

**Kentucky Department for Public Health &
Kentucky Commission for Children with Special Health
Care Needs**

Title V MCH Block Grant Five-Year Needs Assessment

Prepared for the Maternal and Child Health Bureau, Health Resources and Services Administration, Rockville, Maryland. July 15, 2010. (Revised September 17, 2010)

Commonwealth of Kentucky Title V Five-Year MCH Needs Assessment (2010)

Kentucky Department for Public Health
Kentucky Commission for Children with Special Health Care Needs

Table of Contents

1.	Process for Conducting the Needs Assessment	3
2.	Partnership Building and Collaboration Efforts	41
3.	Strengths and Needs of the MCH Population Groups	74
4.	MCH Capacity by Pyramid Levels	98
5.	Selection of State Priority Needs	129
6.	Outcome Measures – Federal and State	139
	Appendices	149
a.	Kentucky Title V Needs Assessment Logic Model	
b.	Kentucky Public Health – Local/District Health Department Map	
c.	Pre-Assessment provider and Stakeholder Survey	
d.	Provider and Stakeholder Web-based Survey	
e.	Kentucky Area Development District Map	
f.	Patient/Consumer Survey	
g.	CCSHCN Family Survey	
h.	CCSHCN Five-Year Assessment Youth Advisory Council Focus Group Meeting Report (YAC)	
i.	CCSHCN Staff Survey	
j.	CCSHCN Provider Survey	

Kentucky Title V Five-Year MCH Needs Assessment

Kentucky Department for Public Health (Frankfort) Kentucky Commission for Children with Special Health Care Needs (Louisville)

Introduction

The creation of the 2010 MCH Needs Assessment document was made possible through a multi-year commitment by both the Kentucky Department for Public Health and the Kentucky Commission for Children with Special Health Care Needs to work in partnership with local communities, private partners and families across the Commonwealth of Kentucky. Our purpose was to assess, analyze and report the current health status and future health needs of mothers, infants, children, adolescents and families.

While both agencies work closely on a daily basis to coordinate programs throughout the Commonwealth, for the purpose of improved clarity and continuity for the reader, each major section will be addressed individually for both agencies. The Kentucky Department for Public Health will lead each section with the Commission for Children with Special Health Care Needs report following. An exception to this rule occurs in both the second “*Partnership Building and Collaboration Efforts*” and fifth section “*Selection of State Priority Needs*”, which are fully integrated to allow the reader a complete picture of Kentucky’s collaborative efforts and vision for maternal and child health.

Section 1: Process for Conducting the Needs Assessment

Kentucky Department for Public Health

I. a. Needs Assessment Goals, Vision, Purpose

The Kentucky Department for Public Health (KDPH) began the process for the 2010 Needs Assessment report in March of 2008. Our purpose was not only to examine quantitative data using internal data systems such as Kentucky Vital Records, Newborn Screening, Youth Risk Behavior Survey and Medicaid data, but to combine our quantitative data with substantial *qualitative* information, obtained directly from Kentucky’s stakeholders: our citizens. To achieve this, Kentucky targeted three different stakeholder groups: local health department patients, health providers and community members.

Gathering such information directly from those providing and utilizing our services, and integrating these results with quantitative data will allow us to accurately isolate our target priorities for the coming five-year period. Further, such cross-examination (or triangulation) validates our results. We are not relying upon a single source of information but instead, four

Our Mission

The mission of Maternal and Child Health (MCH) is to provide leadership, in partnership with key stakeholders, to improve the physical, socio-emotional health, safety and well-being of the maternal and child health population which includes all of Kentucky’s women, infants, children, adolescents and their families.

This mission is carried out in collaboration with partner agencies, primarily local health departments, other state agencies and state universities to provide clinical and community-based services to the MCH population. State level MCH staff support services and infrastructure building through policy development and implementation, surveillance activities, technical assistance, consultation, training, education and case management.

Source: KDPH website at <http://chfs.ky.gov/dph/mch/cfhi/>

independent sources. Examining these sources together enables us to prepare a comprehensive and living needs assessment document for preventive and primary care services for 1) pregnant women, mothers and infants; 2) children and 3) children/youth with special health care needs.

I. b. Needs Assessment Framework

The needs assessment process began in early 2008 when Kentucky received technical assistance on the Title V Needs Assessment on March 24, 2008. Dr. Arden Handler and colleagues traveled to Kentucky for provide technical assistance funded through the MCHB/HRSA State Systems Development Initiative Grant (SSDI). Topics covered included an overview of needs assessment, assessment and priority setting of health issues, examples of needs assessment/prioritization models used by other states, themes across states, and next steps. From this technical assistance, a draft logic model (Appendix A) and a timeline were developed.

A Title V Needs Assessment Committee comprised of Division staff (Division Director, program staff and epidemiology staff), local health department personnel, and representatives from professional and non-profit organizations in Kentucky provided guidance throughout the needs assessment process. Activities included:

- Development of a logic model;
- Evaluation of potential MCH priority issues along with potential data sources and whether it was included as a Healthy People 2010 objective;
- A survey of local health department directors;
- A web-based survey of major MCH stakeholders including local health department management personnel, partners of the Department for Public Health and professional organizations in Kentucky;
- A compilation of the above information to identify potential priority issues;
- Development of county health profiles related to MCH;
- Completion of eleven community forums to prioritize issues;
- A consumer survey of patients who utilize health department services

Table 1: Surveys Developed for the 2010 Kentucky MCH Needs Assessment Process			
Survey Type	Target Group	Start Date	Finish Date
LHD Directors Pre-Assessment pilot	Health Department Directors	Sept. 2008	Sept. 2008
Web-based Survey	MCH Stakeholders including LHD, childcare, physicians, hospitals	Jan. 2009	April 2009
Patient-based Survey	Local Health Department Patients	June 2009	July 2009
Community Forums	Providers and citizens	April 2009	May 2009

1. c. The 2010 MCH Needs Assessment Leadership Team

The Kentucky 2010 MCH Needs Assessment Team (Table 2) for the Kentucky Department of Public Health was led by **Dr. Ruth Ann Shepherd**. Dr. Shepherd was appointed Director of the Division of Adult and Child Health Improvement and began her duties on September 1,

2005. She received her B.A. in Biology/Pre-med from Asbury College, in Wilmore, KY, magna cum laude and her M.D. degree from the University of Louisville, School of Medicine. Dr. Shepherd did her residency in Pediatrics at Methodist Hospital Graduate Medical Center in Indianapolis, Indiana and her Neonatology Fellowship at Medical University of South Carolina in Charleston, SC. She has Board Certifications from the American Board of Pediatrics and the American Board of Neonatal-Perinatal Medicine.

Her professional experience includes in private practice in Neonatology and General Pediatrics in Louisville (KY), followed by 16 years in rural eastern Kentucky as Director of Neonatology Services at Pikeville Methodist Hospital, Regional Level II+/3A Neonatal Intensive Care Unit with Regional Neonatal Transport Service, Infant Apnea Program, Neonatal Developmental Follow-Up Clinic, and Early Intervention System 0-3 Intensive Evaluation Team, and Medical Advisor to the Infant Hearing Screening Program. She is also on the Board of the Greater Kentucky Chapter March of Dimes and the Kentucky Perinatal Association.

Dr. Shepherd has presented on behalf of Kentucky at the American Public Health Association, the National Center for Health Statistics and the Surgeon General's Conference on Preterm Birth. She served on the National Quality Forum Steering Committee for Perinatal Indicators. Her role in the Needs Assessment process was to lead the process and direct the overall focus of the Needs Assessment Team.

Table 2. Roles and Responsibilities of the Kentucky MCH Needs Assessment Leadership Team		
Name	Area of Expertise	Role in the Needs Assessment Process
Ruth Ann Shepherd, MD, FAAP, CPHQ	MCH Director	Oversight of NA Process
Marvin Miller, MSW	MCH Asst. Director	Community Forum Planning and Coordination
Shelley Adams, MSN, RN	MCH	Branch Manager, Child and Family Health Improvement
Jo Ann Blackburn, CSW, MSSW, ACSW	MCH	Title V Administrator, Child and Family Health Improvement
Sarojini Kanotra, PhD, MPH	MCH Epi /Former CDC Assignee	Facilitation of State NA Team; Analysis of Patient Surveys and Community Forums
Tracey Jewell, MPH	MCH Lead Epidemiologist	Quantitative Data Analysis and Presentation; Analysis of Title V Indicators
Joyce Robl, MS, CGC	Evaluation/ MCH	Quantitative Data Analysis
Regan Hunt, MPA	Early Childhood Development	Quantitative Data Analysis
Roshni Matnani, BDS, MPH	Oral Health	Quantitative Data Analysis
Julie McKee, DMD	Oral Health	Community Forum Planning and Coordination
Victoria Greenwell, MA	Coordinated School Health	Community Forum Planning and Coordination
Diana Koonce, BA	Oral Health	Community Forum Planning and Coordination
Lorie Wayne Chesnut, MPH	MCH & Title V	Needs Assessment Document Compilation

Marvin Miller, MSW, is the Assistant Director for this Division. Mr. Miller has worked in public health for over thirty years, and has been assistant director in Maternal and Child Health for over 20 years. Mr. Miller has been instrumental in the development of our WIC program, Well Child Program, and others. A few of his accomplishments include the establishment of EPSDT outreach, a child safety seat program, and our HANDS state-wide home visiting program. Some of Mr. Miller's current functions include legislative liaison for the Division, and oversight of the local health department's plan and budget process. Mr. Miller led the planning and implementation of the state-wide Community Forums during Spring 2009.

Shelley Adams, MSN, RN, became the Branch Manager of Child and Family Health Improvement on March 1, 2009. Ms. Adams came to Public Health from the Department for Medicaid Services after 4 years working primarily with community mental health and waiver programs as a Nurse Consultant Inspector, then as a branch manager in Community Alternatives. Ms. Adams has a Bachelor of Science in Nursing from Northeast Louisiana University and a Master of Science in Nursing from the University of Phoenix.

Ms. Adams worked closely with Dr. Shepherd in the MCH Needs Assessment Coordination. She served as the Grant Administrator for the 2009 Title V MCH Block Grant and now oversees the Title V MCH Block Grant program as the Branch Manager of Child and Family Health Improvement.

Jo Ann Blackburn, CSW, MSSW, ACSW assumed her role as the Health Services Section Supervisor in November of 2009. She has twenty years of experience as a medical social worker in a variety of healthcare settings and is now the administrator of the Federal Title V Block Grant for Kentucky. She will also supervise, coordinate, and administer the activities of the staff of the Pediatric Section of the Child and Family Health Improvement Branch. These programs include the Child Fatality Review and Injury Prevention Program, Childhood Lead Poisoning Prevention Program, Coordinated School Health Program, EPSDT and K-CHIP Outreach Program, School Health Program, and the Well-Child Program. She holds a bachelors degree in Social Work from Eastern Kentucky University and a Master of Science in Social Work from the University of Louisville.

Sarojini Kanotra, PhD, MPH holds a Master's in Public Health from Emory University and Master's and Doctorate degrees in Microbiology from the Indian Agricultural Research Institute in New Delhi, India. Dr. Kanotra is a Certified Health Education Specialist and is a member of numerous professional organizations including the American College of Epidemiology, the American Public Health Association, the Council for State and Territorial Epidemiologists and the Society for Public Health Education. Dr. Kanotra has been a guest researcher at the CDC and an Evaluation Consultant with the Georgia Department of Health. She has experience with PRAMS, PPOR, and FIMR, and has presented her work at the MCH Epi Conference and CityMatch Conference.

Dr. Kanotra led the data collection and analysis for the 2010 Title V Needs Assessment. She also worked to compile several Needs Assessment reports: *Web-Based Survey Findings*; *Maternal and Child Health Community Forums: Qualitative Analysis of Forums Findings*; and *Findings from Patient Survey*. The latter publication was primarily written by Graduate Student

Internship Program Intern **Shontreal Cooper** from the University of Kentucky, College of Public Health.

Tracey D. Jewell, MPH is the lead maternal and child epidemiologist for the MCH Division. Ms. Jewell earned her Master of Public Health degree at the University of Alabama Birmingham, School of Public Health in 1998. She joined the staff at the DPH in February of 1999 and came to the MCH Division in January of 2001 to assume her present position. Effective September 1, 2005, Ms. Jewell was promoted to Lead Epidemiologist for the Division of Maternal and Child Health. Ms. Jewell is involved in all MCH epidemiology efforts, and coordinates the data needed for the MCH Division from other departments and agencies.

Joyce M. Robl, MS, CGC is currently the principal investigator for Kentucky's State System Development Initiative, the evaluator for a nine county pilot project entitled GIFTS (Giving Infants and Families Tobacco-Free Starts), and the evaluator for an infant mortality pilot project exploring racial/ethnic disparities and contextual factors. With a BA in Biology from the University of Maryland and a MS in Human Genetics from the University of Michigan, Ms. Robl is a doctoral candidate in Health Promotion at the University of Kentucky. After receiving her board certification from the American Board of Genetic Counselors in 1993, she began a career in genetic counseling at the University of Kentucky, Department of Pediatrics.

In 1999, Ms. Robl joined the Kentucky Department for Public Health with a focus on birth defect surveillance and early childhood programs. From 2005 to 2007, she was the Branch Manager for the Early Childhood Development Branch, coordinating programs including Newborn Screening, the Kentucky Birth Surveillance Registry, Genetics, First Steps (Kentucky's Part C Program), Health Access Nurturing Development Services (HANDS), Healthy Start in Child Care and Early Childhood Mental Health. Her role in the needs assessment process was quantitative analysis.

Regan Hunt, MPA is a health policy specialist for the Newborn Screening and Birth Surveillance Registry programs, within the Division of Maternal and Child Health. Ms. Hunt received her graduate degree in Public Administration from the University of Kentucky in 2004 and also holds a Certificate in Healthcare Management from the University of North Carolina (2006). She joined the Kentucky Division of MCH in Spring 2009 for this new position which was created to analyze incident and prevalence data for metabolic disorders and congenital anomalies. She provides research, analysis and evaluation for Kentucky MCH programs, including Newborn Screening, Birth Surveillance Registry, HANDS, and First Steps. With topical interests including health equity, maternal smoking and developing measures and indicators to monitor and ensure quality, Ms. Hunt supports the MCH Needs Assessment process through the provision of her skills in quantitative data analysis. She is also taking responsibility for the Early Childhood Home Visiting Needs Assessment required by the Affordable Care Act of 2010.

Nishita "Roshni" Matnani, BDS, MPH is an epidemiologist with Kentucky's Oral Health Program, receiving her Bachelor of Dental Surgery from the Bharati Vidhyapeeth Dental College and Hospital in 2005 and her Master of Public Health from the University of Kentucky College of Public Health in 2009. While at UK, she focused on biostatistics and is a member of the

American Statistical Association as well as the Kentucky Public Health Association and the American Public Health Association. Her role in the needs assessment process was quantitative analysis.

Julie McKee, DMD was named the State Dental Director in September 2007. Dr. McKee has a BS in Biology from the University of Kentucky and her DMD from the University of Louisville. Prior to her appointment at the Kentucky Department for Public Health, Dr. McKee was the Director of the WEDCO District Health Department for more than 12 years. Dr. McKee was the Lead Facilitator of the eleven Community Forums and shared the responsibility of the planning and coordination of the forums process.

Victoria Greenwell, MA is the Coordinated School Health Administrator for the Kentucky Department for Public Health. Victoria has worked for over twenty years in the areas of education, health and social service focusing on improving the lives of children, their families and the community. She holds a BSW from Eastern Kentucky University and a MA in Education from the University of Kentucky. Ms. Greenwell served on DPH teams for statewide forums for Obesity (2004) and Tobacco (2005), and lent her expertise to the planning and execution of the MCH community forums.

Diana Koonce, BA is Health Policy Specialist II for the Kentucky Oral Health Program at the Kentucky Department for Public Health. A graduate of Eastern Kentucky University (1986), Ms. Koonce has an extensive background in social marketing and has received honors for her work with healthy vending options and VERB Summer Scorecard program. The VERB Summer Scorecard program is one of CDC's case studies for community social marketing. Ms. Koonce is working on the development of oral health coalitions in Kentucky and was involved in community forum planning and coordination.

Lorie Wayne Chesnut, MPH is a faculty member in the Department of Epidemiology at the University of Kentucky (UK), College of Public Health. She is currently completing her doctorate (ABD) at the University of Alabama at Birmingham under the Department of Health Care Organization and Policy after receiving her MPH from UK in 2005. Ms. Chesnut has worked in the field of maternal and child health (MCH) for over fifteen years, initially for the Kentucky March of Dimes Birth Defects Foundation and later for the Kentucky Department for Public Health. During her time at the state office, she coordinated reporting for the Title V Maternal and Child Health Block Grant through the federal Title V Information System. Her role in the Needs Assessment process was to compile and create the final document.

1. d. Methods: Assessing MCH Target Populations.

Within this section, details regarding the three survey tools used by Kentucky to assess the well-being and needs of pregnant women, infants and children will be provided. The three survey tools are:

- 1. Web-based Provider Survey**
- 2. Community Forums**
- 3. Statewide Patient Survey**

This includes a brief description of the process, discussion on survey response, and results. Limitations will also be noted for each tool. Information about Children with Special Health Care Needs will be presented in the following Section.

Kentucky's Web-based Provider Survey

Web-based Provider Survey: Process

The team discussed the importance of beginning the needs assessment process with the solicitation of input from Kentucky's Local Health Department (LHD) Directors, before moving beyond to the broader audience of health providers. Kentucky has 15 district health departments and 41 independent health departments providing healthcare services to 120 counties (Appendix B). It was reasoned that an ideal time to approach LHD Directors would be during the annual Kentucky Health Department Directors Association (KDHA) retreat, scheduled in the fall of that year. The purpose of this input would be to pilot test the survey instrument and to gain feedback, which would refine subsequent provider survey efforts.

In September 2008, the Division of Maternal and Child Health sought input from the district and independent health departments by conducting a *pre-assessment pilot survey* at the annual KHDA meeting. Health Department Directors attending the retreat were requested to complete the pre-assessment survey (Appendix C).

Directors reviewed issues affecting the health status of mothers, babies, children, and teenagers residing in their service area. Following completion of the survey, directors commented that the survey should also be completed by their key management personnel.

The results of this survey were used to design a web-based survey for broader dissemination (Appendix D). The target population of the web-based survey was Health Department Directors and their lead personnel, partners of the Division of Maternal and Child Health, contractors,

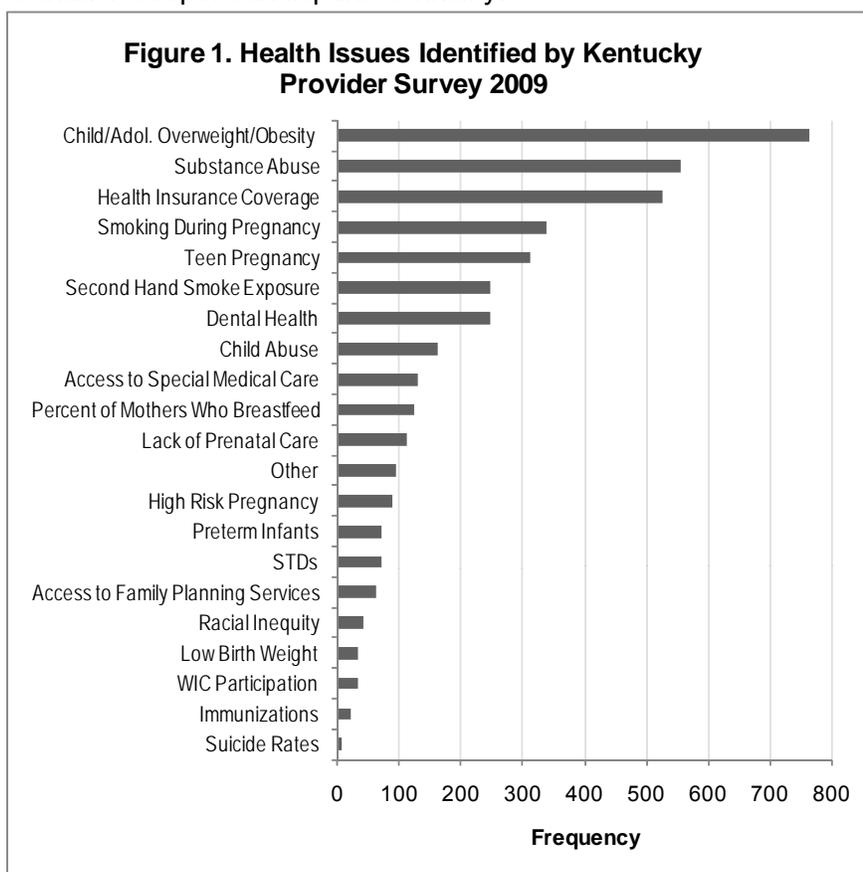
Table 3. Maternal and Child Health Stakeholders for Web-based Provider Survey
Administrative Office of the Courts
Catholic Conference
Commission for Children with Special Health Care Needs (CCSHCN)
Department for Community Based Services (DCBS)
Foundation for a Health Kentucky
Kentucky Academy of Family Physicians
Kentucky Chapter, American Academy of Pediatrics (Kentucky Pediatric Society)
KY Chapter, American College of Obstetricians and Gynecologists (ACOG)
Kentucky Child Now
Kentucky Council of Churches
Kentucky Department of Education
Kentucky Mental Health, Developmental Disabilities and Addiction Services (MHDDAS)
Kentucky Primary Care Association
Kentucky Rural Health Association
Kentucky School Nurses Association
Kentucky Youth Advocates
Local Health Department Directors
Local Health Department Nurse Administrators
School District Health Coordinators
Partnership for a Fit Kentucky
Prevent Child Abuse Kentucky
University of Kentucky, College of Public Health
University of Louisville, Department of Pediatrics, Division of Neonatal Medicine
University of Louisville, School of Nursing
University of Louisville, School of Public Health
Young Professional Association of Louisville

physicians, hospitals and child care providers. Completed in late 2008 and launched in January of 2009 (running through March 2009), the web-based survey targeted advocacy and non-profits (secular and faith-based), medical and health associations, hospitals, universities and state partners. A complete listing is provided in Table 3.

Web-based Provider Survey: Who Responded?

The survey was completed by 1,398 respondents and the majority of these individuals were female (92.3%). Ages varied from 18 years to more than 65 years, with just under one-third of respondents aged 45-54 years. Race of the respondents was primarily white (95.5%) with only 3.9% African Americans. Less than 1% reported Hispanic ethnicity.

When asked whether they were a healthcare provider, 58.3% responded that they were, with 41.7% responding that they were not (n=1379). The highest frequency of responses by Area Development District (ADD) was obtained from the Bluegrass Region of the state (23.4%) with the KIPDA region next at 12.4% following by Barren River at 10.4%. Areas of lowest response was Pennyrite (2.1%) followed by the Gateway and Buffalo Trace ADDS at 2.2% each. (Appendix E)



The majority of respondents were from public health agencies (55.4%) with 20.9% from educational institutions. Private non-profit providers comprised 13.6% and private for-profit, 9%. More than half cited their geographic scope-of-service as county-level, one third as regional and the rest state-wide.

Web-based Provider Survey: Results and Limitations

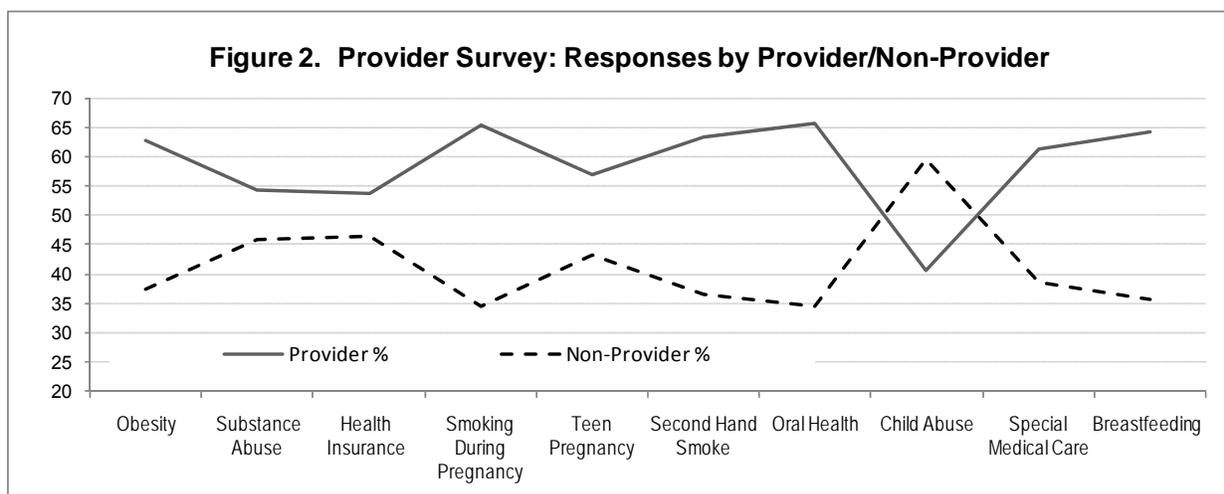
The web-based provider survey yielded 1,398 completed surveys. Participants were instructed to select the *top three health issues* that they felt were affecting the health status of the MCH population in their community. Figure 1 illustrates the frequency that a particular topic was selected.

To demonstrate, of those completing the survey (n=1,398), 763 individuals selected “*childhood and adolescent obesity*” to be one of their top three issue selections. Substance abuse was selected by 555 individuals, health insurance coverage by 527 individuals, and so on.

The top five maternal and child health issues emerging as a need are overweight/obesity in children and adolescents, substance abuse, health insurance coverage, smoking during pregnancy and teen pregnancy. Following closely behind are exposure to second hand smoke and dental health.

In Figure 2, the top 10 (ranked) issues are listed in priority order as selected by the larger group. These issues were further examined using stratification by provider (58.3%) or non-provider (41.7%) status. Providers selected the health issues at a higher frequency than the non-providers except for child abuse where the trend was opposite. This is important, because child abuse rises to the top as one of the primary issues affecting infants and children in the Commonwealth as selected by Kentucky health department patients. Details about this survey follow.

Limitations include the fact that responders provided their views, not necessary factual information about topics of interest. Particular groups of responders may be under-represented due to daily workloads, inability to access a computer or a lack of familiarity with a web-based survey too. This was a self-administered survey, providing interviewers no ability to clarify responses, explain questions that may confuse respondents or complete missing data fields.



For more information about the complete report “*The Title V Needs Assessment: Findings from the Web-Based Provider Stakeholder Survey 2009*”, please call Shelley Adams, Branch Manager of Child and Family Health Improvement at 502-564-2154, ext. 3766.

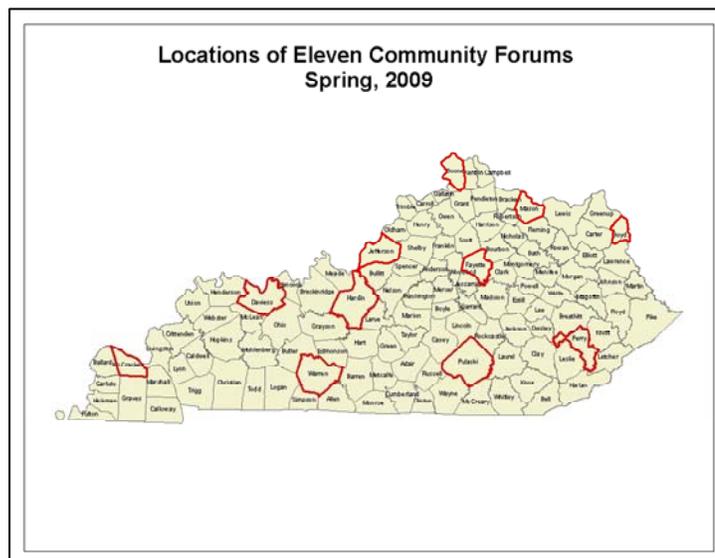
Kentucky Community Forums

Community Forums: Process

In the spring of 2009 (March through May), the State Department for Public Health conducted eleven Maternal and Child Health Community Forums at different locations throughout Kentucky. The main purpose for conducting these forums was to seek input from citizens and stakeholders regarding MCH issues that affect their community.

Forum dates and locations were advertised through local newspapers and the meetings were coordinated by staff at local health department sites. Registrants signed up via the internet at a website designed for the event. The events were also publicized to MCH partners via email with directions on how to register to attend. While individuals were invited to attend, most participants were affiliated with local health departments or other governmental agencies, non-profit organizations, universities, hospitals or private providers. Meetings were one-day long allowing travel before and following the meeting. They also included a simple lunch provided by the local health department hosting the event.

Through the previously discussed statewide web-based survey process, topic areas most frequently identified were used in designing the registration for the community forums. On the registration form, which was web-based, these topics were listed and the registrant was asked to choose their main topic of interest. An additional category of “other” could be chosen and filled in with topics not covered in the list. There were six topic areas identified most frequently: dental/oral health, health insurance coverage, obesity, smoking, substance abuse and teen pregnancy. In the community forums, tables were set to create small groups of seven to ten respondents for each topic area of interest which included all of the above six topics *or any other topics* that the community felt were important. Some communities formed tables based upon topics unique to their communities (i.e. “Vision” in Somerset and “Language Access” in Lexington). Depending upon the total number of respondents and the area of interest, several communities formed more than one group for each topic area of interest. The forum locations were



City	# of Individuals
Ashland	41
Bowling Green	52
Burlington	40
Elizabethtown	31
Hazard	40
Lexington	71
Louisville	65
Maysville	25
Owensboro	33
Paducah	70
Somerset	53

* includes facilitators

representative of entire population in Kentucky. The eleven sites, illustrated above, were Louisville, Maysville, Elizabethtown, Somerset, Lexington, Hazard, Burlington, Ashland, Paducah, Owensboro, and Bowling Green.

Community Forums: Who Attended?

The success of Kentucky's MCH Community Forums is directly attributable to the involvement by local health departments and would not have been possible without their support. Local health departments volunteered or were recruited and asked to coordinate a forum in their region, so that all geographic regions of the state would be represented. Local Health Departments who agreed to host forums were provided with a small grant to help cover the cost of food, meeting supplies and publicity.

To market to the community, a state-wide press release was created, listing locations and times for all eleven forum locations. A website was created for use by participants with on-line registration and additional information about the process and goals of the meetings. Health departments coordinated efforts with local media to provide information about the meetings and the importance of community participation.

The total number of participants who attended the forums exceeded 500 individuals. Attendance by site varied widely from an estimated 25 individuals in rural Maysville to 71 in Lexington, Kentucky's third largest city (Tables 4 and 5). In far Western Kentucky, Paducah, with a 2000 U.S. Census population of only 26,300 individuals, had the highest ratio of attendees per population, with 70 individuals in attendance. It is important for the reader to note that attendance by community site was, in part, associated with local health department enthusiasm for the MCH Needs Assessment process. Coordinators were dependent upon support from local health department administrators and lead staff to assure community participation. Every effort was made to publicize these forums widely throughout the community.

Interest in MCH issues throughout the state is illustrated by the various groups that participated in each community forum. In addition to members of local health departments, community representatives of many organizations were in attendance. Beginning in the far Eastern region of Kentucky, the Ashland community forum was attended by a TANF Nutrition Education specialist, the March of Dimes, Kings Daughters Medical Center, Alert Regional Prevention Center, Northeast Community Action Child Care Resource & Referral, KIDS NOW, the Commission for Children with Special Health Care Needs, and the Pathways Regional Prevention Center.

In the southeastern region of the state, the Hazard forum included representation by the local FRYSC, Regional Child & Family Resource Center, UK dental assistant, Sebastian Middle School Youth Services Center, Post-Partum Support International District Office, and Breckenridge Hospital.

The northern Kentucky forum in Burlington was attended by a TANF Nutrition Education specialist, Children, Inc., Head Start, North Central Area Health Education Center, United Way,

Community Mental Health Center, Brighton Center, St. Elizabeth HC, North Key Community Care, Lloyd Memorial High School, UK Clean Indoor Air Partnership, Campbell County Fiscal Board, Kenton County Schools Family Resource Center, Ft. Thomas Schools, South Family Resource Youth Service Center, Children's Home of Northern Kentucky, Every Child Succeeds, Erlanger-Elsmere Schools, Silver Grove School, and Boone County Local Board.

Continuing near the northern border of the state, the Maysville forum had a smaller attendance that included the regional mental health center, teachers from Mason County Schools, law enforcement, the County Judge Executive, nutritionists, YMCA, and concerned citizens.

Centrally located, the Lexington forum had the highest attendance from the local and surrounding areas. Attendees representing the following organizations included: a TANF Nutrition Education specialist, YMCA Central Kentucky, University of Kentucky Cooperative Extension Service Programs, Kentucky Cancer Program, Kentucky Department of Education, 5 different county health departments, Kentucky Children's Hospital, University of Kentucky and UK College of Medicine/UK College of Dentistry, Family Resource Center, Success Corps, The Nest, Beyond the Birds and the Bees, Mercer County Schools, Family Care Center-HANDS Lexington, Bluegrass Community Health Center, University of California Berkeley, Scott County Board of Education Health Services, Cardinal Crossings Community Center, Volunteers In Service to America, Southeast Center for Agricultural Health and Injury Prevention, Kentucky Children's Health Insurance Program, UK Health Education Extension Office, Lexington Healthy Start, Kentucky Children's Hospital Safe Kids, Chrysalis House, Bluegrass Prevention, Fayette County Public Schools, Medical Home for Coordinated Pediatrics-Lexington, Kentucky Voices for Health, Fayette County Board of Health, Kentucky State University, KDPH Office of Health Equity, and the March of Dimes.

The second-highest attendance was in Louisville, Kentucky's largest urban area. Attendees representing the following organizations included: Louisville Metro Government, Louisville Metro and Lexington Health Departments, Cooperative Extension Services, Metro United Way, Natural Awakening, University of Louisville Health Sciences Center, Suburban Hospital, Kosair Children's Hospital, Family Health Center, HANDS, Planned Parenthood, Catholic Charities, Louisville Metro Public Health and Wellness, Passport Health Plan, Kentucky Dental Hygienist's Association, Jefferson County Public Schools, Governor's Office, Park Duvalle Community Health Center, Congressman Yarmuth's Office, Family Practice office of Southern Indiana, University of Louisville, March of Dimes, Reach of Louisville, Kentucky Coalition WPNM, Jewish Hospital, Our Lady of Peace, Norton Cancer Institute, University Hospital, Seven Counties, and Family Health Center.

Representing the southern-most region of Kentucky, the forum held in Somerset was attended by representatives from the Lake Cumberland Board of Health, Clinton County FRC, Children's Clinic, Knox and Lake Cumberland County Health Departments, a TANF Nutrition Education specialist, a Somerset Dentist, Cardinal Family Resource Center, Family Place at Turner Intermediate Family Resource Center, Lake Cumberland Community Action Agency, Pulaski County Board, Somerset School, Lake Cumberland Regional Hospital, March of Dimes, City of Liberty, City of Somerset, Kentucky Cancer Program, Regional Prevention Center, Operation

UNITE, Lake Cumberland Regional Hospital, Pulaski County UNITS Coalition Southwestern Youth Services Center, Adair County Resource Center, Family Resource Center, Outreach Workers, Eastern Kentucky Social Work, WCHD, and the Commission for Children with Special Health Care Needs.

Toward the west, the Elizabethtown forum was attended by the Family Resource and Youth Service Center, Harrison Memorial Hospital, Army Community Services, Lincoln Trail District and Meade County Health Departments, Youth Service Center Grayson, 4C Childcare, Head Start, Hardin County Mental Health, Outreach, Hardin County School Health, Fort Knox nursing.

Owensboro, the northwest region of the state, hosted a forum with representation from Green River District and Muhlenberg County Health Departments, the Audubon Area Child Care Resource & Referral, PACS NOW, Cleveland PACS NOW, Wooten Kentucky Health Justice Network, AmeriCorps/OPS, Office of Minority Health Services, Care Net Pregnancy Center, Nursing Faculty at OCTC, CHCA, the Commission for Children with Special Health Care Needs, Union County First, Owensboro AIDS Taskforce, Citizens Health Care Advocacy, Owensboro Independent Schools, and the Kentucky Department of Education.

In the far western region of the state, Paducah hosted a larger forum consisting of representatives from Family Resource Youth Center, Murray Head Start of Hickman Kentucky, Lourdes Hospital, a TANF Nutrition Education specialist, 4 different county health departments, Audubon Area High School, Purchase Area Health Education Center, Nutrition Services, Livingston Hospital, Lyon Cooperative Extension, 4H Youth Development, Livingston County Extension office and FRYSC, Marshall County Extension Office, Paducah Head Start, Union County LINKS Youth Service Center, Davis County Health and Youth Service Center, Hope Unlimited Family Care Center, local dentists, Calloway County Family Resource Center, FRIENDS Family Resource Center, Commission for Children with Special Health Care Needs, WIC Field Representative, Calloway County Alliance for Substance Abuse Prevention, Four Rivers Behavioral Health, Union County Family Resources, Family First FRYSC Livingston County Schools, March of Dimes Kentucky, Paducah/McCracken United Way, Lourdes Maternal/Child, Western Baptist Hospital, Ballard County Preschool/High School, Care Bean's DC, Trigg County Hospital, Little Lakes FRC, First Steps, Graves FRC, and University of Kentucky Cooperative Extension Service.

Representative of the west-central region of Kentucky, the Bowling-Green hosted forum included 4 different county health departments, Logan County FRYSC, Western Kentucky University Child Care Resource & Referral, Program of Dental Hygiene, Institute Rural Health Mobile Unit, Child Education Center Family Resource, Community Action, a TANF Nutrition Education specialist, Barren River District HANDS, Youth Service Center Russellville Jr./Sr. High, Bowling Green High School -Youth Service Center, University of Birmingham School of Public Health, Simpson County Family Resource Center, South Central Kentucky Dental Hygienist Association, FRYSC Oakland, FRYSC Richardsville, Bowling Green City Schools, Helping Hands FRYSC, and HOPE FRYSC.

Community Forums: Small and Large Group Process

The web-based registration allowed for anticipating the size of each forum, as well as the topics of most interest. Name tags were pre-printed for those who pre-registered. On site registrants were asked to choose a topic from the list or express interest in a new topic. Staff directed people to their topic table, and monitored the new topics to be able to group those who were interested into a discussion table.

The planning team enlisted the assistance of DPH staff with community forum experience to serve as facilitators for one or more of the forums. In addition, local health departments were asked to provide some facilitators. The web-based registration allowed the team to anticipate how many facilitators would be needed at each forum. Facilitators, state and local, met 2 hrs prior to the forum start time for training. In most cases, they worked as a 2-person team for each table, one state facilitator and one local facilitator, with one person facilitating discussion and the other recording on the flip charts. Dr. Julie McKee and two other staff monitored the room to step in if groups got sidetracked in their discussions.

Rather than discussion in a big group, the forums were designed to cultivate information from small group discussions, getting the most information in the least amount of time. People who attended were constantly involved and engaged during the session, which was designed to be 2 ½ to 3 hours and was successfully accomplished in that timeframe. The process flow was framed in three questions that elicited needs, capacity, and gaps on each topic. Each discussion was held to a specified time frame by the lead facilitator, and followed by a prioritization process, using nominal group technique. After the small groups had worked through all three questions, there was a period of reporting out to the large group, and a determination of community priorities by multivoting. For this, the top three needs that each discussion table had determined in Question #1 were listed on flip charts on one wall of the room. Each participant was given five “dots”, and allowed to put them on any of the identified needs from any of the table topics, so that we could get a sense of which needs were most important to the entire group attending. In each community, patterns visually emerged and the participants could easily see the issues most important to their community as judged by the forum participants.

Facilitated Discussion Questions that were asked in each forum were:

1. What are the issues in *_topic_* (e.g. *obesity*) that you have seen affecting the health of mothers and children in your community?
 - a. Of these, select the top five issues that you consider are most important?

As a group, select the top 5 issues that are affecting your community through a dotting process.

2. What is your community doing now to address *_topic_* (e.g. *obesity*) _____?
 - a. Of these, what are working well in your community?

As a group, select the top 3 things that are working well through a dotting process.

3. What would you like to see your community doing to address *_topic_* (e.g. *obesity*) in your community? ["Wish list"] (These may have already been discussed today or new ideas by the participants)
 - a. For each of the 3 areas selected above in Question 3 describe what actions need to be taken by your community to provide optimal services/to optimally address *_topic_* (e.g. *obesity*) ?
(What needs to happen in your community to move things forward?)

As a group, select the top 3 things that you would like to see your community doing through a dotting process.

To illustrate the flow of a community forum, an agenda from the Community Forum held in Bowling Green, Kentucky on Thursday, May 21, 2009 will be presented.

The Bowling Green Community Forum was held in a church in the heart of the community beginning at 9:00 a.m. Dennis Chaney, Director of the Barren River District Health Department opened with remarks, welcoming the audience of about fifty individuals. He was followed by Marvin Miller, Assistant Director of the Division of Maternal and Child Health (KDPH) who presented basic information about the MCH Needs Assessment process. Dr. Julie Watts McKee, State Dental Director under the Division of Maternal and Child Health, outlined the details of the work day.

Small Group Work

With attendees already seated at topical tables (each with its own flip-chart), Dr. McKee challenged them to identify and record issues that exist in Bowling Green (and surrounding communities) with regards to their selected health topic, such as dental health services, health insurance coverage, obesity, smoking, substance abuse, teen pregnancy or other services for mothers and children. As a group, they were instructed to select the top five most significant issues for their selected topic from all those recorded, voting with five dots which were provided for this purpose. A vote equaled one "dot" and participants were told not to use more than one dot per issue.

Topical groups were then instructed to repeat this process, now discussing what the community is currently doing to address the issues identified in the previous activity. Finally, this process was repeated to address what new activities attendees would like to see their community do

Table 5: Kentucky Community Forums by Region

Region	Communities
Metropolitan	Burlington
	Lexington
	Louisville
Central Kentucky	Bowling Green
	Elizabethtown
	Somerset
Eastern Kentucky	Ashland
	Hazard
	Maysville
Western Kentucky	Owensboro
	Paducah

about these issues. Both of these activities included the voting process, again using five dots and with one vote equaling one “dot”. For this last activity, participants selected the top three new activities and wrote action steps needed to address the health problems.

Large Group Work When the groups had completed all three questions, each small group reported their top three priority needs to the larger group. An illustrative example from Lexington’s “oral health” topical group is provided in Table 6 which follows. At the conclusion of the small group reports, the top three issues selected by each group (assignment #1) were posted around the room. Each forum participant then voted, using dots provided for this purpose, for the five issues that they believed *most* influenced maternal and child health in their community.

Participants were encouraged to think beyond their topic of interest, looking for cross-cutting issues across the MCH spectrum. Each dot counted as a single vote and no more than a single dot could be used per issue. Votes were then tallied and those receiving the highest number became the priority issues for the community. This final activity concluded the Bowling Green Community Forum.

At the conclusion of each of the forums, participants were asked to complete an evaluation of the activity. In addition, facilitators completed a separate evaluation of their experience at the forum. These were reviewed by the planning committee after each forum and adjustments made as needed in the flow of the next forum.

Table 6. Small Group Reports to Large Group: An Illustrative Example from the Lexington Community Forum	
Assignment	Group Response
1. Identify Health Issue	Need for children's dental services but lack of collaboration by existing dental programs.
2. How the Community is Addressing the Problem?	<i>KY Oral Health Network</i> * - a consortium of dentists and other oral health professionals across Kentucky provides varnishes for Head Start students, sealants in schools and comprehensive care.
3. Group "Wish List"	Expansion of dental school-based program with on-site services, and/or transportation to a dental clinic during school.

* Kentucky Oral Health Network: <http://ccts.uky.edu/reach/OralHealth>.

Community Forums: Tabulating Results

For each of the community forums, the top ten priorities were obtained, based on the total number of votes (dots) received. Most communities had some issues that were tied by their rank. Each time that a topic appeared within the “Top Ten” listing, it received points that were weighted by where it fell within the total ranking scheme. These points were added together to create the final total for each topic. Therefore, the final score for a topic at the community level depended upon two things. First, how many times issues associated with the topic appeared in the “Top Ten” priorities listing. Second, where each topic fell within the total ranking scheme, ranging from 1-10. For each community’s final priorities, both mean and standard deviations were calculated. This method was used to rank community-level, regional and state-level priorities.

This process was accomplished through a partnership with the Department of Epidemiology and the Department of Biostatistics at the University of Kentucky, College of Public Health. Additional details about methods may be obtained by contacting Lorie Wayne Chesnut, MPH at 859-218-2226 or lorie.chesnut@uky.edu.

Community Forums: Results and Limitations

Many cross-cutting themes emerged from the eleven community forum sites however unique issues were also identified, primarily based upon rural or metropolitan status and levels of poverty. For instance, smoking and substance abuse received a strong ranking in communities located in the eastern and southern portions of the state. In Hazard, attendees raised issues dealing with this issue so often and ranked them so highly that the final “score” for smoking and substance abuse was substantially higher (25 points) than the next topic identified, oral health, which received a score of 11.5 points. By contrast, in one Western Kentucky community, Owensboro, this same topic received a low ranking of 4.5 points, placing it sixth in the overall priority listing for that community.

Topic (Alpha)	Regional Rankings			
	Central	Eastern	Metro	Western
Breastfeeding	8	7	8	NA
Health Insurance Coverage	7	5	5	4
MCH General	6	8	NA	7
Mental Health	9	6	7	8
Obesity	5	3	2	3
Oral Health	3	4	6	2
School Health	4	NA	3	5
Smoking & Substance Abuse	1	1	1	6
Teen Pregnancy Prevention	2	2	4	1

These widely divergent results prompted the Needs Assessment team to examine data on a regional level. Data were stratified by the four Kentucky regions noted above and the same method used to identify how many times a topic appeared in the “Top Ten” priorities and where it fell in rank order. Results are provided in Table 7.

Limitations: Community forum participation varied widely by region and community with select topics eliciting more participant enthusiasm than others. For instance, health providers supporting the need for increased resources in oral health were highly organized and present in substantial numbers in several Western Kentucky forums. However in Eastern Kentucky, where oral health continues to be an unmet need for children and adults, it was considered a lower priority, although still finishing as one of the top five identified needs. Results from a community forum process depend greatly upon who is present at forum events and in what numbers, so participation bias is an issue that must be considered.

Community Forums: Regional and State Priorities

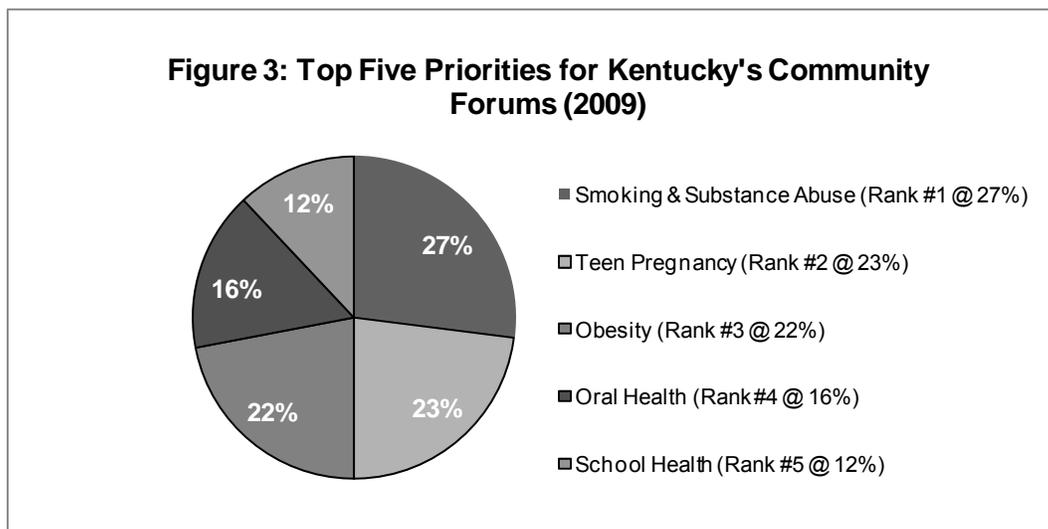
Smoking and Substance Abuse was ranked as the number one priority health issue in three out of four Kentucky regions. In the Eastern Kentucky region, this topic received 31% of the total vote, with the next closest topic (*Teen Pregnancy Prevention*) receiving 21%. Kentucky’s

Central region also strongly ranked this topic with 26% of the total vote, with Teen Pregnancy Prevention following with 17% of the total votes. Interestingly, in the Western Region, Smoking and Substance Abuse was ranked considerably lower, with Teen Pregnancy Prevention assuming the number one position.

The next topics competing for top rankings were *Obesity, Oral Health, Health Insurance Coverage* and *School Health*. These topics were ranked anywhere from second to seventh in the four regions. Western Kentucky ranked Oral Health highly, as the second most critical priorities for their children and adolescents. Kentucky's Metro region voted for Obesity as their second-ranked topic, receiving 21% of the total vote – a close second to Smoking and Substance Abuse's total of 22%.

Finally, *Mental Health, Breastfeeding* and *MCH General*, the catch-all heading for topics such as premature birth, vision services and access to childcare, ranked as lower priorities but still made the cut for inclusion in our communities listing of top MCH priorities.

The final task was to roll the eleven community forum results into a single listing of statewide priorities. Results validated the *Smoking and Substance Abuse* was the issue most often identified by those attending community forums, followed by *Teen Pregnancy Prevention, Obesity, Oral Health* and *School Health*. The top priorities are provided in Figure 3.



Kentucky Statewide Patient Survey (Local Health Departments)

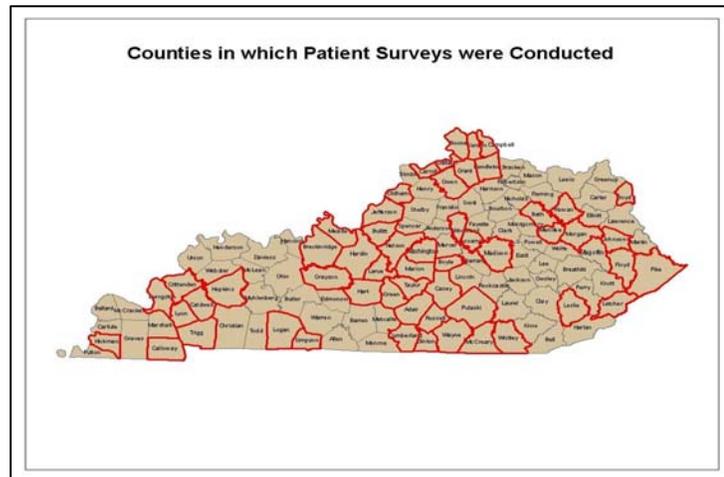
Statewide Patient Survey: Process

As a third step in the process of the 2010 Needs Assessment development, the Division of Maternal and Child Health conducted a survey of patients in local health departments to hear the voice of consumers who were utilizing services provided through the Title V MCH Block Grant. The purpose of the survey was to identify the needs and barriers for this population as they relate to maternal and child health. Voluntary participation was sought from district and

independent health departments who provide health care services in the Commonwealth of Kentucky. There were 22 Health Departments out of a total of 56 who agreed to distribute the survey. Patient participation was also voluntary, with no requirement of identification.

The surveys were available in English and Spanish and this self-administered survey was written at the 6th grade reading level.

The Department for Public Health received approximately 3200 completed surveys. Out of the 22 Health Departments who participated, there were 8 district health departments and 14 independent health departments. The distribution of the population that was surveyed was representative of all Area Development Districts in Kentucky. The patient survey tool is provided under Appendix F. Responses were received from patients residing in 77 out of 120 counties across Kentucky.



Statewide Patient Survey: Who Responded?

Demographic information was available for 97% of the group completing the patient surveys. Of this group, the respondents were primarily non-Hispanic Caucasian (78.5%) with 13% identifying as African American. Ethnicity was reported as 5.1% Hispanic/Latino. The planning team was pleased to observe that patient survey responses appeared to over-sample Kentucky's minority populations, for based upon 2006/2008 U.S. Census data, Kentucky's demographic breakdown is primarily white (89.2%) with 7.5% African American and 2.2% Hispanic/Latino (2006/2008)¹.

Nearly 74% of patients were in the 18-35 year age range with 9% under the age of 18 and 17% older than 36 years. Most participants reported that they were single (43.2%) with 34% married and 13.1% single but living with a partner. About one third of respondents reported cigarette smoke in the home.

A majority of the patients (48%) reported having a Medical Card with 25% using self-pay and 6.5% with private insurance. Most of the patients either had a high school diploma or their GED (32%) with 28.9% claiming some college credit. Associate degrees were held by 7.3% of those participating but only 5.8% had a bachelor's degree or higher.

¹ Source: U.S. Census American Factfinder. Accessed 07/06/10 at http://factfinder.census.gov/home/saff/main.html?_lang=en

Statewide Patient Survey: Results and Limitations

Responses for the 2009 Patient Survey are provided in Table 8. According to the patient responses, the major health issues affecting women are obesity, depression, and drug use. In teenagers, substance abuse, smoking, and teen pregnancy lead the list. For infants and children, major concerns were second-hand smoking, child abuse, and child safety.

These results are very consistent with the view of Kentucky’s major MCH health issues by public health professionals. Many of the consumers faced problems in getting health insurance, being able to see a dentist, getting a medical card and ability to see a medical specialist. These and other capacity issues are presented later within this chapter.

Responses were also analyzed separately for the Spanish version of surveys to see if there were any differences between responses in the two versions. The analysis indicated that obesity, smoking and depression were the major health issues affecting women. They ranked teen smoking as the priority health issue for adolescents followed by teen pregnancy. For infants and children the health issues were similar to the responses received in the surveys completed in English.

Limitations: Every effort was made to acquire a representative sample of patient participants for the survey as local health departments were recruited to distribute surveys. However this distribution was designed through a convenience sample rather than through a random state-wide distribution model, weighted based upon population distribution. Because survey participation was voluntary, participation bias may affect responses.

For more information about the report “*Title V Needs Assessment: Findings from Kentucky’s Patient Survey 2009*” please call Shelley Adams, Branch Manager of Child and Family Health Improvement at 502-564-2154, ext. 3766.

Table 8: Kentucky MCH Needs Assessment Patient Survey Results
<i>Major health issues identified for women included:</i>
Obesity (67%)
Depression (37%)
Drug or Marijuana Use (24%)
Pregnancy and Health Problems Related to Pregnancy (21%)
Women who Smoke (19%)
<i>Major health issues identified for infants and children included:</i>
Second-hand Smoking (56%)
Child Abuse (44%)
Not Putting Infants in Car Seats (29%)
Obesity (21%)
Low-Birth Weight and Preterm Infants (15% each topic)
<i>Major health issues identified for teenagers included:</i>
Drug or Marijuana Use (55%)
Teen Pregnancy (51%)
Teen Smoking (39%)
Sexually Transmitted Diseases (13%)
Motor Vehicle Accidents (12%)

Data Integration: What Do The Three Surveys Tell Us? In the field of social research, a method called “*triangulation*” is often used to improve and validate results. This method, also known as cross-examination or cross-validation, uses three independent methods to ascertain

cross-cutting themes and results. The theory behind triangulation is that a single method will inevitably contain bias. Two independent methods may result in responses or ideas that are very different from one another while by using three independent resources, some overlap of themes and ideas should result that can then be further explored. The following summary provides issues arising in at least two of the three surveys during the 2010 Needs Assessment process.

Substance Abuse and Drug Abuse (3 surveys)

This issue ranked as the number one issue in community forums and was the primary issue (ranking #1 for teenagers and #3 for women) by the patient survey tool. Providers also ranked it highly, giving it second-place overall. While the definition of substance abuse and drug abuse varied by survey method (in community forums, smoking was included as a part of substance abuse), this major topic clearly ranked highly in the minds of Kentucky's citizens and providers. Specific concerns included a lack of treatment facilities for women and youth, the impact of drugs on family structure, too few resources for providers and the need for funding and sustainability for prevention efforts.

Teen Pregnancy (3 surveys)

A major public health topic for decades, this topic once again rose to the top during Kentucky's Needs Assessment process. Community forums and patient providers ranked it as their #2 issue while providers ranked it as the final of their top-five issues. Problems cited were grouped into three major areas: Adolescent Pregnancy and Birth; Prevention and Communication; and School-based Education.

Overweight and Obesity (3 surveys)

The problem of overweight and obesity is a crisis throughout the country and Kentucky leads the way with one of the highest rates for pediatric obesity in the nation. This fact was not lost on patients, providers or community forum attendees. Both providers and patients ranked this issue among the top health concerns for the state. Patients ranked this #1 for women and #4 for infant, children and teens. Providers ranked it #1 overall. Community forum participants agreed, ranking it the 3rd most critical issue for the Commonwealth.

Smoking (including Second-Hand Smoke) (3 surveys)

All three surveys ranked smoking among their top five health problems. Concerns about second-hand smoke were evident from Kentucky's patient population, who ranked this issue #1 overall for infants and children and at a moderately-high level for women. Issues included a lack of political will to support smoke-free laws, the need for education about smoking during pregnancy and the impact of second-hand smoke on infants and children.

Dental/Oral Health (2 surveys)

Dental and Oral Health was selected as a top-ten issue by providers and during community forum events, where it was ranked as the #4 priority need for the state. Concerns included access to care particularly for the "working poor"; lack of Medicaid providers and public health

dental clinics in the state and the need for parental education about the importance of good oral health for both themselves and their children. Also raised was the fact that a new dental screening policy for school entry exists with no guidelines or requirements for the provision of care to address identified needs. This is particularly important in light of the shortage of dental providers in Kentucky.

Mental Health and/or Depression (2 surveys)

Discussion of mental health needs was pervasive throughout the needs assessment process, particularly for women and adolescents. Health Department patients regarded depression for women as their #2 issue with 1,180 individuals (37.34%) citing this issue as a top priority for Kentucky Public Health. Community forum attendees also expressed the needs for addressing this critical area. Concerns included the lack of mental health resources with individuals "*falling through the cracks*" in the current system. Health insurance coverage for mental health was noted as was the social stigma associated with mental health issues and treatment. The need for provider training (including screening and referral) was also highlighted.

Health Insurance Coverage (2 surveys)

The need for expended health insurance coverage was identified as health issue by both providers (ranking #3) and by community forum participants (ranked #6). The latter group raised the concern that "*if insurance is available, it is still not affordable*" and that "*preventive care is not available to the uninsured, and is often not covered even for those with insurance*". Other issues included coverage of chronic conditions, coverage for young adults who are over the age of 19 and an absence of services for women who do not have children and are not pregnant.

Child Abuse (2 surveys)

Concerns about child abuse in Kentucky were ranked as the #2 issue for infants and children by the patient survey with 1,407 individuals (44.52%). Providers also ranked it among their top ten selections, with variations in placement between non-providers and providers (Figure 2, previous section). Interestingly, this subject was not raised during community forums.

Breastfeeding (2 surveys)

The importance of breastfeeding was noted by both the provider survey and community forum attendees, ranked #10 and #9 respectively. Issues noted include the need for OB/Lactation support prenatally and during the post-partum period; the social stigma that exists regarding breastfeeding and the fact that many facilities are not breastfeeding-friendly. The proportion of women breastfeeding and the duration of breastfeeding were also cited as issues of concern.

This concludes Section 1.d. which outlines the methods, process and results for the three primary stakeholder needs assessment populations: *local health department patients, health providers/stakeholders and the community-at-large*. Discussions regarding how these data were integrated with quantitative information, and subsequently rolled up into state priorities and state-select performance measures, will be provided later within this chapter.

1. e. Methods: Assessing State Capacity

While the primary focus of the Kentucky 2010 MCH Needs Assessment process was the identification of health issues affecting the population, the public health system and its ability to meet the public health needs of our citizens was also scrutinized. The health of Kentucky's women, infants and children was also assessed; whether these services were direct, population-based, enabling or categorized as infrastructure.

The accompanying Title V Application for 2011 and Annual Report for 2009 provides an update of agency capacity for the Commonwealth of Kentucky, so this information will not be repeated within the current document. However opportunities to measure capacity for the MCH system of care were presented in two of the three survey tools (community forums and patient) described in detail within the previous section. Questions addressing capacity in both of these surveys will be presented individually with a brief discussion and a summary of results.

MCH Capacity and Community Forums

Issues addressing MCH service capacity were interwoven throughout the entire community forum process. Primary concerns included provider shortages, health insurance coverage, access to care, cost of care, lack of treatment resources, funding sustainability, need for political will to support public health, collaboration between public health, education and juvenile justice. A brief discussion of some of the more critical issues follows.

Provider Shortages and Access to Care

One of the top capacity issues noted was a shortage of providers throughout the state, but with particular emphasis in Kentucky's rural eastern and western regions. This issue was raised for all primary health providers but highlighted in the areas of oral and mental health. The majority of Kentucky 120 counties are Mental Health and Dental Health Professional Shortage Areas (HPSA).

Of those providers practicing in rural areas, many severely restrict the total number of Medicaid clientele that they will serve while others refuse to accept any individual enrolled in public insurance. Public health departments in the highest-risk regions have had great success in enrolling women and children in Medicaid and the Kentucky Children's Health Insurance Program (KCHIP); however enrollment offers no guarantee of access to care. For those seeking dental or mental health services, the outlook is even more troubling. A lack of public health dental clinics was noted by one community forum participant and the need for mental health treatment resources, particularly for women and children, was raised by another.

Health Insurance Coverage/Cost of Care

Ranked as the #6 concern by community forum participants, health insurance coverage is beyond the financial reach of many citizens. Preventive care is often not covered even for those who have insurance and "*the Emergency Room is used too often by the uninsured*" for purposes other than true emergencies. One participant noted that "*if insurance is available, it is still not affordable*" and another that policy barriers restrict treatment, limit days and services as

well as access to providers. Issues regarding Kentucky's Kinship Care program (which places a child who has been neglected, abused or orphaned due to the death of both parents with a relative rather than in foster care) were also raised, noting that when children enter this program they are not allowed to keep their Medical card, thereby losing their health insurance coverage.

Mental and dental health issues were often associated with a lack of health insurance coverage with one participant stating that "*the working poor can't afford care*".

Funding and Political Will

Availability and sustainability of funding for prevention efforts was an issue often cited by forum participants. This was coupled with discussion of the lack of political will associated with the passage of funding for public health, primarily in the area of dental and mental health. Also raised was the reluctance of policy-makers to sponsor and enact smoke-free legislation.

Collaboration between Government Agencies

The effectiveness and sustainability of MCH programming often depends upon support by other government agencies such as education, juvenile justice and social services. Forum participants were concerned about a lack of coordination between the Department for Public Health and Kentucky's Department of Education in relation to childhood obesity, bullying and school food service nutrition. The issue of medically fragile children was also raised. These children are increasingly mainstreamed into the public education system, bringing with them unique medical needs and taxing a system which is often ill-equipped to provide specialized nursing care. Many schools do not have a full-time public health nurse if access to any nursing care at all. Here is another partnership opportunity to benefit both systems as well as students. Finally, Kentucky's Juvenile Justice System was also critiqued with comments noting that "*few consequences exist for adolescent drug users in schools and courts*". This issue also brings to mind partnerships with mental health services across the Commonwealth.

MCH Capacity and the Local Health Department Patient Survey

In addition to prioritizing MCH health issues affecting their community, local health department patients considered several questions which addressed capacity of the health system as a part of patient survey. These questions included the mode of travel to the current appointment, the length of time this travel required and barriers to care including making an appointment, accessing public services such as WIC and whether the respondent felt that their race influenced care delivery.

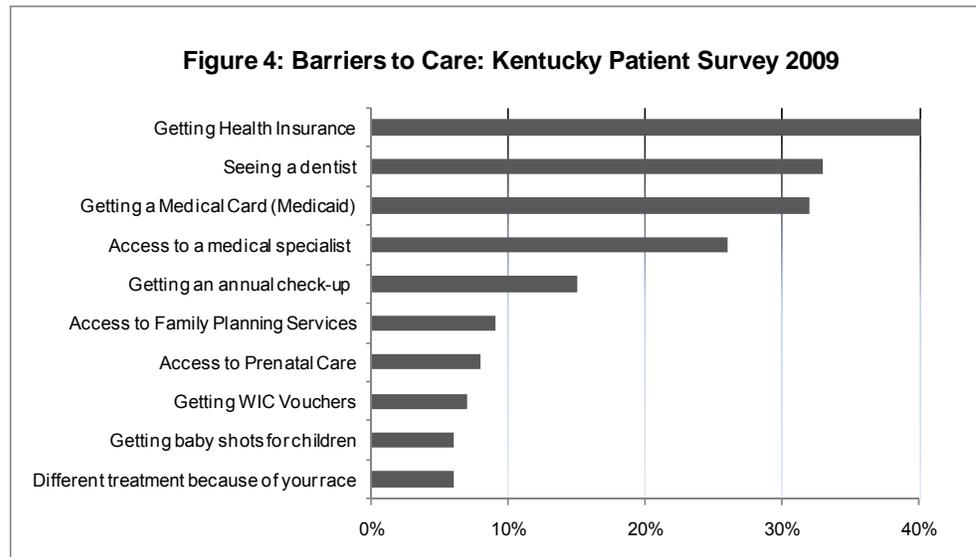
Mode and Length of Travel for LHD Appointment

The vast majority of local health department patients traveled by automobile (85.8%) for the appointment on the day that the survey was distributed. This is not surprising, as the majority of Kentucky counties are rural with little or no public transportation system and substantial distances to the nearest health provider. More than two-thirds of patients reported that the time required to get to their appointment was 15 minutes or less. Twenty-one percent traveled

between 16 and 30 minutes and 3% required more than 30 minutes but less than one hour of travel time.

Barriers to Care

An inability to obtain health insurance was ranked as the #1 barrier to care by Kentucky health department patients, mirroring the results of both the community forums and the provider survey.



Patients also noted barriers to acquiring a medical card (Medicaid or KCHIP) and seeing a dentist or a medical specialist for a specific health problem. Difficulty in scheduling an annual primary prevention health visit was reported by 16% of respondents while a lack of access to prenatal care, WIC vouchers and/or childhood immunizations ranked lower. Six percent of patients (approximately 200 individuals) reported that they felt that they were treated differently because of their race.

1. f. Linking Assessment, Capacity and Developing Priorities

By November of 2009, the Kentucky Department for Public Health had collected data from multiple sources. Fact sheets with quantitative data on the topics of interest were developed by the MCH epidemiology team and were posted on the web site. The MCH Epi team reviewed several methodologies for prioritization. In order to involve as many people as possible in setting priorities, the team undertook developing a prioritization tool that could be distributed electronically. A web-based survey was developed and distributed to all the community forum attendees, providers and other consumers invited to participate. More than 200 individuals responded to this opportunity.

Prioritization Survey

Respondents were asked to review MCH issues which were selected as a result of the 11 Community Forum events. Twenty-six topics were provided, ranging from substance abuse to parental influence on children to preconception care and perinatal depression. Participants were provided a link to the web site where the topical fact sheets were posted. For each topic, consumers were asked to rate the size or magnitude of the problem listed, their perception of the seriousness of the problem and the impact of the problem on them as an individual, their family or their community.

Finally, participants were asked to rank the existence of effective interventions. Ratings were categorized from 1 to 5 with the latter generally reflecting a serious issue in size, seriousness, impact and whether an effective intervention existed with which to address the identified health issue. The scoring rubric for this survey is provided in Table 9.

Scores were added for each topic (i.e. substance abuse) for each of the four measurements and then added across to create a sum for that topic. The top ten issues selected were 1) substance abuse, 2) obesity, 3) substance abuse in children and teens, 4) second-hand smoke, 5) smoking in pregnancy, 6) oral health, 7) health insurance coverage, 8) obesity in infants and children, 9) teen smoking, and 10) oral health access. These issues were closely followed by child abuse, substance abuse in pregnant women and teen pregnancy.

Stakeholder Meeting

The next step was to gather major stakeholders together for a day-long meeting in Frankfort to integrate the multiple data sources, assess the prioritization, determine what was measurable, and look at feasibility of addressing the most measurable of the issues by a brief SWOT analysis.

At registration, participants were assigned to one of five workgroups, depending on the stakeholders they represented. The meeting began with the whole group in an overview of the Title V Needs Assessment process and purpose, followed by review of the data collected, with summaries of the forum results by region and the results of the patient survey. The group then broke into workgroups for (1) Cross Cutting issues, (2) Perinatal (3) Childhood, (4) Youth and Adolescence, and (5) Children and Youth with Special Health Care Needs. Each group had a facilitator and a recorder and each group was given more detailed information from the forums

Table 9: Scoring Rubric for Kentucky Consumer Health Issue Prioritization Survey	
Size or Magnitude of the Problem	
1	Few people affected or KY better than NA ¹
2	Small groups affected or KY Near the NA
3	Several people affected or KY is slightly below the NA
4	More than half of the people affected or KY is worse than the NA
5	Almost everyone affected or KY is much worse than the NA
Seriousness of the Problem	
1	Issue not important to me or to my community
2	People know about this but no one motivated to act
3	People think this is important but don't know what to do
4	People think this is very important and are working to change
5	This is a critical issue in our community and people want to work to change it.
Impact of the Problem	
1	Doesn't make much difference in day-to-day life
2	Effects of this are only short-lived
3	Both short term and long term effects but they are not serious
4	Seriously impacts health with short/long term effects
5	Endangers physical and/or mental health and/or survival with short and long term effects
Effective Interventions	
1	No interventions/programs shown to help this issue
2	Some programs available but not many proven effective
3	Some programs work, some cannot show positive results
4	A few programs nationally that have shown to be effective
5	Several programs that work to improve this health problem
¹ National Average	

on topics in their area, as well as the scoring for those topics from the web-based prioritization process.

The topics were then split up among members of the group, who were asked to report back to their workgroup. Their recommendation was to include (a) should the topic be a state priority need; (b) was there a way to measure progress; (c) should the topic be broken down to a more specific and measurable focus. The small group, after hearing on each topic, then picked their top three topic areas

to present to the large stakeholder group. After gathering back in the large group, each small group reported on their discussion and the top three issues selected. These were recorded for later multivoting. The groups had difficulty narrowing their topics, so

Table 10: An Example of the Prioritization Matrix for the Perinatal Workgroup

TOPICS	SIZE or MAGNITUDE	SERIOUSNESS	IMPACT	EFFECTIVE INTERVENTIONS	SUM
Smoking in Pregnancy	777	711	827	649	2964
Substance Abuse in Pregnant Women	716	698	868	619	2901
Obesity in Pregnant Mothers	733	622	780	579	2714
Infant Mortality	606	622	773	673	2674
Breastfeeding	631	582	599	704	2516
Preconception Care	613	572	701	582	2468
Perinatal Depression	577	540	682	561	2360

instead of refining the information to focus more narrowly on specific topics, in most cases the groups combined several issues into a single topic to report as a priority. For example, the Childhood group chose school health as a priority need, but bundled into that was Pediatric Obesity, Oral Health, Injury prevention, and children’s mental health.

In the afternoon, each small group took their top topics and worked through a SWOT analysis. They then gathered and reported out briefly. After all the analysis, each participant was given 3 dots to vote on the issues they felt best represented the priority needs of the state. At the conclusion of this meeting, obesity was the leading concern of the group. School health, which included childhood obesity, injury prevention, and child maltreatment, tied obesity with the same number of votes. Mental health/self-esteem in teenagers came next, followed by oral health. Substance abuse, smoking, and perinatal depression were bundled by the group and received the same number of votes as oral health. So while the stakeholder group provided a lot of input, it was not specific enough to determine statements of priority need.

Harmonization

The final step in developing state-level priorities was to refine the topics identified from the stakeholder meeting into specific and measureable statements of need, and align them with existing measures or new measures. This included a review of current national and state performance measures, outcome measures and health status indicators in the Annual Title V MCH Block Grant TVIS System.

Gathering all of the information gleaned throughout the past twelve months, each major topic heading was then reviewed by the Title V Needs Assessment planning team meeting with

senior maternal and child health professionals at the state level. Those needs with national performance or outcome measures already listed (such as adolescent births and infant mortality) were noted. Subjects which were deemed important but that were not measurable (such as substance abuse during pregnancy) were identified. Those topics remaining were reviewed for the ability to measure change, effectiveness of existing interventions, ability to modify outcomes and population impact. In addition to survey information, trend data was also examined for incidence and prevalence rates. Data sources included Kentucky Vital Statistics and the Youth Risk Behavior Survey, among others.

National Performance Measures, Outcome Measures or Health Status Indicators already existed for the following topics: Teen pregnancy, teen suicide, and smoking during pregnancy, children's oral health, childhood injury, breastfeeding, childhood obesity/weight and infant mortality. The needs assessment team acknowledged that while substance abuse during pregnancy was a very important topic, Kentucky had no reliable way to measure this health problem. While the issue of preterm birth had only been acknowledged as a priority by one of the three surveys (LHD Patient Survey), the team felt that given the increasing incidence and life-long health impact of prematurity, and its contribution to infant mortality, it should be included as a state priority for the next five years. Late preterm birth was selected as the state measure because late preterm infants constitute over 70% of all preterm infants and are the category of preterm birth associated with the rising rates. Early preterm birth is monitored indirectly by the neonatal and perinatal mortality rates in the required health outcome measures.

The final health topics selected for State Performance Measures included teen smoking and substance abuse (Source: Youth Risk Behavior Survey), pre-pregnancy weight gain (Source: Vital Statistics), late preterm birth (Source: Vital Statistics), and deaths from child abuse (Source: Department for Community-based Service). New state performance measures will be developed for each of these topics.

1. g. Dissemination

Throughout this section, substantial detail has been provided in regard to public involvement in the 2010 Needs Assessment process and this information will not be repeated within this section. Every effort was made to make the process as transparent and as inclusive as possible. Three survey tools were utilized; each designed to reach a different population. Included were local health department patients, health providers across the state and the community at large. The internet was used extensively throughout the process, with web-based surveys and posted summaries. Each of the surveys discussed in this document are available for public review. For more information, please contact Shelley Adams, Branch Manager of Child and Family Health Improvement at 502-564-2154, ext. 3766.

1. h. Strengths and Weaknesses of the Process

Discussion of individual survey strengths and weaknesses (or limitations) is included within Section 1. d. of *Methods: Assessing MCH Target Populations*. Kentucky was actively engaged in the needs assessment process, beginning the planning process in March of 2008. Individually, each survey was carefully composed and formatted, with questions carefully written

to assure validity of information. Each survey instrument was distributed systematically throughout the state to capture the breadth of Kentucky's population. It was important to obtain input from a wide range of consumers, health providers and health advocates. Further, the triangulation of the survey results confirmed needs and provided the process with stronger results. Using evidence from the surveys and data obtained through traditional state systems, a small senior team evaluated each topic looking for issues such as seriousness of the problem, population impact and the ability to measure change. All of these steps lead us to what we feel to be a very comprehensive needs assessment document which fairly and consistently represents the needs of our population.

Weaknesses of the process have been extensively documented throughout this chapter. While every attempt to reach a cross-representation of Kentucky's population was made, we know that under-reporting for high-risk groups such as minorities and the homeless is likely. Further, fewer consumers attended our community forums than predicted and representation by business leaders and leaders of faith communities was lower than expected. Those attending the forums depended, in part, on the interests and enthusiasm of local health departments who assisted in meeting scheduling and publicity. Topics raised were undoubtedly biased toward these interests but this issue is a common problem with community-level events of this type.

This concludes Section 1 "*Process for Conducting the Needs Assessment*" for the Kentucky Department for Public Health.

Kentucky Commission for Children with Special Health Care Needs

1. a. Goal, Vision, Purpose

In order to identify target priorities, the Kentucky Commission for Children with Special Health Care Needs (CCSHCN) began planning for the 2010 Needs Assessment report in 2008. CCSHCN envisioned the process as one not only including quantitative data, but also qualitative data from stakeholders, as CCSHCN actively embraces the concept of youth and family participation and involvement. Information was generated through analysis of data from CCSHCN's health information system for patients (CUP), data from external sources (such as the Child and Adolescent Health Measurement Initiative, Healthy People 2010, HRSA and GAO publications, etc.), a variety of stakeholder/advisory committee meetings and over 1000 responses from separate surveys of the following stakeholder groups: families of children with special health care needs and the general public; CCSHCN staff; and CCSHCN-contracted providers. Key staff convened an ongoing working group to initiate discussion and synthesis of the information, and use the results to guide the development of state performance measures. Focus groups were held with CCSHCN Youth Advisory Council, CCSHCN Parent Advisory Council, Parents as Partners, and CCSHCN Medical Advisory Council in 2009. With input from regional supervisors and staff at every level of the organization, CCSHCN presents the following findings.

1. b. Needs Assessment Framework

Given the organizational structure of public health within the Kentucky Cabinet for Health and Family Services, DPH and CSHCN conducted parallel assessment tools to ensure that their segments of responsibility and the populations served received adequate attention during the needs assessment process. A needs assessment leadership team co-led by staff from each of CSHCN's two divisions and consisting of a parent consultant, transitions staff, director of nursing, and other key staff met regularly to discuss data and guide the Needs Assessment process. Surveys were initiated and analyzed and are described in following sections, and led to the selection of priority needs and development of State Performance Measures. A feedback loop provided input to and from supervisors and managers via e-mails, face-to-face meetings and at regularly scheduled manager/supervisor's meetings. Finally, periodic discussions and meetings with the Kentucky Department for Public Health (KDPH) (such as participation at stakeholder/partnership meetings) were initiated in order to share information, brainstorm, plan, and coordinate efforts.

1. c. The 2010 CSHCN Needs Assessment Leadership Team

Rebecca Cecil, RPh, has served as CSHCN's Executive Director since 2008. Ms. Cecil brings more than 20 years of experience to the position, including serving as CSHCN's Director of Health and Development for 3 years, and Interim Executive Director immediately prior to her appointment. Before her tenure at CSHCN, Ms. Cecil served as Deputy Undersecretary for Health, Acting Commissioner of Mental Health and Retardation Services, and Director of Licensing and Regulation with the Office of Inspector General. Ms. Cecil is a 1979 distinguished graduate of the University of Kentucky's College of Pharmacy.

Shelley Meredith has served as director of CSHCN's Division of Administrative Services since October 2008. Ms. Meredith has over 22 years experience with state government, 19 of which have been with the Cabinet for Health and Family Services in the health care arena. Ms. Meredith played a key role in the establishment and development of CSHCN's health information system and electronic patient record and is now responsible for managing all the operational functions of the Commission including budgets, contracts, purchasing, accounts payable and receivable, health information and technology, personnel, and grant reporting. Ms. Meredith is a Certified Public Accountant and 1985 graduate of the University of Kentucky with a BS in Accounting and a minor in Economics

Anne Swinford has served as director of CSHCN's Division of Clinical and Augmentative Services since 2005. Ms. Swinford's previous experience includes the provision of direct care services to the special needs population, and serving as the Acting Part C Coordinator and supervisor of Kentucky's early intervention program (First Steps). Ms. Swinford is a graduate of Brescia University and Purdue University, where she earned a BA in Speech and Hearing and a MS in Speech Pathology.

Stephanie Mitchell served as CSHCN's Title V coordinator and co-coordinator from 2009 to 2010. A graduate of Transylvania University (BA), Mrs. Mitchell left the agency in May, 2010 to complete her studies toward an MS degree in Communication Disorders at Western Kentucky

University. Mrs. Mitchell worked at CCHSCN for a decade in the areas of newborn hearing screening, training and personnel, and Limited English Proficiency.

Lee Gordon has served as CSHCN's Transition Administrator since 2001. Mr. Gordon works with children, adolescents, families, and service providers to help Kentucky children with disabilities prepare to successfully transition from school to work, from home to independent living and from pediatric to adult health care. Mr. Gordon staffs CSHCN's Youth Advisory Council and Parent Advisory Council; chairs the Statewide Council for Vocational Rehabilitation in Kentucky; and is a member of the Board of Directors for the Center for Accessible Living in Louisville, Kentucky. Mr. Gordon is quadriplegic as a result of a car accident that occurred when he was 18 years old.

Debbie Gilbert serves as co-director for the new Family to Family Health Information Centers and has been employed by CSHCN as a parent consultant since 2005. She is the mother of a child with Down's syndrome and various secondary health issues. Ms. Gilbert has worked with a variety of organizations that serve people with disabilities and their families and serves as the Family Voices representative for Kentucky.

Karen Rundall serves as CSHCN's Director of Nursing. Mrs. Rundall has over 20 years of experience as a registered nurse providing pediatric care for special needs children, including 9 years at CSHCN as a care coordinator and nurse service administrator. Mrs. Rundall is a certified case manager (CCM) and a graduate of Jefferson Community College (ADN) and Bellarmine University (BSN), both of which have contracted with her to teach pediatric clinical experience at Kosair Children's Hospital. Mrs. Rundall is currently a candidate for an MS in Healthcare Leadership and Management through Western Governor's University.

Mike Weinrauch has served in a variety of roles at since joining CSHCN in 2006, including Title V grant backup and co-coordinator for the past year. Other areas of focus at CSHCN include technical assistance with foster care support programs, social work with the bleeding disorder population, guidance to staff on brokering community resources, and general policy analysis/program evaluation. Prior to employment with CSHCN, Mr. Weinrauch served in Kentucky's child welfare and adult protective services agency as a field worker/supervisor and administrator at regional and state levels. Mr. Weinrauch is a Kentucky-certified social worker (CSW) and a graduate of the University of Vermont (BA), the University of Kentucky (MSW), and the University of Louisville (MPA).

1. d. Methods of Assessing CYSHCN

This section details the three (3) survey tools used by Kentucky to assess the wellbeing and needs of children with special health care needs. The survey tools (attached as appendices) are:

1. Web- and paper-based survey of CSHCN consumers and families of children with disabilities;

2. Web-based survey of CSHCN staff; and
3. Web-based survey of CSHCN contracted providers.

Survey of CSHCN consumers and families of children with disabilities

This tool was designed to determine programs that families perceive as important and to assess:

- Needs with respect to geographic location;
- Barriers to access to medical care;
- Insurance coverage;
- Public knowledge of the medical home concept;
- Family satisfaction with CSHCN services; and
- Family perception of transition services.

Format: Surveys were available in electronic, paper and web-based formats. Surveys were available through Survey Monkey, by e-mail, and in paper form at CSHCN clinics for five months.

Distribution: The family survey was announced on the Commission website. The website included a link to the survey. Information about the survey was also disseminated into communities statewide through the Commission regional offices, a statewide press release, by clinical staff during Commission clinics, and countless e-mails to community resource partners by Commission staff, including the transitions coordinator, parent consultants and Family to Family Information co-directors. Community partners shared the link on topical list-serves.

Survey design: The family survey was developed through a coordinated process by the needs assessment leadership team. A peer review was conducted by Kathy Blomquist, Ph.D. of the Healthy and Ready to Work national resource center which resulted in numerous language and organization changes. The survey was piloted with the Parent and Youth Advisory Councils, and feedback was considered for the final version. A final review was provided by executive staff and the Health Information and Technology branch to ensure compliance with HIPAA guidelines in the data collection. Web design was provided by the Health Information and Technology branch.

Survey results/strengths:

- Level of satisfaction with CSHCN:
 - 94% of CSHCN consumers (approximately 500) state that they are very satisfied or satisfied with services.
 - CSHCN families much more likely to “always” be satisfied with services received from doctor than non-CSHCN (82% vs. 50%)
 - CSHCN families more commonly satisfied with doctor’s communication, assistance with coordinating care, amount of time doctors spend at

appointments, doctors listening carefully, doctor's sensitivity to customs/values, and availability of interpreters

- Rate of children receiving yearly routine check-ups:
 - 96% of CSHCN patients and 94% of non-CSHCN respondents report check-ups in last year
- Assistance with navigation through system/referrals:
 - CSHCN families report far easier time accessing community services than non-CSHCN (85% vs. 51% "no difficulty accessing/using services")
 - More CSHCN families felt they could always get a referral when needed (compared to non-CSHCN)
 - 96% of CSHCN staff feel that agency is well-integrated into larger social service/health care system
- Convenience
 - 88% of providers felt that the physical location of CSHCN clinics were convenient
 - 93% of providers felt that clinic dates, times, and frequencies are convenient for families
- Knowledge and Training
 - Providers were almost unanimous in responding that CSHCN clinical staff are well-trained and highly competent and help improve the outcomes of the children they serve

Survey results/weaknesses:

- Rate of children receiving yearly routine dental care:
 - Approximately 80% of CSHCN and non-CSHCN respondents report dental care in the last year
- Receipt or understanding of transition services:
 - Despite exhaustive efforts by agency staff, only 18% of CSHCN respondents report that their children receive transition services. When asked specifically about the elements of transition services (health care, independence, work/education), CSHCN respondents report a significantly higher receipt of such services than non-CSHCN respondents – suggesting a lack of comprehension of the concept of the word "transition" among respondents
 - Staff perception that transitions may not be manageable within clinical setting
- Receipt or understanding of "medical home":
 - 2/3 of all respondents report that the concept is new to them
- Variable levels across regions in terms of integration of CSHCN within larger social service delivery system
 - As evidenced by staff survey responses reflecting higher perception of integration in western part of state

Survey results/top needs identified by families:

- Information on healthy weight/nutrition/obesity;
- Information that will help the individual child become independent;
- Information about different sources of help in the community;
- Getting information on developmental level of my child and learning disabilities;
- Therapy services;
- Dental care;
- Vision services; and
- Hearing services.

Survey of CSHCN staff

This tool was designed with multiple-choice and open-ended questions to gauge the thoughts and ratings of CSHCN's key assets – its staff regarding:

- Quality and convenience of facilities;
- Staff training and knowledge;
- Staff support (available tools to help families) and client orientation;
- Understanding of key initiatives (such as medical home, transitions);
- Barriers to care;
- Availability and knowledge of resources to help families;
- Integration within larger system of community based services; and
- Other workplace issues (such as level of professionalism, etc.)

Format and Distribution: Surveys were available and open for two weeks in a web-based format through Survey Monkey, and linked through CSHCN intranet. E-mail reminders were sent to all staff, with a link.

Survey design: The staff survey was developed by the needs assessment leadership team, based on past surveys, questions on which CSHCN has scored low in past Cabinet for Health and Family Services employee surveys, and the input of the needs assessment leadership team and executive staff. Web design was provided by the Health Information and Technology branch.

Survey results/strengths:

- The response rate of those completing the survey was unusually high (over 80%; 127 completed surveys out of 158 employees at the time).
- A large majority rated CSHCN colleagues highly on questions dealing with the level of caring and professionalism, as well as staff training and support
- 57% of staff felt that the physical location of clinics was “convenient” or “very convenient” for clients.
- Clinical staff report to have understanding of key concepts of initiatives such as “medical homes” and “transitions”.

- A two-thirds (2/3) majority answered affirmatively that they had “a good knowledge of resource available in their area”. When broken down by system, staff was most familiar with public assistance, social services, and health insurance.

Survey results/weaknesses:

- A high rate of responses for open-ended question (61% of those completing the survey) appears to be both a strength and a weakness. Responses point to several common themes as barriers to providing transition support – including funding, time management, and client lack of commitment. Responses seem to indicate that staff feel overwhelmed with unmet needs of families of CYSHCN relative to the time and resources available to meet those needs.
- Disparity in responses on several questions between east and west geographical areas, as well as between field staff and administrative state office staff. For example, responses in the eastern region point toward physical environments more conducive to meeting needs of patients while western region staff felt a better sense of agency integration into the larger community based service system. There also appears to be a predictable perceptual divide between field staff and administrative staff regarding issues such as billing and finance.
- A majority felt that equipment was “average” or below.
- Comments and ratings addressing the perceived ability of senior management to react to front-line issues, and workload distribution will need to be explored further and resolved
- While staff reported adequate knowledge on resources, targeted information dissemination may be needed to familiarize all staff with programs about which they may not be as familiar (for example, work and education programs, financial and emergency assistance).

Survey of CSHCN contracted providers

This tool was designed with multiple-choice and open-ended questions to gauge the thoughts and ratings of CSHCN’s contracted providers regarding:

- Quality of equipment and convenience of CSHCN locations;
- Adequacy of staffing, funding, scheduling, recruitment and retention, and utilization of professional services;
- CSHCN staff knowledge and performance;
- Health care transitions assistance available to children; and
- Overall effectiveness of CSHCN program.

Format and Distribution: Surveys were available indefinitely in a web-based format through Survey Monkey, and sent to all contracted providers on a flyer with a link, with yearly contract renewal paperwork.

Survey design: The staff survey was developed by the needs assessment leadership team, with the input of the medical director and executive staff. Web design was provided by the Health Information and Technology branch.

Survey results: Due to a very limited number of responses (n=24), any conclusion would be considered less than valid. Very generally, the majority felt that:

- CCSHCN staff improve the outcomes of the children they see;
- CCSHCN staff do a good job assisting with the transition from pediatric to adult care;
- Equipment is average;
- Physical locations are convenient or very convenient for patients;
- CCSHCN communication and training is good or very good;
- CCSHCN do a good job educating families about their child's condition;
- CCSHCN has adequate staffing;
- CCSHCN adequately utilizes and schedules providers well, although compensation is low;
- CCSHCN plays a key role in the community based service system; and
- Children who participate in CCSHCN program achieve better outcomes than those who do not.

1. e. Methods for Assessing State Capacity

In addition to identifying the needs of CYSHCN, the ability of the system to meet those needs was also assessed. The accompanying Title V Application for 2011 and Annual Report for 2009 provides an update of agency capacity for the Commonwealth of Kentucky, as does section 4 of this Needs Assessment, so this information will not be repeated here.

1. f. Data Sources

With the insight gleaned from the data realized from the resources cited in subsection (a) above, CCSHCN chose to concentrate quite heavily on family, consumer (families of CYSHCN who were not CCSHCN patients), staff, and provider input. The examination of national and state trends was deliberately more limited due to conditions which include:

- Dire budget circumstances (consecutive decreases in state allocations);
- Recent decline in CCSHCN enrollment;
- Rapid changes in the health care field; and
- Time and staffing constraints (i.e. retirements and turnover).

Given the above, CCSHCN felt that a focus on improving the effectiveness and reach of service delivery to the CYSHCN population would be most appropriate.

1. g. Linkages between assessment, capacity, priorities

As mentioned throughout this section, a concerted effort was made to solicit stakeholder feedback. In addition to initiating three surveys of its own, CSHCN's needs assessment leadership team assessed findings of KDPH forums, described elsewhere in this Title V Needs Assessment. Taken together, along with an evaluation of what would best make services most helpful and accessible to the greatest number of CYSHCN, the needs assessment leadership team and CSHCN executive staff developed the priorities summarized in Section 5 of this Needs Assessment.

1. h. Dissemination

Every effort was made to solicit public involvement. In turn, CSHCN plans to make the information available to stakeholders via:

- Posting on the agency website and intranet site;
- Updates at KDPH partnership/stakeholder meetings;
- Summaries to CSHCN staff and supervisors via e-mails and at meetings; and
- Any other method of communication available.

1. i. Strengths/weaknesses of process

Strengths:

- High response rate from families and staff (also observed in subsequent in-clinic surveys);
- Broad-based participation not only by CSHCN families, but also by families of CYSHCN not currently involved in CSHCN program;
- High degree of satisfaction with services;
- Evidence of two-way communication between the agency and CYSHCN;
- Client input captured from every geographic region; and
- Overall confidence that the survey results fairly and consistently represent the needs of CYSHCN.

Weaknesses:

- Low response from providers rendered the provider effort statistically powerless, although nonetheless interesting. While the survey tool was carefully planned and reviewed by the agency's Medical Director and Medical Advisory Committee, it is possible that the survey tool was too long. While CSHCN felt that mailing the survey link with yearly contract correspondence was a good idea, future efforts at engaging the provider community will need to embrace other means of distribution. E-mail addresses were unavailable and may have yielded a better response than mailings which may have been received by medical office staff and never reached the intended audience.

Staff responsible for development of the needs assessment were new to the process. The capacity of state agencies during budget crises to develop staff to conduct thorough needs assessments presents a challenge.

This concludes Section 1 "*Process for Conducting the Needs Assessment*" for the Kentucky Commission for Children with Special Health Care Needs.

Section 2. Partnership Building and Collaboration Efforts

The Kentucky Department for Public Health (KDPH) with state and local Maternal and Child Health (MCH) programs continue to meet the needs of our women, infants and children through a multitude of services available through 57 local and district health departments, with clinics in all of Kentucky's 120 counties. The range of services provided encompass family planning, prenatal, screenings and follow-up for newborns, and the provision of preventive healthcare and education to parents and caregivers, children, adolescents, and young adults.

Commission for Children with Special Health Care Needs (CCSHCN) provides therapeutic remedial services to Medicaid eligible children through a memorandum of agreement with the Department for Medicaid Services. CCSHCN also provides nursing consultative services for children in the foster care system under a memorandum of understanding with the Department for Community Based Services. CCSHCN maintains numerous relationships with other state agencies in order to streamline services for children with special healthcare needs throughout communities in the state. CCSHCN receives 34.9% of the MCH block grant funding through a contract with KDPH to support the many programs they provide throughout the state.

Services provided by local health departments (LHDs) differ across the state by consumer need. Core services provided in all communities include enforcement of public health regulations, surveillance of public health, communicable disease control, public health education, public health policy, families and children at risk reduction, and disaster preparedness.

LHDs provide oversight, education, and assurance of compliance with all public health laws, federal, state, and local, designed to protect and promote the health of the public, while minimizing health and safety risks. They also monitor public health conditions through collection, analysis, and sharing of information. Through immunizations, investigations, education, and treating outbreaks, public health strives to control communicable disease.

The Division of MCH houses the Nutrition Services, Early Childhood, and Child and Family Health Improvement branches. Within these branches are programs to provide a holistic life course approach to addressing preconception, prenatal, child, and adult mental and physical health care needs. Public Health focuses on prevention, education and provision of care throughout all programs.

MCH collaborates with all divisions in Public Health to assure delivery of services. The Women's Health Division strives to improve the health and well being of Kentucky's women. Created by the Kentucky General Assembly, the office is authorized and required to be a reliable source of data and information, recommend measures of women's health and well being for study and reporting, and administer a Women's Health Resource Center focusing on preventive and comprehensive health education. MCH relies upon data and information related to the Women's Health programs: Abstinence Education, Adolescent Health and Positive Youth Development, Breast and Cervical Cancer Screening, Family Planning and Reproductive Health, Folic Acid Supplementation, and Preconception Care. Both divisions worked very closely together throughout the Needs Assessment process.

Through the work of the Prevention and Quality Improvement (PQI) Division, MCH has assurance standards of care are delivered throughout the local health departments. PQI

coordinates and publishes the Public Health Practice Reference which provides support to LHDs on patient-centered care in clinic and community settings, as well as supportive information to assist in provision of population-based services. MCH relies upon data from PQI's Chronic Disease Branch programs on Asthma, Diabetes, and other chronic disorders as they relate to maternal and child health populations.

The Epidemiology and Health Planning Division provides critical Title V data for HIV/AIDS, immunizations, sexually-transmitted diseases and all reportable disease. Vital Statistics is part of this division from which major birth and death data is received. All divisions participate in activities and rely upon the knowledge of the Public Health Preparedness Branch for our daily health and safety at a state and local level, especially in preparation for natural disasters and issues affecting community health. The division collaborates with and guides injury prevention and control programs at the University of Kentucky's Injury and Prevention Research Center, from which MCH obtains pediatric injury prevention expertise and technical assistance. The Division of Epidemiology also addresses Communicable Disease and Outbreak Investigations.

Critical to the health planning at state and local levels is the knowledge and education provided by the Public Health, Protection, and Safety Division. The division oversees statutorily mandated environmental health programs and trains, provides guidance, and evaluates over 300 LHD inspectors. WIC programs rely upon the food and milk safety oversight to assure all programs meet Federal and Drug Administration, United States Department of Agriculture, and Food Safety and Inspection Service expectations.

The Division of Laboratory Services promotes and protects the public well being by providing high quality and efficient laboratory services and education. The Laboratory partners with MCH in the critical Newborn Metabolic Screening program which links hospitals, test results, families, primary care providers, case managers, and university specialists into a comprehensive system of identification and follow up. The Laboratory division also provides examinations of communicable disease and environmental specimens to support state and local health department programs and emergency preparedness functions. The division plays an active role in the improvement of health status for Kentuckians through on-going consultation with state and local health programs, physicians, hospitals, medical examiners and industrial hygienists.

The Division of Administration and Financial Management (AFM) has statutory and regulatory oversight of finances and allocation of funds to LHDs throughout Kentucky. This division is also responsible for the financial management of KDPH. AFM provides budgets and accounting support, payments, grant allocations, procurement and contracting support for all KDPH divisions and LHDs.

2. a. State and Local MCH Programs

A Partnership in Maternal and Child Health: Collaboration between KDPH and CSHCN

As an entity within the Kentucky Cabinet for Health & Family Services, CSHCN shares the same statewide parent organizational structure as other important social service and health programs such as KDPH, Medicaid, and the state's child protective services and mental health/mental retardation agencies. Such a structure lends well to planning and sharing in order to maximize resources and make services seamless. From the care coordinator who may be

involved in varied activities directly (e.g. provision of folic acid multivitamins/education or application of fluoride varnishing) to more high-level coordination of executive staff (e.g. participating on interagency policy councils with other department heads), critical partnerships exist with most every state agency. CCSHCN has a special relationship with KDPH, particularly with regard to referrals to and from local health departments. Another noteworthy MCH partnership is the Healthy & Ready to Work National Resource Center – for which CCSHCN provides physical space. This arrangement enables a relationship in which HRTW staff is embedded with CCSHCN staff and communication flows freely. For example, when the HRTW center developed a training module for engaging and empowering youth in the needs assessment process, staff met with CCSHCN staff and members of CCSHCN's Youth Advisory Committee to gather input and feedback.

The next pages will provide programmatic detail for some of the many departments, divisions and programs charged with the care of women, infants, children and CYSHCN in Kentucky.

Women's Health Services

The Division of Women's Health (WH) interfaces closely with MCH, sharing and supporting knowledge and information throughout the span of life from pre-conception to young adult.

The division's goal is to improve the health and well being of Kentucky's women. This division was moved to public health in a reorganization in 2007 from an Office of Women's Health, created by the Kentucky General Assembly in 2001, to serve as a reliable source of data and information on women's health; recommend measures of women's health and well being for study and reporting; and administer a Women's Health Resource Center focusing on preventive and comprehensive health education.

Programs administered by the Division of Women's Health and provided through Kentucky's local health departments include Adolescent Health, Breast and Cervical Cancer Screening, Breast Cancer Research and Education Trust Fund, Family Planning, Preconception Health, and Ovarian Cancer Awareness.

Family Planning

Family Planning is a program administered through funds from Title X to educate and assist low-income families to make personal choices in determining the number and spacing of pregnancies in order to achieve the best possible health outcomes for babies. Although not funded by Title V, family planning plays an important role in decreasing the need for services to otherwise at-risk infants and children.

Women's Health has developed special initiatives targeted to service populations identified as having high social and medical risk for unintended pregnancy or poor birth outcomes (i.e. infant death, fetal loss, birth defects, low birth weight, or preterm birth).

One contracted family planning clinic in Fayette County, Bluegrass Community Health Center (BCHC), targets low income under insured Hispanics, work as migrant farm workers in the bluegrass area. Another initiative directed at the Appalachian region known to have a higher rate of sexually transmitted disease and teen pregnancy, is the Pike County Male Special Initiative

Project that services provided in the local health department clinic, and also an in-school programs for middle school males who are taught goal setting and self-esteem skills.

In FY 2010, two additional family planning clinics were awarded Title X supplemental funding for male reproductive services; Coalition for Adolescent Pregnancy Prevention (CAPP) and University of Kentucky Young Parents Program (YPP). CAPP and YPP are two central KY contracted family planning clinics which focus on teen pregnancy prevention. The YPP is partially funded by the MCH Block Grant. Both agencies provide intensive counseling to teens to prevent teen pregnancies and repeat teen births and also comprehensive adolescent preventive health care services. YPP is unique because it places emphasis on medical, nursing, and nutritional care for both mother and child, education toward better parenting, career and educational counseling, psychosocial support of the family unit; and family planning services.

As a critical element to public health family planning, a teen pregnancy prevention team was created in January, 2010. Resulting from eleven public forums held across the state in 2009, teen pregnancy was the number one identified local problem in 9 of the forums and the number two (2) local problem in the other two forums. This team consists of 25 partners that include:

- State public health representation from school health, family planning, adolescent health
- Local health department educators
- KDE representatives
- Adolescent Health physicians at University of Kentucky, University of Louisville, Pike County Health Department
- Governor's Commission on Women's Health representative
- Kentucky Teen Pregnancy Coalition
- Center for Adolescent Pregnancy Prevention (CAPP) Director, Planned Parenthood Director, both in Louisville, Brighton Center Youth Leadership Program Director, Newport
- Family Resource Youth Service Center staff,
- School nurse
- Substance abuse representatives from DBHDID
- Parents and PTA representative
- Teen mother

This team met January 20, 2010 and did a SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis of teen pregnancy in Kentucky. A mission statement was adopted: Empowering Youth to Achieve Optimal Health and Wellbeing. The objective to reduce teen pregnancy by 20% by 2020 was established. Four goals for teen pregnancy prevention were identified:

- 1) State-wide age-appropriate sexuality education ages K-12 based on federal guidelines that includes accountability measures and minimum standards for educator training.
- 2) All Kentucky youth will have access to reproductive health care, contraceptives, and preventative services.
- 3) Educate and engage parents and communities to provide access and opportunities for positive youth involvement.

- 4) Implement ongoing teen pregnancy prevention awareness utilizing multiple modes of communication.

This team will continue to meet one to two times a year to monitor the progress of the plan and reevaluate and develop additional strategies as needed.

Established through the teen pregnancy prevention team, Teen Impact Group is a focus group format that was conducted in 9 high schools across Kentucky with high school juniors and seniors.

Preconception Health

The Preconception Health program provides interventions that identify and modify biomedical, behavioral, and social risks to a women's health and future pregnancies. Women receiving these services are screened for risks, provided health education and promotion, and receive interventions to address identified risks for a healthy life and a healthy pregnancy outcome. This program provides interventions such as smoking cessation, obesity control, and folic acid supplementation.

The Folic Acid Campaign is designed to prevent the high incidence of two common and serious birth defects, spina bifida and anencephaly, in Kentucky by providing all women of childbearing age access to the B vitamin Folic Acid, a known preventive measure. An estimated 50-70% of such birth defects are preventable through the ingestion of folic acid prior to pregnancy and in the early prenatal period. Neural tube defects occur within the first four weeks after conception before most women even realize they are pregnant. According to the CDC the annual medical care and surgical costs for persons with spina bifida in the United States exceed \$200 million, and the average total lifetime cost to society for each infant born with spina bifida is approximately \$532,000 and for many children the cost may be well above \$1,000,000. Based on Kentucky's incidence of spina bifida for the past six years the average estimated annual cost to Kentucky residents is 12.1 million dollars.

The Kentucky Folic Acid Partnership (KFAP) was begun in 1998 as a collaboration of MCH with the March of Dimes Folic Acid Campaign. The KFAP has endured and continues to promote use of folic acid across the state. KFAP has 86 individual members representing 73 agencies, organizations, and businesses. The KFAP provided 344 folic acid awareness activities reaching 638,009 participants statewide. The KFAP added Prematurity awareness in 2005 as a focus to promote healthy pregnancy outcomes. CSHCN's Folic Acid Multivitamin program provides vitamin supplements and preconception health education free of charge to any woman of childbearing age (regardless of enrollment status with CSHCN). During a given year, CSHCN distributes supplements to 1500-2000 women across the state.

Adolescent Health

The Adolescent Health Program is involved in many initiatives, partnering with mental health and child services programs to address issues confirmed through the MCH Needs Assessment process. Some of the newest endeavors, along with teen pregnancy prevention strive to promote improved self image for adolescents and safety.

Through continued efforts of the DBHDID, Women's Health collaborates with and enforces the message from the Kentucky Suicide Prevention Group of training students across Kentucky to recognize the warning signs of suicide. The program is called SOS (Signs of Suicide).

There is strong collaboration with DBHDID on substance abuse prevention and intervention for teens. The message is stressed through works of teen pregnancy prevention.

Women's Health also collaborates with the new Division of Violence Prevention Services within the Department of Child Based Services in development and advancement of the Green Dot Program. This is a domestic violence intervention/prevention program that involves curriculum based education in the schools that encourages bystanders to recognize and address potential violent situations before the violence escalates.

Maternal and Child Health Services

The Division of Maternal and Child Health (MCH) strives to promote and safeguard the health of Kentuckians, helping them achieve the optimum level of health and wellness. MCH identifies risks to good health, develops methods to reduce those risks, and sets standards to improve outcomes. Programs within the division provide accessible and affordable prenatal care in order to prevent adverse birth outcomes. Preventive care and support for children during critical periods of growth and development enables children to reach their fullest potential. There are many preventative clinical care programs for children and expectant mothers that detect and treat life-threatening disorders such as metabolic screening in newborns, intervention and promotion for early childhood, nutrition counseling and food supplementation, oral health screening and education, and collaborative efforts with other agencies.

Prenatal / Pre-term Birth

The Kentucky Department of Public Health, in partnership with the March of Dimes and Johnson and Johnson Pediatric Institute, began a preterm birth prevention initiative in 2007 focusing on "preventable" preterm birth, and specifically late preterm birth, since Kentucky's data indicated those births were the source of our rise in preterm birth rates. The program was a real-world ecological design that built community partnerships to promote research to practice and patient safety initiatives among providers, enhance services to patients, and educate the public on the importance of preterm birth to the entire community. For this project, The Kentucky Folic Acid Partnership developed a Community toolkit for prematurity prevention activities and information. The toolkit, "Healthy Babies Are Worth the Wait", is available at www.prematurityprevention.org. Currently, plans are underway to revise and update the toolkit to be posted on the national March of Dimes web site and available for use by other states and communities for prematurity prevention activities.

As part of their partnership with KDPH, University tertiary care centers serve as regional perinatal centers and provide the highest levels of neonatal care to serve Kentucky's high risk mothers and infants. Their responsibilities as regional perinatal centers include neonatal transport, outreach education, and neonatal medical and neurodevelopmental follow-up. These services assure that mothers and neonates across the state have access to appropriate levels of neonatal and perinatal care for the most complex diseases and conditions. Both University of

Kentucky and University of Louisville offer a full range of pediatric medical subspecialty services, as well as pediatric surgery, open heart surgery, and ECMO.

The Department for Public Health is working with Local Health Departments to develop Fetal and Infant Mortality Review (FIMR) programs as a method for communities to decrease the infant and fetal mortality rates. The goals of the FIMR are 1) to describe significant social, economic, cultural, safety, health and systems factors that contribute to mortality and 2) to design and implement community-based action plans founded on information obtained from reviewing the risk factors in these deaths. Currently, two local FIMR sites are implemented in Louisville and in the Barren River District.

The Prenatal program collaborates routinely with the Kentucky Folic Acid Partnership, breastfeeding and nutrition services, and programs in Women's Health. Currently the MCH Prenatal program also works collaboratively with the Substance Abuse division of the Department for Behavioral Health on the KIDS NOW Plus Substance Abuse in Pregnancy (Case Management) Program, the Substance Exposed Infant Workgroup, and the Fetal Alcohol Advisory committee. The prenatal program within the local health departments are to assess every pregnant woman about their use of alcohol, tobacco, secondhand smoke exposure, and other drug use at each health department visit and provide education and referrals as appropriate.

The Department for Public Health provides an annual Prenatal and Postpartum Training for LHD staff who provide services in health department clinics. The course provides updates on current practices in the care of prenatal patients, and includes training about substance abuse in pregnancy.

KDPH is collaborating with DBHDID, Division of Behavioral Health, to discuss data and potential prevention and treatment strategies related to pregnant women in Kentucky. During the MCH needs assessment forums in 2009 smoking and substance abuse emerged as major themes. Issues associated to these included access to care, increased need for education and awareness, cultural issues and social norms, and lack of policy.

Newborn Metabolic Screening (NBS)

Approximately 60,000 infants are born in KY each year. KY law mandates that all KY-born infants receive the newborn screening unless refused for religious exemption. Infants identified with a positive diagnosis will have prompt evaluation, diagnosis, and initiation of treatment that will prevent or reduce developmental delays, organ failure, and possibly even death.

The NBS program collaborates with the State Public Health Laboratory, University of Kentucky pediatric specialty clinics, University of Louisville pediatric specialty clinics, Cincinnati Children's Hospital pediatric specialty clinics, Vanderbilt University pediatric specialty clinics, primary care providers, local health departments, birthing hospitals, Medicaid, the HRSA Region 4 Genetics Collaborative, the KY Newborn Screening Advisory Group, the KY Fetal and Infant Mortality Review, the KY Child Fatality Review, the KY Birth Surveillance Registry, the National Birth Defects Prevention Network, the March of Dimes, The Saving Babies Foundation, and the National Newborn Screening and Genetics Resource Center. NBS also collaborates internally with the Kentucky Birth Surveillance Registry (KBSR) to include positively diagnosed cases into

the KBSR database for long term tracking and reporting of genetic conditions for the state of Kentucky.

Kentucky Birth Surveillance Registry (KBSR)

The Kentucky Birth Surveillance Registry (KBSR) is organizationally located within the Kentucky Department for Public Health, Division of Maternal and Child Health. Birth defects occur in approximately one out of 33 births in the United States and are a leading cause of infant mortality in the Commonwealth of Kentucky.

KBSR is a statewide birth defects surveillance system, its purposes outlined in KRS 211.651-670, to accurately determine incidence, prevalence and trends of congenital anomalies and high-risk conditions; to investigate possible causes and develop preventive strategies to reduce the incidence and secondary complication associated with birth defects. The reporting sources for the registry include hospital discharge data, vital statistics data covering 55,000 live births and 380 stillbirths each year through a passive surveillance method with follow-up and quality control by medical records abstraction. This system identifies children from birth to five years of age with birth defects, genetic and disabling conditions.

KBSR was awarded a CDC-funded grant in February 2010 in the amount of approximately one million dollars over the next five years. KBSR plans to utilize the funding from this grant to make enhancements to the existing birth defects surveillance system, use of the data for prevention programs, and referral of children identified by KBSR to early intervention services.

KBSR integrates data obtained from hospital discharge (UB-92) data and vital statistics (live births, fetal deaths, death certificates). Additional reporting sources include tertiary care neonatal intensive care units, genetics clinics, and medical laboratories. Objectives related to the data system in the upcoming year are established to improve case ascertainment, the timeliness of reporting, and the quality of data. In addition, KBSR plans to analyze the accumulated data from 1998 to 2008 and develop an ongoing annual report with this data. KBSR plans activities to promote the availability of Kentucky-specific birth defects data to the general public, health care providers, and individuals utilizing the data for research purposes.

The prevention of birth defects is an important aspect of KBSR. In the upcoming year, activities will be completed to reduce the rate of neural tube defects from 6.5/10,000 live and stillbirths in 2004 to 5.8/10,000 in 2009. KBSR will also collaborate with the Substance Abuse Prevention Program to identify activities to promote the awareness of the adverse effects of substance abuse on pregnancy.

KBSR has developed a process to refer children with established risk conditions to Kentucky's Earl Intervention System, First Steps. Once implemented, the evaluation of these referrals will include determining a baseline for the number of children referred by KBSR per year, identification of the percentage of these children that are subsequently enrolled in early intervention, and in future years, changes in the average age at which enrollment occurs for specific birth defects.

First Steps

First Steps is a statewide early intervention system that provides services to children with developmental disabilities from birth to age 3 and their families. First Steps offers comprehensive services through a variety of community agencies and service disciplines and is administered by the Department for Public Health in the Cabinet for Health and Family Services. Early intervention services can decrease the need for costly special education programs later in life by remediating problems early in the child's development.

First Steps has a total of fifteen (15) regional Point of Entry sites which serve as the Local Lead Agency for the program. Collaborative partners include Universities, LHDs, Mental Health Centers, Hospitals, Medicaid, Head Start, Preschools, local school systems and the KDE. First Steps offers a variety of services that include but are not limited to: Service Coordination, Screening, Evaluation, Assessment, Nutrition, Occupational Therapy, Physical Therapy, Developmental Intervention (special instruction), Assistive Technology, Speech Therapy, Vision/Hearing, Respite, Limited health Services, Transportation and Transition.

Children who participate in early intervention can experience significant improvement in development and learning. Children with developmental delays or conditions likely to cause delays benefit greatly from services received during critical developmental years. Services and support also benefit families by reducing stress. Services may be provided in the home, at child development or other designated centers or in a clinical setting, depending on the needs of the child and family and the availability of services in a given area.

First Steps, the Kentucky Early Intervention System, collaborates for child find and various levels of data sharing with several programs that serve infants and toddlers and their families including the Commission for Children with Special Health Care Needs, the Early Hearing Detection and Intervention program, the Birth Registry and Surveillance Registry, Newborn Metabolic Screening Program, Early Head Start, and Medicaid. First Steps also collaborates with the Health Access Nurturing Development Services (HANDS) program, and the Early Childhood Community Councils.

First Steps collaborates with the CCSHN by providing early interventions services to the special needs children, there is a partnership to assure that these high needs children are enrolled in early intervention services. The EDHI program also works closely with the point of entry managers to be sure that infants identified with hearing impairment receive appropriate audiology services as well as enrolled in the First Steps Program. The two programs also have a data sharing agreement to monitor outcomes for these children. KBSR collaborates with the First steps program to allow for referral of children with confirmed risk conditions to appropriate resources. They are currently working on a pilot program for children confirmed to have Down Syndrome who are at high risk for developmental delay to increase the timeliness of these children getting into services. The HANDS program is a home visitation program for at risk parents that begins prenatally and continues until the child reaches two years of age. The HANDS program performs developmental screening at 12 months and 24 months on these infants and assures those with delays are referred to First Steps for further evaluation.

GIFTS

Another program at the local health department level, designed to enable the MCH population is GIFTS (Giving Infants and Families Tobacco Free Starts) Program, which was implemented on

February 11, 2008 as a pilot program to reduce smoking in pregnancy. Nine Eastern Kentucky counties were selected based on the premature birth data and smoking rates. The goal was to see a reduction in low birth weight and preterm births. The initial two-year pilot ended February 2010. The project was a collaborative effort of the MCH Prenatal program, the KDPH Tobacco Cessation and Control program, the University of Kentucky, School of Nursing, and the participating local health departments. Data is still being analyzed, but quit rates were significantly higher than typically seen in heavy smokers. The program is now rolling out to four new sites. The four expansion counties will integrate GIFTS into existing programs such as HANDS and Healthy Start. Training was held in January 2010 and included new and current GIFTS pilot counties. Training also included the introduction of the new web-based reporting system. The original nine pilot counties will continue offering the GIFTS program using the new integration model.

More information about this program is located at <http://www.mc.uky.edu/KYgifts/>.

HANDS

The Health Access Nurturing Development Services (HANDS) program is a voluntary, state-wide home visitation program for new and expectant first time parents. The HANDS program is available through local health departments in all 120 counties in the state. Evaluations by an independent evaluator have shown that participants, compared to a similar non-participating group, have improvements in birth outcomes (less prematurity, less low birth weight, less infant mortality), reductions in child abuse and emergency department utilization, and improved family functioning.

HANDS actively pursues Community Outreach and Screening efforts in order for services to be initiated during the prenatal period, however, but HANDS will accept families identified as high risk into the program up until infant is three months (12 weeks) old. HANDS sites work with collaborative partners to provide an opportunity to all first time mothers or first time fathers to participate in the HANDS program. These include Health Department programs, Department for Community Based Services (DCBS), local hospitals, pediatricians, OB/GYN, parent(s), Family Resource and Youth Service Centers (FRYSC) Community Mental Health Centers, First Steps, Faith Community, Head Start, Even Start, PACE of KY and any local organizations whom share the same goals as HANDS. Each HANDS Coordinator or their designated staffs are a member of at least one local collaborative group. HANDS staff members give an update on the HANDS program at regular intervals to local groups and; as appropriate, share data and evaluation material. Through building these community relationships, the HANDS program is better able to make referrals to/for basic needs, child care, domestic violence, education, employment, First Steps, health department, mental health, oral health, physician care, smoking cessation, substance abuse and transportation.

Kentucky is applying for funding from the Maternal, Infant, and Early Childhood Home Visiting Program of the Affordable Care Act of 2010 (Public Law 111-148). Kentucky Governor, Steven L. Beshear, has designated the Cabinet for Health and Family Services, through the Department for Public Health, as the lead agency for this project. The KDPH has more than a decade of experience administering an evidence-based, state-wide prenatal and early childhood home visiting program for first time, at risk parents and their young children. The State-wide

Home Visiting Needs Assessment required by this new program is underway, and will be integrated with and coordinated with the activities of this Title V MCH Needs Assessment, as well as information from Head Start and the state's CAPTA program.

Child Care Health Consultation (CCHC)

Kentucky has revised the state's model of Healthy Start in Child Care which was begun in 2000, and renamed the program as *Child Care Health Consultation: for a Healthy Start in Child Care* (CCHC). Due to funding limitations, the state was no longer able to fund consultants in every health department. The new design creates a training and technical center at the Lexington-Fayette County Health department, which was the first child care health consultation program in the state. In January 2010, the Technical Assistance and Training Center (TATC) based out of Lexington Fayette County (LFCHD) launched a new CCHC Helpline, 1-877-281-5277. The Helpline acts as a triage point by offering standardized information to child care providers and to other statewide consultants by phone and facilitates a referral to a local CCHC consultant if needed. In addition, through a request for proposals, the program was able to fund 11 regional consultants in health departments around the state.

Consultants collaborate with local Child Care Resource and Referral agencies to develop or enhance existing relationship to provide consultation and training to licensed child care centers and certified family homes. Consultants provide consultation to child care providers asking for assistance with children's health or social emotional issues. Consultants coordinate or participate in area meetings (face to face, teleconference, list serves, etc.) with surrounding early childhood professionals to collaborate training efforts within the CCHC Program, as well as with other child serving agencies. Consultants assist with consultation and training in providing support for early care and education centers working toward a STARS rating or improving a STARS rating. Consultants assist with consultation and referrals from the Office of Inspector General or Division of Regulated Child Care of centers and homes with deficiencies in health and safety.

Other collaborative partners for this program include: Department of Education (Division of Early Childhood Development), Division of Child Care, local Community Early Childhood Councils, UK Human Development Institute, State and Regional Interagency Councils (SIAC and RIAC), Local Health Departments including programs like HANDS and CCHC, First Steps, Kentucky Partnership for Families and Children, Kentucky's System to Enhance Early Development (KY SEED).

Early Childhood Mental Health Program

The Early Childhood Mental Health Program (ECMH) supports and promotes the social and emotional growth of Kentucky's children birth to age five by emphasizing the importance of nurturing relationships in multiple settings. There are currently 29 Early Childhood Mental Health Specialists across the state within the Regional Mental Health/Mental Retardation Boards. These specialists provide consultation to early care and education settings; provide direct interventions to children and families identified as having social-emotional concerns, train front line professionals working with young children birth to five in the importance of social-emotional wellness and dealing with challenging behaviors, and act as a resource person in their own community mental health centers. A key goal of this program is to build capacity of

mental health clinicians in working with the birth-to-five population. TFP to ensure analysis includes key areas of concern for Kentucky.

A training component has been designed to build competency of front line individuals who work with young children birth to five. Trainings are presented statewide on early childhood mental health topics. These trainings are free and clinicians receive CEU's. The Early Childhood Mental Health Specialists have also attended many trainings pertaining to the treatment of young children birth to five. The Early Childhood Mental Health Specialists train individuals within their region on these topics as well.

The final piece of the program concerns building the capacity of early care and education professionals. By increasing the support and knowledge regarding the promotion of early childhood mental health, it is the goal of the program to decrease the number of children expelled from early care and education settings. The Early Childhood Mental Health Specialists provide free trainings and consultations to early care and education programs. The goal is to build capacity of early care and education professionals in addressing social/emotional issues of young children, eventually decreasing the number of referrals to the ECMH Specialists.

Many Early Childhood Mental Health Specialists sit on the Community Early Childhood Councils, some of which hold office within their perspective councils. The ECMH Specialists collaborate with Child Care Health Consultation for a Healthy Start in Childcare Consultants whose task is to increase the capacity of childcare providers to meet the health, safety, nutritional, and social emotional needs of children in their care. The ECMH Specialists also provide consultation to the community on issues effecting early childhood mental health. This community collaboration includes training and serving on Community Early Childhood Councils; making referrals to KY IMPACT through their local RIAC; and sometimes serving on their local DEIC for First Steps.

Early Childhood Comprehensive Systems (ECCS)

ECCS grant funding will be used to develop a fiscal mapping report of all programs in Kentucky serving children pre-natal through age eight (8) and their families; including the KIDS Now initiatives as well as early childhood programming supported by federal, state, local and foundation funding. This project will require collaboration and participation of many partners. The ECCS Advisory partnership team is comprised of representatives from the following areas: Division of Child Care, Department for Public Health, Department for Behavioral Health, Developmental and Intellectual Disabilities, Division of Family Resource and Youth Service Centers, Department of Education, Division of Early Childhood, and Kentucky Head Start Collaboration Office and the private sector. This Advisory team meets at regular intervals to track progress on the fiscal mapping project and to provide direction as well as guidance.

Coordinated School Health

The Coordinated School Health Program (CSHP) is a CDC-sponsored program and a KDPH partnership with the Kentucky Department of Education, designed to improve the health status and school performance of children and adolescents by creating a healthy school environment through policy and evidence-based practices. The State CSH provides professional development, resources and technical assistance to schools, local health departments, and

other community partners in utilizing the 8 component CSH model. CSH helps school districts and schools implement a CSH Program, and through this approach, increase effectiveness of policies, programs, and practices to promote physical activity, nutrition, and tobacco-use prevention among students. Partnerships and collaboration between the Department for Public Health and the Department of Education as well as other partners at the local, state, and national levels have increased coordination of efforts.

KY Action for Healthy Kids (KAFHK), the Coordinated School Health team, and the Kentucky River District Health Department have collaborated to implement Students Taking Charge (STC) in 19 high schools across the state. STC is a program for high school students to use their interest in nutrition and physical activity, over all living healthy, to help their school be a healthier place for everyone. With STC, youth get connected to their school and the school planning process to understand how to improve their school health environment. The high schools were selected through a request for proposals process. The STC assessment pieces (student, parent, and preview of the School Health Index surveys) were reviewed and changes made to reflect our work together and the CSH team's selected School Level Impact Measures; therefore they were "Kentuckyized". Individualized training was provided to the school contacts and their student organizations by KAFHK's in collaboration with CSH beginning in January 2010. Funding for technical assistance came from KAFHK through the national AFHKs-Kellogg's Team Grant Program. Each school's student organization received a \$500 mini-grant after they completed their three assessment pieces (student, parent, and preview of the School Health Index surveys) and local student action plan. The funding was provided by CDC-DASH KY CSH. The variety of student organizations participating include: FBLA, FCCLA, Student Council, Student Newspaper, HOSA, UNITE/SADD, Student Government, Beta Club, Legends and High School Walking Club.

As a result of the collaborative work on the described STC project, a core group of partnering organizations is in the planning process to host a STC Summit on October 1, 2010 at Western Kentucky University. This collaboration includes KAFHK, CSH, Barren River District Health Department, parent representatives, Western Kentucky University Dean of Allied Health Sciences, local AHEC, and Jefferson County Public Schools.

The CSH team is collaborating with several partners to improve school staff wellness in five school districts for a total of 19 schools located primarily in Eastern Kentucky. The partners involved include: KY Action for Healthy Kids, Alliance for a Healthier Generation, local Health Departments, Pennyrite Allied Community Services Nutritional Outreach and Wholeness Program (PACS-NOW), UK and local Extension office and Humana. Funds will be provided at the local level to three health departments to assist in providing training, technical assistance and \$1,000 per school mini grants with the school districts. The school districts selected have capacity to improve their school staff wellness due to their proactive work in areas of CSH such as nutrition and physical activity. Two regional professional development events were held in March 2010 in Booneville and Monticello. The trainings included a national expert speaker in the area of school staff wellness from the Alliance for a Healthier Generation. For the \$1,000 mini-grant funds to be released, school staffs are required to attend the training, complete and submit the Health Promotion for Staff module score from the SHI and school employee wellness action plan. In mid-June schools will submit and update to their work plan and a success story.

The planning team for this professional development event consisted of the Coordinated School Health (CSH), Pennyriple Allied Community Services Nutrition Outreach and Wholeness (PACS NOW) staff, the Practical Living/Career Studies (PL/CS) Consultant at KDE, and higher education representatives from Western Kentucky University (WKU). “The Essential Best Practices in Nutrition Education” professional development event occurred on February 23, 2010 in Shepherdsville. There were 73 attendees – 2 school district personnel, 9 PACS NOW staff, and 62 teachers. The day consisted of an introduction to CSH; an overview of the National Health Education Standards and how they relate to the KY standards; an overview of the “Nutrition Essentials: Teaching Tools for Healthy Choices”; building the participants skills through health education teaching strategies; and an overview of resources from PACS NOW and cooperative extension services that are available to the teachers and schools. Overall the evaluations for the day were positive. The participants really enjoyed the teaching strategies and hands on work, and the participants were very appreciative of the materials they received and of the opportunity to participate in a PD related to the content they teach.

Follow-up support for this event is going to be provided by PACS NOW. Teachers will be keeping track of how much they use the information and activities presented from March – May, and in return will receive either more nutrition education or materials from PACS NOW. A post evaluation survey will be sent electronically in May from the CSH team to all participants to find out if they have or haven’t used the information; what additional support or resources they may need; what topics they would like to see presented in future nutrition education PDs; etc. The CSH team will provide all participants who complete the evaluation survey with some extra nutrition education materials.

Coordinated School Health (CSH), Kentucky Action for Healthy Kids and Pennyriple Allied Community Services Nutrition Outreach and Wholeness partnered to bring the School Health Index training to Western Kentucky in September 2009. CSH obtained a national speaker, through CDC-DASH, on the SHI. Twenty-five school staff and community organizations staff received this intense day long professional development.

The *School Health Index (SHI): Self-Assessment and Planning Guide* was developed by CDC in partnership with school administrators and staff, school health experts, parents, and national nongovernmental health and education agencies for the purpose of: enabling schools to identify strengths and weaknesses of health and safety policies and programs; enabling schools to develop an action plan for improving student health, which can be incorporated into the school improvement plan and engaging teachers, parents, students, and the community in promoting health-enhancing behaviors and better health.

Eight Regional Youth Tobacco Prevention Conferences have been held throughout the state of Kentucky in the fall and winter of 2009/2010. The local planning teams developed their own agenda based upon the expectations in a fall 2009 training which included the students bringing their schools’ tobacco policies to the conference to be reviewed with an assessment tool. Example local planning participants include leaders from the local health department, family resource and youth services centers, Kentucky ASAP, Kentucky Cancer Program, universities, hospitals, faith-based groups, community coalitions, regional prevention centers and school staff. Approximately 811 youth and 175 adults (school sponsors, organizers) were in

attendance. The youth are currently involved with their tobacco prevention activities of which will be reported this summer 2010 along with success stories.

The Kentucky Asthma Leadership team, supported by the CDC- DASH funding through the National Association of School Administrators and the National School Board Association has as one of the team objectives to assist school districts in providing a 24-7 or 100% tobacco free campus for their students, staff and visitors. The Kentucky Asthma Leadership team, CSH team and the Tobacco Prevention and Cessation Program conducted a survey of School District Health Coordinators concerning district's policies on tobacco. Through review of data gathered, materials have been developed (<http://www.site.kytobaccofreeschools.com/Resources.html>) and a pilot informational meeting held on 24-7 tobacco free schools in Montgomery County Kentucky was held in April 2010. The purpose is to increase knowledge and awareness of model policies, practices and enforcement of 24-7 tobacco free schools.

Children's Oral Health

Over the recent past, the Kentucky Oral Health Program has enjoyed developing new partnerships with many agencies and associations in order to extend more comprehensive services throughout the state. Currently, the KOHP is in Year 3 of the four-year Targeted MCH Oral Health Service Systems (TOHSS) Grant through HRSA. TOHSS's goals are supporting the expansion of preventive and restorative oral health services for Medicaid and State Children's Health Insurance Programs (SCHIP) eligible children and other underserved children and their families. To assist in these efforts, the KOHP is partnering with the KY Division of Family Resource and Youth Services Centers (FRYSCs) and the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) programs in the Cabinet for Health and Family Services and local health departments to assist with these efforts.

University of Kentucky College of Dentistry: The KOHP has had a formal relationship with the University of Kentucky's College of Dentistry for many years, but new grants from HRSA and ARC grants have provided the opportunity to involve the UK Dental Public Health Program in the development of a curriculum to train general dentists who practice in rural areas in pediatric techniques. We are working closely with the senior pediatric staff in this curriculum development. The KOHP and UK have embarked on a new relationship in working with the institutionalized elders in the state to improve their oral, therefore overall, health. UK continues to involve the KOHP in their expansion of their outreach dental program as it expands throughout the state.

University of Kentucky Gatton School of Business and Economics: Because of our interest in quantifying the opinions of the dental professionals in the state, we have established a working relationship with the College of Business and Economics to design, test, implement and analyze a survey to dentist to record their practice patterns. Through this new linkage, the KOHP has learned more about surveys, their results and limitations and the Business College is learning more about the economics of a community relative to access to dental care, especially for their children.

University of Kentucky's School for Rural Journalism: The lack of dental services for young Kentuckians has caught the interest of this school's faculty members. Their Chairman Emeritus and a senior professor have become involved in the problem of access and this has resulted in

“op-ed” pieces in Kentucky newspapers. Both gentlemen carry weight in Kentucky’s rural communities and the HRSA Workforce Grant as the ABCD Initiative will only benefit from their new knowledge of our initiative.

University of Louisville: The Kentucky Oral Health Program and the University of Louisville’s School of Dentistry have not recently been engaged in contractual services. Through the curriculum development grant, we have established a positive working relation with the Pediatric Dentistry Department in the implementation of this Workforce Grant. Additionally, their program coordinator for their Office of Continuing Education is bringing to the Steering Committee a wealth of knowledge relative to the design and evaluation of continuing education activities and programs. KOHP will benefit from this knowledge long after the grant activities end.

Kentucky Dental Association: The immediate past president of the Kentucky Dental Association embraced “access for children” as his tenure’s focus. He has been instrumental in opening doors for KOHP staff to promote pediatric training to its membership. During their 2010 Annual Session, the Dental Director spoke to their Past Presidents Meeting as well as their governing House of Delegates with an overview of oral health status in the state and the activities of the state’s Oral Health Program. Through renewed partnerships between the KOHP and the KDA, the Kentucky Dental Association is providing in-kind services in the near future through advertising space in their publication, *KDA Today*, for training updates as well as exhibit space for their next annual session to promote this training opportunity for its members. The KDA is involved in promoting the Dental Director’s offer to speak to component societies about KOHP training opportunities. The involvement continues with the new president committing staff involvement in the development and promotion of the teaching curriculum through representation on the Steering Committee. The Dental Director continues to sit as an ex-officio member of the association’s Executive Board.

Kentucky Board of Dentistry: The Kentucky Board of Dentistry has active participation as an important part of the Steering Committee for the development of the training curriculum. The newly enacted Dental Practice Act includes the state’s dental director as a new member of the board and she has been active in their work on the promulgation of the regulations that parallel the new act. Through this new partnership, the members of the Board of Dentistry have a better working knowledge of public health dentistry and are addressing barriers to care, unique to licensure boards.

Kentucky TRAIN: The Department of Public Health, under Homeland Security funding and support, has developed an integrated training site that offers multi-media training opportunities for all things related to public health and emergency preparedness. The training developed through the HRSA and ARC grants will utilize this system to provide web-based trainings. A TRAIN representative is an active member of the Steering Committee for the development of the curriculum. This strengthened relationship will also result in other training modules that fall outside the scope of this grant, but, nonetheless, will improve dental health for many through this special and popular method of training.

Kentucky Philanthropy Initiative: The Kentucky Oral Health Program was involved in the time-limited task force that addressed health and education issues for the Initiative. The final product

of the Initiative was to assess and prioritize Kentucky's needs as an outreach to private foundations to become involved in improving the standards of living in our state.

Appalachian Regional Commission: This quasi-governmental agency serves the poorest areas of our country in fourteen states. Kentucky has more counties in the ARC than any other state, both in number and percentages. The ARC has begun to look at the health access issues of these areas and chose Kentucky as a state in which they provided funding to assure dentists training for those that serve the geographic areas as well as underwriting the development and sustainability of local coalitions that target local issues regarding oral health. Although not a precedent, funding of health services-related projects is an emerging focus of the Commission and the KOHP is honored to be their partner in their focus on oral health for the people they serve.

Kentucky Chapter of the American Academy of Pediatrics: The national organization, the American Academy of Pediatrics, has supported the provision of oral assessment and preventive services in the physicians' offices. Although a 'seed' grant has been exhausted, the KOHP works closely with the AAP to bring training to pediatricians and their staff—on site to their offices—in oral health development, disease and prevention services such as fluoride varnish application. The state's dental director has expanded the scope of training recipients to include family practitioners and internists as well.

Commission for Children with Special Health Care Needs: Since the last review of the Title V grant, the Department for Public Health's Oral Health Program and the Commission have collaborated on several ideas regarding improved oral health for their special patients. Increases in fluoride varnish application as well as sealant applications should increase due to this new partnership.

Department for Medicaid Services: Although considered a 'sister' agency, the Department for Medicaid and the Oral Health Program have strengthened their relationships while working toward better access to the Medicaid beneficiaries, adding proven dental therapies to the services panel and working with health departments in expanding the services to patients in their clinics.

Family Resource and Youth Services Centers: These school-based, health service-focused centers are a new partner for us in surveying the needs of the educators and school nurses and in the provision of dental information that they can forward to the families that they serve.

Child Fatality Review (CFR)

The Department for Public Health state CFR team is chaired by the CFR Program Coordinator in KDPH. This group is attended by coroners, representatives from LHDs, medical examiners, law enforcement, fire department personnel, DCBS, DBHDID; and various KDPH program staff. As interest arises in topics of concern to communities other professionals may attend. This team is required by statute. The goal is to arrive at potential preventive measures for child injury and death. There are many CFR teams around the state. Many community initiatives arise out of findings of these teams. CFR's goal is review every child death in the state, either at the local or state level. A new initiative this year is a Sudden Unexplained Infant Death (SUID) Committee formed from volunteering members of the CFR State Team. This work group will initially

research a prevention strategy regarding injury and deaths secondary to co-sleeping. Members include medical examiners, pediatricians, and injury prevention coordinators.

The State Coroner's Association and CFR work together in support of each other's practices, attending meetings, and sharing injury-and-death-related data and information. State and local police and sheriff office employees are common threads with both entities.

The KDPH CFR program has begun to focus on the subject of child maltreatment through increasing efforts with the Department for Child-Base Services (DCBS). Detailed Kentucky's 2011 MCH Block Grant application is found issues revealed with incongruent data collection related to child deaths and maltreatment. CFR and DCBS provided input for the 2011 Legislative session on the issue of abusive head trauma and have now begun to collectively discuss data and findings in order to develop databases that both groups can access. It is planned to have increased accuracy in reported findings and the development of awareness and prevention activities aimed specifically at child maltreatment in communities.

Women, Infants, and Children (WIC)

The WIC Program (Women, Infants, and Children) is federally funded and provides services in all 120 counties of the Commonwealth using 58 agencies and 151 sites. WIC is provided as part of the integrated services in each of the health sites. This allows WIC to act as a referral agent to well-child services, immunizations, prenatal services, social services and community services.

Currently, the Kentucky WIC Program issues the food benefits to WIC clients via checks or food instruments. In April 2006, Kentucky WIC was awarded a grant to develop, test and evaluate an integrated online Electronic Benefits Transfer (EBT) solution. This is a WIC EBT system that delivers WIC Program benefits via a magnetic strip card used with existing retail equipment in an online setting. The purpose of the project is to pilot test and evaluate the EBT systems developed and demonstrated with FNS funding that had not been previously integrated into retailer cash register systems or evaluated using the National Cost Model. The pilot program was conducted in western Kentucky, Barren and Warren Counties. The project then rolled out to the rest of the Barren River District and Allen and Monroe Counties which are part of the Barren River Region. This system is being developed as the national model for on-line integrated WIC EBT. Chains such as Walmart have integrated the Kentucky model into their cash register software. Upon further federal approval, rollout of the system is slated to begin in fall of 2010.

The WIC EBT project has required intense collaboration and partnership among multiple parties. EBT is a benefit to the WIC participant, grocer, local agency and state agency. For the participant it; De-stigmatizes shopping experience (a card is not as obvious as the numerous checks), provides flexibility to buy what is needed when needed and simplifies benefit accountability and tracking, eliminates losing checks. For the authorized grocer it; streamlines checkout process, is less burden on cashier by reducing error rate and requiring less training and results in automated reimbursement with overall cost reductions. For the WIC local agency it; enhances program integrity (i.e. takes enforcement out of hands of cashiers), tracks household benefit utilization; manage towards healthy choices and eliminates dealing with and printing checks. For the State Agency it; enhances food management / cost control capabilities,

results in improved detection and management of fraud and abuse and provides better information to assist in improved decision support.

The MCH needs assessment was disseminated to all WIC Coordinators, Nutrition Education Coordinators and Breastfeeding Coordinators in the 58 agencies. Additionally, all of the Coordinators were encouraged to attend the statewide forums, providing valuable input. The strength of the current needs assessment was the involvement of the both public and private entities. Therefore the community was assessed and not just public health.

The key stakeholders of WIC and their involvement are as follows:

1. MCH Programs, Chronic Disease Programs and WIC collaborate in regards to service delivery. Services in the local agencies are integrated; i.e. a person can receive WIC and family planning at the same visit. Additionally, each program has referral levels for referring clients to other services such as medical nutrition therapy.
2. The Program collaborates with Medicaid concerning payment of additional specialized formulas or more than one formula being provided to an infant. The WIC Program also receives the client names from Medicaid and outreaches to clients who could be eligible for the Program.
3. Local health departments, local health department sites and their employees who provide the benefits and direct services for the WIC Program.
4. Groceries and pharmacies that have contracts with the Program to provide proper nutritious foods. The Program approves applications, monitors, and provides technical assistance and training to grocers and drug stores.
5. Physicians' offices, hospitals and social programs that refer participants to or receive referrals from the WIC Program.
6. Physicians' offices, hospitals and social programs or who request training concerning nutrition or breastfeeding.
7. Office of Inspector General who provides expertise in compliance investigations of contracted WIC grocery stores as required by federal regulations.
8. Any citizen of the Commonwealth requesting information regarding nutrition or requesting statistical data concerning the WIC Program or data contained in the Center for Disease Control Pediatric Nutrition Surveillance System (PedNSS).
9. The Department of Education, Department of Agriculture, University of Kentucky Cooperative Extension Service, Department of Community Based Services and other entities that assist the Branch in carrying out its mission.

WIC Breastfeeding Initiatives

The WIC program leads the efforts to improve breastfeeding in Kentucky. Breastfeeding rates remain low compared to many other states. The two counties with the highest breastfeeding rates (Shelby and Fayette) have a high concentration of Hispanic participants. The lowest breastfeeding rates continue to be found in eastern Kentucky. The WIC Program determined the need for education of health professionals in these areas and a need to increase the number of

lactation consultants, and are working towards that end. Partners include birthing hospitals and health departments, most of which now have lactation consultants. Information was gathered on breast feeding at the MCH Community Forums in March-May 2009. From that, a group of stakeholders was convened to develop a state plan.

WIC Breastfeeding Peer Counselor Program continues to expand from original 4 pilot sites. The Program now encompasses 14 agencies and continues to expand. Eleven of the fourteen agencies are in eastern Kentucky. The program is funded through a grant from the federal Food and Nutrition Services (FNS) who has recognized this program as a best practice model. Due to its success, the WIC funding for this program has been increased as breastfeeding continues to receive increased emphasis. The Program can only expand where there are trained lactation consultants available to accept referrals from the Peer Counselors. In order to assist in this expansion, the WIC Program continues to assess training necessary to support the expansion.

In April 2010, a *Breastfeeding Summit*, at the preconference for the Kentucky Dietetics Association, was held for the purpose of developing a Breastfeeding State Plan. The Summit was attended by both public and private entities such as; physicians, staff from the university hospitals, physician offices, social service agencies; etc. The Peer Counselor Program and its proven track record of increasing breastfeeding rates were of interest to the attendees. Increasing the Program is one objective of the newly developed *Breastfeeding State Plan*. It will now be implemented through the state-wide *Breastfeeding coalition*.

The key stakeholders of the WIC Breastfeeding initiatives are as follows:

1. The population who receive the services of the WIC Program and the Breastfeeding Peer Counselor Program.
2. MCH Programs, Chronic Disease Programs and WIC including the Breastfeeding Peer Counselor Program collaborate in regards to service delivery. Pregnant and breastfeeding women are referred to the WIC Program which in turns refers appropriate women to the Breastfeeding Peer Counselor Program.
3. Local health departments and the health department's service sites and the employees and Peer Counselors who provide the benefits and services for the WIC Program and its participants.
4. Physicians' offices and hospitals that refer participants to the Program or receive referrals from the Program.
5. Physicians' offices and hospitals that request training concerning breastfeeding.
6. The Breastfeeding Coalitions throughout the state who assist the Branch in carrying out its mission for the Breastfeeding Peer Counselor Program. The Kentucky Breastfeeding Coalition, along with 9 local breastfeeding coalitions around the state, promotes breastfeeding in communities through mother to mother support groups and education in lactation counseling and management for public and private entities.

WIC Farmers' Market Nutrition Program (WIC FMNP)

The key stakeholders of WIC FMNP and their involvement are as follows:

1. The women and children population who receive the services of the WIC Program and WIC FMNP.
2. MCH Programs, Chronic Disease Programs and WIC including the WIC FMNP collaborate in regards to service delivery. Pregnant and breastfeeding women are referred to the WIC Program which in turns provides nutrition education on fresh fruits and vegetables to the clients.
3. Local health departments and the health department's service sites and the employees who provide the benefits and services for the WIC FMNP.
4. Farmers' Markets and farmers who have contracts with the Program to provide the fresh fruits and vegetables.
5. Kentucky Department of Agriculture provides monitoring and assists with training for the farmers.

As the popularity of the program grows, more requests for the program have come from local health departments and Farmers' Markets to be a part of the program. However, due to continual nationwide cuts in WIC FMNP funding; the Program cannot grow in participation or expand to additional counties.

2. b. Other HRSA Programs

While CCSHCN's main contacts in HRSA pertain to maternal and child health, relationships exist with several prevention and access-to-care programs under HRSA auspices. CCSHCN administrators and staff are often in contact with programs such as Kentucky Physicians Care (charitable health care provision), the Kentucky Pharmacy Assistance Program, rural health & underserved primary care centers, and are participants in responses to topical/emergent public health efforts (such as H1N1 vaccinations) as they occur. The Family to Family Health Information Centers are funded through HRSA and are a vital new aspect to infrastructure for CYSHCN in Kentucky, pairing parent mentors with families of CYSHCN.

Another program, funded for the tenth consecutive year by HRSA is an Early Hearing & Detection (EHDI) grant called Kentucky Infant Sound Start, which provides support to that surveillance system of early detection of permanent hearing loss by providing training, parent networking support and the replacement of equipment to meet the latest technology standards. Many of these children are referred to CCSHCN's clinical programs and are supported up to age 21.

Kentucky Newborn Hearing Screening (EDHI)

The Kentucky Early Hearing Detection and Intervention (EHDI) program consistently reports the screening of over 97% of Kentucky newborns with referrals for diagnostic screening given to all children reported to have a risk factor for hearing loss.

The Early Hearing Detection and Intervention (EHDI) program maintains many relationships in the administration of Kentucky's legislatively mandated newborn hearing screening program. In addition to the partnerships with the state's birthing hospitals, the program collaborates with the Commission on the Deaf and Hard of Hearing and Hands and Voices. Since 2006, a partnership with the Office of Information Technology (OIT) has allowed the program to receive newborn

hearing screening results electronically through the KY-CHILD database. Ongoing efforts at this time include work with OIT to expand online data transmission to include the ability of community audiologists and early interventionists to electronically transmit diagnostic assessment results and early intervention service notes to the EHDI program. Additional efforts are focused on working with Part C leaders to further implement Early Intervention services that more effectively meet the specific needs of newborns diagnosed with permanent hearing loss. In March 2009, Governor Beshear signed HB 5 which requires audiology diagnostic sites who wish to be included as approved centers for pediatric audiological testing agree to meet specific requirements, including best practice standards and reporting to the EHDI program.

In 2009, the EHDI program merged with CSHCN's Audiology Branch, after a period of preparation and training for the staff audiologists so they could support the hospital Universal Newborn Hearing Screening programs in their areas. As a part of this smaller community approach, the audiologists meeting with UNHS hospital staff will begin to assess the need for equipment upgrades. Additionally, the KY-CHILD expansion for audiology follow up has rapidly advanced with training of the trainers in August. CSHCN audiologists and EHDI staff have been trained to support audiologists in other settings throughout the Commonwealth of Kentucky. EHDI team presented a poster on pediatrician responses to a survey regarding their experience with children with hearing loss and their views on the follow up of infants who referred on newborn screening. Regulations for the new mandate, HB 5, were promulgated and then approved December 16, 2009 with full implementation January 1, 2010.

As a part of the State Plan developed at the EHDI National Conference, CSHCN EHDI began to work with the Commission for Deaf and Hard of Hearing and with Kentucky's Hands and Voices (family) organization to facilitate some of their goals including "Guide by Your Side". Supplemental grant funding provided means to support these two organizations so that a facilitator for Hands and Voices could be hired to organize families, fundraising and move forward with Guide by Your Side training.

Kentucky Office of Rural Health

The Kentucky Office of Rural Health (KORH) established in 1991 is a Federal/State partnership, authorized by Federal Legislation. The mission of the KORH is to support the health and well-being of Kentuckians by promoting access to rural health services. The program provides a framework for linking small rural communities with local state and federal resources while working toward long-term solutions to rural health issues. The KORH assists clinicians, administrators and consumers find ways to improve communications, finances and access to quality health care while insuring that funding agencies and policy makers are made aware of the needs of rural communities.

The core functions of the KORH are as follows:

- Collection and dissemination of information
- Coordination of rural health resources and activities statewide
- Provision of technical assistance
- Encourage recruitment and retention of health professionals in rural areas

- Participate in strengthening State, local and Federal partnerships

HIV / AIDS

The HIV / AIDS Branch within the Division of Epidemiology and Health Planning assesses the current and future impact of HIV in Kentucky and provides HIV prevention education to those at risk for infection and to licensed professionals providing interventions. The branch also provides services to persons with HIV infection or advanced HIV disease. The Prenatal Program consults with the HIV / AIDS Branch to determine steps taken in LHDs for counseling women prenatally on identification of risk factors and ways to reduce their risks. Collaboration of knowledge from both branches has resulted in systematic development of guidelines used by nurses in LHDs in screenings, reporting, and treating prenatal patients.

2. c. Other Programs within the Kentucky Department for Public Health

As mentioned in the two previous sections, CCSHCN considers KDPH a key partner. To that end, CCSHCN will continue their close partnership with KDPH to coordinate efforts, supporting the missions of both groups. Local health departments are resources embedded in local communities throughout Kentucky, and some CCSHCN staff are co-located with health departments. Coordinated and informal efforts are robust in the realms of prevention, quality improvement, and protection & safety. For example:

- CCSHCN interfaces closely with First Steps (Kentucky's early intervention program) through referrals and follow-up to close the information gap between the agencies;
- CCSHCN and KDPH are in process on developing memoranda of agreement in relation to the following collaborations:
 - CCSHCN being the preferred audiological assessment provider for First Steps;
 - Meeting the needs and reducing costs of interpreters for both agencies;
 - Exchanging data and information regarding EHDI referrals and follow-up;
- CCSHCN is working to educate its staff on broad-based initiatives and performance measures previously considered KDPH specific. Additionally, CCSHCN has requested that field staff provide feedback about their accomplishments in these areas for reporting;
- CCSHCN is affiliated with KY Outreach and Information Network (KOIN), a collaborative grassroots network of volunteers who assist KDPH in disseminating information regarding emergency situations to people who are hard to reach (e.g. families of CYSHCN; families with hearing or vision impairments; families with limited English proficiency ; families living in remote areas, etc.); and
- CCSHCN naturally supports, through daily operations, larger KDPH goals within the CYSHCN population (e.g. counseling children with regard to teen pregnancy as part of the care coordination, transitions and life skill building process).

Childhood Obesity

Much activity has taken place regarding childhood obesity. Kentucky began their efforts to combat obesity in 2004 with a series of state-wide community forums, long before First Lady

Obama's call to action on the subject. Obesity was highlighted as one of the topics that were discussed in all of the eleven community forums conducted by KDPH in 2009.

Several MCH programs have been, and continue to address obesity as it relates to a specific population. Initiatives of the Kentucky WIC programs are mentioned in this document. Programs addressing the prevention of obesity in our youth are included in the HANDS Home Visiting Program whose curriculum covers nutrition, infant feeding practices, physical activity, and decreasing television and computer time. Turn off the TV and Family Meals initiatives are promoted through Partnership for a Fit Kentucky regional coalitions. Consultation and training is provided to child care directors statewide through Child Care Health Consultants.

Although proposed legislation for mandatory physical activity in Kentucky schools did not pass in 2010, more initiatives are underway in the form of professional development for school staff and in agencies that work with schools regularly to increase capacity of schools, districts and communities to promote and support healthy behavior and choices in school-aged youth. Numerous pilot projects have begun through Coordinated School Health, notably Students Taking Charge in which 19 high schools will be guiding student groups to develop their own action plan related to the physical action and nutrition environment in their schools.

Professional groups have engaged in the fight. The Kentucky Medical Association, particularly the Committee on Rural Health, has partnered with KDPH on raising awareness of obesity and the physician's role in combating the epidemic. The Kentucky Chapter of the AAP has been actively involved in obesity efforts. They recently received a grant from Robert Wood Johnson thru NICHQ to provide Advocacy trainings for health care providers to promote policy and community changes for obesity prevention. In addition, they have developed an office toolkit for obesity prevention. Pediatric Departments at both University of Kentucky and University of Louisville have developed multidisciplinary clinics to address pediatric obesity and provide a referral resource for practicing pediatricians dealing with morbidly obese children.

Chronic Disease Prevention / Disease Management

The Chronic Disease Prevention Branch programs including Diabetes, Heart Disease and Stroke, Asthma, COPD, Arthritis, Preventive Health and Health Services Block Grant and Comprehensive Cancer support a network of partners that includes Local and District Health Departments across Kentucky, private organizations and statewide partnerships. These partnerships include the Kentucky Diabetes Network, the Kentucky Asthma Partnership, the Kentucky Cancer Consortium and the Kentucky Heart Disease and Stroke Taskforce. Through a coordinated effort and collaboration of partners, the programs within the Chronic Disease Prevention Branch are building multi-level programs to address the burden of chronic disease in Kentucky.

For the past two years the CDPB programs have held joint Integration meetings with the Health Promotion Branch which includes Tobacco, BRFS, and Physical Activity and Nutrition Programs. One particular collaborative effort serves as an example of how the mission is being accomplished with joint funding and staff resources. The Healthy Communities Initiative was started in 2009 with a focus on environment and policy change. Obesity, smoking and lack of physical activity are implicated in the high burden of chronic disease in Kentucky and efforts to control and prevent take a team effort. When programs have worked in silos due to categorical

funding much momentum has been lost. The CDPB and HPB branches are working to resolve that issue and have collaborated on four projects in the past year.

Additionally, the Diabetes Program has taken on a contractual service with the Department of Medicaid to provide Disease Management to their clients. This is done at the local level rather than from a state office and has worked extremely well to increase appropriate education, referrals and to assist people in finding resources in their own communities for healthy eating, diabetes education and smoking cessation. All referrals to the Tobacco Quitline are also tracked for intervention by Disease Managers.

The Heart Disease and Stroke Program has formed particularly strong networks regionally across the state with a focus on quality of care of those people with hypertension, high cholesterol and those with symptoms suggesting heart disease or stroke. They are also developing a care collaborative which began with working with women in Northern KY and is now expanding statewide.

The Asthma program has developed a strong coalition in the state with a focus on increasing the use of evidence based tools for those with Asthma with a particular focus on children. The Asthma Educators Institute is held at least twice annually to increase the number of those certified which will improve the quality of care of these patients. Also, local coalitions and support groups are naturally formed by those who have been trained.

The CDP branch has also implemented training on “Unnatural Causes” with UK medical school, Eastern KY University School of Health Administration, extension services and local health departments which focuses on health equity and social determinants of health. By providing this unique training tool to communities risk factors will be addressed in terms of culture and place rather than simple behavior choices.

Barriers continue to be funding distress due to budget cuts and continued reliance on categorical funding with very specific objectives for some programs. These programs continue to collaborate on grant and program objectives as appropriate as well as getting those in community to look at upstream causes.

Office of Health Equity

The Kentucky Office of Health Equity (OHE) was established in September 2008; prior to this, Kentucky was the only state in Region IV without an Office of Minority Health. Establishing this office in the Kentucky Department for Public Health (KDPH) was a priority for the current Commissioner, Dr. Bill Hacker. The OHE receives funding from the U.S. Department of Health and Human Services (US DHHS), Office of Minority Health (OMH). The goals of this office are to identify and establish collaborations to enhance health equity across the state of Kentucky, analyze data specific to health inequities across the state, develop strategies to address health inequities and improve health, and implement a project to eliminate infant mortality inequities.

Accomplishments of KY OHE include participation in meetings and conferences to strengthen prevention in relation to minority health. Relationships with governmental and non-governmental organizations include the Centers for Disease Control, the Foundation for a Healthy Kentucky, the Center for Health Equity, the Kentucky Department for Public Health, the Lexington-Fayette County Health Equity Interest Group, Saint Joseph Health Care and Hospital System, KET

(Kentucky Public Television System), University of Kentucky Hospital, University of Kentucky Office of Multicultural Affairs, Kentucky Office of Quality Improvement and Prevention, Kentucky Governor's Office of Minority Empowerment, and the Kentucky Health Department Director's Association. Other memberships and collaborations include a position on the HIV Prevention Advisory Board, Kentucky Office of Infectious Disease and membership in the KDPH Leadership Executive Council to create a Public Health Manager Model. The Director of KY OHE, in collaboration with the Division of Quality Improvement and Prevention of the KDPH, began an "Unnatural Causes" continuing education training series to inform and educate county health departments across the state of KY. The series was held February 2009 through October 2009.

2. d. Other Governmental Agencies

Both KDPH and CSHCN are connected and involved with outside organizations that are resources to our families and, for CSHCN, serve to make CSHCN known to the agency. CSHCN's own governing board is representative of the community and includes coordinators of such programs as early intervention, the Kentucky Deaf-Blind Project, and a program addressing the needs of the disabled with regard to sexual assault. KDPH committees and leadership are also integrated with members representing stakeholders and community. The active partnerships that both groups maintain with the following agencies are briefly detailed below.

The Department for Medicaid Services (DMS)

DMS has a long history of collaboration with KDPH through several interagency agreements renewed annually to allow preventive health services, early intervention services for infants and toddlers, home visiting services, presumptive eligibility for pregnant women, KCHIP eligibility, and KenPac primary and preventive care case management.

Through an agreement with KDPH, and DMS, the Department for Community Based Services (DCBS) determines eligibility for KCHIP children and provides case management and rehabilitative services for Medicaid children in custody or at risk of being in state custody.

CSHCN's cooperative relationship with the Department for Medicaid Services is unique and significant and includes:

- Receipt of approximately 40% of CSHCN total funding from DMS through cost-based reimbursement for direct services provided in a clinic environment, targeted case management, outpatient therapies and audiological testing;
- Fee-for-service reimbursement from Passport, the Medicaid managed care organization in the Louisville area and surrounding 15 counties;
- Subcontracting of case management by CSHCN for Passport and serving on their advisory board; and
- Serving as a provider for Early Periodic Screening, Diagnosis, and Treatment (EPSDT).

The Kentucky Department of Education (KDE)

KDE collaborates with KDPH through several programs. First Steps has a Memorandum of Understanding with KDE to work with communities to ensure transition and services for

Kentucky's early childhood population into the school setting. Through the Coordinated School Health Infrastructure grant, KDE partners with KDPH to develop, implement, and evaluate the Coordinated School Health (CSH) program which consists of an eight-component model including health education, physical education, health services, nutrition services, counseling / psychological services / social services, health school environment, and health promotion for staff and family / community involvement. The entire KIDS NOW early childhood initiative is administered at KDE, and there are both statutes and reports that reinforce this cross-agency collaboration. By law, KDPH funds a position at KDE to oversee school health nursing, and KDPH has a school nurse consultant that works collaboratively with the KDE nurse on guidance and trainings for school health nurses across the state.

Examples of areas in which CSHCN interfaces with primary and secondary schools are:

- Participation by CSHCN staff in Individualized Education Plans (IEPs) for CYSHCN;
- Provision of audiological assessment and screening for schoolchildren, including testing without cost to indigent families;
- Follow-up evaluations for other screenings required by law for schoolchildren;
- Audiological technical assistance and support to schools for FM systems;
- Provision of summertime Speech-Language services to CYSHCN receiving in-school SLP; and
- Support of a vision program that ensures schoolchildren receive their first vision screening at no cost to the family.

Kentucky Department for Behavioral Health, Developmental and Intellectual Disabilities (DBHDID)

DBHDID provides leadership, in partnership with others, to prevent disability, build resilience in individuals and their communities, and facilitate recovery for people whose lives have been affected by mental illness, intellectual disability or other developmental disability, or substance abuse.

A number of collaborative efforts address substance abuse in maternal and child health populations:

- The prenatal program within the local health departments are to assess every pregnant woman about their use of alcohol, tobacco, secondhand smoke exposure, and other drug use at each health department visit and provide education and referrals as appropriate.
- Division of Mental Health and Substance Abuse has resulted in the initiation of a statewide, inter-departmental "Substance Exposed Infants (SEI) Workgroup". The workgroup is an inter-agency initiative with members from the following: the Department for Public Health, Administrative Offices of the Court, Department for Community Based Services, Early Childhood Development, Early Head Start, and University of Kentucky and University of Louisville faculty and researchers.
- KIDS NOW Plus: This is a program to reduce alcohol, tobacco and other drug (ATOD) use during pregnancy. This program is funded in eight (8) of the Kentucky community

mental health regions. It provides both prevention education to pregnant women on harm to the fetus from ATOD use as well as early identification and case management services to help link higher risk women with needed substance abuse, mental health and domestic violence services. Health departments and private obstetricians assist by screening and referring pregnant women to the program.

- START: This is a child protective services (CPS) initiative in four (4) Kentucky sites that applies research on substance abuse, trauma, poverty, gender specific interventions for women and family preservation to an innovative service model for addicted parents who abuse and neglect their children. CPS workers team with Family Mentors (recovering addicts) to motivate and support parents through treatment, recovery, and sober parenting. To be effective, START requires rapid, intensive, and coordinated treatment for families and professionals striving to challenge myths and enhance flexibility in service delivery.
- DBHDID provides a match for the Medicaid benefit that covers some substance abuse services for Medicaid-eligible pregnant and postpartum women.
- DBHDID and the Community Mental Health Centers (CMHCs) in eight regions through the KIDS NOW Plus program, provide pregnant patients with education on the harmful effects of alcohol, tobacco, and other drugs on the fetus. Many of these local health departments also use the KIDS NOW Plus screening tool and refer at-risk pregnant patients to KIDS NOW Plus for further prevention education, intensive case management, and/or mental health and substance abuse treatment services. Regional CMHCs also collaborate locally with FRYSCS, pregnancy crisis centers, Probation and Parole, Drug Courts, etc. providing substance abuse prevention classes to pregnant women and girls, and case management to those with risk factors for substance abuse.
- DBHDID offers trainings in Brief Intervention for local health departments. Motivational Interviewing has been provided to KDPH's case managers working smoking cessation.
- KY Coalition for Women's Substance Abuse Services: provides up to date information to a listserv and co-sponsors 2-3 trainings per year.

Staff from the Department for Public Health, Division of Maternal and Child Health, and DBHDID meets regularly as they share oversight of the state's Early Childhood Mental Health Initiative and the designated Early Childhood Mental Health Specialists (KDPH funded positions). KDBHDID also has a 6-year, \$9 million federal grant, *Kentucky's System to Enhance Early Development* (KYSEED), which focuses on development of state and local infrastructure and on enhancing the existing service delivery system to better meet the social, emotional and behavioral needs of children ages 0-5 years. The KDPH is a strong partner on the implementation team. The Departments also share aggregated data in various ways, including the sharing of hospital data previously unavailable to mental health. Department for Public Health representatives serve on several Mental Health advisory councils to ensure integrated service delivery.

DBHDID provides consultants to the Early Childhood Mental Health Program in regional mental health centers and childcare centers. DBHDID also provides consultative and direct care

intervention mental health services for childbirth to five years of age. These staff are also trained to deal with referrals for Perinatal Depression, from the HANDS program and other sources. Members of this agency serve on the MCH Child Fatality Review Team; likewise MCH staff serves on DBHDIDS's Suicide Prevention Advisory Group.

Child Welfare

Staff from the Department for Community Based Services (DCBS) and staff from the DBHDID serve on several of each other's formal Councils and workgroups, and KDBHDID staff serve those of DCBS and Public Health as well so the opportunities for data sharing and collaborative planning become easier in working towards common goals. Most recently, there has been interest in collaboratively planning some training opportunities as well as some discussion about using similar assessment and outcomes measurement tools.

Through partnership with the DCBS CSHCN provides support to child welfare clients, caseworkers and foster parents in the following ways:

- Monthly nurse home visits to medically fragile children in foster care for condition-specific education and support;
- Placement of dedicated nurse consultants in regional child welfare offices across the state for consultation on medical needs of children in or at-risk of foster care placement; and
- Coordination of a medical home clinic for children involved with the child welfare system – filling a gap with regard to access to primary care in one regional area.

The State Interagency Council for Services to Children with an Emotional Disability (SIAC) is a group of representatives, from the primary child-serving agencies, and a parent of a child with an emotional disability, who maintain and oversee a framework of collaborative services for children with emotional disabilities. The hallmark program of this framework is Kentucky IMPACT, but other programs and initiatives may also fall under their auspices. There are eighteen Regional Interagency Councils among the fourteen Regional Board service areas and these Councils work under the umbrella of the SIAC. The table below illustrates the composition of the SIAC and RIACs. Some RIACs also have developed Local Interagency Councils (LIACs) at the county level to mirror the composition of the SIAC and RIACs, but to enhance the ability to develop resources at the local level and to problem solve when systemic issues may arise. The Chair of SIAC rotates each year but the Chair for RIACs is legislatively mandated as the DCBS (child welfare) representative. (*The current SIAC Chair is Dr. Hacker, Commissioner of KDPH*)

DBHDID also works with the KDPH in developing a program for teaching non-medical personnel how to administer medication more effectively and efficiently. This education is provided through TrainingFinder Real-time Affiliate Integrated Network (TRAIN). Additionally, DBHDID assists KDPH and the local Health Departments, to formulate Disaster Preparedness Plans in order to ensure the behavioral health of citizens is addressed when a disaster or critical incident occurs in KY. Kentucky Outreach and Information Network (KOIN), through the Cabinet for Health and Family Services, is working to build a person-to-person network that can reach special needs and hard-to-reach populations with preparedness and crisis information through trusted people, agencies and local communities during a public health emergency.

Kentucky Transportation Cabinet (KYTC)

Departments within KYTC partner with entities that interface with public health programs. The Department of Highways provides data and information to the state police, who in turn, provide volumes of data useful to the Child Fatality Review program in determining causes of death and prevention planning related to motor vehicle accidents, safety seats, and all terrain vehicles.

Within the Department of Rural and Municipal Aid, the Safe Routes to School is a program resulting from the enactment of the Safe, Accountable, Flexible, Efficient transportation Equity Act: A Legacy for Users, part of the infrastructure to enable and encourage children, especially those with disabilities to walk and bicycle to school. The program strives to make walking and bicycling safe and more appealing. They facilitate the planning, development, and implementation of projects that will improve safety and reduce traffic, fuel consumption, and air pollution in the vicinity of schools. This program partners with Partnership for a Fit Kentucky in addressing the child obesity issue in the state.

2. e. Other State and Local Public and Private Organizations

Kentucky has taken a very broad look the problems facing families in our communities. By gaining further information about local initiatives, KDPH has been able to partner with more local and private organizations to extend services for the maternal and child populations.

Some of MCH's most important partnerships have been formed with major universities and their medical expertise in not only training but in clinical services. The KDPH contracts with the University of Louisville (UL) for multi-disciplinary neuro-developmental screening assessments for high-risk and premature infants in Louisville hospitals and clinics in Western Kentucky. MCH relies upon UL for medical consultation for newborn screening and for training pediatric assessment for the Well Child program. UL also is developing and will be providing teaching curriculums to train general dentists in effective pediatric technique in order to expand the availability of pediatric dentistry to areas of need.

The University of Kentucky provides trainings for mental health specialists, for child development used by early intervention specialists, and for pediatric assessments for MCH's Well Child program. UK also provides technical assistance and data for multiple MCH programs such as Child Fatality Review and Injury Prevention. The university provides preventive and treatment programs for newborn and children services associated with Reach Out and Read, Young Parents Program, developmental evaluations for children at clinic sites in Western Kentucky, genetic services and consultations. The UK College of Public Health partners with MCH to provide a UK Graduate Certificate in MCH for current public health professionals who are working in or interested in furthering their knowledge of MCH. During 2009 UK's College of Public Health was awarded a HRSA MCH training grant to develop and implement a Graduate Certificate in MCH Epidemiology.

CYSHCN also works closely with state universities who provide expertise for the agency and vice versa including:

- Staffing the Medical Home for Coordinated Pediatrics (primary care clinic for children in foster care);
- Subcontracting to operate the University of Kentucky (UK) and University of Louisville (U of L) Hemophilia Treatment Centers;
- Specialty providers who have become active with CSHCN due to their affiliations with Kentucky's teaching hospitals;
- Provision of educational opportunities at CSHCN for medical residents and internships/externships for a variety of pre-professional programs (audiology, nursing, OT, PT, SLP, social work, etc.);
- Collaborating to ensure the availability and continuity of services not available elsewhere (e.g. when U of L disbanded their cochlear implant clinic, services were folded into CSHCN); and
- Collaborating to provide itinerant pediatric clinics in rural and underserved communities.

There are many organizations throughout Kentucky that are of particular interest to MCH that provide education and outreach to consumers.

The *Kentucky Folic Acid Partnership* has been working to improve perinatal health since 1998. Although nearly every state in the United States had implemented a Folic Acid Coalition at that time, after 10 years Kentucky is one of the few states who have managed to keep their partnership intact and healthy. During this time, the mission of the KFAP has expanded to include additional perinatal health issues, such as prematurity prevention. Folic Acid use remains a top priority of the partnership because it not only prevents neural tube defects it is also linked to decreasing the risk to mothers of miscarriage, stillbirth, and preterm births. Fitting these two priorities together as one focal point has helped us reach larger populations of women with the evidence-based facts that improve outcomes for the mothers and babies in Kentucky. One of the many accomplishments of the KFAP includes participation in the planning, development, and implementation of the *Healthy Babies Are Worth The Wait Community Toolkit*, which may become a national model for prematurity prevention initiatives in local communities. A part time State Folic Acid Campaign Coordinator ensures that the folic acid education and awareness campaign is implemented for Kentucky. The Division of Maternal and Child Health of the Kentucky Department for Public Health and the March of Dimes provide major support for the partnership. The Partnership utilizes three approaches for increasing folic acid awareness. The three approaches are community action, mass media, and health professional education. There are three committees to address the approaches. Each committee develops plans and assures that planned activities are completed. Each Partnership member joins at least one committee. Members of the Partnership are asked to provide in-kind education and awareness activities that will result in behavior change.

KDPH contracts with the *Norton Poison Control Center*, a nationally certified center that provides 24 hour a day service to the general public. Licensed nurses trained in clinical toxicology and board-certified physician toxicologists are on hand to provide immediate information on emergency care and treatment, hazardous materials, and locations of unusual antidotes. Education is available for parents, children and communities. Through this contractual agreement Norton Health Care provides KDPH with reports on poisoning data and serves the state as the primary resource in the event of a chemical terrorist event.

Prevent Child Abuse Kentucky provides education and information that is shared by CFR, DCBS, HANDS, First Steps, law enforcement agencies, schools, day cares, and most agencies throughout the state that deal with children.

Professional organizations are well represented in Kentucky. The *Kentucky Primary Care Association* was founded in 1975 as a private, non-profit corporation of community health centers, rural health clinics, primary care centers and other organizations and individuals concerned about access to health care services for the state's underserved rural and urban populations. Health Centers operating in Kentucky receive funding to offset the cost for providing care to low income uninsured patients.

The *Kentucky Perinatal Association (KPA)* is a non-profit incorporated volunteer association of health care providers, consumers, and organizations with a common purpose toward the recognition of maternal-infant health care issues dedicated to the provision of comprehensive solutions through educational outreach and advocacy. The KPA is comprised of a broad range of health care professionals. Board members meet quarterly, volunteering their time after full work schedules to understand and further the cause of perinatal health issues for mothers and their infants. This representation assists, among other state leaders, the Director of Maternal Child Health for the state, in keeping perinatal health care problems and solutions in focus.

The *Kentucky Chapter of American Academy of Pediatrics* is an active organization promoting the health of Kentucky's children. The mission of the Kentucky Chapter of the American Academy of Pediatrics (KY Pediatric Society) is to improve the health and welfare of all infants, children and adolescents of the Commonwealth. In addition, the KY Chapter of the AAP works on behalf of pediatricians and subspecialists, both those in practice and those in training, to ensure professional development and to facilitate the delivery of quality medical care to the children in the Commonwealth. The Chapter works closely with KDPH on initiatives that include childhood obesity, injury prevention, smoking cessation in pediatric practices, and strategic planning.

The *Kentucky Chapter of ACOG (American Congress of Obstetricians and Gynecologists)* has partnered with KDPH several initiatives such as "Healthy Babies are Worth the Wait", prematurity issues, and smoking cessation in pregnancy. Dr. Connie White, Director of Women's Health is currently the president of Kentucky ACOG.

Kentucky Medical Association in recent years has become very active in public health issues. They have promoted tobacco-free hospitals, and more recently tobacco free schools; they have dedicated entire issues of their journal to obesity prevention, child abuse, and domestic violence. They have working committees on diabetes, obesity prevention, tobacco, radon, perinatal care, and other public health topics. The Kentucky Medical Association hosts the Maternal Mortality Review Committee on behalf of the Department for Public Health and reviews all deaths of women who have had a pregnancy within 12 months of the death. Last year their entire annual meeting was devoted to disaster preparedness, and each specialty group hosted speakers on how disasters might affect their practices and patients.

Kentucky Chapter Kentucky Board of Nursing (KBN) - The KBN has contributed much over the past year to the education of nurses throughout the state. School Health, within KDPH, and the Kentucky Department of Education, partner to provide trainings to nurses on scope of practice

and medication administration in the school setting. Because of these partnerships, medication training follows current nursing practices and allows for the safe administration of medications to a vulnerable population. Also, KBN partnered with KDE and KDPH in the school nurse orientation as related to the nurse's scope of practice.

Finally, in addition to involvement on a case level, several CSHCN staff are active on boards and councils (such as Kentucky Council on Developmental Disabilities, Center for Accessible Living, Kentucky Speech-Language & Hearing Association, Regional Interagency Transition Teams, Dare to Care Food Bank, Kentucky Special Parent Involvement Network, State Interagency Coordinating Council for First Steps, Kentucky Interagency Transition Council for Persons with Disabilities, State Interagency Council for Youths with Severe Emotional Disorders, and condition-specific groups such as Kentucky Hemophilia Advisory or Spina Bifida Association of Kentucky) that further the agency's mission. A particularly visible collaboration includes the Home of the Innocents (HOTI), a private child caring facility; CSHCN and HOTI share a Medical Director, and Louisville CSHCN therapy staffs (PT, OT, and SLP) are housed at the private child caring facility and have access to state-of-the-art equipment.

As a state agency with an 85 year history of service provision, CSHCN has developed formal and working relationships with a variety of programs providing services to children. These are far too numerous to list here. CSHCN's contracted network of direct providers for clients numbers almost 1000. CSHCN strives to remain connected and relevant by remaining involved with outside organizations that are resources to families of CSHCN.

2. f. Stakeholder involvement

Because KDPH stakeholder involvement is described in minute detail within Section 1, the information will not be repeated in this portion of the document. KDPH feels that the needs of Kentucky's MCH population were captured throughout the many surveys and meetings which occurred over the past two years. Of particular relevance to this process was the patient survey portion of the MCH Needs Assessment. As noted by Dr. Shepherd noted "*...our consumers were right on target with current MCH issues and needs in the Commonwealth*".

CSHCN embraces as a guiding value the vital role families play as primary decision makers in ensuring the health and well-being of their children. Through mutually beneficial partnerships among patients, families and providers, they assist CSHCN in meeting best practice standards for stakeholder involvement. CSHCN's stakeholder advisory groups of youths and parents were formally consulted through focus groups (3/09 and 4/09 respectively; formal report attached for 3/09) in the prioritization of needs, as were Parents as Partners (3/09). The KDPH stakeholders meeting was attended by consumers, family advocates, and providers alike and they assisted in the distillation of data obtained from a diverse group of citizens. The data from these sessions strongly influenced subsequent efforts of the Needs Assessment leadership team (which included a parent representative) and had a direct impact on the establishing of priorities and State Performance Measures that were ultimately selected.

Section 3: Strengths and Needs of the MCH Population Groups and Desired Health Outcomes

Kentucky Department for Public Health

In September and October of 2009 members of the Kentucky Needs Assessment Leadership team developed MCH Fact Sheets examining each major health topic raised through the Needs Assessment process. Each fact sheet addresses 1) the problem as it exists in Kentucky today (including seriousness and impact [clinical, economic and disparities]), 2) capacity and current resources, 3) evidence-based interventions, and 4) recommendations. A brief summary of these fact sheets will now be presented, examining both strengths and needs of Kentucky's MCH population. Topics will be divided into three categories: Pregnant Women, Mothers and Infants; Children and Adolescents; Cross-Cutting Issues. MCH Fact Sheets are available on the KDPH website at <http://chfs.ky.gov/dph/mch/>.

3. a. Pregnant Women, Mothers and Infants

Breastfeeding

Introduction: Breastfeeding is one of the most beneficial health interventions for any child. It also has beneficial health effects for mothers. Breastfeeding rates are generally measured at three points – initiation of any breast feeding at the hospital after delivery, breast feeding at 6 months, and breast feeding till the infant is one year of age. Kentucky is behind the national average in all three measures.

The Problem: Current breastfeeding initiation rates are low in Kentucky (53.6% in 2007) and much lower than the National average (60.1% in 2007). The National Healthy People 2010 goal is to increase the initiation of breastfeeding in the early postpartum period to 75% of newborns and to improve breastfeeding rates to 50% of infants at age 6 months and 25% at 1 year. In order for Kentucky to achieve this goal, drastic improvements in both breastfeeding initiation and duration will need to take place. According to the 2007 Pediatric Nutrition Surveillance Survey, only 8.6% of Kentucky infants are breastfed at 6 months of age compared to 25.2% for the U.S., with even fewer reported for 1 year of age (5.0% vs. 18.1%).

Disparities exist among various maternal characteristics for women initiating breastfeeding. In Kentucky, White women are more like to initiate breastfeeding compared to Black women (52.5% vs. 38.3%) and women of older maternal age (30 and above) are more likely to breastfeed than women of younger maternal age. Also, disparities exist between married and unmarried women with married women being more likely to breastfeed than unmarried women (60.8% vs. 37.5%), and those women with greater than high school education initiate breastfeeding more than women with less than a high school education (67.3% vs. 34.8%). In addition, insurance status reflects disparities in breastfeeding with only 35.7% of women on Medicaid breastfeeding compared to 68.2% of those with private insurance and 72.7% of those who were self-pay. Likewise, women participating in WIC had lower breastfeeding rates than those women not participating in WIC (38.3% vs. 66.0%) another reflection of income

disparities. In addition, those women living in urban environments were more likely to initiate breastfeeding than those living in semi-rural or rural environments.

Linking Quantitative and Qualitative Data: Breastfeeding was ranked among the top 10 priorities for Kentucky by both the *web-based provider survey* and *community forums*. Needs identified associated with improved breastfeeding rates included increasing provider education, improved workplace environment for nursing mothers, and the expansion of supplies such as pumps, breast milk storage containers and bottle liners for expressed milk to all lactating women.

Current Title V Measures:

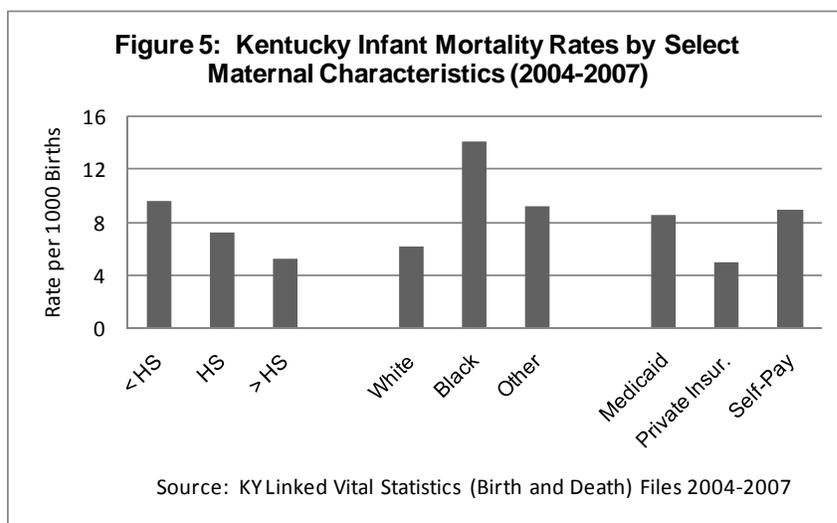
- NPM #11: The percent of mothers who breastfeed their infants at 6 months of age.

Infant Mortality

Introduction: Improving the health of mothers and infants is both a national and state priority. Infant mortality is an important indicator of the health of a nation, as it is associated with a variety of factors such as maternal health, quality and access to medical care, socioeconomic conditions, and public health practices².

The Problem: The Healthy People 2010 target goal for the U.S. infant mortality rate is 4.5 infant deaths per 1,000 live births³. The current U.S. rate (6.7 deaths/1,000 live births in 2006) is about 50% higher than the goal. The Healthy Kentuckian (HK) 2010 goal is to reduce infant mortality in Kentucky to 6 infant deaths per 1000 live births⁴. Kentucky has

over 55,000 births annually with an estimated 861,910 women of childbearing age (15-44 years old) in the state⁵. In the last twenty years, the infant mortality rate in Kentucky has fallen dramatically and has been running very close or lower to the national average since 2000. Each year nearly 400 infants die before their first birthday. The three leading causes of infant



² G K Singh and S M Yu. Infant mortality in the United States: trends, differentials, and projections, 1950 through 2010. *Am J Public Health*. 1995. 85(7): 957.

³ U.S. Department of Health and Human Services. *Healthy People 2010*, 2nd ed. With Understanding and Improving Health and Objectives for Improving Health, 2 vols. Washington, DC: U.S. Government Printing Office, November 2000.

⁴ *Healthy Kentuckian 2010. Mid-Decade Review*. Kentucky Cabinet for Health and Family Services, Department for Public Health. Chapter 12 Maternal, Infant and Child Health, pg 187.

⁵ Kentucky State Data Center: <http://ksdc.louisville.edu/>

mortality in Kentucky are prematurity, congenital anomalies and sudden unexpected infant deaths (SUID).

Kentucky has one of the highest rates of preterm birth in the nation, up to 15.2% in 2007. Even those infants who are just a few weeks early, now called “late preterm” infants, are three times more likely to die in the first year of life than full term infants⁶. Late preterm infants now comprise 72% of all premature births in Kentucky and in the nation⁷.

According to Kentucky Vital Statistics data for 2003-2007, African Americans experienced an infant mortality rate of 13.4 per 1,000 live births in comparison to whites which had a rate of 6.3 per 1,000. The gap has widened since 1995-1999. There are also geographic disparities. Rural regions in Kentucky had the highest infant mortality rate (7.3 infant deaths per 1000 live births) as compared to urban (6.7 infant deaths per 1000 births) and semi-rural (6.1 infant deaths per 1000 births) population.

MacDorman and Atkinson⁸ found that infant mortality rates were highest for teenagers and for women in their 40's and lowest for women in their 20's and early 30's. The infant mortality rate was nearly twice as high for unmarried women as for married women. In general, infant mortality declined with increasing education of the mother. Mothers who had not completed high school had infant mortality rates which were twice that of women with a college education. There was a more than two-fold difference in infant mortality rates by race and ethnicity with African American mothers having the highest rate. This information was confirmed in an analysis of Kentucky's linked birth and death certificate data from 2004-2007.

More information about infant deaths including congenital anomalies and leading causes of death can be found in the *2009 Annual Report of the Kentucky Child Fatality Review System* at <http://chfs.ky.gov/dph/mch/cfhi/childfatality.htm>

Linking Qualitative and Quantitative Data: The problem of infant mortality was not among the top ranked priority needs for Kentucky based upon the results of the three survey tools. Surprisingly, it was not even noted in Louisville's community forum; the community exhibiting the greatest gap in mortality between African American and White births. However, preterm birth and low birthweight were often mentioned and both were included in the local health department patient survey, tied as the #5 issue for infants and children. Preterm birth and low birthweight were ranked as #8 under the broad category of “MCH General” by Kentucky community forum participants.

Current Title V Measures:

- *NHOM #01:* The infant mortality rate per 1,000 live births
- *NHOM #02:* The ratio of the black infant mortality rate to the white infant mortality rate

⁶ Tomashek, KM, Shapiro-Mendoza, K, Davidoff, MJ, and Petrini, JR. Differences in mortality Between Late-Preterm and Term Singleton Infants in the United States, 1995 to 2002. *J Pediatr.* 2007.

⁷ Jain, L. Morbidity and Mortality in Late-Preterm Infants: More Than Just Transient Tachypnea! *J Pediatrics.* 2007. 151(5):445.

⁸ MacDorman MF, Atkinson JO. Infant mortality statistics from the 1996 period linked birth/infant death data set. Monthly vital statistics report; vol 46 no 12, supp. Hyattsville, Maryland: National Center for Health Statistics. 1998.

- *NHOM #03*: The neonatal mortality rate per 1,000 live births
- *NHOM #04*: The postneonatal mortality rate per 1,000 live births
- *NHOM #05*: The perinatal mortality rate per 1,000 live births plus fetal deaths

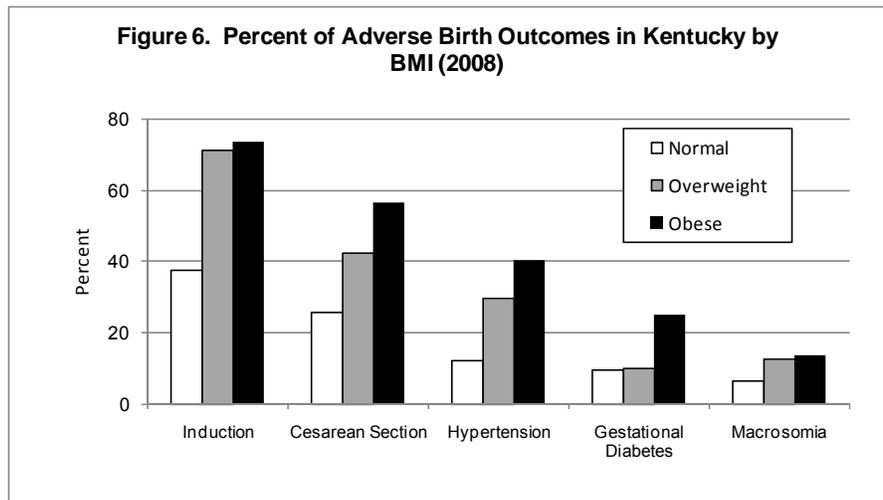
Related Measures

- *NPM#17*: Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates
- *NPM #18*: Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester
- *(2005-2010) SPM #04*: Reduce the percentage of live births that are preterm

Obesity in Pregnant Women

Introduction: Obesity is not only the source of multiple health care problems for women of childbearing age but also in pregnancy, resulting in a higher risk for pregnancy complications, cesarean delivery, and neonatal problems.

The Problem: Since the mid-seventies, the prevalence of overweight and obesity has increased at an alarming rate for both adults and children in the United States. The obesity rates for adults have doubled and rates for children have tripled. According to the Centers for Disease



Control and Prevention's (CDC) Behavioral Risk Factor Surveillance System (BRFSS) (2006-2008) Kentucky has the 7th highest rate, 29 percent, of adult obesity in the nation⁹. This trend is also observed in women of reproductive age¹⁰. The incidence of obesity at the first prenatal visit has increased from 7.3% to 24.4% in a 20 year period¹¹. Data from Kentucky Vital Statistics shows an increasing trend of pre-pregnancy obesity from 26.8% in 2004 to 28.4% in 2007.

⁹ Center for Disease Control's Behavioral Risk Factor Surveillance System (BRFSS), Division of Nutrition and Physical Activity, National Center for Chronic Disease Prevention and Health Promotion. Obesity Trends among US Adults. Atlanta, GA:2006-2008.

¹⁰ Ramachenderan J, Bradford J, Mclean M. Maternal obesity and pregnancy complications: A review. *Australian and New Zealand Journal of Obstetrics and Gynecology*.2008;48:228-235.

¹¹ Phithakwatchara N, Titapant V. The effect of pre-pregnancy weight on delivery outcome and birth weight in potential diabetic patients with normal screening for gestational diabetes mellitus in Siriraj Hospital. *J. Med Assoc Thai*.2007.90:229-236.

Overweight and obesity prior to pregnancy is an important public health issue and deserves more attention. Currently 1 of 5¹² women is obese at the beginning of pregnancy. Kentucky is far from reaching the Healthy People 2010 objectives to reduce adult obesity to 15% with a pre-pregnancy obesity rate of 29.1%.

Data from Kentucky Pregnancy Risk Assessment and Monitoring System (KY PRAMS) shows that there is a difference in adverse birth outcomes (Figure 6) among women that are obese and overweight prior to pregnancy as compared to women with normal Body Mass Index. KY PRAMS data also shows that African American women are disproportionately affected by pre-pregnancy obesity (41.5%)¹³. It was also observed in data obtained from vital statistics birth files (2004-2007) that African American women have a higher prevalence (36.8%) of pre-pregnancy obesity as compared to white women (27.1%).

Linking Qualitative and Quantitative Data: Overweight and obesity was ranked as the #1 health priority issue in both the web-based provider survey and by local health department patients specific to women's health. Community forum participants ranked it as their third top health issue for the population in general. Astute survey participants noted that "...a perception exists that healthy foods are more costly" and that "...economic issues (such as emotional stress) are often tied to poor eating habits". The need for preconception care (discussed in the next section) was highlighted because the pre-pregnancy period is a critical window, offering an ideal time to implement weight-loss interventions and improve nutrition.

Current Title V Measures:

- NONE (*Targeted as a new Kentucky State Select Performance Measure*)

Preconception Care

Introduction: Preconception care is the health care of women of childbearing age before they get pregnant and between pregnancies. The best way to have a healthy baby is for a woman to be healthy going into a pregnancy; much of development of the baby happens even before a woman knows she is pregnant.

The Problem: According to Kentucky PRAMS data, over 40% of pregnancies are unintended. In 2006, about 1 in 17 infants (5.8% of live births) was born to a woman receiving late or no prenatal care in Kentucky. Preconception care is recognized as a critical component of health care for women of reproductive age. The CDC recommends that all women of childbearing age develop a reproductive life plan, plan their pregnancies, and begin preconception care under physician guidance. In Kentucky (2008), nearly 70% of women who present to a local health department receive preconceptual counseling. This is slightly less than the State Select Performance Measure Goal of 74%, set for 2013.

¹² Kim SY, Dietz PM, England L, Morrow B, Callaghan WM. Trends in Pre-pregnancy Obesity in Nine States, 1993–2003. *Obesity* 2007. 15:986–993.

¹³ KY Pregnancy Risk Assessment Monitoring System Report. 2008.

Risk factors for adverse pregnancy outcomes such as smoking, consuming alcohol, obesity, sexually transmitted diseases, and chronic conditions remain prevalent among Kentucky women of reproductive age. Infants of mothers with diabetes are at greater risk for several problems and according to the CDC's MMWR¹⁴ the proportion of pregnant women who smoke in Kentucky is over twice that of the nation. Data shows there are racial/ethnic disparities and disparities in access associated with preconception care. A study by Taylor, Alexander and Hepworth¹⁵ found that those women receiving no prenatal (including preconception) care were more likely to be over the age of 35, African-American, unmarried, without a high school education, uninsured, and making less than \$15,000 a year.

Linking Qualitative and Quantitative Data: The need for preconception care was not raised in isolation by any of Kentucky's survey populations but was frequently noted as a "wish-list" intervention by community forum attendees, particularly for those women who smoke. It is a cross-cutting issue which, if consistently implemented with adequate resources for referral, could have a positive impact on births to women of all ages and socioeconomic backgrounds. Specifically mentioned was the need for inter-conception care, pre-pregnancy checkups and heightened consumer as well as provider awareness.

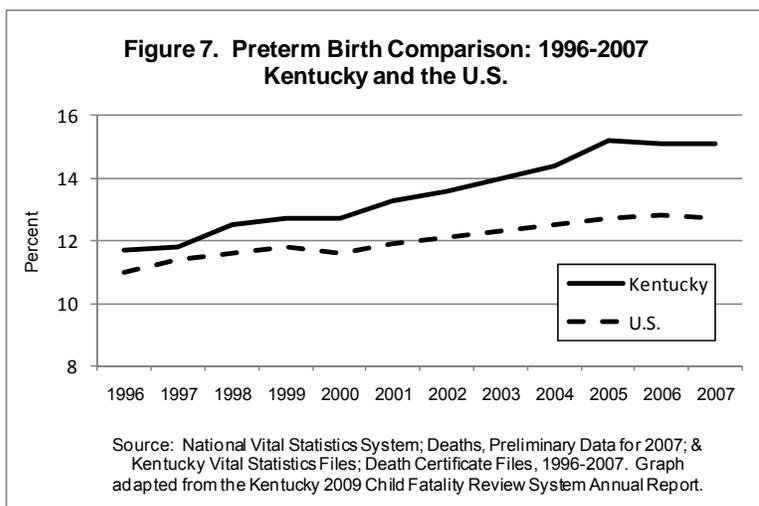
Current Title V Measures:

- (2005-2010) SPM #03: Increase the percent of women of childbearing age that present to a local health department that receive a preconceptional service.

Preterm Birth and Low Birthweight Births

Introduction: Kentucky's 2009 Annual Report for the Child Fatality Review System reported that prematurity and low birth weight was the leading cause of neonatal mortality in Kentucky with 22% of infant deaths reporting prematurity-related conditions under cause of death.

The Problem: Of all the premature births in Kentucky (2007) and nationally, nearly 72% are babies born between 34 weeks and 36 weeks gestation¹⁶, or 4-6 weeks before their due date.



¹⁴ U.S. Department of Health and Human Services. Centers for Disease Control and Prevention (CDC). Smoking Prevalence Among Women of Reproductive Age—United States 2006. Morbidity and Mortality Weekly Report. 2008; 57:849-852.

¹⁵ Taylor, CR, et. al. "Clustering of US Women Receiving No Prenatal Care: Difference in Pregnancy Outcomes and Implications for Targeting Interventions." Maternal and Child Health. 2005; 9: 125-133

¹⁶ Infants born at 36 weeks= 37.2%, at 35 weeks= 21.2%, at 34 weeks=13.5%. Source: Kentucky Vital Statistics Files, 2007, 2009 Annual Report for the Child Fatality Review System. Available at: <http://chfs.ky.gov/dph/mch/cfh/childfatality.htm>

Although these babies may be “big preemies” and have a high chance of survival overall, when compared to full term infants they are six times more likely to die in the first week of life, three times more likely to die in the first year of life, and seven times more likely to have complications at delivery. Long term studies on these infants suggest that they are also at higher risk for behavior and learning problems, ADHD, and long term disabilities¹⁷.

Linking Qualitative and Quantitative Data: Preterm birth and low birthweight were not selected as priority maternal and child health issues by either health providers or by those attending community forums. Both of these issues were mentioned under the broad category of “MCH General” by community forum participants but other than issues regarding the association between elective (as opposed to indicated) cesarean section, the topic of prematurity-related deaths was not highly ranked by participants. The local health department patient survey, however, acknowledged these issues as the 5th most critical priority for infants and children in the state. The maternal and child health needs assessment leadership team agreed with local health department patients and will be developing a new State Select Performance Measure specifically addressing late preterm birth.

Current Title V Measures

- NPM #17: Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.
- (2005-2010) SPM #04: Reduce the percentage of live births that are preterm.

Related Measures

- NPM #15: Percentage of women who smoke in the last three months of pregnancy.
- NPM #18: Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.
- (2005-2010) SPM #03: Increase the percent of women of childbearing age that present to a local health department that receive a preconceptional service.
- HSI #01A, #01B, #02A, #02B
- NHOM #03: The neonatal mortality rate per 1,000 live births
- NHOM #04: The postneonatal mortality rate per 1,000 live births
- NHOM #05: The perinatal mortality rate per 1,000 live births plus fetal deaths

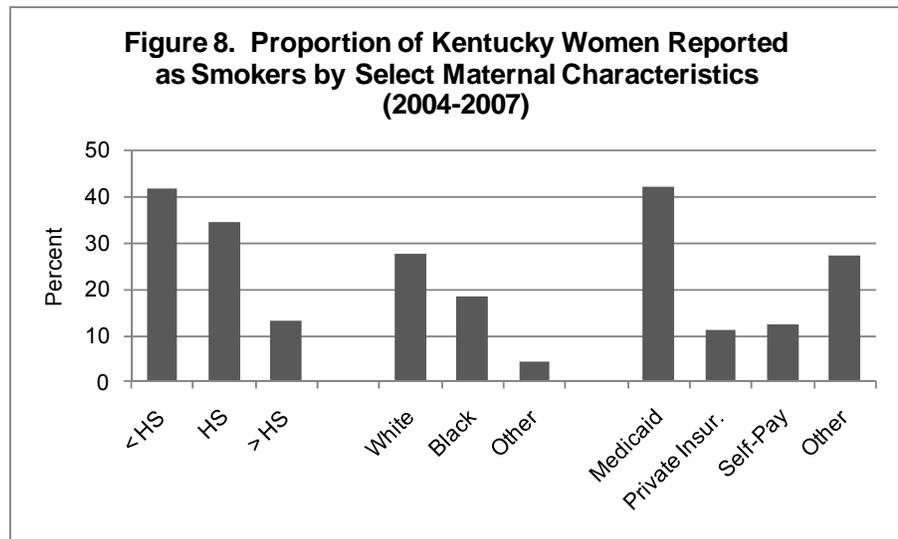
Smoking in Pregnancy

Introduction: Smoking during pregnancy reduces the amount of oxygen going to the developing baby. In addition, there are over 4,000 toxins in cigarette smoke that reach both mother and baby from smoking. The negative effects of smoking on the developing baby are also known to extend into later life.

¹⁷ Child Fatality Review System 2009 Annual Report, Kentucky Department for Public Health.

The Problem: Kentucky far exceeds the nation in current smokers among both women of child-bearing age (34.7% vs. 22.4%)¹⁸ and pregnant women (26.5% vs. 10.7%)¹⁹⁻²⁰. The proportion of pregnant women who smoke in Kentucky is over twice that of the pregnant smokers in the nation, and during 2002, the most recent year of a complete national ranking, Kentucky was ranked second (to worst) in the Nation in terms of women who smoked during pregnancy²¹. An analysis of live birth certificates from 2004 through 2007 revealed that maternal smoking occurred in 22.9% of these births. Additionally, 14.8% of these women were light smokers (10 or fewer cigarettes per day) while 8.1% were heavy smokers (more than 10 cigarettes per day).

Martin et al.²² suggest that women that are white, unmarried, with lower education attainment and lower income were more likely to smoke during pregnancy. An analysis of maternal characteristics and



smoking status using Kentucky’s birth certificate data from 2004 to 2007 identified White, unmarried women with lower education and Medicaid as high risk.

There are also great costs associated with smoking in pregnancy. In Kentucky, smoking attributed to 4.35% of the total neonatal expenditures yielding a total of \$9,902,505 in neonatal expenditures directly related to smoking based on 2001 figures²³.

Linking Qualitative and Quantitative Data: These facts were acknowledged by Kentucky survey participants. Smoking during pregnancy was among the top five priority issues on each of the three survey tools. Community forum participants placed smoking (along with substance abuse) as their #1 public health issue for the state. Several recommendations to address this

¹⁸ Centers for Disease Control and Prevention (CDC). Smoking prevalence among women of reproductive age — United States, 2006. *Morbidity and Mortality Weekly Report*. 2008; 57:849-852.

¹⁹ Kentucky Live Birth Certificate Files, 2006.

²⁰ Martin, JA, Hamilton, BE, Sutton, PD, Ventura, SJ, Menacker, F, Kirmeyer, S, Munson, ML. Births: Final data for 2005. *National Vital Statistics Reports*. 2007; 56:1-104.

²¹ Centers for Disease Control and Prevention. Smoking during pregnancy — United States, 1990—2002. *Morbidity and Mortality Weekly Report* 2004; 53:911-915.

²² Martin, LT, McNamara, M, Milot, A, Block, M, Hair, EC, Halle, T. Correlates of smoking before, during, and after pregnancy. *American Journal of Health Behavior*. 2008; 32:272-282.

²³ Centers for Disease Control and Prevention. Maternal and child health smoking attributable mortality, morbidity, and economic costs. Available at: http://apps.nccd.cdc.gov/sammec/mch_login.asp.

problem were made. First, participants suggested making smoking status a data element that is as commonly and consistently collected as weight and blood pressure are by medical practices across the Commonwealth. Also noted was the need for community buy-in with an emphasis on changing the culture of smoking in all of Kentucky's 120 counties. Finally, forum participants noted the need to make resources available to all health care providers to facilitate cessation counseling. One participant noted that "...a better understanding of the unique needs of our population may be necessary to understand why available resources are not used".

Current Title V Measures:

- NPM #15: Percentage of women who smoke in the last 3 months of pregnancy.

Related Measures

- NPM #18: Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.
- (2005-2010) SPM #03: Increase the percent of women of childbearing age that present to a local health department that receive a preconceptual service.

Substance Abuse in Pregnant Women

Introduction: Substance abuse during pregnancy includes the use of tobacco, alcohol, and drugs during pregnancy. Not only can it have life-long effects on the developing baby but it can also impact maternal morbidity and mortality. Drug use during pregnancy may cause mental and physical impairments, as well as psychological problems in both infants and children. These problems are entirely preventable.

The Problem: Kentucky's birth certificate data (2004-2007) indicate that approximately 22.9% of all Kentucky women that had a live birth smoked during pregnancy and only 0.55% reported drinking alcohol during pregnancy. This information is limited by a high rate of missing data pertaining to alcohol use and the possibility that this risk factor is generally underreported. Due to a limited availability of data, it is difficult to estimate the prevalence of substance abuse in Kentucky's pregnant women.

Kentucky's Office of Women's Physical and Mental Health reports that in a study coordinated by the University of Kentucky Institute on Women and Substance Abuse, of an estimated 72,000 Kentucky women who abused alcohol and/or other drugs, only 22% received treatment. Reasons include a lack of treatment facilities throughout the state and reluctance to report alcohol or drug use due to fear, stigmatization or fear of losing their children. Suzanne Carrier, LCSW, of the Women's Treatment Division of Behavioral Health, indicates that the most commonly abused substances are alcohol, marijuana, cocaine, and then opiates. (S. Carrier, Personal communication, June 24, 2010).

Linking Qualitative and Quantitative Data: Substance abuse (with and without smoking) was ranked as the top public health issue by all survey populations. Community forum participants ranked it #1, the web-based provider survey ranked it second and local health department

patients ranked it the #3 issue for women. While the need for more services and resources is evident, obtaining valid and reliable information for this topic is not currently possible.

The Division of Maternal and Child Health received a clear message about the importance of this issue from the 2010 Needs Assessment process. Plans to strengthen collaborative efforts with the Department for Behavioral Health, Developmental and Intellectual Disabilities (also under the Kentucky Cabinet for Health and Family Services) are underway.

Current Title V Measures:

- None

Related Measures

- NPM #18: Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.
- (2005-2010) SPM #03: Increase the percent of women of childbearing age that present to a local health department that receive a preconceptional service.

3. b. Children and Adolescents

Child Maltreatment in Kentucky

Introduction: Child maltreatment has a negative effect on health. Abused children often suffer physical injuries including cuts, bruises, burns and broken bones. In addition, maltreatment causes stress that can disrupt early brain development and extreme stress can harm the development of the nervous and immune systems²⁴. As a result, children who are abused or neglected are at higher risk for health problems as adults. These problems include alcoholism, depression, drug abuse, eating disorders, obesity, sexual promiscuity, smoking, suicide, and certain chronic diseases²⁵⁻²⁶.

The Problem: Child maltreatment in Kentucky and the U.S. continues to remain a serious problem that affects everyone. In 2007, U.S. state and local child protective services (CPS) investigated 3.2 million reports of children being abused or neglected. CPS classified 794,000 (10.6/1,000) of these children as victims. Of those, 59% were classified as victims of child neglect, 11% as victims of physical abuse, 8% as victims of sexual abuse, and 4% as victims of

²⁴ National Scientific Council on the Developing Child. Excessive stress disrupts the architecture of the developing brain. Working paper No. 3. 2005.

²⁵ Felitti V, Anda R, Nordenberg D, Williamson D, et. al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. *American Journal of Preventive Medicine*. 1998; 14(4): 245-58.

²⁶ Runyan D, Wattam C, Ikeda R, Hassan F, Ramiro L. Child abuse and neglect by parents and caregivers; World report on violence and health. Geneva Switzerland: World Health Organization. 2002. p. 59-86.

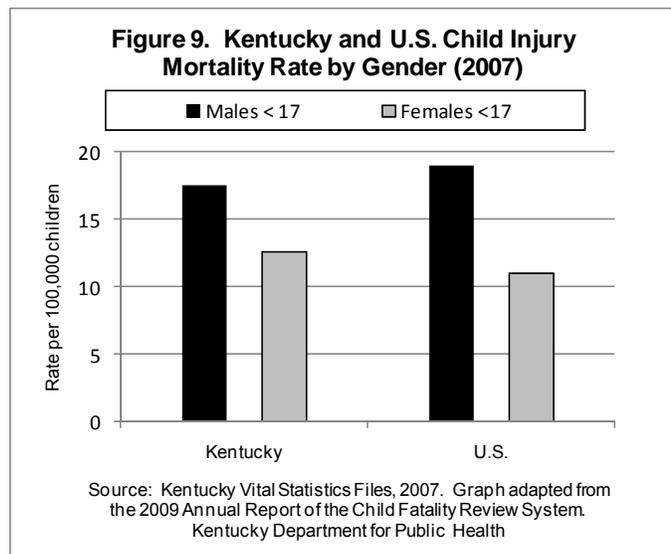
emotional abuse²⁷. In Kentucky, during fiscal year 2007, 48,085 reports of abuse or neglect were investigated and of those, 11,971 were substantiated²⁸.

Gender, race, and age disparities do exist among victims of child maltreatment. Typically, children younger than age four are at higher risk for both maltreatment and death from maltreatment²⁹. Nationally, African American, American Indian/Alaska Native and Multiracial children had higher rates of victimization than others and overall, girls were at slightly higher risk than boys for all forms of child maltreatment (52% vs. 48%)³⁰.

Linking Qualitative and Quantitative Data: Child abuse and neglect was cited by local health department patients as their #2 health priority issue for infants and children. Kentucky providers and stakeholders also considered this issue as one of their top ten priorities but community forum participants never raised this issue. While child abuse cases across the country have been reported as on a decline, substantial concerns remain regarding data validity for this problem. The number of investigated child abuse cases varies greatly by the number of individuals employed to research these cases. As workforce is reduced, the number of cases investigated is reduced resulting in a fewer substantiated child abuse cases. However this does not necessarily mean that fewer cases occurred, only that fewer cases were investigated resulting in a *falsely perceived* reduction in substantiated cases. Child abuse was included as issue #8 by health providers in the web-based survey.

Current Title V Measures:

- (2005-2010) SPM #01: Decrease the death rate for children age 0-18 due to unintentional injury and/or violence.
- (2005-2010) SPM #02: Reduce the rate of substantiated incidence of child abuse, neglect or dependency.
- NOM #06: The child death rate per 100,000 children aged 1 through 14.
- (*Targeted as a new/revised Kentucky State Select Performance Measure*)



²⁷ Centers for Disease Control and Prevention; National Center for Injury Prevention and Control. Child Maltreatment, Facts at a Glance. Spring 2009

²⁸ Kentucky Cabinet for Health and Family Services; Department for Community Based Services; Division of Protection and Permanency. Child Abuse and Neglect Annual Report of Child Fatalities and Near Fatalities. September 2007.

²⁹ Centers for Disease Control and Prevention; National Center for Injury Prevention and Control. Child Maltreatment, Facts at a Glance. Spring 2009.

³⁰ Ibid

Injuries: Intentional and Unintentional

Introduction: More children in Kentucky die of injury related causes than natural cause deaths. Injury related deaths are more likely to be preventable than natural cause deaths. Many factors have been associated with increased risk of injury or death in children including socioeconomic factors, cultural factors, geographical location, education level, and health and safety issues in the community. Understanding these factors is critical to addressing preventable injury related child death through state and community-based interventions.

The Problem: The 2009 Annual Report of the Child Fatality Review System reported that in Kentucky, African American children died at a higher rate (19.0/100,000) than white children in 2007 (15.0/100,000). Kentucky's injury death rate for African American children is lower than the national average of 22.0/100,000, and the injury death rate for white children is slightly higher than the national average which is 14.0/100,000. In 2007, male children under 17 years old were 1.4 times more likely to die from injuries than females however, as illustrated by Figure 9, the rate of injury death for females was higher than the national rate for that same year.

The Child Fatality Review System reported that motor vehicle crashes were the leading cause of death for children aged 1-14 years. For children aged 17 and under, motor vehicles crashes accounted for nearly half of all injury related deaths. According to the 2009 report, there were 28,889 motor vehicle crashes involving children, and in those crashes, 1726 (6.0%) of the children were unrestrained. Of the 65 child *fatalities* from motor vehicle accidents, 44 (68%) were unrestrained³¹. National Performance Measure #10 which monitors the rate of deaths to children aged 14 years and younger demonstrates a steady downward trend for this indicator, declining from 6.1/100,000 (2004) to 2.7/100,000 (2008).

From 1999 to 2007, the rate of transportation crash fatalities in Kentucky has been higher than the United States rate. However, the rate decreased in Kentucky from over 12.0/100,000 in 2000 to 6.5/100,000 in 2007. The recent decrease comes after the implementation of the Graduated Driver Licensing Program in 2006. The program became law from strong legislative leadership, and was supported by the recommendations and efforts of the state CFR team. The "2008 Booster Bill" law may have a similar impact in decreasing child deaths³².

The 2009 Child Fatality Report (<http://chfs.ky.gov/dph/mch/cfhi/childfatality.htm>) may also be accessed for information about other unintentional injuries (fire, poisoning, drowning, etc.) and intentional injuries such as suicide and homicide.

Linking Qualitative and Quantitative Data: Several issues related to childhood injury were raised by local health department patients. This group noted concerns about child abuse (detailed earlier in this section) and ranked it as the second most critical childhood issue today in Kentucky. They also ranked the need for improved car seat use as the #3 issue for infants and children. For adolescents, motor vehicle crashes and self-harm ranked respectively as the 6th and 7th issues. Interestingly, neither the provider survey participants, nor the community

³¹ Child Fatality Review System 2009 Annual Report – Kentucky Department for Public Health. Accessed on 6/8/10 at <http://chfs.ky.gov/dph/mch/cfhi/childfatality.htm>

³² Ibid.

forums ranked injuries among their top ten priorities for maternal and child health. Only one forum had enough people interested in childhood injury to have a discussion table on the topic.

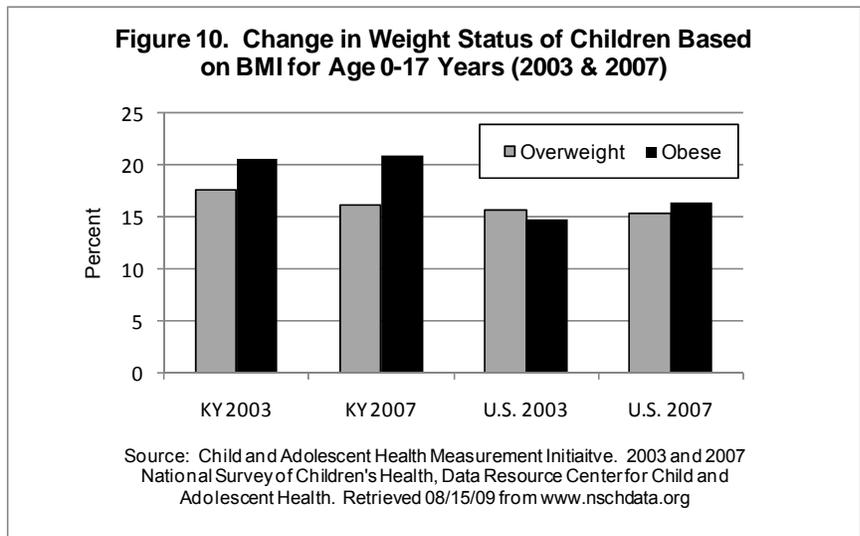
Current Title V Measures:

- NPM #10: The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children.
- NPM #16: The rate (per 100,000) of suicide deaths among youths aged 15 through 19.
- NOM #06: The child death rate per 100,000 children aged 1 through 14.
- (2005-2010) SPM #01: Decrease the death rate for children aged 0-18 due to unintentional injury and/or violence.
- HSI #03A: The death rate per 100,000 due to unintentional injuries among children aged 14 years and younger.
- HSI #03B: The death rate per 100,000 for unintentional injuries among children aged 14 years and younger due to motor vehicle crashes.
- HSI #03C: The death rate per 100,000 from unintentional injuries due to motor vehicle crashes among youth aged 15 through 24 years.
- HSI #04A: The rate per 100,000 of all non-fatal injuries among children aged 14 years and younger.
- HSI #04B: The rate per 100,000 of nonfatal injuries due to motor vehicle crashes among children aged 14 years and younger.
- HSI #04C: The rate per 100,000 of nonfatal injures due to motor vehicle crashes among youth aged 15 through 24 years.

Obesity in Children

Introduction: The growing rates of obesity across the nation begin at early ages. Overweight in weight status is at or above 85th percentile for Body Mass Index (BMI). Obesity is a BMI of greater than the 95th percentile for age. Obesity is a concern in communities all across the Commonwealth.

The Problem: Kentucky has



one of the highest prevalence for pediatric obesity in the nation³³. Approximately 38% of

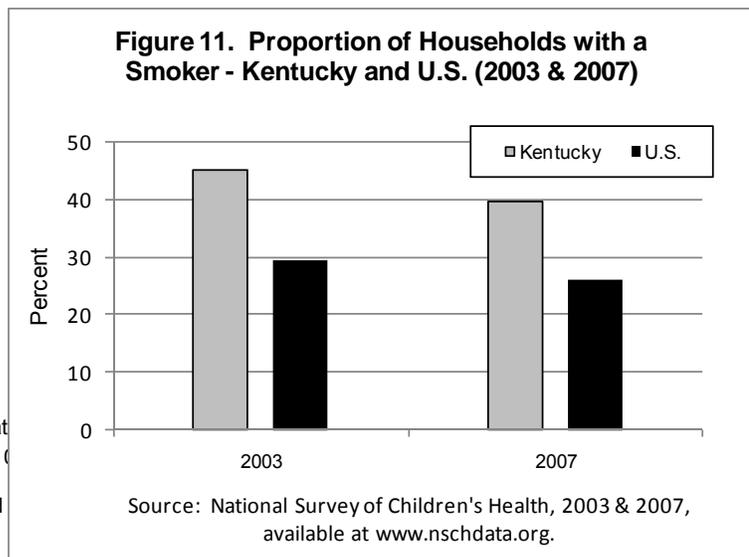
Kentucky children ages 10-17 years are considered overweight or obese according to

BMI-for-age standards. Half of Kentucky's children in poor families are overweight or obese.

According to the 2008 Pediatric Nutrition Surveillance System (PedNSS), 32.3% of children ages 2-5 years from low income families in Kentucky participating in WIC are either overweight or obese³⁴.

Obesity rates in the United States are a serious health concern for children and adolescents. Data from National Survey of Children's Health (NCHS, 2003-2007) show that in Kentucky the prevalence of obesity increased from 16.2% to 21.0% for children ages 0-17 years³⁵. One of the *Healthy People 2010* objectives (19-3) is to reduce to 5% the proportion of children and adolescents who are obese³⁶. According to the Healthy Kentuckians mid-decade review the percentage of adolescents in high school who were overweight increased from 12.3 percent in 2001 to 14.6 percent in 2003³⁷.

A recently published state fact sheet on obesity and physical activity using National Survey for Children's Health data reported that Kentucky children also fared worse than other children in the U.S. on a number of physical activity measures. For those children aged 6-17 in Kentucky, 62.5% participated in 4 or more days of vigorous physical activity per week as compared to 64.3% for the U.S.³⁸ Younger children (aged 1-5)



³³ Child and Adolescent Health Measurement Initiative for Child and Adolescent Health website. Retrieved 06/17/10 at <http://www.cdc.gov/nchs/data/iaia/>

³⁴ National Survey for Children's Health. Accessed 06/17/10 at <http://www.nschdata.org>

³⁵ Ibid

³⁶ US Department of Health and Human Services. *Healthy people 2010: objectives for improving health (part B: focus areas 15--28)*. 2nd ed. Washington, DC: US Department of Health and Human Services; 2000. Available at <http://www.health.gov/healthypeople>.

³⁷ Healthy Kentuckians 2010. Mid-Decade Review Summary Report, 2006.

³⁸ National Survey for Children's Health. Accessed 06/17/10 at <http://www.nschdata.org/Viewdocument.aspx?item=539>

watched television more, reporting that 13.5% engaged in 4 or more hours of screen time per weekday in Kentucky as compared to 12.8% for the U.S.³⁹

Linking Qualitative and Quantitative Data: Obesity in the general population was ranked as the number one priority for Kentucky in the provider survey with this issue ranked third by community forum attendees. School health was also considered a high priority issue by the latter group of participants, with many overlapping issues such as a lack of physical activity in the schools, poor food options for children and childhood bullying. A lack of self-esteem was a concern cited by many participants. The patient survey, which stratified comments by women, children and teens, noted obesity in children and adolescents as the 4th highest priority for the state.

Current Title V Measures:

- NPM #14: Percentage of children, ages 2 to 5 years, receiving WIC services with a Body Mass Index (BMI) at or above the 85th percentile.

Related Measures:

- NPM #11: The percent of mothers who breastfeed their infant at 6 months of age.

Secondhand Smoke Exposure in Children

Introduction: Second-hand smoke is the smoke inhaled by non-smokers who are in an environment where there is smoking. This is significant and can cause health problems in the bystander. It's particularly toxic for children when there are adult smokers in the home or traveling in cars with smokers.

The Problem: Kentucky has the highest proportion of households in the U.S. with children ages 0-17 years in which someone smokes according to the National Survey of Children's Health in 2003 and 2007.^{40,41} There has been a slight decline in the number of households with smokers from 45.2% in 2003 to 39.5% in 2007, but Kentucky remains significantly higher than the national average^{42,43}. The proportion of 0 to 5 years old children living in a household where someone smokes declined from 42.6% in 2003 to 36.9% in 2007 while children 6 to 11 years

³⁹ National Survey for Children's Health. Accessed 06/17/10 at <http://nschdata.org/Viewdocument.aspx?item=539>

⁴⁰ Child and Adolescent Health Measurement Initiative. *2003 National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website. Retrieved 10/08/09 from www.nschdata.org

⁴¹ Child and Adolescent Health Measurement Initiative. *2007 National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website. Retrieved 10/08/09 from www.nschdata.org

⁴² Child and Adolescent Health Measurement Initiative. *2003 National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website. Retrieved 10/08/09 from www.nschdata.org

⁴³ Child and Adolescent Health Measurement Initiative. *2007 National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website. Retrieved 10/08/09 from www.nschdata.org

old decreased from 41.8% to 38.8% and children 12 to 17 years old decreased from 49.7% to 42.9%⁴⁴. These proportions are all significantly higher than national data.

Linking Qualitative and Quantitative Data: Secondhand smoke exposure was ranked as the #1 health concern for infants and children in the local health department patient survey. As noted earlier, smoking in general ranked very highly as a public health priority for Kentucky. The only measure currently available regarding secondhand smoke exposure is the National Survey of Children’s Health (2003 and 2007). This measure will be addressed by counseling pregnant women about the dangers of smoking during and after their pregnancy.

Current Title V Measures:

- NPM #15: Percentage of women who smoke in the last 3 months of pregnancy.

Substance Abuse in Children and Teens

Introduction: One of the leading concerns in communities across the state is Substance Abuse in children and teens. Use of illicit substances and overuse of prescription drugs is a growing problem that is destructive to lives, families, neighborhoods, and communities.

The Problem: Kentucky youth are at a significantly greater risk as compared to youth

nationwide for lifetime cigarette use (62.2% KY versus 50.3 % US), current cigarette use (26% KY versus 20% US) and current smokeless tobacco use (15.8% KY versus 7.9% US)⁴⁵. Students in Kentucky from 9th to 12th grade are similar in their risk status to students throughout the United States in their risks for episodic heavy drinking, lifetime marijuana use, lifetime cocaine use and lifetime inhalant use⁴⁶. The 2007 Youth Risk Behavior Survey (YRBS) findings suggest that Kentucky adolescents are at a significantly higher risk of being offered, sold or given an illegal drug by someone on school property as compared to other students in the

Table 11. Change between 2005-2006 and 2006-2007 Model-Based Estimates by Measure for Adolescents Aged 12-17 Years (Kentucky and U.S.)

Illicit Substance or Drug (%)	Kentucky		United States	
	2005-2006	2006-2007	2005-2006	2006-2007
Past Month Illicit Drug Use (%)	10.08	10.21	9.84	9.66
Past Year Marijuana Use (%)	12.15	13.76	13.26*	12.83
Past Year Cocaine Use (%)	6.59	7.06	6.74	6.67
Past Year Non-Medical Pain Reliever Use (%)	1.58	1.52	1.64	1.57
Past Year Non-Medical Pain Reliever Use (%)	8.83	8.3	7.01	6.91
Perception of Great Risk of Smoking Marijuana Once a Month (%)	37.07	38.86	34.31	34.58
**Average Annual Rate of First Use of Marijuana	5.38*	6.67	5.58	5.56

* Suggests that the change is significant at a p-value of < 0.05. **Please see SAMHSA weblink for definition of "Average Annual Rate". Source: SAMHSA, Office of Applied Statistics, National Survey of Drug Use and Health, 2006 and 2007. Accessed 06/05/10 at <http://oas.samhsa.gov/2k6State/Kentucky.htm#Fig2.2>.

⁴⁴ Ibid

⁴⁵ Centers for Disease Control and Prevention, Youth Risk Behavior Surveillance System: Youth Online Comprehensive Results: <http://apps.nccd.cdc.gov/yrbss/>

⁴⁶ Ibid.

United States (27% versus 22.3%). The prevalence of lifetime methamphetamine use by our youth is 6% as compared to 4.4% in the United States. Kentucky ranks number one among the 39 YRBS states in the prevalence of children who smoked an entire cigarette before age 13 (23.8%), youth smoking cigarettes in school property (9.5%) and youth who take steroids (6.1%). The State ranks 9th in the percentage of children who drank alcohol before age 13 (25.1%)⁴⁷.

Additional comparisons (from The Office of Applied Studies, Substance Abuse and Mental Health Services Administration) between adolescents in Kentucky and U.S. follow in Table 11.

Linking Qualitative and Quantitative Data: Adolescent substance abuse was cited by patient survey respondents as the number one health priority issue for that population. The broader topic of population-level substance abuse was voted as the topic public health issue for the Commonwealth by community forum participants and the second priority by providers.

Current Title V Measures:

- None - targeted as a new State Select Performance Measure.

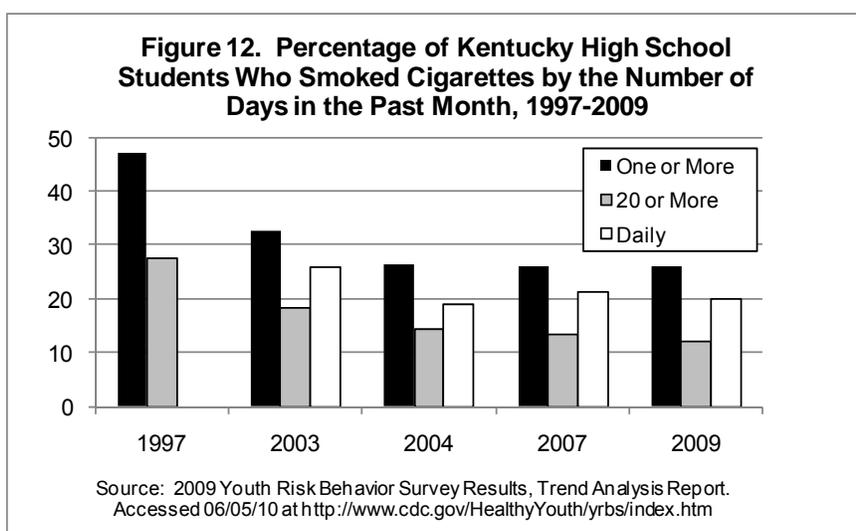
Teen Smoking

Introduction: Prevention for smoking is a better solution than trying to get people who smoke to quit. Ninety percent (90%) of adult smokers begin smoking as teens.

Interventions to prevent teens from starting to smoke will be the most effective in preventing the health consequences of smoking.

The Problem: According to the Youth Risk Behavior Survey⁴⁸, the percentage of high school students in Kentucky smoking cigarettes on a daily basis has declined from 26% in 2003 to 20% in 2009. Additionally, in 2009, 26.1% of high school students reported smoking on one or more days in the past 30 days while 12% reported smoking on 20 or more days in the past 30 days. These numbers have declined from 32.7% and 18.4% respectively in 2003.

There is additional data available from the 2008 Kentucky Youth Tobacco Survey⁴⁹ which is administered to middle and high school students. In 2006, 34% of 6th graders reported use of



⁴⁷ Ibid.

⁴⁸ 2009 Kentucky Youth Risk Behavior Survey Results. Available at: <http://www.education.ky.gov/KDE/Administrative+Resources/Coordinated+School+Health/>

⁴⁹ Tooms MR. Kentucky Youth Tobacco Survey 2008. Frankfort, KY: Kentucky Department for Public Health, Tobacco Prevention

any type of tobacco compared to 26% in 2008. For 12th graders, these numbers were 45% in 2006 and 41% in 2008. A decline was seen in the lifetime use of any type of tobacco in all grades except the 10th grade between 2006 and 2008.

Contextual factors playing a role in teen smoking include smoking policies (smoke free communities, cigarette tax), the influence of media and social interactions (peers and family). In Kentucky, there are 27 smoke-free community-wide ordinances or regulations (8 of 120 counties)⁵⁰. The state cigarette tax in Kentucky is \$0.60 per pack compared to the average of \$1.31 per pack for all states combined⁵¹. Peer influence is demonstrated in the Kentucky Youth Tobacco Survey with 88% of middle school current smokers and 91% of high school current smokers reporting that they have at least one or more friends who currently smoke. An increase was noted in the never-smoking middle school respondents with 21% reporting a friend who never smoked in 2006 compared to 31% in 2008⁵².

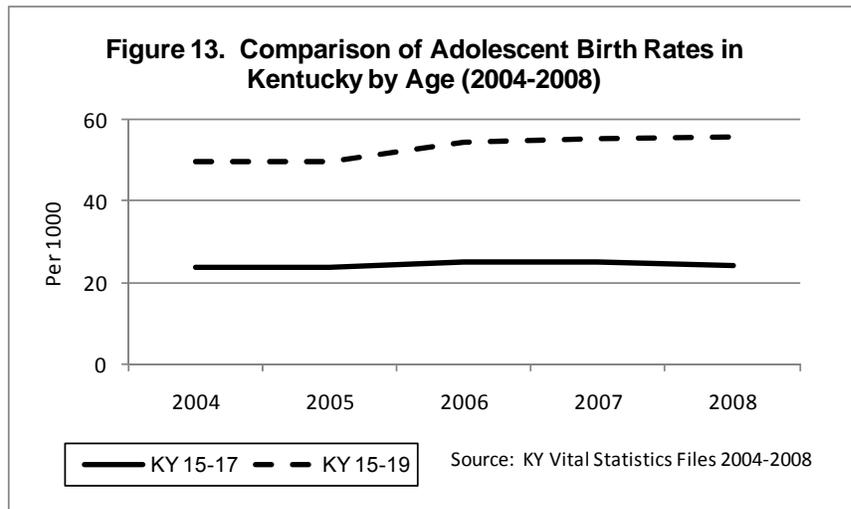
Linking Qualitative and Quantitative Data: Smoking in general or adolescent smoking was identified by all three Kentucky survey tools as a top public health priority. Community forum participants ranked it #1 while local health department patients ranked it the third most critical problem for Kentucky teens. Among issues discussed were risks to unsupervised youth and lack of political will to support smoke-free laws, minimum-age laws and tax increases on tobacco purchases. Also noted were “flavored” products specifically targeting the youth market, the influence of mass media and advertising/promotion by tobacco companies.

Current Title V Measures:

- NONE (*Targeted as a new Kentucky State Select Performance Measure*)

Teen Pregnancy and Births

Introduction: The issue of teen pregnancy and births continues to be one of the most complex and emotionally charged issues facing public health officials today. Teen pregnancy and births are affected indirectly by societal issues such as poverty, inequality, and racism as well as more directly by a lack of



and Cessation Program. 2009.

⁵⁰ Kentucky Tobacco Policy Research Program. Available at: <http://www.mc.uky.edu/tobaccopolicy/Ordinances/Smoke-freeOrdinances.HTM>

⁵¹ Campaign for Tobacco-Free Kids. State Cigarette Excise Tax Rates and Rankings. Available at: <http://www.tobaccofreekids.org/research/factsheets/pdf/0097.pdf>

⁵² Tooms MR. Kentucky Youth Tobacco Survey 2008

access to care and contraception services. Marian Wright Edelman, founder of The Children's Defense Fund, often speaks of hope as the best form of contraception. Hope, as well as self-esteem, education and future planning are all factors which impact adolescent pregnancy and birth rates.

The Problem: While adolescent pregnancy in Kentucky among 15 to 19 year-old females have declined since the late 1980's, the state continues to lag behind national rate reductions with 31% fewer adolescent pregnancies as compared to the national decline of 37%⁵³ in that same period. As illustrated by Figure 13, adolescent birth rates for females aged 15-17 has remained fairly stable in the past five years while rates for older teens has increased.

Disparities are evident when data is stratified by Appalachian and non-Appalachian counties and by race. The birth rate for Appalachia adolescents (15-19) was 62.4/1000 as compared to non-Appalachia at 52.4/1000. Black teens (15-19) had a birth rate of 68.4/1000 as compared to white teens at 55.4/1000. More information about adolescent births and pregnancies in Kentucky can be accessed at the Kentucky Department for Public Health Division of Women's Health Website at <http://chfs.ky.gov/dph/info/dwh/>.

Linking Qualitative and Quantitative Data: Despite documented declines in adolescent pregnancy and birth over recent years, this topic was cited as one of the most important issues facing Kentucky by those participating in the MCH Needs Assessment process. Patients and community forum attendees both ranked this as their second highest priority while providers ranked it in fifth place.

The major issues that emerged in teen pregnancy were: cultural issues and social norms, outcomes of teen pregnancy, increase in education and awareness of the problem and access to care. Lack of access to care and increase in awareness and education emerged as the two needs in the community. It was noted by the forum participants' that the issue of teen pregnancy has become more acceptable in the society, there is an increase in unstable homes and lack of family structure and teens are adopting high risk behaviors that may lead to teen pregnancy.

Current Title V Measures:

- NPM #08: The rate of births (per 1,000) for teenagers aged 15 through 17 years.

3. c. Cross-Cutting Issues Affecting the MCH Population

Finally, a number of issues were highlighted through the MCH Needs Assessment Survey processes which affected individuals across the lifespan – from birth to maturity. These included health insurance coverage and access to services, particularly for dental and mental health.

⁵³ Kost, K., Henshaw, S., and Carlin, L. (2010). U.S. Teenage Pregnancies, Births and Abortions: National and State Trends and Trends by Race and Ethnicity. Retrieved June 2010, from <http://www.guttmacher.org/pubs/USTPtrends.pdf>

Health Insurance Coverage

Introduction: Health insurance coverage is a necessity for all - children, adults, the elderly, and the disabled. Health insurance coverage is the key to accessing health care and staying healthy.

The Problem: As health care costs and insurance premiums rise, more Kentuckians may have to choose between health insurance and life's basic necessities. Lack of health insurance is a risk factor in delaying or not receiving needed care. The average yearly cost of a family health insurance policy is \$5,517⁵⁴. In 2008, the Kaiser Family Foundation reported that over 85% of Kentucky citizens have health insurance whether employee-sponsored coverage, individual coverage, Medicaid or Medicare coverage, or some other type of public coverage⁵⁵. Kentucky does better than the national average at insuring children, but still 1 in 10 children in Kentucky under the age of 19 are uninsured⁵⁶. Over 600,000 Kentuckians are without health insurance⁵⁷.

Linking Qualitative and Quantitative Data: The need for health insurance coverage was an issue raised by each of the three survey populations. The web-based provider survey ranked this issue as the third more critical issue facing the state while community forum participants ranked it as one of their top ten issues. Forty-five percent of local health department patients reported that they had difficulty obtaining insurance with 32% reporting problems getting a medical card.

Table 12: Kentucky Proportion of Uninsured by Select MCH Populations (States, 2007-2008; U.S. 2008)

	Uninsured Kentucky (2007-2008)	Uninsured U.S. (2008)
Health Insurance Coverage of the Total Population*	14.8%	15.4%
Health Insurance Coverage of Children Aged 0-18	9.5%	10.3%
Health Insurance Coverage of Women Aged 19-64	20.2%	18.1%

* Source: Kaiser Family Foundation at <http://www.statehealthfacts.org/profileind.jsp?cat=3&sub=39&rgn=19>

Comments by community forum participants included concerns about availability and affordability, overuse of local emergency rooms, and an underutilization of as well as enrollment in the Kentucky Children Health Insurance Program (KCHIP). In addition to policy reform, more public education and awareness was cited as necessary.

⁵⁴ American Health Insurance Plan Center for Policy and Research. Health Insurance: Overview and Economic Impact in the States. 2006. Available at <http://www.ahipresearch.org/PDFs/StateData/StateDataKentucky.pdf> Viewed on July 27, 2009.

⁵⁵ Kaiser Family Foundation. State Health Facts—Kentucky 2007-2008. Available at <http://www.statehealthfacts.kff.org/profileind.jsp?ind=125andcat=3andrgn=19> Viewed on June 7, 2010.

⁵⁶ Joan Alker, *Serving Low-Income Families Through Premium Assistance: A Look at Recent State Activity, Issue Paper* (Washington, DC, Kaiser Commission on Medicaid and the Uninsured, October 2003). Available at: <http://www.kff.org/medicaid/upload/Serving-Low-Income-Families-Through-Premium-Assistance-A-Look-At-Recent-State-Activity-PDF.pdf>. Viewed on July 29, 2009.

⁵⁷ Kaiser Family Foundation. State Health Facts—Kentucky 2007-2008. Available at <http://www.statehealthfacts.kff.org/profileind.jsp?ind=125andcat=3andrgn=19> Viewed on June 7, 2010.

Current Title V Measures:

- NPM #13: Percent of children without health insurance.

Oral Health and Access to Care

Introduction: Oral health does not just mean the condition of the teeth. The word “oral” refers to the mouth, which includes your teeth, gums, jawbone, and supporting tissues. Good oral health care can prevent a number of diseases in the mouth and is a key to your overall health⁵⁸.

Maintaining proper oral health care and hygiene can help prevent most of these diseases. But for the majority of the rural citizens (and many urban poor as well), access to dental care is one of the largest barriers faced in moving toward a better oral health status. A maldistribution of dentists exists, with the majority locating in urban areas. This makes the provision of dental care in rural areas very challenging.

The Problem: Nearly 8% of the adult population in Kentucky is edentulous due to tooth decay or gum disease⁵⁹. The Kentucky 2008 PRAMS Survey reports that 55.8% of the mothers said that they did not visit the dentist/dental clinic during their most recent pregnancy and 9.1 percent of mothers reported that they needed dental care during their pregnancy but did not get it⁶⁰. The Kentucky State Performance Measure monitoring this issue did demonstrate a slight increase in the proportion of women enrolled in Medicaid who had at least one dental visit during their pregnancy between 2006 (27.3%) and 2008 (33.3%).

About 23% of the high school children and 25% of the middle school children in Kentucky reported that they did not brush their teeth on all seven days of the past week with 85% of the high school and 75% of the middle school children in Kentucky reported that they did not floss on all seven days in the past week⁶¹. Nearly 30% of high school and 36% of middle school children have not visited the dentist in the past 12 months and according to the Kentucky KIDS SMILE program, there are about 4500 three-year-old children who have experienced a toothache⁶². Data measuring the number of third grade children who have protective sealants on at least one permanent molar tooth reported this total at 29% (2004-2007) and with a decline to 23.9% in 2008.

In Kentucky, the ratio of dentists was 5.6 per 10,000 (2006), which is lower than the American Dental Association’s national projected ratio of 6.0 professionally active dentists per 10,000 (population). Kentucky has a total of 77 pediatric dentists of which 65 are practicing in the metro areas. Only 28 of Kentucky’s 120 counties have a pediatric dentist. As of June 10, 2010,

⁵⁸ Oral Health in America: A Report of the Surgeon General – Executive Summary. Rockville (MD): US Department of Health and Human Services, National Institute of Dental and Craniofacial Research, National Institutes of Health; 2000.

⁵⁹ Behavioral Risk Factor Surveillance Survey (BRFSS) 2009

⁶⁰ Kentucky PRAMS Pregnancy Risk Assessment Monitoring Survey (PRAMS) 2008

⁶¹ Youth Risk Behavior Survey (YRBS) 2009

⁶² Youth Risk Behavior Survey (YRBS) 2009

there are 22 Dental Health Provider Shortage Areas (DHPSAs) in Kentucky. Owsley and Robertson counties have no dentists at all and the Appalachian region has the fewest dentists at 3.8 dentists per 10,000, western KY at 4.1 dentists per 10,000, northern KY at 4.6 dentists per 10,000⁶³. Maps illustrating provider shortages by county are available on the fact sheet detailing access to dental care issues provided on the Division of Maternal and Child Health website at <http://chfs.ky.gov/dph/mch/>.

Linking Qualitative and Quantitative Data: The need for dental services and oral health care was noted by all three surveys employed through the needs assessment process. Dental and oral health issues was ranked the 4th most important public health priority by those participating in community forums and among the top ten on the web-based provider survey. One third of local health department patients reported difficulty scheduling an appointment with a dentist.

Current Title V Measures:

- *NPM #09: Percent of third grade children who have received protective sealants on at least one permanent molar tooth.*
- *(2005-2010) SPM #07: The number of Medicaid covered women who had at least one dental visit during their pregnancy.*

This concludes Section 3 “*Strengths and Needs of the MCH Population Groups and Desired Outcomes*” for the Kentucky Department for Public Health.

Commission for Children with Special Health Care Needs

Like many other states enduring budget crises, Kentucky faces difficulties economically. Despite having fewer providers, higher poverty levels, and a higher unemployment rate than the national average, and real issues with childhood dental care and obesity, Kentucky does have strengths to build upon. A document review reveals the following (unless indicated otherwise, sources are CAHMI 2005/2006 NSCSHCN for Kentucky vs. national average and CAHMI, 2007 NSCH for Kentucky CYSHCN vs. Kentucky non-CYSHCN):

Accessibility/Affordability

Strengths:

- Rate of health insurance coverage for CYSHCN ranks better than the national average (6% without insurance, vs. 8.8%)
- Rate of uninsured children enrolled in CSHCN programs is 3.5% of CHSCN at time of encounter (CUP)

Weaknesses:

⁶³ Peterson MR, Williams, JN, Mundt, C. Kentucky Dental Provider Workforce Analysis: 1998-2006

- Kentucky's rate of poor children below the federal poverty level (72%) and children up to 133% of the federal poverty level (70%) are significantly higher than the national average (64% and 62%, respectively) (Kaiser State Health Facts);
- Rate of uninsured children (9.5%) is slightly lower than the national average (10.3%) (Kaiser);
- Insured CYSHCN have a high rate of underinsurance (31.9%, vs. 33.1% nationally);
- Rate of physicians per 1000 population (.27) is lower than the national average (.32) (Kaiser)

Given the high poverty levels evidenced in Kentucky, CSHCN observes that disparities that exist between CYSHCN and non-CYSHCN are actually positive. The lower rate of uninsured children enrolled in CSHCN programs compared to non-enrolled CYSHCN strongly points to interventions being put into place by the Title V program to remedy a significant social problem. However, the residual uninsured population, as well as the problem of underinsurance remains. CSHCN continues to monitor the rapid changes in the health care coverage landscape as they happen and is poised to act.

Quality/Health Status

Strengths:

- Kentucky has a slightly higher rate of appropriate transitions services for CYSHCN (43% to 41%)
- Family-centered care (35.7%, vs. 34.4% nationally) and family partnership in decision-making (58.6% vs. 57.4% nationally) are slightly above average;
- While Kentucky CYSHCN have a high rate of overweight/obesity, they do seem to get roughly an equivalent amount of exercise as non-CYSHCN;
- Kentucky's nutritional standards for school meals and snacks go beyond existing USDA requirement, and nutritional standards exist for food sold a la carte, in vending machines, school stores, and bake sales (Trust for America's Health, 2009).

Weaknesses:

- Obesity rates for the general population of Kentucky children (37%) are higher than the national average (32%) (Kaiser State Health Facts);
- Kentucky's prevalence numbers for CYSHCN are higher than the national average overall (18.5% vs. 13.9%), as well as in each age cluster, in addition to both genders, every poverty level and demographic element;
- The disparity between CYSHCN and non-CYSHCN in terms of overweight/obese is significant (43.8% vs. 34.3%), and Kentucky's state rank for overweight/obese children is 48th (with 1 being best);
- Compounding Kentucky CYSHCN obesity scores is a disparity in TV/computer/video screen time (59.7% report 1 hour or more daily vs. 52.1% non-CYSHCN);
- As is true nationally, a significantly higher rate of CYSHCN receiving public insurance are obese (50%), as opposed to private insurance (28.6%) and both numbers exceed the national average (43.2% and 27.3% respectively);

- Underscoring results found on the family survey mentioned in Section 1 of this Needs Assessment, 42.8% of CYSHCN did not receive services needed for transition to adult health care work, and independence
- Rates of children with 1 or more dental problems are higher (29.4%) in Kentucky than nationally (26.7%)

Kentucky's health care system for CYSHCN is focusing to meet the challenges posed by childhood obesity and its causes, and prioritizing efforts toward this emerging issue, as well as the persistent need to better prepare CYSHCN for adult life. Further information regarding these priorities is described elsewhere in this Needs Assessment, as well as efforts to supplement KDPH's strategy toward improving routine dental care and access.

This concludes Section 3 "*Strengths and Needs of the MCH Population Groups and Desired Outcomes*" for the Kentucky Commission for Children with Special Health Care Needs.

Section 4: MCH Capacity by Pyramid Levels

Kentucky Department for Public Health

Throughout the 2010 Needs Assessment Process, Kentucky not only sought input on needs and identified gaps from survey participants but also on current health care capacity. Each of the three survey tools included questions about capacity and gaps in services and these, as well as issues identified by the 2010 Needs Assessment team, are summarized below. Details contained in the 2011 Application and 2009 Annual Report will be summarized to provide the necessary background for the reader and not repeated verbatim.

4. a. Direct Health Care Services

Kentucky is primarily a rural state with 120 counties which vary significantly in geography, size, demographic and socioeconomic factors. Many regions continue to be isolated and distant from major cities, universities and health care services. The Cumberland Plateau (Eastern Kentucky Coal Fields) is the primary region falling into this category but Western Kentucky (Mississippi Plateau and Jackson Purchase) also experience substantial provider shortages and barriers to care. The majority of Kentucky's population resides in Central Kentucky, also called the Bluegrass Region, an area including the cities of Louisville, Lexington and extending north to just below the Ohio State Line (Cincinnati).



Kentucky Physiographic Regions. Accessed 06/19/10 at <http://en.wikipedia.org/wiki/Kentucky>

Health Professional Shortage Areas (HPSA)

The majority of Kentucky counties are designated as health professional shortage areas for primary care, dental or mental health. In Kentucky, HPSA designation is coordinated by the Health Care Access Branch in the Department for Public Health Division of Prevention and Quality Improvement. (<http://chfs.ky.gov/dph/info/dpqi/HPSA.htm>), the program designated by the federal Health Resources and Service Administration to assess and submit shortage designation data based on required federal criteria. HPSAs may have shortages of *primary medical care*, *dental* or *mental health* providers and may be urban or rural areas, population groups or medical or other public facilities⁶⁴.

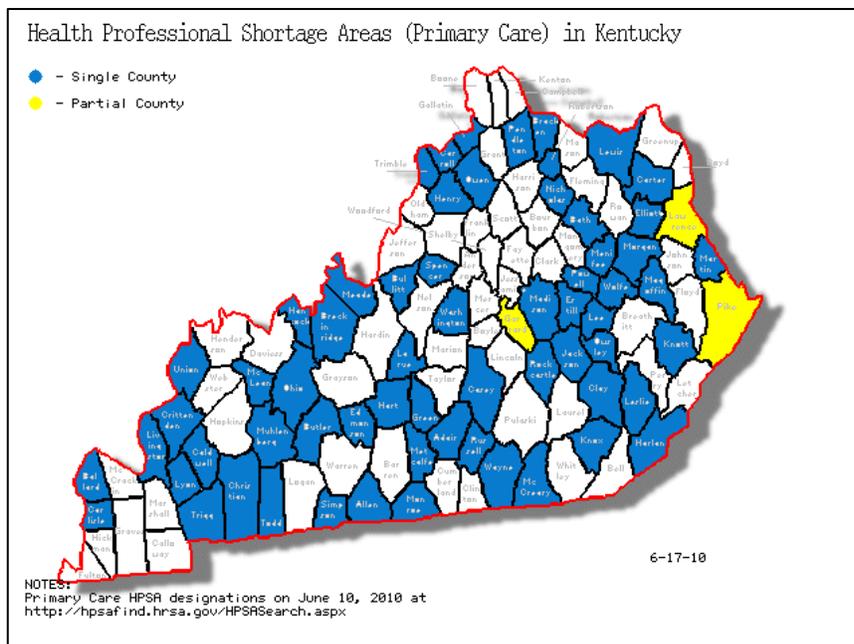
As noted by the Health Care Access Branch, HPSA designation brings many benefits to a community or county. Many federal programs depend on the shortage designation to determine eligibility or as a funding preference, including scholarship/loan repayment programs and Medicaid incentive funding programs. HPSA designation information presented in this

⁶⁴ Source: Health Care Access Branch. Accessed 06/19/10 at <http://chfs.ky.gov/dph/info/dpqi/HPSA.htm>.

document was acquired at the Bureau of Primary Care website at <http://hpsafind.hrsa.gov/> on June 10, 2010.

Primary Care HPSA Designations

Kentucky currently has 63 counties with single-county and three counties with partial county designations (Pike, Garrard and Lawrence). Regions with the highest concentration of HPSA designations are the Cumberland and Mississippi Plateaus. As noted in a press release by the Kentucky Primary Care Association in April of this year, “... only 28% of Kentucky’s primary care physicians work in rural areas, while 43 percent of the state’s population lives in these regions”⁶⁵.



Other primary care providers in short supply in Kentucky and nationally include nurses and certified nurse practitioners, dentists and dental hygienists, mental health professionals, nutritionists and social workers.

Kentucky fares better than most states with its ability to provide its citizens with health insurance coverage; however, there is always opportunity for improvement until every Kentuckian is covered. Currently, there are over 67,000 Kentucky children who are qualified to receive care through the Kentucky Children’s Health Insurance Program (KCHIP) or Medicaid but are not yet enrolled. With every state’s budget straining against the seams, Kentucky needs to get creative with its capacity and resources to provided health insurance coverage for its citizens through state programs such as Medicaid, Health Care Access, and Local Health Department services.

Partners to improve Kentucky’s capacity for direct care include the Kentucky Primary Care Association, Kentucky Health Department Association, Pikeville College School of Osteopathic Medicine and major academic institutions (University of Kentucky, University of Louisville, Eastern Kentucky University, Western Kentucky University, Morehead State University and others). Details about these and other partnerships are included within Section 2 “Partnership Building and Collaboration Efforts”.

⁶⁵ Bishop, LA. Kentucky’s primary care provider shortage – and the National Health Service Corps’ possible solution. Accessed 06/19/10 at http://www.healthkentucky.org/index.php?option=com_contentandview=articleandid=93andcatid=1andItemid=54

Dental HPSA Designations

There are 22 counties currently designated as Dental HPSA's in Kentucky with many more anticipated to qualify for designation and targeted for future efforts. Dental provider shortages permeate the state, occurring primarily in the Cumberland and Mississippi Plateau regions.

Kentucky is fortunate to have two dental schools. One is located at the University of Louisville and the other at the University of Kentucky (in Lexington) with less than one hundred miles separating these two schools. However, while a substantial number of new dentists are *trained* in Kentucky, relatively few *remain* in the state following graduation and even fewer open rural practices. At an average, 55 students enroll into each of the schools every year. As part of their training, the students treat patients during their second, third and fourth year of school. In addition to the dental schools, there are six dental hygienist programs in Kentucky, located in Bowling Green, Henderson, Louisville, Lexington, Paducah and Prestonsburg. Also, there are 20 Federally Qualified Health Centers in Kentucky, 11 of which provide dental services.

To study access to dental care, the State Office of Oral Health (KDPH) commissioned a dental provider workforce study using funding provided by the Maternal and Child Health Bureau's Oral Health Collaborative Systems Grant in 2005. The University of Louisville Health Sciences Center was selected for this project which had two major goals. First, to examine and analyze Kentucky Board of Dentistry data sets from 1998-2006 and second, to survey dentists on various practice aspects.

Study details are posted on the Kentucky Department for Public Health Office of Oral Health website (<http://chfs.ky.gov/dph/info/dpqi/oralhealth.htm>) but revealed substantial shortages in the number of practicing dentists in Appalachia (3.8/10,000 population), Western Kentucky (4.1/10,000 population) and Northern Kentucky (4.6/10,000 population). This compares to the Kentucky's total of 5.6 practicing dentists per 10,000 population which is lower than the ADA's national projection of 6.0 active dentists per 10,000 population.

The second portion of the study which examined practice norms reported the following⁶⁶:

- Approximately two-thirds of survey respondents are individual proprietors
- 29% of respondents reported having no hygienists
- 26% of respondents allow their hygienists to administer local anesthesia
- 28% of respondents accept Medicaid/KCHIP
- 39% are accepting new Medicaid/KCHIP Patients
- 2% of dentists plan to retire in one year, 12% in 2-5 years and 27% in 6-10 years.

Further, if you were a new Medicaid client seeking dental care, if you could find a dental provider, they would be most likely to accept new Medicaid patients if you lived in Appalachia. Western Kentucky providers were the next group who were most likely to accept new Medicaid

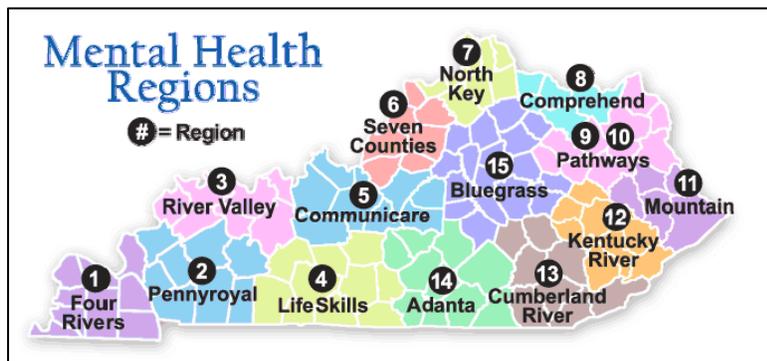
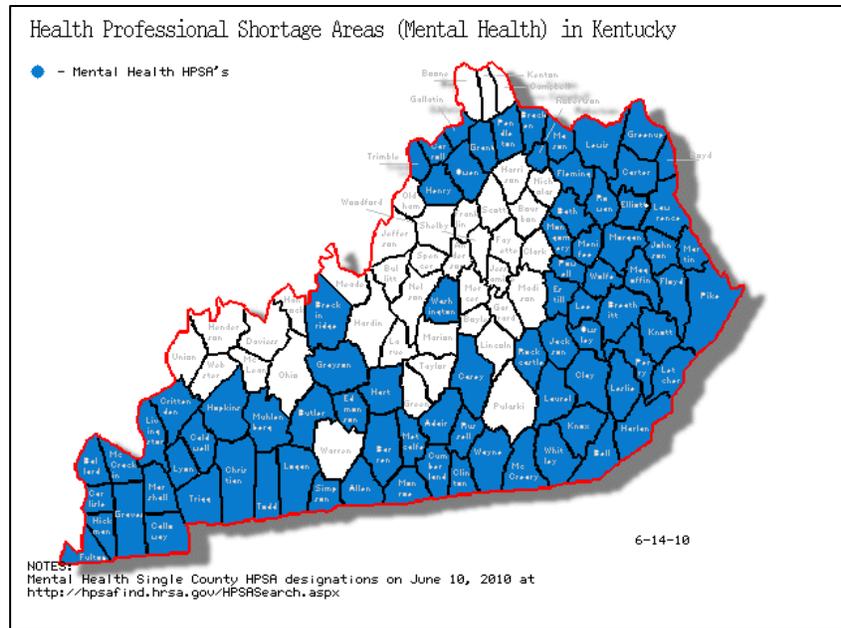
⁶⁶ Peterson, MR, Williams, JN, Mundt, C. Kentucky Dental Provider Workforce Analysis: 1998-2006. University of Louisville, Health Sciences Center and the Kentucky Department for Public Health. Accessed 06/19/10 at <http://chfs.ky.gov/dph/info/dpqi/oralhealth.htm>.

clients. Dental providers in the Central, Northern and Louisville areas often do not accept Medicaid patients.

A more recent study, conducted in 2007 by University of Kentucky researchers and published in the Journal of Public Health Dentistry, confirmed these findings. Using data from the Kentucky Board of Dentistry for practicing dentists in 2007, they identified 1,978 general practice dentists in the state, with 66% of these

located in urban areas, 14% in rural areas and 20% in Appalachia⁶⁷. Pediatric specialists were rare throughout the Commonwealth. With a total of 76 practicing in the entire state, 75% were located in urban areas, 7.9% (6 dentists) in rural areas and 17.1% (13 dentists) in Appalachia⁶⁸.

The authors noted provider disparities in like regions and concluded that “...the number of dentists per unit population will decrease over time in the near future, likely widening this disparity in rural and underserved areas”⁶⁹.



Mental Health HPSA Designations

As of June 10, 2010, 81 out of 120 Kentucky counties were designated as Mental Health Professional Shortage areas.

Kentucky's has 15 Mental Health Regions which are geographically distinct when compared to Area

Development Districts and Health Department Districts. Programs for these districts are coordinated by the Department for Behavioral Health, Developmental and Intellectual Disabilities.

⁶⁷ Saman DM, Arevalo O, Johnson AO. The dental workforce in Kentucky: current status and future needs. Journal of Public Health Dentistry. 2010 Mar 15. [Epub ahead of print]

⁶⁸ Ibid

Within this department, the Division of Behavioral Health (DBH) was created in 2004 as a result of the merger of two divisions (Substance Abuse and the Mental Health) and charged with the administration of state and federally funded programs as well as with the provision of services across the state. This merger reflects the strong correlation between poor mental health and substance abuse and is expected to reduce treatment barriers for both through the unification of these programs⁷⁰.

The Kentucky Department for Public Health, Division of Maternal and Child Health is currently forging new and renewed relationships with staff in the Division of Behavioral Health. Of particular importance is the need for population-based data for mental health and substance abuse. While treatment data is available from several sources, identifying a true picture of need throughout the Commonwealth has proven to be difficult. Part of this is due to the self-reported nature of data associated with substance abuse and mental health. However, if we are to meet the needs of Kentucky's maternal and child population, partnerships and collaborations between the two agencies must continue.

Local Health Departments

The Kentucky Department for Public Health (KDPH) state and local Maternal and Child Health (MCH) programs continue to meet the needs of our women, infants and children through a multitude of services available through 57 local and district health departments, with clinics in 120 counties. The range of direct services provided encompass family planning, prenatal, well-child care, school health, adolescent and adult health screenings, and the provision of preventive health education to parents and caregivers, children, adolescents, and young adults. The health departments across the state play a major role in assuring safety net services are available for people in need.

Other services provided by local health departments (LHDs) differ across the state by consumer need. Core services provided in all communities include enforcement of public health regulations, surveillance of public health, communicable disease control, public health education, public health policy, families and children at risk reduction, and disaster preparedness.

LHDs provide oversight, education, and assurance of compliance with all public health laws, federal, state, and local, designed to protect and promote the health of the public, while minimizing health and safety risks. They also monitor public health conditions through collection, analysis, and sharing of information. Through immunizations, investigations, education, and treating outbreaks, public health strives to control communicable disease.

Commission for Children with Special Health Care Needs (CCSHCN).

The Commission for Children with Special Health Care Needs (CCSHCN) provides therapeutic direct medical services to Medicaid eligible children. When the children are Medicaid-eligible, these services are billed to Medicaid through a memorandum of agreement with the Department

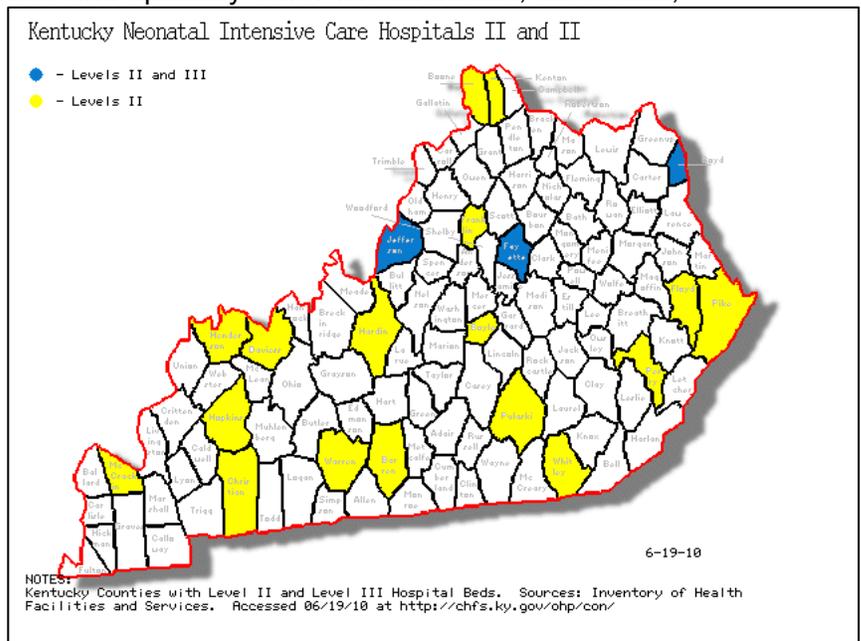
⁷⁰ Division of Behavioral Health, Kentucky Cabinet for Health and Family Services. Accessed 06/19/10 at <http://mhmr.ky.gov/mhsas/default.asp?sub2>

for Medicaid Services. CCSHCN also provides nursing consultative services for children in the foster care system under a memorandum of understanding with the Department for Community Based Services. CCSHCN maintains numerous relationships with other state agencies in order to streamline services for children with special healthcare needs throughout communities in the state. CCSHCN receives 34.9% of the MCH block grant funding through a contract with DPH to support the many programs they provide throughout the state.

Primary Care Centers/ Federally Qualified Health Centers (FQHC)

Kentucky has 18 primary care sites that receive federal funding and operate through licensed primary care centers and rural health clinics; and these have approximately 58 service locations including a mobile van in 35 underserved counties of the state. The importance of primary care is more widely recognized and Primary Care centers cover all of the life stages - prenatal, pediatric, adolescent, adult and geriatric. In addition to offering primary care services, other services offered at these locations include: Dental, Mental Health/Substance Abuse, OB/GYN, Pharmacy, Other Professional Services and Specialty Care. The affordable, accessible,

comprehensive and continuous nature of primary care makes it a vital element to the health care services provided in Kentucky. Formal linkages and collaborative efforts between primary care centers and local health departments vary throughout the state. In 2005, 224,183 individuals received services in the Primary Health Centers. Three Primary Health Centers focus their services toward the homeless and seasonal/migrants farm workers.



Regionalized Perinatal Care

Another critical component of access to care is the ability of pregnant women, infants and children to levels of care appropriate to their risk and needs. This is particularly important for women with high risk pregnancies and sick neonates. Kentucky’s neonatal intensive care beds are regulated by the certificate of need process in the Office of Health Policy under the Kentucky Cabinet for Health and Family Services.

Within the agency resides the office of the Certificate of Need (CON), which “...controls growth of unnecessary, duplicative and underused health care services, and Health Policy

*Development, which works to apply best practices and innovative strategies from the private sector and other states to benefit Kentuckians*⁷¹.

Local hospitals must commit on their application for a CON for neonatal beds to follow consistent with the National Guidelines for Perinatal Care, Sixth Edition, published jointly by the American Academy of Pediatrics and the American College of Obstetrics and Gynecology. However, once they obtain their CON for neonatal beds, there is no subsequent process to assure this alignment. The Cabinet's Office of Inspector General (OIG) investigates complaints against hospitals, including complaints about neonatal care, but currently the OIG has no standards for neonatal care in their hospital licensing regulations. The CON office and the OIG are currently working together to address these issues.

Kentucky's definitions for levels of NICU beds still follow the pre-2004 recommendations of the AAP; they are currently under consideration to update them to the new designations, but this will also involve updating payment regulations in the Medicaid program. The two major universities in the state, University of Kentucky and University of Louisville, serve as the states Regional Perinatal Centers. They have comprehensive perinatal services with maternal-fetal medicine specialist, neonatologists, the full range of pediatric subspecialties, and pediatric surgery including open heart surgery for infants. They provide outreach, specialty expertise, referral and transport, and neonatal follow-up services. Another hospital with a large delivery service in Louisville is licensed for Level III neonatal beds, and one Level III bed is licensed in Ashland, KY's NICU. These units do not have capabilities for pediatric surgery or ECMO, but do not restrict their care by weight, gestational age, or need for ventilation. Kentucky mothers and infants are also served by Level III NICU's at Vanderbilt, Cincinnati, and Huntington WV (affiliated with Marshall University).

Kentucky has 56 hospitals that provide labor and delivery services. Of those, 26 have some designation for Level II Neonatal beds (including the Level III hospitals). Throughout the state, there are 267 Neonatal Level II Beds and 165 Neonatal Level III Beds⁷². However, there are issues of maldistribution which favor urban areas and leave rural areas with limited accessibility to appropriate levels of care in their regions. Only about 8 of the Level II hospitals that are not part of Level III services have obtained full time neonatologists, due to the difficulty of recruiting neonatologists to rural areas with low volume delivery services. The regionalization plan that was developed in 1978 assigned one Level II NICU for each of Kentucky's 15 Area Development Districts, but many of these never developed to the level of care that would have provided a state-wide, tiered system. In addition, market forces, particularly in those places who did recruit neonatologists, have altered referral patterns for perinatal care.

More information about Kentucky's Perinatal System of Care may be found in the Application for 2011 and Annual Report for 2009 under National Performance Measure #17.

⁷¹ Source: Kentucky Cabinet for Health and Family Services, Office of Health Policy. Accessed 06/19/10 at <http://chfs.ky.gov/ohp/>

⁷² Ibid.

4. b. Enabling Services

Because Kentucky's 2011 Application and 2009 Annual Report address capacity details of Kentucky's Cabinet for Health and Family Services including pertinent legislation, agency structure, key personnel and resources (Agency Capacity Sections III.B and III.D), this portion of the Needs Assessment narrative will serve to briefly highlight unique *state-level* programs and partnerships. For this same reason, information about federal initiatives common to all states (Medicaid/SCHIP/EPSTD, WIC) will not be discussed in detail. Programs are listed in alphabetical order.

Breastfeeding

The Kentucky WIC program within the Department for Public Health, partners with many agencies, groups, providers and professionals throughout the Commonwealth to help promote and improve breastfeeding rates. There are breastfeeding coalitions across the state as well as private providers and universities that work with pregnant women to encourage both initiation and duration of breastfeeding. In addition, each local health department has a Breastfeeding/WIC Coordinator that provides education, support, classes, supplies, and numerous other resources for promoting and encouraging breastfeeding and supporting lactating women. In several communities, the WIC program also has an innovative breast feeding peer counselor support program that uses technology not only for training, but during the counseling sessions to provide consistent, accurate responses to the most common breastfeeding challenges. Breastfeeding across the state is supported by the state-wide Breastfeeding Coalition. More information is available at:

<http://chfs.ky.gov/dph/mch/ns/breastfeeding.htm>

Family Resource and Youth Service Centers (FRYSC)

The Division of Family Resource and Youth Service Centers within the Kentucky Cabinet for Health and Family Services coordinates and administers Kentucky's community-based FRYSCs in partnership with the Kentucky Department for Education. The division provides administrative support, technical assistance and training to local school-based Family Resource and Youth Services Centers (FRYSC). The primary goal of these centers is to remove nonacademic barriers to learning as a means to enhance student academic success.

Each center offers a unique blend of programs and services determined by the needs of the population being served, available resources, location and other local characteristics. The mission of FRYSC is to enhance students' ability to succeed in school by developing and sustaining partnerships that promote:

- Early learning and successful transition to school
- Academic achievement and well-being
- Graduation and transition into adult life

FRYSCs have established a record of success based on improved student performance in class work, homework and peer relations as reported by teachers. Parents, too, report they experience greater satisfaction and involvement with the schools as a result of assistance

through their local FRYSCs. More information about Kentucky FRYSCs is available at: <http://chfs.ky.gov/dfrcvs/frysc/>

First Steps

First Steps is Kentucky’s Part C Program required by the Individuals with Disabilities Education Improvement Act of 2004. It is a statewide system that identifies and provides early intervention services to children with developmental disabilities from birth to age 3 and their families. First Steps offers comprehensive early intervention services through a variety of community agencies and service disciplines and is administered by the Department for Public Health in the Cabinet for Health and Family Services.

First Steps, the Kentucky Early Intervention System, participates in the Child Find system with various levels of collaboration and data sharing for programs serving infants and toddlers and their families. These programs include the Commission for Children with Special Health Care Needs, the Early Hearing Detection and Intervention program, the Birth Registry and Surveillance Registry, Newborn Metabolic Screening Program, Early Head Start, and Medicaid. First Steps also collaborates with the Health Access Nurturing Development Services (HANDS) program, and the Early Childhood Community Councils. First Steps is based at the Kentucky Department for Public Health at <http://chfs.ky.gov/dph/firststeps.htm>

Giving Infants and Families Tobacco-free Starts (GIFTS)

The GIFTS Program is available for all pregnant women receiving services at the local health departments in the Kentucky River Area Development District (serving Knott, Lee, Leslie, Letcher, Owsley, Perry and Wolfe Counties), Knox County Health

Table 13: GIFTS Progress from February 11, 2008 through December 31, 2009	
# Pregnant Smokers Identified	1,519
# Pregnant women enrolled in GIFTS	795
# GIFTS Participants who have set quit dates	386 (48.6%)
# GIFTS Participants completing fax referral for the Kentucky Tobacco Quit Line	333 (41.9%)
# GIFTS Participants who have quit smoking	178 (22.4%)
# of positive screens for depression, domestic violence, social support, and second-hand smoke	918

Department and Whitley County Health Department. Through GIFTS, all pregnant women will be screened for smoking status and local health department practitioners will advise smokers about the importance of quitting, referring them to the GIFTS supporter in their local health department.

The GIFTS supporter provides not only traditional case management services to these women, but also an individualized supportive program to facilitate smoking cessation. This includes:

- Completing assessments for depression, social support, domestic violence and a household survey; making referrals as appropriate
- Assisting clients with referrals to Kentucky’s Tobacco Quit Line
- Providing tailored educational materials including health effects for mother and baby, benefits of quitting, tips for quitting and self-help materials

- Monitoring expired carbon monoxide levels
- Providing “GIFTS” (incentives) to participants including a water bottle filled with items to support smoking cessation, a baby bib and a postpartum gift
- Completing a minimum of five counseling and support visits for women enrolled in the first trimester. Contacts will occur during the first, second and third trimesters, within a week of delivery, and at least one postpartum contact within the year following delivery. Additional follow-up may occur as needed by the individual participant.

For more information about GIFTS, contact Joyce Robl at the Kentucky Department for Public Health: 502-564-3756 x 3768

HANDS

The Health Access Nurturing Development Services (HANDS) program is a voluntary state-wide home visitation program for new and expectant parents. First time parents (mom or dad) can be enrolled any time during the pregnancy or until the child is 12 weeks old. The HANDS program identifies those at risk through a universal screening tool, does a comprehensive assessment for families who accept services, and makes referrals to/for basic needs, child care, domestic violence, education, employment, First Steps, health department, mental health, oral health, physician care, smoking cessation, substance abuse and transportation. HANDS sites, in all 120 of Kentucky’s counties, work with collaborative partners to provide an opportunity to all first time mothers or first time fathers to participate in the HANDS program. A population-based program, HANDS serves than 10,000 Kentucky families annually. Independent evaluations show that HANDS home visiting is effective in reducing preterm birth, low birth weight, and infant mortality, and improving child development, ER utilization, and family self-sufficiency. The HANDS Program is coordinated by the Kentucky Department for Public Health with more information available at <http://chfs.ky.gov/dph/mch/ecd/hands.htm>

HANDS Testimonial ~

When we didn't have money for baby's milk, you always helped me get it. And helping us get food when we didn't have any. If it hadn't been for you, I would have lost it all together. You were the only one I could call and talk to.

--Magoffin County

Healthy Start

Kentucky has two federally-funded Healthy Start Programs in Jefferson County (Louisville) and Whitley County (Voices of Appalachia Health Start). The purpose of both initiatives as with all Healthy Start programs is the reduction of infant mortality through an array of comprehensive services including home visiting, resource linkages and other outreach services. This is accomplished in partnership with communities using community-level councils. Services vary depending upon the individual needs of the community.

Louisville Healthy Start was first funded in 1998 and is currently operational in three of Louisville’s most disadvantaged neighborhoods: Bridges of Hope, Ujima and Northwest. In FY 2009 the program received \$ 1,275,000 from the Maternal and Child Health Bureau⁷³. More

⁷³ Kentucky State Snapshot. Accessed 06/27/10 at <https://perfddata.hrsa.gov/mchb/TVISReports/Default.aspx>

information about the Louisville Healthy Start is available at:

<http://www.louisvilleky.gov/Health/PersonalandPopulation/healthystart.htm>

Whitley County's Healthy Start was also funded beginning in 1998 and serves a rural community which has low levels of education, geographic isolation and high levels of poverty. Voices of Appalachia Healthy Start offer outreach, case management, depression screening and referral, interconceptual care and health education. In FY 2009, Whitey County was awarded \$ 400,000 from the Maternal and Child Health Bureau for continuation of Voices of Appalachia Healthy Start⁷⁴. More information about this program is available at:

<http://www.whitleycountyhealthdepartment.com/Index.html>

For more details about both Healthy Start Grants including objectives, coordination and evaluation, please see Kentucky's "State Snapshot" created by the Maternal and Child Health Bureau at <https://perfddata.hrsa.gov/mchb/TVISReports/Default.aspx>. Links to current applications and those from past years are available under "Discretionary Grants".

KIDS NOW

Since 1999, the Governor's Early Childhood Task Force in Kentucky (KIDS NOW) has promoted a collaborative multi-agency approach among public and private agencies that provide services/ resources to support families and communities. The goal of this effort is to ensure that *"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."*

Administered by the Division of Early Childhood Development of the Kentucky Department of Education, public health components include the Healthy Babies Campaign, Folic Acid Supplementation, Substance Abuse Cessation, Eye Examinations, Oral Health, Immunizations, Universal Newborn Hearing, HANDS, Early Childhood Mental Health Program and Children's Advocacy Centers. To enhance early care and education, the program includes STARS for KIDS NOW (a quality rating system program), Child Care Health Consultation, Community Early Childhood Councils, Scholarship Fund, a Professional Development Framework and First Steps. More information about KIDS NOW and programs within the initiative are available at: <http://www.education.ky.gov/kde/instructional+resources/early+childhood+development/>

Kentucky Childhood Lead Poisoning Prevention Program – Case Management System

According to state statute KRS 211:903, blood lead testing for lead poisoning is required for recipients of the Commonwealth's Medical Assistance Program and is made part of the child's regular Immunization, Well Child and Early Periodic Screening, Diagnosis and Treatment (EPSDT) visits, provided by pediatricians and local health departments to identify those children with an elevated blood lead level (EBLL) or lead poisoning. At-risk prenatal patients are identified through the verbal lead risk assessment questionnaire.

⁷⁴ Kentucky State Snapshot. Accessed 06/27/10 at <https://perfddata.hrsa.gov/mchb/TVISReports/Default.aspx>

At-risk children should routinely be screened by a blood lead test at ages 12 and 24 months and anytime an at-risk child 25-72 months does not have a documented blood lead test. At-risk children include those living in targeted zip codes, on Medicaid, and those children identified through the verbal lead risk assessment questionnaire. Blood lead tests are recommended for all at-risk prenatal patients.

Once a child is identified as having an elevated blood lead level (EBLL), case management is provided by the child's local health department. Education is provided as required by KRS211:904 on lead poisoning prevention. Education includes concepts such as increasing the child's hand washing with soap and water as germ gel type sanitizers do not remove lead. Education on home cleaning techniques such as daily damp dusting, wet mopping, and vacuuming are emphasized for reducing lead contamination. A diet high in Calcium, Iron, Vitamin C and also a diet low in fat is recommended and reviewed to reduce lead absorption and to facilitate lead elimination. Follow up blood lead screening is provided by the local health department or by the child's Primary Care Physician (PCP). Collaboration between the child's PCP and Local Health Department is essential in ensuring positive health outcomes for children with elevated lead levels. Possible lead risk sources are identified for children with an EBLL according to KRS 211:905 through home visits by a nurse and an onsite visualization of the home by an environmentalist. If Lead Poisoning is identified in a child, a risk assessment performed by a Certified Risk Assessor is completed on the home.

When a prenatal patient is identified as having a blood lead level of 5µg/dL or greater, a home visit is initiated to identify possible lead sources and to provide education on the lead elimination diet.

The Cabinet for Health and Family Services Department for Public Health provides technical for the local health departments through the Nurse Consultant/Health Educator. Children with elevated blood lead levels and lead poisoning that are being managed at the local health department are also followed by the KY CLPPP Nurse Consultant, entering updates and interventions completed by and as sent by the local health department case managers.

When a child with an elevated blood lead level is reported to the Cabinet, it is usually by way of the Local Health Department Case Manager. Children who are identified with an EBLL through laboratory reporting and who are not actively in the KY CLPPP Case Management System are reported to the local health department and provided with information to initiate case management at the local level.

Healthy Babies Are Worth the Wait (HBWW)

In partnership with national March of Dimes and Johnson and Johnson, the Kentucky Department for Public Health piloted a community-based prematurity prevention initiative starting in 2007. In HBWW, community health leaders, including hospitals, health departments and local March of Dimes partners work on (a) implementing multiple interventions known to work to prevent preterm birth and (b) improving systems of care in their community so that these interventions reach their target audiences, which include providers, patients, and the public.

The pilot/demonstration project was built on an innovative, ecological model designed to work in "real world" settings, where a multitude of factors influence outcomes, not a single intervention.

The program focused on Late Preterm birth, since Kentucky's 2006 data had revealed late preterm rates were driving our rate in preterm birth overall. New information on late preterm infants was just beginning to be published in peer reviewed literature, which highlighted the increased risks, complications, and immaturity of the brain development in these infants. The "brain card", developed by the HBWW initiative, now adapted and distributed by March of Dimes, enables providers to talk with patients about the importance of brain development in the last 4-6 weeks of pregnancy. The four core components of HBWW are Partnerships, Provider initiatives, Patient Initiatives and Public Initiatives. Initiatives include Information, Education, and Engagement/Implementation.

Prior to program implementation, Kentucky's rate of preterm birth was continuing to rise. After the program was implemented, Kentucky had the largest decline in preterm birth of any of our surrounding states. While this is an association and not causality, it is a breakthrough for preterm birth prevention in Kentucky. March of Dimes is sponsoring a roll out to more Kentucky hospitals and exploring a roll out of the program to other states.

Kentucky TeleCare Network

Many rural Kentuckians are isolated from specialty healthcare services. They either cannot or will not travel to see providers that are not available in their home community. The statewide Kentucky TeleHealth Network (KTHN) uses videoconference technology to bring together patients and providers from anywhere in the state. Participants can see and hear each other just as if they were in the same room and medical peripheral devices such as electronic stethoscopes and specialty cameras allow providers to perform diagnosis and treatment for many health conditions.

These services are best used in collaboration with the medical home. KTHN is currently able to deliver, through specialists at University of Kentucky and University of Louisville, several specialty services that support children's needs, including Cardiology, Dermatology, Psychiatry, Developmental Pediatrics (treating conditions ranging from ADHD to the Autism Spectrum Disorders), Pulmonology and Gastroenterology. The technology is available in over 200 Kentucky hospitals, clinics, public health departments, public school clinics and community mental health centers.

Kentuckians should not be penalized with poor access to needed healthcare simply because they choose to live in a rural community. Telehealth is becoming more widely used across the country to improve access to care, reduce expensive and sometimes dangerous travel and speed-up the time to diagnosis and treatment by reducing barriers to care. However, its use cannot substitute entirely for face-to-face, hands on interaction for all cases. It will not replace local primary care providers nor eliminate the workforce shortage issues. Ideally, telehealth will

**Kentucky TeleCare -
Connecting people,
Not just technology**

"People can be telling you he's fine, but it meant a lot to me just to get to see and hear him."

Ruthann Thomas of Lawrenceburg was connected from her home to her 4 month old son Tyler who had just undergone heart surgery. Ruthann could not be close to him because she had contracted Chickenpox from Tyler's twin brother.

provide a support function and much needed subspecialty consultation to assist local providers in delivering quality care without patients having to travel extended distances.

Educational Mission: KTHN extends education from the University Medical Centers to community-based healthcare professionals and reaches out to energize children in public schools to pursue careers in healthcare.

Research Mission: Telehealth brings important medical research and clinical trials from the University Medical Centers to rural communities.

Service Mission: Videoconferencing can help connect isolated hospital patients to their family at home and has been used to connect families to soldiers serving overseas.

More information about Kentucky TeleCare is available at <http://www.mc.uky.edu/kytelecare/>

4. c. Population-based Services

Because Kentucky's 2011 Application and 2009 Annual Report address capacity details of Kentucky's Cabinet for Health and Family Services including pertinent legislation, agency structure, key personnel and resources (Agency Capacity Sections III.B and III.D), this portion of the Needs Assessment narrative will serve to briefly highlight unique *state-level* programs and partnerships. Programs are listed in alphabetical order.

Child Fatality Review

Child Fatality Review is critical to preventing injury and death to children in Kentucky and combines the expertise of the local coroner, health department, Department for Community Based Services, law enforcement, and other critical partners. By working as a team, these agencies gather information that may have otherwise been missed had the death not been reviewed. The team assists the coroner to determine the exact cause of death, ensuring that other children in the home are safe, making certain grief counseling and community resources are offered to the family, identifying factors that may affect other children, and ruling out intentional injury.

This year child fatality staff began a close partnership with staff in the Division of Child Based Services and the State Medical Examiner in order to share and examine data on infant and child deaths. A child maltreatment committee is the newest endeavor of the CFR State Team comprised of team members who voluntarily meet in conjunction with regular state meetings to discuss findings in order to develop and recommend new prevention strategies. The teams first task will be to explore deaths related to co-sleeping.

Kentucky also publishes an annual report examining incidence and prevalence for child deaths called the *Kentucky Child Fatality Review Annual Report*. Required by state statute, this annual report is available for public review at <http://chfs.ky.gov/dph/mch/cfhi/childfatality.htm>. Also located at this site are resources for coroners, the program manual for child death review, state statutes associated with Child Fatality Review and other materials.

Childhood Lead Poisoning Prevention Program

The Childhood Lead Poisoning Prevention Program (CLPPP) offers a comprehensive approach to preventing lead poisoning in children less than six years of age. Medicaid's Early Periodic Screening Diagnosis and Treatment and Well Child programs, the WIC program, and private providers identify children with elevated blood lead levels by performing blood lead testing. The laboratory results are reported to CLPPP and the child's local health department, who assure health education, case management and environmental investigation services are performed. CLPPP provides a variety of secondary and primary prevention services including case management, medical and environmental services, epidemiologic studies, education and connections to other professionals and programs. More information about Kentucky's Childhood Lead Program may be viewed at: <http://chfs.ky.gov/dph/mch/cfhi/clppp.htm>.

Kentucky Oral Health Program

Kentucky's Oral Health program provides population based services to all of Kentucky. The water fluoridation rate of Kentucky is 98%, one of the highest in the nation. The Oral Health program has trained public health nurses to apply fluoride varnish treatments to the teeth of young children; 2,000-3,000 treatments are applied state-wide each month. Fluoride varnish is now reimbursed by Medicaid and hundreds of additional providers have been trained, through collaboration with the Kentucky Chapter of the AAP. The Dental Sealant program provides funding to local health departments who have local dentists to provide sealants to elementary school students.

Recently the Oral Health program received grants for three major initiatives which will address infrastructure issues. HRSA has funded a curriculum and training to train general dentist who practice in rural areas in pediatric-specific techniques. The goal is that more general dentists, who may already be practicing in rural areas, become more comfortable seeing pediatric patients and will accept children from their communities for care. Two other grants fund community coalitions in 24 sites to develop a needs assessment of oral health needs in their community and a plan to address those needs. Additional information on the Kentucky Oral Health Program is provided in the Title V 2009 Annual Report and 2011 Application, as well as in the other sections of this document. Oral health was one of the major issues identified in the 2010 Needs Assessment process.

Kentucky Birth Surveillance Registry

The Kentucky Birth Surveillance Registry (KBSR) is organizationally located within the Kentucky Department for Public Health, Division of Maternal and Child Health. KBSR is a statewide surveillance system covering 55,000 live births and 380 stillbirths each year through a passive surveillance method with follow-up and quality control by medical records abstraction. This system identifies children from birth to five years of age with birth defects, genetic and disabling conditions. Recently funded by the Centers for Disease Control and Prevention to continue this work, KBSR plans to utilize the funding to make enhancements to the existing birth defects

surveillance system, use of the data for prevention programs, and referral of children identified by KBSR to early intervention services.

KBSR integrates data obtained from hospital discharge (UB-92) data and vital statistics (live births, fetal deaths, death certificates). Additional reporting sources include tertiary care neonatal intensive care units, genetics clinics, and medical laboratories. Objectives related to the data system in the upcoming year are established to improve case ascertainment, the timeliness of reporting, and the quality of data. In addition, KBSR plans to analyze the accumulated data from 1998 to 2008 and develop an ongoing annual report with this data. KBSR plans activities to promote the availability of Kentucky-specific birth defects data to the general public, health care providers, and individuals utilizing the data for research purposes.

The prevention of birth defects is an important aspect of KBSR. In the upcoming year, activities will be completed to reduce the rate of neural tube defects from 6.5/10,000 live and stillbirths in 2004 to 5.8/10,000 in 2009. KBSR will also collaborate with the Substance Abuse Prevention Program to identify activities to promote the awareness of the adverse effects of substance abuse on pregnancy.

KBSR has developed a process to refer children with established risk conditions to Kentucky's Early Intervention System, First Steps. Once implemented, the evaluation of these referrals will include determining a baseline for the number of children referred by KBSR per year, the identification of the percentage of these children that are subsequently enrolled in early intervention, and in future years, changes in the average age at which enrollment occurs for specific birth defects. For more information about KBSR, please visit contact Sandy Fawbush, RN, Branch Manager of Early Childhood Development at (502) 564-3756 ext 3563 or visit the KBSR website at <http://chfs.ky.gov/dph/mch/ecd/kbsr.htm>

Kentucky Immunizations Registry

The Kentucky Immunization Registry (KY-IR) is a confidential, population-based, computerized system for maintaining information regarding patient vaccinations. It will include persons served in the geographic area of the Commonwealth of Kentucky and its residents, regardless of the health care source. By cooperative agreement, it will participate in information exchange with the immunization registries of other states. Children's names can be entered into the registry at birth through a link with electronic birth records. When the KY-IR includes all patients in a geographic area and all providers report vaccination and immunization data, the registry will provide a single data source for all community vaccination partners. This enables the implementation of vaccination strategies and decreases the resources needed to measure, achieve, and maintain increased vaccination coverage levels. The Kentucky Immunization registry or immunization information system (IIS) will use the PHIN standards and implementation guides as referenced on the following web site: <http://www.cdc.gov/phn/activities/standards/index.html> .

The KY-IR offers potential benefits to parents, communities, healthcare systems, and the public health system. In addition to tracking the vaccinations children receive, the immunization registry can improve vaccine delivery by a) avoiding duplicate vaccinations, b) limiting the cost

of missed appointments through the use of reminder or recall notices, c) reducing vaccine waste, and d) reducing staff time required to find or produce immunization records or certificates. Information from KY-IR can provide the Department for Public Health and its partners with a rapid and reliable mechanism for evaluating vaccination coverage and patterns of use for specific vaccines, as well as assist in vaccine safety efforts, and vaccine inventory control.

For more information about KY-IR contact Heather Gatewood at (502)564-4478

Kentucky Injury Prevention and Research Center

The Kentucky Injury Prevention and Research Center (KIPRC) is a partnership between the Kentucky Department for Public Health and the University of Kentucky's College of Public Health that combines academic investigation with practical public health initiatives.

KIPRC's purpose is to decrease the burden of injury in the Commonwealth. This partnership is grounded in a belief that most injuries are preventable, cultivating a collaborative approach to problem solving. KIPRC works closely with both groups to reduce injury through education, policy initiatives, public health programming, surveillance, risk factor analysis, direct interventions, and evaluation.

KIPRC programs of particular importance to the MCH population include Pediatric and Adolescent Injury Prevention Program (through funding from the Division of Maternal and Child Health), Intimate Partner Violence Surveillance, Prevention of Fire-related Injuries, Injury Surveillance and Kentucky Violent Death Reporting System (described in detail later within this section). KIPRC is also contracted by the Department for Public Health to monitor Consumer Products Safety information and recalls. KIPRC also provides data specific to injuries and mortality associated with injury. More information about KIPRC is available at:

<http://www.kiprc.uky.edu/>

Newborn Metabolic Screening

Approximately 56,000 infants are born in KY each year. KY law mandates that all KY-born infants receive the newborn screening unless refused for religious exemption. Infants identified with a positive diagnosis will have prompt evaluation, diagnosis, and initiation of treatment that will prevent or reduce developmental delays, organ failure, and possibly even death. In 2005, Kentucky expanded its newborn screening to include all 29 disorders the March of Dimes recommends for screening (SB 24). Currently, the program screens for 49 disorders.

Following collection, blood spot specimens are mailed or transported from local hospitals to the Kentucky Division of Laboratory Services in Frankfort, Kentucky for analysis. The Kentucky State Lab recently announced their new Internet-based electronic laboratory information system called OUTREACH. Starting in March 2010, tests will be ordered and retrieved electronically, reducing turnaround time, decreasing risk for clerical errors and allowing result retrieval over the Internet. Staff training for this new process will be available through TRAIN (discussed further in Section d. Infrastructure Services).

For more information is available about the Kentucky State Lab <http://chfs.ky.gov/dph/info/lab/> and Kentucky's Newborn Metabolic Screening Program with resources for parents and providers at <http://chfs.ky.gov/dph/mch/ecd/newbornscreening.htm>.

Kentucky Violent Death Reporting System (KDVRS)

Recognized by the Centers for Disease Control and Prevention (CDC), violence is a nationwide health problem that results in over 50,000 homicides and suicides each year. In order to better understand why violent deaths occur, the CDC has developed the National Violent Death Reporting System (NVDRS), a nationwide state-based surveillance system designed to track trends and characteristics of violent deaths with the goal of reducing these deaths. The CDC has modeled the NVDRS after the Fatality Analysis Reporting System (FARS), which combines data from fatal traffic crash investigations and has the goal of reducing the rate of motor vehicle-related deaths.

In anticipation of becoming part of the CDC's NVDRS, and with the financial support of the Kentucky Department for Public Health (KDPH), a statewide Violent Death Reporting System for Kentucky was initiated in January 2002. Kentucky joined the NVDRS September 1, 2005 as one of 17 funded states. All participating states are required to collect information about violent deaths from the following investigating agencies: police departments, coroners, medical examiners, forensic crime laboratories and toxicology laboratories. For more information please see the project website at: <http://www.kvdrs.ky.gov/>

4. d. Infrastructure- Building Services

Kentucky has made substantial strides in its ability to collect, analyze and report data since the preparation of the last MCH Needs Assessment Document in 2005. Below are highlights which will provide the reader with an overview of new projects and programs supporting infrastructure within the Division of Maternal and Child Health. Staff short bios are not provided here but can be found in the 2011 Application and 2009 Annual Report in Agency Capacity Sections III.B and III.D.

Formal Inter-Agency Coordination

Kentucky has developed both formal and informal infrastructure to support services for maternal and child health populations. The Cabinet for Health and Family Services, which houses the Department for Public Health, also includes the Department for Community Based Services, the Department for Behavioral Health, and the Department for Medicaid Services, so leadership from all these departments report to the same Cabinet Secretary. In addition, the Department for Public Health works closely with the Department of Education on many initiatives. Some, but not all, of the more formal structures and relationships are listed here.

Early Childhood Development Authority: In 2000, landmark legislation created the Early Childhood Development Authority to oversee and coordinate Kentucky's early childhood programs, and committed 25% of Kentucky's Phase I Tobacco Settlement dollars to fund the early childhood initiative known as KIDS NOW (Kentucky Invests in Developing Success NOW!)

The Early Childhood Development Authority is a public-private partnership with diverse membership including many of the agencies listed below as well as child care directors, Head Start directors, United Way, business leaders, and academic experts in early childhood. The group developed a mission, vision and 20-year plan for early childhood programs in Kentucky. KIDS NOW encompasses many early childhood programs across many departments and divisions, including public health, HANDS Home visiting program, child welfare, mental health, substance abuse, child care, child care subsidy, child care quality rating systems, child advocacy centers, early childhood education and pre-school, Part C early intervention, Head Start, and Early Childhood professional development.

In addition this body oversees 65 Community Early Childhood Councils, who coordinate these services at the local level. The Early Childhood Development Authority meets quarterly to review the progress of programs including program evaluation results as well as budget. In addition, program leads meet quarterly in “Implementation meetings” to assure collaboration across programs. Kentucky is planning to add to this body to create the State Early Childhood Advisory Council now required of the state’s Head Start Collaboration Office, which is taking on a more visible role in developing comprehensive systems of care for early childhood in many states.

Early Childhood Mental Health: This program is a part of the KIDS NOW Initiative, and is co-administered by Public Health/ MCH and the Department for Behavioral Health through an MOA.

State Inter-Agency Council for Services to Children with an Emotional Disability: SIAC is a commissioner-level council that includes Commissioners for Medicaid, Public Health, Behavioral Health, Juvenile Justice, Community Based Services, and Administrative Office of the Courts. It also includes parent and youth representatives. It works to coordinate and problem-solve to assure a multidisciplinary approach to services for this population. The Commissioner for Public Health is the current chair.

School Nurse Leadership: Legislation established a position for a School Nurse Consultant in the Department for Education, and built in collaboration by requiring that Public Health/MCH pay half the salary of this position, which is done through a contract between the agencies. The Department for Public Health/MCH also has a school nurse consultant, and the two work closely on all issues related to school health nursing.

Coordinated School Health: CDC requires that this be a collaborative effort between Education and Public Health. In this case, Education receives the funding, hires one position there, and contracts with Public Health for a second position to lead this program. The two work closely to develop coordinated school health programs in local districts that implement the model of all 8 components.

Kentucky Transition Project: A collaborative funding effort of Public Health and Department of Education, the Transition project has a full time staff person for training and technical assistance to local communities to develop transition plans for early childhood, including Part C Early Intervention, Pre-K, Head Start, and other community support to families of young children.

Trainings for local agency staff as well as parent guides have been developed and implemented in communities across the state.

Department of Medicaid Services: The Department for Public Health has contracts with the Department of Medicaid for many of the services provided to maternal and child health populations. These include the HANDS home visiting program, the Part C Early Intervention Program (First Steps), the EPSDT and KCHIP Outreach program, and the Preventative Health Services program carried out through local health departments.

Department of Agriculture: The WIC program in MCH has an MOA with the KY Department of Agriculture to administer the WIC Farmer's Market program, providing fresh fruits and vegetables to WIC participants.

University Services: The Title V Program and Maternal and Child Health Division contract with universities for many infrastructure services, including pediatric assessment training, well child and school health updates for local health department nurses, pediatric obesity services, teen pregnancy prevention program, pediatric injury prevention specialist technical assistance, maternal mortality review, and perinatal quality initiatives.

Academic Institutions

Both of Kentucky's largest cities (Louisville and Lexington) have major universities, the University of Louisville (<http://louisville.edu/>) and the University of Kentucky (<http://www.uky.edu/>). Each of these schools has a medical, nursing and dental school and a school of public health. Both undertake research activities and have teaching facilities that support public health initiatives. A third medical school, the Pikeville College School of Osteopathic Medicine (<http://www.pc.edu/pcsom/default.aspx>), is located in far eastern Pike County. Other universities with Schools of Public Health include Eastern Kentucky University (<http://www.eku.edu/>) in Richmond, and Western Kentucky University (<http://www.wku.edu/>) in Bowling Green. Eastern Kentucky University is more focused on Environmental Health and Community Health Education. Other Universities are supportive of Public Health including Kentucky State University (Frankfort) and Northern Kentucky University in Ft. Mitchell, Kentucky.

University of Kentucky Center for Excellence in Rural Health

The University of Kentucky Center for Excellence in Rural Health embodies a novel approach to improving rural communities: simultaneously addressing health, education and economic issues. Established in 1990 by legislative mandate, it acts as a conduit between rural needs and university resources. The center's statewide mission includes health professions education, the provision of health care services, research and community engagement.

To help accomplish this mission, UK's College of Health Sciences offers doctoral-level training in physical therapy and the College of Social Work provides master's-level classes at the center's headquarters in the Eastern Kentucky community of Hazard. This is an area of beautiful terrain, strong extended families and innovation in health care. Yet it, along with much of rural Kentucky, is plagued by persistent poverty and very serious health needs.

The center also offers a bachelor's degree in Clinical Leadership and Management. In all, there have been more than 300 graduates from the center's academic programs, which are focused on curbing the health personnel shortages within rural Kentucky.

The center houses the UK North Fork Valley Community Health Center. This facility provides "health care for the whole family" and hosts the East Kentucky family practice and dental residency programs, which provide a training ground for medical and dental school graduates seeking to serve rural areas. Nearly 80 percent of the family practice residency program's graduates now work in rural areas, with the vast majority based in Appalachian Kentucky.

Since 1994, the center's award-winning lay health worker program, Kentucky Home-place, has used trained paraprofessionals from rural communities to link thousands of medically underserved residents with available health and social services.

The center also houses the Kentucky State Office of Rural Health. The information, advocacy and technical assistant services provided by the office are specifically aimed at rural health issues. In addition, the office oversees the Kentucky State Loan Repayment Program, a recruitment tool used to attract providers to rural, underserved portions of the state.

Center research topics include rural health personnel supply, health status and access to care.

In 1997, the Center for Rural Health received the Pew Award for Primary Care, and three years later was named the country's Outstanding Rural Health Program by the National Rural Health Association. In both 2003 and 2004, UK's Rural Medicine Program, of which the Center for Rural Health is the largest component, was ranked in the Top 20 nationally by U.S. News and World Report. And the center's lay health workers division often has been replicated and recognized nationally for its innovation in access to health services and navigation of the health care system.

More information about the University of Kentucky Center for Excellence in Rural Health can be found at <http://www.mc.uky.edu/ruralhealth/>.

TRAIN

The Education and Workforce Branch staff in the Department for Public Health Division of Administration and Financial Management is responsible for maintaining and providing technical assistance to users of the *TrainingFinder Real-time Affiliate Integrated Network (TRAIN)*. TRAIN is a multi-functional Web-based training system for health organizations. Currently used in 27 states, the subscription to Kentucky's TRAIN system is paid for by the Kentucky Department for Public Health.

TRAIN is a free service the health organizations and individuals may use to find training information. Training content providers determine if programs are available to the general public or restricted to specific users. KDPH uses TRAIN to deliver organized, cost-efficient educational programs and training courses using a variety of formats, such as face-to-face, videoconference, Webcast, datacast, satellite and online modules. These programs are available for multiple disciplines and lay individuals. Since TRAIN is an online management

system these programs and training are available to anyone with computer access 24 hours, 7 days a week. The Module Development unit in the Education and Workforce Branch creates training modules for DPH, hospitals, local health departments and DPH partners.

The Kentucky Department for Public Health Distance Learning Network (KEN-NECT) is managed by the The Education and Workforce Branch. The branch is responsible for providing technical assistance and expertise to the multi-media systems used by CONNECT. KEN-NECT communicates training and other information to those involved with the Department of Public Health. The branch works with numerous communication methods, including 48 video sites, 64 satellite sites, live/archived Web-casting through TRAIN, datacasting to all local health departments, DPH and 127 hospitals and Podcasting. More information about TRAIN may be found at <http://chfs.ky.gov/dph/info/lhd/ewdb.htm>

Maternal and Child Health Analytic/Epidemiologic Capacity

Department for Public Health Data Users Group

Coordinated by Sara Robeson, MA, MSPH, senior epidemiologist with the Kentucky Department for Public Health Division of Epidemiology and Health Planning, the Data Users Group brings together all personnel currently working with data (epidemiologists, evaluators, and analysts) or *interested* in data for educational trainings and presentations. Meeting every other month, participants enjoy targeted presentations (such as the basics of survival analysis and how to run logistic regressions using SAS), pose questions or discuss challenges (software, IT, analytic procedures) with peer support paramount.

MCH Epidemiologic and Analytic Staff

Kentucky's capacity for epidemiologic assessment has increased substantially in the past five years with numerous positions adding either analytic or epidemiologic staff. With Tracey Jewell as the senior epidemiologist for the Division of Maternal and Child Health and Joyce Robl as SSDI Administrator and MCH Program Evaluator, other programs with epidemiologic support include Newborn Screening, the Kentucky Birth Surveillance Registry, Oral Health, Childhood Lead, and Child Fatality Review. The MCH epidemiology team meets monthly with the MCH Director to review projects and improve approaches to data collection and analysis.

Further, the Division of MCH is currently seeking an Epidemiologist 1 position funded through the SSDI grant. This individual will have direct responsibility for completing data analyses and epidemiological support for the Division including the PRAMS Pilot Project. Interviews will be scheduled in July 2010.

MCH Analyst Capacity Training

Utilizing funding provided by the State System Development Grant, Dr. Arne Bathke, a statistician from the University of Kentucky has also completed two trainings for MCH epidemiologists and data analysts. These trainings have been very well received and participants have commented on a major strength of these trainings being the ability to focus on

MCH related topics and the use of actual MCH data. The two trainings that were completed were on survival analysis and regression with a focus on logistic regression.

AMCHP Data Mini-grant Training (2009)

The Kentucky Department for Public Health, Division of Maternal and Child Health utilized funds from the Association of Maternal and Child Health Programs Data Mini-grant to complete two days of training on cost benefit and cost effectiveness analyses. Part-one of the training was completed on April 13, 2009 and part-two on May 6, 2009. Eighteen individuals participated in day-one of the training, with most participants returning for day-two activities.

Day one focused on didactic training and the topics included: discount rates and cost-benefit analysis; cost-effectiveness analysis; an overview of the Health Access Nurturing Development Services (HANDS) program; and a group discussion on planning an analysis of the HANDS program. The second day of training focused on group discussion and practical uses of the material. Several articles from newspapers were distributed on day one, and they were discussed during the second day of training. Using Kentucky's home visitation program, HANDS, the trainer also worked through cost analyses for this program. There was also an opportunity to discuss projects with the trainer following the completion of the training.

The trainings were completed by Dr. Scott Hankins. Dr. Hankins is an Assistant Professor with the College of Public Health at the University of Kentucky. He holds a Ph.D. in Economics from the University of Florida. His research investigates factors that affect neonatal health. He currently is studying the effect of state regulations (both insurance and hospitals) on neonatal health outcomes. He also is interested in how obstetricians respond to medical malpractice lawsuits.

Peer-Reviewed Publications and Presentations

In the past two years, Kentucky maternal and child health analytic professionals have contributed or will contribute to the field of MCH through publications and presentations.

In 2009, Dr. Ruth Ann Shepherd worked with colleagues Joyce A. Martin, MPH; Sharon Kirmeyer, PhD; and Michelle Osterman MHS at the National Center for Health Statistics to publish a data-brief on late preterm birth, entitled *Born a Bit Too Early: Recent Trends in Late Preterm Births*. This report highlighted the risk factors for infants born at 34-36 weeks of gestation and examined recent trends across the nation.

Division of MCH analytic professionals Tracey Jewell and Joyce Robl teamed up together and with Dr. Shepherd to contribute to both the 2009 and 2010 Maternal and Child Health Epidemiology Conferences and to the 2010 American Public Health Association Conference.

Table 14 briefly describes their papers, posters or oral presentations.

Table 14. Peer-Reviewed Papers and Presentations by KDPH MCH Personnel (2009-2010)			
Topic	Meeting or Journal	Kentucky Authors	Status
Born a Bit Too Early: Recent Trends in Late Preterm Births	NCHS Data Brief, No. 24. November 2009	Ruth Ann Shepherd, MD et al.*	Article
Prenatal Care Utilization in Kentucky: Are there demographic differences in receipt of care or merely a reflection of a new data collection method?	15 th Annual MCH Epi Conference, December 2009	Tracey Jewell and Ruth Ann Shepherd, MD	Poster Presentation
Epidemiological Analysis of Perinatal Outcome Data from Healthy Babies are Worth the Wait	138 th Meeting of the American Public Health Association, Nov. 2010	Tracey Jewell and Ruth Ann Shepherd, MD	Accepted for oral presentation
GIFTS (Giving Infants and Families Tobacco-free Starts): A Bundled Approach to Help Pregnant Mothers Quit Smoking	138 th Meeting of the American Public Health Association, November 2010	Joyce Robl and Ruth Ann Shepherd, MD	Accepted for oral presentation
The Impact of Pre-Pregnancy Body Mass Index on Low Birth Weight and Preterm Birth	16 th Annual MCH Epi Conference, December 2010	Tracey Jewell and Joyce Robl	Abstract submitted for consideration
Relief for the National Performance Measure #17 Headache? Using Volume of High-Risk Neonatal Delivery to Measure Appropriate Delivery Site	16 th Annual MCH Epi Conference, December 2010	Tracey Jewell and Ruth Ann Shepherd, MD	Abstract submitted for consideration

*Full Citation: Martin, JA, Kirmeyer, S., Osterman M., Shepherd RA. Born a Bit Too Early: Recent Trends in Late Preterm Births. NCHS Data Brief No. 24. Nov. 2009

Data Linkages and Applications for Quality Assurance

The Kentucky Department for Public Health (KDPH) has successfully linked data sources with relevant maternal and child health information with funding from the State Systems Development Initiative (SSDI) grant. Previous efforts have focused on 1) linkage of live birth certificate files with newborn screening data; 2) linkage of birth defects hospital discharge data with live births and death files; and 3) home visitation data with live birth certificates.

Current efforts include linkages with HANDS, Kentucky's home visitation program which has ongoing linkage of their records with birth certificates completed by an external evaluator. In the past year, their report focused on trend data from 2002 – 2007 regarding birth outcomes (prematurity, low birth weight and very low birth weight) and gestational age/birth weight distributions. The KDPH would like to pursue a standardized linkage file. Two master's students from university colleges are currently completing their practicums using linked HANDS data.

Additional efforts in the past year have focused on the linkage of live birth certificate files with death certificates. A standardized linked file has been developed for calendar years 2006 through 2008. Staff will continue to focus on these linked files for more recent years as the live birth certificate files are closed by Vital Statistics. Applications for linked birth-death files include an assessment of Kentucky's infant mortality rate and whether this rate was underestimated in past years.

The Kentucky Infant Death Review Study was conceived when findings in the National Center for Health Statistics, Division of Vital Statistics Data Quality Report #1 estimated the potential for 60 missing infant deaths in Kentucky in the less than 500 gram category. The 2006 linked birth-death dataset report showed that states surrounding Kentucky to the South had the 10 highest infant mortality rates in the country while those states bordering Kentucky to the North were statistically higher than the national average. Kentucky's infant mortality rate, however, was reported as being at the national average. A review of all live birth certificate data for Kentucky residents with birth weights of less than 750 grams was completed, and the linked birth death file was used to determine if a death certificate existed. Numerous infants were identified that probably were infant deaths without a corresponding death certificate. This data is being shared with Vital Statistics and recommendations have been made to determine accurate data for these records as well as to implement quality assurance efforts to minimize this occurrence in the future.

Quality Standards and Monitoring

The Department for Public Health establishes standards for conducting public health activities in local health departments. The standards are regularly reviewed and updated and include two manuals, the Administrative Reference, and the Public Health Practice Reference (PHPR) which are the clinical protocols. Program staff develop and update the sections relating to their programs – for example, the Well-Child program nurse updates the childhood immunization and screening section in accordance with new recommendations as they come out from the AAP.

Each clinical program also develops a monitoring tool that is used by a quality monitoring team based in the DPH Division of Prevention and Quality Improvement, who do intensive reviews of each local health department, including chart reviews, every two years and as needed. Local health departments are given a report of their review, and corrective action plans are required if needed. These reports and plans are posted on a common drive so that programs can access the information as well.

For those programs supported by state program funding, local health departments are required to utilize evidence-based programs. All new program models are required to have an evaluation component based on the current science and literature, and built in data collection from the initial implementation of the program. Service data for the local health departments is collected in a central data and billing system. Maternal and child health data is reviewed annually in preparing the block grant. The MCH county health profiles, developed in the Needs Assessment process, will be used to evaluate the overall progress of health departments in improving the services in their communities. However, that data is retrospective, so the usefulness of those profiles for improvement activities will be limited.

Pregnancy Risk Assessment Monitoring System (PRAMS) Pilot

While Kentucky is not one of the thirty-seven states currently receiving funding from the Centers for Disease Control and Prevention for PRAMS, efforts are underway to prepare the necessary infrastructure so that Kentucky is positioned to submit a competitive application in the future. Pilot projects conducted in 2007 and 2009 (described next section) were implemented in order

to collect this important data for Kentucky as well as to demonstrate the infrastructure and capacity to successfully conduct PRAMS. In the future, Kentucky hopes to become a CDC-funded project and contribute to national reporting.

The first PRAMS pilot project was completed for a sample of women who had eligible birth certificates from September 2007 through November 2007. The results from this three month pilot project were summarized in a 2008 report. A second eight month point-in-time sample was completed from March 2009 through October 2009. This pilot project was limited to Kentucky pregnancies resulting in live born infants and was stratified by race with African Americans oversampled. To maximize the response rates a combination of mail and telephone surveys was used based on survey research. PRAMTrac software, developed by the Centers for Disease Control and Prevention, was used for tracking. The telephone calls were completed through a contractual agreement with the University of Kentucky. Final survey data from the telephone calls was received in June 2010. Dr. Arne Bathke, a statistician at the University of Kentucky is statistically weighting the data now. Statistical analysis and development of a comprehensive report will be completed in the remainder of this calendar year.

To view the 2008 PRAMS report or learn more about Kentucky's pilot PRAMS activities, please contact Tracey Jewell, MPH at 502-564-4830 ext. 3816.

MCH Certificate Program with UK College of Public Health

Kentucky is a state with many maternal and child health problems, but until recently, had no training programs that focused on public health expertise in maternal and child health. With the support of Dr. Steve Wyatt, Dean of the UK College of Public Health, DPH has contracted with the College of Public Health to develop and administer the MCH Certificate to increase Kentucky's capacity to address MCH performance and outcome measures. The initial goal is to set up a certificate program for current public health professionals who are working in or interested in furthering their knowledge of MCH. The Maternal Child Health Graduate Certificate has two main objectives:

- 1) To prepare public health workers to address the multi-factorial Maternal and Child Health issues in Kentucky in their workplaces by enhancing public health-related skills.
- 2) To provide participants with theoretical, practical, and relevant educational experiences in MCH to enhance the health and welfare of children, mothers and families.

Dr. Jim Cecil, former DPH Oral Health Director, is the Certificate Director. The Graduate Certificate in MCH was approved by the Faculty Senate in May 2009 and the Certificate has been available since the Fall 2009 Semester. As of June 15, 2010, one student graduated from the program, one is currently enrolled and several students are exploring the required coursework. More information about the certificate program can be obtained at <http://www.mc.uky.edu/publichealth/certificateprograms.html>.

Maternal and Child Health Epidemiology Graduate Certificate

In mid-May 2009, the University of Arizona (PI) and University of Kentucky Colleges of Public Health were awarded a \$900K HRSA MCH training grant over five years to develop and implement a Graduate Certificate in MCH Epidemiology. The purpose of this project is to

provide graduate-level MCH Epidemiology education to students serving rural and American Indian/Alaskan Native populations who would otherwise be unable to access continuing education. Courses include Intro to Epidemiology, Intro to MCH, MCH Epidemiology, MCH Information and Data Systems, Evidence-based Decision-making, Cultural Competency for MCH professionals and others. Course content is delivered using the internet.

The UK College of Public Health is a major collaborator in this project which enrolled students in May of 2010 with the first class beginning on June 1, 2010. Fifteen students from across the nation are enrolled including three students from rural Eastern Kentucky Health Departments and one dentist from the UK Center for Rural Health in Hazard (KY). Ten students will receive full scholarships annually and academic credits earned will be transferable for this program which is supported by HRSA T04MC16880 from Maternal and Child Health Bureau, Health Resources and Services Administration. More information about this project is available at: <http://mch-epitraining.arizona.edu/default.aspx> or by contacting Lorie Wayne Chesnut, University of Kentucky College of Public Health at 859-218-2226.

Kentucky Perinatal Association

The Kentucky Perinatal Association (KPA) was founded in 1988 and is currently in its 16th year. As a non incorporated volunteer association of health care providers, consumers, and organizations, KPA members work together with a common purpose toward the recognition of maternal-infant health care issues dedicated to the provision of comprehensive solutions through educational outreach and advocacy. In addition to an annual conference, the KPA launched an innovative, web-based training with free CEU's and CME's for providers in 2006. This project, *Health Professional Education on Prematurity Initiative* (HPEP I) attracted more than 700 participants from Kentucky, the nation and beyond. HPEP I focused on "*Pathways to Prematurity*". In 2008, a second HPEP course was launched (HPEP II "*The Late Preterm Birth*") with faculty presenters including Dr. Ruth Ann Shepherd and Dr. Henrietta Bada, Chief of the Division of Neonatology at the University of Kentucky Chandler Medical Center. The third HPEP is on "*Progesterone and Preterm Birth Prevention*" and will be released in summer 2010. The KPA has been awarded the Outstanding State Initiative award from the National Perinatal Association in 2008 and 2009 for this work. The Kentucky Perinatal Association members, goals and other information may be found at <http://www.kentuckyperinatal.com/kpa.html>

Kentucky Health Department Association

The Kentucky Health Department Association (KHDA) has been sharing information and resources with local health departments across the Commonwealth since 1984. Today, the KHDA provide collaborative opportunities for all health departments, from large district health departments and large (Jefferson County, Fayette County and Northern Kentucky) and small independent county-level agencies. Through monthly meetings and an annual meeting, the KHDA fulfills its mission to "*To protect and ensure the health of our citizens through quality individual and population-based services*" with the following goals:

1. To promote better health services.
2. To obtain and exchange information.
3. To investigate problem areas common to health department administration and suggest solutions.
4. To promote continuing education for health department directors and employees.
5. To establish a framework for more effective communication among health departments, state agencies, local agencies and other interested parties.

The KHDA also develops policy statements and resolutions for its membership, and provides input on policy to the Department for Public Health. More information about the KHDA is available at <http://www.khda-ky.org/>.

Kentucky Primary Care Association

The Kentucky Primary Care Association was founded in 1975 as a private, non-profit corporation of community health centers, rural health clinics, primary care centers and other organizations and individuals concerned about access to health care services for the state's underserved rural and urban populations. There are currently 18 Section 330 Health Centers operating in Kentucky that receive funding to help offset some of the cost for providing health care to low income uninsured patients.

More information about the Kentucky Primary Care Association, its members and their locations is available at <http://www.kypca.net/>

Kentucky Public Health Association

The Kentucky Public Health Association (KPHA) has been in existence in Kentucky since 1949 and is a nonprofit, independent voluntary organization. It is an affiliate of the Southern Health Association and the American Public Health Association with the mission “**to promote healthy communities through education, leadership, and commitment to excellence**”.

The KPHA serves public health providers in the Commonwealth through the sponsorship of workshops, trainings, conferences which enhance both the professional and personal growth of those serving Kentucky's population. For information about programming and membership, the KPHA's website is available at <http://www.kpha-ky.org/>.

Public Health Accreditation

Kentucky Department for Public Health is preparing for Public Health Accreditation at the state level. In addition, KPHA (above) is continuing to investigate what accreditation will mean for local health departments in Kentucky. The Franklin County (KY) Health Department is a beta site for testing the national standards for local health accreditation.

This concludes Section 4 “*MCH Program Capacity by Pyramid Levels*” for the Kentucky Department for Public Health.

Kentucky Commission for Children with Special Health Care Needs

4. a. Direct Health Care Services

Kentucky's CSHCN has provided direct health care services for over 85 years, although over the past decade an effort has been made to move down the pyramid towards a broader-based mission. In line with the guidance of the MCH pyramid, CSHCN provides direct health care services in a gap-filling capacity. When services are available elsewhere, CSHCN refers to them or supports them in other ways. Still, CSHCN offered 870 distinct clinics in 18 specialties, serving 8441 children in 12 regional offices covering 120 counties in 2009. The decline in the number of patients served over the past several years is somewhat troubling, yet reflective of the realities of a budget stretched thin. The next two years offer budget cuts of 3.5% and 4.5% respectively, which present difficult decisions to be made and a diminished capacity to provide gap-filling services that are not otherwise available. For example, while there does not seem to be a shortage of nutritionists/dietitians available in the market, CSHCN employs only one statewide which is somewhat of a disadvantage during the childhood obesity epidemic (a contract is being considered for a second, to cover the western part of the state). CSHCN leadership continues to make difficult staffing and service decisions to shield patients as much as possible from the economic distress, but some level of cuts are needed. In the past 2 years, for example, one contracted office has been closed (Northern Kentucky) and two offices in the western part of the state (Hopkinsville and Bowling Green) have merged. Patients are still offered services regionally, although not necessarily in their immediate communities.

Until there is no further need for direct health care services, CSHCN will continue to reach out and extend services to meet the needs of all CYSHCN.

4. b. Enabling services

One aspect of CSHCN's intentional move down the MCH pyramid is the increased emphasis on care coordination during the past 10 years. While seemingly a countercultural push within the Kentucky program where direct services were the tradition, care coordination is now embraced by CSHCN staff. Nurses utilize a variety of professionals to guide CYSHCN towards other services that may meet their social and financial needs, as well as provide assistance in accessing those additional support services (interpreters, transportation, etc.). Services in clinics include contracted medical providers while also providing ancillary supports (e.g. orthotists or x-ray technicians) in a multidisciplinary team including social workers, speech, physical and occupational therapists, audiologists, etc. At a state level, CSHCN has several tools in its arsenal to provide support for service providers, such as:

- Providing space (e.g. Medical Home Clinic);
- Providing financial support (e.g. Pediatric Cardiology itinerant clinics);
- Providing in-home nurse consultation (e.g. medically fragile foster care program); and
- Contracting for medical insurance case management services (e.g. Patient Services Incorporated).

In considering priorities drawn from the needs assessment, CSHCN necessarily factored in capacity. While, for example, the agency does have the ability to realign resources to meet

needs of transition (shifting many transition responsibilities from care coordinators to a transition administrator and social workers) and healthy weight/obesity (using initiatives implemented by care coordinators and other staff), the capacity simply did not exist for some areas, such as broad-based, routine dental interventions and expanded therapy needs, particularly for those with mental and behavior health issues. However, CCSHCN looks forward to assisting in a more enabling role (fluoride varnishing and preventive care, and referrals to available resources) with existing resources or the development of new ones in these areas.

4. c. Population-based services

Kentucky's strength in capacity at this level of the MCH pyramid is the management of the Early Hearing Detection and Intervention program. Through CDC grant funding, the KY-CHILD (vital statistics collection system) expansion included an application for audiologists outside CCSHCN to enter audiology results electronically. The pilot program was completed in November 2009, with full implementation in early 2010, following onsite training of all audiologists in the Approved Infant Audiology Diagnostic Centers. The EHDI program continues to tackle the National 1-3-6 goals (hearing screening by 1 month of age; evaluation/diagnosis by 3 months of age; intervention by 6 months of age), recognizing that as the focus shifts to the follow up goals, CCSHCN must continue to be vigilant to assure that the screening percentage does not diminish.

Another example of population based services is the nurse consultant work in the Department for Community Based services, in which CCSHCN nurses serve as health care resources to stakeholders in the child welfare system. With the experience and knowledge gained from building and managing the EHDI population-based surveillance system, CCSHCN plans hope to apply that information in working to expand a presence with the foster care populations and CYSHCN with obesity, dental and primary care concerns.

4. d. Infrastructure-building services

In order to facilitate surveillance as well as the supports available to the health care delivery system serving CYSHCN, in Kentucky, CCSHCN is interested in building on its established network and services. Regional offices in 12 locations (and outreach clinics in underserved areas) provide local delivery teams across the state, staff of whom collaborates with other health and human service providers to assess and coordinate responses to local needs and nuances. Examples include Developmental Early Intervention Councils (DEIC), Regional Interagency Transition Teams (RITT), Regional Interagency Councils on Services to Children with Severe Emotional Disabilities (RIAC), human service councils, or any of a variety of multidisciplinary teams addressing child abuse, preventive or other such areas. At a state level, CCSHCN staff continue to work on various committees (enumerated elsewhere in this Needs Assessment) towards the goal of interagency agreement and support for coordination of a community-based service system. In addition to the high-level oversight of CCSHCN board and various statewide advisory councils, CCSHCN staff also attend community health fairs not only as outreach to CYSHCN not enrolled, but also to keep attuned to the needs of the community.

While assessment and quality improvement efforts in any agency will tend to concentrate on enrollees of that agency, an example of infrastructure building that reaches beyond CCSHCN enrollees is the interface of CCSHCN's data collection system (CUP) with the KY-CHILD

information system used by birthing hospitals so that electronic medical records are automatically created for all newborns. This has allowed for a significant expansion to CSHCN's ability to detect, identify and serve children early who are at risk for special health care needs based on family history which may otherwise go undetected.

The Family to Family Health Information Centers in Kentucky are an important new support to families of CYSHCN; parents and caregivers are provided the opportunity to connect one-to-one with a parent/caregiver of a child with the same or similar special health care need.

CSHCN recognizes the need to continue to look for opportunities to apply its programming to CYSHCN not enrolled with CSHCN and their whole families, but the population at large. By piloting obesity prevention and intervention efforts within separate specialties (orthopedics and cardiology), the agency is hoping to identify successes and lessons learned and replicate in other clinics to use as a model. The agency intends to apply what has been learned, share what resources are available, and develop what resources are needed with the community at large through every form of information-sharing available.

This concludes Section 4 "*MCH Program Capacity by Pyramid Levels*" for the Kentucky Commission for Children with Special Health Care Needs.

5. Selection of State Priority Needs

Kentucky Department for Public Health

Throughout the Needs Assessment process, the Kentucky Department for Public Health met and communicated with state and community partners to determine needs of children and families across Kentucky. Three top priority needs surfaced out of the MCH forum discussions: Teen pregnancy, substance abuse, and obesity.

5. a. Potential Priorities

There were 24 topics that came up repeatedly in the needs assessment process. All of these were considered in the final prioritization activities. Information on each of these topics is covered in Section 1 which described the prioritization process methodology in detail. Topics that came up repeatedly and were considered from the needs assessment were grouped according to their occurrence in the life course for the prioritization process. In the table to the right, each grouping is listed, with the topics listed in decreasing order of overall score for that group. The scoring from the four key attributes for each topic (Magnitude, Seriousness, Impact, and Effective Interventions) brought out some significant trends.

The highest overall scores in cross-cutting, perinatal issues, and teen issues went to *substance abuse* and *smoking*, making those the leading priority needs. With the scores for Magnitude, *obesity* received the highest scores overall and highest for the pediatric issues and cross-cutting issues. In perinatal issues and teen issues, *smoking* was considered the problem of the largest magnitude. In the rankings for seriousness, the two cross-cutting issues of *substance abuse* and *health insurance coverage* received the highest scores. In the other populations, *smoking in pregnancy*, *substance abuse in teens*, and *child maltreatment* received the highest scores for seriousness. As for the issue in the group that had the highest rated impact on health, *substance abuse* was identified in cross-cutting issues, perinatal, and teen issues. In children, *obesity* was rated as the highest impact issue. In identifying which of the topics had known effective interventions, the highest rated issue was *breastfeeding*. Among the cross-cutting issues, *second hand smoke* was the highest scoring for effective interventions. *School health* was felt to have the most effective

Table 15: KDPH TOPICS For POTENTIAL PRIORITIES (in each category, listed in descending order of total prioritization score)
CROSS CUTTING THEMES
Substance Abuse
Obesity (overall)
Second Hand Smoke
Health Insurance Coverage
Oral Health in Kentucky
PERINATAL ISSUES
Smoking in Pregnancy
Substance Abuse in Pregnant Women
Obesity in Pregnant Mothers
Infant Mortality/Prematurity
Breastfeeding
SIDS/Sudden Unexpected Infant Death(SUID)
Preconception Care
Perinatal Depression
PEDIATRIC ISSUES
Obesity in Children
Child Abuse/Maltreatment
Oral Health Access
Injury Prevention in Children
School Health
Mental Health in Early Childhood
YOUTH AND TEEN ISSUES
Substance Abuse in Teens
Teen Smoking
Teen Pregnancy (general)
Mental Health in Childhood and Adolescence
Parental Influence on Children and Youth
Self Esteem in Teens

interventions in the pediatric population issues. Interestingly, in the teen population, *substance abuse* was identified as having the most effective intervention.

These potential priorities were narrowed and further analyzed (SWOT analysis) at the stakeholder meeting in November, 2009. The result of that meeting was a list narrowed to 12 potential MCH needs with some information on feasibility of measuring and feasibility of making a difference. These 12 topics were then considered and further refined by the internal Needs Assessment Leadership Team with the MCH Epidemiologists. This group sought to harmonize with existing Title V measures, determine if the need was within the scope of MCH responsibility, assess if the need is already being addressed, and if the need was too broad and needed to be more focused.

Commission for Children with Special Health Care Needs

In addition to the indicators expressed through National and State Performance Measures, CSHCN observes that the leading needs expressed by families and consumers include the following:

- Information on healthy weight/nutrition/obesity;
- Information that will help the individual child become independent;
- Information about different sources of help in the community;
- Information on the developmental level of the individual child and learning disabilities;
- Provision of therapy services;
- Lack of attention to/priority of dental care;
- Provision of vision services; and
- Provision of hearing services.

5. b. Methodologies for Ranking/Selection Process

The KDPH MCH needs assessment process included reviewing quantitative data from internal systems and combining qualitative information from Kentucky's stakeholders, local health department patients, health providers, and community members. The methodology for ranking and selection of priorities is discussed in detail in Section 1.

Believing that consumer input is a valuable gift, CSHCN weighted heavily those issues identified by CSHCN families on the family survey mentioned. CSHCN convened a needs assessment leadership team comprising of staff and management from both divisions, including parent representatives and transitions staff. After several meetings studying data from family/consumer surveys, communication with the Kentucky Department of Public Health (KDPH) to ensure integration and non-duplication, and considering possible priorities, the needs assessment leadership team identified the top items mentioned as needs by families and consumers, guided by knowledge of statewide capacity. Those needs logically flowed into proposed action steps, which were refined by input from the executive team, advisory committee, and regional supervisor and manager feedback.

5. c. Priorities Compared with Prior Needs Assessments

The KDPH recognizes that Kentucky's health challenges generally have followed national trends, but keep us in the lower quartile for almost every health indicator. Kentucky ranks 41st

overall in children's health (KIDS COUNT, 2009). Last year Kentucky was ranked # 1 in child deaths from child abuse. This has been a Title V MCH priority need for Kentucky for some time, but now rises to a new level of importance. We have documented success in lowering child abuse in high risk families in our HANDS home visiting program, especially when adjusted for having someone in the home on a weekly basis, but clearly we must expand our horizons to a more comprehensive approach to this problem, and to that end have begun more focused discussions with our partners in the Division of Protection and Permanency and Mental Health partners.

Kentucky's rise in obesity in children is one of the most pressing problems in communities identified in this needs assessment, but was already on the list of priority needs from 2005. The lack of impact reflects the enormity of the problem, and the need for policy-level approaches. Numerous initiatives in the state are occurring towards this end, including Advocacy trainings for policy change by the Kentucky Chapter of the American Academy of Pediatrics, funded by a grant from NICHQ and Robert Wood Johnson. Given the increased focus, the unique needs of CYSHCN (many whom use wheelchairs or have cardiac conditions), and given the high ranking of healthy weight and nutrition, CCSHCN has chosen to supplement overall KDPH efforts to combat childhood obesity with a focus on the CYSHCN population.

Substance abuse and smoking, which led the concerns of communities all across the state, was not on the prior list of needs, but perhaps because the activities to address it are not within the responsibilities of the MCH Program. Certainly there is a perception state-wide that this is now reaching epidemic proportions. While we work with our partners in Substance Abuse, Mental Health, and Protection and Permanency to find meaningful measures and effective interventions, MCH is focusing our new state performance measure on smoking in teens, as the entry to adult smoking and other substance abuse. Smoking in pregnant women, a priority need at the last assessment, continues to rank high on Kentucky's list of health issues but is covered by NPM # 15.

Oral health continues to be an issue for Kentucky, and has been long recognized as such. The oral health program has built significant capacity in the last five years, and we hope to see outcomes improving in the future. Access to care for pregnant women and low income children remains one of the most significant barriers to making progress. We will continue to measure this with existing measures from the block grant.

CCSHCN reports that while methods have been adjusted slightly (different survey tool, and larger distribution, for example), some needs remain constant. As they have in previous years, transition services continue to represent an elusive goal, despite years of efforts to incorporate transition planning into practice. Whether semantic or not (many parents are not familiar with the term "transitions" but do report receiving elements of these services when asked in different language not using the phrase), 82% of CYSHCN report having received no transition services. When adjusted for age and semantics, many more do report having actually received these services (28-56%, depending on element), and CCSHCN cohort does report a significantly higher frequency of services than the non-CCSHCN cohort; however, the numbers are much too low to consider efforts a success.

Previous State Performance Measures focused on the health and wellbeing of children in foster care, both overall and those who were designated medically fragile specifically. As the performance measure regarding medically fragile children has been substantially achieved and as the number of such children (approximately 150 statewide) is dwarfed by the number of CYSHCN, it was felt that over the next five years, a new priority should be targeted, one that affects a greater number of children. The measure regarding children in foster care, while not achieved, will continue to be a focus of the agency (as will medically fragile children), through ongoing efforts of CCSHCN's administratively-established Foster Care Support Section.

Several global outcomes were listed previously as priority needs – “improve the safety and well-being of children”; “decrease the infant mortality rate”; “improve the health and well-being of women of childbearing age”, and “improve pregnancy outcomes” All of these things are important and reflected in the current assessment of needs. We hope to be more specific in our measures of these MCH priorities.

5. d. Priority Needs and Capacity

Resulting from the 2009 community forums, smoking and substance abuse ranked #1 in Kentucky. To address these population-based concerns some services already exist. For example, the Tobacco Prevention and Cessation program in contract with the Kentucky Center for Smoke Free Policy has encouraged smoke free laws to be enacted in 27 cities/counties affecting approximately 38% of the state's population. A collaborative pilot project of MCH and the Tobacco Control Program, the GIFTS program (Giving Infants and Families a Tobacco-Free Start) has continued for 2 years now and will have a completed evaluation with data on birth outcomes from the 9 original pilot counties by September, 2009. The program is now developing a sustainability model and rolling out to 4 new sites, where they are incorporating activities into the existing HANDS and Healthy Start programs. Eventually we hope to have this program state-wide. The legislature in 2010 allocated funding to Medicaid to reimburse smoking cessation counseling for Medicaid participants, so that should assist in expanding these services.

What is lacking in Kentucky is the consistent availability of substance abuse treatment for all populations, especially the pregnant woman. Although the mechanism to immediately access treatment is in place, there continues to be a long waiting period for continuation of treatment when it needs to be long-term. Additionally, there is a shortage of treatment providers, especially those willing and capable of accepting the pregnant population. Furthermore, it is difficult to collect accurate data on substance abuse. Currently the Department for Public Health is working closely with the Department for Mental Health and Developmental and Intellectual Disabilities in an attempt to share information to assist in addressing drug concerns in the state. This will be further discussed in the Home Visiting Needs Assessment required in the new health care reform legislation.

Family planning was an important health concern in the previous needs assessment. Teen pregnancy, springing from the community forums as a top priority across the state in the current needs assessment, is being addressed in direct, innovative ways. Women's Health chose to get to the heart of the matter and met with teenagers face-to-face to determine the issues behind this growing concern. That information has been used to develop a state plan for

addressing teen pregnancy. Multiple partners are collaborating, and funding may be made available through Health Care Reform, which will enhance our capacity to meet this need.

Obesity ranked in the top identified problems for the MCH population in 2005. Today this is still very much a concern, especially for pregnant women and young children, as evidenced by the current priorities. Much capacity has been built around this issue. Both university pediatric programs have begun multidisciplinary clinics for obese children; the KY Chapter of the American Academy of Pediatrics has several initiatives to train pediatricians to address in their offices as a quality improvement activity; the Partnership for a Fit Kentucky continues to work at the state and community level on environmental change. Policy makers are more aware of the issues and proposing things like mandatory physical activity in schools (not passed yet). The Title V program hopes to further advance these initiatives moving forward until we see a change in this adverse trend.

Given the mission and resources of the agency, CCSHCN plans to address the issues of healthy nutrition and weight, and need for transition services through State Performance Measures. CCSHCN's strength is its staff, due to the personal relationships they maintain with CYSHCN, and face-to-face contact in medical clinics with which they can effect growth and change. In addition to these needs having been selected from responses of consumers themselves, these needs were chosen due to the ability for staff to successfully integrate into and improve upon CCSHCN practice without reshaping what staff are doing. An emphasis on these particular needs represents a logical expansion rather than a change in direction, and CCSHCN possesses the internal capacity to successfully provide services to meet these needs. (Given its high ranking, a focus on dental care was considered but not chosen at this time, although CCSHCN looks forward to supporting KDPH and other partners through the provision of fluoride varnishing to CYSHCN and siblings and referrals to appropriate providers.)

5. e. MCH Population Groups

New priorities and accompanying measures were grouped in the prioritization process so that each of the populations would be represented in Table 15 at the beginning of this section. The issues that arose in the needs assessment were a balanced view across all these populations.

Further, the priorities selected through this process span the MCH population and often involve partnerships between CCSHCN and KDPH. CCSHCN staff is aware of and actively collaborates with KDPH to support all public health national and state performance measures.

For example, CCSHCN's Folic Acid Multivitamin program provides vitamin supplements and preconception health education free of charge to any woman of childbearing age (regardless of enrollment status with CCSHCN). During a given year, CCSHCN distributes supplements to 1500-2000 women across the state. This was in support of the former SPM #03 which targeted women of childbearing age, with the goal of increasing the proportion of this population who received preconceptual services.

5. f. Priority Needs and State Performance Measures

The new state priority needs for Kentucky are listed below. Measures used to track progress are identified, including newly developed state performance measures where necessary. Newly developed measures are listed first, with existing national performance measures and/or

continuation state performance measures following. Order of numbering does not necessarily reflect the rank order from the Needs Assessment process or of the measures listed.

Priority 1. Reduce rates of substance abuse and smoking in pregnant women and teens.

The Title V program will not be able to take on this entire issue, but will continue to work closely with those agencies that do have this responsibility and bring focus on maternal and child health populations. To measure progress, Kentucky will rely upon:

a. NEW State Performance Measure #02: The percent of Kentucky High School students who smoked cigarettes on one or more days of the past 30 days. Source: YRBS and Youth Tobacco Survey. Since 90% of adult smokers take up smoking before the age of 18, this measure will allow us to target initiation of this risk behavior, which is often the precursor of other substance abuse behaviors.

b. NEW State Performance Measure #05: The percent of Kentucky residents age 12 through 17 who report illicit drug use in the last year. Source: YRBS Initiatives in the schools and policy level changes hold promise for reducing this number.

c. NPM # 15 – Smoking in the third trimester of pregnancy. Source: Birth certificate data Kentucky ranks next to worse on smoking in pregnancy, and has rates nearly twice the national average; one in four pregnant women in Kentucky continue smoking during pregnancy. Several initiatives are underway to address this issue, but to make a significant impact will require more than individual level interventions.

Priority 2. Reduce rates of obesity in maternal and child health populations in Kentucky.

This continues to be a work in progress and challenging to most every state. Contextual factors in Kentucky, including high rates of poverty and geographic isolation in rural areas make the challenge particularly big for Kentucky. This is a particularly important issue for CYSHCN, hence the need for a specific State Performance Measure for this population. However for both agencies and among all the groups participating in the 2010 Needs Assessment process, there is a high degree of concern which should translate to a bias toward action. Grassroots activities are increasing. Policy level approaches are also under development.

Measures for tracking progress will include:

a. NEW State Performance Measure #01: The percentage of first time births to Kentucky resident women age 18 and older who had pre-pregnancy BMI's in the overweight or obese categories. Source: Kentucky Birth Certificate Files. This measure is a reflection of preconception care, as well as increased risk for the pregnancy, as BMI is more and more associated with adverse birth and delivery outcomes.

b. NEW State Performance Measure #07: Decreased percentage of children, ages 0 to 18, receiving CSHCN services, with a Body Mass Index (BMI) at or above the 85th percentile. Source: CSHCN CUP (Patient Health Information System. This measure is a reflection of the significance of the special problems and increased risks of obesity in CYSHCN).

c. *NPM #11 – The percent of mothers who breastfeed their infants at 6 months of age.* Breastfeeding is a first line of protection against developing obesity later in life.

d. *NPM #14: The percentage of 2 – 5 year olds with greater than 85th percentile BMI.* In many cases, children are already obese before they get to school age. This measure allows us to target and track low-income children in early childhood where there are more opportunities for true prevention and addressing lifestyles.

d. Children and youth overweight and obesity will still be monitored from existing sources, but not used as a measure of progress for the block grant. Numerous initiatives targeting school age children and school policies are underway in Kentucky to address this population.

Priority 3. Reduce the rates of births to teen mothers in Kentucky. One of the top three topics in nearly every part of the Needs Assessment, teen pregnancy is a serious concern for communities all across the Commonwealth. It is also a symptom of the issues underlying not only teen pregnancy, but also substance abuse, smoking, suicide, and other mental and physical health issues in the teen population. Efforts around this need will be lead by the Adolescent Health coordinator in the Division of Women’s Health, who currently works closely with the Title V MCH program. A stakeholder group has been meeting for several months (since the forums), focus groups with teens have been completed, and a multidisciplinary stakeholder group is developing a state plan for action.

Since teen pregnancy is addressed in a current NMP, Kentucky will monitor progress using that measure:

a. *NMP # 8: The rate of births (per 1000) for teens ages 15 through 17.* Data Source: Kentucky Birth Certificate Files

Priority 4. Reduce the number of Kentucky children dying from child abuse or maltreatment.

Deaths from child abuse and maltreatment are exceedingly tragic, and children are especially vulnerable at age less than 5. Kentucky currently leads the nation in child abuse deaths, increasing the urgency of this need.

In collaboration with the Division of Protection and Permanency, MCH is engaging in more discussion of how to address this need on a number of fronts. The first barrier is collecting accurate and complete data, as there is no common definition of child abuse and it rarely is listed as a cause of death on death certificates. In addition, most programs to “prevent” child abuse are secondary prevention, targeted at recognizing the signs after the child abuse has occurred. Kentucky is also now exploring evidence-based primary prevention programs such as Triple P.

a. ***NEW State Performance Measure #04: The proportion of Kentucky children birth to 5 years of age who die from child abuse.*** Data Source: Protection and Permanency Child Fatality Review data files.

b. National Health Outcome Measure (NOM) # 06: The child death rate per 100,000 children aged 1 through 14.

Priority 5. Decrease the Infant Mortality Rate and eliminate the disparities in Infant Mortality in Kentucky. Preterm birth is one of the three leading causes of infant mortality, and the only cause that has been increasing in the last decade. Since the Surgeon General's Conference on the Prevention of Preterm Birth in 2008, it has been recognized that contextual factors and social determinants of health play as important a role in preterm birth as medical risk factors.

Kentucky has a project studying the contextual factors relating to preterm birth in Louisville, KY, in neighborhoods with high populations of African-Americans live. In addition, the Appalachian area is a disparate population with high concentrations of poverty and similar contextual factors. The other focus of prematurity prevention for Kentucky is the Late Preterm Births, those occurring between 34 0/7 weeks and 36 6/7 weeks gestation. Kentucky's Healthy Babies are Worth the Wait initiative, with March of Dimes and Johnson and Johnson, has been recognized nationally for emphasizing strategies to address late preterm births as a population at risk and potentially preventable preterm birth.

Progress on these efforts will be measured by:

a. NEW State Performance Measure #03: Percent of singleton live births to Kentucky residents that are 34-36 weeks (late preterm) at delivery. Data Source: Kentucky Birth Certificate Files

b. NPM #17: Percent of Very Low Birth Weight Infants delivered at facilities for high risk deliveries and neonates

c. National Health Outcome Measures #01 through #05 – infant mortality, black/white infant mortality ratio, neonatal mortality, post-neonatal mortality, and perinatal mortality rates.

d. Health Systems Capacity Indicators # 05 A, B, C, and D, covering low birth weight, early and adequate prenatal care, and infant mortality by Medicaid vs. non-Medicaid

Priority 6. Improve the Oral Health Status of Kentucky's children, youth, and pregnant mothers.

Improving oral health in Kentucky is one of the major access to care issues in the state, as there are few dentists in rural areas, fewer pediatric dentists, and many dentists even in urban areas who do not accept Medicaid patients due to low reimbursement. In addition, there are cultural barriers, as many families accept poor oral health as the norm.

Kentucky will measure progress on this need by:

a. NPM # 9: Percent of third grade children who have received protective sealants on at least one permanent molar tooth.

b. Health System Capacity Indicator #07A: Percent of Medicaid eligible children ages 6-9 who received a dental service

c. State Performance Measure #06 (continuation): Percent of Medicaid-covered women who received at least one dental visit during their pregnancy.

Priority 7. Improve transition services for CYSHCN. As reported earlier 82% of CYSHCN report having received no transition services. When adjusted for age and semantics, many more do report having actually received these services (28-56%, depending on the element), and the CSHCN cohort does report a significantly higher frequency of services than the non-CSHCN cohort however, this area is targeted for improvement over the next five years.

a. NEW State Performance Measure #08: Percent to which CSHCN transition action plan is implemented. Source: CSHCN CUP (Patient Health Information System).

b. NPM #06: The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Through this process, CSHCN utilized staff of the Healthy and Ready to Work National Resource Center to provide a national perspective on SPMs in designing the transition measure with an eye towards developing infrastructure. Using Hawaii's SPM as a model, CSHCN has developed its own transition action plan and offers the following:

1. Develop a transition checklist for families and CYSHCN
2. Initiate tangible outreach to all CSHCN clients upon 14th, 16th, and 18th birthdays, including surveys/assessments of current levels of independence and preparation for school/work
3. Cultivate awareness on available community resources through public resource guide, intranet social service page for staff, community education events
4. Develop and implements systems to measure impact of transition efforts and policies
5. Establish and distribute training documents in a variety of settings for providers regarding their roles in the transition process
6. Increase visibility and active involvement of CSHCN Youth Advisory Committee
7. Revise agency procedures to conform to best practice consensus statement on health care transitions for CYSHCN
8. Initiate CSHCN procedure encouraging children's signature on medical forms starting at age 12
9. Provide support to CYSHCN regarding accommodations available to enable management of health care issues in educational settings
10. Create a written health care transition plan by age 12 for CSHCN children

11. Increase use of social media to reach and educate CYSHCN about pertinent health and transitions issues
12. Counsel and provide assistance with selection of adult health care providers, and encourage meetings with selected provider prior to discharge from CSHCN services.
13. Initiate transmittal of medical records (with release) to adult medical providers upon discharge

Scoring will be based on a total score (maximum=52), and will be measured yearly for increase or decrease from prior year. Scoring: 0: activities have not yet begun; 1: activities have just begun; 2: activities are progressing; 3: activities are well-established; 4: activities are sustained.

Section 6. Outcome Measures – Federal and State

The final section of the 2010 MCH Needs Assessment will provide information only about Federal Title V MCH Outcome Measures as no separate MCH State Outcome Measures currently exist. Because information specific to infant and child mortality, including national performance measures and programs directly associated with mortality⁷⁵, has been provided elsewhere in this document (*Section 2: Partnership Building/Collaboration Efforts, Section 3: Strengths/Needs of the MCH Population; Section 5: Selection of State Priority Needs*) such detail will not be repeated. Rather this section will provide and discuss current mortality rates with select information about projects designed to identify and address disparities occurring in Kentucky.

Title V National MCH Outcome Measures

1. The infant mortality rate per 1,000 live births
2. The ratio of the black infant mortality rate to the white infant mortality rate
3. The neonatal mortality rate per 1,000 live births
4. The postneonatal mortality rate per 1,000 live births
5. The perinatal mortality rate per 1,000 live births plus fetal deaths
6. The child death rate per 100,000 children aged 1 through 14.

6. a. Infant Mortality

As noted in Section 3 of the Kentucky MCH Needs Assessment document, infant mortality has been on a general downward trend since 2006. Figure 14 illustrates the trend movements of this measure as well as associated measures of mortality.

Neonatal: Neonatal mortality has declined in Kentucky since 2006. However, it is uncertain at this point in time as to whether or not this represents a true decline since the 2008 and 2009 data are still preliminary and numbers are expected to change. In addition, as mentioned in the Kentucky Infant Death Review Study, there is an apparent underreporting of infant deaths <750 grams and most neonatal deaths would fall within this category; this underreporting could result in a falsely low mortality rate within this age group.

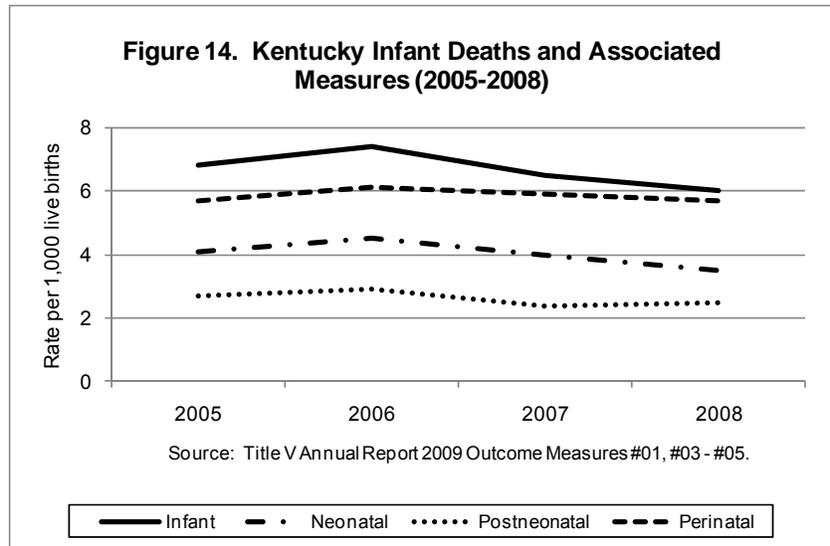
Post-neonatal: Slight fluctuations of post neonatal mortality have been observed in Kentucky since 2006. Most of these fluctuations can be attributed to the change in the way SIDS deaths are defined/classified by the coroners and medical examiners in the state. In addition, there is some shift of very low birth weight infants who die not succumbing until after 28 days, lowering the neonatal mortality and increasing the post-neonatal mortality.

⁷⁵ NPM #'s 01, 10, 16-18, SPM #'s 01-02, 04.

Perinatal: Perinatal mortality in Kentucky has shown a slight decline in recent years; although as stated previously, this decline is not expected to hold as 2008 and 2009 data become finalized. It is hopeful that on-going efforts towards preterm birth prevention will have an influence on the perinatal mortality rate and a true decline will soon be observed for this indicator.

Disparities in Infant Mortality

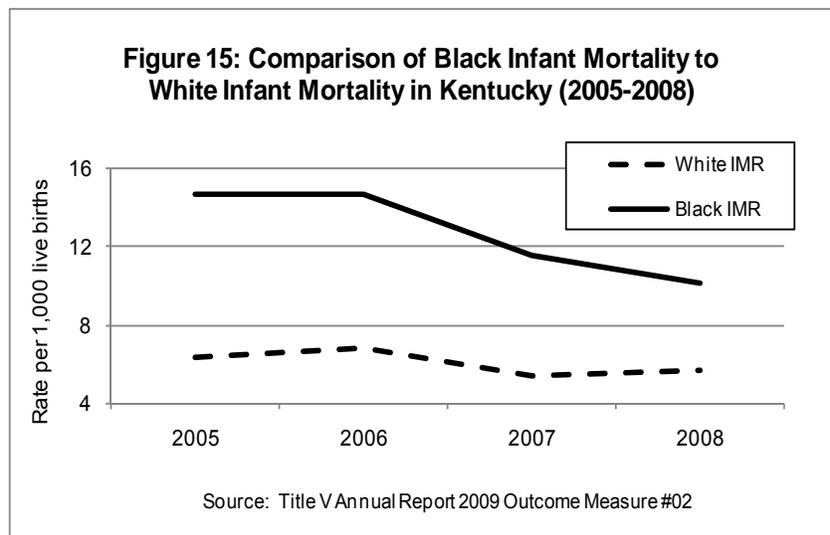
While the overall ratio of black infant mortality to white infant mortality has narrowed from 2.3 in 2005 to 1.8 in 2008, disparities between black and white infant deaths continue to be unacceptable to public health officials (Figure 15).



Kentucky’s Jefferson County (Louisville) is the county of residence for nearly half (45%) of the state’s African-American population according to the U.S. Census 2006-2008 American Community Survey⁷⁶. Given this fact, mortality outcomes in Jefferson County *must* improve if Kentucky hopes to achieve a reduction of the ratio between black and white infant deaths. A target ratio of 1.5 is to be achieved by 2014.

To meet this goal, numerous programming efforts have focused on Jefferson County including the federal Healthy Start Program and Fetal Infant Mortality Review, described in detail under Section 4.b. (Capacity - Enabling Services).

In September of 2008, the Kentucky Office of Health Equity (KY OHE) was established within the Kentucky Department for Public Health, Commissioner’s Office. Funding from the U.S. Department of Health and



⁷⁶ Source: U.S. Census - American Community Survey. Accessed 07/04/10 at http://factfinder.census.gov/home/saff/main.html?_lang=en

Human Services (US DHHS), Office of Minority Health (OMH) supports KY OHE. The office was created to address health disparities among racial and ethnic minorities, and rural Appalachian populations. Specifically, KY OHE seeks to create opportunities for health equity relating to infant mortality and preconception care as well as chronic diseases such as cancer, diabetes, heart disease, and HIV.

The KY OHE is directed by Dr. Torrie Harris who is also an Assistant Professor at the University of Kentucky, College of Public Health. Dr. Harris received her DrPH from the University of Kentucky, College of Public Health in Health Behavior. Prior to coming to UK, she received her Masters of Public Health at Tulane University School of Public Health and Tropical Medicine with a concentration in Maternal and Child Health Care. Dr. Harris worked extensively on maternal and child health programs studying infant mortality and morbidity, child passenger safety, minority health, and public mental health.

The KY OHE recently completed the *Jefferson County Infant Mortality Pilot Project*, developed to address the increasing infant mortality rates among African Americans in Kentucky. The Project targeted African Americans in the West End section of Jefferson County, Louisville, KY.

As a result, the KY OHE, targeted efforts to address the burden and uncover the social determinants of health influencing the rates in this area.

KY OHE worked in partnership with the Center for Health Equity, based out of Louisville Metro Public Health and Wellness and the Louisville Healthy Start to conduct this project. Funding to support this project was sponsored by the Office of Minority Health, United States Department for Health and Human Services. This project serves as a pilot to inform future programming that will continue to focus on eliminating health disparities related to infant mortality in Kentucky.

Participants were asked to complete a brief demographic survey at the beginning of each focus group session. Several photos of the West End, Louisville community were taken. Focus group participants were asked open-ended questions by a CHE Facilitator relating to health/unhealthy pregnancies based on their perceptions of the photographed community.

Jefferson County Infant Mortality Pilot Project
Focus Group Questions

- A. *What do you see in this picture?*
- B. *What do you see in these neighborhoods that help residents be healthy?*
- C. *What do you see that creates barriers to health?*
- D. *Out of those things that you named for a healthy neighborhood, what does that have to do with a having a healthy pregnancy or healthy infants?*
- E. *Unhealthy pregnancy or unhealthy infants?*
- F. *Out of what was said for a health or unhealthy neighborhood, how do you think these things relate?*
 - a. *Residential segregation*
 - b. *Poverty*
 - c. *Environmental hazards such as air pollution, water pollution, etc.*
 - d. *Violence*
 - e. *Housing*
 - f. *Transportation*
 - g. *Inadequate social services*
 - h. *Access to healthcare*
- G. *If a neighborhood had resources to address the barriers, what do you see as the top priority to improve neighborhoods so all moms and infants could be healthy?*

Responses by focus group participants are too lengthy to present in this document, however numerous priority themes revealed including safety, neighborhood appearance and environmental hazards, poverty, housing, local assets, social services, teenage pregnancy/parenting, health access, education, physical fitness opportunities and substance use. Samples of the comments received from women participating in the study follow.

Select Comments from Focus Group Participants in the Jefferson County Infant Mortality Project: Addressing Social Determinants of Health - Final Report

Safety *“Basically, this is what I’m saying, the healthy community; just keep the drug dealers off the streets,we’ve got kids out, we don’t know what’s going on, you know what I’m saying.... There’s just too much going out here; you can’t trust everything. There’s too much going on..... your child should be able to go outside and play anywhere and be safe.”*

Neighborhood Appearance and Environmental Hazards *“So, so if she walks out of her door and she breathes in all, because we can’t smell what’s on this picture but we can imagine what it must smell like because look at what it looks like; there’s trash, there’s cups, there’s brokenness and I could go on and on and on. However, another woman who walks outside her door, who has beautiful landscape, she’s got beautiful trees and violets and roses and stuff growing; you know we breathe that stuff in, it’s photosynthesis. So when that woman walks outside, if she doesn’t have those factors, then she immediately is able to, her baby, that baby is in her womb, immediately has an advantage over that woman, not to mention all of the mental stress, all the mental things that this woman has to process who walks outside and looks at this versus the woman who’s over here who does not have that.”*

Poverty *“They’re not getting the proper care they need because you can’t afford insurance or you know you’re poor so you can’t go out and you know get your prenatal care, you can’t buy vitamins....or groceries.”*

Housing *“And not having housing is stressful and very bothering, very, because you don’t know what you’re going to do when you’re living in somebody’s living room on their love seat and you got a baby or about to have a baby.”*

Social Services *“And I wanted to add about the income level. I would like to see it not be, how can I put it, not encourage for you to have, as soon as you have your child’s father in your life, a lot of these programs disappear.”*

Physical Fitness Opportunities *“Having parks so they’re not playing out in the streets, going to get hit by cars and parking lots like she said. Get them somewhere to play.”*

Research questions for the project were as follows:

1. What social and environmental factors contribute to a healthy pregnancy in African American communities of the West End, Louisville, KY?
2. What social and environmental factors contribute to an unhealthy pregnancy in African American communities of the West End, Louisville, KY?

3. What is the readiness of Jefferson County health leaders to address infant mortality among African Americans in the West End, Louisville, KY?

In addition to focus groups, key informant interviews were also conducted as a part of this project. For more information about Kentucky's *Jefferson County Infant Mortality Project*, contact Dr. Harris directly at <http://chfs.ky.gov/dph/officeofhealthequity.htm>.

6. b. Child Mortality

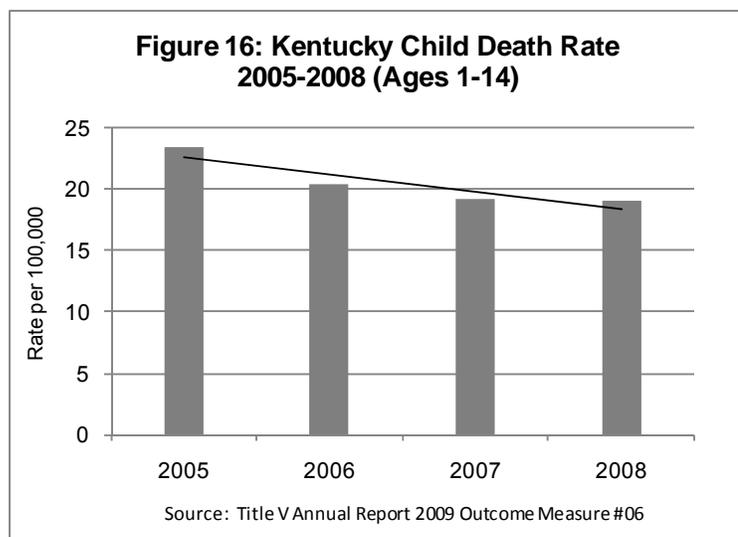
As evidenced by Figure 16, Kentucky's rate of child mortality has continually declined since 2005. Again, while data from 2009 has been reported for this measure, results are provisional and are not included in this illustration for this reason. Evidence for 2009 suggests a continuation in the downward trend for this measure.

Kentucky's Child Fatality Review (CFR) Program was established by statute (section 211.680 et seq.) in 1996. With an annual budget of \$235,600, the CFR is supported through funding provided by the Title V MCH Block grant.

The purpose of Kentucky's CFR program is for local teams to conduct investigations, for state and local health departments and local CFR teams to provide services, to prevent deaths and quality assurance at the state health department. Bereavement services are offered through the local health departments. Services for Sudden Infant Death Syndrome are offered through a separate Kentucky Alliance.

CFR findings have influenced policy changes in Kentucky. Statewide examples of these changes include a possible 2004 General Legislative Assembly passage of primary offense (presently secondary offense) for older child/adult (already primary for infants) seat belt law, primary enforcement law for child booster safety seat and six months extension of existing graduated licensing for new 16-year-old drivers. They are also hopeful for helmet use and restrictions regarding child ATV operators. Kentucky CFR findings motivated prevention activities through the high percentage of health departments that offer community outreach prevention education, in addition to other community child safety action groups (fire, EMS, Safe Kids, Safe Communities, Risk Watch, etc.).

As noted earlier in this report, the Commonwealth of Kentucky produces an annual report based on calendar year data. The report is distributed to selected government officials, Department of Public Health staff, local health departments, coroners and others upon request. Causes of death examined include leading causes of deaths/trends by age, manner and causes of childhood deaths, unintentional injury-related deaths (transportation, drowning, fire, poison and suffocation) as well as intentional (abuse/neglect, homicide, suicide).



Following is a brief update of some of the major causes of child mortality in Kentucky. All data reported is from the 2009 Child Fatality Review System Annual Report. For those interested in additional details regarding infant and child mortality, including risk factors and prevention strategies, this report may be found at <http://chfs.ky.gov/dph/mch/cfhi/childfatality.htm>.

Natural Cause of Death

Deaths classified under the category of “natural cause” are generally linked to a specific disease or condition. Table 16 shows leading natural causes of death for children birth to 14 years old and under in 2007. Deaths due to perinatal conditions account for 29% of all natural deaths among children in 2007. SUDI alone comprise 13% of natural deaths; 24% of natural deaths among children were due to congenital anomalies.

Unintentional Injury

Unintentional injuries, more commonly known as accidents, are the number one cause of all deaths for Kentucky’s children aged 1-17. Perhaps the most unsettling part of these deaths is that they are potentially preventable.

Unintentional injuries include transportation deaths, drowning fatalities, fire fatalities, poison fatalities, suffocation in infants and even the unintentional act of leaving a child in a car alone.

Table 16: Leading Natural Causes of Death Among Kentucky Children 14 and under, 2007

Natural Causes*	Number of Deaths
Perinatal Period Conditions (conditions related to, but not limited to, disorders related to length of gestation and fetal growth, birth trauma, respiratory and cardiovascular disorders specific to the perinatal period, digestive system disorders of fetus and newborn.	130
Congenital Anomalies	106
SUDI	57
Malignant Neoplasm	18
Respiratory Disease	16
Heart Disease	14
Other (digestive system, CNS, mental disorder, infectious disease, other ill-defined conditions etc.)	83

*Causes are based on ICD code groupings, not on individual ICD codes. Perinatal conditions as defined by The Center for Disease Control are certain conditions originating in the perinatal period; perinatal meaning occurring in, concerned with, or being in the period around the time of birth. Perinatal conditions (P00-P96) is used as referenced in International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Volume 1 (1992); with these exclusions: congenital malformations, deformations and chromosomal abnormalities (Q00-Q99); endocrine, nutritional and metabolic diseases (E00-E90); injury, poisoning and certain other consequences of external causes (S00-T98); neoplasms (C00-D48); and tetanus neonatorum (A33).

A key partner with the Kentucky Department for Public Health in addressing unintentional injury for children and adults is the *Kentucky Injury Prevention and Research Center (KIPRC)*. As noted in Section 4.c. (Capacity – Population Based), KIPRC works to reduce injury through education, policy initiatives, public health programming, surveillance, risk factor analysis, direct interventions and evaluation. Within KIPRC, the Pediatric and Adolescent Injury Prevention Program is managed by Dr. Susan Pollack, who is a physician Board Certified in both Pediatrics and Occupational Medicine.

Dr. Pollack is also an Assistant Professor in the General Pediatric Division of the University of Kentucky, Department of Pediatrics and in the Department of Preventive Medicine. Dr. Pollack is interested in all aspects of injury epidemiology and prevention for the pediatric and adolescent

age group. More information about KIPRC and programs to reduce injuries in the MCH population may be found at <http://www.kiprc.uky.edu/index.html>.

Transportation Deaths

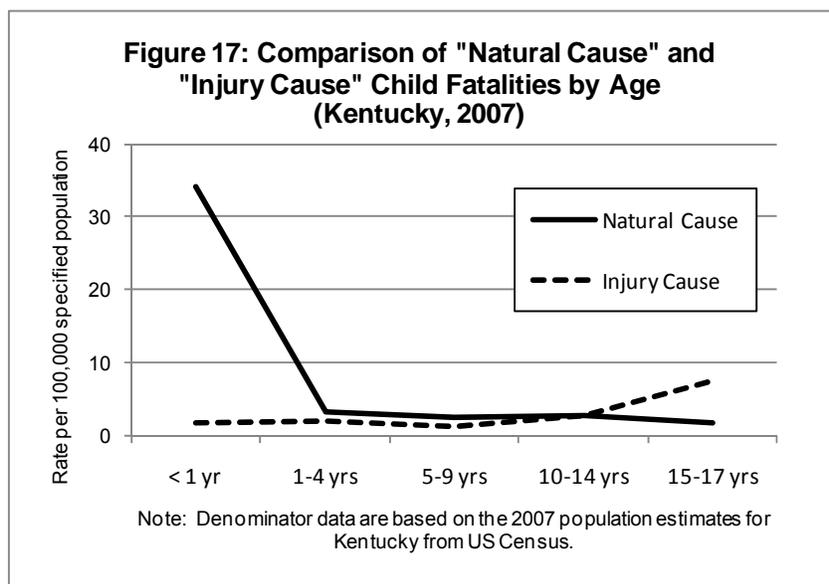
In the United States, as well as in Kentucky, motor vehicle crashes are the leading cause of injury death for people ages 1–44 years; the leading cause of death for children from 1-14 years; and, the second leading cause of injury death for children less than one year. Kentucky Vital Statistics data shows that in 2007, for children 17 and under, motor vehicle crashes accounted for 47%, or almost half, of all injury related deaths.

In 2007, there were a total of 865 Kentuckians (including adults) killed in motor vehicle crashes and 65 (8%) of those motor vehicle fatalities occurred with Kentucky's children less than 18 years of age. There were 28,889 motor vehicle crashes involving children, and in those crashes, 1,726 (6.0%) of the children were not restrained. However, of the 65 child fatalities from motor vehicle accidents, 44 (68%) were unrestrained. This is consistent with past years and makes motor vehicle fatalities the leading cause of injury deaths for Kentucky's children 17 years and under, according to Kentucky State Police Statistics.

Motor vehicle fatalities include drivers, passengers, and pedestrians who are struck by motor vehicles, bicyclists, and occupants in any other form of transportation, including all-terrain vehicles. In 2007, Kentucky's children were killed as car drivers or passengers (40%), vehicle in which the type was not specified (44%), pedestrians or riding a bicycle (6%), and

ATV drivers or passengers (10%). The rate of death for children under 18 from transportation crashes is 6.5/100,000 children. Among white children, nearly 7.0/100,000 died in transportation crashes in 2007. Four per 100,000 African American children died in transportation crashes.

In 2007, 10% of Kentucky's transportation crash fatalities among children under 18 were due to ATV injuries. Of these, most involved riding on roads. An ATV that turns over can lead to serious injury or death, such as blunt trauma to the chest, a combination of chest and head injuries, or positional asphyxia. Overturns typically occur when riding on a steep hillside or when the ATV runs off the road, but can even occur in an open yard. Helmets help protect the head from serious injury while riding an ATV and should always be worn regardless of age, experience, or length of travel time on the ATV. However, in the child ATV deaths that occurred in Kentucky in 2007, most were not wearing helmets. Helmets do not protect against chest injuries that may occur and chest injuries were involved in at least half of the cases.



These ATV fatalities all occurred in different counties, scattered across the state. While summer is generally considered the time when trauma occurs, ATV deaths occurred throughout the year, beginning as early as February and as late as November. The age range of those killed due to ATV accidents is 6 to 17 years. In addition to the ATV deaths, dirt bikes also pose a threat of serious injury or death. Just as with ATV overturns and riding on roads, dirt bikes can be dangerous, especially when the child is not wearing a helmet. Unfortunately, neither ATVs nor dirt bikes are typically thought of as motor vehicles and children are often allowed to drive these vehicles with no driving education. Sixty six percent of all the off-road vehicle deaths in 2007 involved roads and children with no driving experience.

Drowning Fatalities

In 2007, 12 Kentucky children died due to drowning. The place of drowning for these children included natural water, swimming pools, and unspecified places. In 2007, Kentucky trends were consistent with the national trend as there were a number of children under four years of age that died due to drowning. Children under four are at high risk and always need adult supervision. Older children are more likely to drown in creeks, lakes and rivers. In Kentucky, teenagers ages 15-17 had the highest rate of drowning deaths in 2007.

Fire Fatalities

Each year in the United States, at least 850 children under age 14 die and 2,800 are injured in residential fires. According to the National Fire Protection Association, Kentucky is ranked 8th in the United States for fire deaths. Children under age five are particularly vulnerable to fire related injury and death. They are twice as likely as the rest of the population to die in a fire. Safe Kids reports that more than half of the children under age five who die in house fires are asleep at the time of the fire, and recent studies have demonstrated that young children will sleep through sounding smoke detector alarms. Young children must often depend upon adults to help them get out, and when in a fire, young children may seek adults rather than exits, or they may run and hide in a closet. The United States Fire Administration also reports that children living in rural areas have a dramatically higher risk of dying in a residential fire than do children living in more urban areas, and this is probably related in part to the time it takes fire responders to reach rural fires.

In 2007, 12 Kentucky children died from fire-related fatalities according to Kentucky Vital Statistics records. The rate of fire deaths among children in Kentucky is 1.2 per 100,000 children. Four African American children and eight white children died of fire in Kentucky in 2007. No Hispanic children died of fire in Kentucky in 2007. Among those that died, five were males and seven were females.

Intentional Injuries

Abuse/Neglect

The Cabinet for Health and Family Services, Department for Community Based Services, Division of Protection and Permanency (DPP) is the agency in Kentucky responsible for receiving and investigating cases where child abuse or neglect is alleged to have resulted in a child fatality or near fatality. This agency investigates potential abuse/neglect related child fatalities and near fatalities and substantiates abuse or neglect when it is warranted. Each

investigation is reviewed by a policy analyst in Central Office. The following data were collected from the child abuse or neglect child fatalities reported during the 2007 fiscal year.

During the 2007 state fiscal year in Kentucky, 26 children died from child abuse or neglect. However, this may be an underestimation because child abuse and neglect fatalities often mimic illness and accidents, and are particularly difficult to diagnose for the treating physician or the investigating coroner. DPP works with local child fatality review teams to help improve the accuracy of child death reporting.

As in previous reporting periods, there continues to be a strong correspondence between the age of the child victim and the risk for serious or fatal injury. For the 13 child fatalities occurring in the 2007 fiscal year whose families had prior involvement with DPP, 38.5% of the victims were age three or younger and 30.8% were one year of age or younger. These data are consistent with trends seen previously in Kentucky as well as nationally. The distribution of the victim gender during this state fiscal year varied from statewide historical averages with 17 of the fatality and near fatality victims being male (52%) and 16 female (48%).

The cause of the majority of child deaths associated with families that had prior involvement with DPP was from caretaker neglect (85%). Another 15% of the deaths were the result of caretaker physical abuse. Expectedly, physical abuse and neglect, being very different types of maltreatment, present quite differently as well. House fire, inflicted head injury, motor vehicle accidents where other circumstances contributed to the accident; like the driver being impaired or the presence of domestic violence, and child drug overdose were the most common causes of death in physical abuse and neglect fatalities with prior DPP involvement; others included drowning and gunshot wounds.

Homicide

In 2007 the methods of child homicide in Kentucky included gunshot, fire, maltreatment, hanging, strangulation and suffocation, drowning, and unspecified or other. Child abuse can be manifested as homicide. Therefore some cases from the previous section may be captured here as well. Of the 14 homicides to children under the age of 17 in the 2007 Kentucky death certificate file, the majority occurred among children 15-17 years old (2.8 per 100,000). Since 1999 Kentucky has ranked consistently lower than the United States with our rate of homicides in children 17 and under, but this is likely due to underreporting.

In 2007 in Kentucky, the rate of homicide deaths among children 17 and under was 1.4/100,000 children. The rate of white children who died by homicide was substantially lower than that of black children (1.0/100,000 compared to 4.1/100,000 respectively). For 2007 the rate of death by homicide of Kentucky children age 15-17 was highest compared to other age groups (2.8/100,000). The next highest age group was children under age four (1.8/100,000).

Suicide

Suicide is the second leading cause of death for Kentuckians ages 15-34. The rate of suicide deaths among Kentucky children ages 5 to 17 was 2.3 per 100,000 children in 2007. Of the suicides in 2007, there were no documented suicides in children under age 11 in Kentucky. The rate of suicide was highest among children 15 years old (7.4 per 100,000). From 1999 to 2007, the rate of death among children from suicide was lower in Kentucky than the United States for

most years. However, the rate has increased from 1.3 in 2006 to 2.3 in 2007. Suicide is the second leading cause of death for teens 15-17 years old in Kentucky.

Firearms are the most common method of suicide among all groups and suicide crosses all ethnic, economic, social, and age boundaries. In youth who died by suicide in 2007, all but one were white, and the most commonly used mechanism was a firearm. The second most common mechanisms were hanging and poisoning. Surprisingly, just as many females used firearms as did males in 2007 but more males died from intentional poisoning.

Conclusion

This concludes the 2010 MCH Needs Assessment report for the Kentucky Department for Public Health and the Kentucky Commission for Children with Special Health Care Needs.

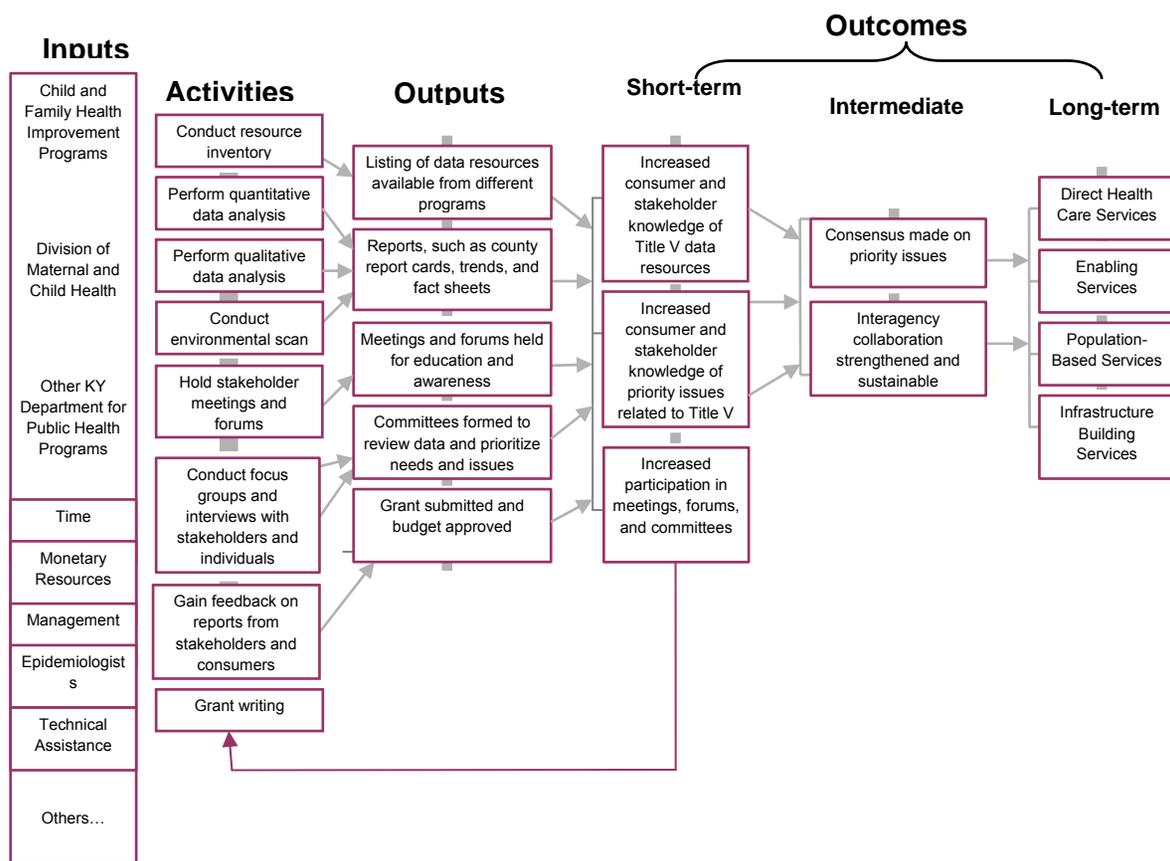
For more information about programs and best practices to improve maternal and child health in Kentucky, please contact Dr. Ruth Ann Shepherd, Division Director of Maternal and Child Health at the Kentucky Department for Public Health at 502-564-4830.

For more information about children and youth with special health care needs in Kentucky, please contact Rebecca J. Cecil, R.Ph, Executive Director of the Commission for Children with Special Health Care Needs at (502) 429-4430.

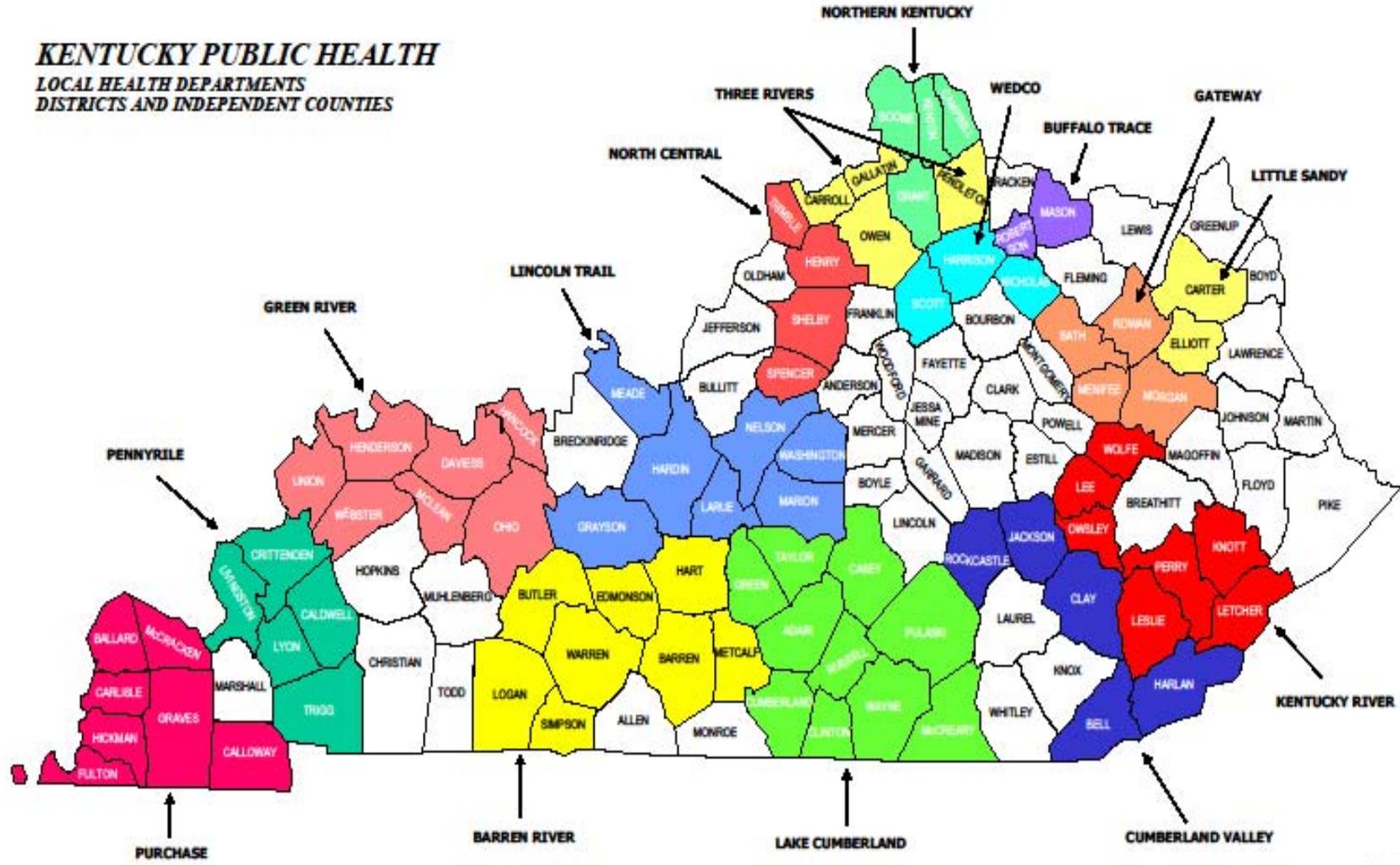


Appendix A: Kentucky Title V Needs Assessment Logic Model

Goal: Conduct needs assessment and determine priority issues in order to provide services under the Title V Block Grant



KENTUCKY PUBLIC HEALTH
LOCAL HEALTH DEPARTMENTS
DISTRICTS AND INDEPENDENT COUNTIES



Rev. 12/2003

Appendix C: Kentucky Department for Public Health, Division of Maternal and Child Health
Pre-Assessment Provider and Stakeholder Survey 2009 for MCH Needs Assessment 2010

**Title V Needs Assessment
Pre-Assessment Survey**

Name: _____ Position: _____

Health Department _____

Has your health department done or planned a community needs assessment in 2007, 2008, or 2009?

___ Yes ___ No

If yes, does it cover maternal and child health issues? ___ Yes ___ No

If yes, would you be willing to share your results to be used in the Title V Needs Assessment?

___ Yes ___ No

Would you be interested in hosting a Community Form in your area for the Title V MCH Needs Assessment? ___ Yes ___ No

1. Please list the three most important maternal and child health issues in the area your health department serves, with most important first (see attachment/back titled **Maternal & Child Health Issue** for list of common maternal and child issues).

- 1. _____
- 2. _____
- 3. _____

2. Do you feel your community has the capacity (staffing, funds, resources, etc.) to address each issue you listed above (please indicate Yes, No, or Not Sure next to each issue)?

- | | | | | |
|----|-------|-----|----|----------|
| 1. | _____ | Yes | No | Not Sure |
| 2. | _____ | Yes | No | Not Sure |
| 3. | _____ | Yes | No | Not Sure |

3. Please list the top three demographics that would be useful to target in your planning to impact MCH issues, with most important first (see attachment/back titled **Demographics** for list of common available maternal and child demographics).

- 1. _____
- 2. _____
- 3. _____

4. What are the three barriers that your clients are experiencing that reduce their access to MCH services?

- 1. _____
- 2. _____
- 3. _____

Appendix C (continued)
Kentucky Department for Public Health,
Division of Maternal and Child Health
Pre-Assessment Provider and Stakeholder Survey 2009 for MCH Needs Assessment 2010

1. What do you feel are the top three training/educational needs for MCH providers in your community?

- 1. _____
- 2. _____
- 3. _____

2. In your opinion, how serious of a problem is infant mortality (less than 12 months of age) in the area your health department serves (please circle one)?

Not At All Serious Somewhat Serious Undecided Serious Very Serious

3. In your opinion, how serious of a problem is child mortality (ages 1-17) in the area your health department serves (please circle one)?

Not At All Serious Somewhat Serious Undecided Serious Very Serious

4. What do you project to be the biggest Maternal and Child Health (MCH) concern in the future (2010-2015) in the area your health department serves?

5. Do you have any other specific areas of concern regarding maternal and children's health that are not mentioned above?

6. How does your health department evaluate effectiveness of your MCH programs?

THANK YOU FOR YOUR PARTICIPATION IN THIS SURVEY

Web Based Survey

Needs Assessment

Every 5 years, the Kentucky Department for Public Health conducts a needs assessment on the health of women of childbearing age, infants, children, and teenagers in order to identify the priority health needs of these groups. This helps us understand the concerns stakeholders and service recipients have regarding the health status of mothers, infants, children, and teenagers. Please take 5 minutes to share your views about the health issues affecting these groups in your community. We value your time and greatly appreciate your input. Please pass this link on to people you feel would be appropriate to answer this survey.

Section A: Introduction

1. Are you a healthcare provider?

***Health care provider means any person, corporation, facility or institution licensed or otherwise authorized by the Commonwealth to provide health care services, including, but not limited to, any physician, coordinated care organization, hospital, health care facility, dentist, nurse, optometrist, podiatrist and public health professional.**

Yes
 No

2. If you answered Yes to Q1 then please answer the following questions for the county that you serve.

List County where you work

3. If you answered No to Q1 then please answer the following questions about the county where you live.

List County of residence

4. Please select the ONE category that best describes your organization.

Educational Institution
 Private, for-profit business/service
 Private, non-profit business/service
 Public Agency/ Government Institution
 Association, civic group or faith-based group
Other (please specify)

5. Please check the ONE phrase that best describes the geographic scope of your services.

Statewide
 County-wide
 Regional
 Other (please specify)

Appendix D (continued)
 Kentucky Department for Public Health, Division of Maternal and Child Health
 Provider and Stakeholder Survey 2009 for MCH Needs Assessment 2010

Section B: Health Issues

1. Please check the top THREE health issues that you feel affect the health status of women, infants, children and teenagers in your community.

- Overweight/Obesity in children and teens
- Lack of prenatal care
- Substance abuse
- Smoking during pregnancy
- High-risk pregnancy factors
- Exposure to second hand smoke
- Access to family planning services
- Child abuse
- Teen pregnancy
- Percent of mothers who breastfeed
- Low birth weight babies
- Pre-term infants
- STD
- Dental health
- Racial inequity
- WIC participation
- Access to specialty medical care
- Health insurance coverage
- Immunizations
- Suicide rates
- Other (please specify)

2. Please rank the three health issues that you selected in the question above.

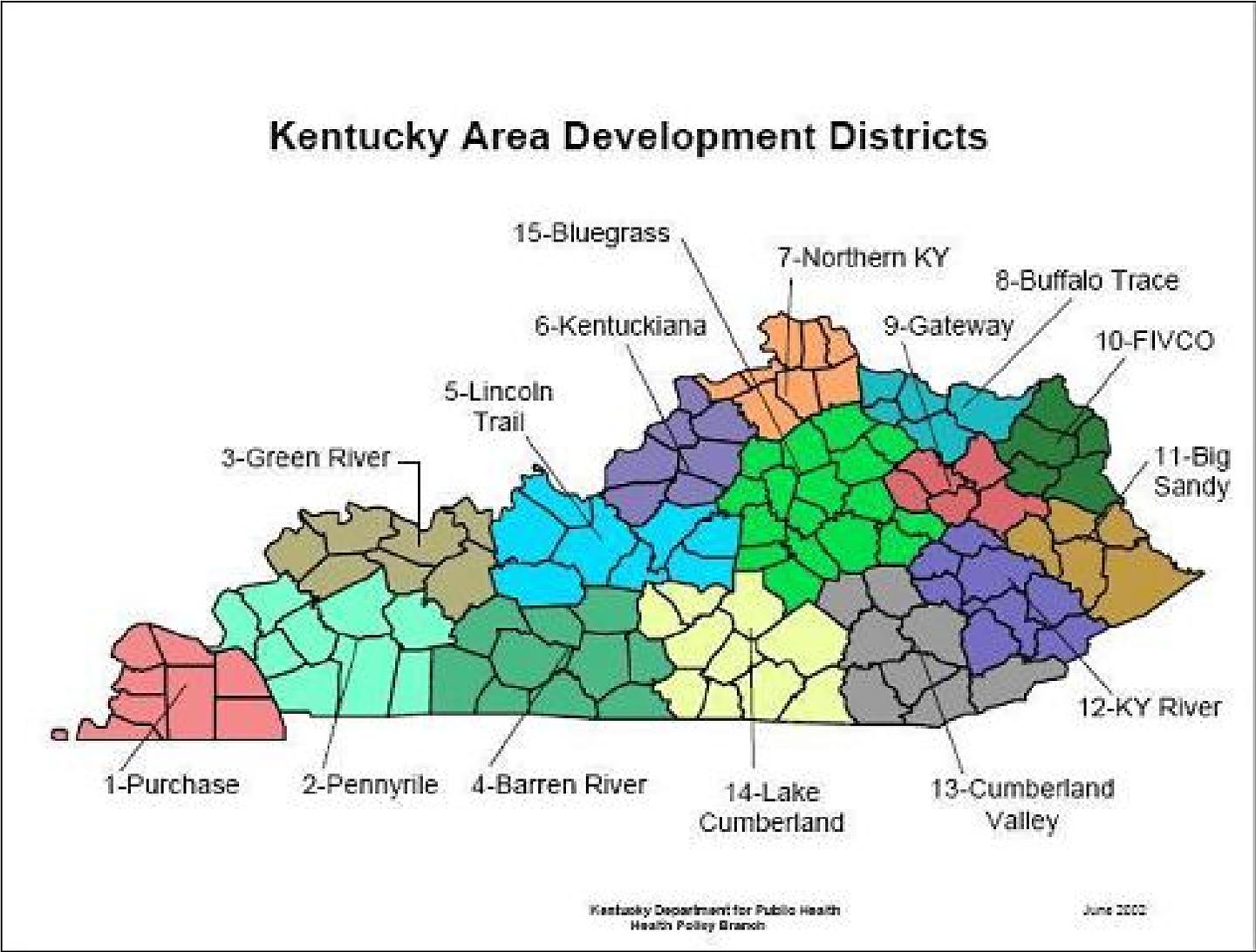
Health Issue #1
 Health Issue #2
 Health Issue #3

3. To what extent do you think your selected three issues are being addressed in your community?

- Not at all Very little Somewhat To a great extent
- Health Issue #1
- Health Issue #2
- Health Issue #3

4. For health issues that you have chosen what assets does your community have to address these issues? (Check all that apply)

- | | Health Issue #1 | Health Issue #2 | Health Issue #3 |
|------------|--------------------------|--------------------------|--------------------------|
| N/A | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Leadership | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Resources | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Funds | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Education | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Awareness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |



Patient Survey

Every 5 years, the Kentucky Department of Public Health does a survey to find out what kinds of health care problems are affecting women of childbearing age, babies, children, and teenagers in Kentucky. This will help us understand how to do a better job serving the people of Kentucky. Please take 5 minutes to share your views about the health issues affecting these groups in your community. We value your time and greatly appreciate your input.

Your participation in this survey is completely voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. The information obtained from this survey will be treated as confidential, and any identifying information will be removed prior to sharing the results of this study.

Your participation in this study should not present any risks to you. You may skip any questions that you do not want to answer.

Section A. Introduction

1. Name the county in which you live: _____
 2. Name the clinic you are visiting today: _____
- | | |
|---|--|
| <ol style="list-style-type: none"> 3. How did you get here? <ul style="list-style-type: none"> <input type="checkbox"/> By car <input type="checkbox"/> By bus <input type="checkbox"/> By taxi <input type="checkbox"/> I walked <input type="checkbox"/> Someone drove me <input type="checkbox"/> Medical Transportation Service | <ol style="list-style-type: none"> 4. How long did it take you to get here? <ul style="list-style-type: none"> <input type="checkbox"/> 10-15 minutes <input type="checkbox"/> 16-30 minutes <input type="checkbox"/> 31-60 minutes <input type="checkbox"/> more than an hour |
|---|--|

Section B. Health Problems

1. Pick **two** health problems that you think frequently affect **women** in your area. You may add things that are not on the list.

<ul style="list-style-type: none"> <input type="checkbox"/> Overweight/Obesity <input type="checkbox"/> Feeling down or hopeless (depression) <input type="checkbox"/> Drug or Marijuana Use <input type="checkbox"/> Pregnancy and health problems related to pregnancy 	<ul style="list-style-type: none"> <input type="checkbox"/> Being in a car or home with other people smoking (Second Hand Smoke) <input type="checkbox"/> Women who smoke <input type="checkbox"/> Sexually Transmitted Diseases (STD's) <input type="checkbox"/> Other (Please write in): _____ _____
--	--

2. Pick **two** health problems that you think frequently affect **babies and children** in your area. You may add things that are not on the list.

<ul style="list-style-type: none"> <input type="checkbox"/> Overweight/Obesity <input type="checkbox"/> Babies born too small (less than 5 pounds) <input type="checkbox"/> Babies born too early (3 weeks before due date) <input type="checkbox"/> Child abuse or neglect <input type="checkbox"/> Breastfeeding problems 	<ul style="list-style-type: none"> <input type="checkbox"/> Being in a car or home with other people smoking (Second Hand Smoke) <input type="checkbox"/> Not putting infants/children in a car or booster seat <input type="checkbox"/> Other (Please write in): _____ _____
--	--

3. Pick **two** health problems that you think frequently affect **teenagers** in your area. You may add things that are not on the list.

<ul style="list-style-type: none"> <input type="checkbox"/> Overweight/Obesity <input type="checkbox"/> Drug or marijuana use <input type="checkbox"/> Teens smoking <input type="checkbox"/> Teen pregnancy <input type="checkbox"/> Sexually Transmitted Diseases (STD's) 	<ul style="list-style-type: none"> <input type="checkbox"/> Teens trying to harm themselves <input type="checkbox"/> Motor vehicle, motor cycle or ATV accidents <input type="checkbox"/> Other (Please write in): _____ _____
--	---

Please list any other health issue that was not included in the lists above that you feel is very important in the area where you live.

Section C. Health Care Needs

Here is a list of **health care services** that many women and their families need. For each one, circle **Y** (Yes) if you or someone you know faced a problem getting this service and **N** (No) if you or someone you know did not face a problem in getting this service.

Did you face a problem in:

- | | | | |
|----|---|---|---|
| A. | Being able to see a dentist----- | Y | N |
| B. | Getting an appointment for care during pregnancy----- | Y | N |
| C. | Getting Health Insurance----- | Y | N |
| D. | Getting a Medical Card (Medicaid)----- | Y | N |
| E. | Getting WIC Vouchers----- | Y | N |
| F. | Getting family planning services like birth control pills----- | Y | N |
| G. | Getting a yearly check-up like a mammogram or pap smear----- | Y | N |
| H. | Being treated differently because of your race----- | Y | N |
| I. | Getting baby shots for baby and children----- | Y | N |
| J. | Being able to see a medical specialist for a specific health problem----- | Y | N |

Please list any other health care services that you or someone you know needed and it is not available in the area where you live.

Section D. Demographic Information

These last questions will tell us a little about you and how your views compare with other people in Kentucky.

- | | |
|---|--|
| <p>1. What year were you born? _____</p> <p>2. Are you?
 <input type="checkbox"/> Married
 <input type="checkbox"/> Single
 <input type="checkbox"/> Single Living with partner
 <input type="checkbox"/> Other</p> <p>3. Please tell the number of people living in your household.
 Number of children (0-18 years) _____
 Number of adults living with you (18 and older) _____</p> <p>4. Do any of the people who live with you smoke cigarettes in the house every day?
 <input type="checkbox"/> Yes
 <input type="checkbox"/> No
 Number of smokers in your house _____</p> <p>5. How old are you? _____ years old</p> <p>6. Are you of Hispanic (Spanish/Latina) origin?
 <input type="checkbox"/> Yes
 <input type="checkbox"/> No</p> | <p>7. How much schooling have you had?
 <input type="checkbox"/> Up to 8th grade
 <input type="checkbox"/> 9th-12th grade no diploma
 <input type="checkbox"/> High school graduate or GED
 <input type="checkbox"/> Some college credit but no degree
 <input type="checkbox"/> Associate's degree
 <input type="checkbox"/> Bachelor's degree or higher</p> <p>8. Please check off the race that you most consider yourself to be. (check only one)
 <input type="checkbox"/> White
 <input type="checkbox"/> Black or African American
 <input type="checkbox"/> Asian Pacific Islander
 <input type="checkbox"/> Native American
 <input type="checkbox"/> Other (Please write in): _____
 _____</p> <p>9. How are you paying for the visit today?
 <input type="checkbox"/> Private Insurance
 <input type="checkbox"/> Self Pay
 <input type="checkbox"/> Medical card
 <input type="checkbox"/> Other (Please write in): _____
 _____</p> |
|---|--|

Thank you for completing the survey. Please return it to the front desk

Welcome to the Children with Special Health Care Needs Family Survey

The Commission for Children with Special Health Care Needs is asking you to take this survey as part of a Five-Year Needs Assessment about health services. The purpose of this survey is to gather important information from families who have children with special health care needs.

If you are a youth or young adult who has a special health care need, please complete this survey for yourself.

Your parent(s) can also complete it.

Every opinion is valued and appreciated. The information obtained from this survey will be used to determine:

- The types of services and programs in your community that are helpful to you and your family;
- How resources can be better utilized to help Kentucky families with children with special health care needs; and
- What services and programs are still needed.

Instructions for completing the survey:

1. There are 37 questions.
2. Most questions have check boxes for answers.
3. Please complete all of the questions. There are no right or wrong answers. We just want to know your opinion.

Thank you!

When you are finished, please take back to your local Commission office, or mail to:

Commission for Children with Special Health Care Needs

Attn: Meredith Evans

310 Whittington Pwky, Ste 200

Louisville, KY 40222

Commission for Children with Special Health Care Needs

Five-Year Statewide Needs Assessment Survey (2010)

I. Number of Kentucky children with special health care needs, services utilized and access to care

1. What county do you live in? _____

Definition: Children with Special Health Care Needs (CSHCN) –

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

from HRSA/MCHB, Guidance and Forms for the Title V Application/Annual Report, exp. 2012

2. Based on the above definition, how many children with special health care needs are in your family? _____
3. Based on the above definition, how many children with special health care needs are in your family with the following conditions?

Categories of children with special health care needs	Number of children with the following medical conditions	Ages of children
Children with chronic physical illnesses or disabilities (such as asthma, spina bifida, cerebral palsy, or other)		
Children with developmental disabilities (not typical development, such as autism, mental retardation, Downs Syndrome, or other)		
Children with behavioral problems (such as ADHD, substance abuse, bullying, or other)		
Children with emotional problems (such as depression, bi-polar, schizophrenia, or other)		

4. Please check all of the services that your child receives or uses (at the Commission or somewhere else):

- | | |
|--|---|
| <input type="radio"/> Primary (general) medical care | <input type="radio"/> Physical therapy |
| <input type="radio"/> Respite care | <input type="radio"/> Occupational therapy |
| <input type="radio"/> Specialty medical care | <input type="radio"/> Financial counseling |
| <input type="radio"/> Mental health care | <input type="radio"/> Speech-language therapy |
| <input type="radio"/> Adult day care (child over 18) | <input type="radio"/> Nutrition counseling |
| <input type="radio"/> Behavioral management | <input type="radio"/> Day care (child under 18) |
| <input type="radio"/> Substance abuse treatment | <input type="radio"/> Special/exceptional education |
| <input type="radio"/> Hearing services | <input type="radio"/> Vocational training |
| <input type="radio"/> Dental care | <input type="radio"/> Vision services |
| <input type="radio"/> Other (please describe): _____ | |

5. Please check all of the following that your child has or needs:

- Eyeglasses
- Hearing aid
- Cochlear implant
- Orthotics/prosthetics (foot support, artificial body part, AFO)
- Assistive listening device (FM system, infrared/light system, loop system, sound field system, etc...)

- TDD or TTY (telephone typewriter)
- Interpreter (sign language or non-English language)
- Assistive technology for computers (special keyboard, footmouse, special computer programs, etc...)
- Assistive technology for visual impairments (Braille, screen readers, dictation system, large print materials, etc...)
- Durable medical equipment (wheelchair, standing frame, special seating, crutches, walker, leg braces, etc...)
- Community mentoring
- Other (please describe): _____

6. Please describe the 3 most important programs or services that your child receives (these can be medical, school or any other type):

Name of Program or Service	# of miles from your home	Travel time from your home	Where is service located (city)?	How is your travel paid for?

7. My family is most interested in (check all that apply):

- Childhood obesity (overweight)
- Teaching my child how to read
- Childhood hypertension (high blood pressure)
- Talking with my child's doctor

- Childhood diabetes (blood sugar problems)
- Nutrition (how well do my kids eat)
- Breastfeeding
- Dental care for my child
- Bullying at school
- Vision services for my child
- Hearing services for my child
- Therapy services
- Help getting to doctor appointments
- Information that will help my child become independent
- Drug addiction (including caffeine) or talking with my child about drugs
- Other (please describe): _____

- Talking with my child's teacher or school counselor
- Autism
- Asthma
- Learning disabilities
- Car safety
- How to stop smoking
- Birth control
- Talking with my child about sex

8. My family can use more help with (check all that apply):

- Finding a doctor
- Finding a doctor close to my home
- Finding a medical specialist
- Getting my child to the doctor during office hours
- Time spent at medical appointments

- Assistance getting insurance coverage
- Learning about different sources of help in my community
- Help finding an adult doctor for my child
- Access to my child's medical records
- Getting good information on the developmental level of my child
- Other (please describe): _____

9. The top 3 barriers to getting the medical care my family needs are (check 3):

- No insurance coverage
- Insurance does not cover enough services
- Insurance is not accepted by the providers we would like to see
- Co-pays are too expensive
- Insurance is too expensive
- Appointment times are not convenient
- The wait time at appointments is too long
- Lack of transportation
- No interpreters
- No child care for other children during medical appointment times
- I do not like to travel outside my local area

Communication problems with my provider

a. Please describe: _____

Other (please describe): _____

10. I lost my job in the last year, or my spouse lost a job in the last year.

a. If yes, have you or your spouse returned to work?

Yes	No
<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>

II. Families of CSHCN are partners in decision-making at all levels and are satisfied with the services they receive.

11. I am satisfied with the services I receive from my doctor?

Yes No Sometimes

11a. My doctor includes me in making decisions.

Always	Sometimes	Not Often	Never
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12. My doctor can include me more in making decisions by (please describe):

III. Children are screened early and continuously for special health care needs.

13. My child/children received routine check-ups in the last year. Yes No
If no, why not?

14. My child/children received routine dental care in the last year. Yes No
If no, why not?
-
-

IV. Families of CSHCN have adequate private and/or public insurance to pay for the services they need.

15. My child has the following types of insurance (check all that apply):

- Medicaid
- Medicaid Managed Care
- KCHIP
- Military
- Private Insurance
- No Insurance

16. My child has lost insurance coverage in the last year. Yes No
a. If yes, what was the reason?
-

17. My insurance meets my child's needs. Yes No
a. If no, please explain.
-
-

V. CSHCN receive coordinated, ongoing, comprehensive care within a medical home; community-based service systems are organized so families can use them easily; and youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

Definition: Medical Home - A model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care (American Academy of Pediatrics). In March 2007, the AAP joined with the American Academy of Family Physicians, American College of Physicians and the American Osteopathic Association to publish a joint set of principles on the patient-centered medical home. This consensus statement describes the principles of a medical home: personal physician, physician- directed medical practice, whole person orientation, coordinated care, quality and safety, enhanced access, and appropriate payment. The critical medical-home principles are:

- **Family-centered partnership:** Trusting, collaborative, working partnership with families, respecting their diversity and recognizing that they are the constant in a child's life
- **Community-based system:** Family centered- coordinated network designed to promote the healthy development and well being of children and their families
- **Transitions:** Provision of high-quality, developmentally appropriate, health care services that continue uninterrupted as the individual moves along and within systems of services and from adolescence to adulthood
- **Value:** A high-performance health care system requires appropriate financing to support and sustain medical homes that promote system-wide quality care with optimal health outcomes, family satisfaction, and cost efficiency.

18. Is the concept of "medical home" new to you?

- Yes No

19. My child has a usual source of medical care (primary care, well care, sick care).

- Yes No

20. My child can get referrals when needed.

- Always Usually Not Often Never

21. Please rate your satisfaction in the following areas:

	Always	Usually	Sometimes	Not Very Often	Never
My family is satisfied with our doctors' communication with other programs.	<input type="radio"/>				
My family gets sufficient help coordinating care, if needed.	<input type="radio"/>				

Doctors spend enough time with my family at our appointment.	<input type="radio"/>				
Doctors listen carefully.	<input type="radio"/>				

a. If you answered "Sometimes," "Not Very Often," or "Never" on any items, please describe:

22. Please rate your satisfaction in the following areas:

	Always	Usually	Sometimes	Not Very Often	Never	Not Applicable
Doctors are sensitive to my values and customs.	<input type="radio"/>					
An interpreter is available when needed.	<input type="radio"/>					

a. If you answered "Sometimes," "Not Very Often," or "Never" on any items, please describe:

23. Who do you call or where do you look when you need help for your child? Please check all that apply:

- Family
- Health department
- Internet
- Library
- Friends
- Church
- Family resource center
- Support group
- Primary care provider
- Phone book
- Youth service center
- Specialty care provider
- Newspaper/Magazines
- Other, please describe: _____

24. What programs, services and resources would you like to have for your family?

25. Have you had any difficulty accessing or using community services?

- Yes No

a. If yes, please describe:

26. If you know of a program or service that is helpful to your family, please let us know who/what it is. If you don't, just leave blank.

27. Does your child go to the Commission for Children with Special Health Care Needs for services? Yes No

28. If yes to #27, how satisfied are you with the overall care that is received from the Commission?

- Very Satisfied
- Satisfied
- Somewhat Satisfied
- Not Satisfied. Please explain:

29. If yes to #27, how well does the Commission for Children with Special Health Care Needs work with your child's school?

- Very Well
- Well
- Somewhat
- I don't know
- The Commission does not work with my child's school. Comment:

30. If you answered yes to #27, why do you go to the Commission for Children with Special Health Care Needs instead of another doctor?

Definition: Transition services: Schools and health care services try to prepare young people for college, work, independence and adult health care.

31. Does your child receive transition services? Yes No

32. What transition services does your child receive:

Name of program or service	Does this program or service help your child become more independent?	How could this program or service improve to help your child plan for the future?
	<input type="radio"/> Yes <input type="radio"/> No	
	<input type="radio"/> Yes <input type="radio"/> No	

33. Has your child received information about work training programs in your community?

Yes No I don't know

34. Has your child's school helped plan for your child's future?

Yes No I don't know

35. If yes to #34, who has discussed this with you (or your child)? Check all that apply:

Guidance Counselor

Social Worker

Teacher

Other – Please describe:

36. If your child does receive Commission for Children with Special Health Care Needs services and is between the ages of 14 and 21, please answer the following questions: (If this does not apply to you, please go to the next question)

i. Has the staff at the Commission ever discussed future health care needs?

Yes No I don't know

ii. Has the staff at the Commission ever discussed future insurance needs?

- Yes No I don't know

iii. Has the staff at the Commission ever discussed your child's plans for after they leave high school?

- Yes No I don't know

37. If your child does not receive services at the Commission for Children with Special Health Care Needs and is between the ages of 14 and 21, please answer the following questions: (If this does not apply to you, please go to the next question)

i. Has your pediatrician or another provider ever discussed future health care needs?

- Yes No I don't know

ii. Has your pediatrician or another provider ever discussed how health insurance changes between ages 18 and 23, and future insurance needs?

- Yes No I don't know

iii. Has your pediatrician or another provider ever discussed your child's plans for after they leave high school?

- Yes No I don't know

Appendix H. Kentucky Children with Special Health Care Needs Five-Year Assessment Youth Advisory Council Focus Group Meeting Report (YAC)

Kentucky Children with Special Health Care Needs

Five-Year Needs Assessment

Youth Advisory Council Focus Group Meeting Report

Commission for Children with Special Health Care Needs

982 Eastern Parkway

Louisville, Kentucky

March 28, 2009

Summary of Five-Year Needs Assessment Focus Group Presentation

Focus Group: CSHCN Youth Advisory Council

Date: March 28, 2009

Location: Commission for Children with Special Health Care Needs – Louisville

Purpose: To attain data and other information pertaining to transition issues for CSHCN

In Attendance: Youth Advisory Council (YAC):

Katherine Lewis, Jackson County

Joan Howell, Jefferson County

Samantha Littlepage, Lyon County

Madison Warren, Henderson County

Deanna Mooney, Meade County

Josh Ising, Jefferson County

Parent:

Kelly Ising

CCSHCN Staff:

Becky Cecil, Executive Director

Anne Swinford, Division Director of Quality Outcomes Management

Lee Gordon, Family Support Services

Stephanie Mitchell, CSHCN Needs Assessment Project Coordinator

Summary:

The meeting convened over lunch, and then formal introductions were made. The Needs Assessment process was introduced by Becky Cecil, and additional information was provided by Lee Gordon and Stephanie Mitchell. Module information, provided by the Healthy and Ready to Work National Resource Center - http://www.hrtw.org/about_us/index.html, was presented by Mr. Gordon and Ms. Mitchell; and was followed by an open-ended question discussion.

Ms. Mitchell distributed the *2010 Needs Assessment Fact Sheet* and discussed the importance of completing the full survey when it becomes available, including forwarding it to other youth and families who would be interested in completing it.

Module 1 involved discussion and comparison of national and state data provided by the 2005/2006 National Survey of Children with Special Health Care Needs. Mr. Gordon distributed:

- 2005/2006 National Survey of Children with Special Health Care Needs Kentucky Chartbook Page
(<http://www.cshcndata.org/Content/StatePrevalence2005.aspx?geo=Kentucky>)
- 2005/2006 NS-CSHCN: Within State Urban/Rural Profile
- Worksheet 1A, Prevalence by age and sex

Katherine Lewis demonstrated access and utilization of the data on the Internet for the group via laptop and projector. Mr. Gordon led discussion of the information and encouraged the group to critically think about the data presented and how it compares to rates in Kentucky.

The *Needs Assessment Tool for Youth* from Module 3 was distributed and all of the youth completed it. The summary of their responses is included in this report.

A copy of the *Needs Assessment Tool for Families* was given to each youth attending the meeting, along with the mailing information to Ms. Mitchell's office. Each member of the YAC was asked to give the assessment tool to a parent for completion and return to the CCSHCN.

A copy of the handout *Successful Health Care Transition* was distributed by Mr. Gordon.

The meeting concluded with open discussion led by Mr. Gordon. Questions were derived from Module 3 Worksheet 3B – *What the NS-CSHCN Tells Us about Preparation for Transition in our State*. The following questions were presented:

- Are youth getting the counseling they need from their doctors? How does this compare to your experience?
- If your doctor hasn't discussed transition with you, would you feel comfortable asking your doctor to help you plan for your transition to adult health care? Why or why not?
- After looking at the survey findings, would you conclude that the most parents of YSHCN in our state consider transition counseling important? Why or why not?
- Has anyone other than your doctor or parents/guardians helped you to plan for transition to adult health care? How are they helping you?
- Is there anyone else that could help you and other youth in your community to plan for transition?
- Has anyone discussed how your insurance might change when you turn 18 or leave school?
- If you could talk to other YSHCN and their families, what would you say to them to convince them of the importance of preparing for health care transition?
- What else can the CCSHCN do to help in the transition process?

Here is a summary of comments that were received:

- Most or all of the youth have transitioned to an adult provider.
- About half of the group felt that they had received some type of transition counseling from their doctors, and half did not.
- Most of the group agreed that they had not received adequate preparation for the transition to an adult provider by their pediatrician.
- The youth who had participated in CSHCN programs did not feel that they had received preparation for the transition to an adult provider by the CSHCN.
- About half responded that they do feel comfortable asking their provider for transition assistance, half did not respond.
- Most responded that their parents talk/ed with their doctor about transition issues. About half reported that a parent still attends medical appointments, and half reported they do not.
- It was reported that CSHCN social workers and care coordinators did not discuss transition issues at all, including changes to insurance. One former patient said she “thought” it may have been discussed.
- Most of the group indicated they did not receive adequate information on insurance changes and still do not feel comfortable knowing for what they qualify or what providers accept Medicaid.
- Portland Family Medical group was cited as being a helpful, caring resource for transitioning to an adult provider.
- Vocational Rehabilitation was reported as not helpful by the majority of the group.
- Guidance counselors were reported as not helpful by the majority of the group.
- One person reported “blaming” between Vocational Rehabilitation and their school guidance counselors. Both parties state that the other neglected to assist when needed.
- In regards to what they would say to youth about the importance of health care transition, the following comments were made, “self-reliance,” “knowing what you are allergic to,” “be able to speak for yourself because no one knows yourself better” were all stated as being important.
- Other comments made about the transition process were:
 - “It’s really hard to get the help you need, (including record requests).”
 - “You have to be able to speak up for yourself.”
- Other issues that stood out as important for this group were:
 - Understanding Medicaid for adults age 21 and over
 - Rights for employees with special health care needs
 - Adequate job training
 - Education for educators on CSHCN – some educators may not feel that all students should receive transition information due to an assumed lack of potential.
- Regarding what else the CSHCN can do, the following issues were cited:
 - Education on the outbreak of community-based MRSA compared to hospital outbreaks.
 - Techniques and strategies to assist with study skills, including testing centers.
 - Peer-to-peer and family-to-family support group linkages

All of the youth were encouraged to contact Mr. Gordon or Ms. Mitchell if they felt like there were any other issues that they need to discuss, or if they need assistance. Ms. Mitchell gave everyone her work phone number, e-mail and mailing address as she is not in regular contact with the group.



*NEEDS ASSESSMENT TOOL
FOR YOUTH*

Please describe your transition activities

Rating: Am I doing this?

Satisfaction: How well am I doing this?

4: Doing well

4 = Excellent/Very Satisfied

3: Have begun doing

3 = Good/Fairly Satisfied

2: Thinking/Planning

2 = Fair/Satisfied

1: Not doing and cannot do now

1 = Poor/Not Satisfied

N/A = Not applicable

TRANSITION ACTIVITIES		
I am getting help with health transition:	Average Rating Score*	Average Satisfaction Score*
If my regular doctor is a pediatrician, he/she is helping me to transition to an adult doctor	2.17	2.33
I know how to stay healthy and manage my health condition	3.50	3.33
I have a portable health record	1.25	1.16
I have the information I need to maintain health insurance past age 18	2.33	2.33
I have/had a transition plan beginning by age 14 that addresses my needs in the following areas:	Average Rating Score*	Average Satisfaction Score*

School and Educational Goals	2.67	2.50
Goals for College and Further Education	2.80	2.80
Employment	3.00	2.83
Staying healthy	3.33	3.50
Community Living	2.83	2.83
Driving/Transportation	3.00	2.40
Assistive Technology	3.20	3.40
Necessary Accommodations	3.33	3.00
Other (please specify):	No Responses	No Responses

I have/had a transition plan that was written with input from:	Average Rating Score*	Average Satisfaction Score*
Me	3.50	2.66
My Family Members	3.33	3.40
My Teachers	2.50	2.33
My Doctor(s) or Other Health Care Providers	2.80	2.40
Vocational Rehabilitation	2.50	2.60
Other Appropriate Agencies, for example an independent	2.50 (< 3)	2.50 (< 3)

living center (please describe): "Thrive helps transition youth from on-campus to community; encourages active community involvement."	responses)	responses)
Other (please specify): "Budget and impulsive control; what to do when doctor moves or retires, follow up care including medication and services."	4.00 (< 3 responses)	3.00 (< 3 responses)
I routinely use the information & practice the skills that I have learned	3.25	3.25
<i>TOTAL SCORE</i>	49.33	46.50
<p>What does your rating mean? Preparing for transition is a process.</p> <ul style="list-style-type: none"> • If your score is 60-80 you are on your way! • If your score is 40-59, you have a start on learning and practicing transition skills, but need to focus more energy on preparing. • If your score is below 40, it is time to prepare for transition! 		

* Rating and satisfaction scores of "N/A" were not calculated in the average scores.

Prepared by Stephanie Mitchell

March 31, 2009

CCSHCN Staff Survey

Thank you for taking the time to complete this survey. There are 20 questions. Some have space in which to elaborate your response.

Answers are completely anonymous and information will be used to improve current programs.

1. Please indicate the area of the state in which you are based:

Western Region (Bowling Green, Elizabethtown, Louisville Clinical/Augmentative & Intake, Owensboro, Paducah)

Eastern Region (Ashland, Barbourville, Hazard, Morehead, Prestonsburg, Somerset)

State Central Office (Administrative Staff - Louisville)

2. Please indicate your primary role at CCSHCN:

Nurse/Program Coordinator Therapist (SLP, PT, OT) or Dietitian Audiologist

Social Worker Office Support

Intake Only Administrative/Management

3. Please rate the quality of CCSHCN facilities & equipment:

Superior

Above average

Average

Below average

Unacceptable

**4. Please indicate what improvements you feel are needed, if any. You may include information regarding a specific office, if you would like:
[Open-ended]**

5. What is your opinion regarding the convenience of the physical location of CCSHCN clinics?

Very convenient for clients

Somewhat convenient for clients

Average for clients

Somewhat inconvenient for clients

Very inconvenient for clients

6. CSHCN Staff Communication & Teamwork:

	Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Disagree
CCSHCN staff members' ideas and opinions are valued	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff conduct themselves in a professional manner with families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN senior management does a good job communicating the agency's goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff members in all areas resolve disagreements in a calm and reasonable manner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My supervisor supports me in my ability to perform my job duties.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6a. How can CSHCN staff communication and teamwork improve? [Open-ended]

7. Communication & Professionalism:

	Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Disagree
CCSHCN staff members project a positive and pleasant attitude	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff members go out of their way to be helpful and cooperative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff members almost always conduct themselves in a professional manner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff members present constructive solutions to problem situations, avoiding unproductive complaining	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7a. How can the level of professionalism at the CSHCN improve? [Open-ended]

8. CCSHCN Staff Training & Knowledge:

	Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Disagree
CCSHCN staff members are knowledgeable in their areas of specialty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff members don't make enough of an effort to listen to families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff members do a great job in educating families about medical conditions that affect their children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am proud to say I work at CCSHCN	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8a. What suggestions do you have for staff training? [Open-ended]

9. Please check all statements with which you agree:

	Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Disagree
I receive the support necessary to be successful in my job.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff members seem more concerned about billing/payment/insurance issues than health care issues.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get a lot of e-mails from CCSHCN staff regarding initiatives that are not very relevant to my job.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN senior management understands and works to resolve problems we face.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The workload is fairly distributed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9a. How would you like for your relationships with co-workers, your supervisor, and/or senior management to improve? [Open-ended]

10. Please indicate what types of additional training or support, if any, would be needed in order for you to be successful in your job (for example – computer technology, working with interpreters, etc.): [Open-ended]

11. How often do you access the CSHCN intranet site?

- I do not know how to access the CSHCN intranet
- I have never accessed the site
- Rarely (0-2 times per month)
- Occasionally (more than 2 times per month, but not regularly)
- Weekly
- Daily

12. What is your level of understanding of the concept of a “medical home”?

- I have no idea what that means
- I am kind of fuzzy on this idea but have a basic understanding
- I am very familiar

13. What is your level of understanding of the concept of “transitions” as the term is used with regard to children with special health care needs?

- I have no idea what that means
- I am kind of fuzzy on this idea but have a basic understanding
- I am very familiar

14. What do you see as barriers to CSHCN providing exemplary transition services? [Open-ended]

15. Do you feel you have a good knowledge of what non-CSHCN resources are available to families in your area?

- Yes
- No

15a. What would help improve your knowledge of available resources? [Open-ended]

16. On a scale of 1 to 5, how familiar are you with each of the following topics (with 1 being the least familiar and 5 being the most familiar)

- Mental/behavioral health & emotional support
- Financial & emergency assistance
- Health insurance and public assistance
- Food & nutrition
- Transportation
- Durable medical equipment

17. Please check all statements with which you agree:

- I am comfortable assisting clients to access services or resolve problems at local schools and Family Resource/Youth Service Centers (FRYSCs) and have working relationships with knowledgeable people who can assist
- I am comfortable assisting clients to access or problem-solve vocational rehabilitation services and have working relationships with knowledgeable people who can assist
- I am comfortable assisting clients access or problem-solve various types of health insurance (including medicaid, disability, waiver, individual, and group coverage) and have working relationships with knowledgeable people who can assist
- I am comfortable assisting clients to access therapy and DME services and have working relationships with knowledgeable people who can assist

18. Please check one statement regarding how well connected you feel that your office is within the health & social service delivery system overall.

- Excellent – we are a relevant and helpful agency that works well with other agencies and professionals in the community
- Good/Average - we serve our clients' basic clinical needs well, but could be better integrated with other agencies and professionals in the community
- Poor – other agencies or programs in the community either have no idea what we do or seem to report a lot of frustration with us

19. Please feel free to elaborate or offer any specific suggestions regarding the question above. [Open-ended]

20. Please specify services that you feel CSHCN should consider providing: [Open-ended]

This concludes the survey. Thank you for taking the time to complete all of the questions provided. Your responses and suggestions are greatly appreciated.

CCSHCN Provider Survey

Thank you for taking the time to complete this survey. There are 22 questions. Some have space in which to elaborate your response.

Answers are completely anonymous and information will be used to improve current programs.

1. Please check all CSHCN regions which you serve:

- Ashland
- Barbourville
- Bowling Green
- Elizabethtown
- Hazard
- Lexington
- Louisville
- Morehead
- Owensboro
- Paducah
- Prestonsburg
- Somerset

2. Please indicate the number of years you have served as a CSHCN provider:

- Less than one year
- 1-5 years
- 5-10 years
- More than 10 years

3. Please rate the quality of CSHCN facilities & equipment:

- Excellent
- Above average
- Average
- Below average
- Unacceptable

3a. Please indicate what improvements you feel are needed, if any, and specify which office:

4. What is your opinion regarding the convenience (to you?) (to clients?) of the physical location of CCSHCN clinics?

- Very convenient
- Somewhat convenient
- Average
- Somewhat inconvenient
- Very inconvenient

5. Communication

	Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Disagree
CCSHCN staff are friendly & cooperative with me and my staff.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff make my job easier.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff effectively coordinate services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff communicate well with families and patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff should make a better effort to listen to families and patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5a. Please elaborate how staff communication can improve: [Open-ended]

6. Clinical knowledge and training needs:

	Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Disagree
CCSHCN nursing staff are knowledgeable in the area of their clinical setting.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN nursing staff need additional training in their area of specialty.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff do a good job educating families about medical conditions that affect their children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff are knowledgeable about clinical procedures.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN staff need additional training about clinical procedures.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCSHCN case managers are effective in their overall coordination of their patients' medical care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6a. Please elaborate as to how staff knowledge and training can improve. [Open-ended]

7. Do clinic schedules meet your needs?

Yes No

7a. How can clinic schedules better meet your needs? [Open-ended]

8. Are there an appropriate number of patients scheduled per clinic?

Yes No

8a. How can patient scheduling improve? [Open-ended]

9. Does the CSHCN have enough therapists, audiologists and dietitians to address patient needs?
 Yes No

9a. In what area(s) does the CSHCN need to increase number of staff? [Open-ended]

10. Which services are delivered most effectively provided at the CSHCN? [Open-ended]

11. Which services need to be improved at the CSHCN? [Open-ended]

12. What services are difficult for families to obtain because of their geographical location?
(Please specify which services and in what areas families have difficulty obtaining)

13. Is the amount of time scheduled for each patient adequate?
 Yes No

13a. How can scheduling improve? [Open-ended]

14. Does the CSHCN adequately recruit and retain providers?
 Yes No

14a. How can recruitment and retention improve? [Open-ended]

15. Are providers appropriately compensated?
 Yes No

15a. How can compensation improve? [Open-ended]

16. Are your services sufficiently utilized?
 Yes No

16a. How can your services be better utilized at the CSHCN? [Open-ended]

17. Are you interested in having access to the patients' electronic medical records?
 Yes No

17a. How would this help you (or not)? [Open-ended]

18. Why do you refer clients to CCSHCN? Please rank in order of importance:

- Care Coordination
- Family needs support services I cannot provide
- Family lacks financial resources
- Family does not have insurance, or has inadequate insurance
- CCSHCN offers a multidisciplinary approach to health care delivery.
- Other (Please specify): **[Open-ended]**

19. Do you feel that CCSHCN staff members are helpful as with regard to transitioning patients from pediatric care to adult medical care?

- Yes
- No

19a. How can health care transition improve? [Open-ended]

20. On a scale of 1 to 5 (with 1 being the least significant and 5 being the most significant), how much do you see CCSHCN as a relevant and vital part of a system of community based resources?

20a. How can the CCSHCN improve its presence in the community? [Open-ended]

21. Please indicate which statement you perceive as most accurate:

- Children who participate in the CCSHCN program achieve better outcomes than children who I see outside the CCSHCN program
- Children who participate in the CCSHCN program achieve worse outcomes than children who I see outside the CCSHCN program
- Children who participate in the CCSHCN program achieve roughly the same outcomes as children who I see outside the CCSHCN program

22. Please specify services or conditions that you feel CCSHCN should consider providing: [Open-ended]

This concludes the survey. Thank you for taking the time to complete all of the questions provided. Your responses and suggestions are greatly appreciated.