



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

Traditionally, the Title V program has focused on providing access to maternal and child health services whether it be through supporting local health departments or through contracts with universities to deliver services within the community setting and on site for the maternal and child health population. Although this continues to be the focus for the Title V programs, a changing health care environment has opened other opportunities to improve the health of women, infants, children and children with special health care needs.

Within the past few years, the Department for Public Health has brought together the stakeholders within the public health community to develop a vision, mission and core values around the role of public health. Emerging from these efforts led by the Deputy Commissioner, a Public Health Improvement Plan was developed for Kentucky. As a result of these strategic planning efforts, coupled with a review of data on Kentucky's health, these priority health issues were determined. These follow:

Teenage pregnancy and low birth weight babies
Infant deaths
Deaths due to heart disease, cancer, and stroke
Health issues related to a rapidly growing elderly population
Immunizations for children
Disability and premature death of children and youth
Lifestyle activities, including physical fitness and exercise, nutrition, sexual practices, use of tobacco, alcohol, and illegal substances, and seat belt use
Prenatal care for pregnant women
Access by both private and public health providers to health and health-related information
Environmental health standards
Food safety
Communicable diseases.

Within this same time frame, Governor Paul Patton developed a simple goal with comprehensive, integrated strategies to achieve the outcome. This goal is "Set Kentucky on the path to achieving economic opportunity and a standard of living above the national average in 20 years." Five distinct strategies were designed to accomplish this goal: Promoting Economic Development; Improving Education Product; Building Self-Sustaining Families; Strengthening Efficiency and Operations of Government; and Reducing Crime and its Cost to Society. Clearly, the Department for Public Health has a role in all of these strategic initiatives, but the efforts identified within the Building Self Sustaining Families domain affect the maternal and child health population most significantly. These strategic initiatives include:

- Early Childhood Development
- Welfare Reform
- Children's Health Initiative
- Child Abuse and Domestic Violence Services
- Health Insurance Reform
- Reductions in Teen Smoking
- Child Protective Services
- Affordable Housing Initiatives

- Sustaining Farm Families and Tobacco Settlements
- Smart Growth Strategy
- Minority Action Initiatives.

Data gathered and reviewed during the needs assessment process support these initiatives leading to performance measures to improve the related indicators.

More recently, the Commissioner of Public Health led an effort to describe the mission of the Department, and therefore, the Title V agency, for the Interim Joint Committee on Health and Welfare and the Health and Welfare sub-committee on Appropriations and Revenue. In August 1999, "Mandated Services of Local Health Departments" was presented to these same committees. This resulted, in part, in revisions to KRS 211.005 during this current legislative session to specify the definition of core public health at the beginning of the chapter on public health laws. This revision mandates that the Department for Public Health develops and operates all programs for assessing the health status of the population, for the promotion of health and for the prevention of disease, injury, disability, and premature death. Services provided by the Department for Public Health and all local health departments include: enforcement of public health regulations; surveillance of public health; communicable disease control; public health education; implementation of public health policy; efforts directed to population risk reduction; and disaster preparedness. This identification by statute fosters the development of the role of the Title V agency to provide a comprehensive approach to health and supports moving resources more towards the population based and infrastructure building services and away from the provision of direct clinical services when indicated. The Department for Public Health, in conjunction with the Title V program, will provide preventive clinical services in those circumstances where providers are not assessable.

This role fosters the continuation of a shared responsibility for the health of Kentuckians between the public and private sector. This type of partnership was formalized with the implementation of Medicaid Managed Care public/private partnerships. In part due to the financial start-up costs, these partnerships did not materialize other than in the two regions in Kentucky. Executive and legislative concern over the implementation of Medicaid Managed Care led to a refocus of this effort. The Department for Medicaid Services developed a transitional plan for Kentucky. They are working to implement managed care statewide through a non-capitated primary care case management system such as a strengthened KenPAC model in the areas without a partnership. In addition there are plans to issue Requests for Proposals for managed care plans allowing responses at the regional, multi-regional or county level. Within this same time frame, the regional partnership (Region 5) serving Lexington/Fayette and surrounding counties decided to disband in July 2000. In all likelihood, the development of a primary care case management model, or strengthened KenPAC program, will be the focus for the Kentucky Medical Assistance Program for the rural areas of the state and a commercial product will be available as well in some of the urban settings. However, the public private partnerships that began developing during this effort continue to be a priority. Within the Division of Adult and Child Health, a new Assistant Director position was established for the purpose of fostering these relationships.

Between a rural model focused on strengthened case management, potential commercial products and implementation of the Kentucky Children's Health Insurance Program (KCHIP,) Kentucky is moving to essentially universal health coverage for children. Besides attempts to assure that every Kentuckian has access to care, there is an effort to assure that every

Kentuckian has a medical home so that continuity of care will augment access to care. Over the past several years the narrowing of the gap between public and private third party reimbursement resulted in more providers being able to accept patients with public third party coverage or without coverage. A strong effort to share the responsibility of the medically homeless, coupled with Medicaid reimbursement rates becoming more attractive to the private sector and the development of KCHIP, resources traditionally targeted for clinical services are becoming available for population based services within the community setting.

Regardless of the universality of coverage for children or the increasing willingness of the private sector to serve patients with Medicaid, Kentucky will still experience access issues due to poverty and geographic and cultural isolation. Of the 120 counties in Kentucky, most of the Health Professional Shortage Areas (HPSA's) are based on the county as the service area. There are 75 Primary Care designations of which 44 are geographic, 25 are population based and 6 are partial county designations. There are 18 Dental designations and 98 Mental Health Designations. Eighty-six of the 120 counties are designated as Medically Underserved Areas and 12 additional counties have portions that are so designated. It should be noted that an update of the Medically Underserved Areas has not occurred for sometime. Likely the only improvements in the equation for designation are relative to the physician to population ratio and the infant mortality rate.

Kentucky continues to experience inequities between the infant mortality rate for black and white infants. It should be noted that only eight percent of the total births are classified as black. During both 1997 and 1998 the infant mortality rate for whites stayed constant at 6.9 where the rate for blacks was 11.0 and 14.7 respectively. Recent information from the MMWR March 20, 2000 comparison of health status indicators by race demonstrates similar differences between the white and black population. These differences are being studied by a taskforce chaired by Senator Gerald Neal with plans to address systems issues. Likewise, in Louisville/Jefferson County, the county with the most significant African American population, the local health department is implementing a Fetal and Infant Mortality Review program in hopes of identifying systemic issues affecting these outcomes.

1.5 The State Title V Agency

1.5.1 State Agency Capacity

1.5.1.1 Organizational Structure

Children with Special Health Care Needs

After being without a permanent director since September 1998, the Commission for Children with Special Health Care Needs (hereafter referred to as the Commission) began a new era under the guidance of Ann Marks, R.N., who was appointed Executive Director effective June 1, 1999. The Cabinet for Health Services supported a period of transition that allowed Ms. Marks to work closely with Eric Friedlander who had been on loan from the Cabinet serving as interim director since October 1998. Upon Ms. Marks' appointment, the Workgroup that had been established to review and advise on Commission operations was disbanded. The summary recommendations of the Workgroup were provided to the new Executive Director and those recommendations have been considered and are reflected in developing program revisions and strategic planning. The new Executive Director's experience and background in the area of

managed health care and development of quality care coordination systems has uniquely prepared her to lead the Commission into the developing arena of managed health care for children with special health care needs (CSHCN) and the increasing requirements for quality assurance and accountable systems of care. To address the agency's desired goal to enhance care coordination and improve capacity to serve CSHCN, some changes have been made in organizational structure. Three new positions have been established for Regional Nurse Consultants who are able to provide more direct and focused supervision to staff in three distinct geographic (East, Central, West) areas of the state. These new positions will allow the Commission to implement a new system for enhanced care coordination that is being phased in beginning with the Central region. The Clinical Director position has been shifted to the executive staff division. The duties of that position have been changed to focus on developing a system of care that is committed to high quality/cost effective outcomes for CSHCN in a managed care environment that demands responsibility and accountability to payors, providers, and consumers.

(See Commission Organizational Chart)

The Commission continues to have the advice and support of a seven member Board of Commissioners comprised of representatives from other health care agencies, parents of special needs children, and one young adult with a disability. A Medical Advisory Board provides guidance and quality review for staff physicians and best practice standards for clinical services. The Hemophilia Advisory Committee whose members include providers and family members assures quality review and community input for the Hemophilia program. The Board of Commissioners, Medical Advisory Board, and Hemophilia Advisory Committee are appointed by the Governor, as are the Executive Director, Medical Director, and Directors of Administrative and Clinical Services. Relevant organizational charts are in the Appendix.

Division of Adult and Child Health

On March 16, 2000, the Division of Adult and Child Health engaged in another reorganization that affected the Title V Program. The Nutrition Branch has stayed in tact throughout several reorganizations. The previous organizational design had responsibilities for the Title V program split between two branches, the Clinical Health Branch and the Community Health Branch. Within each of these branches, there was an adult focus and a pediatric focus. It was anticipated that these two branches would work as teams to affect services to the maternal and child health population as well as other programs within their domain. This organizational setup did not provide a centralized focus for the maternal and child health programs that were necessary during a transitional period. Although not finalized on paper until March of 2000, but functional in performance from September 1999, the reorganization created the Maternal and Child Health Branch. A change in management for the Maternal and Child Health Branch occurred in the beginning of 2000, allowing the previous manager to move into the new Assistant Director position. The responsibilities for this position are to focus on public and private partnerships to improve health outcomes for the maternal and child health population. This move, along with the traditional programs associated with the Title V program housed within one branch as well as primary care and oral health, should result in a stronger Title V programmatic effort. In addition to these changes, the 2000 General Assembly passed legislation that removed the Emergency Medical Services Branch from the Division of Adult and Child Health and established it as an autonomous agency. The Division of Adult and Child Health does maintain the poison control program that had been contracted through the Emergency Medical Services Branch.

During April 2000, the Secretary of the Cabinet for Health Services executed an Administrative Order establishing an Office of Women's Health. This office has the following responsibilities:

- Serving as a repository for data and information affecting women's physical and mental health;
- Analyzing and communicating trends in women's physical and mental health issues;
- Recommending to the Cabinet for Health Services and any advisory committee on health data those elements affecting women's physical and mental health which should be collected, analyzed and reported in a timely manner under health data collection laws;
- Cooperating with the various departments and offices within the Cabinet for Health Services in receiving and disseminating through the internet aggregate data findings derived through health data analysis which affect women; and,
- Planning, developing and administering a Women's Resource Center within the Cabinet to focus on targeted preventive care and comprehensive health education.

A revised organizational chart is included.

State statutes relevant to Title V program authority include:

KRS 194A.095 Directs that an Office of Women's Health be established within the Cabinet for Health Services.

KRS 200.460 – KRS 200.499 Commission for Children with Special Health Care Needs. Establishes the organization and guidelines for providing services to children with special health care needs.

KRS 200.550 – KRS 200.560 Hemophilia. Provides for the detection and treatment of children and adults with bleeding disorders.

KRS 200.650 – KRS 200.676 Establishes First Steps, Kentucky Early Intervention System.

KRS 211.180 Gives the Department for Public Health the responsibility for public health, including improving the health of mothers, infants and children.

KRS 211.651 – KRS 211.670 Authorizes the Birth Surveillance Registry administered by the Division of Adult and Child Health.

KRS 211.680 – Authorizes the Department for Public Health to coordinate efforts to reduce the number of child fatalities through reviews of unexpected child deaths.

KRS 211.900 – KRS 211.905 Authorizes comprehensive lead poisoning prevention services.

KRS 213.046 Outlines requirements for implementing a hearing risk registry administered by CCSHCN.

KRS 213.410 Authorizes SIDS services.

KRS 214.034 – KRS 214.036 Establishes immunization requirements for children.

KRS 214.155 Authorizes newborn screening for inborn errors of metabolism and other hereditary disorders (currently PKU, congenital hypothyroidism, galactosemia and sickle cell).

KRS 214.160 Requires syphilis testing for pregnant women.

KRS 214.185 Permits diagnosis and treatment of minors for contraception, sexually transmitted diseases and pregnancy related care without parental consent.

902 KAR 4:080 Disabled Children's Program. Establishes the Disabled Children's Program within the Commission for Children with Special Health Care Needs to provide rehabilitation services for certain blind and disabled children receiving benefits under Title VI of the Social Security Act -- Supplemental Security Income (SSI) benefits.

1.5.1.2 Program Capacity

The reorganization that occurred during 1998 within the Department for Public Health clustered a variety of programs and activities under the Division of Adult and Child Health. This has resulted in the Title V Director having administrative responsibility for significantly more programs. This has fostered opportunities to collaborate thereby increasing the potential to have a greater impact on the health care delivery system that affects women and children. Programs such as breast and cervical cancer, school health, Five a Day Campaign, and Healthy People 2010 objectives relative to the Preventive Health Block Grant are now housed within the Division. Resources housed within the Division can be reallocated or redirected with greater flexibility as a result of this organizational setup.

The Director of the Division of Adult and Child Health provides leadership not only to the division but to the medical profession in the area of maternal and child health. He is the 2000 Co-Chair of the Maternal and Child Health Conference within the Department for Public Health. This conference has secured continuing education units for physicians. He is a member of the Public Health Practice Committee. Dr. Davis serves on the KY March of Dimes State Program Service Committee, KY Perinatal Society Executive Board, KY Injury Prevention and Research Center Board at the University of Kentucky, the Drug Management Review Advisory Board within the Department for Medicaid Services, the Executive Committee of the KY Pediatric Society, the Cabinet for Health Services' Healthcare Decisions Advisory Committee and Healthy Start Task Force, the Committee on Maternal and Neonatal Health, Committee on School Health Education and the Committee on Maternal Mortality for the Kentucky Medical Association and the Kentucky ACOG Advisory Council. These efforts assist to elevate the voice for pregnant women, infants and children in Kentucky.

A Memorandum of Agreement between the Commission and the State Division of Disability Services assures the referral of children who apply for SSI benefits. Details about the Commission's services to SSI children are addressed later in the discussion of national core performance measure #1.

The Commission continues to provide diagnosis, care-coordination, and on-going medical treatment to eligible children through a statewide network of clinics administered in 14 regional offices. These clinics are both on site at the regional offices and off-site in physicians' offices or at local health departments to assure both accessibility to care and availability of special diagnostic and treatment equipment. The Commission provides family-centered, community-based care by sending treatment teams including nurses and pediatric specialty physicians to 58 clinic sites in 31 of the state's 120 counties. The Commission maintains a provider network through contracts with approximately 350 pediatric specialty physicians and 148 dentists throughout the state. Other medical and ancillary services are available through contracts with local community providers. These include contracts with 83 hospitals (including 3 major pediatric centers), 300 pharmacies, 23 independent laboratories, and numerous providers of durable medical equipment, eyeglasses, hearing aids, and home-care services. Besides the Commission's own staff, augmentative services are available across the state through contracts with 45 physical therapists, 25 occupational therapists, and 29 speech therapists. The Commission also contracts for foreign and sign-language interpretative services to assure access to care for families of diverse cultures including those with hearing impairments. These services are available in each Commission region. A need for interpretative services is identified during intake and arrangements are made for appropriate service prior to clinic or other Commission appointments.

1.5.1.3 Other Capacity

The Division of ACH has thirty-two (32) staff that work on Title V programs. Three of these staff are oral health field staff. The remaining are located in central office. Within the Maternal and Child Health Branch, one staff person is designated to coordinate Title V and related State Systems Development Initiative (SSDI) grants. The local health departments and universities continue to be the arm to deliver services to improve outcomes for the maternal and child health population.

No significant changes have been made in the location of offices and number of employees in the Commission. There are currently 92 employees in clinical positions across the state. In addition to a full time physician medical director and a dental program director based in the central Louisville region, other positions across the state include: 56 RNs, 2 LPNs, 10 social workers, 7 speech pathologists, 12 audiologists, 1 occupational therapist, and 2 dieticians. Three (3) nursing positions are vacant. The executive and statewide administrative staffs are located at the regional office in Louisville. The new regional nurse consultants are located as follows: one for the central region is based in Louisville and provides program supervision to staff in the Louisville, Elizabethtown, and Edgewood (northern KY) regions; a second Regional Nurse Consultant is based in Lexington and supervises the eastern part of the state. A

third Nurse Consultant is based in Owensboro provides supervision to the regional offices in Western Kentucky.

The Commission assures the participation and input of families of CSHCN by the inclusion of family members on both the Board of Commissioners and the Hemophilia Advisory Board, and through the use of contracts for specific collaborative activities with two of the state's primary parent advocacy organizations. Information about these activities is detailed in the Needs Assessment section of this document.

The Commission has been fortunate in 1999 to be able to contract for a full time consultant to assist in the development of a custom computer program that will allow for collection and analysis of patient data for program monitoring and development. An in-house staff task force entitled the Computer Utilization Project (CUP) has been established to work with the consultant to advise and review the information system at each stage of development. This information system is projected for implementation in three phases over a 2-year period that began in August 1999 with completion expected in August 2001.

The Commission has also contracted with a medical case-management consultant to review the agency's existing clinical services and assist with development of a new intake and care coordination model. This new process will result in more efficient service delivery and allow for consistent quality review of services provided. Recognizing that not all Commission patients require case management, acuity measurement tools are being refined to use to establish caseload assignments and enhance the timeliness of care coordination.

1.5.2 State Agency Coordination

Early childhood issues continue to be a focus of coordination among agencies in KY. In the spring of 1999 the Governor established a statewide Early Childhood Task Force to assist the Office of Early Childhood in the research and development of information on the status and needs for services to KY children ages birth to eight. The Task Force's efforts resulted in a report that would serve as the foundation for the Governor's proposed legislation to create an enhanced system of early childhood services in the state. Division of Adult and Child Health and Commission staff members served on various sub-committees of the Task Force. The Commission provided the critical research and information to the Office of Early Childhood for the development of the legislative piece on Universal Newborn Hearing Screening. The Division of Adult and Child Health was instrumental in assisting in the development of the entire section entitled Assuring Maternal and Child Health. This bill was passed during the 2000 session resulting in a significant increase of funds for the Division of Adult and Child Health. Programmatic efforts, besides the universal newborn hearing screening, include folic acid provision, a voluntary home visiting program, underinsured vaccine coverage, health, safety and nutrition consultants for child care centers, and eye examinations prior to school entry. Significant program activities are identified for the Commission for Children with Special Health Care Needs and the Division of Adult and Child Health. In addition, a second major effort on early childhood centers on improving the quality of child care. This allows additional opportunities to collaborate

with the Division of Child Care on general child development, data collection and management and quality issues.

In addition to collaboration with the governor's Early Childhood initiative, on-going collaboration with First Steps, the KY early intervention system, is a priority at the Commission. The Commission's Executive Staff Advisor has been a long-time member of the Interagency Coordinating Council (ICC); and other staff members serve on local District Early Intervention Councils (DEICs). In last year's application, we discussed the possibility of developing a joint application with First Steps. Although we have not pursued this objective, activities occurred in 1999 to enhance collaboration and set the stage for future coordination including a joint application or possible single point of entry. Commission staff members were asked to submit questions and concerns regarding local service coordination with First Steps. Those issues and others were addressed in a meeting between the Commission's Interim Director, the Executive Staff Advisor, and the Director of First Steps. Follow-up answers were provided to clarify and improve coordination of services between the two programs.

Other significant state agency coordination in 1999 included the Commission's continuing coordination of systems development and services with the Division of Adult and Child Health (ACH) at the state level and with local health departments. A Memorandum of Agreement (MOA) assures cooperation between the two programs at the state level for sharing of appropriate information and support for activities to enhance the statewide system of care. ACH staff attend meetings of the Board of Commissioners and staff members of both programs have collaborated on activities related to the Early Childhood initiative, on the statewide folic acid education project, and the development of the state's Birth Surveillance Registry. At the local level, the Commission has an historic alliance with local health departments. In some regions, the two agencies continue to share facilities, and coordination of patient referrals and services is routine, e.g., Commission nurses in the Owensboro region assist with an immunization clinic at the local health department.

The Commission routinely maintains a MOA with the Department for Medicaid Services to "provide therapeutic and remedial health care services for Medicaid recipients that are eligible for services covered by the Commission". Effective 7/1/99, a special Master Agreement was signed between these two programs to provide for implementation of an "outreach campaign to enroll additional children through age 18 into Medicaid and the KY Children's Health Insurance Program (KCHIP) and to inform low income families that they may still be eligible for medical and other assistance without applying for TANF". This agreement is in effect until July 31, 2000. Results of this outreach effort will be reported in the block grant report for FY2000. The Commission also maintains a Memorandum of Understanding (MOU) with the Cabinet for Families and Children, Dept. for Community Based Services (CBS) that authorizes CBS screening of Commission applicants for eligibility for Food Stamps, Medicaid, and the KY Transitional Assistance Program (KTAP). Potentially eligible families are assisted with application for these services.

On July 1, 1999, the Commission was awarded funding for a 4-year transition project from the Maternal and Child Health Bureau. This project Kentucky Youth

Transitioning to Employment And Comprehensive Healthcare (KY Teach) is a statewide collaborative effort that includes many partnering agencies. Examples of types of agencies involved include: pediatric and adult providers, the AAP Medical Home Project, vocational and educational groups, various consumer advocacy groups, insurance benefit organizations, and national experts. Although this group is collaborating on an administrative level, much is also happening on a direct services level. The Life Maps (developmentally appropriate transition tools) that were put in place March of 1998 have strongly encouraged families and staff to collaborate with agencies previously unfamiliar to them. Many staff members are members of a variety of local and state interagency groups including: local school-to-work committees, state interagency transition council, state multicultural accessibility partnership, state Early Intervention taskforce, and disability advocacy group councils.

Children who do not qualify for Commission services and do not have financial or other access to medical providers are referred for free specialty services provided in clinics at the University of Kentucky and the University of Louisville. Free services for orthopedics are available to Kentucky children at Shriner's Hospitals for Children in Lexington, KY and St. Louis, MO. Kentucky children may receive free burn care at Shriner's Hospital in Cincinnati, OH. Although the CHOICES (Children's Healthcare Options Improved Through Collaborative Efforts and Services) initiative ended in December 1999, the coordination of services that was established under that project remains in effect. Services are coordinated so that children who are eligible for both the Commission and Shriner's Hospital in Lexington receive non-duplicative care that is efficient for the family and makes the best use of the areas of expertise in both programs. An agreement between the Commission and the Department for Vocational Rehabilitation (VR) to refer adolescent and young adults patients for VR counseling and other services remains in effect and will be strengthened as the Commission improves transition services under the KY Teach project.

Commission Hemophilia and Sickle Cell clinic staffs are very involved in coordination and collaborative efforts. The Hemophilia program director serves as a member of the World Federation for Hemophilia psychosocial group and helps plan the psychosocial sessions for meetings that are held every 2 years. In 1999, Commission staff in collaboration with the KY Hemophilia Foundation, wrote a grant to the National Hemophilia Foundation to provide outreach to women in KY who might have bleeding disorders. The grant was awarded; and, the project targeted all OB/GYNs, health departments, primary care physicians and internal medicine doctors in KY – sent mailings, pamphlets, etc. to their offices. The project enlisted the help of some female patients and mothers of female patients with Hemophilia to follow up with phone calls and personal visits to the doctor's office as necessary. The goal was to get 5 referrals for the year. 11 referrals were actually received and 2 women were diagnosed.

The role of coordination for the Division of Adult and Child Health is not as direct as that outlined for the Commission. In an attempt to influence access, intervention and outcomes, the Division of ACH participates in a high degree of coordination and collaboration with other state human services agencies. Examples of coordination include active involvement in health related aspects of the Kentucky Education Reform Act, promoting comprehensive school health services, and collaborating with the

Department of Education and the Family Resource/Youth Service Center Branch in the Cabinet for Families and Children. ACH staff serve on the Interagency Task Force on Family Resource and Youth Service Centers, the Interagency Coordinating Council for the Kentucky Early Intervention System (Kentucky's Part H program), and the Department of Education's Early Childhood Advisory Council. ACH staff also work closely with the Department for Mental Health/Mental Retardation in the areas of prevention and treatment of substance abuse among women and promotion of children's mental health. The Project director of the IRIS project, Integrated Resources in Schools, with the Department for Mental Health/Mental Retardation is a staff member of the Division of Adult and Child Health. Other staff are involved with the Substance Abuse and Pregnancy Workgroup, KY Substance Abuse Epidemiology Workgroup, HIV/Prenatal Advisory Committee, HIV/Prevention Planning Group, Women's Health Advisory Committee, Primary Care Physicians Advisory Committee for Breast Cancer and the Cervical Cancer Advisory Workgroup.

The Health Access; Nurturing Development Services or HANDS project, continues to be a collaborative effort between the Cabinet for Health Services and the Cabinet for Families and Children. Funding from the Cabinet for Families and Children supports training, an extensive evaluation of the pilot project, a site development coordinator and inclusion of four additional pilot counties to the existing eleven pilot sites. Initial findings from the pilot project assisted in strengthening the identification of this program as a significant component of the early childhood legislative package. The successful implementation of the project also alleviated many of the legislative concerns over privacy and home visitation. Testimony on the successes from HANDS program recipients and a local health department administrator were extremely helpful during committee hearings on this component of the early childhood development package.

The Division of Adult and Child Health participates on Kentucky's Welfare Reform Task Force. The three main areas of involvement are adolescent pregnancy prevention, immunizations and the sharing of client information. This collaboration with the Cabinet for Families and Children continues to be profitable for the Division of Adult and Child Health. The sharing of a common objective, partly in the context of welfare reform, of reducing teen pregnancies, the Cabinet for Families and Children has provided funding for family planning services to reduce teen births.

The Department for Public Health has an active collaborative relationship with the Kentucky Dental Association and the Kentucky Dental Health Coalition. These organizations are working together to promote programs, surveillance activities, and policies that will improve/promote the oral and general health of Kentuckians. A few examples of these activities are: community and school water fluoridation programs; dental health education activities through the schools, family resource centers and health departments; and beginning the oral health survey for Kentucky.

In addition to governmental linkages, ACH also collaborates with a number of associations, voluntary organizations and advocacy groups with an interest in maternal and child health. For instance, ACH staff members serve on the Migrant Health Coalition and the Kentucky State Coalition on Primary Care. ACH also collaborates

with the March of Dimes, the Kentucky Disabilities Coalition and the Kentucky Perinatal Association.

Formal coordination with the Department for Medicaid Services continues through an Interagency Memorandum of Agreement, reviewed annually. Another interagency agreement, with the Department for Mental Health and Mental Retardation, for early intervention services, is renegotiated annually. A third agreement is in place between the Department for Public Health, Department for Medicaid Services and Department for Social Services. This agreement provides Medicaid reimbursement for targeted case management for Medicaid patients (including children in custody or at risk of being in custody of the state and adults in need of protective services) and for rehabilitative services for Medicaid-eligible children in custody or at risk of being in custody of the state. Another agreement provides Medicaid reimbursement for early intervention services for infants and toddlers who are determined eligible for First Steps, Kentucky's Early Intervention System, authorized by Part C of the Individuals with Disabilities Education Act. Two new activities with the Department for Medicaid Services will require Memoranda of Agreement; reimbursement for home visitation (HANDS) and data sharing.

As mentioned earlier, ACH has contracts with both the University of Louisville and the University of Kentucky for tertiary services such as genetic services, neonatal care, metabolic services, sickle cell and developmental services. The tertiary centers also provide invaluable consultation and educational offerings to ACH and hundreds of providers across the state.

The amount of coordination and cooperative work between ACH and local health departments cannot be overstated. Local health departments are the primary prevention arm for maternal and child health services in Kentucky. Traditionally, this has meant that most of the Title V Block Grant funds have supported direct clinical services in the local health departments. State staff have continue to present opportunities for local health departments to partner with new entities and move from direct clinical to services reflected in other sections of the pyramid. There are essentially three health care delivery system changes that have and continue to impact local health departments all at the same time. These are Medicaid cost based reimbursement phase out; more private providers providing medical homes via Medicaid managed care or the KenPAC physician case management program; and, the overall reduction in the number of Medicaid patients so that those local health departments still providing direct clinical services have less opportunities for generating reimbursement from Medicaid.

The Department for Public Health was instrumental in helping Medicaid establish clinical outcome measures by which Medicaid managed care is evaluated; and assists in the monitoring of these outcomes. More recent collaborative efforts center around data sharing between the agencies. Recent activities relative to sharing data between the Department for Public Health and the Department for Medicaid Services has crystallized as a result of the regional data sharing meeting during April in Atlanta. A proposal is under development for an interdepartmental and divisional focused effort on

data sharing and data quality. Staff continue to work closely with implementation of the KCHIP and on the role of local health departments in outreach.

In an attempt to assure care for the adult population, two related efforts are administered and coordinated by the Division of Adult and Child Health. The Kentucky Physician Care Program operates a hotline for care. Kentuckians with incomes less than 100% of the poverty level can register with the local Department for Community Based Services office and call the hotline for a referral for care. A database is maintained of participating doctors, dentists and pharmacists. This programs covers one office visit and some medications. Also several pharmacy companies provide medication at no cost to the program. It is a coordinated effort between the Kentucky Medical Association, Health Kentucky and the Division of Adult and Child Health. The Charitable Health Care Providers Program is coordinated with the Kentucky Department of Insurance. The Division works to register those physicians who are retired and not routinely practicing, but willing to provide care to the indigent population and state general funds support the cost of their medical malpractice insurance for those who are retired. Both this program, and the Kentucky Physician Care Program, are examples of coordination with partners traditionally not involved with the Title V program.

The tobacco settlement has created an opportunity to work with the Attorneys General in implementing the master settlement. Meanwhile, the Department of Public Health has taken the approach that all contracts must address at least one or more of the Centers for Disease Control tobacco control efforts. These are: keep youth and women of childbearing age from initiating tobacco use, stop tobacco use, eliminate exposure to second hand smoke, and/or assist in removing the discrepancy in tobacco related diseases in minority, economically disadvantaged and rural populations.

The Commission and the Division of Adult and Child Health continue working together in several areas. Two of the most prominent are the development of a state Birth Surveillance Registry and the public health initiative on Folic Acid education to prevent Neural Tube Defects. The Commission has agreed to ensure referrals for genetic counseling for all parents of Commission patients with NTD and to provide counseling by a nutritionist, physician and/or nurses about the role of Folic Acid in preventing further NTD 's. The Folic Acid Resource guide developed by the CDC is the primary tool for education and counseling. Staff from the Commission represent the agency on the Kentucky Folic Acid Partnership, the National Birth Defects Prevention Network, and on the NTD Surveillance/Folic Acid Education Committee.

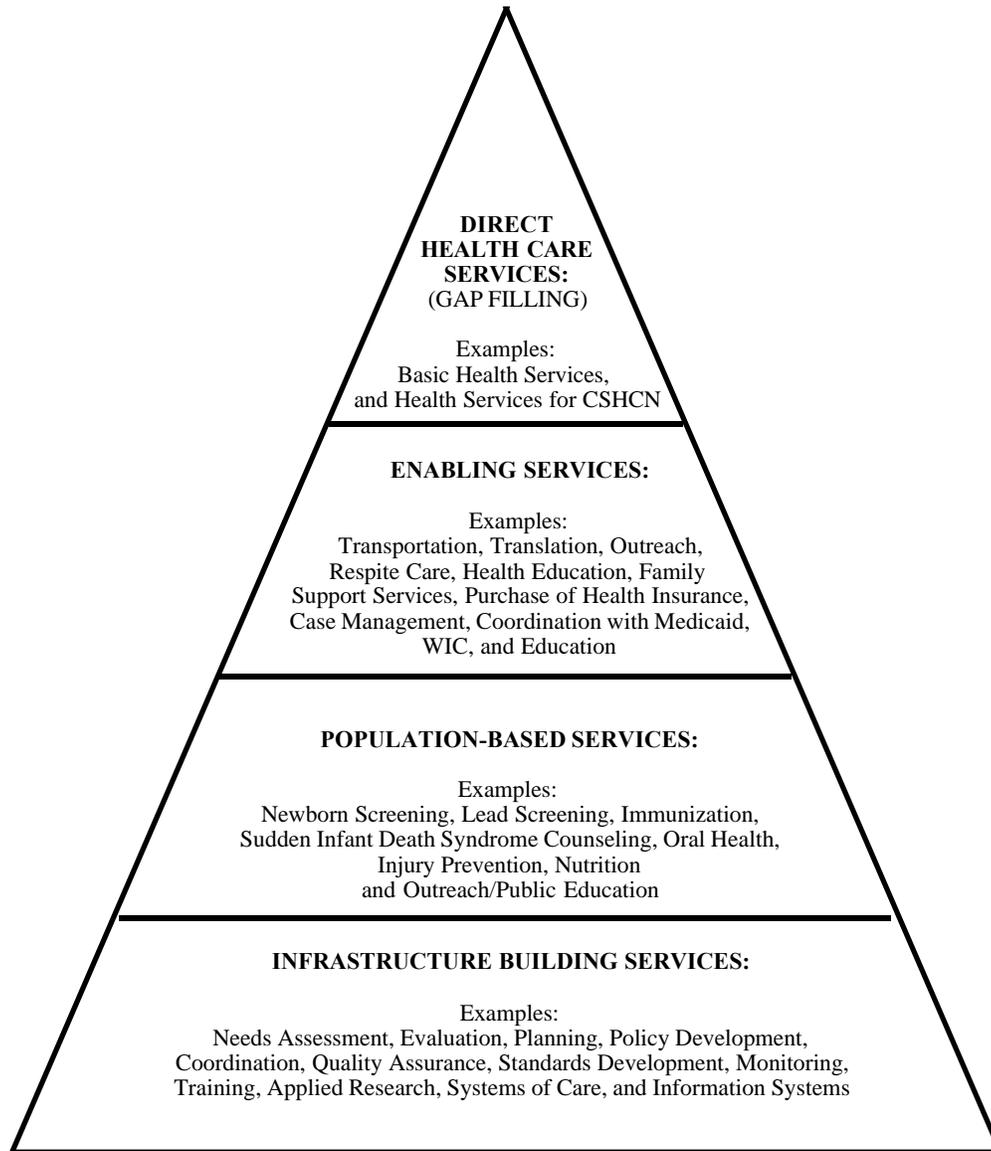
II. REQUIREMENTS FOR THE ANNUAL REPORT

2.1 Annual Expenditures

See Form 3, Form 4, and Form 5

Figure 2

CORE PUBLIC HEALTH SERVICES DELIVERED BY MCH AGENCIES



- 2.2 Annual Number of Individuals Served
See Form 6, Form 7 and Form 9
- 2.3 State Summary Profile
See Form 10
- 2.4 Progress on Annual Performance Measures

Direct Health Care Services

Two national performance measures and one state performance measure relate to this level of the pyramid.

National Performance Measure #1

Percent of SSI beneficiaries less than 16 years old receiving rehabilitative services from the state CSHCN program.

SSI beneficiaries ages birth to 21 that qualify medically are served in the Clinical and Hemophilia programs of the Commission. New Commission applicants and enrollees are screened for SSI eligibility at intake and annual financial reviews. Potential SSI eligibles receive assistance to complete the application, and medical information is provided as necessary. SSI beneficiaries age birth to 4 receive special care coordination and services through the SSI/Disabled Children's Program (DCP). The Commission served 3,416 SSI recipient children in FY' 99 or 17.1% of the average total SSI children (20,000) in the state. Statistics for FY'99 are as follow:

1,506 SSI beneficiaries ages birth to 4 were served in DCP.

1910 SSI beneficiaries ages birth to 21 were served in the CSHCN, Hemophilia and Sickle Cell programs.

The Disability Determinations Services (DDS) reports the following statistics:

KENTUCKY DDS - SSI CHILDHOOD CLAIMS FY 99 (9/25/98 - 9/30/99)

New Childhood Applications:

7215 - Received

3654 - Allowed (3428 Initial + 226 Recon Reversal)

3830 - Denied

Regular Childhood CDR Claims Processed:

3775 - Continuances (3568 - Initial Continuances + 207 Cessations Reversed On Appeal)

1245 - Cessations (Total Initial Cessations Less 207 Reversed On Appeal)

Childhood Re-determination (PL 104-193) Processed:

162 - Continuances (83 Initial Continuances + 79 Cessations Reversed On Appeal) - Met New Childhood Criteria

8 - Cessations (Total Initial Cessations Less 79 Reversed On Appeal)

Re-Reviews of Mental Retardation Denials Processed:

14 - Allowed (Prior Denial Reversed)

49 - Denied (Prior Denial Affirmed)

Re-Reviews of 1997 or 1998 Childhood Re-determinations (PL 104-193) Cessations Processed:

18 - Continuances (Cessations Reversed Met New Childhood Criteria)

45 - Cessations Affirmed

A revised addition of The KY Services for Children and Youth Directory, a collaborative effort of the state SSI for Children Task Force, was printed and distributed throughout the state in the spring of 1999. This directory is an outreach/referral resource provided to families when they apply for SSI and Title V CSHCN services. It is also made available to numerous other public and private service providers for use with families across the state.

National Performance Measure #2

Degree to which State CSHCN program provides or pays for specialty and subspecialty services.

Although there are certain limitations and restrictions for some services, the Commission provides or pays for every type of service listed on the checklist for this performance measure. Children enrolled in the CSHCN, Hemophilia, and Sickle Cell Programs may receive all services with the exception of early intervention. Children enrolled in DCP receive care coordination and financial assistance to support the other services on the checklist. DCP is a supplemental resource for children who need early intervention services not provided or available through First Steps. A complete list of conditions treated and services provided by the Commission is in the APPENDIX.

Treatment for Hemophilia is one of the most costly services provided by the Commission and one that requires intense care coordination. (This is also the only condition for which the Commission provides care to adults.)

In FY '99, the Commission had 326 patients enrolled in the Hemophilia program:

172 were over the age of 20

154 were under the age of 20

275 were male

51 were female

42 were HIV positive, 7 of these patients were under 21

Highlights of services and activities provided to Hemophilia patients in 1999 include:

- provided a home treatment class on a Saturday which taught 15 families how to home infuse their factor or their child's factor
- in collaboration with the hemophilia foundation, provided a seminar on gene therapy for patients/families
- participation (ongoing) in a national Hepatitis C study in which patients who are HIV negative but Hep C positive take 2 medications to hopefully rid their body of the virus. The Commission has 12 patients in this study.
- provided specialty care to patients, including HIV care, Hepatitis C care, dental, orthopedic, gynecological
- held 2 clinics just for females
- joined the Centers for Disease Control Universal Data Collection project which requires blood samples and treatment information, plus physical therapy measurements for each person with hemophilia or vonWillebrand's disease in KY

The Commission began serving children with Sickle Cell disease in 1998, and has seen this program grow by leaps and bounds. The program is currently following approximately 150

children under the age of 21– this is mostly in Louisville and Western KY although about 30 are in the Eastern half of the state.

The program receives an average of 10 newborn screens per month; and, nurses contact the primary care physician and the family within 24 hours of the referral. A repeat diagnostic screen is scheduled with the goal being penicillin by the age of 2 months. Home visits are scheduled with new babies to acquaint the family with services and establish a relationship that will result in good care coordination. Coordination of services with primary physicians and pediatricians is a concern. Some doctors are reluctant to refer young infants for repeat screening or to begin penicillin prophylaxis. To address this service barrier, the Commission has collaborated with the hematologist on staff to provide outreach and information to referring physicians on national standards and treatment recommendations.

Nutritional counseling and support is an example of a specialty service available for any Commission enrollee whose diagnosis requires nutrition services or for whom diet is as an area of concern identified by the family or a member of the Commission treatment team. Children with severe and/or chronic physical or developmental disabilities are at greater risk for nutrition or feeding problems due to altered energy metabolism, muscle tone abnormalities, anatomic abnormalities, drug nutrient reactions, delayed feeding skill development, and oral/tactile hypersensitivity. Nutrition services at CCSHCN are provided by one full time and one part time registered dietitian who are based in the two largest CCSHCN regions of Louisville and Lexington. The part time dietitian is employed directly by CCSHCN and the full time dietitian is contracted from the Jefferson County Health Department. Additional nutrition services are provided by MCH funded nutritionists who attend clinics in Northern Kentucky and Owensboro and who accept referrals from the other CCSHCN regions.

Services provided by the CCSHCN funded nutritionists include: nutrition screening, assessment, and counseling for children in clinics; home or school visits; consultation with CCSHCN and community health professionals; referral of children to community agencies and professionals; assistance to families to obtain funding for nutrition supplements or tube feeding formulas; selection and preparation of patient education material; and consultation and training for nutritionists and other professional in the nutritional needs of children with special health care needs.

One example of the benefits of nutrition services is a 7 year old girl with hydrocephalus, hypotonia and dysphagia who is fed by gastostomy tube. The child had begun to have profuse vomiting after changing her tube feeding formula from an infant formula to a formula for older children. Her pediatrician had diagnosed G.E. reflux and had recommended a Nissen fundoplication. The CCSHCN nutritionist determined that the reflux was due to overfeeding from failure to adjust the tube feeding volume when changing to a more calorically dense formula. The nutritionist advised how much feeding volume to give, and the child's reflux resolved.

Another example is a 7 month old girl with cleft palate, who was gaining weight well on her initial clinic visit after initial feeding problems. The infant's mother did not know that infants with cleft palate can eat table foods when developmentally ready. The nutritionist discussed signs of readiness to advance food textures and advised what to do for the infant's chronic constipation.

State Performance Measure #10

Average age of diagnosis of children with Chronic Otitis Media with Effusion.

Due to factors that complicated data accumulation and review, this measure is no longer being tracked. However, because Otitis Media can cause significant impairment to early childhood development, the Commission remains committed to early intervention and management of Otitis Media and its complications. The Commission will continue to address this issue by:

- Provision of community education and professional workshops presented by Commission audiologists regarding the early identification of all hearing impairments (permanent and transient), and the delays associated with late diagnosis in the areas of speech/language, learning, cognition and social-emotional development.
- Hearing conservation education and direct services provided in pre-schools, Head-Start programs and elementary schools statewide.

Enabling Services

One national performance measure and two state performance measures relate to this level of the pyramid.

National Performance Measure #3

Percent of CSHCN in the state who have a “medical/health home.”

Assuming that all Commission enrollees with 3rd party payors have medical/health homes and an additional 3% of the Commission's total population who are indigent enrollees have medical/health homes, the total % of children with medical/ health homes served in the CSHCN program is 72.19% (Medicaid + Insurance = 69.19% + 3% uninsured = 72.19%). This continues to improve with the inception of KCHIP and we expect this to increase to about 90% and remain there by FY' 2000. Private Insurance portion increased slightly - may be the result of the Welfare to Work programs.

* For this performance measure, the Commission continues to use program enrollees only since we do not have access to data on the broadly defined CSHCN population. However, based on the responses to a query on medical home in the needs assessment family survey, 76.74% of respondents reported CSHCN with medical homes. This is consistent with the % of Commission enrollees with medical homes (72.19%).

State Performance Measure #5

Percent of families receiving support services/parenting assistance through home visiting support programs.

The 1999 data is 20.2% percent that are enrolled in the pilot project. Several programs effect this measure for primary and preventive services for women and infants: Resource Persons

Program, Maternity and Prenatal Care, Injury Prevention, Child Safety Seat Program, Child Abuse and Neglect and Healthy Lifestyle Education. The School Health and Adolescent Preventive Health Services, Family Planning for Teens, Teen Pregnancy Prevention, Abstinence, HANDS, Injury Prevention, Child Safety Seats, Child Abuse and Neglect and Healthy Lifestyle Education, Nutrition Services, WIC all effect the measure for preventive and primary services for children.

Staff have surveyed existing home visitation programs in Kentucky and worked to bring resources from these efforts together in a collaborative effort. Representatives from various programs and those interested in improving pregnancy outcomes, optimal child growth and development and family self-sufficiency have been meeting to coordinate efforts and collaborate on outcomes. This effort has engaged in strategic planning and visioning for the potential of successful legislation during the 2000 session. Plans were made for developing training, community collaboration and implementation plans for the coming year.

This collaborative effort supported the Governor's Task Force on Early Child Development and staff from the Division of Adult and Child Health staffed various subcommittees responsible for research and reporting to the Task Force. The culmination was legislation submitted and passed by the 2000 legislature that included a full implementation of the HANDS or other home visitation programs for all of Kentucky's counties. The percent of counties will significantly increase during the roll-out over the next three years. Projections have been revised to reflect this programmatic expansion.

State Performance Measure #9

Degree to which the Commission provides opportunities for young people to develop skills for transition at critical developmental stages.

KY Teach, a newly funded four-year transition project, is building upon the groundwork laid by the WISH Project. The KY Teach Project began in July of 1999 and has provided additional funds to support statewide collaborative efforts to assist young people to successfully transition to adult life. Specific activities that have taken place related to this performance measure include: 1) use of Life Maps (transition questionnaires) with all patients seen by the Commission; 2) comprehensive survey of 18-21 year olds who left the program in FY'99 to assess baseline outcomes of youth; 3) statewide meeting of collaborating partners to identify goals of each specific agency related to the project; 4) funding for young people, families, and staff to attend local, state, and national conferences; and 5) presentations and dissemination of transition resources developed by the Commission to families, state providers, and agencies 6) held a transition clinic for adolescents with Hemophilia ages 13-15 to come to the adult clinic for a day – 5 participants.

**Note, effective with this application, the Commission has revised SP# 9 to read as follows: Degree to which Commission ensures that children with special health care needs and their families receive the services and opportunities necessary to make appropriate transitions to adult life, including adult healthcare, work, and independence. (See Discussion of State Performance Measures and Revised State Performance Detail Sheet.)*

Population Based Services

Seven national performance measures and four state performance measures address this section of the pyramid.

National Performance Measure #4

Percent of newborns in the State with at least one screening for each of PKU, hypothyroidism, galactosemia, hemoglobinopathies combined.

Data for this measure is 97.1% of newborns with screening for these conditions, a decrease from 1997 when 98.6% of newborns received testing. Newborn screening tests are performed by the Division of Laboratory Services. Follow-up for positive screens is coordinated through the newborn screening program in the Division of Adult and Child Health. The Division of Adult and Child Health has a designated staff person as administrator of the newborn screening program. In addition, contracts are made with both the University of Kentucky and the University of Louisville Medical Centers to provide medical consultation for the newborn screening program. In addition to providing a confirmatory diagnosis of the screening result and medical management, the universities engage in medical education and training throughout the state. Formula, and now food products will also be provided for individuals with certain newborn metabolic conditions including PKU. The Commission for Children with Special Health Care Needs provides outreach and case management services for children with positive sickle cell disease results.

National Performance Measure #5

Percent of children through age two who have completed immunizations for Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, Hepatitis B.

During 1998, Kentucky experienced 81.9% completed immunization status. At many points within the health, education and social service delivery system, a child's immunization status is assessed and referral made when indicated. This comprehensive approach has allowed Kentucky to surpass the national average. Specific programs that effect this measure within preventive and primary services for children include the following: Regional Pediatrics Program, Children and Youth Project, Well Child Program, Health Access, Nurturing Development Services (HANDS), WIC and Healthy Lifestyle Education. Legislation passed during the 2000 General Assembly provides support for the underinsured for immunizations.

National Performance Measure #6

The rate of births (per 1,000) for teenagers aged 15 through 17.

Data for 1998 indicate a 31.5 rate and has been on a downward trend. This rate is less than the Healthy People 2000 objective identified in the performance measure. A full array of family planning services throughout the local health department system contributes to this success through primary and preventive services for women and infants. In addition, the preventive and primary services for children that effect this measure include: the School Health and Adolescent Preventive Health Services, Family Planning for Teens, Teen Pregnancy Prevention, Abstinence and Healthy Lifestyle Education.

National Performance Measure #7

Percent of third grade children who have received protective sealants on at least one permanent molar tooth.

The most recent data for this objective is from 1987. Plans were under development to survey for this data. Contracts have been negotiated to receive this information for the next reporting period. The Kentucky Department of Public Health is guiding an effort to develop an oral health status surveillance system for Kentucky.

National Performance Measure #8

The rate of deaths to children 1-14 caused by motor vehicle crashes per 100,000 children.

The most recent data for this objective is 1998. Kentucky experienced a 6.7 rate for this time period. It is hoped that this rate will decline in coming years through the variety of preventive and primary services for children programs that can impact this rate. The Children and Youth Project, the Well Child program, the HANDS program, WIC, Child Fatality Review, Injury Prevention, Child Safety Seats, Child Abuse and Neglect and Healthy Lifestyle Education. Within the primary and preventive services for women and infants, the injury prevention program can expand understanding of safety for women.

Two specific efforts by the Maternal and Child Health Branch include the Kentucky Safe Kids Coalition and prevention measures identified through the Child Fatality Review Program. During 1999, the Kentucky Safe Kids Coalition received grant funds to assist in fully implementing the "Buckle That Child" program. This program operates an 800 number for citizens to report other Kentucky drivers by license number who are noticed driving without the child or children in their car buckled up. Information on the importance of securing children and wearing seat belts is mailed to driver. This grant provides safety seats as a resource for low income families in hopes that law enforcement will ticket and judges will fine which has at times been lax because of the economic burden on families. The second effort was the receipt of a mini van from the General Motors and National Safe Kids Campaign partnership that is fully equipped to perform safety seat checkups. Partnering with the Department for Transportation, Governor's Drive Smart Program has allowed these efforts to be implemented.

National Performance Measure #9

Percentage of mothers who breastfeed their infants at hospital discharge.

Data for 1998 indicate that 50.2% of mothers breastfeed their infants at hospital discharge, an increase from 47% during 1997. A variety of primary and preventive services for women and infants address this performance measure. These include: Family Planning Services, Resource Persons Program, HANDS, Maternity and Prenatal Care Program, Nutrition Services, WIC, Healthy Lifestyle Education and WIC Breastfeeding Promotion.

National Performance Measure #10

Percent of newborns who have been screened for hearing impairment before hospital discharge.

- In 1999, 52% of Kentucky's infants without hearing risk factors received hearing testing before hospital discharge. The Hearing High Risk Registry identified 4,134 infants as having risk factors for hearing loss. 76% (3,180 infants) of Kentucky's At Risk infants received hearing screenings before hospital discharge.

- The Owensboro Regional office collaborated with a local hospital, Owensboro Mercy Health System, to pilot a newborn I-HCP (Infant-hearing Conservation Program). The hospital refers all newborns that fail hospital hearing screening directly to the Commission for recheck of hearing. Families are not charged for the retest. The Commission treats these referrals in the same fashion as school hearing conservation testing; that is no record is established unless a hearing loss is established and the family applies for services and meets financial and diagnostic criteria for the program.
- In support of early identification and universal newborn hearing screening, Commission audiologists participated in several outreach activities including an informational and appointment scheduling booth during the Kentucky State Fair. In addition to outreach activities, informational brochures were re-designed to offer more information to parents about the importance of hearing screening and hearing screening options.
- A significant enhancement to the HHRR's early intervention efforts has been increasing the amount of provider outreach and direct physician contacts. Due to improvements in the HHRR database system in 1999, physicians were contacted an average of 3 more times annually, per high-risk child in their practice.

State Performance Measure #1

Percent of women of childbearing age taking folic acid regularly.

During 1999, 43.4% of women were taking folic acid regularly, an increase from 36.2% in 1997. The importance of folic acid is stressed for both primary and preventive services for women and infants and preventive and primary services for children via Nutrition Services, WIC, Genetics, Healthy Lifestyle Education and the Birth Surveillance Registry. The Folic Acid Module was deleted from the Kentucky Behavior Risk Factor Survey for 1998 due to the inclusion of other categorical questions and the need to balance the number of survey questions for that year. The Folic Acid Module was reinstated into the Kentucky Behavior Risk Factor Survey for 1999.

The Division of Adult and Child Health engages in a folic acid campaign in partnership with the March of Dimes. In addition, a program to provide for folic acid for low-income women of childbearing years was included as part of the early childhood development package passed during this legislative session. This supplement will augment the folic acid awareness campaign currently underway.

State Performance Measure #2

Percent of counties with comprehensive child safety education and injury prevention programs in place.

Eighty-one percent of Kentucky's 120 counties had programs in place during 1998, an increase from 76% the previous year. For primary and preventive services for women and infants the following programs affect this measure: Injury Prevention, Child Safety Seat Program, Child Abuse and Neglect and Healthy Lifestyle Education. These same programs and the HANDS program are programs offering preventive and primary services for children. With an emphasis on population-based services at the local health department level, it is anticipated that there will be an increase in counties that are offering child safety education and injury prevention programs. Traditionally this has been done via services provided within the health department

as patients received preventive health services. As the demand for preventive health services from local health departments decreases, new opportunities are available for population based injury prevention efforts that can reach the entire community.

State Performance Measure #6

Percent of children with inappropriate weight for height.

Data for this measure is 1998 data. There were 12.7% of children with inappropriate weight for height. Performance on this measure has steadily declined. This mirrors the national trend of increased obesity in children. Renewed efforts towards population based services by the local health departments can contribute towards improving this measure. Nearly all of the programs within Preventive and Primary Services for Children can affect this measure, with significant focus on primary prevention. These include the Regional Pediatrics Program, Children and Youth Project, Well Child, Lead Screening, School Health and Adolescent Preventive Health Services, Teen Pregnancy Prevention, Nutrition Services, HANDS, WIC, Child Abuse and Neglect and Healthy Lifestyle Education. For primary and preventive services for women and infants, the Resource Persons Program, Maternity and Prenatal Care, Nutrition Services, WIC, Child Abuse and Neglect, Healthy Lifestyle Education and WIC Breastfeeding Promotion effect this measure.

State Performance Measure #7

Percent of child deaths undergoing local multidisciplinary investigation.

During 1998, 63.5% of child deaths were reviewed by coroners, an increase from 47.3% in 1997. Programs that can affect this measure for primary and preventive services for women and infants include the Grief Counseling Program, Injury Prevention, Child Safety Seat Program, Child Abuse and Neglect, Healthy Lifestyle Education and Infant Mortality Review. For preventive and primary services for children, the programs are Child Fatality Review, HANDS, Injury Prevention, Child Safety Seats, Child Abuse and Neglect and Healthy Lifestyle Education. Staff have been working collaboratively with partners to increase training opportunities for child fatality review. Seed monies to local health departments to take the lead on developing child fatality review teams assisted in this improvement.

Infrastructure Building Services

Eight national performance measures and three state performance measures address this section of the pyramid.

National Performance Measure #11

Percent of CSHCN in the state with a source of insurance for primary and specialty care.

Again, for the purposes of this measure, the Commission defines CSHCN as those children who are enrolled in our program. Actual statistics for children enrolled in the Commission in FY'99 are as follows:

Commission Enrollees with Medicaid and Medicaid Managed Care-----	6,309 (41. 56%)
Commission Enrollees with Medicaid/MMC and Private Insurance-----	451 (2. 97%)
Commission Enrollees with Private Insurance-----	3,745 (24. 67%)
Commission Enrollees without any 3 rd party coverage (uninsured)-----	4,677 (30. 81%)

For those identified with private insurance, the insurance may not cover services needed; the deductibles may be unreachable for families; or the out-of-pocket expenses may be too great. The Commission assists those families with limited coverage. Again, as with PM# 03, the % of CSHCN with insurance is increasing with the implementation of KCHIP; however this information will not be reflected until the report for the year 2000. The slight increase in Private Insurance may be a result of the Welfare to Work programs.

National Performance Measure #12

Percent of children without health insurance.

During 1998, 14.1% of children in Kentucky did not have health insurance, a slight improvement from 14.5% for the previous year. With the implementation of the child health insurance program, it is anticipated that this figure will decrease substantially. During 1999, the Department for Medicaid Services engaged in an extensive outreach campaign for the KCHIP in hopes of reducing this figure significantly. By January of 2000, cumulative enrollees for all phases of the KCHIP totaled 36,714. Currently for primary and preventive services for children there are several programs that effect this measure. These include the Regional Pediatric Program, Children and Youth Project, Well Child Program, Lead Screening, School Health and Adolescent Preventive Health Services, Genetics, Developmental Evaluation and KY Early Intervention Services and Dental Services.

National Performance Measure #13

Percent of potentially Medicaid eligible children who have received a service paid by the Medicaid Program.

There were 50.93% of potentially eligible children who received a service paid by Medicaid during 1998. This percentage appears to have decreased significantly for 1998, but in actuality this rate has increased due to incorrect evaluation of those eligible for services being mistaken for recipients who received services. In 1997 49.3% of those eligible actually received a paid service from the Medicaid Program. Outreach activities occur within all preventive and primary care services for children. The Department for Medicaid Services comprehensive outreach campaign for the KCHIP program may have an effect upon this measure as well. Local health departments have engaged in outreach for the population potentially eligible for Medicaid and efforts continue by the Title V Director to increase physician participation.

National Performance Measure #14

Degree to which the State assures family participation in program and policy activities in the State program. (See attachment to PM#14 in the forms section.)

- Families were involved in Commission activities in 1999 using contracts with two prominent statewide parent education and advocacy groups, which developed and administered surveys and conducted focus groups as a component of the statewide needs assessment.
- To assure family input to program development and monitoring, the Commission has family members appointed to both the Board of Commissioners and the Hemophilia Advisory Committee. In 1999, a parent representative member of the Board of Commissioners met with social workers and a non-Commission parent representative

from the Owensboro region to discuss family concerns and begin to gather ideas towards development of a formal network of parents of Commission enrollees.

- Young adult patients and parents served as consultants to the development of the KY Teach grant and have participated in initial grant activities including helping with construction of surveys of graduates and planning for workshops for teens and family members. Young adults with disabilities and parents of children with disabilities were session leaders in the CHOICES national conference in April 1999.

National Performance Measure #15

Percent of very low birth weight live births.(<1500 GMS).

Most recent data for this measure is 1998 data. The percent of very low birth weight live births was 1.7 percent, an increase from 1.4% for the previous two years. A variety of primary and preventive services for women and infants effect this measure. These include the Resource Persons Program, Prenatal Care Program, Perinatal Home Visiting Program, Nutrition Services, Birth Surveillance Registry Program, Genetics, Developmental Evaluation, Kentucky Early Intervention Services, WIC, Child Abuse and Neglect, Healthy Lifestyle Education and WIC Breastfeeding Promotion. Contracts with the two university medical centers for neonatal services support this measure. Recent requirements for all contractors and local health departments regarding CDC four recommendations regarding smoking cessation and disparities should have an effect on this measure in the future.

National Performance Measure #16

The rate (per 100,000) of suicide deaths among youths aged 15-19.

Data from 1997 indicate a rate of 8.4 for this population, somewhat higher than the Healthy People 2000 goal of 8.2. Several preventive and primary services for children programs address this measure. These include: Regional Pediatrics Program, Well Child Program, School Health and Adolescent Preventive Health Services, Family Planning for Teens, Teen Pregnancy Prevention, Abstinence and Healthy Lifestyle Education.

National Performance Measure #17

Percent of very low birth weight infants delivered at facilities for high risk deliveries and neonates.

In 1998 52.8% of very low birth weight infants were delivered at Level III facilities in Kentucky. This was a decrease from 57.3 in 1997 according to data from the 1998 RNDMU report. When changes in the clinical standards were implemented where babies with low birth weight less than 2500 grams did not have to be delivered or transported to a Level III facility, this allowed the Level II hospitals to become more proficient at caring for babies with low birth weight. In addition, more areas were employing full time neo-natologists and babies were born and staying at Level II hospitals. This change warrants monitoring to assure that the outcomes for these infants are not negatively affected.

National Performance Measure #18

Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.

Data for 1998 indicates that 85.5% of women received prenatal care in the first trimester, a very slight increase from the previous year. For primary and preventive services for women and infants, the Maternity and Prenatal Program addresses this measure. Title V agency plans to review systems issues that may be present to determine any barriers for early entry and develop measures to promote early entry into prenatal care.

State Performance Measure #3

Rate of unintended or mistimed pregnancies.

The rate for 1998 was 33.2 for this measure, compared to 57 for the previous year. Effective with the 2000 application, this measure is no longer tracked. Questionable data sources resulted in this change and the needs assessment and new priorities provided the opportunity to gather data relative to this measure in a standardized format. Primary and preventive services for women and infants that effect this measure include: Family Planning Services, Genetics, Child Abuse and Neglect and Healthy Lifestyle Education. For Preventive and Primary Services for children, the School Health and Adolescent Preventive Health Services, Family Planning for Teens, Teen Pregnancy Prevention, Abstinence, HANDS, Injury Prevention, Child Abuse and Neglect and Healthy Lifestyle Education effect the measure.

State Performance Measure #4

Rate of substantiated incidence of child abuse, neglect or dependency.

During 1998, the rate for Kentucky was 28.7, an increase from 1997 and 1996. The Resource Persons Program, Maternity/Prenatal Care Program, Injury Prevention, Child Safety Seat Program, Child Abuse and Neglect and Healthy Lifestyle Education within primary and preventive services for women and infants effect this measure. These same programs as well as the School Health and Adolescent Preventive Health Services, Family Planning for Teens, Teen Pregnancy Prevention, Abstinence and HANDS effect this measure for preventive and primary services for children. One of the anticipated outcomes for the statewide home visitation program is the reduction of child abuse and neglect. This should contribute to a decline in this rate over the next few years.

State Performance Measure #8

Percent of primary providers in Kentucky who use the agency to provide care for children with special health care needs.

Recognizing provider outreach and referral base as a significant concern, the Commission began an attempt to track the number of PCPs referring children to the program in FY'98. A completely accurate and reliable count has not been possible due to lack of information technology to collect this data. However, our manual tracking efforts have improved and we have steadily added to our information. As of July 1999, the Kentucky Medical Directory lists 2,142 physicians in the categories of Family Practice, General Practice and Pediatrics. Physicians in these categories are those most likely to be providing primary care services to children enrolled in the Commission. As of 12/31/99, the Commission had documented 338 different physicians actively referring patients. This was an increase of 19% over the total number (284) that we had documented on the same date in 1998.

2.5 Progress on Outcome Measures

Because Kentucky Vital Statistics Data for FY 99 was not available at the time of this application and report, (the target date for its completion is November of 2000), FY 98 data has been used for reporting outcome measures.

Kentucky outcome measures for infant, perinatal, neonatal and post-neonatal periods had shown overall improvement since FY 91. That positive trend was attributed to improvements in early access to prenatal care, regionalization of perinatal care, and expansion and enhancements in perinatal care through neonatal intensive and specialty care in tertiary, regional and community settings. Development of a network of genetic and developmental clinics, folic acid education and supplementation, injury prevention coalitions and education, home visiting, encouragement of breast feeding, targeted efforts to reduce unintended, mistimed, and/or teen pregnancies, and child fatality reviews have contributed to these changes. However, although sustainability efforts have continued, over the past year, four of the six outcomes have shown a reversal in progress.

Kentucky's infant mortality rate continues to have a wide black-white gap ratio in infant mortality. Kentucky's black population in 1998 was 284,529 with 4820 live births. Forty-two percent of Kentucky's black population lives in one urban area (Jefferson County.) This area accounted for 48% of all black live births in the state in 1998. Of the state's total 71 black infant deaths, 62% occurred in this urban setting, and the black infant mortality rate has been consistently higher in this urban area than Kentucky's overall black infant mortality rate.

The Louisville/Jefferson County Health Department had established a Fetal Infant Mortality Review System (FIMR) with a \$12,000.00 grant from the March of Dimes to review infant mortality issues. An active FIMR Planning Group was exploring other funding/grant possibilities at the local, state, and national levels. The Louisville/Jefferson County FIMR Project continues piloting an infant mortality review effort in 3 sectors of Jefferson County (Ujima 97% black, Bridges of Hope 44% Black, and Northwest 58% black), to assess service systems and community resources for women, infants, and families with the intent of identifying disparities and improving systems. Several staff involved in this effort have taken other positions and the project and the efforts have been at a standstill. Recent information from the Louisville/Jefferson County Health Department indicates a renewed effort is underway.

Also, the Kentucky Cabinet for Health Services has initiated an African-American Strategic Planning Group to focus on black/white health disparities, one of which is infant mortality. This planning group was established in part, as a result of concerns expressed by key legislators in the Kentucky General Assembly. Therefore, we anticipate broader support in working to narrow the racial gap on critical outcome measures.

The only area of improvement for these measures is the child death rate. Much of the decline in child deaths can be attributed to seat belt and child restraint/safety seat advocacy and legislation. Education for professionals and the general public and the availability of child restraints/safety seats through local health department loaner programs, local Kentucky Safe Kids chapters and other local community initiatives have proven to be effective strategies.

The infant mortality rate per 1,000 live births. Kentucky's infant mortality rate was 7.6 in FY 98, with 410 infant deaths of 54,125 live births.

The ratio of the black infant mortality rate to the white infant mortality rate. Kentucky's rate of black infant births to white infant births in FY 98 was 2.13, with a rate of 14.7 for black infant mortality compared to a rate of 6.9 for white infant mortality. It should be noted that the white infant mortality rate stayed constant while the black rate worsened from 11.0 to 14.7, the worse since 1995.

The neonatal mortality rate per 1,000 live births. Kentucky's neonatal mortality rate was 4.9 in FY 98, with 267 neonatal deaths per 54,125 live births. Again, this rate has worsened over previous years.

The postneonatal mortality rate per 1,000 live births. The FY 98 postneonatal mortality rate was 2.6, with 143 postneonatal deaths of 54,125 live births. This is the only measure that stayed constant from the previous year.

The perinatal mortality rate per 1,000 live births. Kentucky's FY 98 perinatal mortality rate was 10.3, with 561 deaths between 20 weeks fetal gestational age and under 7 days of age. This rate was only a slight increase from 10.2 the previous year.

The child death rate per 100,000 children aged 1-14. In FY 98, 197 children between the ages of 1 to 14 died for a rate of 26.0. This represents the only improvement from the FY 95-97 rates.

III. REQUIREMENTS FOR THE APPLICATION [Section 505]

3.1 Needs Assessment of the Maternal and Child Health Population

3.1.1 Needs Assessment Process

Information for the needs assessment for Children with Special Health Care Needs was gathered from:

- Two surveys of recent graduates from the Commission and the Lexington Shriner's Hospital programs (1997 and 1999),
- Two statewide family survey initiatives conducted in collaboration with two of the state's most prominent parent advocacy organizations, the KY Special Parent Involvement Network (KY-SPIN) and the Parent Information Network of KY (PiNK). KY-SPIN contracted to develop and conduct a statewide mailed survey of families of CSHCN drawn from both the KY-SPIN and PiNK databases. PiNK staff members conducted focus groups with family representatives from PiNK and Commission enrollees in six (6) different areas of the state.
- Input from health and social service providers through two statewide surveys of health care professionals in private practice (including physical, speech, and occupational therapists, physicians, and pharmacists) and other public and private agencies serving children with special needs (early intervention, head-start, family and youth resources centers, local health departments, regional comprehensive care (mental health /mental

retardation/developmental disabilities) programs; Easter Seals; Home Health agencies; the Louisville Deaf-Oral School,

- United Cerebral Palsy Kids Center, et.al.).
- Statewide data sources pertaining to the numbers and distribution of health care professionals and statistics about health, education, unemployment, and disability services in the state.

Although the state lacks the infrastructure necessary to allow data sharing across programs, the rate of response to the various surveys and the level of participation by families in the focus groups has provided a useful snapshot of the statewide system of care as well as information that can be used to develop and enhance programming to respond to identified needs.

Variables of interest in each process included:

Surveys of recent Commission and Shriners' Hospital (Lexington) graduates to determine:

- Status of health care following discharge from pediatric specialty programs
- Access and established linkages to adult health care providers
- Involvement in higher education or vocational training
- Degree of self-sufficiency indicated by independent living and employment status.
- Quality of life indicated by personal satisfaction with life status, involvement in community recreation and social life

Focus Groups with families of children including those meeting criteria for the broad CSHCN definition as well as Commission enrollees. These Focus Groups addressed the following questions:

- What services does your child receive?
- What services does your child need?
- What are the barriers to receiving those services?
- What should we (the Commission) do for parents?
- If you could pick one thing to change about the way the Commission does business, what would that be?

A statewide survey of families of CSHCN that addressed a number of concerns, but especially focused on the following:

- Understanding of and linkage to a Medical Home
- Access to specialty care—availability of providers
- Access to care—financial resources including Medicaid, KCHIP, and private insurance
- Degree of satisfaction with existing services
- Perceived unmet needs

A statewide survey of providers conducted by Commission staff to determine a variety of information. Some of the most significant issues addressed included:

- Number of children served in a variety of individual programs serving the special needs population
- Types of services available (including transitional services for CSHCN) and extent of inter-agency service coordination
- Community and provider awareness of the medical home concept and extent of coordination of care and services between organizations and medical homes.
- Cultural competency of provider organizations
- Perceived barriers to care including lack of transportation, poor communication, lack of family financial resources, lack of child care

- Indicators used to monitor quality of care
- Capacity for data collection

While the Commission for Children with Special Health Care Needs focused on surveying the population and the providers that serve them, the Division of Adult and Child Health relied upon the many existing secondary data sets available to them for the preventive and primary care services for pregnant women, mothers and infants and children. In most instances, the analysis of the data generated by partner agencies and within the Department for Public Health provided sufficient information to identify needs of the population and set priorities for the state. Information from The Kentucky Long-Term Policy Research Center, RNDMU, Federal Interagency Forum on Child and Family Statistics, CDC, Annie E. Casey Foundation and Kentucky Youth Advocates and the Kentucky Office of Women’s Health supplemented Vital Statistics and Census data sets. Sources of data are established and limitations are commonly understood. In addition, analysis of data from key informant interviews and presentations by leadership around the issues of healthcare supplemented the data that was reviewed.

The Title V Director is engaged in routine assessment of the health care delivery system and the status of women and children in Kentucky through numerous partnerships and attendance at meetings throughout the year, such as the Kentucky Medical Society, Kentucky Pediatric Society, Kentucky Perinatal Society and Kentucky Association of Health Department Directors. This information, along with the secondary data sets and programmatic data, information from key informant interviews or studies, legislative issues and concerns, citizen comments and issues, discussed among the leadership within the Title V program led to the determination of priorities. Resource allocation continues to be driven by local assessment and plan development coupled with prioritization from the Title V Director in concert with the Director of Resource Management and the Commissioner for Public Health.

3.1.2 Needs Assessment Content

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

Setting the framework for the overview of the state can be accomplished by comparing Kentucky to other states in reference to both economic and health status indicators besides providing basic demographic data. This allows a comparison with the nation that assists in determining the role of the Title V program in Kentucky and begins the discussion of understanding the health needs of the overall population. A variety of data sources set the stage for the contextual discussion.

Population data demonstrates increases in all age groups except the 18-19 year old cohort. The following table published by the 1999 Kentucky Kids Count also reflects the racial/ethnic change.

<i>Population Trends</i>	<i>1990</i>	<i>1998</i>	<i>% change</i>
Total Persons	3,686,891	3,936,499	7
0-4	254,640	263,567	4
5-17	702,848	724,726	3
18-19	123,840	121,562	-2
20-64	2,140,495	2,333,789	9

65 & Older	465,068	492,855	6
Whites	3,398,776	3,618,693	6
Blacks	264,178	284,861	8
Hispanics	22,025	32,508	48

Although population data are not available for the current Hispanic population, like many other predominately agricultural states, Kentucky has experienced a growth in the number of people of Hispanic culture according to anecdotal data. In addition, the “golden triangle,” the area of Louisville to Lexington to Northern Kentucky, has experienced low unemployment rates and the Northern Kentucky area has experienced an economic boom period. This has also attracted more people of Hispanic descent to work in the service industries in this area. It is anticipated that if data were available now for 2000, the percent change would be even more significant. Data regarding the ethnicity of children in Kentucky from 1997 projected to 2005 published by The Annie E. Casey Foundation demonstrates an increase in all racial/ethnic groups except whites. Projections are that Black children will increase in total number by four percent, Hispanic children by 10% and over 20% for the Asian and Pacific Islander and the Native American groups. One should be cautious in interpreting the larger percentages due to small numbers. Even though the numbers may be small, this shift does reflect a changing ethnic demographic profile for Kentucky. In addition to the Hispanic population, other areas of the state have experienced immigration from the eastern bloc countries and the Asian countries. The development of a large Toyota manufacturing plant in central Kentucky and the relocation of the North American Toyota headquarters to the Northern Kentucky region has brought many families of Japanese heritage whereas many other states in this region have experienced only an increase in population from Southeast Asian countries. Although current census estimates demonstrate Kentucky as having over 90% white population, the population is becoming increasingly diverse.

From a social and economic perspective, the overall number of children in poverty has increased from 1985-1996 according to The Annie E. Casey Foundation and Kentucky ranks 42nd on this indicator. When viewing other indicators relative to social and economic health of children, many of the economic related indicators have declined. Kentucky ranks 49th in the percent of teens who are high school dropouts (ages 16-19), 43rd in the number of teens not attending school and not working, and 42nd in the percent of children living with parents who do not have full-time year round employment. Similarly, both the percent of 4th grade students and the percent of 8th grade students that scored below basic reading levels were worse than the national average. Likewise, the median income of families with children, the percent of female-headed families receiving child support or alimony and the percent of children in extreme poverty (income below 50% of the poverty level) were worse than national data. From an economic outlook perspective, the Progressive Policy Institute ranked Kentucky 39th overall on The State New Economy Index, while specific rankings for workforce education of 49th, scientists and engineers at 47th and the online population at 46th does not indicate a changing economic picture for Kentucky in the near future. Fortunately, Kentucky ranks 6th in technology in schools and 15th and 18th in the aggregated economic globalization scores and economic dynamism scores, respectively, boding for success with improvements in the education and skills of the population.

With this as the economic picture, Kentucky has fared better for many of the child health indicators, again according to The Annie E. Casey Foundation. The percent of children

without health insurance equaled the national average. The percent of children covered by Medicaid or other public sector health insurance was higher than the national percent and Kentucky has offered a rich Medicaid benefit package. Kentucky ranked 35th for the percent of low birth weight babies; 34th in the teen birth rate; 28th in the infant mortality rate; 24th in the child death rate and 33rd in the rate of teen deaths by accident, homicide and suicide. The USA Today newspaper recently published data from the National Association of Independent Insurers that listed Kentucky as worst in the nation with 52 deaths per 100,000 teenage drivers in 1998 compared to a national rate of 30 deaths.

The 1999 Kentucky Kids Count profiled the adolescent population. The following tables were developed from data presented in this publication.

<i>Adolescent Demographics</i>	<i>Ages 10-14</i>	<i>Ages 15-19</i>
Total Persons, 1998	274,990	299,578
Percent Female	49	48
Percent White	89	89
Percent Black	9	9
Percent Hispanic	1	1
Total Deaths 1994-1998	313	1,246
By Injury	186	1,019
Death Rate (per 100,000)	29	106
Total Births 1994-1998	841	43,242

This data clearly identifies the public health need to reduce injuries to the older teen population in that 82% of deaths within this cohort were associated with injuries. Partly a result of the rural nature of Kentucky and the road system, but also a result of the low number of teens who routinely wear seat belts, significant challenges are posed for the public health community around “unnecessary” deaths for the older adolescent population.

The trend data on teen births in Kentucky provides an improving picture in most categories. However, one of every three births to teens occurred to a mother who reported smoking during pregnancy.

<i>Teen Birth Trends</i>	<i>1980 -1982</i>	<i>1990-1992</i>	<i>1996-1998</i>
Average annual births to teens 15-19	11,389	9,052	8,493
Teen birth rate (per 1,000 females 15-19)	67	65	59
Average annual births to younger teens 15-17	4,376	3,200	2,949
Younger teen birth rate (per 1,000 females 15-17)	43	41	35
Teen births as a percent of all births	20	17	16
Percent of teen births occurring to unmarried teens	33	23	21
Percent of teen births that are repeat births	23	23	21
Percent of teen births receiving late, after second trimester, or no prenatal care	10	8	5
Percent of teen births to mothers who reported smoking during pregnancy	Not Available	32	32

The data on the number of youth who smoke from the 1997 Youth Behavior Risk Survey is alarming in Kentucky. The number of youth that reported current cigarette smoking overall was 47% whereas the same data for the nation was 36.4 percent. For males, 48.4% and for females, 45.3% reported current cigarette smoking. In terms of the frequency of smoking, Kentucky youth reported 27.6 percent as using tobacco on 20 or more days in the past month where the national data was 16.7 percent. Data from the National Youth Tobacco Survey of 1999 for the high school student population was 28.4%, with male and female students smoking at equal rates, 28.7 and 28.2 percent respectively. In terms of smokeless tobacco data from the YRBS of 1997, overall youth reporting current use was 15.6% and 28.6% of males reported currently using smokeless tobacco. The 1999 National Youth Tobacco Survey demonstrated that 11.6 percent of male high school students used smokeless tobacco products. The “tobacco culture” of Kentucky, tobacco as a source of income and acceptable for use, contributes to the higher percentages of Kentucky youth who smoke compared to the national data.

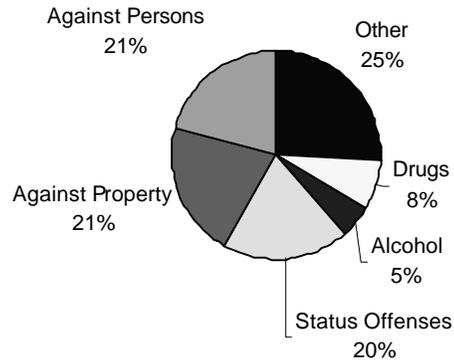
Social and educational data for Kentucky’s adolescent population includes data on juvenile court referrals and post high school transition. The percent of students in grades 7-12 who dropped out has remained essentially the same at four percent. The total public high school graduates for the same years, 1994-1998, was 184,269. Data on post high school transition are represented in the following table.

<i>Six Months Post Graduation</i>	<i>Total Number</i>	<i>Percent of H.S. Grads</i>
In College	93,724	51
In Vocational/Technical School	8,296	5
Employed	56,092	30
In the Military	5,622	3
Combined work and school	10,584	6
Not Successful	9,951	5

While approximately 50% of the high school graduates are in college six months after graduation, data are not available to determine how many of those same students remained enrolled or graduated from a college. Although only five percent of the high school graduates were classified as not successful, the nearly half who did not enter college generates concern due the positive association between education and health outcomes. Likewise, no data are available on the occupations of the 30% who are employed. Data on the occupational classification and income potential would provide a more informative picture of “success”.

Juvenile court referrals totaled 45,678 for FY99 although data for the largest urban county in Kentucky reflected the previous year. The following pie chart depicts the reasons for the referral to juvenile court.

Juvenile Justice Court Referrals



The demographic data listed for these referrals are reflected in the following table. It should be noted that this data are for referrals and one offender may have multiple referrals. Status offenses are those offenses that if committed by an adult would not be considered a crime such as run-away.

<i>Demographics</i>	<i>Status Offenses</i>	<i>Delinquency</i>
Ages 12 & Under	1,248	3,357
Ages 13 – 14	2,575	7,310
Age 15	2,067	6,554
Age 16	1,699	8,034
Ages 17 & Over	1,392	11,118
Percent Female	46	21
Percent White	84	75
Percent Black	16	24

It cannot be said that Kentucky has fared well with health indicators for the adult population. The March 20, 2000 MMWR identifies Kentucky as faring worst in the nation in several areas. The percent of white adults reporting having less than a high school education at 22.2% (median of 9.8%,) the percent of white adults who reported fair or poor health status at 21.7% (median of 11.6%,) the percent of white adults who were obese at 21.2% (median of 15.6%,) and the percent of white adults who reported current cigarette smoking at 30.8% (median of 23.6%) all placed Kentucky as the absolute worst in the nation for these indicators. Those indicators in which Kentucky fared worse than the national median for adults include the percent not having a routine physical examination within the past two years, who have ever been told by a health professional they had high blood pressure, diabetes, or had high blood cholesterol levels and their cholesterol checked, reported no leisure-time physical activity, and do not always wear a seat belt. For data relative to cancer and screening, Kentucky fared closer to the national median and for data relative to drinking and binge drinking, Kentucky performed

much better than the national median. Clearly this comparison of Kentucky to the nation shows that in the area of adult health, and adult preventive health, there are significant improvements to be made. Similar findings occurred in an analysis of women's health during 1999.

For women in particular, A Profile of Women's Health Status in Kentucky was developed in 1999. This publication emerged from a partnership between the Kentucky Commission on Women and the Department for Public Health. The findings of the document emerged from key interviews, an inventory of existing public and mental health services, information from group efforts at women's health conferences and workshops, an informal survey of Kentucky women and a Task Force on women's health. Overall demographic data presented included the following items:

- In 1996, 1,996,854 females comprised 51% of the Kentucky population.
- Currently, the majority of females in Kentucky are in the 20-44 age range.
- In 2020, the largest population of females is projected to be in the 60-64 age group.
- Women comprise 73% of the total population 85 and older.
- The number of females in the under 19 age range is shrinking, contributing to the aging of the population.
- Approximately 7% of Kentucky's female population are African American and 1% are other minorities.
- African Americans represent a greater proportion of Kentucky females in the under 45 population than the over 45 population.
- Currently, Kentucky females meet and exceed the education levels of males.
- More Kentucky females graduate from high school and attain some level of higher education than men.
- Female enrollment in state higher education institutions is rising, and in many cases, currently exceeds male enrollment.
- Approximately 65% of those enrolled in community colleges are females.
- Nationally, 59% of women are in the labor force compared to 56% in Kentucky.
- Nationally, 59% of white females and 60% of African American females are in the labor force.
- In Kentucky, 55% of white females and 65% of African American females are in the labor force.
- Kentucky's female unemployment rate (5.1%) is slightly lower than the statewide male rate (5.6%).
- Though more females are in the labor force, single women with children represent the highest proportion of Kentuckians living in poverty.
- 17% of Kentucky women live in poverty compared to 14% nationally.
- Kentucky's median household income is consistently less than the national average, \$10,700 and \$16,600, respectively.

Data on the leading causes of death for women demonstrated the following findings:

- The three leading causes of death among women and men are heart disease, cancer and stroke.
- Heart disease accounts for a greater proportion of female than male deaths, 33.3% compared to 31.9%.

- Heart disease mortality rates are highest among African American women than any other population.
- Lung cancer, chronic obstructive pulmonary disease (COPD), and diabetes mortality rates are increasing.
- Kentucky breast cancer rates showed only a slight decrease during the past ten years.
- Age-adjusted lung cancer rates show a significant upward trend on a national level and in Kentucky.
- Lung cancer mortality rates are nearly double breast cancer mortality rates among women in Kentucky.
- The African American female mortality rate for diabetes is nearly double that of white females, 46.85 and 26.38 per 100,000 respectively.

Other selected natality data from this report include the following:

- In 1997, of the nearly 53,000 live births, 16% were Cesarean deliveries.
- The birthrate for teen mothers has decreased.
- The fastest growing birthrate is found in the 25-29 age group, 98.7 in 1993 to 108.0 births per 100,000 population in 1997.
- African American birth rates were higher than white birth rates in younger age groups (24 and under) and lower in older age groups (over 25 years.)
- In 1997, low-birth weight infants accounted for 7.8% of live births in Kentucky and more low-birth weight infants are born to mothers under 15 than any other age group.
- More African American mothers deliver low-birth weight infants than white mothers across all age groups.
- African American mothers were less likely to receive prenatal care in the first trimester of pregnancy than white mothers across all age groups.
- Maternal smoking accounts for as much as 25% of low-birth weight births.
- The highest birthrate for African American mothers is represented by high school educated women in the 20-24 age range.
- The highest birthrate for white mothers is found in the 25-29 age group among those who hold some college education.

Sexually transmitted disease information from this report found the following:

- In women, many sexually transmitted diseases can cause pelvic inflammatory disease, tubal infertility, ectopic pregnancy, and chronic pelvic pain.
- Chlamydia is among the most prevalent of all sexually transmitted diseases in Kentucky.
- The highest incidence rate of chlamydia is in the 15-19 age range.
- Pregnant women infected with chlamydia can infect their babies during delivery, causing pneumonia in the newborn.
- Incidence rates of gonorrhea among Kentucky females are slightly less than national rates for women and less than Kentucky rates for men.
- Syphilis is less prevalent in Kentucky than in the United States.

The discussion previously about the risk factors for the population in Kentucky and for women in particular creates an alarming prognosis for the demand on health resources within the next twenty years. The improvements in the access to care and for both geographic and financial access to care for children with the expansion of the Medicaid Program and the

Kentucky Children’s Health Insurance Program has alleviated some of the concern for children’s health coverage as we move toward more universal care for this population. However, the behavioral health aspects for children have not demonstrated the same types of improvement as other health indicators. The data clearly demonstrates the importance of multiple efforts to provide preventive health services for all Kentuckians.

3.1.2.2 Direct Health Care Services

3.1.2.3 Enabling Services

Combined for both the Commission for Children with Special Health Care Needs and the Division of Adult and Child Health

Maternal and Child Health

Each year Kentucky experiences approximately 53,000 live births. Data from Kentucky’s participation in the Region IV Network for Data Management and Utilization from the 1999 publication provides the framework for this assessment of the population. Data for 1998 are currently under development for submission to the network.

During 1997 there were 887,672 women aged 15-44 in Kentucky. There were 52,843 births to women and 381 infants died within the first year of life. The following table indicates a variety of data relative to fertility and pregnancy for women in Kentucky as compared to other Region IV states and the United States. These data are taken from the RMDMU 1999 publication.

Measures from 1997	KY	Reg. IV	US
Fertility Rate (15-44)	59.3	63.9	65.0
Percent of Live Births to Teens < 18	6.0	6.1	4.9
Percent of Live Births to Women >35	6.0	7.2	12.6
Percent of Live Births w/ High Parity Controlling for Age	16.6	15.9	N/A
Percent of Live Births to Women Parity 4+	17.0	16.6	N/A
Percent of Live Births to Women >18 with < 12 th Grade Education	16.2	15.9	16.9
Percent of Live Births to Teens (<18) Who Smoked	28.9	15.8	15.1
Percent of Live Births to Women (18+) who Smoked	23.2	13.5	13.1
Percent of Live Births to All Women Who Smoked	23.5	13.6	13.2
Estimation of % Women who are Current Smokers	28.6	21.9	N/A
Estimation of % Women who are Overweight	32.2	33.0	N/A
Percent of Live Births with No Prenatal Care (10-17)	1.4	2.1	2.5
Percent of Live Births with No Prenatal Care (18+)	0.6	1.0	1.2
Percent of Live Births with Prenatal Care after 1 st Trimester	13.4	15.3	16.3

Percent of Live Births with Inadequate Prenatal Care (Kessner Index)	4.7	5.1	N/A
Percent of Live Births Paid for by Medicaid	38.9	40.9	N/A
Percent of 500-1499 Gram Infants Delivered at Level III Hospitals	52.5	65.0	N/A
Percent of 1500-2499 Gram Infants Delivered at Teaching Hospitals	30.0	43.8	N/A
Summary Very Low Birth Weight Rate (<1500 Grams)	1.4	1.7	1.4
Summary of Low Birth Weight Rate (<2500 Grams)	7.8	8.7	7.5
Infant Mortality Rate	7.2	8.4	7.2

Data presented in the above table demonstrates that Kentucky's commitment to the effect that availability and early entry into prenatal care can have for reducing the infant mortality rate. This has resulted in the Kentucky infant mortality rate equal to the national data and better than the other states in the southeast region. However, significant issues still are identified that would improve pregnancy outcomes, relative to smoking, obesity and age. Kentucky's fertility rate is less than the region and the nation, yet the percent of live births to teens less than 18 years of age is worse than the nation and only slightly better than the region. When controlling for age for the percent of live births for moms with high parity, Kentucky fared worse than the region.

Over the years, Kentucky's local health departments have had a very comprehensive prenatal program. Services within this program have declined partly due to increasing numbers of providers within the state and changes in the delivery system. The percent of births paid for by the Medicaid Program decreased from 42.4% to 38.9% from 1996 to 1997. This warrants further study when the data for 1998 becomes available. Regardless, local health departments assure that all women in need of prenatal care are provided that service when the existing provider community cannot meet the need.

Utilizing the 1997 Vital Statistic Report, the infant mortality rate for children shows marked differences between the black infant mortality rates and the total state rates. The following table shows those differences.

Measure	Total	Black
Neonatal Mortality Rate	4.6	7.4
Under One Week	3.6	5.6
Perinatal Mortality Rate	10.2	17.5
Infant Mortality Rate	7.2	11.0

This discrepancy warrants additional study to determine the effect of the health care delivery system on these variances verses other measures of access such as poverty or behavioral risk factors.

There was a slight increase in the number of live births in 1997. Of the resident white live births, approximately 25% of the babies were born to unmarried mothers. Of the resident black live births, nearly 75% of the babies were born to unmarried mothers. Eighty five

percent of all mothers received prenatal care in the first trimester. Over 58% of all mothers less than 15 years of age received prenatal care in the first trimester. However, married mothers were more likely to have received prenatal care during the first trimester than unmarried mothers by 89.2 percent to 75.0%, respectively. These figures support the need to further study differences between circumstances surrounding births by race and the predictive value of what is traditionally viewed as determinants of positive pregnancy outcomes by race.

Implementation of the Child Fatality Review System to review all child deaths as opposed to only those deaths that were “unexpected” should provide additional information on the causes of infant mortality and morbidity in Kentucky. In addition, further development of Fetal & Infant Mortality Review (FIMR) systems should provide a more comprehensive view. These systems, along with full implementation of the Kentucky Birth Surveillance Registry will provide the Title V program with additional and comprehensive population based data on infants and the delivery system to assure positive pregnancy outcomes.

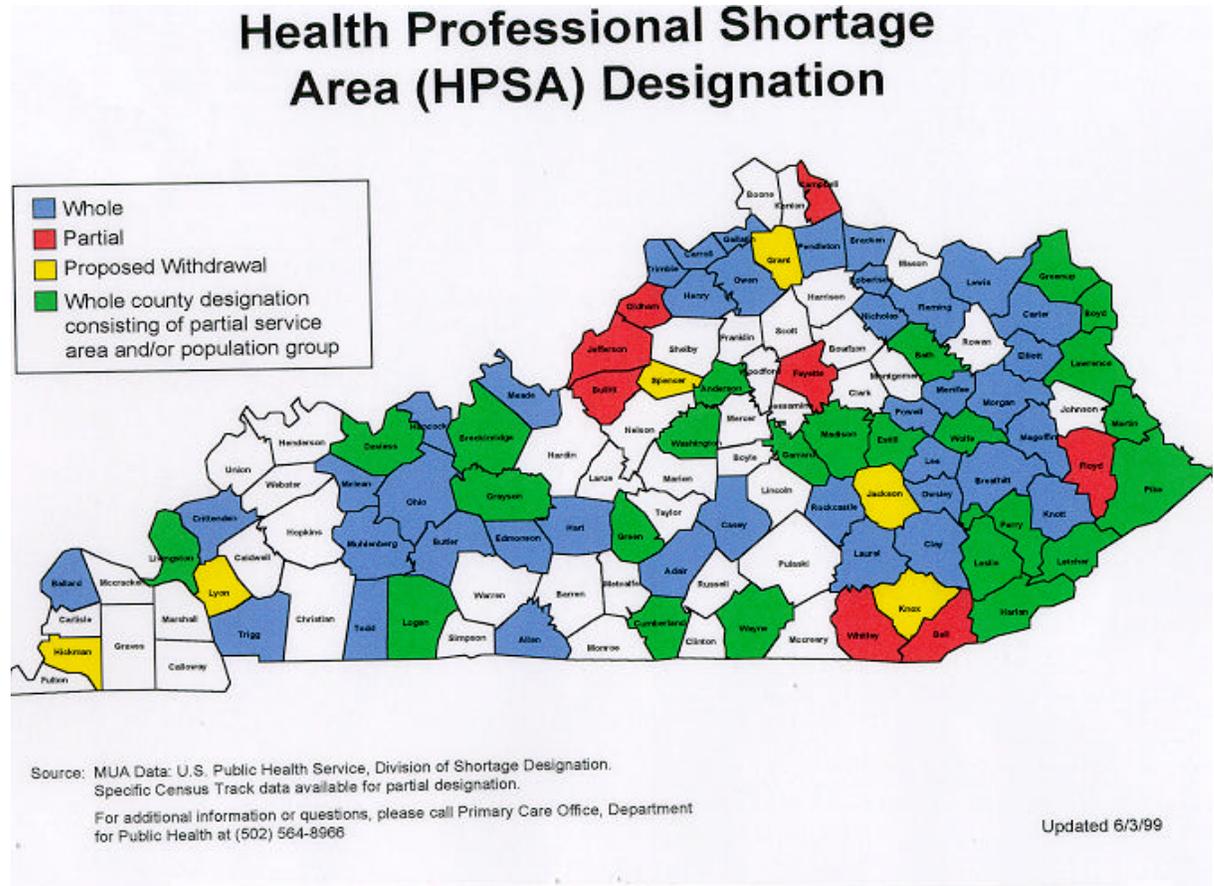
The most significant event that has affected direct and enabling services for the child population in Kentucky has been the implementation of the Kentucky Child Health Insurance Program. Beginning July 1, 1998, Kentucky began implementing the KCHIP in phases. When KCHIP began, it was estimated that 123,000-150,000 low-income children in Kentucky had no insurance at all. The first phase expanded coverage to children 14-19 years of age who are in families at or below 100% of the Federal Poverty Level. The second phase that began in July 1999 expanded Medicaid to cover uninsured children from birth to 19 with families at or below 150% of the Federal Poverty Level. Phase III recently went into effect providing coverage for children birth to age 19 who live in families with incomes at or below 200% of the Federal Poverty Level.

KCHIP has exceeded enrollment goal in both Phase I and II and are close to reaching their goal in Phase III even though it recently began. An extensive outreach program has resulted in a total of 44,511 children enrolled through the end of March 2000. An estimated 25,000 children had qualified for the Medicaid program by using the simplified two-page KCHIP application. Local health departments have engaged in various forms of outreach to KCHIP potential applicants.

This Medicaid expansion for KCHIP allows the same comprehensive benefits as traditional Medicaid. These benefits include office visits, dental care, immunizations, mental health, pharmacy, vision care, hospital care, behavioral health and more. However, those children enrolled in Phase III do not receive non-emergency transportation and EPSDT special services. This comprehensive array of benefits, coupled with the proposed enhanced KenPAC program, provides more accessibility for Kentucky’s children than ever before. However, as indicated in the overview of the maternal and child health, there remains a general access issue due to shortages of physicians, dentists, and other primary care providers. There still are areas of Kentucky in which access remains an issue. In those localities, resources must still be allocated to meet the primary and preventive needs of pregnant women and infants and children. However, the Title V Director has been meeting and working with the private medical community to assure their participation in the Medicaid Program and to agree to provide services to the medically homeless. Local health departments are encouraged to follow-up with this focus by offering direct clinical care only to those who remain medically homeless

after attempts to find a medical home have failed while focusing on core public health functions.

The map of HPSA's in Kentucky will provide a visual that documents the shortages of primary care providers.



Within the Division of Adult and Child Health and the Maternal and Child Health Branch, the Primary Care Team is located. These staff coordinate the Primary Care Cooperative Agreement, Kentucky Physician Care Program, work collaboratively with the KY Primary Care Coalition and the KY Rural Health Association and maintain data on underserved areas.

The Kentucky Physician Care Program is a collaborative effort between the Cabinet for Families and Children (CFC,) the Cabinet for Health Services (CHS) and the Kentucky Medical Association (KMA). If a citizen is in need of primary care services, they can contact the CFC Department for Community Based Services local office to determine their eligibility for the program. If eligible, they contact the CHS, Primary Care Team via an 800 number who will coordinate a visit with a local primary care physician who has agreed to participate through the KMA. The Title V Director, in his involvement with the KMA has identified one of the goals for the KMA as increasing the number of doctors who participate in the Kentucky Physician Care Program.

The Division of Adult and Child Health has continued their commitment to providing a system of care that has linkages throughout primary, specialized and tertiary care. Further description of this is addressed under Infrastructure Building Services.

Children with Special Health Care Needs

In 1998-1999, the Commission served 15,181 patients. In the 1997-1998 school year, the Kentucky Department of Education reported that 87,973 students were identified as having disabilities. Although many of the students with mental illness, mental retardation, and behavioral disabilities are not eligible for Commission services, the disparity between the numbers indicates that the Commission is not reaching many children who might be eligible.

In the Needs Assessment surveys, many of the reported children had a combination of special health care needs. The average age of those with chronic physical and developmental disabilities was 8 while those identified with behavioral and emotional problems were 11. Although 95% of these families had third party insurance coverage, almost 40% of the services they received were free.

Despite the fact that there are a good number of free services, availability and access to care is a concern and a factor in the lives of many families of cshcn. Discussion in the statewide focus groups as well as responses to the provider and family surveys all indicate that lack of specialty providers, transportation difficulties, and child-care for siblings are barriers to receiving services.

Commission regions vary in population, income, education levels, and availability of primary and specialty care. The following table compares the Regions on some of these variables.

Table 1: Comparison of KY Commission Regions on Poverty and Health Services

Population Statewide and by Commission Regions	Infant Mortality per 1000 Live Births	% Poverty	Unemployment Rate %	School children with disabilities	Commission patients (% of school children)	Physicians per 1000	Pharmacists per 1000	Hospital Beds per 1000
Kentucky 3,936,499	7.4	17.9	4.0	87,973	15,181 (17%)	2	.9	4.6
Ashland 135,514	7.2	25	8.6	3247	429 (13%)	2	1	4.5
Barbourville 234,303	7.6	31.8	5.6	6422	1459 (23%)	1.3	.7	3.4
Bowling Green 244,182	8.1	19.3	5.2	5288	1499 (28%)	1.5	.8	4.6
Edge-wood 374,883	8.6	14.4	2.8	7785	339 (4%)	1.9	.8	3.4
Elizabeth-town 238,377	9.0	17.1	6.2	5577	1200 (21%)	1.3	.6	2.5

Hazard 125,282	8.6	36.1	5.8	3625	1245 (34%)	1.4	.6	4.4
Hopkinsville 215,023	7.3	17.2	4.1	5120	600 (12%)	1.4	.7	6.4
Lexington 651,939	6.2	16.3	3	13,596	1555 (11%)	3.3	1.2	5.1
Louisville 837,432	7.0	12.6	2.9	16,907	2022 (12%)	3.3	1.0	5.9
Morehead 127,703	8.1	24.6	5.1	3010	712 (24%)	1.2	.7	2.9
Owensboro 206,446	7.2	16.1	6.4	4832	1086 (22%)	1.6	.9	4.0
Paducah 190,694	7.8	16.5	4.9	4019	929 (23%)	1.9	.8	5.9
Salyersville 165,441	6.9	30.9	8.6	3595	938 (26%)	1.7	.7	3.9
Somerset 189,280	8.3	26.5	7.0	4420	1168 (26%)	1.2	.8	3.3

Discussion related to Table 1: Many of the Regions serve 20% and more of the CSHCN. Ashland, Edgewood, Hopkinsville, Lexington and Louisville have lower percentages of the children with disabilities being served by the Commission. Three obvious reasons for this variation include:

- There are large Medical Centers readily available in each of these regions.
- More specialists live in and near these urban regions so families have access to private practices.
- Other state and private programs are also concentrated in and near these areas, such as, the KY School for the Blind, the Child Evaluation Center, Bingham Child Guidance, the Easter Seals Center, Louisville Deaf Oral School, Visually Impaired Pre-School Services, and Cerebral Palsy Kids Center all in Louisville.

Possible reasons for the higher percentage of CSHCN served in other Commission regions include:

- Quality and extent of outreach in rural areas of the state where a smaller population base means Commission staff have more time to engage in community education activities and to develop referral resources.
- Historical role of the agency especially in Eastern KY's Appalachian communities (Hazard, Salyersville, Barbourville) where the Commission has held a valued reputation in local communities and where due to genetic conditions among this predominantly indigent and culturally distinct population, the Commission continues to see new generations in families with genetic disorders.
- The provision of some major specialty services, e.g. Cardiology clinic (joint service of University of KY and Commission) that due to lack of local providers would not be accessible to most patients.

Inconsistencies in health care coverage still appear to be an issue in Kentucky. This survey was undertaken in the early implementation stages of the state's children health insurance plan (KCHIP). Hopefully, KCHIP will significantly reduce the number of uninsured children in the state; however, the issue of underinsured still remains. Kentucky elected to do an expansion of the Medicaid benefit package for those under 200% of the federal poverty line, up to age 19, without other sources of insurance. Since those with poor insurance are not eligible unless they go without health insurance coverage for a minimum of six months, they are the ones who are vulnerable at this point. Low wages and high policy deductibles result in a catch 22 situation. Providers identified the lack of financial resources for these families as a primary restriction for accessing care.

The needs assessment indicated that the loss of Medicaid and KCHIP eligibility at age 19 is a significant barrier to care for young adults with special health care needs. The Commission has seen a slight increase in families with private insurance that may be the result of the Welfare to Work initiative. However, the survey pointed out that the health of young adults is jeopardized when those who may have had coverage under their parent's insurance lose that coverage if they have graduated/dropped out of high school or are not enrolled in a higher education program following high school graduation. Although SSI may be a resource for some of these young people, the Commission's goal is to move families away from life-long dependency on SSI and other welfare programs. This goal is the focus outcome of the Commission's transition services to motivate and enable young people to pursue higher education and vocational training that will result in gainful employment and self-sufficiency.

Remarkably, 81% of families responding to the Needs Assessment survey reported that the programs they participate in do not promote their child's independence. Prolonging and increasing/intensifying available services that encourage the improvement and maintenance of physical health, placing the child in an assisted environment that provides the necessary skill training, and links to the community through a network of employers were the most common recommendations made to improve this situation. In response to the question (How helpful was your primary care provider in helping your child transition from pediatric to adolescent healthcare?), 44% responded that providers were either helpful or very helpful. When asked the same question in regard to transition from adolescent to adult healthcare, 31% responded that their primary care providers were either helpful or very helpful.

Most of the providers surveyed felt that transition services in Kentucky were inadequate or claimed to have no knowledge of the efforts in this area. This point was driven home by an example, which outlined the different eligibility requirements, funding resources and focus by health care professionals in the early childhood intervention programs and all other programs available to children in our state. Inconsistencies like these have resulted in poor care coordination for families particularly across these transition lines.

Only 18% of the respondents actually served children from ages birth to 21. Most served a subset of the population – pediatrics, pre-adolescents, adolescents, adults or some combination. The most successful transition area appeared to be between the pediatric and adolescent areas.

Surprisingly, only 5% of the reporting families were uninsured. This appears to be highly correlated to the high usage of primary medical care services (81%) by this group.

Additionally, over 50% reported usage of specialty and dental care, speech and occupational therapies and exceptional/special education services. Unquestionably, the greatest barrier to care for families was the inconvenience in accessing care resulting from conflicts between home/work responsibilities and keeping scheduled appointments. Lack of financial resources and health insurance restrictions were also cited but to a much lesser degree. Even with the high number of families with health insurance coverage, 18% of the services they receive are paid for entirely out of their pocket.

Providers are making great efforts to communicate and exchange information with the primary care physicians, which is a positive outcome of the managed care environment. Although not all providers require clients to have a medical home, overall it appeared that the trend was definitely in the direction of coordinating care with a medical home.

Approximately two-thirds of the responding families live in rural locations and most of them reported that their primary care provider was also rural. There was, however, an obvious disparity with respect to their specialty providers where only 14% were reported to be located in rural areas. In order to participate in these specialty programs, this rural population must travel an average distance over 30 miles. This obviously further complicates the time and convenience issues. Although most of the respondents have privately owned autos, the reliability of that transportation becomes a player in this process.

Providers across the board appear to be struggling with the difficulty of scheduling appointments and maintaining contact with clients in the extremely transient society in which we now live. Providers report high no-show rates resulting in increased expense to providers. Families are using primarily private autos for transportation, which are often unreliable and report conflicts with work/family responsibilities in keeping daytime appointments.

The problem identified with accessibility and funding of health services was also an issue with the recent graduates surveyed. The young adults who were surveyed reported that they have a medical home (77%), but only 23% have found an adult specialist. A correlating factor to this is the high rate of uninsured (38%) among these young people; 39% have Medicaid, 16% have insurance through a family member, and only 10% have insurance through their employment.

It was also evident from the young adults surveyed that transition services are not being successful in helping young adults with work and independent living. While a national sample of young adults without disabilities shows an employment rate of 88%, fewer than 50% of the young adults surveyed are employed full or part time; 20% of those surveyed did not graduate from high school and 25% receive SSI. Many more of these young people are still residing with their parents, 60% compared to a national average of 40%; it is notable that 22% of these young people are married and 18% have children.

These young adults did indicate that they were interested in and taking steps towards improving their skills and independence. Some highlights reflective of this include: 61% say they use a computer, 60% can drive, 85% reported doing chores while growing up, and 57% felt that their independence improved with getting a job. Much more certainly needs to be done to help these young adults to successfully transition to adult life. It is important to begin laying the foundation and creating expectations at an early age. The Commission hopes that its

transition interventions with young children will show an improvement in these figures as time goes on.

3.1.2.4 Population-Based Services

The role of the Division of Adult and Child Health relative to population-based services has been expanding over the last several years. Traditionally, the Division of Adult and Child Health allocated resources more towards the provision of direct care as the need for preventive health services demanded a significant portion of the funding. With a changing delivery system, especially for pregnant women and infants and children, the Title V program has an opportunity to broaden its traditional focus. Newborn screening, lead screening, fluoridation and Sudden Infant Death surveillance and SIDS's related grief counseling have been the traditional population-based programs. In recent years, more efforts have been targeted towards birth defects surveillance, folic acid awareness, nutrition, early child development, injury prevention, health, safety and nutrition consultation for child care agencies and child care resource and referral agencies, child fatality review, fetal and infant mortality review and the expansion of grief counseling for all families experiencing a child death regardless of the cause.

Leadership within the Department for Public Health, the Department for Medicaid Services and at the local level have encouraged local health departments to partner with managed care to provide the population based services necessary to achieve their health outcomes. The experience of the local health departments in working with racially and ethnically diverse populations, low income populations, and the mandate for the health of the entire community has allowed for new opportunities to work collaboratively instead of competitively to serve the community.

In addition, the Department for Public Health's move away from categorical funding of programs to a flexible funding arrangement has provided the impetus for local health departments to focus on population-based services. In those areas of the state with limited resources for preventive health services, obviously the Title V assurance role is geared to provision of direct health services. In the other areas with more resources, new partnerships have developed between the local health department and others in the community.

Data presented earlier and below about the health status of women and health related behaviors while pregnant provide numerous opportunities to provide population-based services outside of the local health department prenatal clinical setting.

Percent of Live Births to Teens (<18) Who Smoked	28.9	15.8	15.1
Percent of Live Births to Women (18+) who Smoked	23.2	13.5	13.1
Percent of Live Births to All Women Who Smoked	23.5	13.6	13.2
Estimation of % Women who are Current Smokers	28.6	21.9	N/A
Estimation of % Women who are Overweight	32.2	33.0	N/A

Studies by numerous researchers demonstrate the impact of smoking on low birth weight and the effects of second hand smoke on children. Each of the Department for Public Health contracts with universities and with local health departments require the following language and one or more programmatic efforts regarding tobacco use:

- Keep youth and women of childbearing age from initiating tobacco use.
- Assist youth and women of childbearing age to stop using tobacco.
- Eliminate exposure to second hand smoke.
- Assist in removing discrepancies in tobacco related diseases in minority, economically disadvantaged and rural populations.

The Governor's Task Force on Early Childhood Development provided one of the most comprehensive assessments for children's issues. In a series of 10 public forums throughout Kentucky with over 1,400 parents and providers of health, education and child-care in attendance, priorities on early childhood issues were identified. This assessment, in conjunction with research from a variety of workgroups, provided the foundation for the Governor's Task Force to make recommendations and a wealth of qualitative data for the five-year assessment. As indicated earlier, the leadership and staff of the Division of Adult and Child Health played a vital role as members on the workgroups and presenters to the Governor's Task Force. The Task Force membership was comprised of large and small business representatives, state and local elected legislative and judicial officials, education, labor and the Secretary of the Cabinet for Families and Children and the former Secretary of the Cabinet for Health Services.

The Task Force was charged with developing a long-term strategy that would enhance the opportunities for Kentucky's children to succeed as citizens. This led to a vision statement for the Task Force of "All young children in Kentucky are healthy and safe, possess the foundation that will enable school and personal success, and live in strong families that are supported and strengthened within their communities." The Task Force, upon reviewing and processing information from communities, presenters and workgroups, identified "Assuring Maternal and Child Health" as one of four areas of recommendations.

The Task Force recognized Kentucky's poor ranking compared to other states, the contributing factors and resulting complications from low birth weight babies, birth defects, women who use tobacco, alcohol or other drugs, have poor diets and fail to understand the importance of being healthy before they conceive. They documented that those most at risk for not receiving prenatal care are teenagers, low-income women, minorities, substance abusers and domestic violence victims. Identifying outcomes that babies are born healthy and go home to a supportive environment, they identified the following strategies:

- Make prenatal care more accessible and affordable, particularly in the first trimester, by increasing the Medicaid eligibility limit to 200 percent of the federal poverty level.
- Provide preconceptional and prenatal vitamins, including folic acid, to local health departments for appropriate distribution and develop a statewide public awareness campaign to increase the use of prenatal multivitamins that include folic acid.
- Provide regular screenings and referrals to women of childbearing age for health conditions that may affect a baby's health.
- Discourage the use of tobacco, alcohol, and drugs before conception and during pregnancy.
- Before conception and pregnancy, ensure that women of childbearing age receive genetic information from trained providers during doctor or other primary care consultations.
- Provide resource and referral information and/or basic health care to pregnant teenagers at non-clinical sites such as schools and community outreach centers.

- Increase public awareness and outreach for the Women, Infants and Children (WIC) program, food stamps, and the Expanded Food and Nutrition Education Program.
- Promote family-centered practices that contribute to parents' knowledge about the birth process and early development.
- Promote family-centered childbirth models and recognize facilities that practice family-centered policies.

Strategies related to the outcome that children's basic physical and health needs are met included the following:

- Ensure that all newborns, before leaving the hospital, receive a comprehensive health and developmental screening/examination, including audiological testing, from professionals trained in newborn screening and discharge planning.
- Ensure that high-risk newborns, such as low birth-weight babies, receive the appropriate developmental care in the hospital as defined by the Newborn Individualized Developmental Care and Assessment Program guidelines.
- Ensure that babies identified on newborn screenings leave the hospital with a plan for a follow-up evaluation.
- Provide a home visit by a qualified professional—agreed to voluntarily by the mother—during the first week following birth.
- Implement periodic home visits by family and child development specialists who also work in community settings such as health departments, physicians' offices, schools, or Family Resource Centers.
- Provide regular, periodic developmental and basic health screenings for all children at specific age intervals. Refer children with health or developmental risk factors for further evaluations as appropriate.
- Ensure that children identified through evaluations as having special health or developmental needs receive appropriate services, such as those provided by the Kentucky Early Intervention System.
- Offer Individualized Family Service Plan training for providers and parents of children with special developmental needs.
- Encourage families to establish a continuing relationship with a primary health care provider by increasing KCHIP eligibility to 200% of the federal poverty level and reimbursing non-clinical sites, including schools and child care centers, for offering the services of medical professionals such as nurse practitioners and health educators.
- Promote public awareness and ensure access to immunizations for birth to 2 year olds by using federal programs designed to increase the availability of vaccines.
- Ensure that children who are removed from their natural homes receive appropriate health and developmental assessments that determine what services they need.

With qualitative data presented from the Governor's Task Force, coupled with the quantitative data presented before, the Department for Public Health has support to increase population based services. In addition, the Commissioner for Public Health has set the directive that programs and resources need to target primary prevention and eliminate disparities. Traditionally, when the staff or public health partners thought of primary prevention, often it was focused on immunizations or other programs that in reality provided secondary prevention. For instance, regulations require that local health departments provide grief counseling for parents that experience of loss of an infant due to Sudden Infant Death Syndrome. While the Department for Public Health has encouraged local health departments

to provide grief counseling for any family who suffers a loss of a child, there are no systematic efforts to require SIDS prevention education or counseling other than perhaps via the Reference Manual for providing clinical services within local health departments. A Back to Sleep Campaign would be classified population based primary prevention. Leadership stressing the importance of primary prevention via population based services serves as additional qualitative data setting the agenda for population based services for pregnant women, infants and children.

Dental and oral health is identified as a priority within the Division of Adult and Child Health. Recent studies have indicated the relationship between poor dental hygiene/disease and pregnancy outcomes and child growth and development. Kentucky is undergoing a comprehensive oral health survey in partnership with the University of Kentucky and the University of Louisville dental schools. In addition, staff within the Title V program are exploring opportunities to provide oral health screening in child care centers in order to varnish erupting baby teeth. The Healthy Start in Child Care program, based on the North Carolina model, could be the methodology for accomplishing this objective.

The Healthy Start in Child Care program is providing training throughout the state for local health department staff on becoming health, safety and nutrition consultants. Training is being provided throughout the state with a regional approach developed for collaborative partnerships between child-care providers, local health departments and the child care resource and referral agencies. Although a regional approach for staffing, these services will be available throughout Kentucky.

The Title V Program has supported newborn screening for PKU, Galactosemia, Congenital Hypothyroidism and Sickle Cell and the necessary follow-up. For Sickle Cell Disease, the Division of Adult and Child Health partners with the Commission for Children with Special Health Care Needs as well as the universities.

A 1998 report by Christine Yoshinaga-Itano in the Journal of the American Academy of Audiology (Vol.32), indicated that “ 3 of every 1,000 infants are born with invisible, significant hearing loss; if undetected, the loss will lead to significant delays in speech, language, cognition, social and emotional development.” The Commission strives for early identification and treatment of hearing loss by administration of a Hearing High Risk Registry and efforts to establish a Universal Newborn Hearing Screening Program. (See other discussion under Progress on Performance Measures, PM# 10)

In 1999, the HHR screened 19,134 newborn infants prior to hospital discharge and identified 4,134 infants as having risk factors for hearing loss. Those identified were referred for additional diagnostic services; referral information was tracked by the hospitals providing services, the HHRR, and by First Steps, the Kentucky Early Intervention system.

The Commission HHRR provides technical assistance to birthing hospitals that implement UNHS. The total number of hospitals in Kentucky providing UNHS is now 22, with three more hospitals requesting aid from the HHRR to move to UNHS.

The Commission also monitors and assists with training volunteers and school personnel who administer scoliosis screenings mandated for KY public school children in grades 6 and 8. 85,339 children were screened in school year 1998-1999.

3.1.2.5 Infrastructure Building Services

The Division of Adult and Child Health has traditionally promoted comprehensive systems of services in Kentucky. Contracts with both the University of Kentucky and the University of Louisville have assured these systems of care. Areas of support include the following:

- physicians and public health nurses continuing education for pediatric assessment,
- continuing education on women's health care,
- staffing for maternal mortality review,
- medical consultation, establishment of standards and educational materials, confirmatory diagnosis of screening results and follow-up and treatment for positive newborn screening results,
- genetic services and training and technical assistance on genetic issues and data collection and reporting for the Birth Surveillance Registry,
- assessment and evaluation services for infants in the Neonatal Intensive Care Unit and medical and developmental follow-up for infants after discharge.
- developmental screening assessments for high risk and premature infants including technical assistance and training on high risk infants for health professionals and health care and treatment for these infants in selected census tracts and patient populations,
- evaluation of children birth to 16 with complex developmental disorders, eligibility determination/and or services for children birth to three for First Steps, Kentucky's Early Intervention Program and professional guidance and training to community physicians and evaluators for the First Steps Program,
- community based clinics providing comprehensive developmental evaluations in areas of the state lacking these resources,
- comprehensive nutritional services for pregnant women and infants,
- prenatal, postpartum and family planning services to teens and pediatric services to their infants through the Young Parents Program,
- case management and medical services for children with chronic diseases in areas of the state lacking these resources,
- dental screenings, sealants and case management for high risk children, and
- injury prevention consultation and support for local health departments and communities.

In addition to the efforts through our contracting partners, the Title V Director provides the leadership for collaboration between staff with other agencies, organizations and state and community based efforts. Recent efforts within the early childhood development field, coupled with the designation of staff to assist with this effort, culminated in the comprehensive early childhood legislative package discussed under population-based services. Nursing leadership at the Commissioner for Public Health's executive level was filled by an individual transferred from the Department for Medicaid Services, Managed Care Quality Assurance program. Although the role of Chief Nurse is significantly broader, the expertise relative to quality assurance in general, and to Medicaid Managed Care in particular, provides a valued resource to the Title V Program.

Also, Title V staff have been developing their data and assessment skills over the last two years. The State Systems Development Initiative has supported, in part, the technology attainment for Title V and local health department staff working with two community based programs in order to collect programmatic and evaluation data. As staff vacate positions, the Title V agency has the opportunity to re-classify positions for research and evaluative purposes. In addition, opportunities made available from the Maternal and Child Health Bureau through such programs as Dataspeak, and from the developing Schools of Public Health in Kentucky have been made available for all staff for participation.

At the departmental level, a Commissioner's Conference on Public Health Information provided the enticement for the public and private state and local sectors on how technological resources can impact every component of public health. Specific attention was given on resources relative to the core public health functions of assessment, policy development and assurance. This conference showcased opportunities for revisions in the information technology system for public health that ultimately resulted in securing significant technology resources for the local health departments.

Staff at both the state and the local health department levels are being reduced in part because of changing needs brought about by the health care system, but also as a result of attractive retirement options presented to career employees. Efforts are being made to work with the developing University of Kentucky School of Public Health to assure a skilled workforce is available to perform the core public health functions of assessment, policy development and assurance.

Other examples of ACH infrastructure building are in 1.5.2.State Agency Coordination.

The overall number of children with special health care needs in the state remains a mystery. Even given the broad definition of children with special health care needs, the payers and providers of health care continue to account for this population based on their perception of a phrase or phrases in the definition. Additionally, no method exists for removing duplication of patients seen across programs. The data systems in Kentucky are still very immature and disjointed. The information/data that exists is not in true, exchangeable electronic format, except for a few that have basic accounting software capable of exporting electronic billing information. Understandably, there continues to be great discomfort in this arena due to the issue of confidentiality. Overall, there were very few inter-agency agreements reported to facilitate referrals and sharing patient information.

There seems to be a great focus on referrals and satisfaction with services. Providers are trying to track where the referrals come from and the satisfaction levels of all parties through fluctuations in numbers and service levels. There seemed to be great value on the opinions and perceptions of other health care professionals from the responding organizations.

3.2 Health Status Indicators

3.2.1 Priority Needs

The five year needs assessment demonstrates that for Kentucky to reach the Governor's goal efforts must be targeted toward exercising the core public health functions (assessment, policy development and assurance), primary prevention and reducing health disparities. Governor Patton's goal is to set Kentucky on the path to achieving economic opportunity and a standard of living above the national average in 20 years. Sadly, the overview of the maternal and child health population demonstrated that compared to other states, children are growing up poorer, dropping out of school and not working when they do drop out and if they are living at home, their parents do not have full time year round employment. Too many teens are involved in accidents, smoke and have low birth weight babies. White adults in Kentucky lead the nation in having less than a high school education, view their health as fair or poor, are obese and current smokers. All of these findings demonstrate the aggressive efforts that must be targeted to improve outcomes for women, children and children with special health care needs to bring Kentucky above the national average within 20 years.

Direct Health Care and Enabling Services:

Kentucky has many areas of the state that are listed as medically underserved or health profession shortage areas. While this has improved in terms of more providers and more providers seeing patients with Medicaid, for those children with special health care needs and their families, the Commission for Children with Special Health Care Needs must play not only a care coordination but a direct provider role. Contracts with providers assure specialty services are available and the local health department system provides clinical preventive services when necessary.

Population Based Services:

The Title V agency, (CCSHCN and ACH) value the need for preventive services often delivered through this level of the pyramid. Needs assessment data demonstrate the need to prevent neural tube defects, hearing loss, injuries, obesity, dental disease, smoking, birth defects and secondary conditions. As local health departments continue to transition toward population based services, the flexible funding through the Maternal and Child Health Block Grant and the related performance measures, have provided numerous opportunities for local health departments to engage in primary prevention. The Commission continues to provide leadership in the area of newborn hearing screening and providing education on issues affecting children with special health care needs.

Infrastructure Building Services:

The assessment for children with special health care needs identified medical homes and independence as issues to be addressed via this level of the pyramid. For the maternal, infant and child population, these issues emerged as well. Both agencies have identified performance measures that promote systems of care, standards and coordination. The staff at both agencies and contracted providers address these needs.

The top ten priorities follow: In addition, most address part of Governor Patton's strategy to build self sustaining families.

Increase the percent of women of childbearing age taking folic acid regularly.

Increase the percentage of families receiving support services/parenting assistance through home visiting support programs.

Increase the number of fetal and infant deaths that are reviewed by a multidisciplinary team.

Increase the percent of coroner case child deaths undergoing local multidisciplinary investigation.

Increase the percent of children with appropriate weight for height.

Reduce the percent of young people who smoke.

Decrease the rate of substantiated reports of child abuse, neglect or dependency.

Increase the percent of primary care providers in Kentucky who are competent and willing to serve as medical homes for children with special health care needs and assure that each Commission enrolled child has a medical home.

Assure that children with special health care needs enrolled in the Commission receive comprehensive coordinated care.

3.3 Annual Budget and Budget Justification

3.3.1 Completion of Budget Forms

3.3.2 Other Requirements

The federal KCHIP initiative will cause the Commission to experience a significant change in how Title V funds are utilized to fund direct care, enabling, and infrastructure services. Because of the overall state KCHIP initiative, direct care expenditures for the Commission are projected to decrease significantly. The reduced level of expenditure related to direct care services for patients without coverage will shift from funding direct care services to increasing the effectiveness of enabling services and infrastructure building. The Commission is currently developing a case management initiative which when complete is anticipated to improve the overall quality and coordination of services to special needs children. Title V funding will play a major role in the development of the overall case management initiative.

The Commission's Hemophilia and Sickle Cell programs are funded by grants in addition to Title V. A CDC grant of \$66,000 focuses on prevention and provision of care for the complications of hemophilia. The focus of an MCHB grant of \$40,000 is centered on HIV, education, outreach, and increased services to families and children, staff training. Both of these grants are solely for salaries of staff. They cannot be used for services or payment for equipment, travel, etc. In an effort to reduce costs for factor, the director of the Hemophilia program has worked to include provisions in the MCHB grant to provide for the University of Louisville and the University of Kentucky to participate in PHS pricing for factor.

When the Maternal and Child Health Block Grant was consolidated, the programs previously receiving funds for Kentucky were: Sudden Infant Death Syndrome, Lead-Based Paint Poisoning Prevention, Title V Crippled Children's Program, Title V Maternal and Child Health, Supplemental Security Income for Disabled Children and the Genetics program. These programs have continued with a combination of MCH Block Grant and general funds.

Certain special projects have been continued with MCH Block Grant and/or general funds. The Children and Youth Project has remained as a continued project. The Dental Health Project has become a part of the Office of Oral Health Program. The activities of the Maternal and Infant Care Project were incorporated into the statewide Prenatal Program to have a larger impact on reducing the state's infant mortality rate. The Family Planning Project was

incorporated into the statewide Family Planning Program and is no longer identifiable as a special entity. The Intensive Infant Care Project continues to be an identifiable project through a contractual arrangement with the University of Kentucky.

Kentucky's Child Health Insurance Program (KCHIP) began July 1, 1999. While it will take time for that caseload to develop, the KCHIP program should give relief to Title V funded providers. For example, most infants and children previously served through Title V funding will now be served through KCHIP funding. This will free up Title V funds to help augment other important services such as prenatal care, early childhood development and injury prevention.

Traditional Title V agencies are also helping work toward TANF objectives. For example, four county health departments are now receiving funds to support home visitation services modeled after the Healthy Start model. These four demonstration sites, as well as eleven other sites, are operating and being evaluated with strict outcome indicators to determine if Kentucky's home visitation model should be expanded statewide with additional state general funds and, where appropriate, with Medicaid funds.

Federal funds Kentucky received for statewide systems development initiative (SSDI) are used for data systems and analysis for the five year needs assessment and tracking of relevant performance and outcome measures. Systems development activities over the past several years have provided a model to build upon. Technological infrastructure continues to be a significant need within the local health departments.

3.4 Performance Measures

3.4.1 National "Core" Five Year Performance Measures

Figure 3 TITLE V BLOCK GRANT PERFORMANCE MEASUREMENT SYSTEM

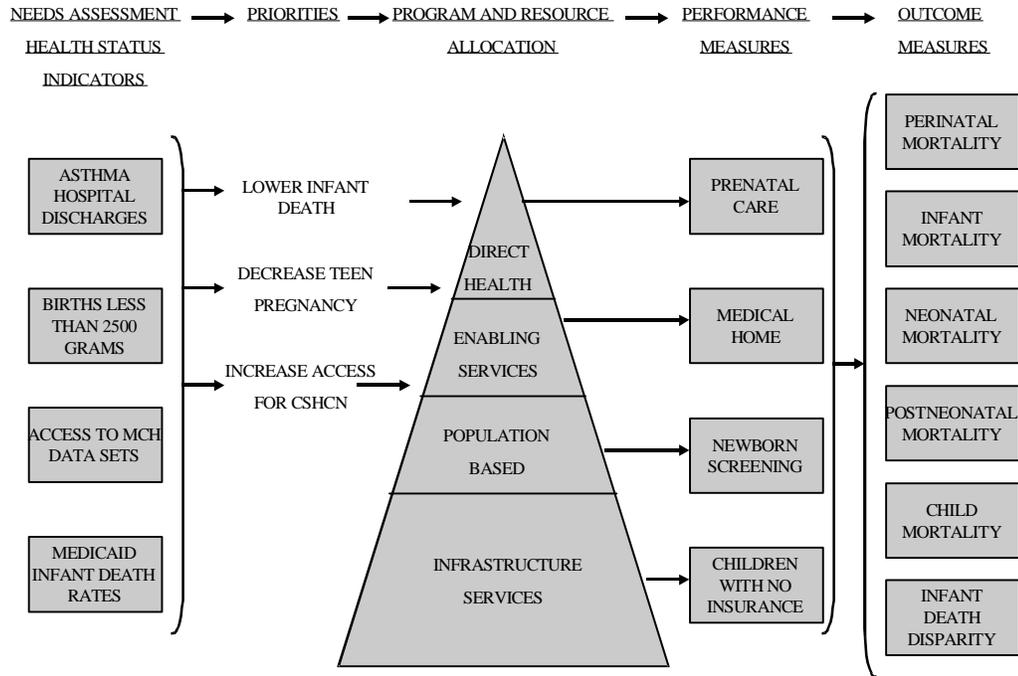


Figure 4
PERFORMANCE MEASURES SUMMARY SHEET

Performance Measure	Pyramid Level of Service				Type of Service		
	DHC	ES	PBS	IB	C	P	RF
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, Haemophilus 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 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

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

Negotiated Performance Measures	Pyramid Level of Service				Type of Service		
	DHC	ES	PBS	IB	C	P	RF
1. Percent of women of childbearing age taking folic acid regularly.			X				X
4. Rate of substantiated incidence of child abuse, neglect or dependency.				X		X	
5. Percent of families receiving support services/parenting assistance through home visiting support programs.		X			X		
6. Percent of children with inappropriate weight for height.			X			X	
7. Percent of child deaths undergoing local multidisciplinary investigation.			X				X
8. Percent of primary care providers in KY who use the agency to provide care to children with special health care needs.				X	X		
9. Degree to which CCSHCN ensures that CSHCN have opportunities necessary to make appropriate transitions to adult life, including adult healthcare, work, and independence.	X					X	
11. Degree to which CCSHCN ensures enrolled children with special health care needs receive comprehensive coordinated care.		X				X	
12. The percent of counties covered by standardized fetal and infant mortality reviews.		X					X
13. The proportion of young people who have smoked cigarettes within the past 30 days.			X				X

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

3.4.1.1 Five Year Performance Objectives

3.4.2 State "Negotiated" Five Year Performance Measures

3.4.2.1 Development of State Performance Measures

Performance measures developed according to guidelines.

3.4.2.2 Discussion of State Performance Measures

#1 Percent of women of childbearing age taking folic acid regularly. Studies indicate that consumption of folic acid preconceptionally and during early pregnancy reduces the frequency of neural tube defects by an estimated 50-70 percent. Kentucky wants an increase in the number of women who are taking this preventive action. This measure falls within the

population based services section of the pyramid and is potentially linked to all of the outcome measures with the possible exception of infant death disparity.

#4 Rate of substantiated incidence of child abuse, neglect or dependency. Kentucky plans to continue work with collaborating agencies to identify and target resources to prevent child abuse, neglect or dependency. This measure falls within the infrastructure building section of the pyramid and has a direct link to all outcome measures with the exception of perinatal death.

#5 Percentage of families receiving support services/parenting assistance through home visiting support programs. Research has shown that pregnant women who enter early prenatal care have better pregnancy outcomes and home visiting support services/parenting to overburdened families close to the birth of their child is successful in reducing levels of abuse, neglect and emotional abuse. The measure falls within the enabling section of the pyramid and has a direct link to all of the outcome measures.

#6 Percent of children with inappropriate weight for height. Maintaining appropriate weight for height during childhood can reduce the risks of developing chronic conditions in later years. Obesity increases the risk for diabetes, heart disease, hypertension, cancer, arthritis and other causes of death and disability. This measure falls within the population based services section of the pyramid and is linked to the outcome measure for child death.

#7 Percent of coroner case child deaths undergoing local multidisciplinary investigation. Local multidisciplinary investigations and data collection can lead to improved information that enhances identification of prevention strategies to reduce the number of future deaths. This measure falls within the population based services section of the pyramid and is linked to all outcome measures except perinatal death.

SP#8 Percent of primary care providers in Kentucky who are competent and willing to serve as medical homes for children with special health care needs and assure that each Commission enrolled child has a medical home. Outreach and education for this provider community is vital for continuing and expanding access to the comprehensive, coordinated care that has been shown to best meet the needs of children with chronic illnesses and disabilities. This measure falls within the direct health care section of the pyramid and is linked to all outcome measures.

SP#9 Assure that children with special health care needs and their families receive the services and opportunities necessary to make appropriate transitions to adult life, including adult healthcare, work, and independence. The KY Teach Project, an MCHB federally funded transition project, builds upon the transition efforts that began with the Kentucky CHOICES Project- WISH. The Commission places a strong emphasis on helping children with special health care needs so that they can grow up to become successful adults who have adequate healthcare, work skills, and independence. This measure falls within the direct health care section of the pyramid and is linked to all outcome measures.

SP#11 Degree to which the Commission ensures enrolled children with special health care needs receive comprehensive coordinated care. This new performance measure builds upon

PM#2 by expanding our accountability to coordinate care with the additional specialty and sub-specialty services that a child or family receives. Lack of care coordination was a major concern of families who participated in the needs assessment surveys and focus groups. Results of the provider surveys supported this concern, as did the survey of 18-21 year old graduates of the program that indicated few had found adult specialty providers. This also becomes more important as the Commission is establishing real methods to measure quality outcomes and shifts to a case management model that will identify those patients who require more comprehensive coordination along the continuum of care. This measure falls within the enabling section of the pyramid and is linked to all outcomes.

SP#12 The percent of counties covered by standardized fetal and infant mortality reviews. This new performance measure emerged from the need to address the declines in the outcome measures and the disparities between the white and black infant mortality rates. Fetal and infant mortality reviews are conducted with the expectation of gaining a broader perspective in understanding the various causes of fetal and infant deaths and with the hope of reducing preventable factors attributed to those deaths. This measure falls within the enabling section of the pyramid and is linked to all outcomes except the child death rate.

SP#13 The proportion of young people who have smoked cigarettes within the past 30 days. This new performance measure emerged from the significant number of young people smoking and that Kentucky leads the nations in the number of white adults that smoke. Studies document the association between smoking and cancer, heart disease and premature death. This measure falls within the population based section of the pyramid and is linked to the outcome measures in the effect that smoking has on low birth weight and its correlation with the outcome measures.

3.4.2.3 Five Year Performance Objectives

3.4.2.3 Review of State Performance Measures

To be determined.

3.4.3 Outcome Measures

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

4.1 Program Activities Related to Performance Measures

This discussion is separated between the Division of Adult and Child Health and the Commission for Children with Special Health Care Needs.

National Performance Measures

#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). Within the Department for Public Health, the Division of Laboratory Services performs the newborn screening testing for Kentucky and newborn screening follow-up is coordinated by staff within the Division of Adult and Child Health. Contracts exist with the University of Kentucky and the University of Louisville for the confirmatory diagnosis and treatment for

these conditions. Results are shared with the Commission for Children with Special Health Care Needs for children with sickle cell disease for comprehensive management and coordinated care.

#5 Percent of children through age 2 who have completed immunizations for Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, Hepatitis B. Within the Department for Public Health, the Division of Epidemiology is the lead division for the immunization program. Programs operated by the Title V agency and local health departments routinely assess immunization status. Immunizations are provided through the local health departments and supplied through the Department for Public Health. Recent legislation fully funded the cost of vaccines for underinsured children. This program expansion is one of the items within the early childhood development program.

#6 The birth rate (per 1,000) for teenagers aged 15 through 17 years. The abstinence efforts and other teen pregnancy efforts are coordinated through local health departments and community groups to reduce the birth rate for teens. In addition, family planning services are widely available throughout the local health departments.

#7 Percent of third grade children who have received protective sealants on at least one permanent molar tooth. Oral health staff are engaged in supporting the development of a dental surveillance system and implementation of a comprehensive survey of dental needs in Kentucky. In addition, efforts are underway to increase the number of dental providers serving the Medicaid population.

#8 The rate of deaths to children aged 1-14 caused by motor vehicle crashes per 100,000 children. Support for the development of injury prevention coalitions and child fatality review teams coordinated by the local health departments and at the state level continues. In addition, the Division of Adult and Child Health supports the Pediatric and Adolescent Injury Prevention Program at the University of Kentucky. Partnership with the Governor's Drive Smart Team to provide child safety seat checkups and other safe driving initiatives contribute to the Division of Adult and Child Health's efforts to reduce deaths to children aged 1-14.

#9 Percentage of mothers who breastfeed their infants at hospital discharge. The breastfeeding program and the prenatal program both support the importance of breastfeeding for optimal health of babies.

#12 Percent of children without health insurance. The Division of Adult and Child Health through partnership with the Division of Local Health Operations and the Department for Medicaid Services has been working to provide outreach, education and referral for the Kentucky Children's Health Insurance Program. All indications are that this targeted and extensive outreach has resulted in many new Medicaid recipients and also the enrollment targets have been surpassed for the KCHIP as well. These efforts will continue through the next year.

#13 Percent of potentially Medicaid eligible children who have received a service paid by the Medicaid Program.

As discussed under item 12, significant outreach efforts are made to get children enrolled in the Medicaid Program. Efforts to increase the Medicaid providers should be eased with the potential of the incentive KenPAC program. It is anticipated that the items "incented" will focus on preventive health services. These two efforts should increase the data for this measure.

#15 Percent of very low birth weight live births.

Kentucky is engaging in a significant campaign to improve pregnancy outcomes via the home visitation program, tobacco cessation and folic acid awareness. Although the anticipated outcomes for these efforts are many, the reduction of low birth weight births should be significantly impacted.

#16 The rate (per 100,000) of suicide deaths among youths 15-19.

Grief counseling services are available through the school system for youths and through the local community mental health system. Local health departments are encouraged to routinely offer grief counseling to families who have lost a child regardless of the reason although this service developed from the SIDS counseling services.

#17 Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.

The Division of Adult and Child Health will continue to monitor this measure due to the reduction in the percent of very low birth weight infants delivered at such facilities.

#18 Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.

Like with the previous performance measure there is a need to monitor this measure closely as well. Traditional prenatal services through the local health departments have routinely stressed the importance of early prenatal care. Plans to develop FIMR projects should assist with identifying those systems issues that may impact this measure.

State Performance Measures

#1 Percent of women of childbearing age taking folic acid regularly.

One of the initiatives of the early childhood effort, a train the trainers program to build an infrastructure throughout Kentucky of staff will have a significant impact on the awareness of the importance of folic acid use for women of childbearing years. Participants in the family planning programs will receive supplements for their use.

#4 Rate of substantiated incidence of child abuse, neglect or dependency.

The home visitation efforts have been demonstrated in other states to have an impact on the incidence of child abuse and neglect. Partnerships with the Cabinet for Families and Children to increase home visitation services and information on the importance of early brain development should assist in meeting this measure. The child fatality review system has strong support at both the community and state level for expertise in this area. All parenting components in local health department services stress the expectations for normal child growth and development and resources available to families.

#5 Percentage of families receiving support services/parenting assistance through home visiting support programs.

Another program of the early childhood initiative, significant collaboration, training, service delivery and evaluation efforts are outlined for the coming year. This program is built upon a pilot project and researched based with the intent of providing home visiting services to all first time mothers during the prenatal period and up to the child's second birthday.

#6 Percent of children with inappropriate weight for height.

Another program of the early childhood initiative, the health, safety and nutrition consultants for child care coupled with existing nutrition efforts for children by the local health departments should work toward reducing this measure.

#7 Percent of coroner case child deaths undergoing local multidisciplinary investigation.

Increased community, multidisciplinary education by local health departments and state staff of the importance of child fatality review and the development of data driven preventive strategies is necessary to improve the number of local child fatality review teams.

#12 The percent of counties covered by standardized fetal and infant mortality reviews.

This measure was chosen to provide a systematic review of fetal and infant deaths in Kentucky. Three sites were chosen that serve the largest population. Local health departments in those sites will be asked to begin the collaboration necessary to develop standardized FIMR. Future plans will include a rural site as well.

#13 The proportion of young people who have smoked cigarettes within the past 30 days.

A significant issue in Kentucky is the number of adults and children who smoke. Getting serious about youth tobacco use has been elevated within a tobacco producing state. All public health efforts are being required to address one or more of the Centers for Disease Control four priorities.

Commission for Children with Special Health Care Needs:

PM #01 Percent of SSI beneficiaries less than 16 years old receiving rehabilitative services from the State

In 2000, the Commission will continue to receive transmittal notices of new SSI eligible children from the state DDS. Those eligibles will be screened for referral to the Disabled Children's Services to assure that SSI children ages birth to 4 receive outreach and follow up for service assessment in their local community. The Commission will also assist enrollees to apply for SSI as appropriate. The State Title V CSHCN Liaison will continue to monitor federal and state activities relative to the CSHCN/SSI population to assure timely responses to any program initiatives and monitor opportunities for collaboration on behalf of SSI recipients. The KY Teach Project will work with Social Security Administration local SSI staff to incorporate SSI policies related to work incentives into the transition services provided by the Commission.

PM # 02 Degree to which State CSHCN Program provides or pays for specialty and subspecialty services.

The Needs Assessment supports the Commission's continued role as a provider of direct health care in those areas of the state that lack specialty providers and other resources. The

Commission will continue to consider the best and most efficient manner to assure access to care for KY CSHCN. Expansion of services to children with Asthma is an example of the Commission's effort to identify and address unmet needs. During the first year of serving children with asthma (1998), the clinic was incorporated with the cystic fibrosis clinic but was moved to its own clinic day effective Nov. 1, 1999 due to its growth. Activities planned for next year include:

- using Life Maps and case management to focus on transition needs of our adolescent patients
- assuring care coordination for pharmacy management and medication education for patients and families
- continued development of a database to collect information on Commission patients to compare with children not enrolled in the Commission for compliance issues, number of hospitalizations/emergency room visits, etc.
- the Commission also plans to collaborate with the pulmonary center to incorporate this data with theirs for presentation of an asthma study.

There is still insufficient evidence to support the Commission's expansion of services to children with Diabetes. The Commission's request for expansion funding to provide services for Diabetes was not approved in the last biennium budget for the Cabinet for Health Services. At this point, the Commission continues to document requests for services for children with Diabetes and provides referral to the most appropriate resources.

For patients with Sickle Cell, the following activities are planned for 2001:

- initiate a monthly group for parents of children with sickle cell to provide parenting information, education about sickle cell and treatment, plus support for the families
- publish a monthly newsletter with information about sickle cell and a Q&A section to respond to specific family/patient concerns

PM #03 Percent of CSHCN in the State* who have a "medical/health home"

The Commission received funding for the KY Teach Project (Kentucky Youth Transitioning to Employment and Adult Healthcare) in July of 1999. One of the two primary goals of this project is to increase the number of Kentucky CSHCN who have medical homes. A key part of this initiative is the training of state providers; this will be accomplished through collaborative efforts with the national Medical Home Training Project through the American Academy of Pediatrics. A state training meeting is scheduled to take place fall of 2000 and a collaborative team of families, providers, and service agencies are meeting to plan this training and to identify trainees.

SP #8 Percent of primary care providers in KY who use the agency to provide care for children with special health care needs.

Based on feedback from our PCP providers and partners in Medicaid managed care, the Commission became aware of the need to easily identify current "medical home" information. Because our medical records include volumes of specialists' reports, augmentative reports, etc. it is sometimes difficult to identify the primary care physician without searching through pages of records. A colored label has been developed to be placed on the hard copy medical record. The information on the label is identical to what will eventually be on the patient computerized record screen when the new information system is complete. With each visit the registration staff verifies the current information on the label as correct, or updates the correct information.

Clinic providers, Commission staff and any person with access to our medical records is instructed to refer to this label, which is always in the same place on the chart, for current/accurate update of PCP information. This promotes exchange of medical records and communication with the PCP about specialist recommendations and proposed changes in treatment plan.

SP #9 Degree to which Commission ensures that children with special health care needs and their families receive the services and opportunities necessary to make appropriate transitions to adult life, including adult healthcare, work, and independence.

Training workshops for youth and for families will be held throughout the state on issues related to transition. Many of these will be done by parent advocacy groups and through centers for accessible living through contracts. Paid summer work experiences will be available for up to ten youth and other youth will have opportunities to attend educational camps and workshops throughout the summer. Other plans include developing a strong network of mentors (employed adults with disabilities) to serve as role models to youth and ongoing staff training about available resources to assist with successful transitions.

PM # 10,

In FY 2001, the Commission plans the following activities related to Newborn Hearing Screening and Chronic Otitis Media:

- Researching opportunities and writing for grants to further fund equipment and support programming
- Continue to support UNHS legislation efforts and work towards mandated UNHS
- Improve outreach programs to include rural areas and populations less likely to obtain hearing screening, or to
- Have access to hearing screening resources
- Continue to provide free follow-up for children that fail their neonatal screening.
- Place advanced infant testing equipment (OAE) in each Commission regional office and provide training to
- Improve diagnostic capabilities of audiologists throughout the state

SP #10 Degree to which Commission ensures enrolled children with special health care needs receive comprehensive coordinated care

The Commission has developed a comprehensive review tool that will be used to review charts in all of the 14 district offices. An important piece of this will be looking at care coordination with both medical home providers and other services that a child receives. This tool will be used beginning in August of 2000. Staff will be assisted in meeting the outcomes identified on this tool through detailed workshops about Case Management and the implementation of a new computerized care coordination /information system. Other agency activities that will help with this performance measure include increased outreach activities, improved dictation technology, and teaching families about the value of care coordination services.

PM #14 Degree to which the State assures family participation in program and policy activities in the State program.

As indicated in previous discussion related to transition activities and the Needs Assessment, family input is a priority at the Commission. In 2000, a new Intake/Eligibility process is being

implemented. Included in the staffing for this unit will be a Parent Professional position. Every effort will be made to provide this employee with opportunities to participate in conferences and workshops for CSHCN parents and to empower this individual to serve as an advocate for Commission families. Through the KY Teach project, the Commission has several objectives that will require collaboration with families and with parent professional organizations. Family participation is an integral component in the medical home training initiative. The Commission contract with both KY-SPIN and PiNK for activities focused on family participation.

4.2 Other Program Activities

Two years into Medicaid Managed Care in Kentucky, family responses to the Commission's Needs Assessment indicate that the impact on CSHCN and their families is negligible. However, the Commission has seen a major impact on the roles and responsibilities of staff members. It is reasonable to conclude that the Commission's ability to serve as an arbiter between families and the MMC partnerships accounts for the families' perception. The Commission continues to intervene with such problems as families failing to understand the process for getting PCP referrals to clinics; and, Commission nurses are able to advocate with the partnerships to allow CSHCN continuation of a case management model that best serves this population. Another impact for the Commission has been recognition of the low referral rate of patients from primary care providers participating in the partnerships. This has caused the Commission to increase outreach efforts to PCPs and to work to improve coordination of care with referring physicians.

Over the next year, the statewide MMC plan will undergo significant changes. In December 1999, the Commission was notified that Kentucky Health Select (KHS) the MMC partnership serving counties in the Lexington region would be dismantled by 6-30-00. Children enrolled in KHS would be transferred to the traditional Medicaid KenPAC program and the Commission began efforts to transfer patients to that system. The Commission was also notified of the opportunity to "carve out" CSHCN under the pending revised state plan. Recognizing that not all CSHCN require the same level of care, the Commission drafted language regarding the segment of CSHCN population that would qualify for case management and be appropriate for a "carve out". This draft language was provided to the state Dept for Medicaid Services for review and submission to HCFA.

Since the initial implementation of MMC in the state, only PassPort the partnership operating out of Louisville and affecting families primarily seen in the Commission's Louisville and Elizabethtown regions has been fully functioning. The Commission has had a good working relationship with PassPort with regular dialogue to discuss issues identified as they have emerged. In 2000, the Commission and PassPort have initiated a project to:

- share data on patient population quarterly and annually to identify children enrolled in both programs; and,
- to define criteria (acuity) that will result in placement of those identified children into the appropriate level of care, case management vs. monitoring
- improve the rate of referral of children from Passport to the Commission
- monitor and improve quality of care via monthly report from the Commission to Passport on number of complaint calls received relative to Commission enrollees as a whole and specific to PassPort members
- monitor transition from pediatric to adult healthcare services

Historically the Commission has striven to provide quality care to children. However, the Commission recognized the need to measure quality, not only through the performance measures identified for the purpose of the block grant, but to meet the expectations of families, providers and other contracted entities (MCO's, Medicaid, third party carriers, etc.). This endeavor requires the full time attention of a professional staff member to coordinate training, define performance measures and assemble data into reports that medical and social services staff can interpret to improve services as well as outcomes. Therefore, the role of the Director of Clinical Services was redefined to encompass the duties of a quality manager.

A quality improvement committee comprised of various Commission department leaders was convened during the last quarter of 1999. The committee will meet on a monthly basis, beginning March 2000, with its first objective being to define a quality audit/review tool. 2000 will be used as a baseline-gathering period for Commission operations, as well as education of all Commission staff about the use of the audit tool.

As discussed earlier, significant program efforts around the passage of the early childhood legislation has resulted in numerous opportunities for the Division of Adult and Child Health and the Department for Public Health. This significant funding and legislative commitment for the next two years provides the incentive to systematically address all of the strategies outlined within his plan. The education of the workforce, quality of education for families and general quality of life issues have always played a significant role in determining private economic development commitments within Kentucky. The early childhood development legislative package provides the foundation for *Promoting Economic Development*. Research shows that brain is not developed at birth but continues to make connections during the first few years of life. Efforts on brain development will pay off for Kentucky's strategy of *Improving Education Product*. The significant allocation associated with the home visitation program, the resources targeted for consultation in child care centers on health, nutrition and safety and the folic acid campaign coupled with existing maternal and child health efforts all work toward *Building Self-Sustaining Families*. The multitude of collaborative work necessary to implement all the components of the early childhood legislation and the accountability issues arising for meeting the outcomes necessitates *Strengthening Efficiency and Operations of Government*. Like with charge from the Health and Human Resources Administration, Maternal and Child Health Bureau to improve data capacity and resources, the early childhood development legislation elevates the necessity to share data and resources across agency lines as well as more effectively within agencies. Finally, the strategy *Reducing Crime and its Costs to Society* can best be addressed by having well educated, healthy and economically successful families and communities.

4.3 Public Input [Section 505(a)(5)(F)]

General information submitted to the Department for Public Health was in support of efforts identified within the application. A public hearing was held on July 12, 2000. There were no comments to report as a result of the hearing. A copy of the proceedings is on file in the Title V office.

4.4 Technical Assistance [Section 509 (a)(4)]

No technical assistance is directly requested.

V. 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 Marshall 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 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.

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 doe 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.

- 5.3 Other Supporting Documents
- 5.4 Core Health Status Indicator Forms
- 5.5 Core Health Status Indicator Detail Sheets
- 5.6 Developmental Health Status Indicator Forms
- 5.7 Developmental Health Status Indicator Detail Sheets
- 5.8 All Other Forms
- 5.9 National “Core” Performance Measure Detail Sheets
- 5.10 State "Negotiated" Performance Measure Detail Sheets
- 5.11 Outcome Measure Detail Sheets