related to the deaf and hard of hearing. It also has resulted in the purchase of portable TTY equipment for the Division and the *Special Kids Network*.

The Division of SHCP has formed Regional Action Teams comprised of Departmental personnel, families of CSHCN, representatives of our contracted programs, and other public and private agencies in order to assess and discuss issues impacting CSHCN at the community level. These teams then make recommendations to the Department on rising issues that should be addressed at the local or statewide level.

The Bureau Director represents the Department on the Pennsylvania Developmental Disabilities Council. Under its federal mandate, the Council's mission is to encourage and support the creation of an environment in which all citizens of Pennsylvania with developmental disabilities can thrive. As a council member, the State Title V agency participates in reviewing and responding to grant proposals submitted by community-based agencies interested in developing service systems for members of their local communities who are developmentally disabled.

Additionally, Division staff has an ongoing partnership with the Departments of Education and Public Welfare to assess the capacity of day care facilities to serve CSHCN. The objective of this activity is to help identify barriers families of CSHCN are experiencing in their communities and discuss means of overcoming them.

The Division funds a position in the Office of Maternal and Child Health of the Philadelphia Department of Public Health through which the Special Needs Work Group (a group of families, providers, children's health and legal advocates; and representatives of local, state, and federal government who meet regularly to discuss how the implementation of *HealthChoices* affects CSHCN) was developed and facilitated. The Division is continuing to support Philadelphia and is expanding their role of planning, implementing, and evaluating community-based services for CSHCN. The Division is participating with other city/county health departments to develop similar initiatives in support of the Department's SHIP.

The Division of SHCP administers renal, cystic fibrosis, spina bifida, Phenylketonuria (PKU), and Maple Syrup Urine Disease (MSUD) pharmaceutical reimbursements through the Pennsylvania's Department of Aging's *Pharmaceutical Assistance Contracts for the Elderly (PACE) Program*. The *PACE Program* is a very large pharmaceutical assistance program for low income Pennsylvania residents over age 55. The agreement we have

with the Department of Aging allows our programs to take advantage of Aging's on-line pharmaceutical claims adjudication system, expands accessibility for our clients to over 2,000 pharmacies, and consolidates the Department's pharmaceutical claims processing with one administrator. The Department of Aging validates all requests for pharmaceuticals to assure quality and cost effectiveness. In addition, the programs receive support from staff pharmacists for the development of drug product formularies.

The Division's *Head Injury Program (HIP)* participates in a system of interagency service coordination among the Departments of Health, Labor and Industry, Public Welfare, and Education. In this system, clients are referred to the appropriate State agency based upon the level of rehabilitation services they require and move from one agency to another as they progress or decline.

The coordination of Division of SHCP programs with other agencies, organizations, and service systems has significantly improved as a result of our taking an active role in advocating for CSHCN, as well as informing others of our programs and activities.

Pennsylvania Statutes that Affect Title V Programs

Statute Name and Citation	Brief Description of Statute
Act 251 of 1965 Newborn Screening	This Act is the initial screening mandate, which requires physicians, hospitals and other institutions to test all newborn infants for PKU (phenylketonuria) and other metabolic diseases.
Act 86 of 1992, the Newborn Child Testing Act	This Act amended the Act of 1965 to include screening for maple syrup urine disease and sickle cell disease and to permit the addition of other conditions through regulation.
Act 191 of 1996, the Medical Foods Insurance Coverage Act	This Act mandates certain carriers to provide insurance coverage for metabolic formulas that are equivalent to a prescription drug medically necessary for the therapeutic treatment of genetic metabolic disorders.
Act 44 of 1995, The Lead Based Paint Certification Act	This Act deals with certification and accreditation of lead-based paint activities.
28 PA. Code Chapter 27 Reporting of Communicable and Non-communicable Diseases	This statute outlines reporting requirements for physicians and laboratories for communicable and non-communicable diseases. It includes language requiring laboratories performing blood lead analysis to report results to the Pennsylvania Department of Health.
71 P.S. § 546 Adult Cystic Fibrosis	Requires the Department of Health to conduct a program of care and treatment of those suffering from cystic fibrosis who are 21 or more years of age.

71 P.S. § 545 Speech and Hearing	This Act requires the Department of Health to provide, maintain, administer and operate speech and hearing rehabilitation centers – (1) For the diagnosis and treatment of children with or suspected of having hearing loss. (2) To provide auditory training for preschool children. (3) To provide consultative services for hard of hearing children of school age and their parents. The Department of Health may purchase such services whenever it is not feasible to provide and maintain such centers.
35 P.S. § 6201 <u>et.seq.</u> Chronic Renal Disease	This Act establishes in the Department of Health a program for the care of persons suffering from chronic renal disease, provides for and designates powers and duties to an advisory committee, and creates an appropriation for funding the Chronic Renal Disease Program.
35 P.S. § 6935 (e) Head Injury EMS Act 45 of 1985 Catastrophic Medical and Rehabilitation Fund	Provides post-acute head injury rehabilitation services, including case management, to residents who have experienced a traumatic head injury after July 3, 1985, and have exhausted alternative financial resources.

II. REQUIREMENTS FOR THE ANNUAL REPORT [Section 506]

2.1 Annual Expenditures

Form 3 (State Maternal and Child Health Funding Profile), Form 4 (Budget Details by Types of Individuals Served and Sources of Other Federal Funds), and Form 5 (State Title V Program Budget and Expenditures) have been completed in accordance with the guidance.

2.2 Annual Number of Individuals Served

Form 6 (Number and Percentage of Newborns and Others Screened, Confirmed, and Treated), Form 7 (Number of Individuals Served under Title V), Form 8 (Deliveries and Infants Served by Title V and Entitled to Benefits under Title XIX), and Form 9 (State Maternal and Child Health Toll-Free Telephone Line Reporting) have been completed in accordance with the guidance.

2.3 State Summary Profile

The State's accomplishments during the fiscal period are summarized in Form 10.

2.4 Progress on Annual Performance Measures

2.5 Progress on Outcome Measures

The annual performance indicators for performance measures, beginning in Federal Fiscal Year (FFY) 1996, have been listed on Form 11. A narrative describing the accomplishments of the Title V program by each level of the pyramid follows.

Direct Services

Preventive and Primary Care Services for Pregnant Women, Infants, and Children

The *Genetic Services Program* has service contracts with twelve clinical genetic centers to provide genetic counseling services for low-income/uninsured pregnant women and children. In addition, the Department has two contracts to (1) develop and conduct genetics educational programs for primary care physicians, (2) provide genetics education for staff in family planning agencies, and (3) through a pilot project to provide family planning clients better access to family-centered genetic services. Under the pilot project, a genetic counselor goes into the family planning clinics to provide genetic counseling services.

As previously mentioned, the Family Planning (FP) service system in Pennsylvania incorporates several funding sources into one integrated system operated through the four regional Family Planning Councils. The funding sources involved in family planning services are the Pennsylvania Department of Health's Title V Maternal and Child Health (MCH) Block Grant, the Pennsylvania Department of Public Welfare's Title XX Social Services block grant, the Department of Public Welfare's Medical Assistance (MA) program (Title XIX funding), state funding (for breast cancer screening, women's medical services, and non-invasive contraceptive supplies), and the United States Department of Health and Human Services Title X direct funding to the Family Planning Councils. Title V funds support services to teens 17 years of age and under.

All of the funding sources contract with the four regional FP Councils to provide reproductive health services through a subcontractor network of approximately 192 local family planning clinics. Patients are transferred from one funding source to another with no interruption of services. Patient records are collectively stored to allow periodic site visit inspections or audits by any of the above program offices. Patient care records for clients of the various entitlement programs involved with family planning services are processed and coordinated through the Family Planning Invoicing System. Performance Measure *SP #1* (Percent of sexually active teens who use Family Planning Services systems) was developed to gauge the impact of publicly funded reproductive health services on the eligible target population in Pennsylvania.

The Federal *Healthy Start* projects are trying to improve pregnancy outcomes and reduce the barriers that prevent pregnant women from receiving early and consistent prenatal care.

The Pittsburgh/Allegheny County *Healthy Start* Project uses core teams, outreach, case management, male and sisters initiative and community involvement strategies. The project served more than 1,000 pregnant women, 1,200 postpartum women, and more than 1,200 infants through the Core Team model of personalized case management. Eighty participants received substance abuse prevention and treatment support. Additionally, more than 100 enrollees were involved in the male initiative support network. The project continues to try to improve collaboration

and system integration for perinatal services. Allegheny County received a grant award to implement a new project in Fayette County.

Chester City Healthy Start is a project that addresses access issues based in the community. This is the project's first year for service and it was able to serve 163 families, providing case management/care coordination to 82 families. Transportation needs were provided to 57 families and translation services were provided to ten families.

The *Healthy Start* Project in Chester County is regarded as a motivating force within the local service provider community regarding infant mortality and maternal and child health issues. Chester County is trying to reduce barriers preventing women from receiving early and ongoing prenatal care. These efforts are based in communities that have high rates of infant mortality, teen pregnancy, low birth weight and child poverty. Some of the accomplishments of the project in its first year of implementation include the following: enrolling 272 women into the program, 30% (79) of which were teens; and assisting 145 women with no health insurance to complete Medical Assistance (MA) applications. There were 216 births in the project with 200 (93%) born with a healthy birth weight.

Philadelphia *Healthy Start* is one of the original projects. The project has focused on West Philadelphia. Some of its accomplishments in the last year included providing services to 1,458 pregnant women and 1,064 infants. Services to empower youth (adolescent population) were provided to 288 teens. One thousand three hundred people attended parenting education classes, and job training was provided for 230 individuals. Eight hundred fifty-one infants received their immunization services through the project. Philadelphia received an additional grant award to implement a new project in north central Philadelphia.

In addition to the individual project accomplishments, the *Healthy Start* projects have begun meeting regularly with the Bureau of Family Health. The purpose of these meetings is to coordinate program efforts to more effectively improve pregnancy outcomes. The coordinated effort addresses NPM #15, 17 and 18, as well as OM #1, 2, 3, 4 and 5.

Children with Special Health Care Needs

In 1999, the Division of Special Health Care Programs (SHCP) utilized the Maternal and Child Health (MCH) Block Grant, the Federal Black Lung Grant, and various State funds to support direct health services for approximately 4,410 children with special health care needs (CSHCN) and 8,264 adults with chronic disabling conditions. Outpatient and limited inpatient services were provided by 640 enrolled providers and included medical and surgical sub-specialty services, occupational therapy, physical therapy, speech, hearing and language services, laboratory services, specialized therapy, home therapy, medications, radiology, nutritional supplements, durable medical equipment and supplies, and disposable supplies. The Pennsylvania Department of Aging's *Pharmaceutical Assistance Contract for the Elderly (PACE) Program* began processing all drug claims for the

Bureau. This resulted in a significant increase in clients' access to pharmacies (from approximately 150 to over 2000). The Division also supports the delivery of comprehensive specialty care by multi-disciplinary teams which provide the medical management of children and adults with chronic disabling conditions including hemophilia, Cooley's anemia, cystic fibrosis, spina bifida, and congenital skeletal/neuromuscular conditions in children. The services include diagnosis, evaluation, treatment, care coordination, vocational planning, family counseling, and referral for genetic screening and counseling. These comprehensive services can be classified as direct health care services as well as enabling services, since children and their families receive both direct medical care from various specialists as well as care coordination, health education, family support, social services, and advocacy.

The medical payment programs contributed toward NPM #02 (providing specialty services and coordination of care), and address Priority Needs 1 through 4 (identification/education/outreach, information/knowledge, coordination of care, and remove financial barriers). The target was not fully met because early intervention and home health care services are not provided by the State CSHCN program, but are provided through other State agencies. The Division's medical payment programs pay for all other specialty and subspecialty services included on the scale which grades attainment of NPM #02.

Enabling Services

Preventive and Primary Care Services for Pregnant Women, Infants, and Children

As previously mentioned, the Departments of Insurance and Public Welfare joined the Department of Health in a coordinated interagency outreach campaign. The "Love 'em with a Checkup" program focused on airing ethnic radio and print outreach stressing the importance of early and regular prenatal care and encouraging pregnant women to call the *Healthy Baby Helpline* for a prenatal care referral. Community health staff continues to promote "Love 'em With a Checkup" in their local communities. The *Medicaid* program developed and aired outreach commercials in southeastern Pennsylvania to inform families that their children remain eligible for *Medicaid* even though the parents were no longer eligible for Temporary Assistance for Needy Families (TANF). The *Children's Health Insurance Program (CHIP)* continued to run television and radio outreach directing callers to the *Healthy Kids Helpline* for assistance with health care coverage and *CHIP* applications. Since the beginning of the *CHIP* media campaign, *CHIP* enrollment has been increasing at a rate of two percent a month.

In 1999, there were 12,552 calls to the *Healthy Baby Helpline* and 96,767 calls to the *Healthy Kids Helpline*. Of the 96,767 calls to the *Healthy Kids Helpline*, 62,549 were for a *CHIP* referral and 30,965 were for a MA referral. In 1999, the *Healthy Kids Helpline* sent out 65,739 *CHIP* applications and 30,936 MA applications. These outreach efforts contribute to NPM#12, 13, 15 and 18, as well as OM# 1, 2, 3, 4 and 5. On NPM #12, we are within 1% of our target. We are not currently able to demonstrate progress against NPM #13, 15 and 18. We believe that the expanded interagency outreach campaign will have future impacts, particularly against NPM # 13.

In FFY 1998, the Department began implementation of a five year comprehensive statewide plan to promote abstinence as a positive lifestyle decision for young adolescents utilizing a variety of strategies aimed at increasing the number of young adolescents who decide to abstain from sexual activity before marriage. The *Abstinence Education and Related Services (AERS)* Initiative awards support to community-designed and driven activities and services to conduct abstinence education and related services, and when appropriate, mentoring, adult supervision and counseling. The program focuses on large and small, rural and urban communities based on: demonstration of need, socioeconomic, racial and ethnic status, and high risk for teen pregnancy. Twenty-eight community-driven and designed *AERS* projects, serving approximately 26 counties, received awards as a result of a Request for Application. *AERS* projects were established in a variety of settings: health organizations, education organizations, social service organizations, faith based institutions, local school districts, and city or county social service agencies. The primary population served were youth 9 to 14 years of age, both male and female. In addition to the *AERS* projects, a media vendor and a university-affiliated evaluator were selected for the development and implementation of a media campaign and an *AERS* statewide process and outcome evaluation, in years 2 to 5 of the *AERS* initiative respectively. This initiative is responsive to NPM #6. The Department has essentially met this objective. The rate of births for 15 – 17 years old is within 1% of our target. In addition, Pennsylvania’s pregnancy rate for this population was 32.0 per 1000 for 1998, well below the Year 2010 target of 46 per 1000.

Children with Special Health Care Needs

While the Department’s Title V programs continue to play a decreasing role in direct health care, we have expanded the delivery of programs which enable children with special health care needs (CSHCN) and families to access other available services. The Division of Special Health Care Programs not only determines the eligibility of clients for Division programs, but also enables clients to access other basic health and medical services through a referral process coordinated with other State programs. This activity evaluates and determines eligibility of applicants by using income, residency, citizenship, age, and diagnosis. Children and adults who meet the eligibility requirements are enrolled. Children under 18 years of age not eligible for Medical Assistance (MA) and with no health insurance are referred to the *Children’s Health Insurance Program (CHIP)*. Applicants with low income or children with disabilities that meet the Supplemental Security Income (SSI) definition are referred to MA when it appears they may be eligible. Coordinating the referral of families with children with disabilities requiring medical care, specialized services, or other resources to the appropriate agencies, e.g., MA or *CHIP*, on the state and community level assures access to needed care. By facilitating linkages and outreach to home and community supports, parent-to-parent networks, and other social services the Division remains active in advocating for and working with families to help them make informed choices about maintaining critical services for their CSHCN. The number of children enrolled with the Division of Special Health Care Programs' for direct health care services declined in 1999 due to a combination of factors which include eligibility safeguards by providers and the Division’s Eligibility Section and improved coverage of special needs by MA/*CHIP*. The referral activities are responsive to NPM #03 (increasing the number of CSHCN who have a “medical/health home”) and NPM #11 (assure a source of insurance,

including Medicaid, for primary and specialty care required to meet the needs of CSHCN). These activities also are consistent with the Department's objective of expanding interagency collaboration.

The Division utilized the family survey findings as indicators for selected National and State performance measures related to CSHCN. While data collection for NPM #03 is still in a developmental stage, the Division of Special Health Care Programs is in the process of improving its capacity to assess CSHCN access to a medical home. Until this process is finalized, the Division used results of the family survey (percent of CSHCN with access to a primary care provider) as an indicator for this measure. The results of the family survey revealed that 93% of CSHCN had a family doctor or pediatrician and confirmed that availability and access to health care services seems to be a strength of Pennsylvania's Title V programs. As an indicator for NPM #11 (assuring a source of insurance, including Medical Assistance, for primary and specialty care required by CSHCN), the survey findings revealed that 95% of families of CSHCN had a source of insurance. Again, the objective is to have all families of CSHCN possess health care coverage.

The Division of Special Health Care Programs continued to fund the *Family Consultant Program* in the four tertiary children hospitals. This program employs the parent or family member of a child with special health care needs in each hospital, which contributes to NPM #14 (the degree to which the State assures family participation in program and policy activities in the State CSHCN program). Through referrals to other programs, the *Family Consultant program* also contributes to SP #7 (the percent of increase in awareness of Title V CSHCN activities). In 1999, the Family Consultants interacted with family members (approximately 2500 adults) of 1667 children. This represented a 10% increase in family contacts over the previous year. Of the families receiving services from a Family Consultant in the tertiary centers, 47% of the families seen by the Family Consultant were referred from outside of the hospital, an increase of 17% over 1998, attesting to the links developed by the Family Consultants with other programs and organizations. The Family Consultants also conducted 45 hospital staff education sessions and 25 promotional presentations. All families (1667) were referred to the *Special Kids Network* for information. In addition, a referral mechanism exists for the Family Consultants to refer families of children with special health care needs, who require assistance after their child is discharged from the hospital, to the Special Health Care Needs Consultants located in each of the six Health Districts for follow-up.

Parent to Parent of Pennsylvania contributed to NPM #14 (the degree to which the State assures family participation in program and policy activities in the state CSHCN program). This program is run by and for parents of CSHCN. Its mission is to provide a mentor parent for parents of CSHCN with similar conditions and circumstances. The majority of its advisory board is composed of parents of CSHCN. 461 parents were trained as parent mentors during 1999. A total of 2607 adults and 1378 children were involved in the parent-matching process accounting for 689 family matches statewide. *Parent to Parent* also provided technical assistance to support groups targeting families of CSHCN exclusively during its annual *Parent to Parent* days.

The Division of Special Health Care Programs supported access to care coordination and respite care to families of infants and children with chronic respiratory failure through the *Ventilator Assisted Children/Home Program (VAC/HP)*. The *VAC/HP* provides professional and family education, monitoring and quality assurance, and care coordination to children living at home who are ventilator dependent. It also provides respite care services for their family caregivers. During 1999, the *VAC/HP* continued to assure that 188 infants and children under age 21 with chronic respiratory failure and their family caregivers had access to care coordination and respite services. These enabling services contributed toward *NPM #02* (providing specialty services and coordination of care) *NPM #03*, (increasing the number of CSHCN who have a "medical/health home"), and *NPM #11* (assuring a source of insurance, including Medical Assistance, for primary and specialty care required by CSHCN) by providing services that were not available through other resources. In 1999, the Division of Special Health Care Programs redesigned the *VAC/HP* monitoring/reporting system by developing a Client Encounter Form to collect data on services provided by the statewide *VAC/HP* contractor. This revised reporting system contributed towards addressing Pennsylvania's priority needs by improving the ability to assess the health status of the population served by the *VAC/HP* (former Pennsylvania Priority Need # 07), enhancing and improving the quality of the system of services available for their use (former Pennsylvania Priority Need # 08), and by connecting ventilator dependent children and their families to providers of community-based services (former Pennsylvania Priority Need #10).

The Division of Special Health Care Programs continued to administer various outreach and support services. The Epilepsy Foundations of Southeastern and Western Pennsylvania continued to implement statewide epilepsy and related seizure disorder outreach and support service programs using community-based education and training programs. With additional state funding to supplement federal support, both service agencies strengthened and expanded their diverse array of core support services. Most notably during 1999, the epilepsy providers shifted their service model to one of shared rather than separate responsibility. This service model required the providers to develop a community-based marketing plan. It engages the community to accept ownership in the delivery of epilepsy supports services, e.g. peer-to-peer programs and recreational camps. An in-house marketing and communications department developed targeted educational and training materials for children and adolescents, adults, health care professional and schools. In high prevalence markets, billboard advertising helped reinforce the provider's community-based messages. In order to track and report outcomes better, the providers invested resources in the development of new client database software which can be accessed by the field staff.

During 1999, with state funding and Division technical assistance, the Pennsylvania Tourette Syndrome Association increased its administrative staff and offered a broad array of outreach and support services. These services are targeted to schools, employers groups, healthcare providers/hospitals, specialty physicians and medical schools. As a result, the client base grew over 500% to 5,224 by the end of 1999. Based on current census figures, they should be serving up to 152,000 clients statewide. This is a classic example of utilizing limited funding to build statewide services.

Population-Based Services

Preventive and Primary Care Services for Pregnant Women, Infants, and Children

State law mandates that all infants born in Pennsylvania be screened for phenylketonuria (PKU), primary congenital hypothyroidism, sickle cell hemoglobinopathies, and maple syrup urine disease (MSUD). Approximately 145,000 newborns are tested for all four of the diseases each year. While the state does not currently test newborns for galactosemia, NPM #04 was met for the other conditions. The Department plans to screen all babies for galactosemia after October 1, 2000.

In 1999, 24 infants were found to have PKU, 45 were diagnosed with congenital hypothyroidism, 72 infants were identified with sickle cell disease, and four infants were identified with MSUD. Delays in diagnosis and treatment for PKU and congenital hypothyroidism may lead to severe mental/developmental retardation. Among the children with sickle cell disease, deaths caused by pneumococcal infections can be prevented through early identification and treatment. Among the children with MSUD, early deaths may be avoided, and severe medical problems and mental retardation can be prevented or reduced.

The Department of Health's *Newborn Screening Program* has an agreement with the Department of Public Welfare's Medical Assistance Program for the reimbursement of newborn screening services for medical assistance-eligible patients. There are approximately 35,000 to 40,000 births each year of infants who are eligible for Medical Assistance. The *Newborn Screening Program* is reimbursed a flat fee of \$12.00 per initial newborn screening test, which includes testing for phenylketonuria (PKU), hypothyroidism, sickle cell disease, and maple syrup urine disease (MSUD).

Program services include specimen collection, laboratory testing, diagnostic evaluation, treatment, and follow-up. The State Public Health Laboratory establishes standards, and evaluates and approves the testing methods which are utilized. Maternal and Child Health (MCH) program staff provide direct follow-up services for newborns with abnormal and inconclusive test results, linking these newborns and their families with treatment specialists who conduct diagnostic testing and coordinate the required care.

With a state funding appropriation, the Department began preparations for a newborn hearing screening demonstration project. This project will assist the Department to be responsive to NPM # 10.

According to the National Center for Health Statistics, *Sudden Infant Death Syndrome (SIDS)* is the leading cause of death in children between one and twelve months of age. This experience frequently disrupts family stability and may have an adverse impact on the outcome of subsequent pregnancies. In 1999, the program provided services to approximately 83 families who experienced an infant death during the year. The Department has implemented a centralized, statewide *SIDS* service system for all families affected by *SIDS*. The program provides:

- 1) Follow-up education and support for affected families by Community Health District Staff and staff in the county/municipal health departments;
- 2) Coordination of services by all members of the *SIDS* Referral Network;
- 3) *SIDS*-related training for all professionals;
- 4) Support and expansion of parent support groups; and
- 5) Ongoing assessment of service quality.

Nationally, there has been a decrease in the number of infant deaths due to *SIDS*, which is reflected in Pennsylvania's recent annual statistics. The reason for this decrease is not completely clear, although a public awareness campaign *Back to Sleep* has been implemented to encourage parents to put babies to sleep on their backs, thereby helping to reduce *SIDS* deaths. In 1997, there were 103 *SIDS* deaths in Pennsylvania, as compared to 89 in 1998. The decrease in *SIDS* deaths is responsive to OM #1, 2, 3 and 4.

During fiscal year (FY) 98-99, some children enrolled with the Pennsylvania *Women, Infants and Children (WIC) Program* were assessed for their immunization status. Due to limited funding, immunization assessments were carried out in fewer counties during this report period than the prior report period. This initiative resulted in the completion of 161,835 assessments, and more than 40% of the children who were assessed were referred for immunizations. Another immunization initiative of the Department, known as Tot Trax, continued to operate statewide during this period. This unique program is a partnership between the Department, birthing hospitals, and volunteer groups to educate new mothers on immunizations while in the hospital. Tot Trax operated in 79 of 156 birthing hospitals in the State during this period, excluding Bucks, Erie, and Philadelphia county hospitals. These initiatives contribute to NPM #05, timely and complete immunization status for children through age two. Our continuing progress against this measure is not adequately reflected in Form 11. Because Haemophilus Influenza and Hepatitis B have been added to the list of required vaccinations since 1996, our reported rate has gone down. Without including these two conditions, our rate has continued to rise.

Comprehensive childhood lead poisoning prevention services were provided during this period in targeted identified high-risk areas of the Commonwealth through 11 Department of Health (DOH)-funded *Childhood Lead Poisoning Prevention Program (CLPPP)* projects. The following services were provided: 1) approximately 43,000 children were screened, 2) over 3,711 children with blood lead levels of 15 ug/dL and greater were referred for Early Intervention services, 3) over 7,200 children received case management services, which included but was not limited to education, counseling, and technical assistance regarding the remediation of lead hazards, and 4) over 2,126 children had blood lead levels over 20 ug/dL and received environmental investigations. Over 1,620 presentations were conducted at the local level to a wide range of audiences including but not limited to health care providers, social service agencies, child care providers, parents, lead abatement contractors, and realtors.

In non-*CLPPP* project areas, over 850 children were provided case management and tracking services by DOH District Field Staff (DFS). The average blood lead level at the time of referral was approximately 22 ug/dL, with an average blood lead level at the time of case closure of 12 ug/dL. Environmental investigations (EI) for non-*CLPPP* projects areas were and continue to be provided by DOH funded-*CLPPP* projects. During this period, DFS provided case management and tracking services. Screening in these areas is carried out by pediatric health care providers at the community level.

The *CLPPP* has worked closely with the Department of Public Welfare (DPW), Medicaid Mandatory Managed Care Organizations (MCO), and the *CLPPP* projects regarding the delivery of childhood lead poisoning prevention services. Attempts to implement agreements between the Health Choices MCOs, as required by the *HealthChoices* RFP, were unsuccessful. DPW currently reimburses the *CLPPP* for EIs provided to Medicaid enrolled and Medicaid Health Maintenance Organization (HMO) enrolled lead-poisoned children.

A statewide toll-free Lead Information Line (LIL) responded to over 2,300 telephone inquiries, and distributed a total of over 65,000 pieces of the top ten most requested educational materials. A Lead Abatement Training Center (LATC) operated in collaboration with the DPW provided training at no cost to state and local government agencies and nonprofit organizations. Training has been provided to 1,326 individuals in various lead abatement disciplines, including training of *CLPPP* project staff necessary for Risk Assessor certification. Regulations for Act 44, known as the Lead Certification Act, and which requires certification and accreditation of lead-based paint activities, were completed during this period.

In addition to Title V funding and Medicaid reimbursement, the *CLPPP* receives funds from the Center for Disease Control and Prevention (CDC), the Housing and Urban Development (HUD), and the United States Environmental Protection Agency (EPA). The services provided by the *CLPPP* are responsive to SP#2.

Children with Special Health Care Needs

As part of a public health nutrition awareness and disease risk factor prevention campaign, the Division of Special Health Care Programs assumed a leadership role in the development of a statewide folic acid education and awareness campaign. This program's goal is to emphasize the health and disease prevention benefits that childbearing age women can realize by consuming a daily minimum of 400 micrograms of folic acid and reduce the incidence of neural tube birth defects. This prevention initiative is significant because it targets approximately 2.6 million resident childbearing age women and supports outreach efforts by the March of Dimes, The Mid-Atlantic Regional Human Genetics Network, and the health departments of contiguous states.

Beginning in 1999, the Division of Special Health Care Programs utilized the Department's marketing contractor to initiate discussions that will lead to the development and printing of a proprietary folic acid brochure and poster during 2000. These folic acid materials will be produced in English and Spanish versions. The Division formed an

internal workgroup composed of staff from the Bureau of Chronic Diseases as well as the Divisions of Women, Infants, and Children (WIC) and Maternal and Child Health (MCH). This workgroup served as professional consultants to the folic acid initiative and the Department's marketing contractor.

The Division of Special Health Care Programs, working with the Bureau of Community Health Systems, drafted and implemented a folic acid promotion component into the Department's Community Health Services Integration Plan. Specifically, the Special Health Care Needs Consultants in each Health District have identified community-based educational opportunities to promote folic acid consumption within their respective Health Districts.

In cooperation with the Division of Health Statistics and Research, a statewide, stratified sample of childbearing age women was surveyed to determine their knowledge and consumption of folic acid. This information was tabulated during 1999 and will serve as a baseline from which to gauge the results of the 2000 folic acid promotion campaign. The folic acid survey and methodology used was developed by the Center for Disease Control and Prevention (CDC) and is incorporated as part of the Department's Behavioral Risk Factor Surveillance System annual survey. The folic acid survey module will be conducted again during 2000 to determine the impact of folic acid interventions. This initiative contributed to *SP # 6* (participation in prevention initiatives that impact conditions and services for CSHCN).

In addition, we have reviewed our medical payment programs as well as our education/outreach programs to better define and describe the prevention components in each. This has resulted in allowing us to take credit for many of the prevention services that we have always provided to CSHCN, but had not recognized. For example, all of our multi-disciplinary specialty clinics provide treatment and education focused on preventing complications of the condition which might result in hospital admissions or emergency room visits.

Pennsylvania Law 1994-102 gave the Department expanded responsibility for heightening awareness to the need for organs and tissue needed for transplantation and the necessity for increasing participation in the voluntary contribution system. The Law established the Organ Donation Awareness Trust Fund and the Organ Donor Advisory Committee. The Law designated that up to 10% of the Organ Donation Awareness Trust fund may be expended by the Department for the reimbursement of funeral expenses incurred by the donor or donor's family in connection with making a vital organ donation. The Committee recommended a plan to the Department as to how the reimbursement is to be implemented. The Division of Special Health Care Programs continued to provide technical assistance to the Committee in their efforts during 1999 to develop a pilot program for the Department to reimburse for organ donation expenses under Pennsylvania Law 102. Following numerous revisions, the Committee submitted its proposed "Voluntary Benefit Program" to the Secretary of Health in 1999. Following an extensive internal review of the ethical and legal implications of the plan, the Department submitted an alternate plan to the Committee and requested their recommendations for implementation.

Infrastructure Building Services

Preventive and Primary Care Services for Pregnant Women, Infants, and Children

Through service contracts, the Bureau of Family Health supports the role of the state's ten local county/city health departments in planning, implementing, and evaluating community-based services for maternal and child health populations within their jurisdictions. The local health departments are required to conduct a local needs assessment and develop a three-year plan with measurable, prioritized objectives that are consistent with national maternal and child health objectives for the Year 2010 and state objectives. Services provided through the local health departments include direct services, enabling services, population-based services and infrastructure services. Each local health department must develop relationships with other local agencies serving mothers and children, in order to facilitate coordination of services and minimize the duplication of efforts. Each local health department was faced with new challenges by dramatic local systems changes caused by welfare reform and the continuing shift to Medical Assistance managed care.

During FY 98-99, the Pennsylvania SAFE KIDS Coalition provided technical assistance and training to 35 local coalitions/chapters through site visits, telephone hotline services, and three statewide meetings. An inline skating poster and safety tips card were developed and distributed to school nurses across the state. In addition, 26 mini-grants were awarded to coalitions/chapters for bicycle safety, fire safety, new prevention programs and coalition startup activities. SAFE KIDS sponsored the sixth annual Injury Prevention Conference, in which 99 people participated. The conference targeted members of the local SAFE KIDS Coalitions/Chapters, health departments, hospital pediatric trauma centers, and childcare centers. Conference speakers provided information on injury specific topics, injury trends, and prevention strategies for addressing both intentional and unintentional injuries. A training on bicycle safety was conducted in July for participants from health departments, SAFE KIDS organizations, police departments, highway safety programs, and other community groups. Child passenger safety was a major focus. Child safety seat checks were conducted in partnership with General Motors dealers across the state. State and local SAFE KIDS coalitions conducted forty-two child safety seat checks. Four National Highway Transportation Safety Administration (NHTSA) four and a half day technician trainings were conducted in cooperation with the Pennsylvania Traffic Injury Prevention Project, the Pennsylvania State Police, and the Pennsylvania Department of Transportation. A total of seventy-two technicians were trained in these sessions. Also, local coalitions sponsored seven additional NHTSA trainings. This initiative contributes to NPM# 8 and OM#6.

Since January of 1990, the Department of Health (DOH) has collaborated with the Pennsylvania Chapter of the American Academy of Pediatrics (PA AAP) and the Department of Public Welfare (DPW) in the development and maintenance of the *Early Childhood Education Linkage System (ECELS) Program*. The program utilizes health professionals, including Community Health Nurses, as health consultants to improve the health and safety practices in child care programs in Pennsylvania. *ECELS* interacts with approximately 11,000 child care programs directly and indirectly (through Better Kid Care and the Child Care Information Services agencies) and another 50,000

providers who do informal neighbor/relative care. The total number of children involved in all of these programs is about 418,000. The following core services are offered to all child care providers: (1) linkages between health professionals, known as health consultants and child care programs so that care and safety of children in these programs may be enhanced; (2) technical advice about health and safety issues for childhood education professionals via phone using toll-free access and via e-mail; (3) free lending library of audio-visual and print materials; (4) quarterly newsletter, HealthLink, that brings health and safety information to 15,500 child care providers and health professionals; (5) health and safety training for child care providers, state agency staff and health consultants for early childhood education programs, and (6) audit of a sample of child health records maintained at child day care centers to document regulatory compliance for up-to-date preventive health services among enrolled children. The *ECELS* program is responsive to several performance measures, including NPM #05, NPM #12, and SP#09.

The purpose of the Department of Health's smoking cessation initiative for pregnant women and the parents/guardians of young children training program is to improve the smoking cessation counseling and education practices of health care providers in Pennsylvania by encouraging them to incorporate smoking cessation and counseling in their services and programs. The Department, through a contract with the PA AAP, has developed a statewide self-help training program entitled, "Clean Air for Healthy Children" (CAFHC). As a state-of-the-art program, it has received considerable national recognition for meeting the United States Agency for Health Care Policy and Research Clinical Practice Guidelines on Smoking Cessation, 1996. The Department's Bureau of Community Health Systems staff is trained to conduct local training to providers and are involved in recruiting providers to participate in the program. During FY 98-99, 511 health care providers representing 247 provider sites were trained at 59 training session sites. Of those sites with trained staff, 144 sites chose to partially implement and 11 sites chose to fully implement the program by submitting patient data on quit rates. Fully implemented programs resulted in 59% of women who either quit or made a positive change towards reducing their smoking levels. This is responsive to NPM #15, the percentage of live births that are low birth weight. Smoking among pregnant women is a major contributor to low birth weight infants.

To identify the causes of childhood deaths and develop strategies to protect the safety and well-being of children, the Department of Health continues its collaborative efforts with PA AAP and the DPW to expand the child death review team (CDRT) efforts in Pennsylvania. State and local child death review teams review deaths, investigate risk factors that lead to the death, recommend policies and educational programs that can prevent future child deaths. By determining the risk factors involved, we can design the most appropriate prevention strategies for intervention at the state and local levels. The multi-disciplinary State CDRT provides training and technical assistance for local team development, software to facilitate data transfer and aggregate data collection, monitoring of the outcomes of local CDRTs, proposals for necessary law(s) and regulatory or policy changes through appropriate state entities, and continued advocacy for the accurate and timely investigation, reporting, and recording of child deaths. They also do a calendar year child death report that addresses trends and patterns of child death, the status of preventable child

deaths in Pennsylvania and recommendation for the most effective prevention strategies to reduce the number and causes of preventable child deaths in Pennsylvania. Since its inception, 28 local teams representing 32 counties have been established and they have retrospectively reviewed 78% of annual child deaths in Pennsylvania. These activities address the following objectives: NPM #8, the rate of deaths to children (1-14) caused by motor vehicle crashes; and the NPM #16 the rate of suicide deaths among youths 15-19.

Children with Special Health Care Needs

In order to provide a foundation for the development of children with special health care needs (CSHCN) services in Pennsylvania that would support the improvement and maintenance of the health status of CSHCN, the Division of Special Health Care Programs focused its energies on the following infrastructure-building activities. The Division again contracted with the University of Pittsburgh Graduate School of Public Health to carry out the CSHCN needs assessment as designed by the Division. Results were obtained from surveys of families, specialty providers, and pediatricians. The assessment included issues such as access to and satisfaction with primary care physicians, specialty services, involvement in day care, impact of a special health care needs child on the family, insurance coverage, coordination of care, awareness of services, barriers to accessing services, health care needs of families, access and provider involvement with children who have chronic or disabling conditions, and knowledge of Title V programs. Several topics were quite pervasive among survey results such as access and coordination of care. This needs assessment addresses *SP #7* (helping to increase the awareness of Title V CSHCN activities among families, providers and agencies) and *SP #8* (assure that children with special needs in managed care environments have appropriate medical and ancillary care including access to specialists and care coordination).

The *Special Kids Network* provided Pennsylvania with a very strong community-based program that collected data on family needs, provider availability, and service acceptability in order to impact local planning for systems development, systems coordination, and service provision for CSHCN. The *Special Kids Network* is a statewide system designed to help families of CSHCN find services for their children. The Network does this in two ways. First, using a database of over 8,000 providers of non-medical but health-related services, it responds directly to callers (both parents and providers) of the 800 number who are seeking specific services for CSHCN. Second, and perhaps most significant, it uses the data generated by the calls to identify local unmet needs for CSHCN throughout the State. This information is compared to and analyzed with needs assessments compiled by various local agencies as well as input from parents and providers in the community. Network staff, working with parents of CSHCN and local health improvement partnerships (SHIP), or local community leaders, facilitated local planning and decision making to fill gaps in service needs for CSHCN.

This activity contributed to *NPM #14* (assuring family participation in program and policy activities). In addition, it assisted in fulfilling *SP #7* (increase in physicians, providers, and public/private agencies knowledge of conditions and services for CSHCN) in that information about Title V activities are distributed during the process to families, providers, and agencies. During 1999, community groups supported by the Network raised \$579,000 in foundation

and other grant funding to accommodate the financial needs of projects and programs designed to fill gaps in services. An estimated 80,000 community members (CSHCN and their families) were served by projects or initiatives supported by the Network involving each of the 67 Pennsylvania counties in one or more of these projects.

Since the inception of the *Special Kids Network*, parents of CSHCN have been involved with the Network as paid staff, in-service trainers, and members of various focus groups, which addresses *NPM #14* (ensure family participation in program and policy activities). In response to parent feedback, a new generation of television outreach spots was developed. The new spots used children with actual disabilities, and two parents of children with special needs were hired to provide consultation during commercial shooting. Hearing first hand from parents has been particularly effective in conveying issues and concerns. Parents continue to participate in focus groups to provide input on the development of all outreach materials. Outreach is an ongoing function aimed at increasing the level of awareness of services available through the Network to parents and providers. Outreach activities of the Network contributed to *SP# 7* (increasing awareness of Title V CSHCN activities). To accomplish this, the Division contracted with a marketing agency that coordinated the statewide outreach campaign for the Network, including paid TV/radio campaigns, development of print material and special events. In addition to this outreach effort, the Network was promoted through outreach activities that included presentations to community organizations, participation in health fairs and mailings to schools. Outreach resulted in 17,421 call to the Network, an increase of 3% over 1998 totals. Effectiveness of the outreach effort is measured in part by volume of calls to the Network and whether the population being targeted is reached. The target populations are parents with children from birth to twenty-one years of age who have special needs and providers who serve them. For 1999, 94% of all clients served were under the age of twenty-one.

With the support of a State Systems Development Initiative grant and the assistance of an internal workgroup and an ad-hoc advisory committee, the Bureau of Family Health developed a comprehensive work plan to determine the merit and feasibility of implementing a birth defects registry in Pennsylvania. The internal workgroup consisted of staff from the Bureaus of Family Health, Health Statistics, and Epidemiology. The ad-hoc advisory committee consisted of health and medical professionals with knowledge and expertise in birth defects. In the Bureau of Family Health, the Division of Special Health Care Programs coordinated efforts with the Division of Maternal and Child Health (MCH) and our contracted computer applications development personnel to analyze and design a joint data base to include information about individuals with special health care needs who are served by the Division of MCH in the existing automated system. We conducted preliminary analysis of data needs and coordination of data exchanges with Vital Records. In addition, we have begun receiving batch files from Health Statistics on infants born with birth defects. We are receiving social security numbers on these children. All of this data has enabled the Bureau of Family Health to gather additional information on infants with birth defects.

Over the past year, the Division of Special Health Care Programs continued to enhance the automated data system. Clients served by the *Head Injury* and *Chronic Respiratory Disease Programs* have been added to the automated system which allows client and provider data collection and claims processing to be automated and accurate reports to be produced. The automated system continues to be an asset to the Division in the collection, analysis, and production of data for needs assessment and planning purposes. The Division continued to monitor, track and collect data on applicants who were ineligible for Division programs. This enables us to analyze where there are deficiencies concerning health care coverage for special needs conditions. As gaps in service are identified, new efforts can be directed to strengthen Pennsylvania's infrastructure. Having data on all individuals served by the Division, as well as the data for individuals with special health care needs served by the Division of MCH, and the birth defects information from Vital Records will provide the foundation for expanding this registry to a statewide birth defects surveillance system should our feasibility study determine its efficacy.

Collaboration with other programs and agencies is another way in which the Division of Special Health Care Programs supported and strengthened the infrastructure. The Department, through the Division's *Special Kids Network*, participates in an interagency outreach collaborative along with the Departments of Public Welfare and Insurance. One of the outcomes of this collaboration has been the coordination of outreach activities that have targeted families whose children are underinsured or have no insurance. The collaboration expands opportunities for the targeted population to learn about and access services, including health care insurance. This activity contributed to *NPM #3* (percent of CSHCN in the State who have a "medical/health home").

The Division supported the activities of the Department's Bureau of Community Health Systems by providing funding for community health nurses throughout the State to work at the community level providing clinic services, training, home visits, case management, and technical assistance to families and individuals with special health care needs. This activity addressed *NPM #2* by contributing to the provision of services and coordination of care. The Division also supported a Special Health Care Needs Consultant (SHCN) in each of the Department's six Health Districts. These staff provided education, consultation, coordination, evaluation, and implementation of programs for CSHCN. Through referral from the Family Consultants in the tertiary care children's hospitals, the SHCN Consultants were able to provide follow-up for CSHCN and their families after discharge. The SHCN Consultants assured that CSHCN had access to services. They also represented the Department on various community boards and committees (including the Local Interagency Coordinating Councils) to assure that services for CSHCN were addressed at the local level. In 1999, the SHCN Consultants developed and implemented an objective to complete resource mapping for programs, services and coalitions within the community health districts for CSHCN.

During 1999, Regional Action Teams were formed in each Health District. These teams, led by the Special Health Care Needs Consultants, included representatives of the Division's programs in the Districts, staff of the *Special Kids Network*, *Family Consultants*, *Parent to Parent* Coordinators, City/County Health Department representatives, School Health Consultants, and others appropriate to the specific activities of each team. These teams

communicated regarding the population's and individual families' needs, and conveyed issues to the Division and the Department through the Special Health Care Needs Consultants. Collaborative partnerships were formed between the programs, bureaus and agencies represented on the team, further closing the gaps in service and care coordination for CSHCN and their families. The Regional Action Teams meet centrally at least once each year to bring statewide issues to the Division and develop uniformity in purpose and activity. In 2000, funding will be provided to support the participation of parents of CSHCN on each of the six Regional Action Teams.

In 1999, the Special Health Care Needs Consultants provided training/updates for the community health nurses regarding Division of Special Health Care Programs' services for CSHCN. In conjunction with the Division, the Consultants began to design a case management model for the follow up of children with special health care needs by community health nurses.

The Special Health Care Needs Consultants also conducted a special project to assess the capacity of the special needs licensed child care facilities to serve CSHCN. A register of the special needs licensed child care centers was obtained from the Department of Public Welfare. The facilities were divided according to the Health District in which they are located. The number of special needs child care centers used for this project was 66. Using a questionnaire, the Consultants collected data from each facility in their District by an on-site visit, telephone contact, or mailing the questionnaire to the facility. A total of 793 or 31.4 % were identified as children with special health care needs receiving services in these child care centers. Developmental delay and speech impairment was the most often cited type of condition of the children receiving child care services. The findings of this project were shared with the State Interagency Coordinating Council. In 1999, the Council established a child care subcommittee to review issues related to children with special health care needs. The subcommittee will be submitting a report identifying barriers to child care for CSHCN and will include recommendations to the Departments of Education, Health and Public Welfare in 2000.

In 1999, the Division of Special Health Care Programs collaborated with the Pennsylvania Chapter of the American Academy of Pediatrics (PA AAP) to strengthen the *Early Childhood Education Linkage System (ECELS) Program* (*ECELS* is dedicated to linking scarce resources to improve health and safety in early child care and education programs). The Division provided information about Division-approved service providers including physicians, speech therapists, audiologists, and other health care providers. *ECELS* enlisted these health care professionals, along with the Division's Special Health Care Needs Consultants, to serve as members of the *ECELS* Health Consultant Registry to assist in the education and training of child care providers who serve CSHCN. Division staff participated in the annual *ECELS* Advisory Committee meeting to maintain a focus on CSHCN.

The Division of Special Health Care Programs contracts with the Philadelphia Department of Public Health to fund the position of a CSHCN program consultant in the Office of Maternal and Child Health to support the planning, implementation, and evaluation of community-based services and to collaborate with the Division to link systems of

services for CSHCN within Philadelphia. In 1999, this collaboration included identification of new CSHCN service providers for inclusion in the Division's *Special Kids Network* provider database, and promotion of the *Special Kids Network* and other state Title V programs and services for CSHCN and their families. In addition to conducting numerous activities to increase access to systems of care for CSHCN in Philadelphia, the Philadelphia CSHCN program consultant continued to facilitate a monthly Special Needs Workgroup consisting of families, providers, advocacy groups, and representatives of local, state and federal government and managed care organizations to focus on safeguarding services to CSHCN in Medicaid managed care. During 1999, collaborative efforts through this contract contributed toward *NPM #2* (providing specialty services and coordination of care), *NPM #3* (assuring a medical home for CSHCN), *NPM #14* (degree of family participation in programs), *SP #5*(increasing awareness of Title V CSHCN activities among families, providers, and public and private agencies), and *SP #6* (assuring that CSHCN in the managed care environment have access to appropriate medical care, including specialists and care coordination). The Philadelphia Department of Public Health CSHCN consultant also conducted a local needs assessment and submitted its three-year plan, including measurable, prioritized objectives, in an application to the Bureau of Family Health for a grant to continue its collaboration with the Division to provide services to CSHCN and their families through 2002.

In addition to the Division's continued surveillance of Medical Assistance (MA) managed care services to CSHCN in southeastern Pennsylvania (conducted as a result of our contract with the Philadelphia Department of Health), the Division monitored managed care services by participating in the Health Care Financing Administration (HCFA) site visits to the southeast Pennsylvania Managed Care Organizations participating in the MA managed care program, *HealthChoices*. This activity commenced in 1997, when *HealthChoices* was first implemented. With the expansion of MA managed care to southwestern Pennsylvania, the Division expects to be included in all planned HCFA site visits to assure appropriate services for CSHCN.

Many of the Division's infrastructure building efforts are evidenced by our strong collaborative relationships with other state programs for CSHCN. Supported by the Division of Special Health Care Programs, the Director of the Bureau of Family Health represents the Secretary of Health on the Pennsylvania State Interagency Coordinating Council (SICC) which is a 15-member advisory board appointed by the Governor. The role of the SICC is to advise and assist state agencies by making recommendations to the Departments of Health, Education, and Public Welfare about the implementation and maintenance of the Statewide Early Intervention System; sources of fiscal and other support from federal, state, local, and private sources; and personnel issues, including the provision of in-service training. In addition, there are 50 Local Interagency Coordinating Councils (LICCs) in Pennsylvania that meet regularly to address local concerns and to share information with the SICC. The Special Health Care Needs Consultants represent the Division at the LICC meetings in their Districts. This meets *NPM #14* by assuring family participation in program and policy activities in the Division through the exchange of information between families and staff at the SICC and LICC meetings, and the feedback provided to the Division. In 1999, this SICC represented and advocated for approximately 42,927 CSHCN.

Through the initiatives described in the preceding paragraphs, the Division of Special Health Care Programs has addressed the six characteristics documenting family participation in CSHCN programs. The participation of family representatives in Regional Action Teams, as referenced above, has increased our score to 12 on a scale of 18.

The Division of Special Health Care Programs provided consultation and technical assistance on CSHCN issues to assist in the coordination of activities between Early Intervention Technical Assistance (EITA) and the Division. EITA provided training and technical assistance to county Mental Health/Mental Retardation and Mutually Agreed Upon Written Arrangements early intervention agencies based on the philosophies of family-centered practices, supports for children in their natural environments/least restrictive environments, and quality early intervention/early childhood practices. The focus for support was defined through a technical assistance plan that was developed with each county Mental Health/Mental Retardation program and agency. EITA also provided technical assistance through statewide initiatives developed through an analysis of stakeholder needs assessments, relevant research and other identified needs. EITA supported the Department's Bureau of Drug and Alcohol Programs and Division of HIV/AIDS to implement statewide priorities related to children and families that they serve. Division staff participated in monthly EITA meetings to exchange information and to assure coordination among programs.

The Division of Special Health Care Programs represented the Department on a governmental interagency workgroup charged with implementation of the Personal Responsibility and Work Opportunity Act of 1996 (PRWOA) and the Balanced Budget Act of 1997 for residents of Pennsylvania. This workgroup has developed and is in the process of implementing a collaborative, statewide outreach strategy targeted to the parents and guardians of child Supplemental Security Income (SSI) beneficiaries. The goal of this outreach is building awareness and providing education about the appeal process and right to request continuation of SSI benefits in the event of a denial because of the new SSI eligibility requirements for disabled children resulting from PRWOA (*NPM #1*). The number of resident child SSI beneficiaries during 1999 was 39,340 versus 40,340 in 1998. The Division continues to assist eligible families in obtaining needed services for their children. This SSI focus contributes to *NPM #1* (provision of rehabilitative services for blind and disabled individuals under the age of 16 receiving benefits under the SSI Program to the extent Medical Assistance for such services is not provided), *NPM #2* (providing specialty services and coordination of care), and *SP #7* (helping to increase the awareness of Title V CSHCN activities among families, providers and agencies).

The Division of Special Health Care Programs, along with the Division of Maternal and Child Health (MCH), participated on the Child Death Review Team to determine the extent to which CSHCN are at increased risk for premature death due to their particular health needs or conditions. The Special Health Care Needs Consultants represent the Division at the local Team meetings in their Districts.

The Division participated on the Advisory Council for the Deaf and Hard of Hearing which is coordinated by the Office for the Deaf and Hard of Hearing in the Department of Labor and Industry. This relationship provided the opportunity to share information regarding Department programs for individuals with hearing impairment such as the Newborn Hearing Screening Demonstration Project currently being developed. The Division continued to maintain TTY communication devices and utilized AT&T's Language Line that provides interpreter services in 140 languages. The availability of these services demonstrates the Division's desire to serve all persons, regardless of ability or cultural background.

CHOICES, Children's Healthcare Options Improved through Collaborative Efforts and Services, is the private/public partnership developed in 1997 between the Division of Special Health Care Programs and the Shriners Hospital for Children. The CHOICES partnership continued to promote access to coordinated services for children and adolescents with special needs during 1999. Shriners Hospital care coordinators in Pennsylvania, Ohio, and West Virginia accessed assistance and information about the availability of community-based providers and resources for children with special needs throughout Pennsylvania through the CHOICES link with the *Special Kids Network* and the Division's Special Health Care Needs Consultants. Pennsylvania Shriners Hospital care coordinators also refer families of children receiving treatment in their facilities to the Division of Special Health Care Programs to determine their financial eligibility for Title V services. This partnership resulted in 111 calls to the *Special Kids Network* from staff at the Shriners Hospital on behalf of their patients. Division staff determined their eligibility for Title V assistance or referred the families to Pennsylvania's Medical Assistance or *Children's Health Insurance Program (CHIP)*. By assisting the Shriners Hospital for Children care coordinators in finding community-based services and providers for their Pennsylvania pediatric and adolescent patients with special needs following hospital discharge, minimizing the need for their return to the Shriners Hospital for out-patient follow-up and treatment, the CHOICES program in 1999 contributed toward assuring the availability of specialty services and care coordination (*NPM #2*), providing a medical home for CSHCN (*NPM #3*), identifying CSHCN without health insurance (*NPM #12*), and increasing the awareness of Title V activities (*SP #7*).

III. REQUIREMENTS FOR APPLICATION [Section 505]

3.1 Needs Assessment of the Maternal and Child Health Population

3.1.1 Needs Assessment Process

The Bureau of Family Health (BFH) uses a variety of public and private sources of information to assess the need for core public health services. The Department's Division of Health Statistics and Research (DHSR) provides regular annual reports on birth and death statistics, as well as special reports requested by BFH (e.g., report on teen pregnancies by age group). Certain programs, such as childhood lead poisoning prevention, conduct special needs assessments through subcontracts with state-related agencies. Public, nonprofit groups such as the Pennsylvania Partnerships for Children conduct ongoing assessments of the uninsured population of children in the state and publish annual and special reports. The State's *Children's Health Insurance Program (CHIP)* and Medical Assistance (MA) programs provide reports of enrollment and services to the Maternal and Child Health (MCH) population that facilitate needs assessment activities and service planning.

For this year's five-year needs assessment, the Bureau of Family Health pursued a wide variety of internal and external data sources to assess the needs of maternal and child health populations, including children with special health care needs (CSHCN) and their families. The Bureau emphasized the need for out-of-the-box thinking and collaboration both within and outside the Department to be included in the needs assessment process. Early activities included the brainstorming of the possible universe of data elements that might be collected to give insight into the factors that affect our populations. Data collection efforts were coordinated between the Division of Special Health Care Programs and the Division of Maternal and Child Health to obtain information from various agencies that included, but were not limited to, the Departments of Labor and Industry, Public Welfare, Education, and Insurance, as well as other specific organizations within various other departments.

Various specialized sources of CSHCN information were also identified and reviewed such as information from the Division's automated client and provider database, the Family Consultant Survey, and the Philadelphia Needs Assessment, the Division's hospital survey to identify available CSHCN services, and the Health Care Cost Containment Council's hospital discharge data. The Division also reviewed CSHCN literature including Newacheck and Halfon's article "Research study: Prevalence and Impact of Disabling Chronic Conditions in Childhood;" the University of California's booklet *Adolescents and the State Children's Health Insurance Program (CHIP): Healthy Options for Meeting the Needs of Adolescents*; and Gortmaker and Spensfield's "Chronic Childhood Disorders: Prevalence and Impact." The needs assessment process further consisted of collaboration with the University of Pittsburgh School of Public Health, which conducted the Division's surveys of families of CSHCN, pediatricians, and specialty providers.

In addition to intra- and inter-agency collaboration and review of materials, the Bureau encouraged public input and dialogue. The staff from the Bureau met with the Maternal and Child Health Advisory Council to gather input on

the needs assessment process and their perspective and recommendations on possible needs that remained unidentified. A stakeholder's meeting was also held where public testimony was heard in order to identify needs, improve our understanding of these needs, and establish priorities.

The Bureau prioritized needs by population groups, pregnant women and infants, children and adolescents and children with special health care needs. Priority was assigned on the basis of the following considerations:

- 2010 Goals and Objectives
- Clearly Demonstrated and Documented Needs
- Needs that could benefit from Title V Leadership and Resources
- Lack of Alternative Dedicated Resources to Address the Need(s)

Health indicators characterized by significant disparities among population groups tended to be higher priorities e.g., infant mortality, teen/unplanned pregnancy and childhood lead poisoning. Health indicators documented by clear unmet needs were typically rated as higher priorities, e.g., access to dental care for low-income populations, the need to provide information and outreach to the families of CSHCN regarding available services, and the need to enhance service coordination for the families of CSHCN. Although needs such as immunizations, youth smoking and substance abuse, and children's health insurance were identified, they were ranked lower on the Title V priority list because other resources were available to address the need.

The final listing of Title V priorities, as described in Form 14 was submitted to and approved by the Secretary of Health and the Deputy Secretary for Public Health Programs. This approved listing formed the basis for our Annual Plan.

3.1.2 Needs Assessment Content

3.1.2.1 Overview of the Maternal and Child Health Population's Health Status

Preventive and Primary Care Services for Pregnant Women, Infants and Children

The Commonwealth of Pennsylvania has a wealth of health care resources which tend to be concentrated in the major metropolitan areas. As indicated in the Overview of the State, the Department's Bureau of Health Planning serves as the Primary Care Office for the Commonwealth. That Bureau is responsible for the Federal/State Primary Care Cooperative Agreement grant from the United States Public Health Service. One of the primary functions supported by the grant is the identification and development of requests for designation of Health Professional Shortage Areas (HPSAs) and Medically Under-served Areas (MUAs). As of March 30, 2000, there are 85 areas which have received federal designation as a primary care health professional shortage area. They tend to be in rural areas of the state, including the northwest, northeast, southwest and central areas.

In addition to the HPSAs and MUAs, there are numerous other reasons that many Pennsylvania children and families do not have access to primary health care, including poverty, lack of health insurance, the lack of information and education. 15% of Pennsylvania's MA-eligible children and 40% of its CHIP-eligible children are not enrolled. Approximately 18% of the state's pregnant women do not receive prenatal care initiated with the first trimester.

To address the primary and preventative health care needs of pregnant women, infants and children, the Commonwealth has established an array of programs and services. These include the following:

- A public health system that includes 10 local county/municipal health departments, as well as some 60 county-based state health centers administered by the state health departments through six district offices.
- A statewide nutrition program for pregnant women, infants and children (WIC) with 383 service sites serving 232,168 individuals.
- A statewide family planning service system with 192 local clinics serving 210,510 individuals, including 45,767 teens under 17 years of age.
- A childhood lead poisoning prevention program with eleven projects in high risk areas of the state which screen over 40,000 children annually, and case management and tracking services provided by District field staff for children with elevated lead levels in the remainder of the state.
- An interagency outreach program (Health, Public Welfare and Insurance) designed to link un-enrolled and eligible children to CHIP and Medicaid.
- A statewide Safe Kids Coalition working through 35 local chapters/coalitions to reduce preventable childhood injuries.

In reviewing the health status of pregnant women, infants and children in Pennsylvania, we find some very encouraging movement in relation to some indicators, as well as some persistent, frustrating and disturbing health indicators, and other new issues that require our attention.

Among the most encouraging indicators are the reductions in unintentional injuries, teen pregnancy and uninsured children. While injuries remain the leading cause of deaths for children 1-14, the rate has declined from 7.1 per 100,000 in 1986 to 3.9 in 1997. During 1997, 212 children under age 15 died from injuries.

Pennsylvania's teen pregnancy rate continues to come down for all population groups. The state rate is already below the national year 2010 target. Significant disparities remain between racial and ethnic groups.

The number of uninsured children in Pennsylvania is decreasing. In part due to the state's coordinated interagency outreach effort, the number of uninsured children in Pennsylvania is now down to approximately 260,000. Pennsylvania now ranks fifth in the country among states with the lowest percentage of uninsured children.

Among the indicators that require diligent and focused attention in Pennsylvania are disparities in perinatal outcomes, dental disease, childhood lead poisoning and youth tobacco, alcohol and drug use.

Infant mortality continues to come down for the population as a whole, decreasing by 20 percent between 1990 and 1997. Unfortunately, the rate for African-American babies remains nearly three times the rate for Caucasian babies. The rate for Hispanic babies is one and one-half times that of Caucasian babies. One contributing factor appears to be the continuing disparity in the timing of the start of prenatal care.

Pennsylvania remains well behind the national year 2010 targets for breastfeeding. While 55% of new mothers in Pennsylvania are breastfeeding at hospital discharge, the national target is 75%. The same is true for maternal mortality. While Pennsylvania's maternal mortality rate is seven per 100,000, the national 2010 target is 3.3 per 100,000.

Dental disease is the single most common preventable disease of childhood. Using national statistics, we can project that 52% of all Pennsylvania children have dental caries. Only 23% of children 8 years of age have dental sealants. Only 3% of poor children have sealants.

Lead poisoning remains the major preventable pediatric environmental health problem because 45% of Pennsylvania housing was built prior to 1950. According to the most recent National Health and Nutrition Examination Survey (NHANES), 4.4% of children ages 1-5 years have blood lead levels 10 micrograms per deciliter or greater. While lead poisoning occurs most frequently among low-income children, 80% of Medicaid children are not screened for blood lead.

Smoking and alcohol related problems are common among adolescents. Drug use among adolescents 12-17 doubled between 1991-1997 from 5.3% to 11.4%. In grade 12, the reported use of beer has been slowly increasing since 1991. Thirty percent of high school seniors smoke every day. Smoking is rapidly increasing among African-American youth.

Among the emerging issues upon which we will focus is the increase in childhood obesity. In Pennsylvania between 1991 and 1997, obesity increased from 7.3% to 9.1% for children under age five. Research shows that 60% of 5-10 year olds already have at least one risk factor for heart disease.

Children with Special Health Care Needs

A Newacheck and Halfon study, "Research Study: Prevalence and Impact of Disabling Chronic Conditions in Childhood," estimates that there are approximately 209,193 children with special health care needs (CSHCN) in Pennsylvania. While each CSHCN represents a specific need and unique situation, it is therefore only with careful consideration that broad generalizations on the population as a whole can be made. The priority health needs selected by the Division of Special Health Care Programs (SHCP) from its five-year needs assessment findings represent problems, gaps, and weaknesses of the health service system as a whole in regard to CSHCN.

The Division of Special Health Care Programs' priority needs follows a hierarchical progression from higher priority infrastructure building services to lower priority direct health care services. It is a preventative model in logic based on solving problems at their root rather than reacting to symptoms with band-aid solutions. Front-end actions, such as education and research, drive solutions on the back-end, such as the need for ancillary services.

The foremost need in this hierarchical model is for early identification of CSHCN. National statistics indicate that annually 4% of live births are diagnosed with congenital anomalies. For two decades, birth defects have been a leading cause of infant mortality, contributing to 10.3 infant deaths per 1000 births. Congenital malformations are the leading cause of death in infants less than 12 months. One third of children hospitalized in tertiary care medical centers have genetic disorders. In Pennsylvania, congenital anomalies are the second leading cause of death for children under age five. To effectively identify and serve this population, the Department has developed a registry of all individuals with special needs served by Title V, state-supported programs, and other federal programs administered by the Bureau of Family Health. In addition, the Department is considering the development of a birth defects surveillance and follow-up system. This is responsive to Healthy People 2010 Objectives 16-14 and 16-15.

The Department currently screens all Pennsylvania newborns for four conditions: phenylketonuria (PKU), primary congenital hypothyroidism, sickle cell hemoglobinopathies, and maple syrup urine disease (MSUD). Approximately 150 newborns are identified each year with one of these conditions. In recent years, scientific technological advancements have enabled testing of newborns for many additional diseases and disorders. Improved health for more children through early identification, education and outreach would reduce expenditures for health care, special education, welfare and other expenses related to caring for children with these diseases and would protect more children from severe irreversible disabling mental and physical conditions. Because of this, Pennsylvania has investigated expansion of its newborn screening program and has decided to add galactosemia and congenital adrenal hyperplasia to our program. We anticipate ten to fifteen additional newborns will be identified and referred for treatment within the coming year. This is responsive to NPM#4, and Healthy People 2010 Objective 16-20.

Division of Special Health Care Programs' research suggests that CSHCN function in a health environment where doctors are not knowledgeable about the condition of the child they serve and where families need better information about their child's condition. According to our 1999 needs assessment, 29% of families responded that

their child's family doctor or pediatrician does not know a lot about their child's special needs condition and 34% reported that doctors do not provide enough information about the care of their child. Poor exchange of information also negatively impacts coordination of care, the Division's third priority need. Less than satisfactory communication between family doctors and specialists seems to be endemic in the CSHCN environment. Survey data suggesting that a significant number of specialists seldom or never contact the primary provider of the child they serve highlights communication and exchange problems as a component of care coordination. In the Division's 1999 needs assessment, 25% of specialists reported that they seldom or never contact the primary care physician of the children they serve, and over 30% of families reported communication between the primary care practitioner and specialist is a problem. Several initiatives to remedy these problems of communication, coordination, information and knowledge are discussed in the Annual Plan. They include providing additional information/education about CSHCN to primary care providers, additional support and information for families in the form of home visits, and specific definitions and requirements for care coordination in Division contracts with providers.

As with care coordination, the need to remove financial barriers may be related to systemic health care problems as well as the nature of CSHCN. The status of many families with CSHCN is one of financial hardship due to the nature of their child's condition. In 1999, 58% of families surveyed indicated that having a child with a special health care needs causes hardships. Inadequate payments by insurance providers for medical expenses, trouble paying for both medical and non-medical services, and a number other financial barriers such as health related transportation, medication/prescriptions, and out-of-pocket medical supplies constitute financial hardships. According to our 1999 needs assessment, for instance, 28% of families reported having trouble paying for medical services and 29% had trouble paying for non-medical services. Access to services, priority need #7, becomes an issue once financial barriers are removed. The Division intends to take a more pro-action role in informing families of CSHCN about various State programs, including MA and *CHIP*, that are available for their child. This will take the form of educational information in addition to the usual referral.

Needs regarding access to service express themselves as barriers pertaining to distance, transportation, and racial disparities. Transportation issues such as lack of reliable transportation, long distances to specialists, and difficulty in obtaining services because of social, ethnic, and special needs condition are pertinent to the need for improving access to health care services. The Division is exploring various options for increasing access to providers. These may include identifying other providers qualified to deliver specialty services, establishing satellite services and clinics directed by current tertiary specialty centers, or using technology to improve specialty consultation for the less accessible areas of the State.

Lastly, the need for ancillary services such as respite care, mental health services, and dental care all are pressing needs among CSHCN. Respite care was indicated as inadequate by 70% of specialists; dental care by 48% of pediatricians in the 1999 needs assessment. Since respite care has also been identified by parents, Special Needs Consultants and the *Special Kids Network* as a priority need for families of CSHCN, the Division has developed

several options for addressing it in the next several years.

The above needs express inherent weaknesses in the health care system, but further insight may be needed on issues of disparities as pertaining to CSHCN. We know through much research that racial health disparities exist in the general population for children of ethnic backgrounds and minorities such as in teen pregnancy, drug and alcohol use, and uninsured rates, but less is known about disparities within the CSHCN community specifically. One may say with some certainty that disparities present in the population in general such as higher uninsured rates, language as a barrier to quality care, and lack of reliable transportation as a barrier to access are a problem in the CSHCN population as well. Income disparities exist in the general population for children of ethnic backgrounds for the likelihood of having health insurance, but to what extent this situation extends to the CSHCN community has not been fully determined. We speculate that parallels exist.

While weaknesses and disparities are eminent in the health system which serves the CSHCN population, strengths do exist. Satisfaction is a great indicator of service quality, and the Division's needs assessment findings suggest that families of CSHCN are quite satisfied with the service they receive from their day care and insurance providers. In addition, the awareness of cultural competence seems to be increasing among physicians, and families seem to have adequate access to primary and specialty physicians. Yet, while Pennsylvania still has problems with underinsured and uninsured children, the State has lower rates of uninsured than a majority of states. Ultimately, as a strength, Pennsylvania has a sincere population of providers and as active a group of CSHCN advocates as any state.

3.1.2.2 and 3.1.2.3 Direct Health Care Services and Enabling Services

Children with Special Health Care Needs

As has been alluded to above, availability and access to service seem to be strengths of Pennsylvania's direct and enabling health care services, perhaps because our citizens have higher insurance coverage than most states. Ninety-three percent of families reported having a regular family doctor, and a majority of respondents with two or more specialists reported being satisfied with access to these specialists in the Division of Special Health Care Programs' 1999 needs assessment.

Problems still exist, however, for children with special health care needs (CSHCN) in terms of financial barriers and access. (See Overview of the Maternal and Child Health Population's Health Status above). While the results may not be definitive of the need, our research suggests that cultural competence and acceptability may be on the rise in CSHCN, and the State received high marks here too. In 1999, encouraging findings suggest that families overwhelmingly (91%) felt that health care providers showed respect for their cultural beliefs. In comparison, our 1993-1995 needs assessment indicated that only 30% of specialists had heard of the term "cultural competency."

In recent years, welfare reform has been a pre-eminent force on the landscape of health care and has had an effect on the service needs and condition of the special needs community. The impact of welfare reform has been and will be felt among the families with the least income and least work experience. Definitional changes will result in a growing number

of children no longer having access to Medicaid because their disabilities do not meet the disability definition revisions authorized by the Welfare Reform Act (Philadelphia Needs Assessment). While the success of welfare reform may result in loss of benefits and changes in eligibility, an equal result and impact may be confusion among former welfare recipients on health care regulations and their eligibility for health-related coverage. This “graying” or confusion over these regulations may result in a small group of uninsured or underinsured and a greater need to inform families and CSHCN of the services for which they may be eligible.

The move to managed care delivery systems has accompanied welfare reform in impacting the CSHCN population. Yet, the weakness of managed care has been that it has not met the coordination and comprehensive care goals it was originally set out to achieve. Coordination still remains an inherent problem with the health care delivery system under managed care. Despite the required referrals instituted by the system, communication problems still exist between primary care providers and specialists (See Overview of Maternal and Child Health Population’s Health Status). Providing a medical home for CSHCN is still a major issue for the population. While managed care has provided the framework for a coordinated care system, it is still not a reality for many CSHCN. This problem seems to be further exacerbated by primary care physicians who do not have the comfort level or expertise to deal with certain CSHCN thereby decreasing the effectiveness of coordination under the managed care system. At the same time, Medicaid managed care along with the *Children’s Health Insurance Program (CHIP)* have been the primary source of assistance for needy families of CSHCN. The combination of these two programs has given Pennsylvania a greater potential for reaching the uninsured population, including CSHCN, in the State.

Staff from the Division of Special Health Care Programs, DPW’s Office of Medical Assistance Programs (OMAP), and the *Children’s Health Insurance Program (CHIP)* have developed a work group whose purpose is to identify and coordinate common interests between Title V, OMAP and *CHIP* Programs for CSHCN. This workgroup addresses a need for coordination (Priority Need #6) by identifying issues that impact CSHCN receiving services in Medicaid managed care and fee-for-service, Title V Programs, and *CHIP* that require coordination to achieve desired outcomes for this population. These issues include differences in definitions of CSHCN among agencies providing services; as well as lack of knowledge about available services, programs and initiatives, and the results of respective agency needs assessments and satisfaction surveys. All the above issues not only help improve coordination of service and access to care (Priority Need #5), but also prevent duplication of services and prevent CSHCN from falling through the gaps of health care services by helping to provide a seamless delivery of services through the three programs.

The Division has many linkages that exist through which we can improve referrals between primary level care, specialized secondary level care, and highly specialized tertiary care. The specialists providing comprehensive care through the multi-disciplinary team specialty clinics, for instance, are expected to be in regular communication with their client’s primary care physicians. Our 1999 needs assessment found that the communication between the tertiary and primary care level providers was better for clients in managed care than for those with private insurance.

Resources exist for comprehensive medical care provided to children and adults with cystic fibrosis, hemophilia, Cooley's Anemia, spina bifida, and children (only) with musculoskeletal/neurological conditions delivered by multidisciplinary teams. Payment is made by means of an annual capitation fee paid to the tertiary care centers located in major metropolitan areas of the state (Pittsburgh, Philadelphia, Hershey, Reading). The Division pays for these services for Pennsylvania residents regardless of their ability to pay. The care provided by these centers represents the highest quality of care available.

Direct medical services not included in the comprehensive specialty clinics described above are delivered by a variety of provider types (private physicians, dentists, free standing surgical centers, hospitals) and reimbursed against the Division's fee schedule through a five year Participating Provider Agreement. Services are limited by the program, but may include inpatient, outpatient, specialized therapies, laboratory, radiology, medications, equipment and supplies. For children under 21, the special needs conditions covered are: cardiac, cleft palate, hearing, speech, and orthopedic conditions. For children and adults the conditions covered are: cystic fibrosis, hemophilia and spina bifida. Coverage is available only for clients enrolled with the Division. Enrollment eligibility criteria include having an income of less than 300% of the most current Federal Poverty Income Guidelines and not being eligible for *CHIP* or *MA*. An annual renewal is required. The purpose of this program is to assure support for those clients not eligible for other third party coverage or with limited insurance. The number of clients served by these programs has dropped dramatically since the increased care coverage for children by *MA* and *CHIP*. The Division's automated data system has greatly simplified the payment procedures and enhanced staff's ability to monitor contracts and analyze patient care trends.

In Pennsylvania, mental health services are administered by the Department of Public Welfare, although our needs assessment did review the adequacy of services for CSHCN. Mental health services for CSHCN were perceived as inadequate by nearly half (49%) of all specialists in the 1999 needs assessment. The need for mental health services was also emphasized by the Department's Maternal and Child Health Advisory Council who emphasized focusing on quality of life issues. The council members stated that mental health providers may not transfer CSHCN to appropriate care or may not acknowledge that they cannot provide care. The need for mental health services for CSHCN is a complex one, for it can be extended to include the mental health of the families and caregivers of these children who may be under increased stress or who may have unrelated mental health problems which may impact the CSHCN or the care given to the child. In addition, mental health services were also identified as a problem in the stakeholder's meeting.

Additional ancillary services for CSHCN were researched such as dental care, respite care, substance abuse counseling, case management, pediatric care, and child care, but it was determined that there is insufficient information available to draw any conclusions. Continued work with other agencies/departments will be necessary

to explore ways to gather CSHCN specific information. Mental Health and other ancillary services will be presented as one of the issues to be dealt with the Title V/CHIP/MA CSHCN interagency workgroup.

3.1.2.4 Population-Based Services

Preventive and Primary Care Services for Pregnant Women, Infants and Children

Oral Health

Oral health is an essential and integral component of health throughout life. Poor oral health and untreated oral diseases can have a significant impact on quality of life. Dental caries is the single most common disease of childhood. Studies indicate that if sealants were applied routinely to susceptible tooth surfaces in conjunction with the appropriate use of fluoride, most tooth decay in children could be prevented. There are Year 2010 objectives to reduce the proportion of young children with untreated dental decay in primary and permanent teeth, and to increase the number of children who have received dental sealants on their molar teeth.

In order to assess the actual oral health status and dental treatment needs of Pennsylvania's children, the Bureau of Family Health worked with the Department's Dental consultant in the Division of Health Promotion in the development and implementation of an oral health needs assessment. The assessment developed with technical assistance from the Association of State and Territorial Dental Directors (ASTDD), and conducted by the School of Public Health at the University of Pittsburgh is expected to be completed by October 1, 2000. Once completed, the needs assessment will provide the information necessary for the Department to answer questions related to: 1) oral health status and how it varies throughout the State, 2) access to fluoridated water, 3) access to necessary dental care, 4) policies and programs to address the oral health need of Pennsylvania's children, and 5) the extent and severity to which Pennsylvania's children experience dental fluorosis.

Using national statistics to project oral health status of Pennsylvania's children, 52% of all children had dental caries. While the percent of White and African-American children who had dental caries is 50% and 51% respectively, 68% of Hispanic children had dental caries.

In regard to sealants to prevent dental caries, only 23% of children aged 8 years and 15% of children aged 14 years have sealants according to national figures. Distribution is as follows: 26 % of White children, 11% of African-American children, and 7% of Hispanic children. This again shows a disparity for African-Americans and Hispanics. With state-specific information on this indicator from the state's oral health needs assessment, we will be better able to measure our programs against NPM #7.

The disparity continues when looking at dental care and dental health on the basis of income, as the following distribution indicates: 3% poor, 18% near poor, and 35% mid-high income children have sealants, and 62% poor, 60% near poor, and 42 % mid-high, had dental caries. A Dental Summit convened by the Department of Welfare, with support from the Pennsylvania Dental Association, sought to provide a forum for key stakeholder groups to

collaboratively develop recommendations to improve access and utilization of dental services for all recipients in both the Medical Assistance Fee-for-Service Delivery System and the Medical Assistance Managed Care Delivery Systems.

Childhood Lead Poisoning

Although considerable progress has been made in reducing blood-lead levels in the nation's children and in Pennsylvania, lead poisoning remains a major preventable pediatric environmental health problem. Approximately 45% of Pennsylvania housing was built prior to 1950 and therefore contains a significant amount of lead-based paint. Over 80% of zip codes in Pennsylvania have 27% or greater housing units built before 1950. There are Year 2010 objectives to increase the proportion of persons living in pre-1950s housing which has been tested for the presence of lead-based paint, and to eliminate elevated blood lead levels in children.

The National Health and Nutrition Examination Survey (NHANES) indicates that 4.4% of children ages 1-5 years have blood lead levels of 10 micrograms per deciliter or greater, a level associated with harmful effects on a child's learning and behavior. Studies have shown an association between lead poisoning and school behavior problems, school drop out, and juvenile delinquency. The NHANES report also points out a great disparity for African-American children whose lead poisoning rate is 11% higher than for White children. In addition, a direct correlation has been found between high blood lead levels and low income, yet a Government Accounting Office report reveals that 80% of Medicaid children have not been screened.

Childhood Obesity

Obesity has been identified as one of the major public health problems in this country. Nationally, the prevalence of overweight children ages two to five has increased from 7% in 1989 to 8.6% in 1997. In Pennsylvania between 1991 and 1997, it has increased from 7.3% to 9.1% for children under five years of age. Overweight and obesity acquired during childhood or adolescence may persist into adulthood and increase the risk for some chronic diseases later in life. Obese children also may experience psychological stress. According to the Centers for Disease Control, the American life style of convenience and inactivity has had a devastating toll on every segment of society, especially children. Research shows that 60% of overweight five to ten year-olds already have at least one risk factor for heart disease, including hyperlipidemia, elevated blood pressure or insulin levels.

Childhood Immunizations

Infectious diseases remain major causes of illness, disability, and death. Vaccines can prevent the debilitating and, in some cases, fatal effects of infectious diseases, and provide significant cost benefits. The Year 2010 objective is to achieve and maintain vaccination coverage levels of 90% for universally recommended vaccines among young children.

Pennsylvania immunization rates are ahead of national levels. In 1998, immunization rates for children two years of age were above 90% for three vaccines. Despite this, disparities remain with African-American, Hispanic, and American Indian/Alaskan Natives showing the lowest rates. For varicella, a newly administered vaccine, American Indian/Alaskan Native are only at 28% immunized, while other groups show 41.9% and higher.

Risky Adolescent Behaviors

Substance abuse and its related problems are among society's most pervasive health and social concerns. Smoking and alcohol related problems are common among adolescents. Nationally, drug use among adolescents aged 12-17 doubled between 1991-1997, from 5.3% to 11.4%. Both alcohol and drugs are associated with a number of dangerous behaviors (drinking and driving, poor school attendance, theft, and violence). There are many Year 2010 objectives related to the use of substances by adolescents. These include 26-6, 26-7, 26-9, 26-10, 26-11, 26-15, 26-16, 26-17, 27-2, 27-3, 27-4 and 27-7.

Thirty percent of high school seniors smoke every day. Smoking is rapidly increasing among African-American youth. More American youth are smoking alternative tobacco products. In grade 12, reported use of beer and alcohol has been slowly increasing since 1991.

- Regular smoking rates among high school seniors were higher in 1997 than in 1995
- 40% of Pennsylvania seniors smoke regularly, compared to 34% of high school seniors nationally.
- 11% of Pennsylvania seniors use smokeless tobacco regularly, compared to 10% of seniors nationally.
- Alcohol use remained level or rose slightly among 9th and 12th graders from 1995 to 1997.
- 51% of Pennsylvania seniors drink alcohol regularly, compared to 51% of high school seniors.
- 1997 levels of marijuana use are more than twice as high as in 1991.
- The use of depressants, while still low in absolute terms, increased sharply from 1995 to 1997 among all grades surveyed, reaching levels higher than in any previous survey going back to 1989.
- Regular stimulant use among 9th and 12th graders rose to 7%, higher than in any previous survey year. Nationally, 4% of high school seniors report regular stimulant use.
- Cocaine use rose slightly among most grades from 1995 to 1997. Three percent of Pennsylvania seniors report regular use of cocaine, compared to 2% of high school seniors nationally.
- 12% of seniors regularly drove after drinking, 12% drove after smoking marijuana, and 7% drove after both drinking and smoking
- 22% of seniors and 15% of 9th graders regularly ride with a driver who has been drinking, and similar percentages report riding with a driver who has been smoking marijuana.

Unintended Pregnancy/Teen Pregnancy

As described in Healthy People 2010, unintended pregnancy in the United States is serious, costly and occurs frequently. About 49% of all pregnancies are unintended, resulting in reduced educational attainment, greater

welfare dependency and increased potential for child abuse and neglect. With an unintended pregnancy, the mother is less likely to seek prenatal care in the first trimester, less likely to breastfeed, and more likely to expose the fetus to harmful substances, such as tobacco and alcohol. For teenagers, these problems are compounded and well-documented. Estimates of the overall cost to United States taxpayers for teenage child bearing between \$7 billion and \$15 billion, attributable to higher public assistance costs, increased child welfare and higher criminal justice costs. The Year 2010 objective 9-7 is to reduce pregnancies among adolescent females.

Fortunately, Pennsylvania's teen pregnancy rate, (age 15-17) for all populations continues to come down. The state rate at 31.7 per 1000 is already below the year 2010 target for all races (46 per 1000).

Breastfeeding

As stated in Healthy People 2010, breast milk is widely acknowledged to be the most complete form of nutrition for infants' health growth, immunity and development. The benefits of breastfeeding include decreased new cases or severity of diarrhea, respiratory infections and ear infection. In addition, breast-feeding has shown to improve maternal health, including reduction in postpartum bleeding, earlier return to pre-pregnancy weight, reduced risk of pre-menopause/breast cancer, etc.

While 55% of Pennsylvania women are breastfeeding at hospital discharge (1997 data), the year 2010 target is 75%. The lowest rates of breastfeeding are found among women under 21 years of age and at low educational levels. Their infants are at highest risk of poor health and development.

Maternal Mortality

The Maternal Mortality rate in Pennsylvania has been consistent over the last four years (1994-1997). There is data that indicates the number of maternal deaths are occurring disproportionately among the minority populations in the state. Also, Pennsylvania's maternal mortality rate is currently more than twice as high as the Healthy People 2010 objective, 7 per 100,000 versus 3.3 per 100,000. The consistency of the number of maternal deaths suggest that there needs to be some intervention that would impact and lower the number of mothers dying in Pennsylvania.

HIV/AIDS

HIV prevalence data suggest that the age group 20 – 44 years constitutes the predominant pool of infected persons who are the main potential sources of new HIV infections. AIDS incidence trends for those probably infected through injecting drug use (IDU) have been increasing as a proportion of all AIDS cases, surpassing transmission through men having sex with men (MSM). IDU has become the predominant mode of transmission among both male and female AIDS cases across the state, with racial/ethnic minorities, especially African-Americans constituting the overwhelming majority of IDU cases across the state. Among all AIDS cases, the proportion of AIDS cases diagnosed each year that are racial/ethnic minorities are increasing, especially for African-Americans. The proportion of African-Americans with AIDS has more than doubled in the 10-year period from 1987-1997.

This pattern suggests that racial/ethnic minorities, especially African-Americans, have become the predominant racial/ethnic group affected by HIV/AIDS in Pennsylvania. AIDS incidence trends for those probably infected as adolescents/young adults (13-24 years) may be stabilizing, however, the small numbers of AIDS cases in this age group limit the interpretability of AIDS trends as a reflection of HIV incidence trends. STD data on adolescents 13-19 suggest that females in this age group have a higher incidence of recent Gonorrhea and syphilis infections, which suggest a higher likelihood of recent HIV infections.

Among maternal and child health populations, the proportion of women among all AIDS cases is increasing, suggesting that women have been undergoing a markedly increasing likelihood of new HIV infections. Over 80% of female AIDS cases over the past 10 years have been women of childbearing age (13-44). 60% of the women with AIDS are African-American, and 70% are directly or indirectly associated with intravenous drug use (IDU). Over 65% of perinatal transmission is directly or indirectly associated with IDU. HIV prevalence data from previous serosurveys of childbearing women, including the most recent serosurvey in 1997, have consistently indicated that Philadelphia, with 4–6% prevalence rate, and the Southeastern Health District, with $\pm 2\%$, have higher rates of HIV-infected childbearing women. The higher prevalence of HIV among women of childbearing age (CBA) in these parts of the state suggests a higher risk for perinatal transmission of HIV. Although there are effective antiretroviral treatments for preventing perinatal transmission of HIV, perinatally infected pediatric AIDS cases still occur suggesting that transmission of HIV from infected mothers to children may still occur. There is thus a need to assess the likelihood of perinatal transmission of HIV, to determine the barriers to prevention, and how best to reach and intervene among those at risk.

Pennsylvania participates in CDC-initiated studies to evaluate the effectiveness of these interventions at the population level and to assess the additional operational/programmatic and social barrier factors not factored into controlled clinical trials. The Department is considering expanding its surveillance of HIV and perinatal exposure to HIV (with or without subsequent HIV transmission) to monitor the risk of perinatal transmission on an ongoing basis. This will enable the Department to obtain data needed to assess the likelihood of perinatal transmission of HIV, to determine the barriers to prevention and causes of missed opportunities, and how best to reach and intervene among those at risk. The Division of MCH participates in the statewide Ryan White Care Act Integrated HIV Planning Council advising on maternal and child primary and preventive health concerns.

Essential interventions that we plan to undertake to prevent mother-to-infant transmission would therefore target outreach and preventive programs directed at a) female IDU of childbearing age (CBA), b) women of CBA who have sex with IDU, c) women of CBA who have sex with men of unknown risk, and d) IDU males who are sexual partners of women of CBA. These include:

- Outreach, health education, and preventive and harm-reducing interventions for IDU-mediated HIV transmission;

- Outreach, health education, HIV testing and preventive counseling for at risk hard-to-reach target populations;
- Outreach and timely prenatal care for at risk pregnant women;
- Timely maternal HIV testing before birth; and
- Prenatal, intrapartum and newborn antiretroviral therapy.

Children with Special Health Care Needs

The need for population-based services is inherent in the existence and design of the Division's *Folic Acid program*, needs assessment findings, and general data on health-related folic acid facts. Neural tube defects (NTDs) are a class of birth defects characterized by defective closure of the neural tube during the first six months of gestation. Resident child-bearing-age women give birth to approximately 160,000 children annually, but Pennsylvania does not have a formal system to track NTD incidence and prevalence. Using the national NTD annual rate of 3.8 cases per 10,000 live births, and applying this to the annual birth rate in Pennsylvania yields an annual NTD incidence of approximately 60 new cases annually. Basic science and recent epidemiological evidence has demonstrated that folic acid plays a significant role in the primary prevention of NTDs. To establish baseline folic acid awareness and consumption information about resident child-bearing-age women, the Department of Health conducted an assessment using the folic acid module of the Center for Disease Control and Prevention's "Behavioral Risk Factor Surveillance System." The baseline folic acid awareness and consumption data implies that more work needs to be done to educate child-bearing-age women and allied health care professionals about the importance of consuming the recommended daily allowance of 400 micrograms of folic acid to reduce the incidence of NTDs. The data indicates that 41.9% of resident child-bearing women do not currently take vitamin pills or supplements. The data further reveals that of the 55.9% that do take vitamin pills or supplements, 46.3% of the vitamins and supplements taken by such women do not contain folic acid. As for awareness of the importance of folic acid intake, only 13.2% were aware that health experts recommend folic acid to make strong bones, to prevent defects (27.9%), to prevent high blood pressure (6.7%) and for other health-related reasons (15.1%).

As a result of the statewide need for women and healthcare professionals to become more proactive regarding folic acid education and consumption, the Department has developed a proprietary folic acid outreach and education promotion to address the goals outlined in Healthy People 2010. The Division will target the promotion campaign to childbearing age women 18-45 with the uniform message to consume at least 400 micrograms of folic acid daily. In addition, radio spots will specifically target minority women of childbearing age.

3.1.2.5 Infrastructure Building Services

Preventive and Primary Care Services for Pregnant Women, Infants, and Children

Childhood Morbidity and Mortality

The asthma rate is rising more rapidly in pre-school aged children than any other group. In 1995, the rate of self-reported asthma among children and adolescents under the age of 18 was 7.5% compared to 5.7 percent among the general population. The rates were higher in boys under age 18 than in girls in the same age group and higher for African-Americans than for Whites. Death from asthma is more likely to occur among African-Americans and Hispanics than among Whites. Although the number of deaths annually from asthma is low compared to other chronic diseases, the death rate for children aged 5-14 years and young adults 15-24 years doubled from 1979-80 to 1993-95. Rates for hospitalization demonstrate similar variations. Rates for African-Americans are almost triple those for Whites. Asthma hospitalization rates have increased dramatically among children under age 5 years. From 1980-1993 the rate increased from 36 to 65 children per 10,000 hospitalized under age 5. Some of this increase may be related to changes in diagnostic practices and changes in coding and reimbursement, while some may represent a true increase in illness and disability. There are Year 2010 objectives to reduce asthma deaths, and reduce hospitalizations and emergency room deaths for asthma.

Pennsylvania's death rate is 35.0 per 100,000 children ages one through nineteen. There is an increasing trend of violence toward children and a lack of comprehensive data on violent childhood deaths. There has been an increase in homicides as follows a 4% increase from 1995 to 1996, and a 7% increase from 1996 to 1997. In 1996 (71%) and 1997 (64%) firearms accounted for the majority of deaths, and deaths by homicide were highest for males 1996 (82%) and 1997 (74%).

Pennsylvania has a Child Death Review Initiative. The Department of Health (DOH) in collaboration with the Department of Public Welfare reviews deaths of all children, birth through 19 years of age, through a Child Death Review process contractually administered with the Pennsylvania Chapter of the American Academy of Pediatrics (PA AAP). This is accomplished by a state team and 28 active local child death review teams (CDRTs) covering 32 of the 67 counties. Two (2) teams are in the development stage and six counties have been identified as priority counties for team development. These local teams review 78% of Pennsylvania child deaths. The state and local teams review deaths, identify and investigate risk factors that lead to the death, recommend policies and educational programs that can prevent future child deaths. This initiative addresses NPM #8, as well as OM #1, 2, 3, 4, 5 and 6.

Infant mortality rate continues to serve as a measure of a community's social and economic well-being as well as its health. It is also a measure of the organization and abilities of its health and human services resources. As such, there is a strong need to evaluate the service systems and community resources to assure that the needs of women, infant and families at the local and state level are met, especially those identified disparate populations.

Expanding the current Child Death Review Process to incorporate the national fetal infant mortality review (FIMR) model is under consideration. We believe that this would enhance our ongoing process for assessing, planning, improving and monitoring the services system and broad community resources that support and promote the health and well-being of women, infants and families. Information from the process will be used to guide policy development and define and maintain quality maternal, child and family health programs.

Youth Suicides

Although the number of youth suicides is low, this is an area that is currently not at all addressed with Maternal and Child Health Block Grant funds. Pennsylvania's 1997 rate is 8.3 per 100,000 youths (total number of youth suicides in 1997 was 67). The rate for self-inflictions was two times higher for females (211.3) than for males (102.4). Rates are higher for White males than for African-Americans. Although the numbers are not high for youth ages 15-19 in relation to total suicides, this is an area that is currently not being addressed in an intra/interagency manner. The Year 2010 objective is to reduce the rate to six (6) deaths per 100,000.

Health and Safety in Child Care Settings

There is a critical need for the availability and access to healthy and safe child care environments for children of working parents. The Pennsylvania rate of regulated childcare capacity per 100 estimated children under 14 years of age in need of such care, is 88. The average Pennsylvania county rate is 66 per 100 children in need. The estimated need for childcare is best met in Pennsylvania's urban counties (104 spaces per 100 children under 14). The estimated need is least well met in rural counties (56 spaces per 100 children under 14 in need).

With regard to the health and safety of child care environments, an evaluation of reports of incidents in child care facilities submitted by child care providers to the Pennsylvania Department of Public Welfare, revealed the lack of a refined system of incident reporting. Additionally, there is no system in place that would allow those sites reporting health and safety incidents to be linked with the services of a health care consultant.

A telephone survey conducted by the *Early Childhood Education Linkage System (ECELS)* indicated: 1) most of the providers want information and training on infectious diseases, 2) only twenty-nine percent of center directors indicated that they had consulted a health care professional about their program in the past 12 months, and 3) 41% of center directors and 52% of family childcare providers put infants to sleep on their backs.

Health Care Coverage

Access to quality care is important to eliminate health disparities and increase the quality and years of life for all Americans. A significant component of the access problem is the lack of health insurance. Approximately 126,000 children eligible for Medical Assistance (MA) are not currently enrolled in MA. Approximately 70,000 children are eligible for Pennsylvania's *Child Health Insurance Program (CHIP)*, but are not enrolled. Though there is a 2%

increase enrollment. Approximately 40% (113,000) of uninsured children are not eligible for MA or *CHIP*. Our interagency efforts to reduce the number of uninsured children contribute to NPM #12 and 13.

Injury Prevention

Priorities for injury prevention programs are established by reviewing mortality, morbidity and behavioral risk factor data. Mortality data point to the most serious injuries among children, but they represent only a small part of the burden. Hospital discharge data reveal data on injuries that are serious enough to require hospitalization and are more useful to local communities.

Injury is the single greatest killer of Pennsylvania children between the ages of one and 14, while homicide is the fourth leading cause of death. Under age one, perinatal conditions (short gestation, low birthweight, respiratory distress syndrome, etc.), congenital anomalies, and Sudden Infant Death Syndrome (SIDS) claim the lives of the largest number of children, followed by unintentional injuries and other causes. During 1997, 212 children and youth under age 15 died from unintentional injuries while 50 children died from homicide. The number of Pennsylvania children hospitalized for unintentional and assaults in 1997 exceeded 7,300. Among children under age 15, the leading causes of unintentional injury deaths are fire and burns, pedestrian injuries, and motor vehicle occupant injuries. The leading causes of injury-related hospitalizations are falls, followed in order by poisoning, being struck by an object, bicycle crashes, pedestrian injuries and motor vehicle occupant injuries. There are Year 2010 objectives to reduce the number of deaths caused by motor vehicle crashes, increase the use of child restraints in automobiles and to increase the use of helmets by bicyclists.

Since 1986, the rate of unintentional injury death among children aged 0-14 has declined while the rate of death from all types of motor vehicle crashes, including occupant, pedestrian and bicycle crashes, among children ages one through fourteen declined until 1992 and then stayed the same. Generally, the rate of unintentional injury death is higher among males than females and higher among blacks than whites.

Data from the 1998 Behavioral Risk Factor Surveillance Survey suggest the need to promote the use of safety practices known to be highly effective in preventing childhood injuries. Smoke alarms are present on all floors in the homes of only 73 percent adults in Pennsylvania. Only 46 percent of adults who live in a household with children aged 5 –15 report that their oldest child always wears a bicycle helmet when riding a bicycle. Ninety-five percent of adults with a child under age five in the household reported that they always used a child's car safety seat. Inspections conducted during 1991 in Pennsylvania of over 1,000 car seats in Pennsylvania revealed that 88 percent were misused.

Infant Mortality

Infant Mortality continues to come down for the population as a whole. From 1990 through 1997, the state's infant mortality rate had come down by 20%. This is the good news.

The bad news is that large disparities remain in infant mortality rates for different population groups. The rate for African-American babies (17.4) is nearly three times the rate for Caucasian babies (6.0). The rate for Hispanic babies (9.8) is over one and one-half times the rate for Caucasian babies. Disparities in neonatal and post neonatal death rates are comparable. The Year 2010 objective is to reduce infant deaths to 4.5 per 1000 for all population groups.

Partial explanations for the disparities in Infant Mortality Rate may be available in other health status data. While over 85% of White pregnant women have their first prenatal visit during the first trimester of pregnancy, only 65% of African-American women and 69% of Hispanic women do so. Further, 10.7% of African-American newborns and 7.3% of Hispanic newborns are low birth weight (less than 2500 grams) compared to 5.4% of Caucasian newborns.

Sudden Infant Death Syndrome (SIDS)

According to Pennsylvania vital statistics, the incidence of *SIDS* decreased by 58% from 1992-1997. Of the 310 infant deaths due to causes other than congenital anomalies and perinatal conditions, over 33 percent were due to *Sudden Infant Death Syndrome (SIDS)*. Over 92 percent of the *SIDS* deaths occurred during the post-neonatal period (28-364 days of age). Despite the decrease in the incidence of *SIDS*, figures still show a disproportionately higher number of *SIDS* deaths among black infants (1.9%) than white infants (.53%). The Year 2010 objective is to reduce post-neonatal deaths to 1.5 per 1000.

Children with Special Health Care Needs

The Division of Special Health Care Programs' needs assessment included extensive research and effort aimed at addressing the infrastructure of children with special health care needs (CSHCN) services. The needs assessment itself, as an infrastructure building tool, aided in uncovering and addressing needs of CSHCN by identifying priority needs, gaps in CSHCN health care services, and the health care delivery systems, and information on CHSCN as well as forming the basis of need and support for the Division's infrastructure building programs.

In its needs assessment efforts, the Division contacted both private and public organizations and agencies in an attempt to ascertain the strength of the infrastructure for CSHCN in Pennsylvania. While various state agencies were contacted, private professional organizations were also contacted such as the American Dental Association, the Pennsylvania Medical Society, and the State Board of Medicine. Through contact with these private and public entities, the needs assessment itself, as an infrastructure building tool, clearly revealed the need for readily available data on the CSHCN population. Particularly limiting was the fact that no uniform definition existed of CSHCN, which not only hampered data collection, but also exemplified a need in itself. The Department of Public Welfare's Medical Assistance Office, for instance, allows clients under managed care to self-declare their special needs condition, the need therefore having the possibility of running the gamete including, but not limited to, an actual

health condition, housing needs, transportation, and/or childcare. Lack of a uniform definition of special needs makes accurate collection of information on CSHCN, such as the number of CSHCN on a primary care physician's caseload, the number of CSHCN enrolled in managed care, and length of hospital stay for CSHCN by specific condition hard to accurately obtain without the discretionary use and application of ICD – 9 diagnostic codes. Specific data on the ethnicity, socioeconomic status, race and condition of CSHCN is also problematic and not readily available. The *Children's Health Insurance Program (CHIP)*, for instance, does not currently track CSHCN; the number of deaf children by age, race, ethnicity, and county of residence is not available from the Bureau of Special Education; Mental Retardation does not keep data on CSHCN specifically; and the number of African American and Hispanic CSHCN is perhaps only obtainable through prevalence estimates. Other data and information on CSHCN is not available at all: the number of homeless CSHCN, the incidence rate of abuse (towards CSHCN) in such families, and the number of adoptions of CSHCN in Pennsylvania, to name a few.

This lack of readily available information on CSHCN, particularly race, socioeconomic status, and special needs conditions supports the need for a continual process to assess CSHCN programs. It also underscores the importance of continued collaboration with other state agencies, particularly the Departments of Labor and Industry, Insurance, Public Welfare, and Education, as well as other offices within the Health Department. *CHIP* is included in this dialog in order to find ways to capture data about CSHCN enrolled in that program.

In addition to this inter-agency collaboration, the needs assessment forms the basis for various infrastructure building of the Division. The assessment revealed a need for better coordination of services for the CSHCN population, stemming from the fragmentation of information and gaps in health care services. While the needs assessment reveals that communication between primary care practitioners and specialists is a component of coordination that is problematic (Priority Need #5), the Division has several programs to meet this need. The need for coordination supports the existence of The Shriners Hospital for Children CHOICES Program, which provides an information and referral linkage to assist Shriners Hospital care coordinators to identify and locate accessible, coordinated, community-based services for CSHCN following discharge from Shriners Hospital. The Division's eligibility process, which works to refer qualified CSHCN to Medical Assistance and *CHIP*, also supports coordination needs and efforts. The Regional Action Teams attempt to coordinate the Department's effort to find community-based solutions to systems needs, empower communities to find solutions to these needs, as well as provide a seamless system of care for CSHCN. Coordination also takes the form of transition issues for CSHCN. Transition to adulthood issues for CSHCN became apparent in needs assessments, clearly voiced by both Advisory Council members and public stakeholders. *Parent to Parent (P2P)* has an infrastructure building component to its program in its process of linking families of CSHCN for the purposes of a number of transitions: early intervention, school age, age 18 to adult living, as well as for those children who are entering the community again after being in an institution. *P2P* links these families with other families, which have successfully transitioned and offer support and information having to do with transition. These programs and services also meet infrastructure service needs by improving access to service (Priority Need #7) for CSHCN.

Access to care also was the subject of the Division's Special Needs Hospital Survey Project. Beginning in late 1999, the Division of Special Health Care Programs began taking action to address access to care issues, especially as it relates to care for CSHCN in under-served areas. The Division surveyed all of the licensed acute care hospitals (excluding hospitals with which the Department already had a contract, rehabilitation, veteran's administration, and other governmental hospitals). The purpose of this survey was to determine their interest in and capability to serve CSHCN at their facility. Needs assessment findings suggested that there was a potential to expand services for CSHCN to include hospitals and physicians who are not currently Title V providers and not contracted with the Department. The finding supports Division efforts to find ways to address the need to provide condition-specific CSHCN services in under-served and rural areas.

In addition, Priority Need #5 (information/knowledge) is supported by the *Early Childhood Education Linkage System (ECELS) program*, which seeks to provide health and safety training for child care providers, state agency staff, and health consultants. Training helps meet the need for knowledge on the part of providers in an environment in which a provider's understanding of a child's condition is deemed inadequate by the families of CSHCN.

The assessment also continues to support for the need for the *Special Kids Network*. Infrastructure building in the form of community systems development, system coordination, and filling gaps in services is the main emphasis of the *Special Kids Network*. A secondary focus is support of families, provision of information and facilitating access to services. Family survey results suggested that support services provided by the *Special Kids Network* are still needed. Fifty percent of respondents, for instance, said that they would like to talk to someone with a similar problem or experience, and 41% felt that a support group would be useful. Respondents also expressed the need for Medical Assistance and other kinds of help not mentioned on the survey. With regard to medical help, families mentioned the need to find caring physicians; and they need information about their child's condition. Some respondents mentioned that they needed financial help to defray medical costs, which is consistent with needs assessment findings that led to Priority Need #7 that addresses access to affordable health care services. Childcare for other children and in-home help were also mentioned, consistent with Priority Need #6 that addresses interagency coordination to improve availability of ancillary services.

Respondents were also asked to indicate the best ways for them to learn about services available for CSHCN. Over half of the respondents preferred to learn about services from *Special Kids Network* (55%). Other popular sources for information included the child's doctor (45%), a printed directory (32%), mailings (31%), phone book and the Internet (17% each), newsletters (15%), TV ads (10%), newspaper (8%), and the library (5%). Twenty-two respondents made other suggestions, including condition-specific foundations and groups, word of mouth from other parents, case managers, social workers, parenting magazines, and their own efforts. Yet, the need for information and knowledge of services (Priority Need #5) is still apparent in this program. While this survey may indicate that people seem aware of services, it also suggests that they are not taking advantage of all that are available to them.

Furthermore, among families who called the Network, there were concerns from over 35% of the respondents that physicians did not appropriately understand the needs of their families which is also consistent with Priority Need #5 (information/knowledge).

In other areas, findings among Network callers were consistent with those determined elsewhere. Families were generally satisfied with access to care issues, with close to 90% of respondents indicating a specialist regularly saw their child. Yet, the communication between the specialist and the primary care providers was identified as a problem by over 40% of the families. Again, respondents generally were happy about their involvement in their child's care, but over 25% indicated dissatisfaction with the communication between providers, and well over 40% indicated dissatisfaction with their ability to get information about available services. Nearly 60% of the Network's callers indicated dissatisfaction in this area.

Ultimately, the results of the survey indicated that there was a need for interventions and initiatives which would satisfy the needs of families of CSHCN. The findings clearly showed the need for initiatives related to improving communication efforts to families and providers of CSHCN, helping families to locate and access caring physicians, helping physicians understand more about CSHCN conditions and needs, facilitating families access to support groups, facilitating referral of families to insurance plans, and helping families in care coordination.

In addition, the Division has several local delivery systems and collaborative efforts that meet the needs of the CSHCN population. By forming partnerships at the local level, the capacity of the Division to reach the population in need has significantly improved. Examples of where this has occurred include capacity-building activities such as the community systems development activities of the *Special Kids Network*; the formation of Statewide Action Teams at the regional level; community building through the Special Health Care Needs Consultants and Community Health Nurses in our District Offices; and the CSHCN consultant at the Philadelphia Department of Public Health.

The Division of Special Health Care Programs (SHCP) also collaborates with various agencies at both the public and private level, recognizing the importance of coordinating the State's Title V activities. Staff from the Division of SHCP maintain an ongoing advisory role and consultative relationship with the Department of Public Welfare (DPW) to assure that CSHCN, who are enrolled in managed care plans, have access to and receive services appropriate to their special needs. Staff participates with DPW in quality assurance site visits to the Medical Assistance (MA) Managed Care Organizations to assure a focus on the specific needs of CSHCN. This interagency role is expected to be increasingly important as DPW mandates Medicaid managed care statewide. This role will assure that CSHCN in managed care environments have appropriate medical and ancillary care, including access to specialists and care coordination.

In order to assure that eligible CSHCN receive comprehensive health care coverage, the Division has institutionalized a process for referring eligible applicants and clients to MA and *CHIP*. The Division has been electronically linked to DPW's MA patient enrollment system, which facilitates coordination of services and referrals. In addition, we work with DPW to maintain standard payments for inpatient services using the MA Diagnostic Related Grouping system, and we maintain current and uniform fees for outpatient services by a regular comparison of our fees to MA and making updates when necessary. We also participate on the DPW Enrollment and Outreach workgroup. The Workgroup developed and recommended a common application for MA and *CHIP*, as well as enhancements to current outreach strategies that will increase enrollment of eligible children into MA and CHIP, addressing Priority Need #4 & #6.

3.2 Health Status Indicators

3.2.1 Priority Needs

MCH Priority Needs

The priority Maternal and Child Health (MCH) needs identified through our needs assessment process are as follows:

- Eliminate racial ethnic disparities in the health status of Pennsylvania families focusing on: unplanned/teen pregnancy; infant/childhood mortality and morbidity; health care for children, adolescents and CSHCN. (Reference Form 14, Priority Need #1)
- Improve oral health for Pennsylvania's children, including dental services for CSHCN. (Reference Form 14, Priority Need #2)
- Reduce the number of lead-poisoned children by increasing the number of Medicaid enrolled children screened for lead poisoning and facilitating lead hazard reduction in Pennsylvania. (Reference Form 14, Priority Need #8)
- Improve the quantity and quality of safe Child Care Centers through technical assistance and training for child care givers and the provision of incentives to assure the availability of day care and respite services to CSHCN. (Reference Form 14, Priority Need #3)
- Build resiliency among Pennsylvania's youth thereby reducing unintentional injuries, the incidence of youth violence, suicide and adolescent risky behaviors (Tobacco and other drugs, STDs, teen pregnancy). (Reference Form 14, Priority Need #10)

Several comments on these priority needs are important. First, the elimination of disparities in health status goes beyond the first priority need. Disparities also exist, for instance, and will be addressed in the next two priority needs, oral health and childhood lead poisoning. Secondly, some of these priorities will be addressed primarily with resources other than Title V funding. This is true of reducing youth substance abuse, increasing enrollment in health care coverage, and increasing immunization rates. Thirdly, some priorities will require interagency and intra-agency

attention, and whether there is a need for additional Title funding is currently unclear. These include oral health, and childhood morbidity and mortality, e.g., asthma and obesity.

CSHCN Priority Needs

The Division of Special Health Care Programs five-year needs assessment activities included internal and external processes to assess the needs of children with special health care needs (CSHCN). Activities included brainstorming the possible universe of data elements that effect CSHCN; data collection from state agencies such as the Departments of Public Welfare, Education, and Insurance; a review of various CSHCN information and literature; public input from the Department's Maternal and Child Advisory Council and public stakeholders; as well as a review of survey research done in collaboration with the University of Pittsburgh School of Public Health.

The Priority Needs were established by the Division based on the five-year needs assessment, including the input of stakeholders, and using the levels of core public health services described by the pyramid. The Priority Needs represent problems, gaps, and weaknesses of the health care delivery system. The Priority Needs listed on Form 14 form the basis for several new initiatives including the following:

- An expanded *Newborn Screening Program* and a CSHCN registry that will form the basis for a birth defects surveillance system should Pennsylvania decide to implement one. (Priority Need – Facilitate and improve identification, education, and outreach to CSHCN.) (Reference Form 14, Priority Need #4)
- The provision of education to physicians and health care professionals, as well as additional support and information for families, in the form of home visits. (Priority Need – Increase physicians' knowledge about conditions of CSHCN and information available to families about the condition and available services.) (Reference Form 14, Priority Needs #5 and #9)
- Provide specific guidelines and requirements to specialty clinics related to care coordination. (Priority Need – Improve care coordination for CSHCN – both to insure adequate contact as well as effective communication between the specialist and the primary care physician.) (Reference Form 14, Priority Need #5)
- Undertake a pro-active education and information process for families regarding the availability of resources such as MA and *Children's Health Insurance Program (CHIP)* as well as the appropriate and expeditious methods for accessing those resources. (Priority Need – Improve access to affordable health care services for CSHCN.) (Reference Form 14, Priority Need #7)
- Explore ways to add other qualified providers to serve CSHCN in our medical programs. (Priority Need – Remove barriers to accessing services – particularly related to transportation, long distances to providers, and difficulty in obtaining services because of social, ethnic, geographic and special needs condition.) (Reference Form 14, Priority Needs #6 & #7)

- Provide training for potential respite care providers as well as incentives for child care providers to serve CSHCN. (Priority Need – Increase access and availability of ancillary services such as respite care, mental health care services, and dental care.) (Reference Form 14, Priority Need #7)

These Priority Needs support the continuation of many of our current programs and will drive the new initiatives alluded to above and described in the Annual Plan.

3.3 Annual Budget and Budget Justification

3.3.1 Completion of Budget Forms

Form 2 (Maternal and Child Health Budget Details for FY 2001), Form 3 (State MCH Funding Profile), Form 4 (Budget Details by Types of Individuals Served and Sources of Other Federal Funds), and Form 5 (State Title V Program Budget and Expenditures by Types of Service) have been completed for FFY 1999 expended and FY 2001 budgeted.

3.3.2 Other Requirements

Pennsylvania's proposed budget for Federal Fiscal Year 2001 is in full compliance with the federally mandated "30%-30%" requirements. Of Pennsylvania's federal grant award for 2001, \$8,218,664 (32%) is designated for the support of preventive and primary services for children, and \$8,515,098 (33.77%) is designated for the support of services for children with special health care needs. Following is a summary of the utilization of available funds in relation to the levels of the pyramid.

1) Core Public Health/Infrastructure

Core public health services represent an increasing proportion of the services supported by Title V/Maternal and Child Health (MCH) Block Grant funds. Needs assessment, community development, local planning, and program evaluation have become the focus of our activities. We are actively engaged through local systems developed in our contracts with the county and municipal health departments, services provided by the Department's Bureau of Community Health Systems, the support of Safe Kids coalitions to prevent childhood injuries, and *the Early Childhood Education and Linkage System (ECELS)*. We are actively working with other state agencies to assure appropriate services for MCH populations, including cooperation in local service system reform, interagency outreach efforts to get pregnant women and the families of young children into health care, and the expansion of mandatory Medical Assistance managed care.

In the Division of Special Health Care Programs (SHCP), the majority of staff time is focused on infrastructure building services which benefit all children with special health care needs (CSHCN) regardless of condition. We are actively engaged in expanding our registry (the foundation of needs assessment) of all individuals with special needs served by Title V and state funds. The 1999 CSHCN needs assessment has been completed and supports our FFY 2001 community development and local planning initiatives. We continue to actively seek additional ways to secure

family input into policy and program decisions. We have improved linkages with other state agencies and private organizations to enhance the coordination of service systems for CSHCN. Numerous other activities, such as the provision of technical assistance, advocacy, education, and outreach, contribute to the quality of services provided to CSHCN.

2) Population-Based Individual Services

These services include newborn screening and follow-up, childhood lead poisoning prevention, school health services, and *Sudden Infant Death Syndrome (SIDS)* follow-up.

Current services for children with special health care needs include several outreach initiatives including folic acid, epilepsy and Tourettes syndrome, as well as promotion of Division programs including Title V.

3) Enabling and Non-Health Support

The Interagency Outreach Campaign was designed to eliminate barriers and improve access to care. It is targeted to pregnant women and the families of young children at or below 200% of the federal poverty level.

Programs for children with special health care needs (CSHCN) which enable families to access services include the *Family Consultant Program*, which gives parents of CSHCN enhanced understanding of the hospital system; *Parent to Parent of Pennsylvania*, which connects parents of CSHCN to mentor parents and parent support groups; and the *Ventilator Assisted Children's Home Program*.

4) Direct Health Care Services

Title V support for direct services to children with special health care needs has been dramatically reduced because Pennsylvania has significantly expanded its *Children's Health Insurance Program (CHIP)*, and because the Medical Assistance Program provides comprehensive coverage for children based on their meeting the Supplemental Security Income (SSI) definition of disability regardless of their parents' income. However, Title V and other state funds will always be needed to support direct health services for those CSHCN who are uninsured or under-insured and whose parents' income exceeds the MA and *CHIP* criteria. Services for CSHCN provided by the Division of SHCP include direct health care, both inpatient and outpatient, as well as comprehensive multi-disciplinary team specialty clinics.

Administrative Costs

Section 505 of the Maternal and Child Health (MCH) Block Grant legislation limits the amount of the State's allocation that can be used for administration to not more than 10 percent. In FFY 2000, Pennsylvania plans to expend \$1,730,000 or 6 percent for administration. The following is the definition of Administrative Costs used by the Pennsylvania Department of Health in administering the Maternal and Child Health Services Block Grant.

1. Personnel Costs

Personnel costs, including salaries and associated fringe benefits, are considered administrative if those costs are not incurred in the direct or indirect provision of prevention, education, intervention, or treatment services.

All personnel costs not included in this definition would be considered program and would not fall under the block grant administrative costs restriction.

2. Operational Costs

Operational costs are considered administrative if they are not required for the delivery of direct or indirect program services. Operational costs are considered program if they are utilized to support program-designated activities.

The designations are by minor object of expenditure.

Maintenance of Effort Match

Section 505 of the Maternal and Child Health (MCH) Block Grant legislation requires that a State receiving funds shall maintain the level of funds being provided solely by such State for maternal and child health programs at a level at least equal to the level that the State provided for such programs in fiscal year 1989.

Pennsylvania bases maintenance of effort on a federal fiscal year, only including those state appropriations which are solely used for MCH; i.e., 100 percent MCH-related. In Federal Fiscal Year 1989, Pennsylvania's maintenance of effort was \$20,065,574.58, as detailed in Table 2. For Federal Fiscal Year 2001, Pennsylvania's match will exceed the 1989 maintenance of effort level. The proposed expenditure of state funds is detailed below.

Table 2
Maintenance of Effort (Match)
Federal Fiscal Year 1989

State Funded Appropriations	Amount
108 School Health Services	\$17,265,914.86
112 Maternal and Child Health	1,661,120.00
120 Sickle Cell Summer Camps	35,000.00
137 Tourette Syndrome	100,000.00
164 Home Ventilators	<u>1,003,539.72</u>
TOTAL	\$20,065,574.58

Table 3
Planned Maintenance of Effort (Match)
Federal Fiscal Year 2001

State Funded Appropriations	Amount
107 Renal Dialysis	\$ 8,255,000.00
108 School Health Services	40,464,000.00
112 Maternal and Child Health	3,905,000.00
120 Sickle Cell	1,503,000.00
123 Adult Cystic Fibrosis	721,000.00
124 Hemophilia	1,594,000.00
128 Cooley's Anemia	198,000.00
130 Coal Worker's Respiratory Disease	200,000.00
137 Tourette Syndrome	100,000.00
149 Services for Children with Special Needs	1,732,000.00
170 Epilepsy Support Services	450,000.00
182 Newborn Hearing Screening Demo	750,000.00
186 Newborn Screening	4,000,000.00
192 EMSOF – Head Injury	3,000,000.00
221 ODATF – Organ Donor	<u>101,000.00</u>
TOTAL	\$66,973,000.00

3.4 Performance Measures

Figure 3 has been prepared to illustrate Pennsylvania's Title V Block Grant Performance Measurement System, tying together the priorities identified by the Needs Assessment, and the Program and Resource Allocation identified by the Pyramid's category of services to specific performance and outcome measures.

3.4.1 National “Core” Five Year Performance Measures

3.4.1.1 Five Year Performance Objectives

Annual Performance Objectives and Indicators have been determined for each of the National Performance Measures for the state of Pennsylvania, beginning in FFY 2000. This data is listed in Form 11. Progress on achieving these objectives has been described in the Annual Report, Section 2.4. The relationship between national and state performance measures, pyramid level of services, and type of service is shown in Table 5.

**TABLE 5
PERFORMANCE MEASURES SUMMARY SHEET**

Core Performance Measures	Pyramid Level of Service				Type of Service		
	D H C	E S	P B S	I B	C	P	R F
1) The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs (CSHCN) Program.	X				X		
2) The degree to which the State Children with Special Health Care Needs (CSHCN) Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable to its clients.	X				X		
3) The percent of Children with Special Health Care Needs (CSHCN) in the State who have a “medical/health home.”		X			X		
4) Percent of newborns in the State with at least one screening for each of PKU, hypothyroidism, galactosemia, hemoglobinopathies (e.g., the sickle cell diseases) (combined).			X				X
5) Percent of children through age 2 who have completed immunizations for Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Hemophilus Influenza, Hepatitis B.			X				X
6) The birth rate (per 1,000) for teenagers aged 15 through 17 years.			X				X
7) Percent of third grade children who have received protective sealants on at least one permanent molar tooth.			X				X
8) The rate of deaths to children aged 1-14 caused by motor vehicle crashes per 100,000 children.			X				X
9) Percentage of mothers who breastfeed their infants at hospital discharge.			X				X
10) Percentage of newborns who have been screened for hearing impairment before hospital discharge.			X				X
11) Percent of Children with Special Health Care Needs (CSHCN) in the State CSHCN Program with a source of insurance for primary and specialty care.				X	X		
12) Percent of children without health insurance.				X	X		
13) Percent of potentially Medicaid eligible children who have received a service paid by the Medicaid Program.				X		X	
14) The degree to which the State assures family participation in program and policy activities							

Core Performance Measures	Pyramid Level of Service				Type of Service		
	D H C	E S	P B S	I B	C	P	R F
in the State CSHCN Program.				X		X	
15) Percent of very low birth weight live births.				X			X
16) The rate (per 100,000) of suicide deaths among youths 15-19.				X			X
17) Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.				X			X
18) Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.				X			X

State (Negotiated) Performance Measures	Pyramid Level of Service				Type of Service		
	D H C	E S	P B S	I B	C	P	R F
1) Percent of sexually active teens (ages 15-17) who use Family Planning Services systems.	X						X
2) Percent of Medicaid children (ages 1-2) screened for elevated blood lead levels.			X				X
3) Rate of deaths among children (ages 0-14) that are a result of unintentional injuries.			X				X
4) Ratio of trained child care health consultants to the number of regulated child care centers.				X	X		
5) Percent of child deaths (ages 0-19) reviewed by a local Child Death Review Team.				X		X	
6) The degree of improvement in the Division of SHCP participation in prevention initiatives that impact conditions and complications affecting children with special health care needs.			X		X		
7) Percent of increase in awareness of Title V CSHCN activities among families, providers and public and private agencies.		X			X		
8) Percent of children with special health care needs, in managed care environments who have appropriate medical and ancillary care including access to specialists and care coordination.				X	X		
9) Percent of children in regulated center-based child care who are getting vision screening.				X			X
10) The degree to which the state specialty clinic contractors coordinate services for CSHCN with primary care physicians.				X		X	
11) Percent of increase in families of CSHCN awareness of services provided by Title V for CSHCN		X			X		
12) Percent of increase in access to specialty care among CSHCN.					X		

NOTE: DHC = Direct Health Care ES = Enabling Services PBS = Population-based Services
IB = Infrastructure Building C = Capacity P = Process RF = Risk Factor

3.4.2 State “Negotiated” Five Year Performance Measures

3.4.2.1 Development of State Performance Measures

Form 16 has been completed for each of the State Performance Measures. Form 16 has also been placed in Supporting Document Section 5.3 of this application.

3.4.2.2 Discussion of State Performance Measures

Preventive and Primary Care for Pregnant Women, Infants and Children

SP #1 Percent of sexually active teens (ages 15-17) who use Family Planning Services systems.

By monitoring the percentage of teens served by the FPS system, the program staff will be able to gauge the impact of funding and service system changes on the family planning population. If noticeable decreases occur, appropriate action will be taken to bolster any decreases in patient levels by working with the Department of Public Welfare to facilitate contract and reimbursement efficiencies, encourage outreach activities in targeted high-risk communities, and support other funding efforts by the regional Councils.

SP #2 Percent of Medicaid children (ages 1-2) who have received a blood lead screening test.

It is important to develop policies for childhood lead poisoning prevention. Blood lead levels (BLL) as low as 10 ug/dL are associated with harmful effects on children’s learning and behavior. Primary prevention activities prevent children from being exposed to lead. Especially significant are actions to reduce residential lead hazards before children are sufficiently mobile to be at increased risk for exposure to household lead, or before children move into a home with lead hazards. Secondary prevention activities reduce the harmful effects of elevated blood lead levels (BLL) after elevations have occurred. Activities include BLL screening and follow-up care. Children ages 1 and 2 are at greatest risk of lead poisoning based upon their mobility and hand-to-mouth activity. A national survey showed that only about one-fourth of young children had been screened and only about one-third of poor children, who are at a higher risk of lead exposure than other children, had been screened. Blood lead screening is part of a comprehensive program to eliminate childhood lead poisoning.

SP #3 Percent of children in regulated center-based child care who are getting vision screening.

Vision problems begin well before children reach school age and early recognition of disease results in more effective treatment that can be sight-saving or even life-saving. Therefore, every effort must be made to ensure that all children, including those in pre-school, receive an age appropriate vision screening exam from their health care provider. ECELSTRAK is a software program that analyzes a 10 percent stratified sample of child health records for children served in regulated center-based child care. This analysis identifies whether the documented services on the sampled records show that the children are up to date with the recommendations of the American Academy of Pediatrics for age appropriate health assessments. Since the ECELSTRAK system generates compliance summary reports we will be able to identify rates of non-compliance or reduction in the compliance rate for vision screening efforts. Based on these findings, we will have information that show gaps in the

delivery of age appropriate screening services so we are able to provide needed technical assistance to ensure that all children have access to, are referred for and receive required preventive health services.

Children with Special Health Care Needs

SP #6 The degree of improvement in the Division of Special Health Care Programs participation in prevention initiatives that impact conditions and complications affecting CSHCN.

Chronic disabilities and conditions are often disregarded by prevention campaigns, because it is assumed that there is no way to prevent many of these conditions. However, recent research into folic acid as a prevention of neural tube defects shows us that there is a role to play in the primary prevention of some chronic conditions; even more widespread is the potential to prevent condition complications. In cooperation with the Division of Health Statistics and Research, a statewide, stratified sample of childbearing age women was surveyed about their knowledge and consumption of folic acid. This information was tabulated during 1999 and will serve as a baseline from which to gauge the results of the 2000 folic acid promotion campaign. The folic acid survey and methodology used was developed by the Centers for Disease Control and Prevention and is incorporated as part of the Department's Behavioral Risk Factor Surveillance System annual survey. The folic acid survey module will be conducted again during 2000 to determine the impact of the folic acid interventions and initiatives that have occurred.

SP #11 Percent of increase in families of CSHCN awareness of services provided by Title V for CSHCN.

The 1999 needs assessment revealed that 48% of families were aware of the State's Title V program. Also, 47% of the families cited not knowing what services are available as the number one barrier to obtaining services. A sizable minority (30%) disagreed that their physician or pediatrician knows a lot or provides enough information about the care of the child. 47% of responding pediatricians would like information about the Title V program. The Division of Special Health Care Programs has developed several initiatives which will target the State's priority need for information and knowledge on the part of physicians to know more about the conditions affecting CSHCN and families' need to obtain better information on their child's condition and the services available to them. Another method by which we will increase awareness of Title V and CSHCN programs is to require our providers to promote Title V and Division programs for CSHCN by providing consumers with the promotion materials that we are developing.

SP #12 Percent of increase in access to specialty care among CSHCN.

It is necessary to assure that CSHCN, including those in managed care programs, have access to appropriate medical and ancillary services including specialty care. CSHCN are particularly vulnerable in the managed care environment, as chronic and disabling conditions are not necessarily amenable to prevention and these children often require specialty treatment as part of their routine care. With the expansion of HealthChoices to southwestern and central Pennsylvania, it is necessary to assure that children receive medical and ancillary services under managed care that are equal to or

exceed those previously received under fee-for-service. Staff from the Division of SHCP maintain an ongoing advisory role and consultative relationship with the Department of Public Welfare to assure that CSHCN who are enrolled in MA managed care plans have access to and receive services appropriate to their special needs. This interagency advisory role is expected to be increasingly important as DPW mandates MA managed care statewide. This role also will be extended to CHIP through the Department of Insurance.

SP #10 The degree to which the State specialty clinic contractors coordinate services for CSHCN with primary care physicians.

The State has contracts with comprehensive specialty clinics for direct health services. It is important to evaluate the contractor's efforts in addressing the State's priority needs. This will be accomplished through evaluation of key performance indicators including coordination of care.

3.4.2.3 Five Year Performance Objectives

The State Performance Measures have been added to Form 11, and performance objectives have been determined.

3.4.2.4 Review of State Performance Measures

We understand that the state performance measures will be reviewed by and negotiated with federal Maternal and Child Health staff.

3.4.3 Outcome Measures

Annual Outcome Objectives and Indicators have been listed in Form 12.

IV. REQUIREMENTS FOR THE ANNUAL PLAN [Section 505(a)(2)(A)]

4.1 Program Activities Related to Performance Measures

The following narrative describes the relationship among the priority needs, the National and State performance measures, and the capacity and resource capability of the State Title V program. This information is reported using the levels of the pyramid.

Direct Medical Services

Preventive and Primary Care Services for Pregnant tWomen, Infants, and Children

The Department's Maternal and Child Health (MCH)/Title V staff and the *Healthy Start* projects have initiated meetings for the purpose of coordinating plans and resources in an effort to enhance access to and utilization of perinatal systems in Pennsylvania. During the upcoming year it is our mutual intent to develop a common workplan to improve perinatal systems, to link our plans to the Department's developing the State Health Improvement Plan (SHIP) initiative, and to look at the impact of mandatory Medicaid managed care on perinatal services. An example of how the SHIP partnership linkage has already been successful is the Healthy Start project in Allegheny County.

Allegheny County has applied for additional Federal Healthy Start grant funding to assist Fayette County to meet priority needs related to teen pregnancy and pregnancy outcomes.

Staff from the Department of Health, the federal *Healthy Start* projects, and the state's local health departments are developing a common workplan with the intention of improving perinatal systems in Pennsylvania. Initiated at a March 2000 meeting in Philadelphia, the workplan will focus on three objectives, reducing disparities in perinatal health outcomes, improving access to care, and striving for a common data set to measure achievements toward desired health outcomes. A steering committee composed of Department of Health, Healthy Start and Local Health Department representatives will coordinate and direct the group's efforts. One of the group's first activities under the Access to Care objective is the assessment of whether Medical Assistance Managed Care Organizations (MCOs) are meeting the *Healthy Beginnings Plus* standards required by *HealthChoices*. This initiative will address NPM #15, 17 and 18, as well as Priority Needs #1, 2, 3, 4 and 5.

The Department is planning to conduct an assessment of perinatal care in Pennsylvania during the coming year. Expansion of technology, including the availability of surfactants, the greater use of antenatal steroids and the availability of highly trained neonatologists, has resulted in the proliferation of high-risk neonatal intensive care units. The impact of this proliferation and the consequent allocation of patients to hospitals that may not offer all of the services of traditional perinatal centers has resulted in the deregionalization of high risk perinatal care. The consequence of these changes is not well understood, but there has been some research evidence in California that severity adjusted outcomes may not be optimal in facilities that do not offer the full array of high-risk care. There is, in addition, a general impression that the proliferation of high risk services has resulted in compromised patient care and, therefore, poor outcomes. It is important to determine if this perception has validity, and if so, to provide a strategy that allows for the state to respond to encourage risk appropriate perinatal care. There are two goals inherent in this study. The first goal is to document whether high-risk care is provided appropriately in Pennsylvania and to assess whether it is provided with optimal efficiency. The second goal is to set-up the mechanism for ongoing assessment and monitoring of the status of perinatal care statewide.

The National Perinatal Information Center has provided a proposal for conducting the study. It would answer the following questions for Pennsylvania:

- Are high-risk births delivered in settings that have the necessary high risk services?
- Is there evidence that high risk care is inappropriate in specific settings
- How do severity adjusted outcomes across different levels of care compare? How do they compare regionally, statewide and nationally? Is there evidence that risk adjusted outcomes are sub-optimal in some groups of hospitals and locations?

- How efficiently are special care nurseries being managed? What is the severity adjusted length of stay and cost? What types of units are most competitive?
- How do Hospitals vary with regard to obstetrical management? What are the c-section, repeat c-section and vaginal birth after cesarean section (VBAC) rates across hospitals?
- How efficiently are OB units managed?

This study will address NPM #17, as well as OM #1, 2, 3, 4 and 5.

Children with Special Health Care Needs

In order to address the need for care coordination for children with special health care needs (CSHCN) (Priority Need #5) and the need to remove the financial hardships of families of CSHCN, particularly hardships of paying for medical and non-medical expenses and out-of-pocket supplies (Priority Need # 7), the Division of Special Health Care Programs (SHCP) will continue to deliver comprehensive specialty care services through contracts with hospitals and community health clinics. These services provide a multi-disciplinary team approach to medical management of CSHCN and adults with chronic disabling conditions. Currently the State has annual contracts with 14 Pennsylvania providers to deliver comprehensive specialty care to adults and children with cystic fibrosis, Cooley's anemia, spina bifida, hemophilia and to children with musculoskeletal/neurological impairments. To be eligible for this care, clients must be a resident of the State and have the appropriate diagnosis. Financial need is not a requirement for eligibility. Providers are paid an annual per capita fee regardless of the number of times a client must be seen. As part of the Division's transition efforts, reimbursement for services through this State funded program (except rehabilitation services) are available to adults with special health care needs. To further address the need for care coordination, the Division will place more specific requirements and guidelines in our contracts with the specialty clinics and will continue to monitor communication between the specialists and the primary care physicians.

Since the majority of clients have some medical care coverage from third party sources, the Department will be reviewing the current payment policy. The Department is considering limiting our payments to that portion of comprehensive care which is not reimbursed by third party sources. An example of these services is care coordination provided by the specialist as well as the clinic nurse and social worker through extensive phone contact. Reimbursement for medical services would continue to be available for those clients without other support, but would be provided on a fee-for-service basis. Discussion of possible payment revisions has been initiated with the medical directors of the eight state-supported hemophilia centers and movement in this direction has been favorably received. The ultimate goal of the Special Needs Medical Programs is to have more payment flexibility in order to extend the provision of comprehensive care to more eligible Pennsylvania residents with special needs who do not qualify for other reimbursement sources.

To remove the financial hardship of paying for specialty care, the State pays for certain procedures for enrolled children and adults against an approved fee schedule through Participating Provider Agreements. Enrolled children and adults must meet financial eligibility criteria and must have one of the following conditions: cleft palate, speech and hearing, orthopedic, cardiac, spina bifida, cystic fibrosis or hemophilia. This program has maintained a small but steady enrollment. Since Pennsylvania children receiving Supplemental Security Income (SSI) are automatically enrolled in Medical Assistance (MA), these direct payment programs do not provide services for these individuals. The reimbursement for cleft palate services address Healthy People 2010 objective (#21-15), increase the number of States and the District of Columbia that have a system for recording and referring infants and children with cleft lips, cleft palates, and other craniofacial anomalies to craniofacial anomaly rehabilitative teams.

The Medical Programs are measured through NPM #2 (the degree to which the State CSHCN Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable) and NPM #3 (increasing the number of CSHCN who have a “medical/health home”) and SP #10 (the degree to which the State assures that contractors provide care coordination with primary care physicians).

In addition, the Division of Maternal and Child Health will continue to contract with pediatric hospitals and their sub-contractors to insure timely diagnostic assessment and access to comprehensive medical services for children phenylketonuria, maple syrup urine disease and sickle cell disease.

The Division of Maternal and Child Health will continue support of its *Genetic Services Program* toward its effort to address the identified Priority Need #4 (need for identification, education, and outreach). The *Genetic Services Program* provides services to low income individuals affected with, at-risk for transmitting, or concerned about a genetic disorder. It enables individuals to make informed health decisions, and ensures that they are provided access to comprehensive genetic services. The program also promotes, organizes and supports educational programs for health care providers and the general public regarding the role of genetics in disease and the value of genetic counseling. It encourages and supports the assessment of genetic risks by primary care providers in relation to the patient’s future pregnancies. It pays directly for counseling services for low-income patients, Priority Need #5 (need for information and knowledge).

Clinical genetic centers are located in 12 university affiliated genetic centers across the Commonwealth. A statewide education program has been developed with Family Planning agencies, primary care physicians, and other health care providers regarding genetic screening and counseling. In addition, the four family planning councils provide genetic risk screening through their clinics and provide appropriate referral to the local genetic counseling center.

Enabling Services

Preventive and Primary Care Services for Pregnant Women, Infants, and Children

The *Abstinence Education and Related Services (AERS)* Initiative, a part of the Governor's Project for Community Building (PCB) is fully implemented. This project is funded through a special supplemental federal Title V Maternal and Child Health (MCH) Service Block Grant in the amount of \$1.82 million annually for a five-year period that began with federal fiscal year October 1, 1997. This amount is being matched annually by approximately \$1.4 million in state funds, which have been appropriated in Governor Ridge's FY 2000-01 budget. The Department is engaged in a five-year comprehensive statewide plan to promote abstinence as a positive lifestyle decision for young adolescents. A variety of strategies will be supported to realize the goal of increasing the number of young adolescents who decide to abstain from sexual activity. The Department is supporting the following: parent, peer, and health care professional training programs; the development of a statewide media campaign to promote abstinence among the target population; a statewide evaluation to assess the effectiveness of the abstinence-related services supported through this initiative; and the planning and development of an abstinence curriculum that is culturally and linguistically sensitive, targeted to Latino youth in Pennsylvania and available for future use by schools throughout the Commonwealth. Approximately 85% of combined state and federal funds appropriated for this initiative will be distributed directly to communities to support community-based activities and services to conduct abstinence education and related services that may include mentoring, adult supervision, and counseling in support of the abstinence goal. The *AERS* Initiative will contribute to a reduction in the pregnancies and births among teenage women out of wedlock who are under the age of 18 years. The *AERS* Initiative addresses *NPM #06*, the rate of births (per 1,000) for teenagers 15 through 17 years.

Infectious diseases remain a major cause of illness, disability, and death. Vaccines can prevent the debilitating and, in some cases, fatal effects of infectious diseases. There is a need to continue efforts to increase vaccination coverage for children living in poverty. The Department will continue to address this need through the Division of Immunization, and through supportive efforts of the *Early Childhood Education Linkage System (ECELS) program* which provides immunization educational materials and is working on the development of tracking software for use by child care providers.

Our needs assessment showed continuing disparities in infant mortality. The infant mortality rate for African-Americans remains almost three times the infant mortality rate for whites in Pennsylvania. The Hispanic rate is one and a-half times the rate for whites. To address these persistent disparities, the Department expects to support new services in the neediest areas of the state, possibly selected through an Request For Proposal (RFP) process. Services will include home visitation and care coordination provided by nurses and lay home visitors for pregnant, low-income minority women, education and outreach to pregnant women and new parents regarding the importance of prenatal care, breastfeeding, well child care and planned pregnancies. We will select models and strategies that have proven successful in other settings, i.e., *Healthy Start*. This initiative will address *NPM #8, 9, and 15*, and *OM #1, 2, 3, 4 and 5*.

In assessing childhood morbidity, asthma was identified as an area of priority need. Asthma hospitalization rates have increased dramatically for children under five years of age. Illness and disability from asthma can result in high medical costs, restricted activity, and missed school days. Asthma's greatest burden is in poor, urban, and minority communities. The Bureau of Family Health will initiate the first step in developing an asthma plan for Pennsylvania by identifying key stakeholders and specialists in the Department and establishing a work group to develop a statewide strategy. Steps were taken in FFY 00 to convene a meeting to begin this process.

Another area of priority need identified in regard to childhood morbidity was obesity. Research shows that 60% of overweight five to ten year olds already have at least one risk factor for heart disease, including hyperlipidemia, and elevated blood pressure or insulin levels. During the coming year, efforts will be carried out in collaboration with the Women, Infants and Children (WIC) program and the Bureau of Health Promotion and Chronic Disease to develop a plan to address childhood obesity in Pennsylvania.

Children with Special Health Care Needs

The *Family Consultant Program* and the *Parent to Parent Program* are two current initiatives which address multiple Priority Needs. These include the need to identify, educate, and provide outreach to the population of children with special health care needs (CSHCN) on the impact of their condition(s) and the services available to them (Priority Need #4); the need for information and knowledge on the part of families about their child's condition (Priority Need #5); and the need for care coordination for CSHCN (Priority Need #5).

The *Family Consultant Program* will continue the employment of parents of CSHCN. Division staff will analyze the performance of the program during the upcoming year and gather input from families and professionals to determine the plausibility of expanding the program to community or rural hospitals. The *Family Consultant Program* addresses Priority Need #5 (need for information and knowledge) by educating hospital staff and family members on the conditions and needs of CSHCN which widely differ from those of hospitalized children in general; Priority Need #5 (need for care coordination) by interfacing with families and hospital professionals to achieve care which is family-centered and appropriate to the child's condition; and Priority Need #7 (need for access to services) by linking families to services in the hospital as well as the community upon the child's discharge from the hospital. This is done by referrals to specialized services and programs, both in the hospital and community, and generated by the Division. The *Family Consultant Program* contributes to SP #11 (the percent of increase in the knowledge of services for and special conditions of CSHCN) through education of staff and families, as well as SP #12 (the percent of CSHCN who have appropriate medical care including access to specialists and care coordination) through referral of families of CSHCN to appropriate professional and community providers.

The Division of Special Health Care Program's continuing support of *Parent to Parent of Pennsylvania* enhances fulfillment of NPM #14 because parents of CSHCN will continue to administer and deliver program services and

provide input to Division policies and programs related to CSHCN. In addition, *Parent to Parent* addresses multiple priority needs and performance measures. Of particular note are the need for education and outreach (Priority Need #4), addressed by contact with parents of similarly affected CSHCN; the need for information and knowledge (Priority Need #5), which is shared by parents in matches as well as support groups; the need for access to services (Priority Need #7), which is facilitated by parents who communicate with each other as to the source of services for their children; and the need for ancillary services (Priority Need #6) which has been felt by a parent who has located services and a parent who has not been able to access those services. This program has also been able to eradicate the intense isolation felt by parents of CSHCN who are dealing with rare disorders and syndromes which segregate them from the general population.

The Division of Special Health Care Programs will continue its support of the *Ventilator Assisted Children/Home Program* in its efforts to address Priority Need #5 (need for care coordination) and Priority Need #6 (need for ancillary services). The Program provides professional and family education on the home care of ventilator dependent children, monitoring and quality assurance of home care provided to children enrolled in the Program, and coordination of medical and non-medical services required by ventilator dependent children living at home. The Program also provides respite care to the child's family caregivers. The enabling services provided by this Program contribute to NPM #2 (the degree to which the State CSHCN Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable).

Pennsylvania Law 1994-102 gave the Department expanded responsibility for heightening awareness to the need for organ and tissue needed for transplantation and the necessity for increasing participation in the voluntary contribution system. The Law established the Organ Donation Awareness Trust Fund and an Organ Donor Advisory Committee. The Law designated that up to ten percent of the Organ Donation Awareness Trust fund may be expended by the Department for the reimbursement of funeral expenses incurred by the donor or donor's family in connection with making a vital organ donation. The Organ Donor Advisory Committee recommended a plan to the Department as to how the reimbursement was to be implemented. Following extensive review of the ethical and legal implications of the plan, implementation will be delayed since it was determined that citizens might become subject to prosecution if the plan was found to be in violation of federal statute. The Division of Special Health Care Programs will continue to provide technical assistance to the Committee to develop an alternative pilot program for the Department to reimburse for incidental organ donation expenses incurred by organ donors and their families that will not conflict with federal statutes. Funding for the program is derived from contribution to the Organ Donation Awareness Trust Fund established by Pennsylvania Law 102. The program ultimately may benefit children and adults with special needs by heightening awareness to the need for organ and tissue needed for transplantation and the necessity for increasing participation in a voluntary contribution system.

Population-Based Services

Preventive and Primary Care Services for Pregnant Women, Infants, and Children

One of the major *Childhood Lead Poisoning Prevention Program (CLPPP)* initiatives for FFY 2001, will be the distribution of statewide childhood lead screening recommendations to pediatric health care providers throughout the Commonwealth. These recommendations, completed in FFY 99, were developed by an Ad Hoc Work Group of key stakeholders convened by the Department. They are based upon guidance provided in the Center for Disease Control and Prevention's (CDC's) updated statement (November 1997) entitled *Screening Young Children for Lead Poisoning: Guidance for State and Local Public Health Officials*. The recommendations designate all Pennsylvania zip codes as universal screening areas. This recommendation is based upon the amount of pre-1950 housing in the Commonwealth (80% of zip codes have >27% pre-1950 housing). In order to track the number of children screened, the *CLPPP* surveillance system will collect all blood lead levels from laboratories. The Department's main objective associated with the distribution of the screening recommendations, as outlined in *SP #02* established for this program will be to increase blood lead screening of one and two year old children throughout the Commonwealth.

A second major *CLPPP* initiative for this period, is the continuation of the United States Department of Housing and Urban Development (HUD) grant for the reduction of lead-based paint in properties occupied or expected to be occupied by low-income families with children under six years of age. Six communities at high-risk for childhood lead poisoning are participating in this project.

The Department will continue to provide comprehensive childhood lead poisoning prevention services in identified targeted high-risk areas of the Commonwealth through 11 Department of Health (DOH) funded-*CLPPP* projects as outlined in the Annual Report section of this Application. In non-*CLPPP* project areas these same services, exclusive of screening and environmental investigations, are provided by DOH District Field Staff. Environmental investigations (EIs) for non-*CLPPP* project areas are provided by DOH-funded *CLPPP* projects.

The Department will continue to work closely with the Department of Public Welfare (DPW) and the Mandatory Medicaid Managed Care Organizations (MCO) regarding the delivery of childhood lead poisoning prevention services and the collection of data. Reimbursement to the Department for EIs conducted by *CLPPP* projects in the homes of lead-poisoned Medicaid enrolled children is provided directly by DPW.

A statewide toll-free Lead Information Line (LIL) will continue to respond to citizen inquiries via the telephone and the distribution of educational materials. The Lead Abatement Training Center (LATC), operated in collaboration with the DPW, will continue to offer training at no cost to state and local government agencies and nonprofit organizations.

In addition to Title V funding and Medicaid reimbursement, the Department anticipates the continuation of funding for childhood poisoning prevention services from the Center for Disease Control and Prevention (CDC), HUD, and the United States Environmental Protection Agency (EPA).

The Division of School Health, which was integrated into the Bureau of Community Health Systems in 1997, completed a process of capacity building in 1998 to better serve the school age population by placing a full time School Health Consultant in each of the Department's six health district offices. This proved to be a very successful initiative, and these positions have become a permanent aspect of the health district complement. These positions will continue to be the point-of-contact, linking the State's 501 school districts with the Department of Health. Main responsibilities of these positions include: identify and prioritize school health needs; coordinate implementation of the Department's various program initiatives; provide information, consultation and technical assistance; monitor compliance with statutes, regulations, and policies; develop and implement quality assurance strategies at the local level; facilitate development of school health advisory teams; and assess needs for and provide education/training to school district personnel.

The Department of Health continues to prepare proposed revisions to the Health Services Section of the Public School Code. Written in 1949, Article 14 of the statute mandates specific health services to be provided to the Commonwealth's nearly 2.1 million children attending public, private, and parochial school. Those services include medical and dental examinations; health screens; nursing services, including treatment of acute and chronic conditions, first aid, emergency care, medication administration, health counseling; maintenance of student health records; and compliance with immunization requirements. The law also provides parameters under which school health programs must operate. The Department of Health has major responsibility for the administration of the program and provides partial reimbursement to the State's 501 school districts and nine comprehensive vocational technical schools. Regulatory authority also rests with the Department of Health.

Although various sections of the statute have been amended since 1949, the last being 1971, much of it is either inadequate for today's school setting, inflexible or represents outdated medical practice in serious need of updating and revision. It is expected that the proposed revisions will (1) redesign the school health program to be more in line with national comprehensive school health models, (2) enhance health care to students, including preventive health, by redefining and realigning the health requirements, (3) provide increased flexibility and creativity in how school districts deliver health services, and (4) improve the formula and process for reimbursement to school districts.

The Bureau of Community Health Systems' Division of School Health has taken the lead in moving this legislative initiative through an open, statewide participatory process to solicit input into the proposed changes. An Interagency Steering Committee with representation from the Departments of Health, Education, Public Welfare, and State (State Board of Nursing) reviewed the first draft. The Department also invited eighteen statewide

organizations representing such constituent groups as public and nonpublic school administrators, school boards, school nurses, professional nursing organizations, doctors, dentists and hygienists, parent/advocacy groups, students and county/municipal health departments to participate in a Stakeholder Work Group. During 1998, a focus group was held in each of the Department's six districts to solicit additional comment at the local level and the Department's Health Advisory Board reviewed the document. The Department of Health has had discussions with the Governor's Policy Office and Department of Education to reach consensus on proposed language. It is hoped that continued meetings will finalize language for legislative consideration.

The Division of School Health has identified an objective to provide ongoing educational opportunities for school nurses to meet the increasing challenges of today's student population. This will be accomplished via the inclusion of a school nurse track within the Department's biannual Public Health Institute. In May 2000, a six-day continuing education program "Excellence in Mental Health Nursing in the School Setting" will be offered. Additionally, regional school health updates and new nurse orientations are provided biannually.

Dental health has been identified as one of the priority needs in our FY 2001 needs assessment, it is increasingly clear that this is an area that requires our attention. Failure to prevent dental disease or provide timely and appropriate treatment can result in expensive treatment, missed school days, dysfunctional speech, and compromised nutrition, in addition to pain and suffering. With the assistance of the Oral Health Needs Assessment being conducted currently by the Department in conjunction with the University of Pittsburgh, the Department will be in a better position to understand the needs of Pennsylvania's children and what measures are required to address these needs. In addition, staff from the Department participated in the Dental Summit convened by Department of Public Welfare's (DPW's) Office of Medical Assistance Programs (OMAP) in May of 1999. We will continue to 1) encourage fluoridation of water systems at the community level and 2) work with the Bureau of Chronic Disease and Injury Prevention and OMAP as well as the Department of Insurance and City/County Health Departments during the coming year to address the dental needs of low-income children in Pennsylvania (NPM #07) and special needs children. Dental activities are currently carried out by city/county health departments based upon local needs assessments, and the Department's Maternal and Child Health (MCH) Consultants provide consultation at the community level on fluoridation.

During SFY2001, the Department will be changing the telephone numbers that coroners and citizens use regarding *Sudden Infant Death Syndrome (SIDS)*. In the recent past, the coroners have used an 800 number located at *our Healthy Babies/Healthy Kids Line* to report a possible *SIDS* death. Parents have called 1-877-PA-HEALTH for information and support. Both the coroners and families will use the PA Health number in the future. This will mean that staff in the Department's Bureau of Community Health who provide the direct services to families will also be directly receiving the reports of *SIDS* deaths from the coroners. We believe that this change will improve our statewide service system.

Again, there are great disparities in the rate of *SIDS* deaths between population groups. African-American babies die from *SIDS* much more frequently than White babies. In the coming year, we will expand education and outreach to minority communities regarding *SIDS*, with specific attention to Philadelphia and Pittsburgh. We will continue to promote the *Back To Sleep Campaign* (Priority Needs #1, 4 and 7).

Children with Special Health Care Needs

The Division's population based services are structured to meet the need to identify, educate, and provide outreach to the population of children with special health care needs (CSHCN) on the impact conditions will have on them and the services available to them (Priority Need #4) and the need for information and knowledge on the part of physicians to know more about the condition of CSHCN and families to obtain better information on their child's condition (Priority Need #5). This is consistent with Healthy People 2010 objective (#6-13), increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.

The Division maintains contractual relationships with several grantees that provide statewide outreach to individuals and families affected by specific conditions. Presently, the Department administers CSHCN condition-specific programs for epilepsy and Tourette syndrome support services. It is anticipated that the number of statewide, condition specific, outreach programs administered by the Department could grow to include outreach for high prevalence chronic conditions (e.g., pediatric asthma).

The Department's statewide epilepsy outreach and support service providers estimate that one in ten residents will have a single seizure in their life, and that up to one in every one hundred residents have epilepsy or seizure disorders. This illustrates the magnitude of the need for families and physicians statewide to be knowledgeable about this condition. Furthermore, the national epilepsy foundation estimates that, on average, an additional 15% of newborns every year will be diagnosed with a seizure disorder. Following the national trend, for Pennsylvania, this equates to an additional 2,000 children diagnosed next year with epilepsy, in addition to the 13,150 recurring child epilepsy cases currently receiving outreach and support services. These estimates suggest there will be a protracted need for the families of CSHCN, who are diagnosed with epilepsy, to become more knowledgeable about the condition and treatment modalities.

Another example of the significance of the priority need to educate families, schools administrators, employer groups, and providers about CSHCN is the gap in services provided to the estimated 100,000 individuals statewide who have Tourette syndrome. The Department's statewide contractor has indicated that only 3,100 individuals have been identified and provided support services to date, due to their limited outreach resources. Provider education initiatives may help reach individuals who require support services.

Over the five (5) year period beginning in 2000, each of the Department's service grantees will develop a work plan to increase physician and allied health care professional knowledge about specific special needs diagnoses. The goal is to facilitate improved community-based care plans and communications between providers and individuals diagnosed with specific health care needs and their families. This will be accomplished through a series of action steps. For example, condition-specific grantees will produce practical, printed educational "field" guides about a specific condition(s), typically with the support of their respective national offices. Thereafter, the grantees will implement a longitudinal plan to educate and update physicians and health care professionals (both specialists and general practitioners) about contemporary best practices and approaches to managing specific special health care conditions. The action steps to accomplish this will be varied and will include partnering with public and private agencies to accomplish meeting this priority goal. To illustrate, grantees will collaborate with the community health improvement partnerships throughout the State in order to include them in their education and outreach efforts targeted to physicians and health care professionals. Also, the grantees will collaborate with field staff located throughout the State in the Department's Health District offices. The goal is to inform them about condition specific best practices and to help them integrate and disseminate CSHCN information to health care professionals in their catchment area.

The Division of Special Health Care Programs has taken an active role in increasing the number of healthcare agencies, hospitals, managed care organizations, and private/public partnerships who are actively engaged in condition-specific prevention strategies. These strategies include folic acid awareness promotion to reduce the incidence and statewide prevalence of neural tube birth defects. The Division has identified three areas of prevention that it continues to address in its day-to-day activities with providers and constituents:

1. Primary Prevention – e.g. folic acid/spina bifida; genetic counseling/birth defects;
2. Secondary Prevention – minimizing the complications of an existing condition/special need; and
3. Safety – avoiding injury/accidents, e.g. helmets, hot water regulators, and in-house safety practices.

These initiatives address *SP #6* (improve the Division's participation in prevention initiatives). The primary measures that will be used to track outcomes of prevention related activities are those that help quantify a change in the incidence of individuals diagnosed with specific special needs, a change in the occurrence of preventable conditions, and/or reducing the risk of future complications of existing conditions. In lieu of a mandated birth defects registry, the baseline to track prevention-related outcomes will be provided by the Division's medical program providers, managed care organizations, county and municipal health departments, and health care agencies that incorporate prevention-related initiatives into their daily agenda. Finally, the Division intends to utilize data from our needs assessment, the *Special Kids Network*, and other internal databases to help understand the impact of prevention related strategies.

The referenced activities will be measured through *SP #6* (degree of improvement in the Division of Special Health Care Programs participation in prevention initiatives that impact conditions and complications affecting CSHCN), *SP #11* (percent of increase in families of CSHCN awareness of services Title V CSHCN), and *SP #10* (the degree to which the State assures that contractors provide care coordination with primary care physicians).

Screening of newborns ensures prompt diagnosis, assessment and treatment of conditions to prevent severe mental retardation, serious medical conditions and death. In recent years, scientific technological advancements have enabled testing of newborns for additional diseases and conditions. Pennsylvania will expand its program to include galactosemia and congenital adrenal hyperlasia during the coming year. Thereafter, policy options will be explored as they relate to further expansion of the program (NPM #4).

The Bureau of Family Health will continue a universal newborn hearing screening demonstration project this year. This is in relation to Priority Need #4 (need to identify the population with special health care needs, educate them and their families as to the impact conditions will have on them, and provide outreach for information on available services). The purpose of the demonstration project is to determine the guidelines and protocols required for a statewide universal newborn hearing screening and tracking system, in order to assure that every baby screened for hearing loss receives timely follow-up and intervention based on screening results. Twenty-seven hospitals are participating in this project. At the end of the second year of the demonstration project, the data will be analyzed to determine if every baby screened for hearing loss received timely follow-up and intervention. Also, after the data analysis, recommendations will be made regarding the possible development of a statewide uniform newborn hearing screening program (NPM #10).

Infrastructure Building Services

Preventive and Primary Care Services for Pregnant Women, Infants, and Children

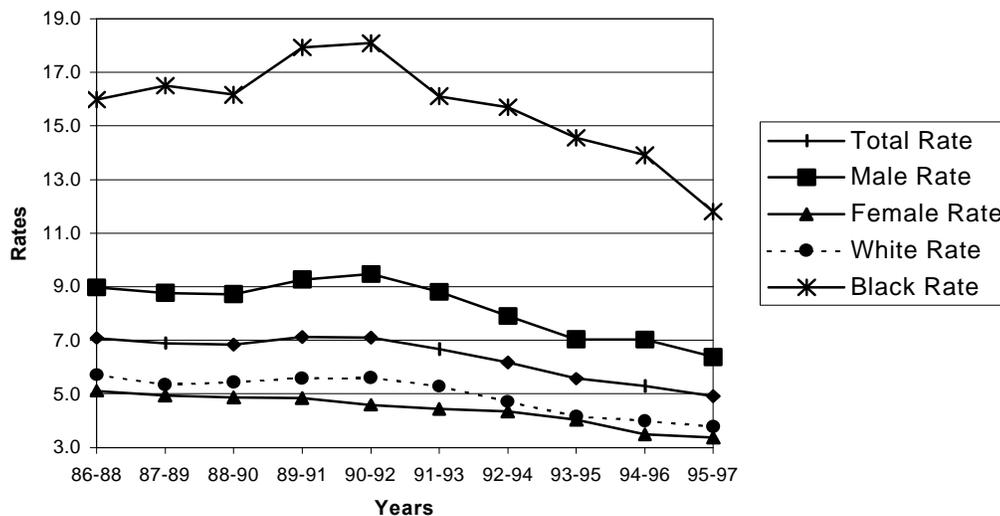
The Department will continue to work in partnership with the Pennsylvania SAFE KIDS Coalition to promote awareness among health professionals and caregivers that injuries are the leading health threat facing children and to foster efforts to reduce those risks. The Coalition will continue community-based injury prevention activities through support of existing coalitions and the development of at least one additional coalition. Additionally, the Department will continue to collaborate with the Pennsylvania Department of Transportation, which provides funding for activities to reduce motor vehicle deaths.

Pennsylvania SAFE KIDS will provide unintentional injury educational programming for children 14 years and under. Mini-grants will continue to be provided to SAFE KIDS coalitions and chapters to conduct bicycle and fire safety educational programs to low income families. Bicycle helmets and smoke alarms will be purchased and provided to children and families during the program. Through its General Motors Buckle Up Program, Pennsylvania SAFE KIDS will conduct car safety seat checks and provide child safety seats to families across the Commonwealth. Intentional injuries will also continue to be addressed through the Violence-Free Youth Challenge

supported with funds from the Prevention Block Grant. This campaign is an initiative to prevent youth violence. This wide range of activities will address *NPM #08*, rate of deaths to children aged one through fourteen caused by motor vehicle crashes, and *OM #06*, the child death rate for children aged 1-14.

Title V funds will continue to support Maternal and Child Health (MCH) Consultant positions in each of the six (6) District Offices. The MCH Consultants are a valuable resource to communities in their respective districts by 1) monitoring service delivery and providing technical assistance to entities under contract to the Department; 2) promoting information regarding the Department’s State Health Improvement Plan (SHIP) initiative; 3) assisting with service linkages at the community level; and 4) providing information on current standards and best practices to providers serving the maternal and child health population. The consultants have a major role in the implementation and expansion of child death review, serving as and training health care consultants for the *Early Childhood Education Linkage System (ECELS) program*, monitoring of and technical assistance to community-based *Abstinence Education and Related Services (AERS)* projects, consultation at the community level on fluoridation,

**Unintentional Injury Deaths Among Youth Aged 0-14
Number and Three-Year Average Annual Rates*
Pennsylvania Residents, 1986-1997**



local injury prevention programs, and follow-up for lead poisoning (*SP #02*). Beginning in FY 2001, the MCH Consultants will participate with MCH staff in joint monitoring site visits at the City/County Health Departments.

The Department will continue to work with the Pennsylvania Chapter, American Academy of Pediatrics (PA AAP) and the Department of Public Welfare (DPW) in the development and maintenance of the *Early Childhood Education Linkage System (ECELS) Program* with plans to increase and support the linkage of health care consultants to child care providers demonstrating a need. Efforts will be made to utilize child care health data collected using ECELS TRAK Software to identify areas of need and highlight areas of success (*NPM #05* and

SP #3). *SP#3* will no longer be used to reflect our achievements in ECELS because it proved to be unmeasurable. *SP #3* will replace it because (1) vision screening is measurable through ECELSTRAK, and (2) vision screening will serve as an indicator of whether these children are receiving age appropriate screening services. With this information, we can provide technical assistance to the child care centers to ensure that children have access to, are referred for, and receive required preventive health services.

In collaboration with DPW and the PA AAP, the Department will expand child death review in Pennsylvania by increasing the number of local child death review (CDR) teams. Activities will include: training and technical assistance for local team development; monitoring of outcome of local CDR teams; publication of an annual report; proposals for necessary law, regulatory, or policy changes through appropriate state entities; and prevention efforts at the state and local levels to replace the number and causes of preventable child deaths in Pennsylvania. To date, CDR has been a highly successful initiative in terms of its growth. Efforts will be made to evaluate the impacts of CDR, identify needed changes and to implement them to ensure the continued success of this initiative (*NPM #08* and *OM #6*).

The Division of Maternal and Child Health Programs is planning to expand the current Child Death Review Process which is contractually administered by the Pennsylvania Chapter of the American Academy of Pediatrics (PA AAP) to incorporate elements of the national Fetal Infant Mortality Review (FIMR) model and to consider the review of Maternal Mortality cases. We believe this will be particularly useful in addressing the differentials/disparities in infant mortality across communities or in racial and ethnic groups. It will also provide local communities with better information on the effectiveness of existing service delivery systems and to strategize locally on better policies for women, infants and families in their community. To accomplish this, we will develop a short range plan that includes, but is not limited to: 1) providing local teams with birth records for all infant deaths in addition to the death certificate they currently review, 2) exploring the expansion of our current contractual efforts with the PA AAP to include collaborative efforts with professionals and/or organizations that deliver perinatal care, 3) implementing a pilot project with a local CDRT that incorporates the national FIMR model, and 4) expanding our community partnership outreach efforts to gain their support in elevating fetal and infant mortality as priority issues in their community planning and prevention efforts. At the same time, a long term plan will be developed to identify strategies needed to accomplish implementation of a comprehensive review of fetal, infant, child and maternal deaths, and continually assess the services systems and resources to ensure the quality of services provided at the state and local levels. The initiative will address *OM #1, 2, 3, 4, 5* and *6*.

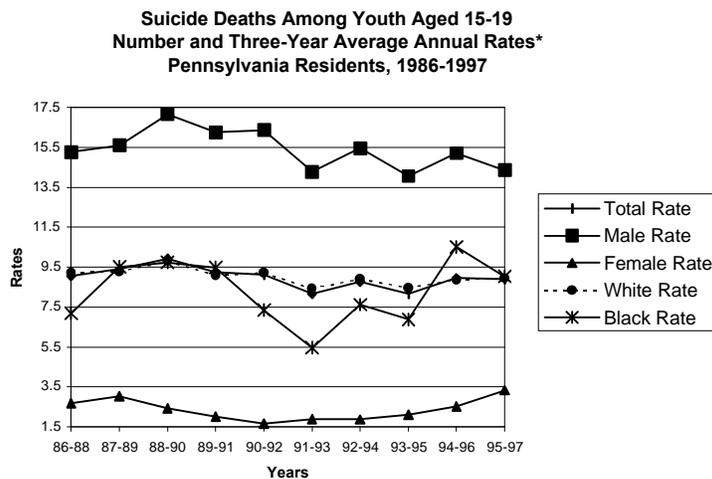
The Department, through a contract with the PA AAP, has developed a statewide self-help training program entitled: "Clean Air for Healthy Children" (CAFHC), a smoking cessation initiative for pregnant women and the parents of young children and teens. CAFHC strives to improve the smoking cessation counseling and education practices of health care providers in Pennsylvania by encouraging them to incorporate smoking cessation and counseling in their services and programs. As a state-of-the-art program, it has received considerable national recognition for meeting

the United States Agency for Health Care Policy and Research Clinical Practice Guidelines on Smoking Cessation 1996. Staff in the Department's Bureau of Community Health Systems are trained to conduct local training to providers and are involved in recruiting providers to participate in the program. In FY 2000, oversight for CAFHC was transferred to Bureau of Health Chronic Diseases and Injury Prevention. Future plans include program expansion, with the support of tobacco settlement.

Asthma in children has been identified as a new priority need for FY 2001. An Interagency Work Group will be convened to develop baseline data and to explore activities currently being carried out to address this need. Parties to be convened include but are not limited to: the Bureau's of Community Health Systems, Chronic Diseases and Injury Prevention, and Environmental Health Assessment, the Department of Public Welfare, and the American Lung Association.

Obesity in children has also been identified as a new priority need for FY 2001. This too is an area where Intra-Agency Work Group activity will be pursued to develop possible strategies to address this area of need. Key to this Work Group will be the involvement of the Department's Women, Infants and Children (WIC) program and the Bureau of Chronic Diseases and Injury Prevention. Dietary information is provided to parents of young children and the *Early Childhood Education Linkage System (ECELS) program* provides dietary information to child care providers.

Although the numbers of youth suicides are low, this is an area that is currently not at all addressed with Maternal and Child Health Block Grant funds and is not being addressed in an interagency manner. It has been identified as a priority for FY 2001. Plans are to create an Interagency Work Group with representatives from the Department's of Health, Public Welfare, Education, the Governor's Project for Community Building, and the Pennsylvania Partnerships for Children. The purpose of the Work Group will be to explore the subject of youth suicide and possible strategies to address this area of need (NPM #16).



Smoking, and drug and alcohol related problems are common among adolescents. Both alcohol and drugs are associated with a number of dangerous behaviors (drinking and driving, poor school attendance, theft, and violence). These adolescent high-risk behaviors were identified as a priority need. Activities targeted to youth tobacco, drug, and alcohol use are carried out by the Bureau's of Chronic Disease and Injury Prevention and Drug and Alcohol Programs respectively. A recommendation will be made to target Tobacco Settlement Funds to address this need if the Governor's plan is adopted.

Access to quality care is important to eliminate health disparities and increase the quality and years of life for all citizens. A significant component of the access problem is the lack of health insurance. There remain children who are eligible but not enrolled in Medical Assistance (MA) or the *Children's Health Insurance Program (CHIP)*. We will continue to collaborate with the Departments of Insurance and Public Welfare in a media outreach campaign to increase enrollment (NPM #12 and 13). The Department's *Healthy Baby/Healthy Kids (HB/HK) Helplines* serve as the common telephone numbers identified to callers in all advertising for assistance with MA and *CHIP* enrollment.

In the coming year, we will be dedicating additional resources to outreach for the hard to reach Hispanic population(s) through the *Love 'em With a Check-up* Campaign. This is in line with our desire to reduce disparities in perinatal health outcomes. To insure that this outreach is effective, we conducted research on the changing and growing Hispanic populations within Pennsylvania during the past year. The Hispanic population is changing within the state. While in 1990, virtually the entire Hispanic population was Puerto Rican, in 2000, diversity within the resident Hispanic population has come to Pennsylvania. Our Hispanic population now includes significant numbers of Mexicans, South Americans, Cubans as well as Puerto Ricans. The research indicates that there is feeling of helplessness and disenfranchisement within the Hispanic Community. There is a general distrust of many public and private organizations, including the Managed Care/Health Maintenance organizations.

New outreach materials, including television commercials, will be developed based upon the finding of the research. We will need to incorporate cultural sensitivity into the materials, not simply the translation of health messages. We will need to involve/engage the Hispanic community in getting these messages out and accepted in the communities. Utilization of Hispanic community organizations will be key to our success. The messages have to be targeted both regionally and by ethnicity.

Children with Special Health Care Needs

The Division of Special Health Care Programs (SHCP) continues to implement as well as improve initiatives which target many of the State's Priority Needs. These programs and initiatives include the *Special Kids Network*, the Division's eligibility and referral efforts (to Medical Assistance and the *Children's Health Insurance Program*), the Division's Inter-Agency Coordination initiatives, Regional Action Teams, increasing the role of Special Health Care Needs Consultants, collaboration with Shriners Hospital Private/Public Partnership (CHOICES), and participation in the Department's State Health Improvement Partnerships (SHIP).

The *Special Kids Network* is a Division program that provides the infrastructure and program capacity from which many linkages have been made in the community with public and private agencies. The information and referral staff of the Network respond directly to callers to the Network's 800 number who are seeking specific services. Trained information specialists access a comprehensive database containing over 8,000 service providers to assist families in making connections to needed services. Callers who indicate they are underinsured or have no insurance are quickly transferred to the Department's *Healthy Baby/Healthy Kids line*. Periodic training on the *Children's Health Insurance Program (CHIP)* and Medical Assistance (MA) for the various Division program staff and Division contractors is being developed to maintain a sufficient level of understanding of these insurance programs. An assessment of the entire referral process will be conducted to determine if families who are underinsured or have no insurance are being identified and when they are, is their need for insurance being met. In addition, the database has been revised to improve identification of individual's insurance status leading to improved referrals. This function will address the need to remove the financial hardships of having a CSHCN, particularly hardships of paying for medical and non-medical expenses and out-of-pocket supplies (Priority Need # 7). The appropriate performance measurement is NPM #11 (percent of Children with Special Health Care Needs in the State CSHCN Program with a source of insurance for primary and specialty care).

The Division is seeking accreditation of the Special Kids Network from the Alliance of Information and Referral Systems (AIRS). The purpose of engaging in the accreditation process is to ensure that the Network is operating according to nationally accepted standards for information and referral systems. The accreditation process will involve a review of staff qualifications, data collection and utilization procedures, and telephone protocols, among others.

The *Special Kids Network (SKN)* is a rich repository of caller and provider data which is used in needs assessments. Through the caller database, we can identify the needs most frequently expressed; utilizing the provider database, providers can be identified by the type of service(s) they offer and their geographical location (county, zip code) in Pennsylvania. An analysis of this data will help to determine where specific types of services are and are not available. Armed with that information, the Department will be better able to effectively target resources to those areas of the State in need of services. Special Health Care Needs Consultants in our District Offices provide the link between the *SKN* data and the community health partnerships and the State Health Improvement Partnership (SHIP) process.

The Division's Community Systems Development initiative, as implemented through the *Special Kids Network* is designed to take collected needs assessment data back to local communities to solve local problems. At present, it is focused on three issues of paramount importance to parents of CSHCN: respite care, dental care, and transportation. This focus is consistent with the need for ancillary services (Priority Need # 6). During the upcoming year, staff from each *Special Kids Network* region in collaboration with the Special Health Care Needs consultants will form

coalitions to address the issues of respite care and dental care. A plan will be devised in the first half of the year to address each of these issues. This will be an effort to establish a long-term mechanism for providing these services to CSHCN on a statewide basis. When a plan to address one of these two issues is implemented, transportation will be adopted as the next initiative. The Division's Community Systems Development initiative addresses all six priority needs in their execution, as well as making contributions to performance measures. SP #4 is improved by engaging the community in activities that promote awareness of the needs of children with certain conditions while informing the community of services that are available or potentially available to CSHCN. SP #6 (the percent of CSHCN who have appropriate medical care and care coordination) is enhanced by filling gaps in services through analysis of Network data as well as other data collected from the community. NPM #2 is bolstered by the facilitation of the provision of services previously unavailable in each region. NPM #3 (percent of children who have a medical home) is improved by the location of family-centered services, which care for CSHCN. NPM #14 is enhanced by the inclusion of parents of CSHCN in any coalition, regional or statewide, working with the Network.

Statewide media campaigns (TV, radio, print ads) for the Network consistently demonstrate an increase in awareness of our services as indicated by increased call volume. We are shifting outreach activities and resources to a ratio of 75% media to 25% grass roots outreach. Some of Pennsylvania's rural areas are under-represented when caller data is analyzed. A classified ad campaign in rural newspapers and weekly shopping guides is planned to improve utilization of Network services by the rural population. Production of radio and TV outreach will continue to include input from parents and providers to ensure the message is on target and will generate the greatest awareness possible of services. The current marketing firm responsible for outreach hired parents of children with special needs to consult on all aspects of production, from script review to on-site input on the day of commercial shooting. Any future marketing contractor will be required to involve parents of children with special needs in the development of outreach materials.

The Division of Special Health Care Programs has embarked on an initiative to conduct a program evaluation of the *Special Kids Network*. The purpose of the evaluation is to determine what impact the Network is having on the consumers it is purported to serve. The outcome of the evaluation will guide the future development of the Network and ensure that a roadmap is in place to provide the best possible service to consumers. The evaluation will influence future Requests for Proposals and subsequent contracts.

The Division also has laid the foundation for the establishment of a toll-free recreation and leisure helpline. The new information and referral line is a statewide, cross-age, cross-disability information and referral line for individuals seeking recreation and leisure resources. Maintained as a separate and distinct line from the *SKN* 800-number, the new line will take advantage of the existing infrastructure of the *SKN*. Most beneficial to the development of the recreation and leisure line was input from a stakeholder group of nearly 80 representatives (including parents of CSHCN) in the field of recreation and leisure. Stakeholder input contributes to NPM #14 (degree to which the State assures family participation in program and policy activities in the State CSHCN

program). Further development will continue through early 2000 with calls to the new line anticipated in the spring of 2000.

The Division is moving forward with plans to create a web site. Accessibility to resource information has been an issue for physicians, parents and other professionals working with children with special needs. Initially, the web site will provide access to information about 8,000 different services that is currently available only by calling the *Special Kids Network*. The web site name will be included on all Network promotional materials, including TV and radio advertising. Contractors will be required to link their web sites to the Network's web site. Future plans include online updating of the Agency Database, opportunities to perform online surveys of consumers, special needs bulletin boards, etc. The web site will address the need for information and knowledge on the part of physicians to know more about the condition of CSHCN and families to obtain better information on their child's condition and the need for care coordination for CSHCN (Priority Need #5). The appropriate performance measurement is SP #11 (percent of increase in families of CSHCN awareness of services for Title V CSHCN).

The Department of Health in collaboration with the Departments of Aging, Education, Labor and Industry, and Public Welfare will be working with the Governor's Policy Office, specifically the Office of Information Technology, as part of the Governor's Disability Agenda. The goal is to eliminate barriers so all persons with disabilities are afforded the opportunity to be as productive as possible, and allow them to fully participate in work, family, and recreational opportunities. Consistent with this goal, the interagency workgroup will develop a web-site or "portal" that provides one stop access to consistent information about Pennsylvania programs and services for individuals with disabilities. This single site, providing access to any and all information on programs offered and services provided by Commonwealth agencies, will promote independence and quality of life for those living with disabilities. Initially, the Special Kids Network and Medical Payment Programs for CSHCN will be included on the web-site.

The Division of Special Health Care Programs and the Bureau of Community Health annually collaborate in the development of Integration Plans to support the implementation of CSHCN programs at the community level. For example, one objective of the Integration Plan is the development of a limited case management/care coordination program whereby callers identified by the *Special Kids Network*, *Family Consultants*, physicians, providers, schools, etc., as being in need of specific, face-to-face assistance would be referred to the Special Health Care Needs Consultants in our District Offices. The Consultants would assess callers needs and determine an appropriate course of action which may include a home visit. This new program will enable more families to access available resources. The referrals to the Bureau of Community Health Systems and Special Health Care Needs Consultants will address the need for families to obtain better information on their child's condition and the need for care coordination for CSHCN (Priority Need #5). The appropriate performance measurement is SP #6 (percent of improvement in the Division of Special Health Care Programs participation in prevention initiatives that impact conditions and complications affecting CSHCN).

Since the Department's Bureau of Community Health Systems is responsible for the Statewide Health Improvement Planning (SHIP) process, the Division will continue to focus responsibility for local needs assessment, community development, and community-based planning on the Special Health Care Needs Consultants in our District Offices. The consultants will continue to assess regional issues and work with inter-agency contacts and coalitions to find solutions and facilitate the enhancement of service delivery. The consultants will continue to assume the leadership role in coordinating such community systems development activities of local planning partnerships, the *Special Kids Network*, Regional Action Teams, and District Offices as they relate to CSHCN. The consultants are the Division's representatives in each of the Department's six regions. They provide community input into Division statewide plans and program development.

The Regional Action Teams referred to above include staff from the Department's District Offices, Division staff, providers, other agencies, and parents of CSHCN. The purpose of the Team is to meet both regionally and statewide to share activities and common goals; discuss overarching issues and gaps in the service system for CSHCN; make recommendations to the Division of Special Health Care Programs; and provide information about Title V/CSHCN services back to local communities and constituents. Through funding from a State System Development Initiative (SSDI) Federal Grant, the Division of SHCP will provide reimbursement for up to three parents per team for expenses such as travel, meals, lodging and child care incurred when attending the Team meetings. The Regional Action Teams will be linked with local health improvement partnerships to coordinate resources at the local level. This will be achieved through invitation and active participation of representatives of local health improvement partnerships in Regional Action Team meetings and the mutual exchange of information.

As noted, Special Health Care Need Consultants in each of the six Health District Offices are responsible for a variety of issues with respect to services for CSHCN. Several of the Department's population-based statewide grantees have limited personnel and funding to provide comprehensive outreach and support services to CSHCN in under-served and rural areas. The Consultants have begun filling in the gaps for the epilepsy and Tourette syndrome grantees by referring CSHCN and other individuals to condition-specific grantees for support services and resource referrals. Over time, the grantees expect to reach more CSHCN in the under-served areas, link them to appropriate services, and help assure care coordination.

The regional activities referenced above are designed to address the need for information and knowledge on the part of physicians to know more about the condition of CSHCN and families to obtain better information on their child's condition (Priority Need #5). The appropriate performance measurements are NPM #14 (assure family participation in program and policy activities of the state CSHCN Program), and SP #11 (percent of increase in families of CSHCN awareness of services provided by Title V for CSHCN).

Working in collaboration with the National Organization of Rare Diseases (NORD), other Department offices, the Pennsylvania Chapter of the Academy of Pediatrics, and the Pennsylvania Medical Society, the Division of Special Health Care Programs will produce disease/condition specific fact sheets to address Pennsylvania Performance Measure #5. Fact sheets will also be developed for each Division program and become part of general information packets to include brochures and posters. A distribution and fulfillment plan will be developed to ensure the information reaches the target audiences of physicians, families, and public and private agencies. As part of the distribution plan, the Division will require that contractors distribute the information packets.

The Division has developed initiatives to ensure access to appropriate primary and specialty care and care coordination services. They address the need for care coordination for CSHCN both to insure adequate contact between the primary care physician and specialists and effective communication between them (Priority Need #5) and the need to remove access to services barriers which particularly pertain to lack of reliable transportation, long distances to specialists, and difficulty in obtaining services because of social, ethnic, and special needs condition (Priority Need #7). These initiatives, which address Healthy People 2010 objective (#1-5), increase the proportion of persons with a usual primary care provider, are described below.

The Division of Special Health Care Programs began to take steps in 1999 to ensure children with special health care needs enrolled in managed care plans have a medical home that provides quality medical and non-medically related care that is accessible, family-centered, comprehensive, continuous, coordinated, compassionate and culturally competent that is responsive to needs of the children and their families. The ideal source of a medical home for CSHCN in managed care is a primary care pediatrician or pediatric sub-specialist who is knowledgeable of the needs of CSHCN and their family, knowledgeable of available resources to meet those needs, and works in partnership with the child's parents to ensure the needs are met.

The Division began promoting training of the medical home concept for CSHCN to managed care organizations by participating in planning meetings conducted by the American Academy of Pediatrics and the Shriners Hospital for Children. The outcome of this project is the development of Pennsylvania's edition of a nationwide "Train-the-Trainer" program for physicians, health care professionals and families of CSHCN entitled "Every Child Deserves a Medical Home." This nationwide initiative funded by a grant from the federal Bureau of Maternal and Child Health is a joint effort of the American Academy of Pediatrics, National Association of Children's Hospitals and Related Institutions, Family Voices, and Shriners Hospitals for Children.

The first Pennsylvania training program was conducted at the Philadelphia Shriners Hospital for Children in March 2000. The Division will continue to promote the medical home concept for CSHCN to managed care organizations by supporting replication of the initial "Every Child Deserves a Medical Home" training program in other areas of the State. This initiative will address Priority Needs #5, #7, and #9 (information/knowledge, coordination of care, and enhance workforce competencies). This continued support will contribute toward NPM #3 (the percent of

CSHCN in the state who have a medical/health home), SP #12, (percent of CSHCN, who have access to specialists), and Healthy People 2010 objective (#16-22), increase the proportion of CSHCN who have a medical home.

The Division of Special Health Care Programs has a private/public partnership with the Shriners Hospitals for children known as CHOICES (Children's Healthcare Options Improved through Collaborative Efforts and Services). The Division of Special Health Care Programs provides an information and referral linkage through the Division's *Special Kids Network* for Shriners Hospitals CHOICES care coordinators to access coordinated, community-based services for Pennsylvania children and adolescents with special needs following discharge from Shriners Hospitals. The linkage promotes the use of local service providers for the Shriners Hospital patients' follow-up care in the patient's home community rather than returning long distances to the Shriners Hospital. The Shriners Hospitals for Children are also listed in *the Special Kids Network* provider database as a resource for families, physicians and providers of services who may require information about services available to CSHCN. The Division of Special Health Care Programs will continue its support of the CHOICE Program to address the Priority Need #5 (need for coordination of care), and will be measured by NPM #2 (the degree to which the State CSHCN Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable), and NPM #3 (the percent of CSHCN in the State who have a medical/health home).

Beginning in late 1999, the Division of Special Health Care Programs began taking action to address access to care issues, especially as it relates to care for children with special health care needs (CHSCN) in under-served areas. The Division surveyed all of the licensed acute care hospitals (excluding hospitals with which the Department already has a contract, and rehabilitation, veteran's administration and other governmental hospitals). The purpose of this survey was to determine their interests in and their capability to serve CSHCN in a regional setting versus a designated multi-disciplinary clinic. This is important, since distance to specialty services is a major problem for many families of CSHCN, particularly when several visits over the course of a year may be necessary. During the first phase, the Division hopes to arrive at some conclusions about the potential for certain hospitals to serve condition-specific CSHCN in underserved and rural areas, i.e., facilities with appropriate professional staff, equipment, etc. Another opportunity will be to investigate the potential for local hospitals to collaborate with "Centers of Excellence," multi-disciplinary hospitals that serve CSHCN patients. Over the long-term, it is expected that the Department will be able to improve access to services for CSHCN and identifying additional service endpoints for CSHCN as part of the Department's State Health Improvement Plan (SHIP).

The referenced activities, which are targeted to improve access to care for families with CSHCN, will be measured by NPM #3 (percent of CSHCN in the State who have a medical/health home) and SP #12 (percent of CSHCN who have access to specialists).

The Division of Special Health Care Programs has engaged in several Inter-Agency collaborative efforts which will help to address multiple priority needs, particularly the need to remove access to services barriers which pertain to

lack of reliable transportation, long distances to specialists, and difficulty in obtaining services because of social, ethnic, and special needs condition (Priority Need #6).

The Division of Special Health Care Programs continues to expand its role in strengthening the CSHCN infrastructure by providing technical assistance, consultation, and education to a variety of public and private programs and agencies that deal with CSHCN. We will continue to provide technical assistance to the State and Local Interagency Coordinating Councils which provide an excellent forum for family input in advising and assisting state agencies by making recommendations to the Departments of Health, Education, and Public Welfare about the implementation and maintenance of the Statewide Early Intervention System, its sources of fiscal and other support from federal, state, local, and private sources, and personnel issues, including provision of in-service training. In addition, Division staff continue to participate in monthly Early Intervention Technical Assistance (EITA) meetings to exchange information and to assure coordination among programs. EITA Consultants assist agencies to provide family-centered supports and services in natural environments and inclusive settings. This activity will be measured by NPM #14 (assure family participation in program and policy activities of the state CSHCN Program).

The Department will continue its initiative related to the Memorandum of Understanding (MOU) with the Department of Public Welfare which has accountability for administering Medical Assistance (MA) and MA managed care programs. The MOU delineates specific program responsibilities for the Departments related to monitoring, evaluation and fiscal areas.

The Division of Special Health Care Programs will continue to provide technical assistance to the Child Death Review Team at both the state and local level. Division staff provides technical assistance on the statewide Team related to the review of cause of death of CSHCN to determine if there is any prevention measures that can and should be implemented. At the local level, increased participation by Special Health Care Needs Consultants will improve the ability of local Teams to address issues facing CSHCN. This activity will be measured by SP #4 (participation in prevention initiatives).

The Division of Special Health Care Programs contracts with the Philadelphia Department of Public Health to support needs assessment, planning, implementation, and evaluation of community-based services for CSHCN and to collaborate with the Division to link systems of services for CSHCN and their families within the City of Philadelphia. The Division of Special Health Care Programs will continue to support the Philadelphia Department of Public Health to identify and meet the needs of CSHCN in the City of Philadelphia. The Division plans to expand support to other county and municipal health departments as those needs are identified through local needs assessments. This support and assistance is consistent with addressing Priority Need #5 (information/knowledge, coordination of care), and Priority Need #7 (access to affordable health care services). By continuing support to county and municipal health departments, the Division's activities will be measured by NPM #2 (degree state

CSHCN pays for speciality and subspeciality case), NPM #3 (CSHCN with a medical home), SP #11 (families increased awareness of services) and SP #12 (increase in access to specialty care).

The Division recognizes the importance of developing mechanisms to include families of CSHCN in program planning, and program implementation. This will be accomplished through family input in existing programs and related collaborative activities such as the Maternal and Child Health (MCH) Advisory Council, participation in Regional Action Teams, MCH Block Grant planning and preparation, monitoring, surveys, focus groups, etc. Initiatives relating to adolescent health care issues and transition to adulthood services will be incorporated in the planning discussions.

The Maternal and Child Health Advisory Council was created to provide advice on Department services to families, mothers and women of childbearing age, children and youth, and CSHCN. Membership consists of persons representing service providers, families, and service recipients of the ethnic and geographic diversity of the State. The Division of Special Health Care Programs provides information and assistance to the MCH Advisory Council regarding the programs, initiatives, and services it promotes or supports for children and adults with special needs and their families. A sub-committee of the Advisory Council works closely with the Division providing input and recommendations regarding Division's programs, needs assessment activities, and Block Grant planning and preparation.

By continuing its interaction with the Maternal and Child Health Advisory Council, the Division will continue to address Priority Need #5, by acquiring information about the needs of CSHCN and sharing information on programs, initiatives, and services available through the State Title V Agency for CSHCN. Continued collaboration between the MCH Advisory Council and the Division will contribute toward NPM #14 (the degree to which the State assures family participation in program and policy activities in the State CSHCN Program) and SP #5 (percent of increase in physicians, providers, and public and private agencies knowledge of specific conditions and services for Title V CSHCN).

As noted before, the Division of Special Health Care Programs will provide reimbursement for parents for expenses such as travel, meals, lodging and child care incurred when attending the Regional Action Team meetings, through funding from a State System Development Initiative (SSDI) Federal Grant. The goals are to focus needs assessment at the community level through community-based planning, including family input. Also to develop and enhance database files for future needs assessment activities. These family participation activities are measured by NPM #14 (ensure family participation in program and policy activities of state CSHCN program) and SP #11 (increase in families of CSHCN awareness of services provided by Title V for CSHCN).

The enrollment of eligible children with special health care needs into either Medical Assistance (MA) or the *Children's Health Insurance Program (CHIP)* is a broad Commonwealth initiative. There are an estimated 258,000

children in the Commonwealth without health insurance coverage who are eligible for either medical assistance (MA) or the *Children's Health Insurance Program (CHIP)*. As part of its goal to address Priority Need #6 (improved interagency coordination), the Division has stepped up its efforts to facilitate referrals to appropriate agencies for client enrollment in MA (including individuals receiving Supplemental Security Income (SSI)) or *CHIP*. The SSI eligibility/referral activities are measured by NPM #1 (the percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State (CSHCN Program)). In addition to the referenced *Special Kids Network* initiatives, other initiatives will drive improving NPM #11 (percent of (CSHCN) in the State Program with a source of insurance for primary and specialty care), including coordination of MA and *CHIP* eligibility/enrollment activities implemented by Department of Public Welfare and the Department of Insurance. Also, the Division intends to collaborate with State Health Improvement Partnerships, Department contracted providers, and others whose daily activities directly involve CSHCN. Beginning in SFY 2001-2002, contracted providers will be required to assure the Division that insurance eligibility outreach has been performed as a component of every encounter with a special needs client served directly or indirectly through State CSHCN programs.

Like many state Title V agencies, Pennsylvania understands unmet need for respite care for CSHCN and is aware of the resource limitations that prevent development of a comprehensive respite care program. However, medically fragile CSHCN who are ventilator dependent have had access to a limited state-funded respite care program. This home-based program allows eligible families to have access to additional skilled nursing care for their ventilator dependent child over and above the skilled care provided through MA. According to families, this supplemental respite care model has been of benefit. The Department is also aware that some CSHCN, whose primary diagnosis is a mental disorder, may be eligible and be receiving respite care through the Mental Health/Mental Retardation (MH/MR) Office of the Department of Public Welfare. The Division's Community Systems Development initiative has fostered the organization of productive respite care coalitions in Southwestern Pennsylvania. In at least one county, respite services and after-school drop-off have been implemented as community-generated activities. This is in addition to the statewide respite care initiative, which will involve community partnerships, including the statewide respite coalition, to create a statewide community-based approach to the provision of respite care. It is hoped that through this initiative, which will be planned on a statewide basis, communities will find local solutions to funding respite care. In the future, the Department will continue to explore respite care program opportunities for other CSHCN as a response to the need for ancillary services such as respite care, mental health care services, and dental care (Priority Need #6).

The Division of Special Health Care Programs continues to improve the infrastructure to support needs assessment, health status indicators and performance measures. This is evidenced by our continued enhancement of our automated data system and our improved capacity to collect and report data and information. Efforts will be made to compile, link, integrate and improve the accessibility of data for use at the regional, state and local levels. For example, the linkage of data such as birth and death files; immunization; Medicaid; Women, Infants and Children

(WIC) and hospital discharge and emergency room information could improve the identification and location of emerging issues, gaps in the provision of services and the assessment of strengths and weaknesses in service delivery amount sub-groups. The expanded information systems also will improve monitoring and tracking of CSHCN sub-populations (i.e., adolescents and SSI). The data will be used for program planning as well as for monitoring improvements in health status at the state and local levels.

Due to the importance of surveys as a means to obtain relevant CSHCN information and data, the Division will evaluate various survey instruments to use for program evaluation and needs assessment. These include the Questionnaire for Identifying Children with Chronic Conditions (QuICCC), Family Voices (Your Voices Count), and survey tools developed by The Foundation for Accountability (FACCT), which includes measures from Health Plan Employer Data Information Set (HEDIS) and CAHPS® (Consumer Assessment of Health Plans).

The Division of Special Health Care Programs, in collaboration with the Division of Maternal and Child Health (MCH), is also developing a registry of clients who are served through our specialty clinics. This registry will enable us to identify all CSHCN served by both Divisions. Condition-specific demographic patient data will enhance the Division's needs assessment, program evaluation, outcome monitoring, and program development and will be measured by NPM #2 (providing specialty services and coordination of care).

The Bureau of Family Health has been conducting a study of the merit and feasibility of a birth defects surveillance system. The study is nearly complete. The Department is currently attempting to determine if existing secondary data sources could be used for the purpose of the registry. These secondary data sources include birth and death records, hospital utilization data available from the health care cost containment council, Title V patient service data, and outpatient records available from Medical Assistance and the Children's Health Insurance Program. This project will support state-level activities designed to develop a state and community infrastructure that results in comprehensive, coordinated, quality, community-based systems of care for all children and their families. This activity assists in meeting Priority Need #4 (identify the population with special health care needs). The development of a Birth Defects Surveillance System (BDSS) would provide the vehicle to address the need for improved information about children with birth defects and related conditions. The information will be used to improve access to services for these children and their families, design and tailor public health programs to address unmet needs of the population, and contribute to the improved health status of these infants and children.

The Bureau of Family Health is uniquely positioned to maintain a myriad of state and community-based relationships for addressing needed health care system improvements that develop and enhance existing resources. The Bureau is charged with maintaining and enhancing programs and services conceptualized and organized within the Title V agency, as well as a group of intra- and inter-agency initiatives. The development of a BDSS would provide the vehicle to address the need for improved information about children with birth defects and related conditions. The information will be used to improve access to services for these children and their families, design

and tailor public health programs to address unmet needs of the population, and hopefully contribute to the improved health status of these infants and children. The purpose is to also develop and structure program initiatives at the community level. The intent is to meet community needs.

4.2 Other Program Activities

Preventive and Primary Care Services for Pregnant Women, Infants and Children

The Lead Information Line (LIL) is a statewide toll-free lead poisoning prevention and control help line that serves as a single point of contact for inter- and intra-agency information. The help line is a resource for the general public, state, federal, and local agencies, as well other interested parties. Information available from the LIL line includes, but is not limited to, the following: screening, treatment, case management, identification of source(s) of exposure, environmental management, resources for inspection and abatement and laboratory analysis, lead in soil, lead in water, lead in paint, current state and federal regulations and policies, current research, current consumer alerts, etc. LIL has the ability to transfer calls to the Department's *Healthy Baby/Healthy Kids line*. Additionally, a supply of resource material about lead poisoning prevention and control, current legislation, sources of lead exposure, and lead hazard reduction may be obtained by calling LIL.

Children with Special Health Care Needs

An activity is proposed by the Division that will have its planning stage occur in the upcoming year. This activity is both infrastructure-building and enabling. Surveys have shown that both professionals and parents concerned with children with special health care needs (CSHCN) issues are still citing lack of information as their number one concern. An annual institute is proposed for either the Division's population or for the broader audience of the Bureau of Family Health. This statewide institute would have the capacity to target and educate physicians, health care professionals (public and private sector), parents, and employees of allied agencies with concerns for the CSHCN or Maternal and Child Health (MCH) population. Among the topics of education could be: newborn screening issues, prevention activities, Global Information Systems, an overview of Division/Bureau programs, evaluation methods and resources, interagency education, coursework geared toward Title V objectives, family participation and advocacy, insurance, managed care and eligibility, and special conditions of CSHCN. There are a number of models available for the Division to use. It is proposed that the institute would be designed in the upcoming year, approvals and budgetary allocations would be granted in the second year, and implementation should follow in the 2002-2003 FFY. Evaluation of this effort should be considered during the planning phase, and implemented during the first year of performance. Such an institute could be tailored to improve all performance measures and respond to all priority needs. The scope of such a project does not permit for its inclusion within another conference or institute, but does allow for a "one-stop shopping" experience for all of those whose work and lives center on children with special health care needs.

Pursuant to Individuals with Disabilities Education Act (IDEA) 1997, Governor Ridge in his Executive Order 1998-4, established an Interagency Committee to develop a Memorandum of Understanding (MOU). In December 1999,

the Departments of Education, Public Welfare, Labor and Industry and Health executed this MOU. The MOU sets forth an Interagency Agreement, which defines the entitlements of students with disabilities, identifies other programs and services students may be eligible to receive, establishes a process for interagency collaboration, defines fiscal and programmatic responsibilities for each agency, and establishes a dispute resolution process related to fiscal or programmatic responsibilities. The Departments established an Interagency Training Subcommittee that planned and implemented the training for the families, individuals with disabilities, and individuals involved in coordinating services for students with disabilities.

As noted in the Annual Plan Section, the Department has been awarded a State Systems Development Initiative (SSDI) Grant. One goal of the work to be accomplished through this grant is to compile and merge data from various sources through the use of appropriate software to create specialized database files. Information and data gleaned from these specialized databases is to be used for needs assessment and program planning. The various sources and types of information include but are not limited to Department of Health (Women, Infants and Children; Early Intervention data); Department of Public Welfare (Medical Assistance, Supplemental Security Income, and Early and Periodic Screening, Diagnostic, Treatment Program (EPSDT) data); Department of Insurance (*CHIP* data); Pennsylvania Interagency Coordinating Council (Early Intervention data) and Department of Education (Special Education data, IDEA data).

The Division of Special Health Care Programs continues to maintain toll-free telephone service with TTY access through the Special Kids Network for families and providers to ask questions about Division programs, client eligibility, reimbursement status, etc. We received 2430 calls in 1999.

4.3 Public Input

A draft of the FFY 2001 Maternal and Child Health Services Block Grant Application has been distributed to over 300 agencies, organizations, and individuals. The cover letter accompanying the draft application described the application process and requested comments concerning the application contents. The Director of the Bureau of Family Health received written and oral input on the draft application from members of the Department's Maternal and Child Health Advisory Council and other interested parties. All comments were appreciated, and have been incorporated into this final application.

4.4 Technical Assistance

The Bureau of Family Health seeks to increase and clarify its role in managed care, particularly with reference to data gathering, needs assessment, and quality assurance. Managed care for Medical Assistance populations is implemented through the Department of Public Welfare in Pennsylvania. As managed care is becoming increasingly important to health care delivery for children, and especially to children with special health care needs, the Bureau is challenged to effectively assist with policy and program decision-making in managed care issues for maternal and child health populations. Form 15 has been completed.

SUPPORTING DOCUMENTS

5.1

GLOSSARY

GLOSSARY

Adequate prenatal care - Prenatal care were the observed to expected prenatal visits is greater than or equal to 80% (the Kotelchuck Index).

Administration of Title V Funds - The amount of funds the State uses for the management of the Title V allocation. It is limited by statute to 10 percent of the Federal Title V allotment.

Assessment - (see “Needs Assessment”)

Capacity - Program capacity includes delivery systems, workforce, policies, and support systems (e.g., training, research, technical assistance, and information systems) and other infrastructure needed to maintain service delivery and policy making activities. Program capacity results measure the strength of the human and material resources necessary to meet public health obligations. As program capacity sets the stage for other activities, program capacity results are closely related to the results for process, health outcome, and risk factors. Program capacity results should answer the question, “What does the State need to achieve the results we want?”

Capacity Objectives - Objectives that describe an improvement in the ability of the program to deliver services or affect the delivery of services.

Care Coordination Services for Children With Special Health Care Needs (CSHCN, see definition below) - those services that promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families. [*Title V Sec. 501(b)(3)*]

Carryover (as used in Forms 2 and 3) - The unobligated balance from the previous years MCH Block Grant Federal Allocation.

Case Management Services - For pregnant women - those services that assure access to quality prenatal, delivery and postpartum care. For infants up to age one - those services that assure access to quality preventive and primary care services. (*Title V Sec. 501(b)(4)*)

Children -A child from 1st birthday through the 21st year, who is not otherwise included in any other class of individuals.

Children With Special Health Care Needs (CSHCN) - (*For budgetary purposes*) Infants or children from birth through the 21st year with special health care needs who the State has elected to provide with services funded through Title V. CSHCN are children who have health problems requiring more than routine and basic care including children with or at risk of disabilities, chronic illnesses and conditions and health-related education and behavioral problems. (*For planning and systems development*) - Those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Children With Special Health Care Needs (CSHCN) - Constructs of a Service System

1. State Program Collaboration with Other State Agencies and Private Organizations

States establish and maintain ongoing interagency collaborative processes for the assessment of needs with respect to the development of community-based systems of services for CSHCN. State programs collaborate with other agencies and organizations in the formulation of coordinated policies, standards, data collection and analysis, financing of services, and program monitoring to assure comprehensive, coordinated services for CSHCN and their families.

2. State Support for Communities

State programs emphasize the development of community-based programs by establishing and maintaining a process for facilitating community systems building through mechanisms such as technical assistance and consultation, education and training, common data protocols, and financial resources for communities engaged in systems development to assure that the unique needs of CSHCN are met.

3. Coordination of Health Components of Community-Based Systems

A mechanism exists in communities across the State for coordination of health services with one another. This includes coordination among providers of primary care, habilitative and rehabilitative services, other specialty medical treatment services, mental health services, and home health care.

4. Coordination of Health Services with Other Services at the Community Level

A mechanism exists in communities across the State for coordination and service integration among programs serving CSHCN, including early intervention and special education, social services, and family support services.

Classes of Individuals - authorized persons to be served with Title V funds. See individual definitions under “Pregnant Women,” “Infants,” “Children with Special Health Care Needs,” “Children,” and “Others.”

Community - a group of individuals living as a smaller social unit within the confines of a larger one due to common geographic boundaries, cultural identity, a common work environment, common interests, etc.

Community-based Care - services provided within the context of a defined community.

Community-based Service System - an organized network of services that are grounded in a plan developed by a community and that is based upon needs assessments.

Coordination (see Care Coordination Services)

Culturally Sensitive - the recognition and understanding that different cultures may have different concepts and practices with regard to health care; the respect of those differences and the development of approaches to health care with those differences in mind.

Culturally Competent - the ability to provide services to clients that honor different cultural beliefs, interpersonal styles, attitudes and behaviors and the use of multicultural staff in the policy development, administration and provision of those services.

Deliveries - women who received a medical care procedure (were provided prenatal, delivery or postpartum care) associated with the delivery or expulsion of a live birth or fetal death.

Direct Health Care Services - those services generally delivered one-on-one between a health professional and a patient in an office, clinic or emergency room which may include primary care physicians, registered dietitians, public health or visiting nurses, nurses certified for obstetric and pediatric primary care, medical social workers, nutritionists, dentists, sub-specialty physicians who serve children with special health care needs, audiologists, occupational therapists, physical therapists, speech and language therapists, specialty registered dietitians. Basic services include what most consider ordinary medical care, inpatient and outpatient medical services, allied health services, drugs, laboratory testing, x-ray services, dental care, and pharmaceutical products and services. State Title V programs support - by directly operating programs or by funding local providers - services such as prenatal care, child health including immunizations and treatment or referrals, school health and family planning. For CSHCN, these services include specialty and subspecialty care for those with HIV/AIDS, hemophilia, birth defects, chronic illness, and other conditions requiring sophisticated technology, access to highly trained specialists, or an array of services not generally available in most communities.

Enabling Services - Services that allow or provide for access to and the derivation of benefits from, the array of basic health care services and include such things as transportation, translation services, outreach, respite care, health education, family support services, purchase of health insurance, case management, coordination of with Medicaid, WIC and education. These services are especially required for the low income, disadvantaged, geographically or culturally isolated, and those with special and complicated health needs. For many of these individuals, the enabling services are essential - for without them access is not possible. Enabling services most commonly provided by agencies for CSHCN include transportation, care coordination, translation services, home visiting, and family outreach. Family support activities include parent support groups, family training workshops, advocacy, nutrition and social work.

EPSDT - Early and Periodic Screening, Diagnosis and Treatment - a program for medical assistance recipients under the age of 21, including those who are parents. The program has a Medical Protocol and Periodicity Schedule for well-child screening that provides for regular health check-ups, vision/hearing/dental screenings, immunizations and treatment for health problems.

Family-centered Care - a system or philosophy of care that incorporates the family as an integral component of the health care system.

Federal (Allocation) (as it applies specifically to the Application Face Sheet [SF 424] and Forms 2 and 3) -The monies provided to the States under the Federal Title V Block Grant in any given year.

Government Performance and Results Act (GPRA) - Federal legislation enacted in 1993 that requires Federal agencies to develop strategic plans, prepare annual plans setting performance goals, and report annually on actual performance.

Health Care System - the entirety of the agencies, services, and providers involved or potentially involved in the health care of community members and the interactions among those agencies, services and providers.

Infants - Children under one year of age not included in any other class of individuals.

Infrastructure Building Services - The services that are the base of the MCH pyramid of health services and form its foundation are activities directed at improving and maintaining the health status of all women and children by providing support for development and maintenance of comprehensive health services systems including development and maintenance of health services standards/guidelines, training, data and planning systems. Examples include needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, information systems and systems of care. In the

development of systems of care it should be assured that the systems are family centered, community based and culturally competent.

Jurisdictions - As used in the Maternal and Child Health block grant program: the District of Columbia, the Commonwealth of Puerto Rico, the Virgin Islands, Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, the Republic of the Marshal Islands, the Federated States of Micronesia and the Republic of Palau.

Kotelchuck Index - An indicator of the adequacy of prenatal care. See *Adequate Prenatal Care*.

Local Funding (as used in Forms 2 and 3) - Those monies deriving from local jurisdictions within the State that are used for MCH program activities.

Low Income - an individual or family with an income determined to be below the income official poverty line defined by the Office of Management and Budget and revised annually in accordance with section 673(2) of the Omnibus Budget Reconciliation Act of 1981.[Title V, Sec. 501 (b)(2)]

MCH Pyramid of Health Services - (see “Types of Services”)

Measures - (see “Performance Measures”)

Needs Assessment - a study undertaken to determine the service requirements within a jurisdiction. For maternal and child health purposes, the study is to aimed at determining:

- 1) What is essential in terms of the provision of health services;
- 2) What is available; and,
- 3) What is missing

Objectives - The yardsticks by which an agency can measure its efforts to accomplish a goal. (See also “Performance Objectives”)

Other Federal Funds (Forms 2 and 3) - Federal funds other than the Title V Block Grant that are under the control of the person responsible for administration of the Title V program. These may include, but are not limited to: WIC, EMSC, Healthy Start, SPRANS, HIV/AIDs monies, CISS funds, MCH targeted funds from CDC and MCH Education funds.

Others (as in Forms 4, 7, and 10) - Women of childbearing age, over age 21, and any others defined by the State and not otherwise included in any of the other listed classes of individuals.

Outcome Objectives - Objectives that describe the eventual result sought, the target date, the target population, and the desired level of achievement for the result. Outcome objectives are related to health outcome and are usually expressed in terms of morbidity and mortality.

Outcome Measure - The ultimate focus and desired result of any set of public health program activities and interventions is an improved health outcome. Morbidity and mortality statistics are indicators of achievement of health outcome. Health outcomes results are usually longer term and tied to the ultimate program goal. Outcome measures should answer the question, “Why does the State do our program?”

Performance Indicator - The statistical or quantitative value that expresses the result of a performance objective.

Performance Measure - a narrative statement that describes a specific maternal and child health need, or requirement, that, when successfully addressed, will lead to, or will assist in leading to, a specific health outcome within a community or jurisdiction and generally within a specified time frame. (Example: “The rate of women in [State] who receive early prenatal care in 19__.” This performance measure will assist in leading to [the health outcome measure of] reducing the rate of infant mortality in the State).

Performance Measurement - The collection of data on, recording of, or tabulation of results or achievements, usually for comparing with a benchmark.

Performance Objectives - A statement of intention with which actual achievement and results can be measured and compared. Performance objective statements clearly describe what is to be achieved, when it is to be achieved, the extent of the achievement, and target populations.

Population Based Services - Preventive interventions and personal health services, developed and available for the entire MCH population of the State rather than for individuals in a one-on-one situation. Disease prevention, health promotion, and statewide outreach are major components. Common among these services are newborn screening, lead screening, immunization, Sudden Infant Death Syndrome counseling, oral health, injury prevention, nutrition and outreach/public education. These services are generally available whether the mother or child receives care in the private or public system, in a rural clinic or an HMO, and whether insured or not.

PRAMS - Pregnancy Risk Assessment Monitoring System - a surveillance project of the Centers for Disease Control and Prevention (CDC) and State health departments to collect State- specific, population-based data on maternal attitudes and experiences prior to, during, and immediately following pregnancy.

Pregnant Woman - A female from the time that she conceives to 60 days after birth, delivery, or expulsion of fetus.

Preventive Services - activities aimed at reducing the incidence of health problems or disease prevalence in the community, or the personal risk factors for such diseases or conditions.

Primary Care - the provision of comprehensive personal health services that include health maintenance and preventive services, initial assessment of health problems, treatment of uncomplicated and diagnosed chronic health problems, and the overall management of an individual's or family's health care services.

Process - Process results are indicators of activities, methods, and interventions that support the achievement of outcomes (e.g., improved health status or reduction in risk factors). A focus on process results can lead to an understanding of how practices and procedures can be improved to reach successful outcomes. Process results are a mechanism for review and accountability, and as such, tend to be shorter term than results focused on health outcomes or risk factors. The utility of process results often depends on the strength of the relationship between the process and the outcome. Process results should answer the question, "Why should this process be undertaken and measured (i.e., what is its relationship to achievement of a health outcome or risk factor result)?"

Process Objectives - The objectives for activities and interventions that drive the achievement of higher-level objectives.

Program Income (as used in the Application Face Sheet [SF 424] and Forms 2 and 3) - Funds collected by State MCH agencies from sources generated by the State's MCH program to include insurance payments, MEDICAID reimbursements, HMO payments, etc.

Risk Factor Objectives - Objectives that describe an improvement in risk factors (usually behavioral or physiological) that cause morbidity and mortality.

Risk Factors - Public health activities and programs that focus on reduction of scientifically established direct causes of, and contributors to, morbidity and mortality (i.e., risk factors) are essential steps toward achieving health outcomes. Changes in behavior or physiological conditions are the indicators of achievement of risk factor results. Results focused on risk factors tend to be intermediate term. Risk factor results should answer the question, "Why should the State address this risk factor (i.e., what health outcome will this result support)?"

State - as used in this guidance, includes the 50 States and the 9 jurisdictions. (See also, Jurisdictions)

State Funds (as used in Forms 2 and 3) - The State's required matching funds (including overmatch) in any given year.

Systems Development - activities involving the creation or enhancement of organizational infrastructures at the community level for the delivery of health services and other needed ancillary services to individuals in the community by improving the service capacity of health care service providers.

Technical Assistance (TA) - the process of providing recipients with expert assistance of specific health related or administrative services that include; systems review planning, policy options analysis, coordination coalition building/training, data system development, needs assessment, performance indicators, health care reform wrap around services, CSHCN program development/evaluation, public health managed care quality standards development, public and private interagency integration and, identification of core public health issues.

Title XIX, number of infants entitled to - The unduplicated count of infants who were eligible for the State's Title XIX (MEDICAID) program at any time during the reporting period.

Title XIX, number of pregnant women entitled to - The number of pregnant women who delivered during the reporting period who were eligible for the State's Title XIX (MEDICAID) program.

Title V, number of deliveries to pregnant women served under - Unduplicated number of deliveries to pregnant women who were provided prenatal, delivery, or post-partum services through the Title V program during the reporting period.

Title V, number of infants enrolled under - The unduplicated count of infants provided a direct service by the State's Title V program during the reporting period.

Total MCH Funding - All the MCH funds administered by a State MCH program which is made up of the sum of the *Federal* Title V Block grant allocation, the *Applicant's* funds (carryover from the previous year's MCH Block Grant allocation - the unobligated balance), the *State* funds (the total matching funds for the Title V allocation - match and overmatch), *Local* funds (total of MCH dedicated funds from local jurisdictions within the state), *Other* federal funds (monies other than the Title V Block Grant that are under the control of the person responsible for administration of the Title V program), and *Program Income* (those collected by state MCH agencies from insurance payments, MEDICAID, HMO's, etc.).

Types of Services - The major kinds or levels of health care services covered under Title V activities. See individual definitions under "Infrastructure Building", "Population Based Services", "Enabling Services" and "Direct Medical Services".

YRBS - Youth Risk Behavior Survey - A national school-based survey conducted annually by CDC and State health departments to assess the prevalence of health risk behaviors among high school students.

SUPPORTING DOCUMENTS

5.2

ASSURANCES AND CERTIFICATIONS

ASSURANCES -- NON-CONSTRUCTION PROGRAMS

Note: Certain of these assurances may not be applicable to your project or program. If you have any questions, please contact the Awarding Agency. Further, certain federal assistance awarding agencies may require applicants to certify to additional assurances. If such is the case, you will be notified.

As the duly authorized representative of the applicant I certify that the applicant:

1. Has the legal authority to apply for Federal assistance, and the institutional, managerial and financial capability (including funds sufficient to pay the non-Federal share of project costs) to ensure proper planning, management and completion of the project described in this application.
2. Will give the awarding agency, the Comptroller General of the United States, and if appropriate, the State, through any authorized representative, access to and the right to examine all records, books, papers, or documents related to the assistance; and will establish a proper accounting system in accordance with generally accepted accounting standards or agency directives.
3. Will establish safeguards to prohibit employees from using their position for a purpose that constitutes or presents the appearance of personal or organizational conflict of interest, or personal gain.
4. Will initiate and complete the work within the applicable time frame after receipt of approval of the awarding agency.
5. Will comply with the Intergovernmental Personnel Act of 1970 (42 U.S.C. Sects. 4728-2763) relating to prescribed standards for merit systems for programs funded under one of the nineteen statutes or regulations specified in Appendix A of OPM's Standards for a Merit System of Personnel Administration (5 C.F.R. 900, Subpart F).
6. Will comply with all Federal statutes relating to non-discrimination. These include but are not limited to (a) Title VI of the Civil Rights Act of 1964 (P.L. 88 Sect. 352) which prohibits discrimination on the basis of race, color or national origin; (b) Title IX of the Education Amendments of 1972, as amended (20 U.S.C. Sects. 1681-1683, and 1685-1686), which prohibits discrimination on the basis of sex; (c) Section 504 of the Rehabilitation Act of 1973, as amended (29 U.S.C. Sect. 794), which prohibits discrimination on the basis of handicaps; (d) The Age Discrimination Act of 1975, as amended (42 U.S.C. Sects 6101 6107), which prohibits discrimination on the basis of age; (e) the Drug Abuse Office of Treatment Act of 1972 (P.L. 92-255), as amended, relating to non-discrimination on the basis of drug abuse; (f) the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act of 1970

- (P.L. 91-616), as amended, relating to non-discrimination on the basis of alcohol abuse or alcoholism; (g) Sects. 523 and 527 of the Public Health Service Act of 1912 (42 U.S.C. Sect. 3601 et seq.), as amended, relating to non-discrimination in the sale, rental, or financing of housing; (i) any other non-discrimination provisions in the specific statute(s) under which application for Federal assistance is being made; and (j) the requirements of any other non-discrimination statute(s) which may apply to the application.
7. Will comply, or has already complied, with the requirements of Titles II and III of the Uniform Relocation Assistance and Real Property Acquisition Policies Act of 1970 (P.L. 91-646) which provide for fair and equitable treatment of persons displaced or whose property is acquired as a result of Federal or federally assisted programs. These requirements apply to all interests in real property acquired for project purposes regardless of Federal participation in purchases.
 8. Will comply with the provisions of the Hatch Act (5 U.S.C. Sects 1501-1508 and 7324-7328) which limit the political activities of employees whose principal employment activities are funded in whole or in part with Federal funds.
 9. Will comply, as applicable, with the provisions of the Davis-Bacon Act (40 U.S.C. Sects. 276a to 276a-7), the Copeland Act (40 U.S.C. Sect 276c and 18 U.S.C. Sect. 874), the Contract Work Hours and Safety Standards Act (40 U.S.C. Sects. 327-333), regarding labor standards for federally assisted construction subagreements.
 10. Will comply, if applicable, with flood insurance purchase requirements of Section 102(a) of the Flood Disaster Protection Act of 1973 (P.L. 93-234) which requires recipients in a special flood hazard area to participate in the program and to purchase flood insurance if the total cost of insurable construction and acquisition is \$10,000 or more.
 11. Will comply with environmental standards which may be prescribed pursuant to the following: (a) institution of environmental quality control measures under the National Environmental Policy Act of 1969 (P.L. 91-190) and Executive Order (EO) 11514; (b) notification of violating facilities pursuant to EO 11738; (c) protection of wetlands pursuant to EO 11990; (d) evaluation of flood hazards in flood plains in accordance with EO 11988; (e) assurance of project consistency with the approved State management program developed under the Coastal Zone Management Act of 1972 (16 U.S.C. Sects. 1451 et seq.); (f) conformity of Federal actions to State (Clear Air) Implementation Plans under Section 176(c) of the Clear Air Act of 1955, as amended (42 U.S.C. 7401 et seq.); (g) protection of underground sources of drinking water under the Safe Drinking Water Act of 1974, as amended, (P.L. 93-523); and (h) protection of endangered species under the Endangered Species Act of 1973, as amended, (P.L. 93-205).

12. Will comply with the Wild and Scenic Rivers Act of 1968 (16 U.S.C. Sects 1271 et seq.) related to protecting components or potential components of the national wild and scenic rivers systems
13. Will assist the awarding agency in assuring compliance with Section 106 of the National Historic Preservation Act of 1966, as amended (16 U.S.C. Sect. 470), EO 11593 (identification and preservation of historic properties), and the Archaeological and Historic Preservation Act of 1974 (16 U.S.C. Sects. 469a-1 et seq.)
14. Will comply with P.L.93-348 regarding the protection of human subjects involved in research, development, and related activities supported by this award of assistance.
15. Will comply with Laboratory Animal Welfare Act of 1966 (P.L. 89-544, as amended, 7 U.S.C. 2131 et seq.) pertaining to the care, handling, and treatment of warm blooded animals held for research, teaching, or other activities supported by the award of assistance.
16. Will comply with the Lead-Based Paint Poisoning Prevention Act (42 U.S.C. Sects. 4801 et seq.) which prohibits the use of lead based paint in construction or rehabilitation of residence structures.
17. Will cause to be performed the required financial and compliance audits in accordance with the Single Audit Act of 1984.
18. Will comply will all applicable requirements of all other Federal laws, executive orders, regulations and policies governing this program.

CERTIFICATIONS

1. CERTIFICATION REGARDING DEBARMENT AND SUSPENSION

By signing and submitting this proposal, the applicant, defined as the primary participant in accordance with 45 CFR Part 76, certifies to the best of its knowledge and belief that it and its principals:

- (a) are not presently debarred, suspended proposed for debarment, declared ineligible, or voluntarily excluded from covered transactions by any Federal Department or agency;
- (b) have not within a 3-year period preceding this proposal been convicted of or had a civil judgment rendered against them for commission or fraud or criminal judgment in connection with obtaining, attempting to obtain, or performing a public (Federal, State, or local) transaction or contract under a public transaction; violation of Federal or State antitrust statutes or commission of embezzlement,

theft, forgery, bribery, falsification or destruction of records, making false statements, or receiving stolen property;

- (c) are not presently indicted or otherwise criminally or civilly charged by a governmental entity (Federal, State or local) with commission or any of the offenses enumerated in paragraph (b) of the certification; and
- (d) have not within a 3-year period preceding this application/proposal had one or more public transactions (Federal, State, or local) terminated for cause or default.

Should the applicant not be able to provide this certification, an explanation as to why should be placed after the assurances page in the application package.

The applicant agrees by submitting this proposal that it will include, without modification, the clause, titled “Certification Regarding Debarment, Suspension, In-eligibility, and Voluntary Exclusion -- Lower Tier Covered Transactions” in all lower tier covered transactions (i.e. transactions with sub-grantees and/or contractors) in all solicitations for lower tier covered transactions in accordance with 45 CFR Part 76.

2. CERTIFICATION REGARDING DRUG-FREE WORKPLACE REQUIREMENTS

The undersigned (authorized official signing for applicant organization) certifies that the applicant will, or will continue to, provide a drug-free workplace in accordance with 45 CFR Part 76 by:

- (a) Publishing a statement notifying employees that the unlawful manufacture, distribution, dispensing, possession or use of a controlled substance is prohibited in the grantee’s workplace and specifying the actions that will be taken against employees for violation of such prohibition;
- (b) Establishing an ongoing drug-free awareness program to inform employees about-
 - (1) The dangers of drug abuse in the workplace;
 - (2) The grantee’s policy of maintaining a drug-free workplace,
 - (3) Any available drug counseling, rehabilitation, and employee assistance programs; and
 - (4) The penalties that may be imposed upon employees for drug abuse violations occurring in the workplace;
- (c) Making it a requirement that each employee to be engaged in the performance of the grant be given a copy of the statement required by paragraph (a) above;
- (d) Notifying the employee in the statement required by paragraph (a) above, that, as a condition of employment under the grant, the employee will-
 - (1) Abide by the terms of the statement; and
 - (2) Notify the employer in writing of his or her conviction for violation of a criminal drug statute occurring in the workplace no later than five calendar days after such conviction;

- (e) Notify the agency in writing within ten calendar days after receiving notice under paragraph (d)(2) from an employee or otherwise receiving actual notice of such conviction. Employers of convicted employees must provide notice, including position title, to every grant officer or other designee on whose grant activity the convicted employee was working, unless the Federal agency has designated a central point for the receipt of such notices. Notice shall include the identification number(s) of each affected grant;
- (f) Taking one of the following actions, within 30 calendar days of receiving notice under paragraph (d)(2), with respect to any employee who is so convicted-
 - (1) Taking appropriate personnel action against such an employee, up to and including termination, consistent with the requirements of the Rehabilitation Act of 1973, as amended, or
 - (2) Requiring such employee to participate satisfactorily in a drug abuse assistance or rehabilitation program approved for such purposes by a Federal, State, or local health, law enforcement, or other appropriate agency;
- (g) Making a good faith effort to continue to maintain a drug-free workplace through implementation of paragraphs (a), (b), (c), (d), (e), and (f).

For purposes of paragraph (e) regarding agency notification of criminal drug convictions, the DHHS has designated the following central point for receipt of such notices:

Division of Grants Policy and Oversight
Office of Management and Acquisition
Department of Health and Human Services
Room 517-D
200 Independence Avenue, S.W.
Washington, D.C. 20201

3. CERTIFICATION REGARDING LOBBYING

Title 31, United States Code, Section 1352, entitled “Limitation on use of appropriated funds to influence certain Federal contracting and financial transactions,” generally prohibits recipients of Federal grants and cooperative agreements from using Federal (appropriated) funds for lobbying the Executive or Legislative Branches of the Federal Government in connection with a SPECIFIC grant or cooperative agreement. Section 1352 also requires that each person who requests or receives a Federal grant or cooperative agreement must disclose lobbying undertaken with non-Federal (non-appropriated) funds. The requirements apply to grants and cooperative agreements EXCEEDING \$100,000 in total costs (45 CFR Part 93).

The undersigned (authorized official signing for the applicant organization) certifies, to the best of his or her knowledge and belief that:

- (1) No Federal appropriated funds have been paid or will be paid, by or on behalf of the undersigned, to any person for influencing or attempting to influence an officer or employee of any agency, a Member of Congress, an officer or employee of Congress, or an employee of a Member of Congress in connection with the awarding of any Federal contract, the making of any Federal grant, the making of any Federal loan, the entering into of any cooperative agreement, and the extension, continuation, renewal, amendment, or modification of any Federal contract, grant, loan, or cooperative agreement.
- (2) If any funds other than Federally appropriated funds have been paid or will be paid to any person for influencing or attempting to influence an officer or employee of any agency, a Member of Congress an officer or employee of Congress, or an employee of a Member of Congress in connection with this Federal contract, grant, loan, or cooperative agreement, the undersigned shall complete and submit Standard Form-LLL, "Disclosure of Lobbying Activities," in accordance with its instructions. (If needed, Standard Form-LLL, "Disclosure of Lobbying Activities," its instructions, and continuation sheet are included at the end of this application form.)
- (3) The undersigned shall require that the language of this certification be included in the award documents for all subawards at all tiers (including subcontracts, subgrants, and contracts under grants, loans, and cooperative agreements) and that all subrecipients shall certify and disclose accordingly.

This certification is a material representation of fact upon which reliance was placed when this transaction was made or entered into. Submission of this certification is a prerequisite for making or entering into this transaction imposed by Section 1352, U.S. Code. Any person who fails to file the required certification shall be subject to a civil penalty of not less than \$10,000 and not more than \$100,000 for each such failure.

4. CERTIFICATION REGARDING PROGRAM FRAUD CIVIL REMEDIES ACT (PFCRA)

The undersigned (authorized official signing for the applicant organization) certifies that the statements herein are true, complete, and accurate to the best of his or her knowledge, and that he or she is aware that any false, fictitious, or fraudulent statements or claims may subject him or her to criminal, civil, or administrative penalties. The undersigned agrees that the applicant organization will comply with the Public Health Service terms and conditions of award if a grant is awarded as a result of this application.

5. CERTIFICATION REGARDING ENVIRONMENTAL TOBACCO SMOKE

Public Law 103-227, also know as the Pro-Children Act of 1994 (Act), requires that smoking not be permitted in any portion of any indoor facility owned or leased or contracted for by an entity and used routinely or regularly for

the provision of health, day care, early childhood development services, education or library services to children under the age of 18 if the services are funded by Federal programs either directly or through State or local governments by Federal grant, contract, loan, or loan guarantee. The law also applies to children's services that are provided in indoor facilities that are constructed, operated, or maintained with such federal funds. The law does not apply to children's services provided in private residences; portions of facilities used for inpatient drug or alcohol treatment; service providers whose sole source of applicable Federal funds is Medicare or Medicaid; or facilities where WIC coupons are redeemed. Failure to comply with the provisions of the law may result in the imposition of a monetary penalty of up to \$1,000 for each violation and/or the imposition of an administrative compliance order on the responsible entity.

By signing this certification, the undersigned certifies that the applicant organization will comply with the requirements of the Act and will not allow smoking within any portion of any indoor facility used for the provision of services for children as defined by the Act.

The applicant organization agrees that it will require that the language of this certification be included in any subawards which contain provisions for children's services and that all subrecipients shall certify accordingly.

The Public Health Service strongly encourages all grant recipients to provide a smoke free workplace and promote the non-use of tobacco products. This is consistent with the PHS mission to protect and advance the physical and mental health of American people.

SIGNATURE OF AUTHORIZED CERTIFYING OFFICIAL	TITLE Deputy Secretary for Administration	
APPLICANT ORGANIZATION Pennsylvania Department of Health		DATE SUBMITTED July 14, 2000

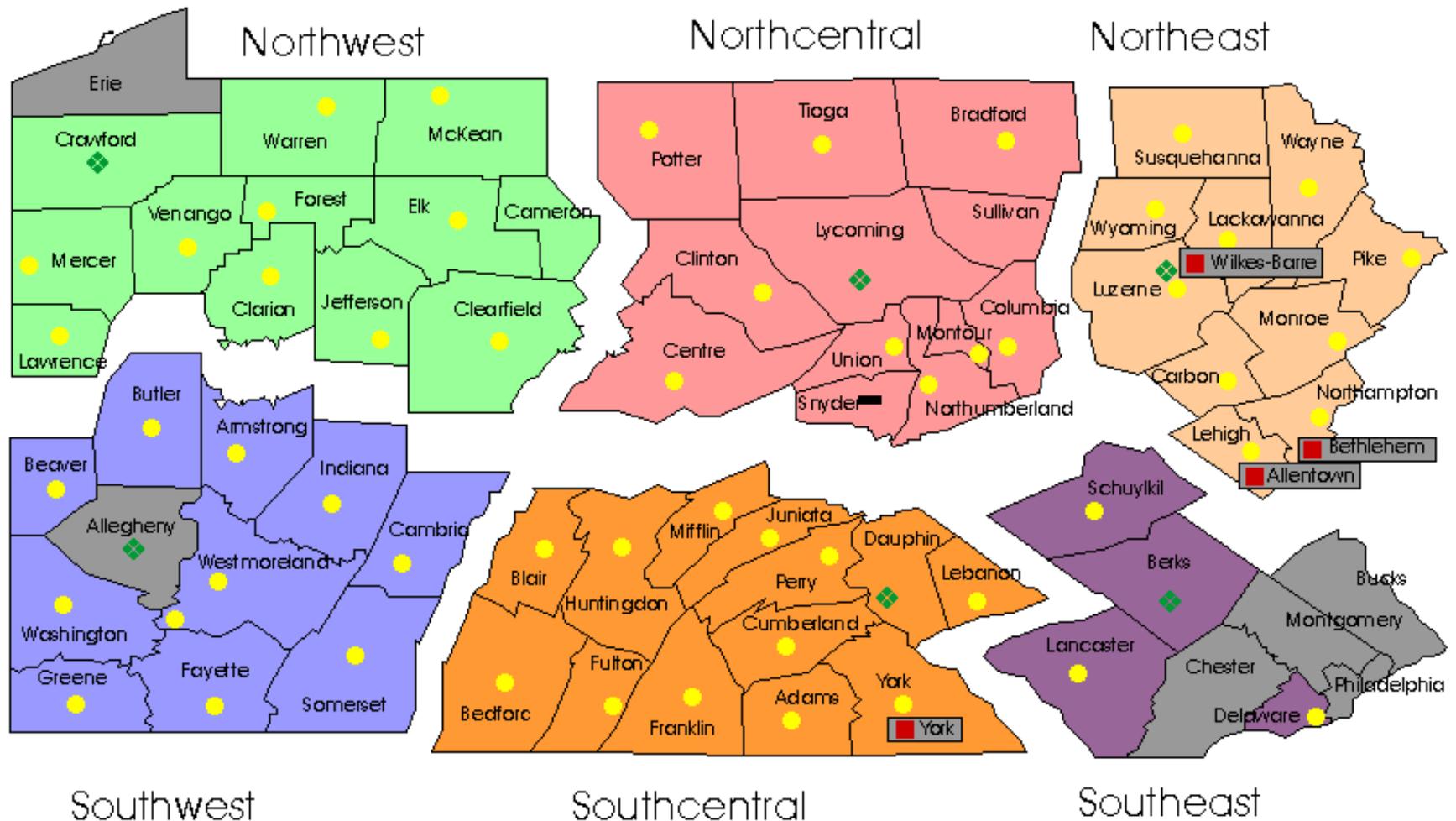
SUPPORTING DOCUMENTS

5.3

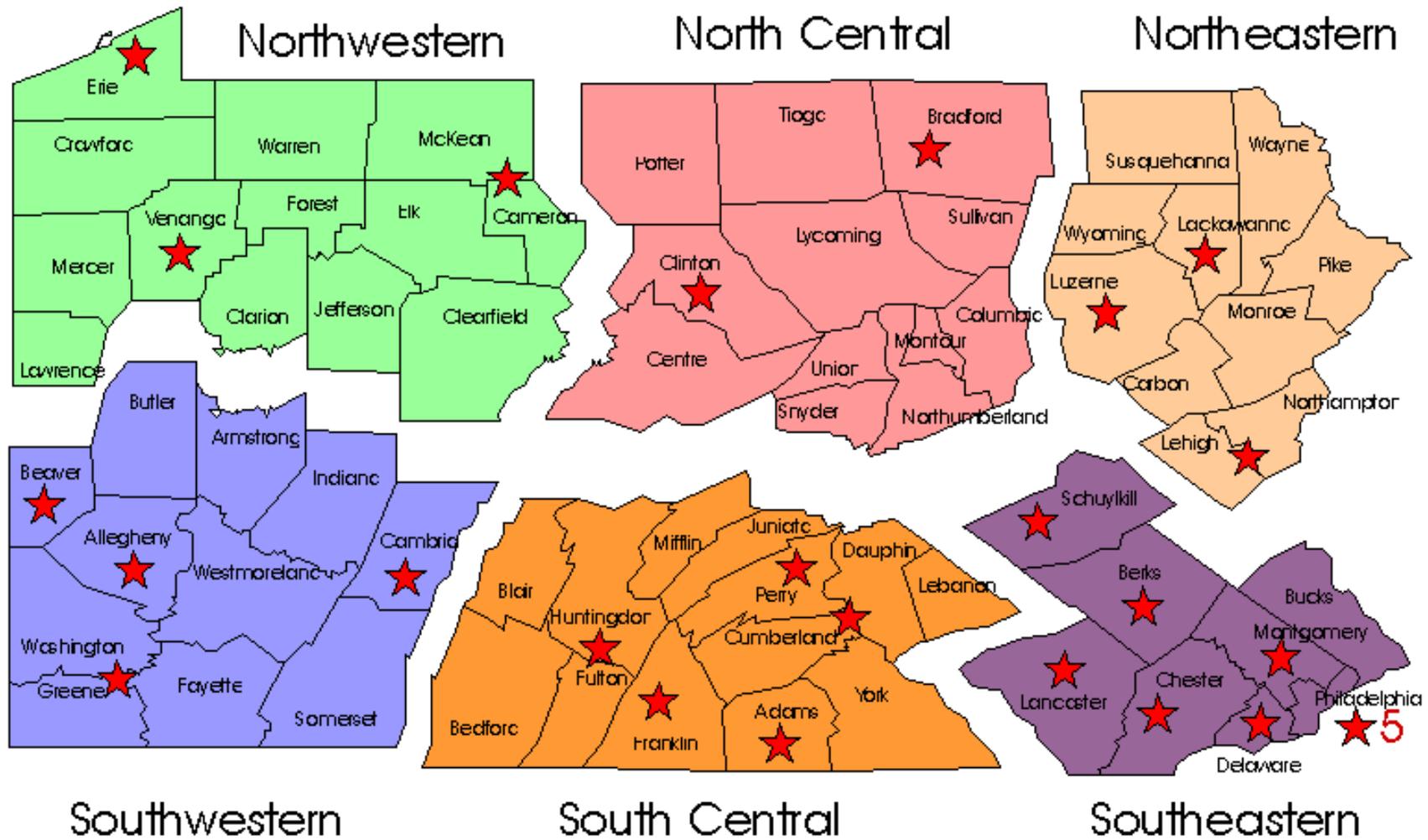
OTHER SUPPORTING DOCUMENTS

Pennsylvania Department of Health Community Health Districts

- County Health Departments
- State Health Centers
- Municipal Health Departments
- District Offices



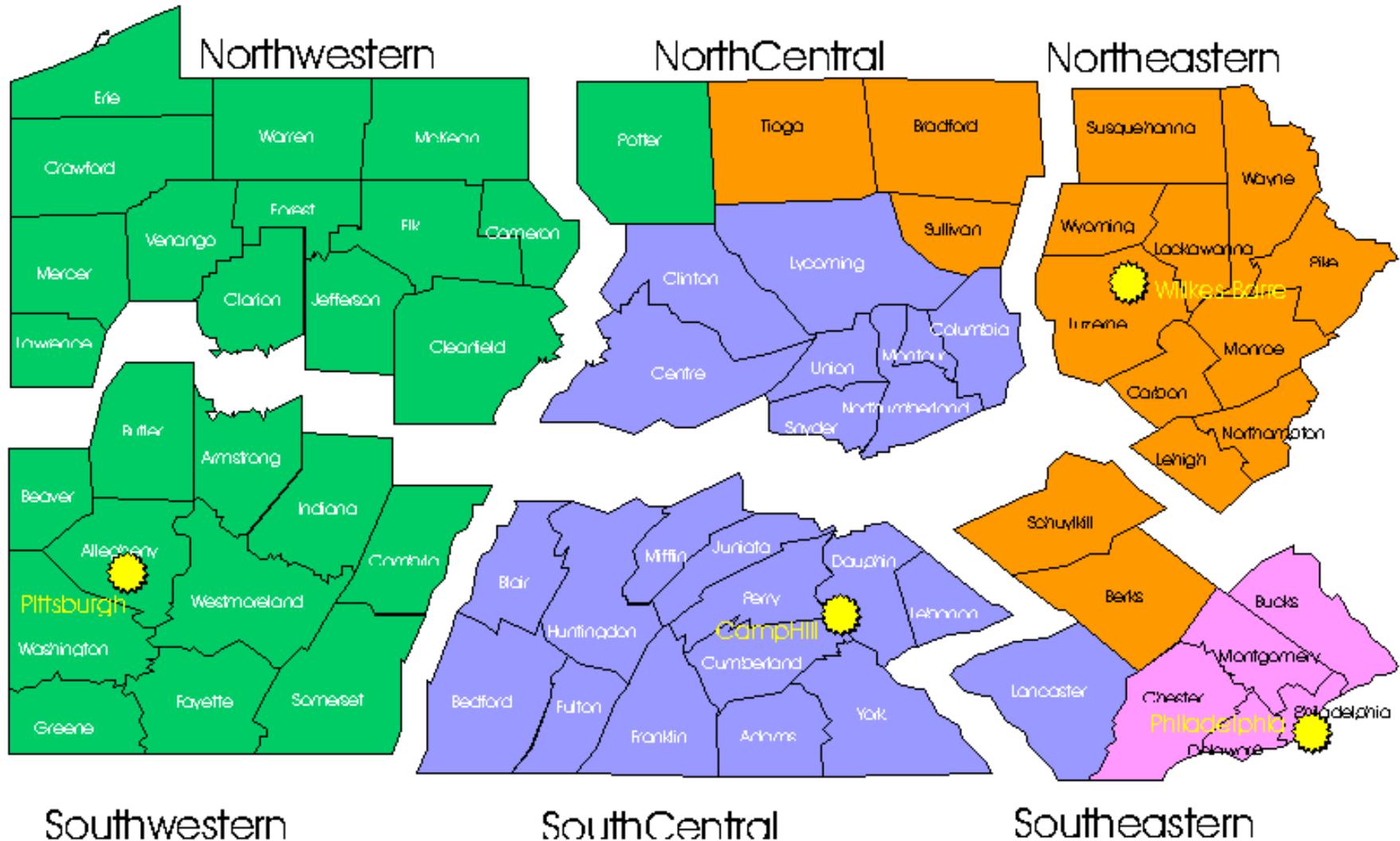
Pennsylvania Department of Health AERS Recommended Projects to date



Pennsylvania Department of Health Family Planning Service Regions

- Family Health Council (Western PA)
- Family Health Council of Central PA

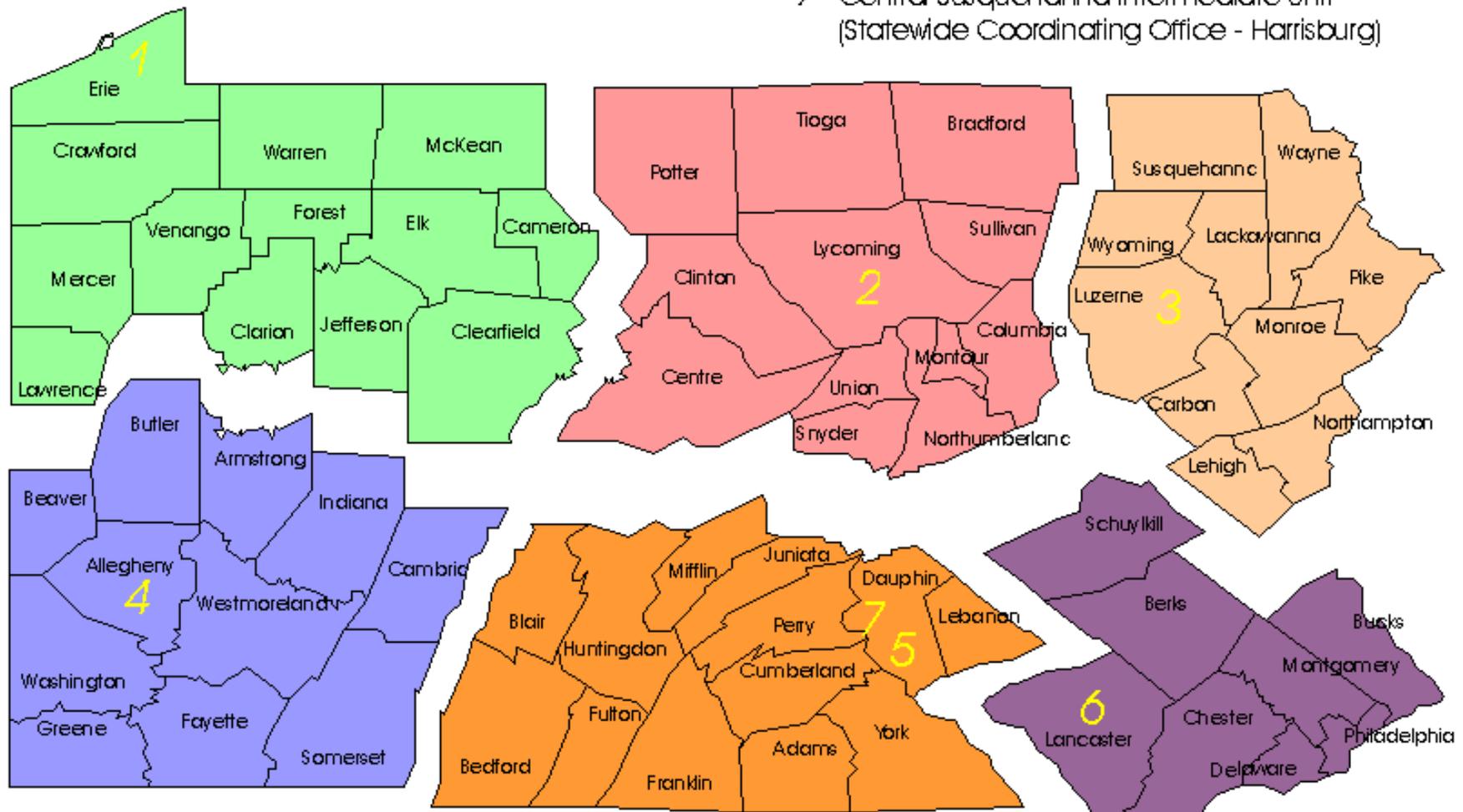
- Maternal and Family Health Services, Inc.
- Family Planning Council of Southeastern PA



Pennsylvania Department of Health Special Kids Network

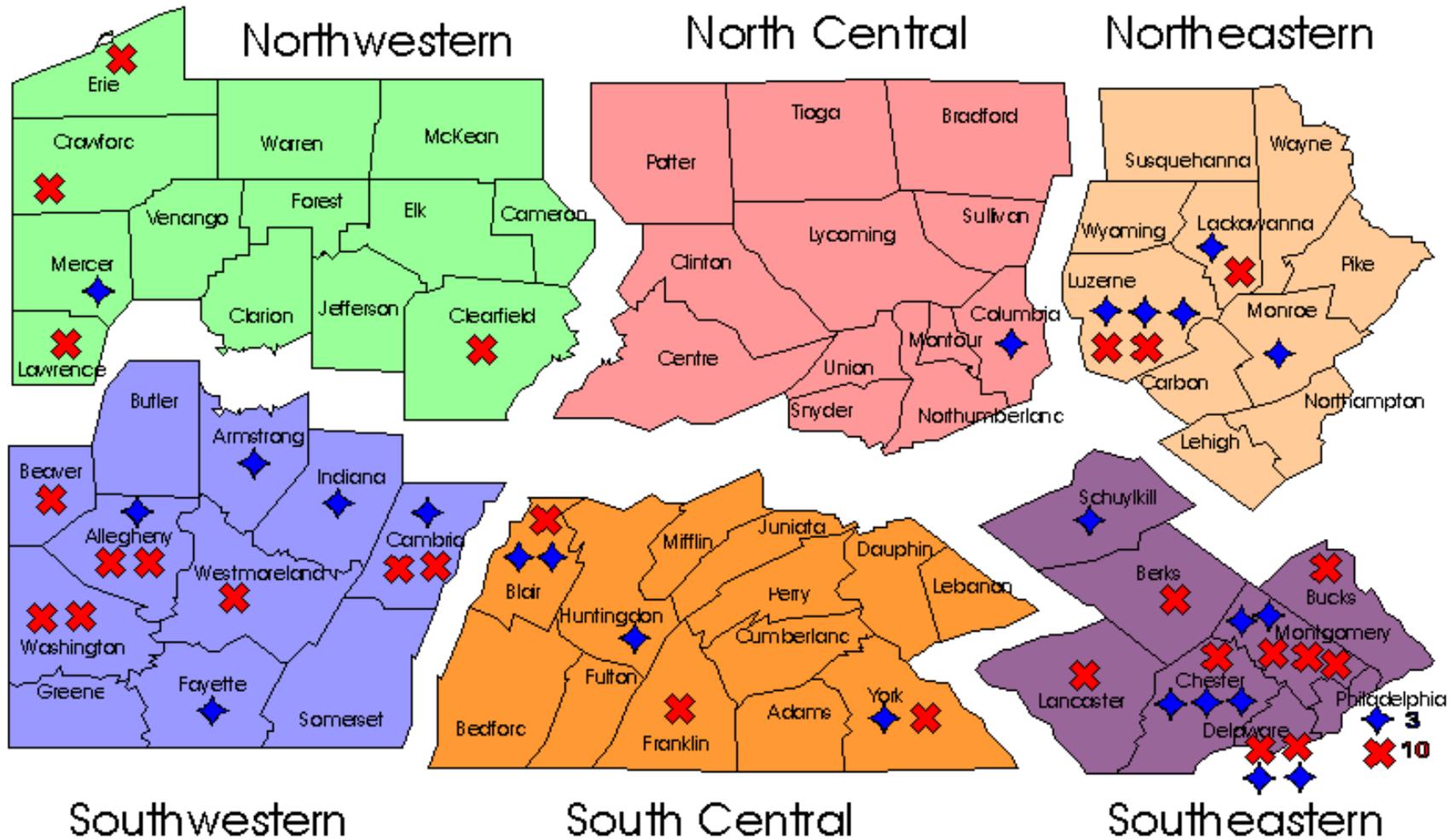
- 1 MECA, Inc. (Erie)
- 2 LCOCCS Children's Development Center (Williamsport)
- 3 Family Service Assoc. of Wyoming Valley (Wilkes-Barre)

- 4 Allegheny Intermediate Unit (Pittsburgh)
- 5 Milton S. Hershey Medical Center (Hershey)
- 6 United Cerebral Palsy of Lancaster (Lancaster)
- 7 Central Susquehanna Intermediate Unit (Statewide Coordinating Office - Harrisburg)



Pennsylvania Department of Health Core System: Providers by Type

- ◆ Audiology and/or Speech Services
- ✕ Hearing Aid Dispenser, Fitter/Dispenser, and Device Dealer



SUPPORTING DOCUMENTS

5.4

CORE HEALTH STATUS INDICATORS FORMS