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## SECTION 1

### Process for Conducting Needs Assessment

- **Goals and Vision:** The goal of the WV Title V Needs Assessment is to assure availability of a comprehensive quality, accessible maternal and child health system that will positively affect pregnancy outcomes and have positive health status (family well-being) for infants, children, adolescents and children with special health care needs by involving multiple stakeholders across the State. The WV Office of Maternal, Child and Family Health (OMCFH) identifies health needs based on data/outcomes and partners with community and state stakeholders to develop interventions that will achieve positive results. Other goals of the Needs Assessment are to: collaborate around collection activities that support the evaluation of care availability, service utilization and the quality of health services for maternal and child health populations; administer population-based health surveillance activities, such as birth defects registry and newborn metabolic screening which are used to prevent and/or lessen disability and death among children; and collaborate with community resources, government agencies, families and other stakeholders to identify resources essential for healthy families such as childcare services, health care and economic support. The vision of the OMCFH is to provide leadership to support state and community efforts to build systems of care that assure the health and well-being of all West Virginians throughout the life cycle.

Allocation of resources is based on need that takes into consideration other available resources, population served and desired outcomes.

- **Leadership:** The Needs Assessment process was managed by the OMCFH senior staff comprised of the Office Director and Division Directors including: the Research, Evaluation and Planning Division Director; the Perinatal and Women's Health Division Director; the Infant Child and Adolescent Health Division Director; and the Birth To Three, Early Intervention/Part C Director. The management team provides guidance and coordinates efforts among programs and stakeholder partners within the community. Staff from multiple programs provided information and the Division Directors provided review and feedback, as well. Coordination was divided into three groups: 1) Women and Infants, 2) Children and Adolescents, and 3) Children with Special Health Care Needs. The Research, Evaluation and Planning Director is responsible for organizing the Needs Assessment, collecting, analyzing and reporting of data, and directing the Needs Assessment process. The OMCFH has long standing community partners and is involved/participates on many agency boards, advisory committees and study groups. The WV OMCFH has long been recognized for its

willingness to engage in developing processes/systems of care to increase access for the residents of WV to attain positive health outcomes.

- **Methodology:** Findings from the federally required Title V Maternal and Child Health (MCH) Block Grant Needs Assessment are the basis for selecting priorities, objectives and action plans for the WV Maternal, Child and Family Health programs and other partner organizations. The Needs Assessment methods are designed to: a) provide factual information and data to guide activities and policies, b) to provide a tool for better decision making, and c) to be used as a guide for discussions about health issues and continuing assessment efforts.

The WV Office of Maternal, Child, and Family Health involves program advisories and critical stakeholders in all facets of charting a course for the use of multiple funding streams that support maternal, child and family health activities. The use of stakeholder advisories and task forces to study particular population groups and issues, engagement with established non-Title V advisories where the OMCFH has a seat at the table, surveys about specific topics and lastly, public forums and specific engagement of parents using the parent-to-parent networks are the methods used to gather input and information throughout the year. The end result is that there is not one isolated effort or method to seek input about the OMCFH Needs Assessment, but rather there is continuous study and action plan development throughout each year. These activities culminate in the development of the Five-year Needs Assessment as well as the yearly Progress Report and Application. Findings from the Needs Assessment are used to develop state performance and outcome measures. The OMCFH gathers data based on performance measures, health status and capacity indicators and compiles the results and narrative for the Needs Assessment. Through the use of stakeholders, activities and polices are developed to address the needs as well as allocating resources and monitoring progress.

- **Methods for Assessing Three MCH Populations:** The following chart displays the methods for assessing West Virginia pregnant women, mothers and infants.

**Pregnant Women, Mothers and Infants**

<b>West Virginia Methods for Assessing Pregnant Women, Mothers and Infants</b>	
<b>Methods</b>	<b>Key Activity Samples</b>
Community Partnerships	<ul style="list-style-type: none"> <li>• Participation and involvement with the Perinatal Partnership resulting in the publication: <i>A Blueprint to Improving WV Perinatal Health</i>. Extensive data collection and evaluation efforts occurred with multiple recommendations and actions.</li> <li>• Use of the cord blood study conducted by</li> </ul>

	<p>Marshall University located in Huntington, West Virginia financed by the OMCFH.</p> <ul style="list-style-type: none"> <li>• Participation as a member of the Child Fatality Review Team to investigate causes of preventable deaths and make recommendations.</li> <li>• Spearhead the legislatively mandated Maternal Mortality Review Team to investigate practices that may prevent deaths and determine needs.</li> <li>• Spearhead the legislatively mandated Maternal Risk Screening Advisory to develop a universal risk screening tool for pregnant women to be used by all OB/GYNs</li> <li>• Spearhead the Newborn Metabolic Screening Advisory and discuss practice standards and guidelines for specific newborn disorders and needs within this particular area.</li> </ul>
Surveys	<ul style="list-style-type: none"> <li>• <i>West Virginia Key Informant Survey</i></li> <li>• <i>Worksite Wellness and Perinatal Health Survey</i></li> <li>• <i>Perinatal Education and Support Program and Services Survey</i></li> <li>• <i>Right From The Start (the state's perinatal home visiting program) Satisfaction Survey</i></li> </ul>
Data Sources	<ul style="list-style-type: none"> <li>• <i>Legacy of Inequality: Racial and Economic Disparities in West Virginia</i></li> <li>• <i>Blueprint to Improve West Virginia Perinatal Health</i></li> <li>• WV Vital Statistics</li> <li>• Right From The Start, (the state's perinatal program)</li> <li>• Pregnancy Risk Assessment Monitoring System (PRAMS)</li> <li>• WVU Birth Score (risk tool used to determine risk for post neonatal death and developmental delay in newborns)</li> <li>• Medicaid</li> </ul>

The following is a brief description of efforts and stakeholder engagement across the State that the Title V Program has either initiated or been involved with. Resulting identification of needs have driven the recommendations and action steps to improve health that are documented throughout the Needs Assessment. This is not an all inclusive list of efforts.

For the past four years, thirty-three public and private health organizations, including the OMCFH, partnered to uncover reasons for declining healthy birth outcomes in West Virginia and find solutions. These organizations, made up of health care professionals, formed the Perinatal Partnership.

The Partnership developed several surveys that were conducted in the spring of 2006 in order to better understand the barriers and issues faced by local perinatal providers. The surveys included 1) *West Virginia Key Informant Survey*, 2) *Worksite Wellness and Perinatal Health Survey*, and 3) *Perinatal Education and Support Programs and Services Survey*. In addition, all payers were contacted about their policies on care management of pregnant women.

The West Virginia Key Informant Survey was an essential source of information for the *Study to Improve West Virginia Perinatal Wellness* with close to 200 professionals from 34 West Virginia counties and four adjoining states participating. The purpose of the survey was to gain input from West Virginia medical, nursing and other personnel serving pregnant women and their newborn infants. The survey sought information and opinions regarding why West Virginia has not made the same progress toward the reduction of infant mortality and low birth weight as the rest of the Nation. The survey method was intended to reach those practicing in rural areas of the State, as well as urban areas. It was the hope that West Virginia medical and nursing personnel not able to participate in the Perinatal Wellness Study Summit could apply their expertise to these issues through survey participation.

Important responders to the survey were nurses representing 62 percent of the hospitals and birthing centers, including obstetrical hospital nurses and nurse managers. One hundred and sixty-five (165) health professionals' responses were submitted complete and in time to be included in the report. A total of 200 responses were received, but 35 were either not complete with respondent's name or arrived after the deadline.

Responders to this survey talked about the many barriers and issues they face in providing perinatal care that, if modified, could help reduce the infant mortality rate and the incidence of low birth weight. Issues cited by local providers were staggering. These formed the basis for a listing of Potential Policy Implications that were further studied during the West Virginia Perinatal Wellness Summit in May 2006 and led to the development of a document called the "*Blueprint to Improve West Virginia Perinatal Health*". This document contains multiple recommendations and action steps to make needed system improvements. (The recommendations are listed in Section 5.)

One of the recommendations arising out of the *Blueprint* was to identify a maternal risk screening instrument to be used universally by all obstetrical medical providers and all payers to insure that high risk pregnant women were identified uniformly. As a result,

the Subcommittee on Universal Prenatal Risk Screening was formed to address the issue.

### **Maternal Risk Screening Advisory Committee**

In 2009, the Uniform Maternal Screening Act (Senate Bill 307, signed into law 5/29/09) provided a more comprehensive and uniform approach to maternal risk screening by requiring development and use of a standardized tool to alert OB providers of the need for further evaluation and assessment of high-risk pregnant women. The Committee members were to identify perinatal high risk factors to be included on the assessment tool. The bill established an advisory committee on maternal risk screening within the Office of Maternal, Child and Family Health. Selection and appointment of the initial Maternal Risk Screening Advisory Committee was completed in late 2009. The following individuals agreed to participate on the Committee:

- David Butler, DO, WV School of Osteopathic Medicine designee (medical school representative)
- Kimberly Farry, MD, Associates for Women's Health (public/private maternity provider representative);
- Michael Stitely, MD, WVU School of Medicine (medical school representative);
- Michael Lassere, MD, Summersville Women's Health (public/private maternity provider representative);
- Victoria Shuman, DO, Family Medicine of Clarksburg (public/private maternity provider representative);
- Phyllis Bradley, RN, MS-HCA, Camden-Clark Memorial Hospital designee (additional stakeholders);
- Tina Williams, United Hospital Center designee (additional stakeholders);
- Steve Dexter, CEO, Thomas Memorial Hospital (additional stakeholders);
- Lyn Haley, CNM, Chair, WV Chapter, American College of Nurse Midwives (public/private maternity provider representative);
- Robert Nerhood, MD, Chair, Marshall University School of Medicine (medical school representative);
- Luis Bracero, MD, Chair, CAMC Department of Pediatrics designee (tertiary care facility representative);
- Chris Curtis, Commissioner, WV Bureau for Public Health; and
- Pat Moss, Director, Office of Maternal, Child and Family Health.

The first meeting occurred in January 2010 and another in May 2010 resulting in the development of a universal maternal risk screening tool with final approval pending. Implementation is targeted to begin in January 2011.

## **Newborn Metabolic Screening**

Members of the Perinatal Partnership and March of Dimes along with the OMCFH Advisory Committee advocated for the expansion of newborn screening to include the 29 nationally recommended disorders. Collaborative methods used to establish a payment system included discussions with Medicaid, the Public Employees Insurance Agency, Blue Cross/Blue Shield, and the Insurance Commission. In 2008, Legislation was enacted mandating the recommended screening and included payment from the insurance companies. In February 2009, the State Laboratory began screening for all recommended disorders. In that same year, two disorders were identified that would have otherwise gone undetected causing the child to suffer negative consequences. The State Legislature also agreed to give \$460,000 a year to support program expenditures. The OMCFH receives newborn metabolic results from the State Lab and uses this data to match against birth files to determine if any infant did not receive a screen. The OMCFH newborn screening case management nurses provide follow-up contact for all infants with a positive screen and records follow-up data within an OMCFH developed database. The OMCFH uses this database to track National Performance Measure # 1, “The percent of screen positive newborns who received timely follow-up to definitive diagnosis and clinical management for conditions mandated by their State sponsored newborn screening programs”.

Newborn screening data is used to identify infants at birth with a potential debilitating disorder that, if not treated early, can cause permanent physical and or mental impairment. The Advisory Committee uses the data to identify needs to serve infants with rare disorders and to make capacity recommendations and protocol decisions. For example, because WV only has one geneticist, it was determined that increased genetic capacity was needed to provide medical follow-up for infants identified with disorders, hence financial support was given to the Department of Pediatrics at West Virginia University to hire a second geneticist.

## **Drug and Alcohol Use Among WV Pregnant Women**

Providers have long suspected that women do not accurately report substance use during pregnancy. As a result, a cord blood study was recommended by Marshall University physicians, Dr. Nerhood and Dr. Chaffin to provide the State of West Virginia a snapshot of the prevalence of drug and alcohol use in the pregnant population. OMCFH agreed to fund the project. Several hospitals were recruited from around the state to a) provide a large enough population of deliveries (1,000) in a suitably short time frame (1 month) and provide enough geographic diversity to be able to discern regional variations.

Anonymous testing was used to avoid ascertainment bias as all of the patients delivering in the specified time frame were to be tested. To ensure anonymity, no per-

sonal information was obtained. The study was designed to use the most recent technology of testing the tissue of the umbilical cord for drug metabolites.

The project, multi-hospital anonymous collection and assay of umbilical cord segments in as many patients as delivered in the month of August 2009, was approved by the Joan C. Edwards School of Medicine Institutional Review Board (IRB) and subsequently sent to 11 hospitals for review and approval. Ultimately, 8 hospitals agreed to participate:

- Bluefield Regional Medical Center (BRMC)
- Raleigh General Hospital (RGH)
- Thomas Memorial Hospital (TMH)
- Charleston Area Medical Center (CAMC)
- Cabell Huntington Hospital (CHH)
- Ruby Memorial Hospital (RMH)
- Wheeling Hospital (WH)
- City Hospital Martinsburg (CH)

Each hospital was provided with a specimen freezer and specimen collection supplies. The goal was to collect a 6-9 inch segment of cord from every delivery. Arrangements were made for the specimens to be boxed and shipped to a specific laboratory at least weekly or semi-weekly from the busier hospitals.

The drugs chosen represented those most often seen clinically and include: methamphetamine, cocaine, cannabinoids, opiates, methadone, benzodiazepines, buprenorphine, and alcohol- phosphatidylethanol.

Of the 759 cords tested for the above mentioned drugs, 146 or 19% were found positive meaning that almost one in every five WV pregnant women are using drugs or alcohol during their pregnancy.

This study was funded by the Office of Maternal, Child and Family Health using Title V dollars and presented to the 2010 Legislature to secure additional funds to continue the Study. Results have been shared with obstetrical providers to increase awareness and to encourage providers to assess their pregnant patients for drug use.

### **Racial Disparities**

In February 2010, *Legacy of Inequality: Racial and Economic Disparities in West Virginia* was published as a joint project of Partnership of African American Churches, West Virginia Center on Budget and Policy, and West Virginia Economic Justice Project of the American Friends Service Committee. The report briefly chronicles the experience of African Americans in West Virginia and presents a data analysis of disparities, causes and suggested policy initiatives. The OMCFH used data from this



report as a resource within the Needs Assessment. Recommendations from this report are listed in Section 5.

### Infant Mortality/SIDS/SUID

The Perinatal Partnership, using data from West Virginia Vital Statistics, studied the causes of infant mortality and included recommendations in the “*Blueprint*”. The OMCFH, alongside the Child Fatality Review, Team has looked at the often preventable burdensome occurrence of Sudden Unexplained Infant Death (SUID). The OMCFH compiled ten years of data from 1998-2007 and analyzed the following associated risk factors: age in months at death of infant; gestational age; birthweight; co-sleeping at time of death; prenatal entry of mother; smoking exposure; position of infant at time of death; feeding practice; and bedding. Data on the risk factors were identified during the Child Fatality Review Team meetings. Findings are used to drive education efforts for new parents and physicians. More on this study and the findings are in Section 4.

### Data

Multiple data sources were used to explain health outcomes and compare previous years and/or compare to U.S. statistics, i.e., PRAMS, Birth Score, Vital Statistics, Newborn Metabolic Screening, SUID, etc.

### Children

West Virginia Methods for Assessing Children	
Methods	Key Activity Samples
Community Partnerships	<ul style="list-style-type: none"> <li>• Participation and involvement with PIECES, a group of stakeholders whose assignment is to determine needs and design and implement universal pre-K education.</li> <li>• Bureau for Children and Families</li> <li>• Healthy Kids-Preschool Screening</li> </ul>
Surveys	<ul style="list-style-type: none"> <li>• Oral Health Advisory and survey</li> <li>• Advisory/Stakeholder meetings</li> <li>• Town Hall Community meetings at 9 sites across the State.</li> </ul>
Data Sources	<ul style="list-style-type: none"> <li>• Vital Statistics</li> <li>• YRBSS</li> <li>• WV Department of Education</li> <li>• Birth to Three (The State’s Early Intervention Program/Part C)</li> <li>• Early Periodic Screening Diagnosis and Treatment (EPSDT) called HealthCheck in WV</li> <li>• Oral Health Project</li> <li>• Medicaid</li> <li>• CHIP</li> <li>• Bureau for Children and Families</li> </ul>

	<ul style="list-style-type: none"> <li>• WIC</li> <li>• Bureau for Behavioral Health</li> <li>• Department of Highways</li> <li>• Obesity Project</li> </ul>
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The following is a brief description of methods/efforts involving stakeholders across the State that the Title V Program has either initiated or been involved with, and has used the information to assist in developing the Needs Assessment. This is not an all inclusive list of efforts.

**Partners Implementing an Early Care and Education System (PIECES)**

For West Virginia's Early Childhood Comprehensive Systems (ECCS) project, the primary collaborative platform is PIECES, Partners Implementing an Early Care and Education System. In 2002, the West Virginia State Legislature mandated a partnership between the Department of Education and the Department of Health and Human Resources to design and implement universal Pre-K education for West Virginia's four year olds by 2012. The OMCFH is an integral part of this partnership.

The Early Childhood Education Council (ECAC) will work to strengthen state-level coordination and collaboration among the various sectors and settings of early childhood programs in the State. The Council will conduct periodic statewide needs assessments on the quality and availability of programs and services for children from birth to school entry, identify opportunities for and barriers to coordination and collaboration among existing Federal and state-funded early childhood programs, and develop recommendations for: (1) increasing overall participation of children in existing Federal, State, and local child care and early education programs, including outreach to underrepresented and special populations (2) the establishment or improvement of core elements of the State early childhood system, such as a statewide unified data collection system; (3) a statewide professional development system and career ladder for early childhood educators; and (4) high-quality State early learning standards. The Council will also assess the capacity and effectiveness of institutes of higher education in the State toward supporting the development of early childhood educators.

Consistent with section 642B (b)(2)(A), the states shall also use the funds to carry out activities to facilitate the development or enhancement of high-quality systems of early childhood education and care designed to improve school readiness through one or more of the following activities: promoting school readiness of children birth to five, supporting professional development, recruitment and retention initiatives for early childhood educators, enhancing existing early childhood and development programs and services in existence on the date of the grant award and carrying out other activities consistent with the State's plan. The funding appropriated by ARRA to support the work of the State Advisory Council is for one-time startup grants to develop and implement

the plans of the State Advisory Council. OMCFH will work closely with this Advisory Council in order to understand needs identified through the ECAC needs assessment, and to coordinate this with the needs assessment required for the new Affordability Care Act Home Visiting Program.

## **Oral Health**

The Office of Maternal, Child, and Family Health (OMCFH) partnered with Marshall University and other key stakeholders in oral health to develop a statewide comprehensive oral health plan in accordance with CDC recommendations. Marshall University applied for and received a grant from the Claude Worthington Benedum Foundation in the amount of \$45,000.00 to provide logistical support and technical assistance to OMCFH in the planning process. The OMCFH Oral Health Advisory Board took the lead in this effort and met every other month to review data and discuss progress. Board members divided into workgroups and conducted nine community forums to gather stakeholder input that was used to develop goals and objectives.

Key components in the development of the State Oral Health Plan were the input and involvement received from all key stakeholders, as well as data/information collected from regional/community town hall meetings. These meetings were held in nine (9) different locations in the state with over 285 participants in attendance on the dates and locations listed below:

- July 17, 2009 at the Greenbrier, White Sulphur Springs, WV (in conjunction with the WV Dental Association)
- August 6, 2009 at Oglebay Resort and Conference Center State Park, Wheeling, WV (in conjunction with the West Virginia Primary Care Association-WVPCA)
- September 11, 2009 at the Blennerhassett Historic Hotel, Parkersburg, WV (in conjunction with the Mid-Ohio Valley Oral Health Task Force)
- September 24, 2009 at Stonewall Resort and Conference Center, Roanoke, WV (in conjunction with the WV Public Health Dental Section)
- September 28, 2009 at the Boone County Armory, Madison, WV (in conjunction with REV Up Madison, All About Health, The Wellness Council of WV & The Robert Wood Johnson Foundation)
- October 22, 2009 at the WVU Health Sciences Center, Morgantown, WV (in conjunction with the WVU School of Dentistry)
- October 22, 2009 at Glade Springs Resort (in conjunction with WVPCA)
- November 13, 2009 at Charleston CAMC (in conjunction with Growing Healthy Children Conference)
- November 20, 2009 in Martinsburg, WV (in conjunction with the WV Healthy Smiles Partnership of the Eastern Panhandle)

Findings and recommendations were discussed in the Oral Health Advisory and resulted in the development of an Oral Health Plan for WV which can be found in Section 5.

## Injuries

Unintentional injury information was used from the Children’s Safety Network funded by the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services and the WV Health Statistics Center. Indepth information is presented in Section 4.

## Children with Special Health Care Needs

West Virginia Methods for Assessment of Children with Special Health Care Needs	
Methods	Key Activity Samples
Community Partnerships	<ul style="list-style-type: none"> <li>• Commission for the Deaf and Hard of Hearing</li> <li>• WV Early Intervention Interagency Coordinating Council (WVEIICC)</li> <li>• WV Department of Education</li> <li>• Statewide Transition Committee</li> <li>• Child Protective Services</li> <li>• Medicaid</li> <li>• WVU Center for Excellence in Disabilities (CED)</li> <li>• School Based Health</li> <li>• Learn the Signs Act Early Team</li> </ul>
Focus Groups	<ul style="list-style-type: none"> <li>• Town Hall meetings for Deaf and Hard of Hearing – 9 Sites</li> <li>• Four consumer, workforce, and agency discussions on direct service supports for persons with disabilities.</li> <li>• Eight Birth to Three/IDEA meetings</li> </ul>
Surveys	<ul style="list-style-type: none"> <li>• WV BTT/Part C Parent Outcome Surveys</li> <li>• Parent surveys related to children with special health care needs, services and supports, conducted by CED.</li> <li>• Oral Health Survey of parents of children with special needs</li> <li>• Oral Health Family Survey</li> </ul>
Data Sources	<ul style="list-style-type: none"> <li>• Social Security Disability</li> <li>• Early Intervention/Part C</li> <li>• Integrated Data System-Annual Performance Report (APR)</li> <li>• Children with Special Health Care Needs Program</li> <li>• WV Department of Education</li> <li>• Vital Statistics</li> </ul>

	<ul style="list-style-type: none"> <li>• Birth Defects Surveillance</li> <li>• Newborn Metabolic Screening Program</li> <li>• Childhood Lead Poisoning Prevention Project</li> <li>• Newborn Hearing Screening Project</li> <li>• Child care programs</li> <li>• Bureau for Children and Families</li> </ul>
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The following is a brief description of efforts across the State that the Title V Program has either initiated or been involved with, and have used the information to assist in developing the Needs Assessment. This is not an all inclusive list of efforts.

### **Deaf and Hard of Hearing – Town Hall Meetings**

The West Virginia Commission for the Deaf and Hard of Hearing has as its mission to advocate for, develop, and coordinate public policies, regulations and programs to assure full and equal opportunity for persons who are deaf and hard of hearing. Two OMCFH staff are members of the Commission: the OMCFH Director and a representative for CSHCN/Part C.

The Commission held nine (9) Town Hall meetings across West Virginia to gather information, and generate recommendations to improve policy and programs. The OMCFH contributed Title V resources to pay for the meetings.

A consumer survey was also distributed as a method to gather input about available community supports and gaps. Priority concerns from Town Hall meetings and stakeholder surveys are cited below:

- Access to communication.
- Increased availability of qualified and certified interpreter personnel who can communicate with the deaf and hard of hearing.
- Opportunity to fully participate in community services.

### **Infants and Toddlers with Developmental Delay**

West Virginia Part C System, known as WV Birth to Three, reports annually on 14 national performance indicators. Comprehensive data analysis provides the basis for performance reporting.

The West Virginia Department of Health and Human Resources is the lead agency for Part C/IDEA, with the Program administered through OMCFH. The West Virginia Early Intervention Interagency Coordinating Council (WVEIICC) has been the primary stakeholder group for development of the State Performance Plan and Annual Performance Report. The WVEIICC is established under WV Code Chapter 16-5K. The

Council meets every other month, with membership that meets IDEA requirements, including parents, service providers, and representatives of various state agencies; as well as other key stakeholders identified by the Council. These additional members include representatives of various advocacy and community groups, including West Virginia Advocates, and West Virginia Parent Training and Information.

WVBTT gathers child outcome data via tools and processes developed by the federally funded Early Childhood Outcome Center in Chapel Hill, NC.

The lead agency provides updates to the WV Early Intervention Interagency Coordinating Council at each meeting. These updates include data reports that reflect regional and state level performance on Annual Performance Report indicators. The Council contributed input regarding establishment of improvement activities and rigorous targets for the State Performance Plan and the FFY 2008 Annual Performance Report.

In addition to the WV Early Intervention Interagency Coordinating Council, coordination with other interagency partners on an ongoing basis was crucial to evaluating the effectiveness of current strategies and identifying future improvement strategies. Ongoing collaboration occurred with the West Virginia Department of Education, the statewide Transition Steering Committee, universal screening programs within the Office of Maternal, Child, and Family Health (OMCFH), Child Protective Services, and the monitoring and research arms of OMCFH.

Data for family outcome measures is gathered through a survey developed by the National Center on Special Education and monitoring using a Rasch analysis.

The lead agency provides information to the eight Regional Administrative Units (RAUs) and obtains feedback throughout the year. The Regional Administrative Units act as system point of entry and local collaboration functions for the WV Birth to Three System. State staff utilizes a variety of strategies to obtain data needed for evaluation of performance and identification of improvement strategies across the outcome indicators. The data sources include: information from the WV Birth to Three statewide integrated data system; service coordinator and practitioner feedback; onsite monitoring reviews conducted by the Office of Maternal, Child and Family Health (OMCFH) Monitoring Unit; parent telephone surveys; family outcome surveys; specific data surveys of Regional Administrative Units; complaint logs; and claims payment data. In addition, the State utilizes technical assistance from Mid-South Regional Resource Center, National Early Childhood Technical Assistance Center, National Early Childhood Transition Center, Early Childhood Outcomes Center and Office of Special Education Programs through direct state contact and national conferences.

## **Oral Health for Children with Special Needs**

Access to dental care for children with special needs continues to be a problem in West Virginia. Because their special needs add to the complexity of their dental treatment, these children have a higher rate of unmet dental care compared to children without special needs. While a survey was conducted by the West Virginia Department of Health and Human Resources in 2002 on the “Attitudes of West Virginia Dentists” toward children with special health care needs, no study has evaluated their needs from the parents’ perspective until a parent survey was conducted in 2007. Following is a synopsis of that survey.

The objective was to determine the knowledge base that parents of special needs children have about dental care, to determine the most common problems parents of special needs children face when trying to find a dentist, and lastly, to determine if parents of special needs children feel their child is receiving adequate dental care and what improvements are needed.

Collaboration with West Virginia University’s Center for Excellence in Disabilities (CED) program for children with disabilities/special needs allowed a more accurate representation of West Virginia’s special needs population. An IRB approved survey consisting of 10 questions and demographic information was sent out to 650 parents in 30 West Virginia counties by the Parent Network Specialists of CED. Parents/guardians were asked to list any improvements or suggestions that could be made for their child’s access to dental care. The surveys were returned without any personal identifiable information to CED and then given to the investigators. (It is important to note that the Parent Network Specialists are supported with Title V funds under grant agreements with CED). A total of 183 surveys were returned from the 650 distributed, a 28% return. Survey results are reported in Section 3 and recommendations are in Section 5.

### ***WEST VIRGINIA CHILDREN WITH SPECIAL HEALTH CARE NEEDS PROGRAM FAMILY SURVEY April 2006***

With the assistance of the Parent Network Specialists from West Virginia University (WVU) Center for Excellence in Disabilities (CED), all parents of children enrolled in the Children with Special Health Care Needs Program were sent surveys in early 2006.

Survey objectives were, to determine the overall satisfaction with services provided by the CSHCN Program, to ascertain the medical and social service needs of the participants and families served by the CSHCN Program and to help define the scope of services offered by the CSHCN Program in the future.

In addition, all focus groups reflected the importance of self-determination needs in the state. The State OMCFH received multiple documentations that reinforce this priority need.

- **Methods for Assessing State Capacity:** By involving stakeholders, advisory committees, participation with State as well as community focus groups, several methods were used to evaluate State capacity that included review of: the financing structure to ensure access to care and treatment; legislation that assures mandates for access and financing; availability of appropriate health care providers and facilities; program capacity offered throughout the State to address population needs; partnerships to utilize resources and not duplicate efforts; and data availability to analyze needs and outcomes.

<b>WV Methods for Assessing State Capacity</b>	
<b>Needs</b>	<b>Capacity</b>
Financing	Evaluated funding from the following sources to support population needs: <ul style="list-style-type: none"> <li>• Medicaid (Title XIX)</li> <li>• CHIP</li> <li>• Title V</li> <li>• Title X</li> <li>• State Appropriations</li> <li>• American Recovery and Reinvestment Act</li> <li>• Patient Protection and Affordable Care Act 2010 (Home Visiting)</li> <li>• CDC Funds</li> <li>• HRSA</li> <li>• Insurance</li> </ul>
Programs	Evaluated services and ability of the following entities to support population needs: <ul style="list-style-type: none"> <li>• OMCFH</li> <li>• Bureau for Children and Families</li> <li>• Department of Education</li> <li>• Mental Health-Bureau for Behavioral Health and Health Facilities</li> <li>• Office of Environmental Health Services</li> <li>• Health Statistics Center</li> </ul>
Partnerships/Access to Care	Evaluated access to care systems to support population needs: <ul style="list-style-type: none"> <li>• Partnerships</li> <li>• Agency Agreements</li> <li>• Health Care Providers-Federally Qualified Health Centers, Local Health Departments, Community Free Clinics</li> <li>• Other State Agencies</li> <li>• Universities/Schools of Medicine</li> </ul>
Legislation	Evaluated legislation targeted to support population assessment and needs: <ul style="list-style-type: none"> <li>• Newborn Metabolic Screening</li> <li>• Newborn Hearing Screening</li> </ul>



	<ul style="list-style-type: none"> <li>• Maternal Mortality Review Team</li> <li>• Birth Defects Surveillance</li> <li>• Sudden Infant Death Surveillance</li> <li>• Maternal High Risk Screening</li> <li>• Childhood Lead Poisoning Prevention Program</li> <li>• Birth Score (Identification of high risk infants at birth)</li> <li>• Oral Health Status Study</li> </ul>
Data	<p>Evaluated the ability to collect and analyze data sources.</p> <ul style="list-style-type: none"> <li>• Data Availability</li> <li>• Data Access</li> <li>• Analysis Capacity</li> <li>• Data Linkages</li> </ul>
Outcomes	<p>Evaluated performance measures and outcomes from surveys.</p> <ul style="list-style-type: none"> <li>• Performance Measures-State and Federal</li> <li>• Surveys</li> </ul>

In determining capacity it is necessary to involve stakeholders, be involved with partnership collaboratives, review current systems of care to determine if the systems are adequate to achieve identified desired health outcomes, and identify current health status of each of the desired outcomes.

West Virginia examined current national and state performance measures, health status indicators and state capacity measures and compared WV status data with national and Healthy People 2010 objectives. In most measures, WV comes up short of the national average.

For the Needs Assessment OMCFH needed to ask staff, stakeholders, constituents, colleagues, parents and residents, “What will it take to improve health status among West Virginians?”

Capacity to address the multiple needs of the State’s women, infants, children and children with special health care needs is analyzed throughout the Needs Assessment, with strengths and weaknesses noted.

- **Data Sources:** Data sources are cited throughout the document. In addition, the following data sources are noted that identify the current status of perinatal wellness in the State. Information and data was provided by the organizations and agencies that follow:

## **West Virginia Health Care Authority**

The WV Health Care Authority analyzed UB-92 Hospital Discharge Data Reports for 1999 through 2004 to identify important information, including:

- Major Payer Groups
- Cesarean Section Rates by WV Hospital
- Cesarean Section Rates by Payer Group
- Vaginal Birth After Cesarean Section (VBAC) Rates by WV Hospital
- Neonatal Intensive Care Unit Utilization in WV Hospitals by Payer Group
- Neonatal Intensive Care Unit Utilization- Charges and Length of Stay
- Maternity Care in WV Hospitals – Average and Median Total Charges
- WV Hospitals and Birthing Centers Providing Maternity Services

## **Health Statistics Center**

The Health Statistics Center compiled numerous reports for review including births, low birth weight, infant mortality, premature birth (<37 weeks gestation), multiple births, and maternal smoking. All data are reported by births by county, by age of mother, and by race of mother. Births with abruptio placenta to mothers who smoked during pregnancy by age of mother are also reported. The Office reported certain medical risk factors identified by the West Virginia birth certificate, including diabetes, chronic hypertension, hypertension associated with pregnancy, eclampsia, abruptio placenta, labor induction followed by c-section rates for first time mothers, transfer of infant to a tertiary care facility, neonatal deaths, and postneonatal deaths.

## **Office of Maternal, Child and Family Health**

The Office of Maternal, Child and Family Health in the WV Department of Health and Human Resources contributed several reports including the WV Pregnancy Risk Assessment Monitoring System (PRAMS). PRAMS is an ongoing, population-based surveillance system designed to identify and monitor selected maternal experiences and behaviors. The Office also provided a comprehensive report, *Perinatal Care: Improving Pregnancy Outcomes 5/4/06*, defining the infrastructure of care providers, progress made in access to care, and identifying some of the major medical and social factors affecting pregnancy outcomes.

## **Birth Score Program**

The West Virginia University School of Medicine, Department of Pediatrics, provided an analysis of the experiences of 12,756 pregnant women, comparing outcomes of Medicaid eligible women receiving RFTS services to those who did not participate in RFTS. This information is extremely useful in assessing program impact by demonstrating that West Virginia has a program in place that has made significant progress toward improving pregnancy and newborn outcomes.

## **The Women, Infants and Children (WIC) Program**

WIC is a federally funded program under USDA that provides education and food for those qualifying for the Program. WIC provided a report regarding breastfeeding rates of WIC participants for 2004.

Data and information have also been gathered from other sources and programs including: Vital Statistics, Youth Risk Behavior Survey, the State's perinatal home visiting program called Right From The Start including participant surveys, Family Planning, Newborn Metabolic and Hearing Screening, the State's newborn universal risk screening called Birth Score, Birth To Three (Part C/IDEA), PRAMS, BRFSS, Child Trends, Hospital Discharge data, Medicaid, Maternal Mortality Review Team, publications such as the Legacy of Inequality: Racial and Economic Disparities in West Virginia, information from the Perinatal Partnership's A Blueprint to Improve West Virginia Perinatal Health, Oral Health Planning Advisory, WV Department of Education and the Deaf and Hard of Hearing Commission.

- **Linkages between Assessment, Capacity and Priorities:** According to the 2010 Needs Assessment, West Virginia continues to have many health care issues such as smoking, smoking among pregnant women, infants born prematurely, infants born with low birth weight, high rate of sudden unexplained infant deaths, obesity, injuries, adolescent suicide, fatal car accidents involving youth and asthma that contribute to poor outcomes.

Geographic and socio-economic issues that influence the ability to achieve desired health outcomes include:

- According to the 2008 Census data, 15% of the population in the State does not have health insurance.
- Six percent (6%) of children do not have health insurance.
- There are still parts of WV where health care is not easily accessible. Winding secondary roads connect the majority of the State's population with little to no public transportation available between many of the small isolated towns.
- The WV Perinatal Partnership has reported that the availability of OB/GYNs and other practitioners to provide prenatal care and delivery continues to be problematic. Not every county has sufficient births to justify labor and delivery at local hospitals, making it necessary for some WV women to be served outside the State's boundaries or several miles from home. Only six counties in the State were considered to have adequate medical manpower to meet the population need.
- Because of the loss of higher paying jobs over the past thirty years in West Virginia, there has been a concurrent rise in the State's poverty rate. WV continues to rank fifth in the Nation of the State's population living in poverty.

- West Virginia's unemployment rate reached a 15-year high at 10.5 in January 2010. The number of unemployed people grew from 29,000 in September 2008 to 64,200 in September 2009, an increase of 121 percent.
- A significant issue that plagues WV is that only 75.2% of the population, 25 years and over is a high school graduate or higher.
- Work disability is also a significant problem in West Virginia. The 2000 U.S. Census Bureau states that 22.5% of the population 16-64 years of age had a disability and 13.2% had a work disability.

It is evident when data/statistics are analyzed for health care outcomes, the higher the education and income level, the better the outcomes. If West Virginia is going to experience better outcomes, education and higher paying jobs must be a top priority. Evidence of this is in Monongalia County, where West Virginia University is located. Because of the availability of a higher educated work force, the city of Morgantown has been one of the fastest growing cities in the U.S. and experiences some of the best health outcomes in WV. It has also been ranked as one of the best small cities in the U.S. to live and raise a family.

West Virginia has capacity to address most health related issues as shared throughout the Needs Assessment, however, there remain areas that need improvement to have an impact on outcomes.

West Virginia Governor Joe Manchin III, signed legislation to expand SCHIP eligibility up to 300 percent of the federal poverty level, and on January 1, 2007, the State began a phase-in expansion by enrolling children in SCHIP with family incomes up to 220% of the federal poverty level. Adoption of this change is estimated to provide comprehensive health care coverage to approximately 400 uninsured children of working families during the first year of implementation. WVCHIP expanded the upper income limit to cover families with incomes at 250% of poverty January 1, 2009. A plan to cover adults has not taken shape at the time this assessment was written.

Community health centers have played a critical role in improving access to health care for all populations across WV. The community health center network is supported with state appropriations and there are multiple centers that receive both state and federal resources. Rural areas are in need of additional community health centers.

Governor Joe Manchin III has placed emphasis on education and has introduced several bills to address the issue. Using American Recovery and Reinvestment Act funds several schools have added "coaches" to assist those students at risk of not graduating. Several other schools have introduced initiatives to also facilitate keeping kids in school.

WV has systems in place to address access to care, identification of health issues at birth and health care coverage for pregnant women, infants, children and children with

special health care needs. There still exist areas that need improvement such as increased Medicaid reimbursement for home visiting for high risk pregnant women and oral health. These are two identified areas where health care providers have limited the number of patients they treat due to low reimbursement rates.

Mothers surveyed by PRAMS report that one of the reasons they do not see a physician in their first month of pregnancy is that they have not yet received a medical card. A process to expedite the issuance of a Medicaid card for the pregnant woman needs to be reviewed.

- **Dissemination:** Because of the extensive partnerships that the WV OMCFH has developed and utilized throughout the last few decades it is acknowledged throughout the State that the OMCFH is a leader involving an ongoing process of stakeholder input through the variety of collaborative efforts described herein, as to the health concerns of the MCH population. The WV OMCFH has involved multiple varied stakeholders and audiences in developing strategies to address health concerns and choosing state performance measures and priority setting. The Needs Assessment is widely distributed and made readily available with web access, to the multiple partners, stakeholders and advisories that help shape activities to influence outcomes and have a positive impact on the MCH population.

- **Strengths and Weaknesses of Process:**

**Strengths:** The OMCFH has highly qualified, dedicated staff throughout the Office that serve on many community task forces, summits, focus groups, advisories, special focus teams, etc., allowing for extensive partnerships and involvement throughout the State. This provides the ability and opportunity to continuously assess the needs of the State's MCH population. OMCFH staff provides the Research Division with results from advisories, summit meetings, focus groups, etc., that aids in the summation of activities to be included in the yearly Title V Application as well as the Five-Year Needs Assessment. West Virginia has no single method for completing the Five-Year Needs Assessment but rather uses its partners and numerous data and outcome resource data to identify current needs.

**Weaknesses:** Including the most current data and information available for all health care issues is a challenge for managing the Needs Assessment due to the large volume of information included and the need to start several years in advance. The process is lengthy and cumbersome and the guidance for reporting is difficult. Within the OMCFH, the Title V application, progress report and needs assessment is not any one staff person's single responsibility thus adding to other assignments.

## SECTION 2

### Partnership Building and Collaboration Efforts

Historically, many West Virginians have to survive with fewer of life's essentials than many others in the United States. This lack of resources makes working together essential. Because this lesson has not been lost on those in public service and advocacy organizations at the state and community level, WV has learned the value of collaboration. The OMCFH knows that WV cannot afford to duplicate systems that exist and are working well, and knows that it is imperative to join with other stakeholders to create partnerships to achieve goals.

The West Virginia Office of Maternal, Child and Family Health has been well known for its willingness to engage and participate alongside stakeholders in designing systems of care to serve the Title V population. It is imperative that agencies collaborate and not duplicate services when resources are scarce.

The Office of Maternal, Child and Family Health has historically contracted with the Title XIX agency for the administration of EPSDT. In addition to EPSDT, there have also been formalized agreements with community agencies for services offered through the Right From The Start Perinatal Program, Family Planning, and Children with Special Health Care Needs. The Office of Maternal, Child and Family Health administers and participates in the coordination of programmatic services funded under Title XIX to prevent duplication of effort, as required by federal regulation 42 CFR sub-section 431.615 (C)(4). The Office of Maternal, Child and Family Health has administrative responsibility for dental and vision care for persons moving from Welfare to Work, financed by Temporary Assistance to Needy Families (TANF) resources; a copy of the grant agreement may be obtained from the OMCFH. As a component of the Birth to Three/Part C system change initiative, an additional interagency agreement was finalized with the Bureau for Medical Services, utilizing the unique statutory relationship between Title XIX and Title V. The agreement established the Office of Maternal, Child and Family Health as the sole provider of early intervention services. The Department of Health and Human Resources has contracted with a private agency to serve as a central finance office to coordinate all funding sources for early intervention services, house a centralized data system, and provide claims processing.

The Office of Maternal, Child and Family Health has in place many systems that contribute to the early identification of persons potentially eligible for services. These population based systems include Birth Score (administered by WVU), birth defect registry, newborn metabolic screening, childhood blood lead level screening, and newborn hearing screening. In addition, because OMCFH administers the EPSDT Program, children who have conditions that may be debilitating and/or chronic diseases, are referred to the CSHCN Program for further evaluation. This connection with EPSDT,

which targets some 200,000 eligible children yearly, provides public health with a vehicle for identifying youngsters with problems, knowing that economically disadvantaged children are at increased risk. OMCFH, in an effort to increase public awareness, routinely participates in health fairs and community events. The toll free lines established in 1980, average over 1,000 calls per month. Each caller receives individualized follow-up from our Systems Point of Entry staff to assure referrals and pertinent information related to the request met their need. OMCFH toll free lines always receive accolades from monitoring reviews. Evaluation materials are on file and available if desired.

### **EPSDT (called HealthCheck in WV)**

One of the strategies the Office of Maternal, Child, and Family Health has applied to ensure the quality of EPSDT/HealthCheck services, is to partner with others. Partnerships bring additional experience, expertise and resources to bear on improving EPSDT. HealthCheck and WV Birth to Three routinely work in partnership for the early identification of developmental delays in children. Recently, HealthCheck and WV Birth to Three purchased more than four hundred (400) Ages & Stages Questionnaires, Third Edition (ASQ-3™) starter kits after consulting with the WV Chapter of the American Academy of Pediatrics (AAP). HealthCheck Regional Program Specialists distribute the ASQ-3™ starter kits and provide training to primary care providers (medical homes) throughout the State. WV Birth to Three has planned to incorporate the ASQ-3™ in their initial intake process. Furthermore, HealthCheck and the WV Immunization Program have agreed on a collaborative effort to diminish unnecessary barriers to achieving better immunization rates among the child population by promoting the Vaccines for Children (VFC) Program with primary care physicians (medical homes). The VFC Program is an effective means to reduce immunization referrals, which may not be accomplished a significant percentage of the time and, as a consequence, constitute a barrier to achieving the vaccination.

### **Partners Implementing an Early Care and Education System (PIECES)**

PIECES is a partnership between the West Virginia Department of Education, the WVDHHR/Bureau for Children and Families, Division of Early Care and Education and the WVDHHR/Bureau for Public Health, Office of Maternal, Child and Family Health Division of Infant Child and Adolescent Health/Early Childhood Health Project. The goal is to determine the needs and design and implement universal Pre-K education for West Virginia's four year olds by 2012.

The PIECES collaborative also includes representatives from other State and local programs, the advocacy community, child care providers and parents. The vision initially adopted by PIECES was for all children and families in West Virginia to have access to high quality early care and education programs that provide a foundation for academic success and lifelong learning while supporting parents' ability to work. However, all

stakeholders understood the need to address more than simply Pre-K education for West Virginia's young children to be ready to learn and to later become healthy, productive adults. Five focus areas were designated: collaboration, professional development, quality initiatives and curriculum, regulations and standards, and child well-being. The realization of the need for a stronger health component led to the Office of Maternal, Child and Family Health (OMCFH) being asked to take on this assignment. Considering other key programs within OMCFH and that OMCFH has been involved with PIECES since its inception, this was a perfect fit. Accordingly, West Virginia designed its Early Childhood Care System project to fill that role (rather than duplicate parts of the system that are working well) and named it the Early Childhood Health Project (ECH).

It is evident from conversations with counterparts from other states that partnerships between education and human services organizations such as PIECES are rare. This collaboration has been supported by two governors and continues to be the platform for pooling resources, human and financial, to benefit our State's very young children. Using an established collaborative relationship that includes representation from all relevant sectors is considered the most efficient and effective platform for collaboration.

The American Recovery and Reinvestment Act of 2009 (ARRA) (P.L. 111-5) made funding available to improve coordination and collaboration among early childhood education and care programs and services. The Administration for Children and Families (ACF) announced the availability of \$100,000,000 through ARRA to be awarded to eligible states, commonwealths and territories to enable states to develop and implement a plan established by their State Advisory Council on Early Childhood Education and Care for children from birth to school entry, referred to as the Early Childhood Advisory Council (ECAC). Staff of OMCFH participated in development of the State's application for these funds, providing critical data that will assist the ECAC to prioritize goals and activities.

In the Improving Head Start for School Readiness Act of 2007 (Head Start Act, 42 USC 9801 et seq.), Congress authorizes the Governor of each state to designate or establish such a Council. Governor Joe Manchin III issued an executive order and appointed members of the ECAC Advisory Council. The PIECES Advisory Council will transition into the ECAC. The overall responsibility of the State Advisory Council will be to facilitate the development or enhancement of high-quality systems of early childhood education and care designed to improve school readiness.

### **Helping Appalachian Parents and Infants (HAPI)**

The OMCFH and West Virginia University finalized an Agreement for joint implementation of the Risk Reduction Through Focus on Family Well-Being/Helping Appalachian Parents and Infants (HAPI) Project, a Healthy Start grant, in RFTS Region VII. Several providers including mental health providers and dentists signed agreements



to participate in the program to provide patient services. The services encompass care coordination provided to pregnant women and infants, including a preconception phase, as per the existing RFTS Project. The HAPI Project focuses on helping women become healthier before becoming pregnant, encourages spacing of pregnancies, provides child care services, oral health care reimbursement, substance abuse screening and referral, outreach services utilizing former consumers, transportation assistance to doctor appointments and payment for mental health services. Curriculum for patient education was developed by WVU. OMCFH, as the subcontractor, acts as the fiscal agent for HAPI. Billing procedures have been developed by OMCFH and patient services invoices are processed by the State on behalf of the grantee, WVU.

The long-term goal of the project is to decrease the incidence of low birth weight infants born in West Virginia by reducing recurrent low birth weight. It is hoped that resulting data may also show that there is a significant benefit of cost savings through the risk reduction plan for at risk families. Hopefully, using data obtained from this Healthy Start/MCH partnership, RFTS can justify the benefit in expanding the current case management program to include the risk reduction plan for families and allow implementation of a longer period of eligibility for case management to assist at-risk families.

### **Perinatal Wellness Partnership**

Another initiative is the West Virginia Perinatal Wellness Partnership that includes stakeholders from all across the State. Convened in 2006, WV Perinatal Partnership stakeholders include obstetrical and neonatal physicians, Medicaid, private insurance providers, OMCFH, Vital Statistics staff, the Hospital Association and the March of Dimes to mention a few. The 2007 work plan of the Partnership includes the following: 1) establish a statewide perinatal transport system, 2) identify and address obstetrical provider shortage areas, 3) address the lack of oral health care in pregnancy, 4) identify costly medical procedures associated with poor birth outcomes, 5) develop an approach to identifying and treating drug use during pregnancy, 6) promote perinatal worksite wellness, and 7) support and promote breastfeeding.

One policy recommendation was to create a coordinated statewide perinatal system including the request that the State identify a maternal risk scoring instrument to be used universally by all obstetrical medical providers and all payers.

Comprehensive risk screening enables the prenatal care provider to determine whether the woman, the fetus, or the infant are at increased risk and provides the basis for further assessment and intervention. Risk factors are characteristics that indicate a higher probability of adverse outcome and help guide the action by the woman, social supports, and the medical provider.

The Perinatal Partnership Universal Risk Screening Committee believed that early prenatal care, with an emphasis on risk screening at the first prenatal visit and appropriate follow-up, was critical. In WV, the most likely adverse pregnancy outcome is preterm labor and/or low birthweight. A review of health data and key informant survey responses confirmed that smoking during pregnancy plays a huge role in poor pregnancy outcomes.

Since the 1980s, West Virginia has screened low income, government-sponsored women for adverse outcomes, and although the screening instrument has changed numerous times over the last 25 years, the use of the information to prevent or treat conditions associated with poor pregnancy outcomes has remained the same. Low income pregnant women who receive government-sponsored health care are routinely screened using the Prenatal Risk Screening Instrument (PRSI), developed by WVU, Department of OB/GYN. The risk scoring forms completed by the medical practitioner triggers a referral to the RFTS Project. The RFTS provider network are community-based licensed social workers and nurses who provide individual care planning, taking into account medical and psychosocial patient risks. The RFTS workforce has responsibility to arrange for community resource referral and consultation, as well as offering in-home educational services designed to affect patient behavior. While other insurers support prenatal risk screening for their beneficiaries, the intensity and the type of management offered in response to the probability of adverse patient outcome varies by carrier. There is no insurer that provides the care management equivalent of RFTS, i.e., home visits and one-on-one education.

A survey of West Virginia medical obstetrical practitioners was completed by OMCFH to determine their current risk screening practices including the instrument used and the PRSI was most often cited as the tool used. Out of 120 surveys returned, 40% reported regular use of the PRSI, 14% used an ACOG tool, 4% used the POPRAS, 14% used an in-house tool and 28% were not using a risk assessment form.

The Universal Prenatal Screening Committee recommended (1) the PRSI, a screening instrument unique to West Virginia and not copyrighted, can be used statewide without significant cost investment; (2) the PRSI is one page and not burdensome for the medical practitioner or other office staff; (3) the PRSI, as evidenced by the survey, already enjoys widespread acceptance and use; (4) there is the option to modify the PRSI; (5) modifications to the form can, in time, be a result of data gathering, analysis and evaluation to better reflect West Virginia's need and patient risks.

Legislation passed during the 2009 session as Senate Bill 307, creating the Maternal Screening Act, relating to development of a maternal risk assessment advisory council; providing for legislative findings; setting forth responsibilities of the advisory council; providing for legislative rule-making authority within the Department of Health and Human Resources to develop a uniform maternal risk screening tool; providing for

applicability of the screening tool once developed; and providing confidentiality of the tool.

The bill stated the "Legislature finds that there is a need for a more comprehensive and uniform approach to any screening conducted by physicians and midwives to discover at-risk and high-risk pregnancies. A uniform approach would simplify the process, standardize the procedure and better identify those pregnancies that need more in-depth care and monitoring. Additionally, a uniform application would provide better and more measurable data regarding at-risk and high-risk pregnancies. This would allow public health officials to gain a better understanding of those conditions that are most frequently observed and to develop methodology to address those concerns." The bill established an advisory council within the WV DHHR, Office of Maternal, Child and Family Health to provide the Office with assistance in the development of a uniform maternal risk screening tool. Following implementation in January 2011, all health care providers offering maternity services will be required to utilize the tool in their examinations of any pregnant woman, maintain confidentiality and notify the woman of any high-risk condition which they identify along with any necessary referral.

West Virginia's Office of Maternal, Child and Family Health is known for its positive partnerships with the medical community, the University affiliated programs, the State Department of Education, and the March of Dimes Chapter, among others. These partnerships have resulted in shared initiatives. One initiative is the folic acid campaign, a national March of Dimes assignment, used in West Virginia to advocate for the distribution of this supplement preconceptually to reduce the incidence of neural tube defects.

Another initiative made possible was the George Washington University National Institute of Health Study; Smoking Cessation of Reduction in Pregnancy Treatment (SCRIPT) Project incorporated within the RFTS Project. This smoking cessation program was implemented in partnership with the Office of Epidemiology and Health Promotion, who contributed tobacco funds for the purchase of CO monitors for the 233 care coordinators for use with pregnant women statewide.

### **Kids First**

A recent initiative is school entrance screening using the EPSDT (HealthCheck) protocol, called Kids First. The objectives of the initiative are: to establish a medical home for the child, to allow school systems to focus on providing needed services for children with identified deficits, to assist families in finding treatment resources, and to promote healthy lifestyle activities. The focus of the screening will be on the domains of oral health, vision, hearing, speech and language, and behavior/development. Kids First is an example of high-level collaboration in government. Three Cabinet level agencies, the Department of Education, the Department of Health and Human Resources and the

Department of Administration, are working closely together to bring this project to the families of West Virginia. All insurers agreed to pay for the services.

### **Birth to Three/Part C**

The Birth to Three/Part C Program partners with a multitude of agencies to assist with child find efforts and to ensure needed services are arranged. WV Birth to Three has institutionalized a variety of strategies for the early identification of infants and toddlers with developmental delay or significant risk factors. WV Birth to Three's interagency agreements with Title V, CHIP, Bureau for Children and Families, Head Start, and Medicaid assist in the early identification and referral of potentially eligible children. West Virginia finds that coordination with primary health care providers and other community partners is important to assure that children potentially in need of early intervention services are identified as early as possible.

WV Birth to Three continues coordination with Title V/CSHCN, Newborn Hearing, and Right From The Start programs to assure that infants failing the newborn hearing screen receive diagnostics, and referral to Part C and Ski \*Hi when hearing loss is confirmed. The Birth Score universal newborn screening, conducted on all children born in West Virginia, identifies infants who are born with conditions that may make them at risk for developmental delay. Referrals are made directly to the appropriate Birth to Three Regional Administrative Unit (RAU). Public awareness and child find activities are conducted collaboratively with interagency partners, including Part B preschool, Child Care and Head Start. Examples of this collaboration include the publication and distribution of a quarterly magazine, annual calendars, and developmental wheels to county schools, physicians, Family Resource Networks, medical clinics, early childhood providers, and higher education faculty. The publications include information about how to make a referral to Part C, Part B, Head Start and/or child care. The WV Birth to Three Public Information Coordinator has worked closely with WV CHIP to develop parent educational and child find materials, to be distributed collaboratively. The WV Birth to Three Public Information Coordinator has participated in faith based planning initiatives coordinated through WV CHIP to provide information about WV Birth to Three as a resource for families.

Child find strategies have also included coordination with the Right From The Start and HealthCheck Programs coordinated through the Office of Maternal, Child and Family Health. Local Right From The Start personnel who work directly with high risk mothers and infants are able to identify those children who may be in need of early intervention services. Program Specialists within the HealthCheck Program, in their work with physicians, are able to provide information about the criteria and requirements, and importance of identifying children who may be in need of early intervention services. Recent policy direction by the AAP to its members encouraging early screening for

developmental delays and subsequent referral to Part C have also contributed to increases in the number of children served by the Program.

WV Birth to Three staff have coordinated with the Bureau for Children and Families, Child Protective Services, in the development of procedures to assure the referral of children who have experienced substantiated abuse and/or neglect. Training is provided to WV Birth to Three service coordinators and practitioners related to the requirements and coordination with Child Protective Services and Foster Care, as required by the Federal Child Abuse and Protection Act (CAPTA).

**OMCFH Agency Partners include:** (list not all inclusive)

- Birth to Three/Part C provides grants to local entities to act as system point of entry for eligibles and service agreements with over 600 professionals from specialty disciplines such as OT, PT, SLP
- Memorandum of Understanding with WIC and SSA for referrals as referenced earlier
- Working agreement with the Office of Social Services (Title IVB) for children in state custody to receive enhanced health screens through OMCFH's medical provider networks
- Working agreement with the Office of Social Services for interagency training for professionals and para-professionals serving young children-including use of assistive technology and understanding ADA
- Agreements with WVU for genetic services and administration of the Birth Score Project
- Agreements statewide with 150+ private physicians, community health centers and local health departments for Title X family planning services.
- Agreements serving 300+ sites statewide for Breast and Cervical Cancer Screening Program services
- Agreements with 8 regional lead agencies to locally administer the Right From The Start Project and subsequent agreements with multiple agencies to provide direct services to perinatal populations who employ more than 165 licensed social workers and nurses, 83 Designated Care Coordination Agencies, and 76 OB providers (contracted)
- March of Dimes
- Developmental Disabilities Council
- Medical advisories for all programs and projects
- University Center for Excellence in Disabilities
- Interagency Coordinating Council for Birth to Three/PartC (state statute established)
- WV Training Connections and Resources (interagency collaboration professional development)
- Department of Education/Healthy Schools

- Starting Point Centers (Early Childhood Initiative, initially funded with Carnegie Foundation monies)
- Head Start
- Cancer Coalition (established state statute)
- Membership, West Virginia Association of Community Health Centers
- WV Commission for the Deaf and Hard of Hearing (Board Member)
- Division of Perinatal and Women's Medical Advisory Committee
- Children's Mental Health Collaborative
- WVU Healthy Start HAPI Project
- American Lung Association
- WV Division of Tobacco Prevention
- George Washington University and National Institute of Health, Pregnancy Smoking Cessation Research Project
- All Offices within WV DHHR

## SECTION 3

### Strengths and Needs of the Maternal and Child Health Population Groups and Desired Outcomes

- **Pregnant women, mothers, and infants**

#### Health Status of Women:

Women and men in West Virginia share many of the same health care concerns. Women, however, often face unique challenges in dealing with health issues, even when coping with illnesses, conditions, and health-related behaviors that are common to both sexes. In some instances, women are faring worse than men in the pursuit of a longer and healthier life. A recent study by researchers at Harvard University found that, while life expectancy was increasing overall in the United States for both women and men, this was not true in all parts of the country. Actual reduction in life expectancy from 1983 to 1999 occurred in a large number of U.S. counties, including many in Appalachia, and was substantially greater among women than among men in some of those areas. Women in West Virginia were found to have lower life expectancies in general than their counterparts nationwide, with women in some parts of the State showing the marked reduction in life expectancy reported in the Harvard study. In 1999 no West Virginia county had a life expectancy among women that was at or above the national average of 79.6 years.

In part as a result of these findings, the West Virginia Health Statistics Center, Bureau for Public Health, prepared a series of fact sheets on selected health concerns facing women in the State. The fact sheets, 22 in all, cover a wide variety of health topics, from chronic diseases such as cancer and cardiovascular disease, to risk factors such as smoking and obesity, to sexually transmitted diseases and violence toward women. They are available online at <http://www.wvdhhr.org/bph/oehp/hsc/vr/publicat.htm> to be downloaded and copied for distribution.

The most recent data available for West Virginia and the United States have been included, with comparisons between women in the State and Nation where possible. The data were obtained from a variety of sources, primarily the Health Statistics Center; the Behavioral Risk Factor Surveillance System (U.S. Centers for Disease Control and Prevention [CDC]); the Youth Risk Behavior Survey (West Virginia Department of Education/CDC); and the West Virginia Cancer Registry and the HIV/AIDS/STD Program in the West Virginia Division of Surveillance and Disease Control. Other sources are provided where used. It is hoped that the fact sheets are found useful by health professionals, public health personnel, legislators, policymakers, and consumers

in addressing the challenges shared in the effort to improve both the quality and quantity of life experienced by West Virginia women.

### Demographics for WV Women

According to Census Bureau estimates, women made up 51.0% of West Virginia's population in 2007; in the United States, women accounted for 50.7% of the population. Women in West Virginia were older than women in the nation as a whole, more likely to be white, less likely to be in the labor force, and more likely to live below the poverty level if they are the head of the household.

#### In 2007

- The median age of women in West Virginia was 41.8, compared with 37.9 in the United States.
- 17.5% of women in West Virginia were aged 65 or older; in the United States, 14.3% of women were 65 or older. In West Virginia, 22.9% of the female population was under the age of 20, compared with 26.3% in the United States.
- 94.8% of women in West Virginia were white, 3.4% were African American, and 1.8% were Asian or other races; in the United States, 79.5% of women were white, 13.3% were African American, and 7.2% were Asian or other races.
- Only 1.0% of women in West Virginia identified themselves as Hispanic; in the United States, 14.4% of women reported being Hispanic.

#### In 2006

- 49.0% of State women aged 16 and older were in the labor force, compared with 58.7% in the Nation.
- The median earnings of women in West Virginia were \$25,758; in the United States, it was \$32,649 (full-time, year-round workers).
- In West Virginia, 16.1% of families were headed by women (no spouse present), compared with 18.7% of families in the United States.
- 50.6% of West Virginia families headed by women (no spouse present) with children under the age of 18 were living in poverty; in the United States, 36.9% of such households were living in poverty.
- A higher percentage of women in West Virginia (64.9%) were married or widowed than in the United States (58.4%). Only 21.4% of women in West Virginia have never been married, compared with 27.3% in the United States as a whole.

Source: Population Division, U. S. Census Bureau: <http://www.census.gov>



## Women and Pregnancy Outcomes

Women in West Virginia have been giving birth at a lower rate than the United States as a whole since 1980. The State's birth rate has changed little over the past decade, ranging from 11.3 to 12.2 births per 1,000 population. It has consistently been among states with the lowest birth rates in the Nation; in 2006, West Virginia had the 47<sup>th</sup> lowest birth rate, with only New Hampshire, Maine, and Vermont recording lower rates. In 2007, the overall birth rate was 12.2 births per 1,000 population compared to a U.S. rate of 14.3 per thousand.

### In 2007

- There were 22,017 resident births in West Virginia, for a birth rate of 12.2 births per 1,000 population; the U.S. birth rate was 14.3.
- There were 2,737 births to teenage mothers, which represented 12.4% of all births. Nineteen of these births were to young teens aged 10-14.
- 11.9% of the births to State residents were pre-term. The percentage of premature births in West Virginia has increased over the past decade; it was 10.1% in 1997.
- West Virginia had the 5th highest percentage of low birthweight births in the nation at 9.5%.; the U.S. rate was 8.3%. The State ranked 1st in low birthweight births among white women (9.3%) and 2nd in low birthweight births among African American women (14.9%) in 2007.
- 81.5% of women giving birth in West Virginia with known prenatal care received care in the first trimester, compared with a national average of 86.1% in 2005.
- 37.8% of the women giving birth in West Virginia were unmarried, slightly lower than the National average of 38.5%.
- There were 120 resident fetal deaths occurring after 20 or more weeks of gestation.
- There were 155 infant deaths in the State. The State's infant death rate was 7.4 deaths per 1,000 births; the 2005 U.S. rate was 6.9.

### Births

Year	1947	1950	1960	1970	1980	1990	2000	2008
# Births	54,170	50,850	39,696	30,194	29,438	22,582	20,860	21,492
Population (millions)	1.84	2.01	1.86	1.74	1.94	1.7	1.81	1.82

**Population Trends 1947 – 2007:** Since 1947 the size of the population, numbers of births, birth rates, and infant mortality have all declined in West Virginia. Although there have been very slight increases in some years, the annual number of births in West Virginia has declined from a high of 54,170 in 1947 to 21,492 in 2008. West Virginia’s population peaked in 1950 with 2,005,552 people and has stayed about 1.8 million since 1960.

West Virginia is mostly homogenous in race with 95% being Caucasian, close to 4% Black and a little over 1% of Other races which is typical of the births in any given year. Below is a chart from the WV Health Statistics Center that shows birth characteristics by race of the mother for WV in 2008.

Selected Factors by Race of Mother  
West Virginia Resident Births, 2008

Factor	White or Caucasian		Black or African American		All Other Races		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total Births	20,412	95.0%	811	3.8%	269	1.3%	21,492	
<u>Low Birthweight</u>	1,918	9.4%	118	14.5%	14	5.2%	2,050	9.5%
<u>Maternal Age</u>								
Mothers < 20 Years	2,626	12.9%	129	15.9%	26	9.7%	2,781	12.9%
Mothers < 15 Years	24	0.1%	2	0.2%	0	0.0%	26	0.1%
<u>Births with Known Prenatal Care</u>								
First Trimester	16,249	81.3%	563	69.9%	189	71.3%	17,001	80.8%
Second Trimester	3,030	15.2%	187	23.2%	63	23.8%	3,280	15.6%
Third Trimester	591	3.0%	40	5.0%	12	4.5%	643	3.1%
No Prenatal Care	110	0.6%	15	1.9%	1	0.4%	126	0.6%
<u>Gestational Age</u>								
< 32 Weeks	328	1.6%	29	3.6%	3	1.1%	360	1.7%
32-36 Weeks	2,081	10.2%	83	10.2%	17	6.3%	2,181	10.1%
37-38 Weeks	7,421	36.4%	281	34.6%	95	35.3%	7,797	36.3%
39+ Weeks	10,545	51.7%	418	51.5%	153	56.9%	11,116	51.7%
Unknown	37	0.2%	0	0.0%	1	0.4%	38	0.2%
<u>Place of Birth</u>								
Hospital	20,314	99.5%	810	99.9%	268	99.6%	21,392	99.5%
Non-Hospital	98	0.5%	1	0.1%	1	0.4%	100	0.5%

West Virginia Bureau for Public Health  
Health Statistics Center, 2010

West Virginia, along with the rest of the Nation, continues to struggle with low birthweight infants attributed to the highest pregnant smoking rate in the nation at 26% with only minimal shifts from year to year. Low birthweight infants are born to White mothers at 9.4%, while born to Black mothers at 14.5%.

Selected Factors by Birthweight of Infant  
West Virginia Resident Births, 2008

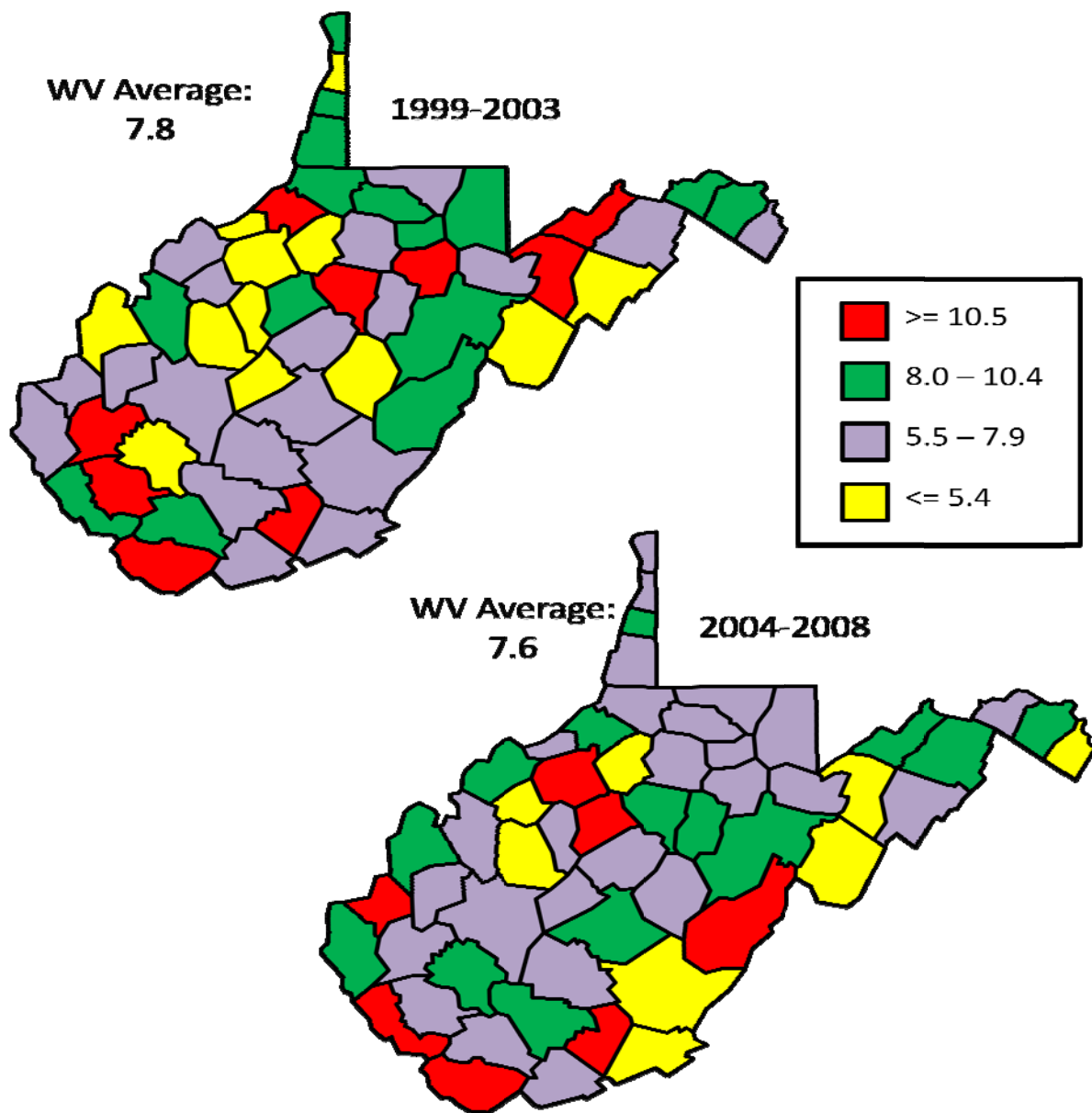
Factor	Very Low Birthweight <1,500 Grams		Moderately Low Birthweight 1,500-2,499 Grams		Normal Birthweight 2,500+ Grams		Unknown Birthweight	Total
	Number	Percent	Number	Percent	Number	Percent	Number	Number
Total Births	305	1.4%	1,745	8.1%	19,422	90.4%	20	21,492
Maternal Age								
< 20 Years	47	1.7%	248	8.9%	2,484	89.3%	2	2,781
< 15 Years	0	0.0%	4	15.4%	22	84.6%	0	26
Maternal Race								
White or Caucasian	276	1.4%	1,642	8.1%	18,474	90.5%	20	20,412
Black or African American	26	3.2%	92	11.3%	693	85.5%	0	811
All Other Races	3	1.1%	11	4.1%	255	94.8%	0	269
Births with Known Prenatal Care								
First Trimester	235	1.4%	1,299	7.6%	15,463	91.0%	4	17,001
Second Trimester	44	1.3%	314	9.6%	2,922	89.1%	0	3,280
Third Trimester	3	0.5%	42	6.5%	598	93.0%	0	643
No Prenatal Care	12	9.5%	31	24.6%	83	65.9%	0	126
Gestational Age								
< 32 Weeks	269	74.7%	75	20.8%	16	4.4%	0	360
32-36 Weeks	30	1.4%	980	45.0%	1,170	53.6%	1	2,181
37-38 Weeks	3	0.04%	549	7.0%	7,242	92.9%	3	7,797
39+ Weeks	3	0.03%	140	1.3%	10,971	98.7%	2	11,116
Unknown	0	0.0%	1	4.2%	23	60.5%	14	38
Mother's Education Level								
8 Years or Less	5	1.2%	55	13.3%	355	85.3%	1	416
9-11 Years (No High School Diploma)	58	1.6%	357	10.1%	3,106	88.2%	2	3,523
12 Years (High School or GED)	124	1.6%	690	8.7%	7,144	89.7%	3	7,961
13-15 Years (Some College or Associates Degree)	56	1.2%	328	7.2%	4,201	91.6%	1	4,586
16+ Years (Bachelor's Degree or Higher)	57	1.2%	284	5.9%	4,440	92.8%	4	4,785
Unknown	5	2.4%	31	14.6%	176	79.6%	9	221
Mother's Marital Status								
Married	154	1.2%	870	7.0%	11,435	91.7%	8	12,467
Not Married	149	1.7%	874	9.7%	7,969	88.5%	10	9,002
Unknown	2	9.5%	1	4.8%	18	78.3%	2	23

West Virginia Bureau for Public Health  
Health Statistics Center, 2010

## Birth Outcomes

Infant mortality is the result of a complex set of biological and social factors, and infant deaths have long been viewed as an important indicator of a population's health. From 1976 to 1988 there was considerable effort in West Virginia to reduce the incidence of neonatal mortality and post-neonatal mortality. The infant mortality rate in West Virginia made the most rapid decline in the 1970s and continued to decline in the 1980s until 1989. Many factors may be responsible for the decline. The advent of a strong federal and state supported Family Planning Program and the legalization and availability of abortion may also have played important roles in reducing infant mortality. For most of the 1980s the infant mortality rate in West Virginia was below the national average. While the rest of the Nation has shown an almost steady decline in the rate of infant mortality since 1994, West Virginia's rate has remained slightly above the national average for each of the last 10 years. Because of the relatively low numbers of births in West Virginia, it is best to look at infant mortality rates in five-year averages.

## Resident Infant Death Rates by County West Virginia, 1999-2003 and 2004-2008



West Virginia Bureau for Public Health-Health Statistics Center

The following table shows the decline in the national and state infant mortality rates from 1950 through 2008.

1950 – 2008 Infant Mortality  
West Virginia and United States  
(Number and Rate per 1,000 Live Births)

Year	West Virginia	United States
1950	31.4	29.2
1955	27.1	26.4
1960	25.3	26.0
1965	27.1	24.5
1970	23.3	20.0
1975	18.3	16.1
1980	11.8	12.6
1985	10.7	10.6
1990	9.8	9.1
1995	7.6	7.5
2000	7.6	6.9
2001	7.3	6.9
2002	9.1	7.0
2003	7.3	6.9
2004	7.6	6.8
2005	8.1	6.9
2006	7.4	6.9
2007	7.4	6.7
2008	7.7	NA

## **Racial Disparities**

Racial disparities in health status, health care, and mortality are well documented. In the United States, African Americans are more likely than non-Hispanic Whites to have diabetes or hypertension, to be overweight or obese, and to be uninsured. In addition, infant mortality, cardiovascular disease mortality, cervical cancer, and breast cancer mortality are all higher among African Americans than Whites.

Measuring health-related racial disparities in West Virginia is challenging due to the small population of racial minorities in the State. For most available data sources, racial and ethnic minority groups must be combined and multiple years of data must be aggregated to obtain reliable estimates and rates for non-white groups. Nonetheless, *Minority Health in West Virginia*, published by the Bureau for Public Health in April 2007, identifies racial disparities related to STD infection, birth outcomes, and mortality.

## **Socioeconomic Disparities/Poverty**

"The following data underscores the increasingly important role of area socioeconomic deprivation in producing health disparities in US childhood mortality," state the authors of an article published in the September 2007 issue of the American Journal of Public Health. Because childhood mortality rates are the lowest of all age specific mortality rates and because national mortality statistics lack relevant socioeconomic information, socioeconomic disparities in childhood mortality are rarely documented, particularly in a temporal fashion. The article presents an analysis of changing socioeconomic inequalities in U.S. childhood mortality in the past three decades.

Socioeconomic data from the 1990 decennial census were linked with data from the National Vital Statistics System to obtain county and cause specific childhood death data for the period 1969 through 2000. Each of 3,097 counties was assigned to one of five deprivation quintiles, ranging from the most socioeconomically deprived to the least socioeconomically deprived. Trends in childhood mortality by deprivation were computed annually and across different time periods, after adjusting for the effects of age, gender, and race and ethnicity.

The authors found that:

- Compared with children in the least deprived socioeconomic quintile the mortality rate for children in the most deprived socioeconomic quintile was 52% higher in 1969-1971, 65% higher in 1988-1990, and 86% higher in 1998-2000.
- In 1969-1971, children in the most deprived socioeconomic quintile had a 69% higher rate of unintentional injury mortality than did children in the least deprived socioeconomic quintile. The differential widened to 177% in 1998-2000.
- In 1998-2000, children in the most deprived socioeconomic quintile had a 159% higher homicide rate than did children in the least deprived socioeconomic

quintile. The rate for the most deprived socioeconomic quintile was only 76% higher in 1969-1971.

- In 1969-1971, children in the most deprived socioeconomic quintile had a 13% higher birth defects mortality rate than did children in the least deprived socioeconomic quintile. The differential widened to 44% in 1998-2000.

"Narrowing the socioeconomic gap in child mortality may require designing strategies that are not only aimed at improving child health services but also aimed at mitigating the effects of inequalities in material and social living conditions," conclude the authors.

West Virginia has one of the highest rates of poverty in the Nation with 62% of the births being paid for by Medicaid. While both Whites and African Americans have poverty rates above the national average, deep racial disparities exist across all age groups. Overall, 28.5 percent of WV African Americans are in poverty compared to 16.5 percent of Whites. WV African American children under age five are more than twice as likely as White children to be poor, with 58 percent living below the poverty line. African American adults also experience significantly higher poverty levels, including one in four working-age adults and one in five seniors. The level of uninsured African Americans and those living in poverty contribute to the high rate of infant mortality within the African American population in WV as noted in the chart below. Source: WV CBP analysis of U. S. Census Bureau, 2006-2008 American Community Survey.

West Virginia has one of the highest White and Black infant mortality rates in the U.S.

**2000-2006 West Virginia Resident Infant Mortality Rate  
By Race of Decedent**

<b>Year</b>	<b>Total</b>	<b>White</b>	<b>Black</b>	<b>All Other</b>
2000	7.6	7.3	18.6	4.7
2001	7.3	7.3	16.3	0.0
2002	9.1	8.7	29.1	2.8
2003	7.3	7.2	13.0	4.0
2004	7.6	7.5	15.5	3.4
2005	8.1	8.1	18.0	1.2
2006	7.4	6.9	31.6	1.1
2007	7.4	6.9	22.0	3.8
2008	7.7	7.3	21.0	0.0
<b>2000-2008</b>	<b>7.7</b>	<b>7.5</b>	<b>20.6</b>	<b>2.3</b>

In 2006, African Americans were 30 percent more likely than Whites to be uninsured. African American men had the highest rate of being uninsured at 25.1 percent, followed by African American women at 20.8 percent, White men at 18.7 percent and White women at 16.6 percent. Source: U. S. Census Bureau, Small Area Health Insurance Estimates.

In WV, the combined average percent of individuals attaining a high school diploma is 17% less than the National average. The combined average percent of individuals attaining a bachelor's degree is only 16.08%, a full 35% lower than the National average of 24.4%.

“You can't get there from here”, is a well-known expression in WV. In fact, for WV rural residents who need to see a doctor, the isolation, poor road conditions and lack of transportation can be a grim reality.

According to the WV Perinatal Partnership, since the early 1970's, WV has lost thirty (30) low volume obstetrical units. When the Perinatal Partnership published the *Reports on the Blueprint to Improve West Virginia Perinatal Health* in 2007, the only board-certified perinatal specialists in WV were located in Charleston, Huntington, and Morgantown. Women and babies needing the services of high-risk specialists often have to travel long distances for them. Many do not keep appointments because of the long distances on difficult WV roads. According to the Centers for Disease Control, insufficient prenatal care is concentrated in certain geographic areas, most often in inner cities and isolated rural areas. Poverty is one of the most important predictors of insufficient prenatal care. Women with income levels below the federal poverty line consistently show higher rates of late or no prenatal care and lower rates of early care than women with larger incomes.

#### Strengths:

Ensuring access to health care for low-income women and children has been an ongoing concern for state and federal officials. The Bureau for Medical Services (Medicaid) and OMCFH have worked collaboratively to develop special initiatives that extend support services to women and infants at risk of adverse health outcomes. This partnership has not only expanded the State's capacity to finance health care for women and children, but has also strengthened the delivery of care by establishing care protocols, recruiting medical providers and developing supportive services such as case management and nutrition counseling which contribute to improved patient well-being.



## Right From The Start Program:

Early preventive prenatal care and education are recognized as the most effective and cost effective ways to improve pregnancy outcomes. West Virginia's Right From The Start Program (RFTS), was founded in 1989 as a partnership between the OMCFH and WV Medicaid to provide access to early and adequate prenatal care to low-income pregnant women and infants. Currently, RFTS provides comprehensive perinatal services to low-income women up to sixty (60) days postpartum and care coordination for Medicaid eligible infants up to one (1) year of age. Right From The Start also provides direct financial assistance for obstetrical care for WV pregnant women who are uninsured or underinsured and are above income guidelines for Medicaid coverage. These pregnant women may qualify for assistance for prenatal care if they are a WV resident, have income between 150%-185% of the federal poverty level, are a pregnant teen age 19 or under, or are a non-citizen. Under this Title V funded service, women who have no funding source for prenatal care coverage or have not yet been approved for coverage can receive assistance for payment of their first prenatal visit, ultrasound, and routine laboratory procedures if ordered on their first visit.

The RFTS Program has a highly qualified, dedicated network of more than 167 DCCs, registered nurses and licensed social workers throughout WV, and 50 Designated Care Coordination agencies that have contracted with the OMCFH to provide in-home care coordination and enhanced education services to high risk pregnant women and infants. The 167+ DCC providers are dedicated to the core public health function of assisting these populations with access to early and adequate prenatal/health care.

The DCCs are specially trained registered nurses and social workers licensed to practice in WV, and follow *American College of Obstetricians and Gynecologists* (ACOG) guidelines and protocols identified in the *RFTS Program Policy and Procedure Manual*. The RFTS protocols focus on the improvement of birth outcomes by providing education on the mother's personal health, quality of care-giving and life-course development. Women voluntarily enroll as early in pregnancy as possible with home visits beginning ideally by the 16<sup>th</sup> week of pregnancy, and continuing through the first year of the infant's life. DCCs involve the mother's support system including family members, fathers and friends, and help families access other health and human services they may need. Each pregnant woman and family of the infant receives individualized services which they develop jointly with the DCC. The plan of care, activities identified to meet objectives and outcomes, are shared with the medical provider. Additional medical and social services offered in the community are also used to assure efficient use of resources.

In addition to RFTS DCCs, there were seventy-three (73) obstetricians, nurse practitioners, nurse midwives and family practice physicians in WV and bordering states

that have Letters of Agreement with the Project to provide quality obstetrical and delivery care to pregnant women.

In WV, RFTS Project providers and partners understand and embrace the philosophy that meeting the health care needs of women requires a comprehensive approach of multiple interrelated issues including: social, cultural, economic, and physical environments; financial and physical access to health care services; provider and partner awareness of the need for health services; and the resulting outcomes.

#### Telehealth Project:

The WV Perinatal Partnership is committed to better utilizing telecommunications for perinatal consultation and training and make recommendations. Charleston Area Medical Center (CAMC) Institute, along with many other organizations across the State, is working with the WV Perinatal Partnership to design and develop a statewide Perinatal Telehealth Program. The Program plans to provide rural health care sites with the equipment and training necessary to link rural health organizations (and obstetricians, nurse practitioners, certified nurse midwives, nurses, pregnant women and their families) with tertiary care centers and perinatologists so high risk pregnant women and their health care providers can receive perinatal consultation services, education and obstetrical referrals.

In 2009 the CAMC Institute was awarded a \$370,000 grant from the USDA which will be used to purchase equipment for telehealth sites in rural WV areas across the State. This will allow for perinatal consultations for patients in WV with high-risk pregnancies who might otherwise have to travel a great distance to see perinatal specialists.

Each of the rural WV hospitals and primary care centers slated to participate in the WV Perinatal Telehealth Project, a program that would provide rural health care sites with the equipment and training necessary to link rural health care providers with tertiary care centers, are considered “extremely rural” or “rural by USDA RUS definitions. The combined average per capita income for project participants are a full 42% less than the National average, with 45% more individuals living in poverty (when compared with the National average).

#### OB Provider Availability:

Results from a study conducted by the WV Perinatal Partnership reveal the need to increase the number of perinatal care providers in underserved counties. In 2007, the Partnership conducted a statewide study to identify private obstetrical practices in the State that might benefit from being matched to an existing Federally Qualified Health Center (FQHC) site. This designation would allow the medical professionals to have medical liability coverage under the Federal Trades option. The group also worked with

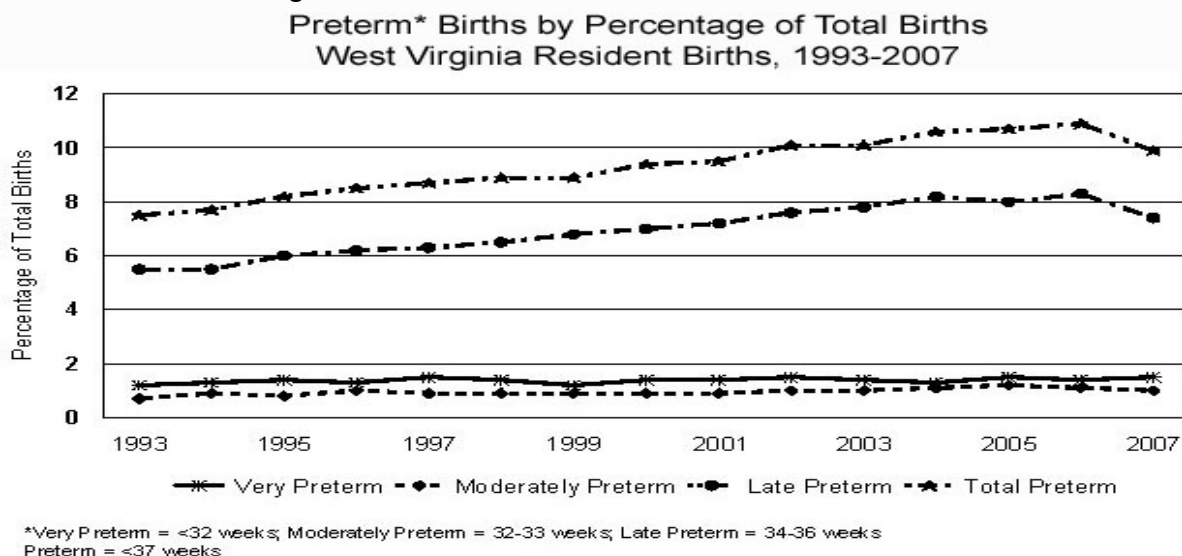
the 2007 WV State Legislature to support elements identified to improve perinatal health.

### Preterm/Premature births

There has been an increase in preterm, or premature, births (i.e., those occurring before 37 weeks of gestation) in both West Virginia and the United States. Analysis shows that these increases are primarily associated with increases in late-preterm births, those births that occur from 34 through 36 weeks. According to data from the National Center for Health Statistics, West Virginia ranked fifth in the Nation in 2005 in the percentage of total singleton births that were born in the late-preterm period.

Recent research points to increased risks of morbidity and mortality among late-preterm infants. While infants born from 34 to 36 weeks gestation can be the size and weight of some full-term infants, a report published by the American Academy of Pediatrics notes that they are less physiologically and metabolically mature than infants born at 37+ weeks of gestation and at higher risk of developing medical complications during and after birth. Cerebral palsy is three times more likely among these infants than among full-term infants. Respiratory problems are more common in late-preterm infants, as are feeding problems, jaundice, and re-hospitalization during the neonatal period. A study published in the October 2008 *American Journal of Obstetrics and Gynecology* found increased risks of developmental, social, and neurocognitive deficits among children who were late-preterm infants.

The West Virginia Health Statistics Center examined birth certificate data from singleton births from 1993 through 2007 in order to determine the scope of the problem of late-preterm birth in the State. As illustrated in the following table, the increase in these births was responsible for the increase in the overall rate of prematurity over the 15 years; the rates of very preterm (<32 weeks) and moderately preterm (32-34 weeks) births show little change.



The following table presents the number and percentages of total births represented by very preterm, moderately preterm, and late-preterm births.

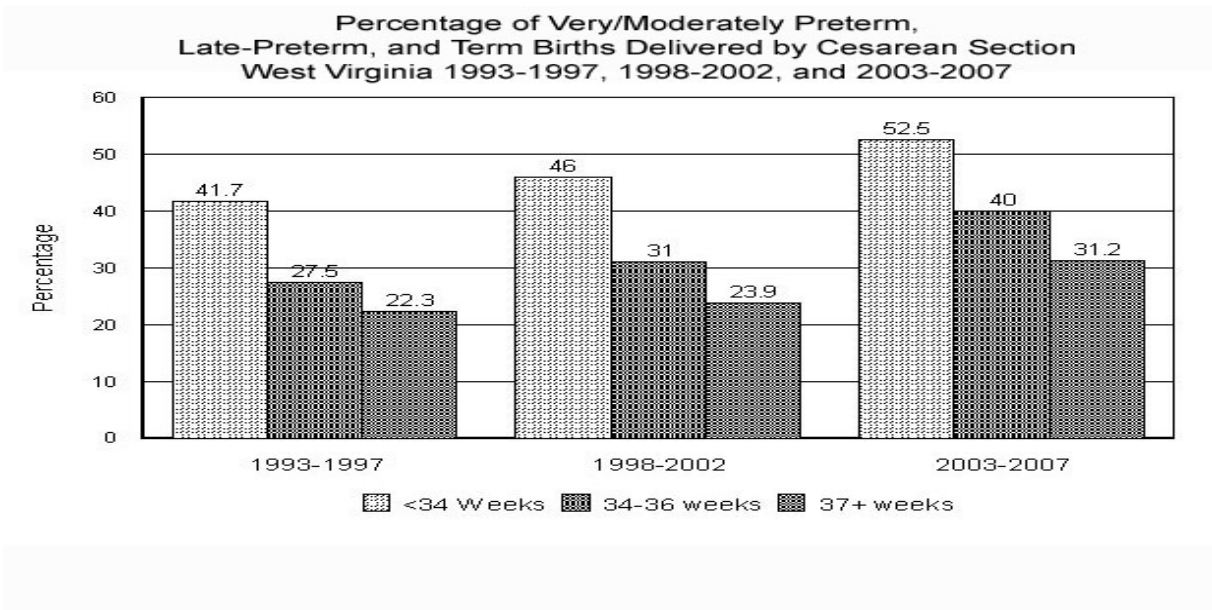
Very, Moderately, and Late-Preterm Births, Number and Percentage of Total Births West Virginia Resident Singleton Births, 1993-2007								
Year	Very Preterm (<32 weeks)		Moderately Preterm (32-34 weeks)		Late Preterm (34-36 weeks)		Total Preterm (<37 weeks)	
	#	%	#	%	#	%	#	%
1993	254	1.2	155	0.7	1,150	5.5	1,559	7.5
1994	268	1.3	190	0.9	1,126	5.5	1,584	7.7
1995	275	1.4	170	0.8	1,204	6.0	1,649	8.2
1996	262	1.3	190	1.0	1,231	6.2	1,683	8.5
1997	299	1.5	183	0.9	1,243	6.3	1,725	8.7
<b>1993-1997</b>	<b>1,358</b>	<b>1.3</b>	<b>888</b>	<b>0.9</b>	<b>5,954</b>	<b>5.9</b>	<b>8,200</b>	<b>8.1</b>
1998	286	1.4	181	0.9	1,294	6.5	1,761	8.9
1999	236	1.2	173	0.9	1,347	6.8	1,756	8.9
2000	287	1.4	188	0.9	1,389	7.0	1,864	9.4
2001	280	1.4	183	0.9	1,420	7.2	1,883	9.5
2002	291	1.5	197	1.0	1,523	7.6	2,011	10.1
<b>1998-2002</b>	<b>1,380</b>	<b>1.4</b>	<b>922</b>	<b>0.9</b>	<b>6,973</b>	<b>7.0</b>	<b>9,275</b>	<b>9.3</b>
2003	275	1.4	210	1.0	1,576	7.8	2,061	10.1
2004	273	1.3	216	1.1	1,663	8.2	2,152	10.6
2005	297	1.5	238	1.2	1,622	8.0	2,157	10.7
2006	293	1.4	228	1.1	1,683	8.3	2,204	10.9
2007*	310	1.5	217	1.0	1,563	7.4	2,090	9.9
<b>2003-2007</b>	<b>1,448</b>	<b>1.4</b>	<b>1,109</b>	<b>1.1</b>	<b>8,107</b>	<b>7.9</b>	<b>10,664</b>	<b>10.4</b>

\*provisional data

Selected factors were examined to better understand the recent increase in late-preterm births, including delivery method, certain demographic characteristics of the mother, and the reporting of maternal medical risk factors. To provide adequate sample size for analysis, data were aggregated into three 5-year groupings: 1993-1997; 1998-2002, and 2003-2007.

**Delivery Method**

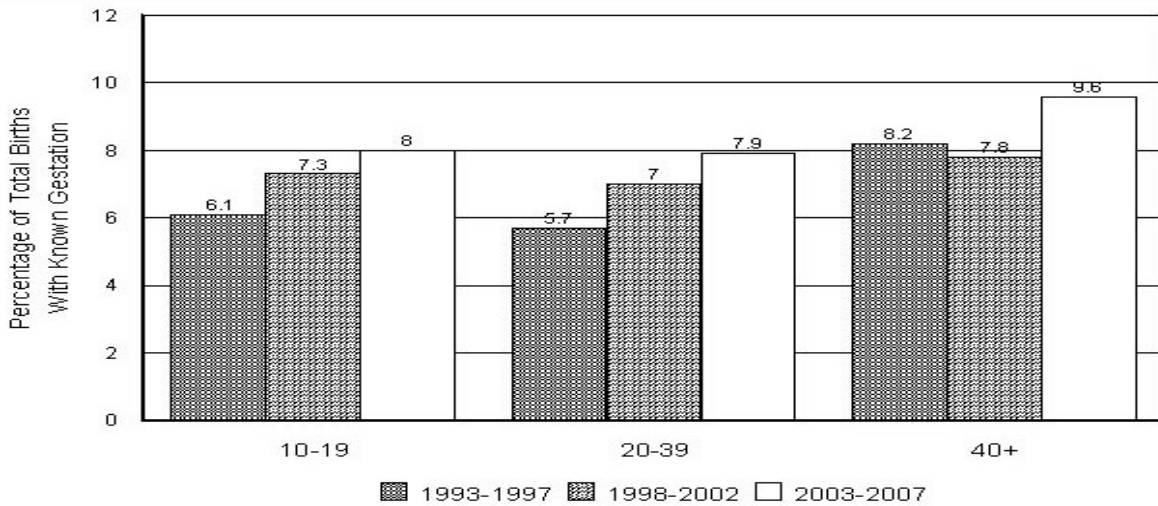
The percentage of all births that were delivered by Cesarean section increased over the time period among both preterm and term infants. The percentage of late preterm births delivered by Cesarean section increased at a faster rate, however, than either very to moderate preterm or term births. Between 1993-1997 and 2003-2007, the overall Cesarean rate among late-preterm births increased 45.5% (27.5% to 40.0%).



**Maternal Characteristics**

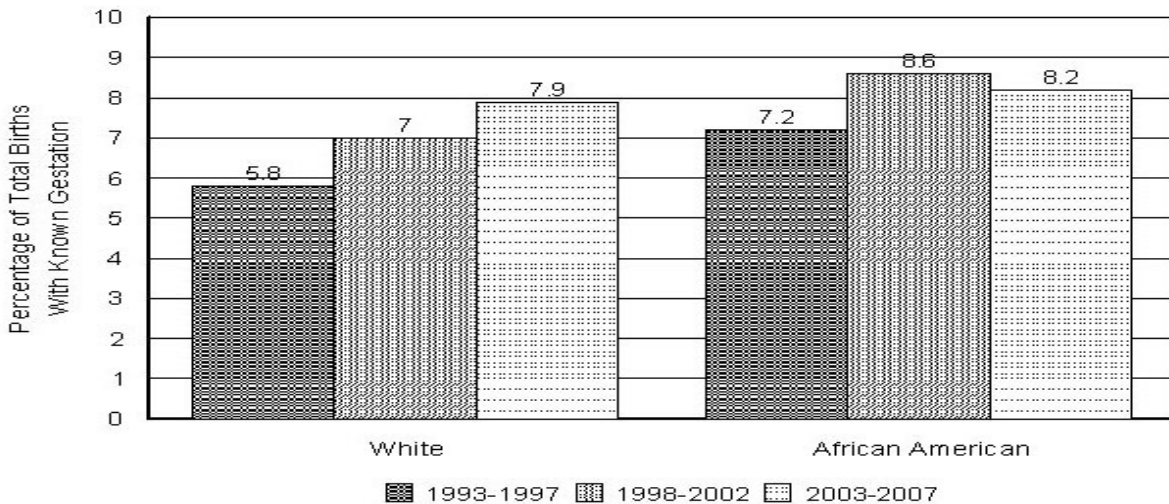
Late-preterm births increased among all maternal age groups examined. Mothers aged 40 and older were more likely to have a late-preterm delivery than younger women in all three time periods; however, the proportion of late-preterm births increased at a higher rate among younger women: 31.1% among teenage mothers (6.1% to 8.0%) and 38.6% among mothers aged 20-39 (5.7% to 7.9%), compared with 17.1% among older mothers (8.2% to 9.6%). By 2003-2007, nearly 1 in 10 births to older women were born between 34 and 36 weeks of gestation.

**Late-Preterm Births by Age of Mother**  
West Virginia 1993-1997, 1998-2002, and 2003-2007



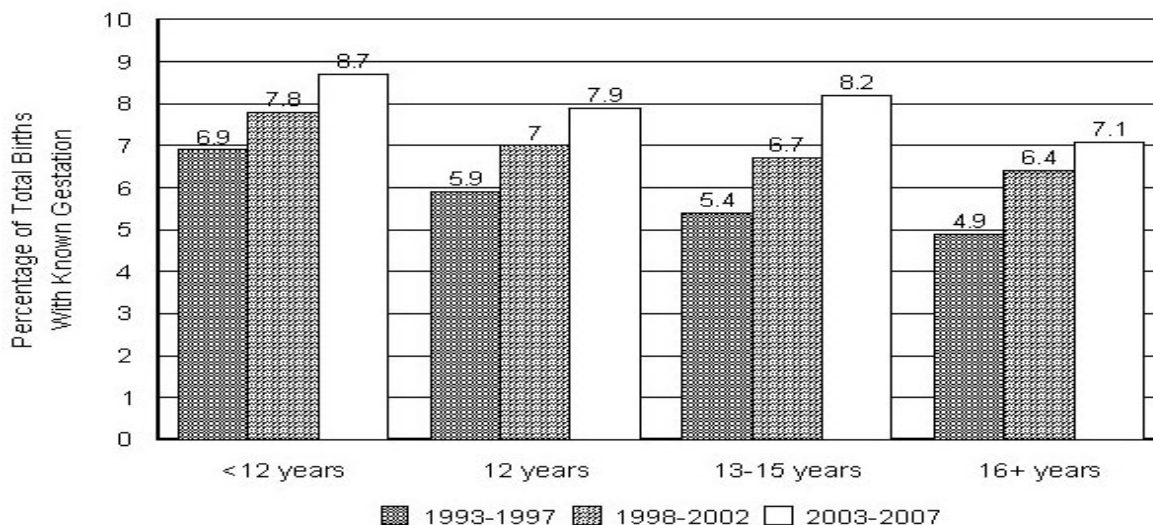
When race was examined, there were different findings for White and African-American mothers. Among White mothers, a consistent increase was noted in late-preterm births over the three time periods; this was not found among African American mothers. A 36.2% increase in the proportion of late-preterm births occurred among White women (5.8% to 7.9%), compared with an increase of 13.9% among African American women (7.2% to 8.2%). The rate among African American women actually decreased slightly between 1998-2002 and 2003-2007.

**Late-Preterm Births by Race of Mother**  
West Virginia 1993-1997, 1998-2002, and 2003-2007



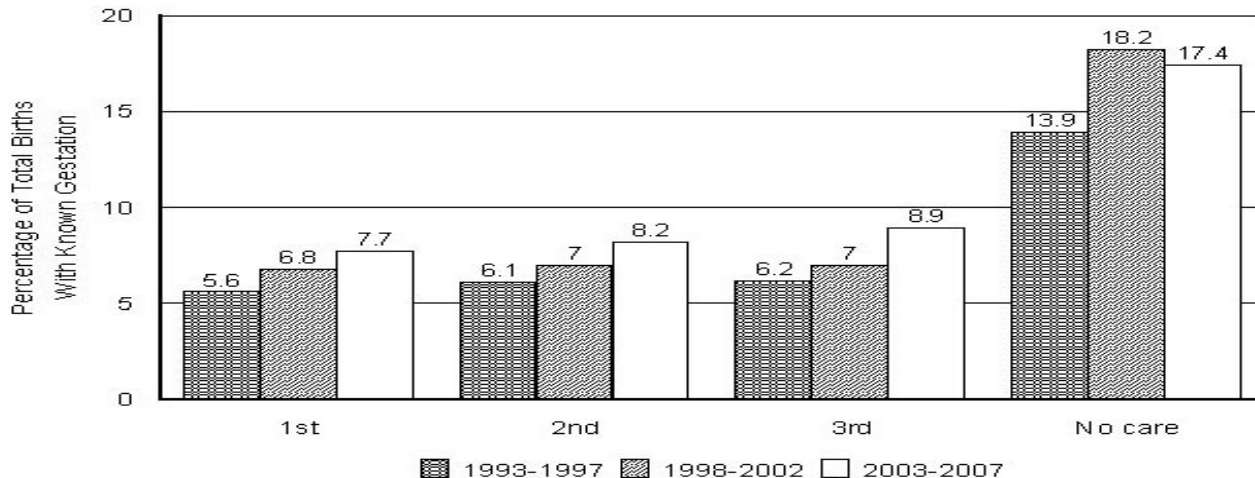
Information on maternal income was unavailable from the birth certificates, but maternal educational level was obtainable. While late-preterm deliveries were consistently most likely to occur among women with the least education (<12 years) and least likely to occur among college-educated women, the rate of late-preterm birth increased over the study period among all levels of educational attainment. Women with more education (i.e., 13-15 and 16+ years) showed the largest increases in proportion of births occurring from 34 through 36 weeks (44.9%: 4.9% to 7.1%).

**Late-Preterm Births by Maternal Education**  
West Virginia 1993-1997, 1998-2002, and 2003-2007

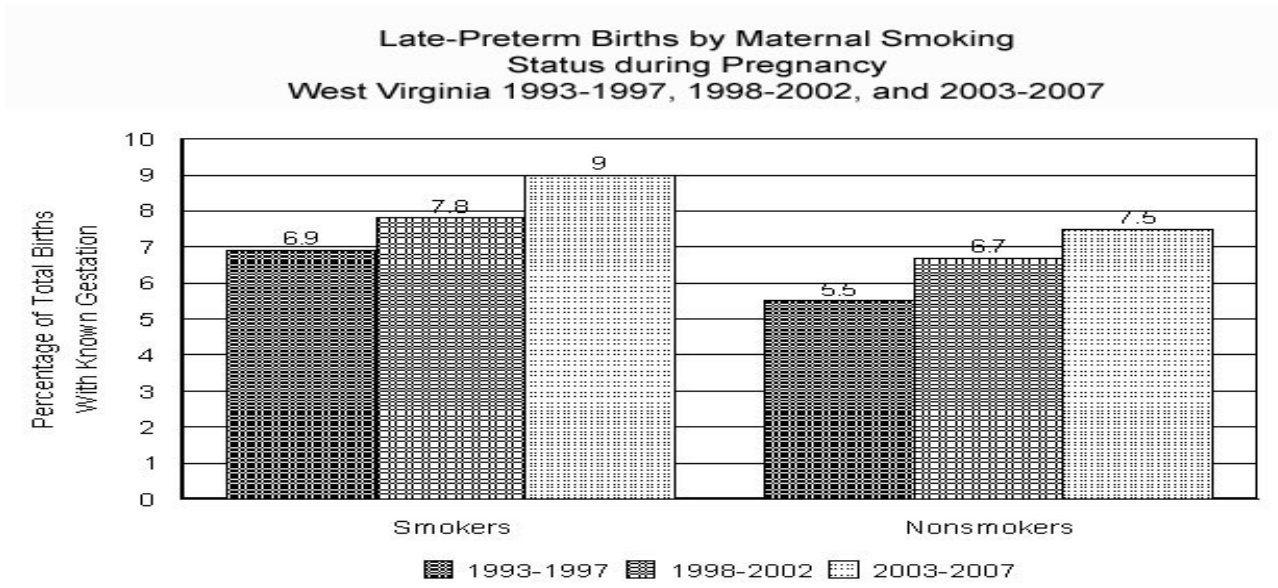


An increased rate of late-preterm birth over the 15 years was found regardless of the trimester in which a woman began prenatal care. Women who received no prenatal care were much more likely to have a late-preterm birth than other women in all three time periods. Little difference in rate was noted, however, between women who began care in the first, second, or even third trimester of their pregnancies, with a similar increase in rate noted for each group.

**Late-Preterm Births by Prenatal Care**  
West Virginia 1993-1997, 1998-2002, and 2003-2007



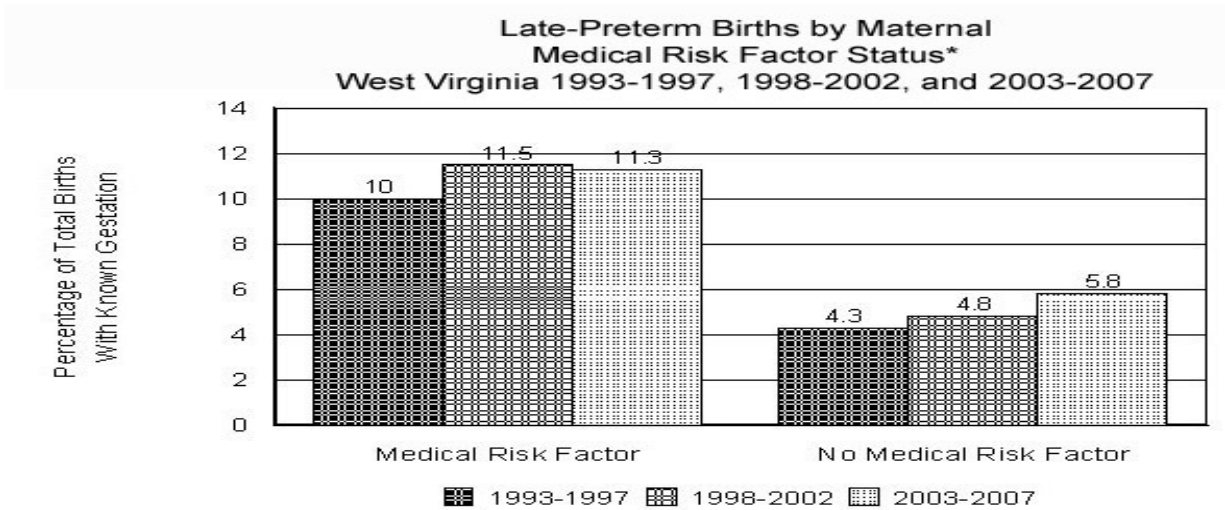
While late-preterm deliveries were more likely among mothers who smoked during pregnancy, the percentage of infants born from 34 through 36 weeks rose among both women who smoked and those who did not. Nearly 1 in 10 (9.0%) women who reported smoking during pregnancy delivered a late-preterm infant in 2003-2007, an increase of 30.4% from 6.9% in 1993-1997. The percentage of late-preterm births increased at an even higher rate (36.4%) among women who did not smoke (5.5% to 7.5%).



### Maternal Medical Risk Factors

Women who had at least one medical risk factor noted on the infant's birth certificate were approximately twice as likely to have a late-preterm delivery as women with no medical risk factors. However, there was an increase in the rate of late-preterm birth among both mothers who had a medical risk factor and those for whom no medical risk factor was noted. The rate among women with no medical risk factors increased 34.9% (4.3% to 5.8%) between 1993-1997 and 2003-2007, compared with a smaller increase of 13.0% (10.0% to 11.3%) among women with at least one medical risk factor.

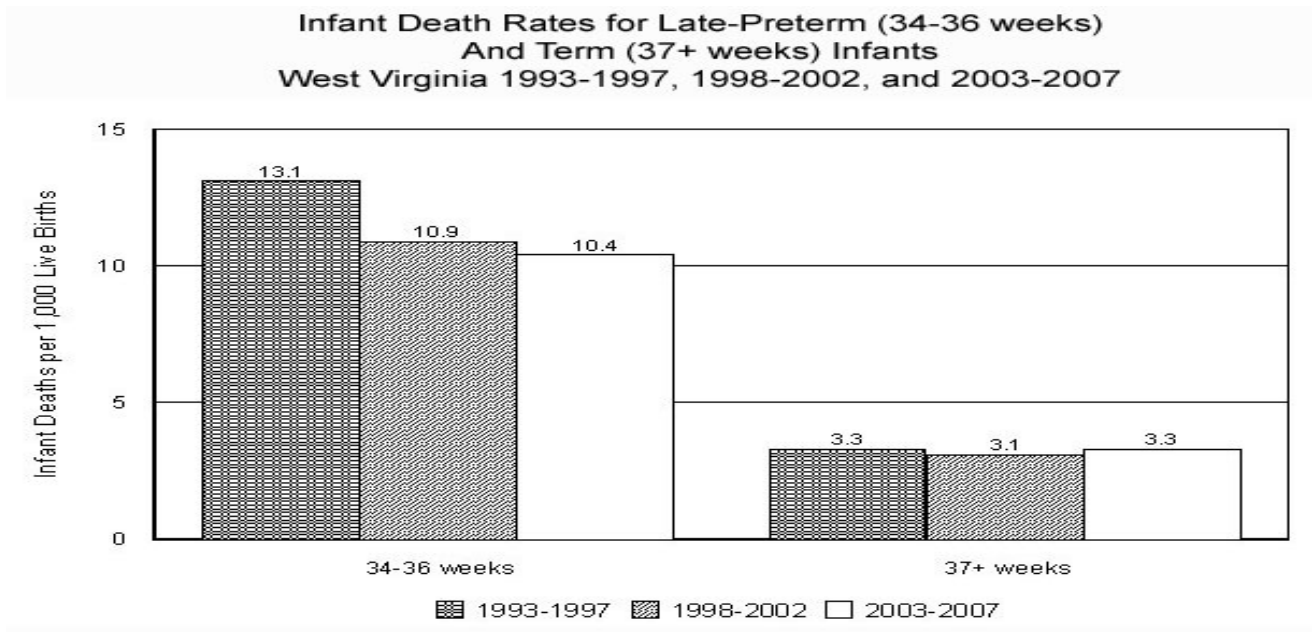




\*As noted on the birth certificate

## Infant Mortality

The infant mortality rate among late-preterm infants was approximately fourfold that of infants born at 37 weeks or more in 1993-1997. The gap in the infant death rate between late-preterm and term infants closed slightly in 1998-2002 and 2003-2007. While the infant mortality rate among term infants showed no change between 1993-1997 and 2003-2007, the rate among late-preterm infants decreased by 20.6%, from 13.1 infant deaths per 1,000 live births in 1993-1997 to 10.4 in 2003-2007.



## Discussion

An examination of West Virginia birth certificate data showed a marked increase since 1993 in the rate of births occurring at 34 through 36 weeks of gestation. The rate of Cesarean delivery among late-preterm births increased at a faster pace than that among other births over the study period. An increase in late-preterm deliveries was found regardless of maternal age, educational attainment, trimester of initiation of prenatal care, or smoking status during pregnancy. The increase in percentage of late-preterm births was greater among White mothers than African American mothers. The rate of increase was greater among women with no maternal medical risk factors than among those with at least one medical risk factor noted on the birth certificate. While the infant mortality rate has declined among late-preterm infants, it still far exceeds that among term infants.

The risks associated with births occurring at 34 through 36 weeks of gestation noted at the beginning of this discussion are concerning. The fact that the rate of these births has increased substantially in West Virginia over the past 15 years causes even greater concern. In addition, a recent study published in the *New England Journal of Medicine* suggests that elective Cesarean deliveries occurring even later, at 37 and 38 weeks of gestation, also face increased health risks for the infant. The study, which analyzed 13,258 elective Cesarean sections performed at 37 and 38 weeks between 1999 and 2002 on women who had no reported maternal medical risk factors, found an increased occurrence of respiratory problems among these infants compared with infants born at 39 weeks, as well as higher risks of infections, five or more days of hospitalization, and a need for cardiac resuscitation. According to the American College of Obstetricians and Gynecologists, "elective c-sections should occur at 39 weeks or later if no medical concerns are present for the woman or infant."

The birth certificate data presented confirm a growing problem of late-preterm births in West Virginia, pointing to a need for a more comprehensive examination of these births. The emerging evidence of problems with infants delivered by elective Cesarean sections at 37 and 38 weeks needs to be examined among West Virginia births as well. Additional sources such as hospital discharge data, data gathered by the Pregnancy Risk Assessment Monitoring System, birth score data, and data from early childhood intervention programs could provide valuable information on the range of problems and costs to the State associated with these births.

A goal of the West Virginia Perinatal Partnership 2010 Work Plan is to: Identify Costly Medical Procedures Associated With Poor Birth Outcomes by: continued work on the *Obstetrical Collaborative Quality Initiative* to reduce the high rates of elective deliveries in West Virginia; work to gain participation of hospitals not yet engaged in this project; and work to reduce elective c-sections.

## **Sudden Infant Death Syndrome/Sudden Unexplained Infant Death (SIDS/SUID)**

Sudden Infant Death Syndrome and Sudden Unexplained Infant Death, SIDS/SUID, is one of the leading causes of post neonatal deaths in West Virginia. Sudden Infant Death Syndrome is a diagnosis of exclusion, meaning that all other possible causes of death must be ruled out before the diagnosis is made. Sudden Unexplained Infant Death is defined as an infant death for which the cause of death is stated to be unknown even after a complete autopsy, thorough case investigation, examination of death scene and review of clinical history. Sudden Unexplained Infant Death comprises a spectrum of possible infant death circumstances, and subsumes many deaths that would have previously been attributed to SIDS. With the institution of more effective death investigation practices, certain deaths that previously would have been classified as SIDS have been reported as accidental suffocation or strangulation in bed (ASSB) or unknown cause of death.

In 2004, the Centers for Disease Control and Prevention (CDC), together with many other agencies and entities with an interest in the reporting of infant death, started an initiative to improve the investigation and reporting of SUIDs. One result of the initiative was a standardized Sudden, Unexplained Infant Death Investigation (SUIDI) Reporting Form, as well as regional training sessions for appropriate personnel in comprehensive death scene investigation.

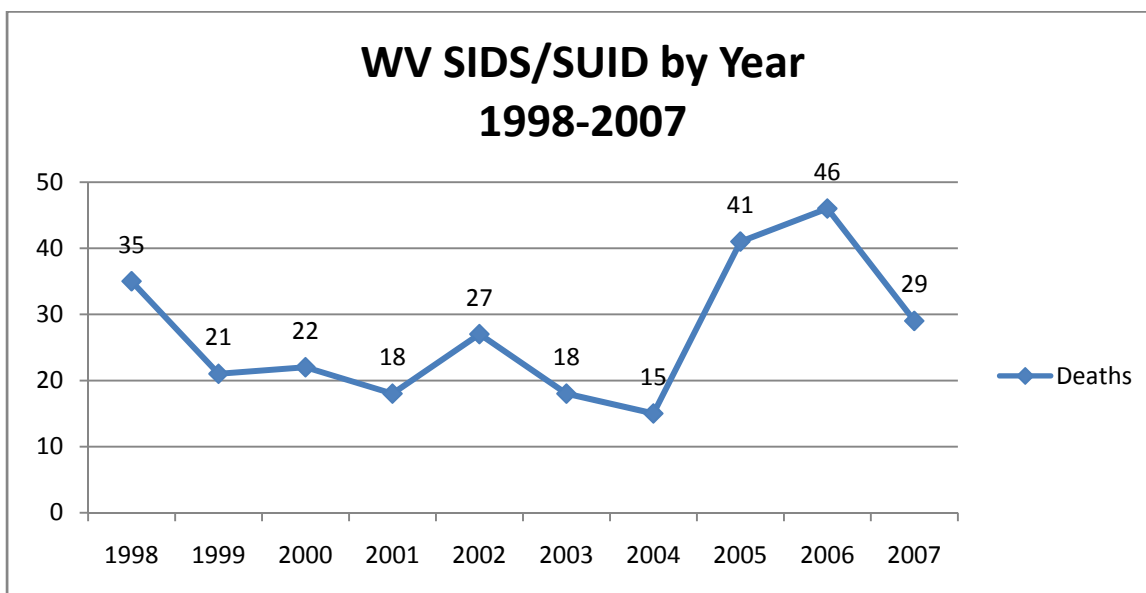
The Child Fatality Review Team (CFRT) was established by the West Virginia Legislature in 1996 to review potentially preventable child deaths. The Team is a multidisciplinary group of professionals whose purpose is to make recommendations on policies and procedures that may reduce child mortality in West Virginia. The CFRT is coordinated by the Office of the Chief Medical Examiner, Bureau for Public Health, Department of Health and Human Resources. The OMCFH Office Director and the SIDS/SUID Coordinator both serve on the CFRT.

The CDC and AAP (American Academy of Pediatrics) have identified several major risk factors that increase the chance of both SIDS and SUID. These risk factors include:

- Sleeping on stomach or side
- Prenatal smoking and exposure to secondhand smoke after birth
- Bed sharing (also called co-sleeping) with others, particularly adults
- Soft sleep surfaces and loose bedding
- Overheating and use of heavy bedding
- Premature birth and low birthweight

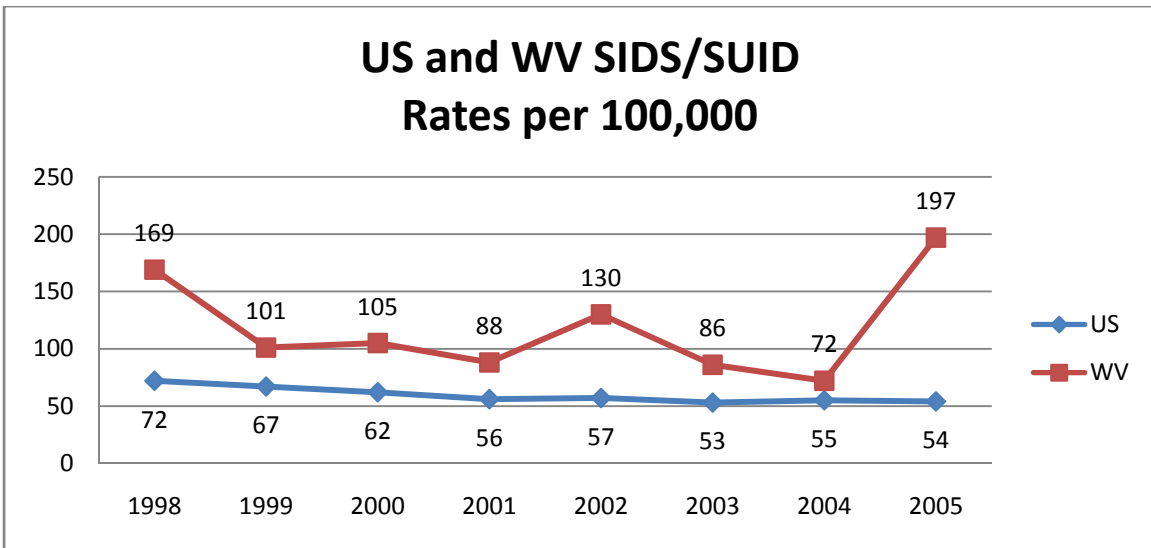
The following charts indicate the demographic prevalence of SIDS/SUID in West Virginia for 1998 to 2007. Data were collected from Vital Statistics and the SIDS/SUID Project.

With the change in definition for the coding in Vital Statistics for sudden infant deaths (R95s) there was an increase in the number of cases beginning in 2005.

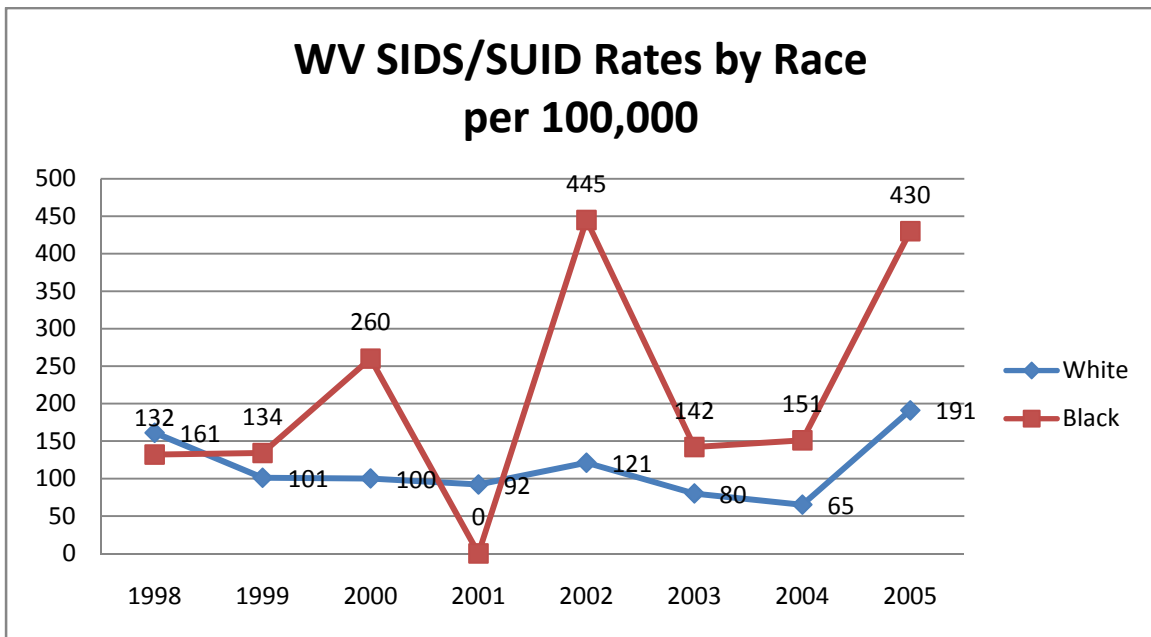


The overall SIDS/SUID rate for all West Virginia counties was 13.0 per 10,000 births between 1998 to 2007 with a rate increase to 18.2 per 10,000 births between 2005 to 2007 when the inclusion of SUID was added to the Vital Statistics coding of R95s (SIDS).

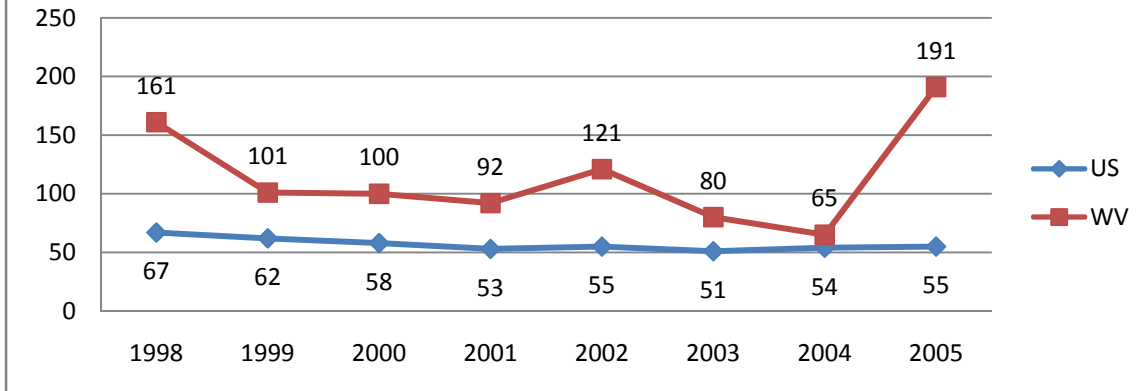
The following charts indicate the comparison of SIDS/SUID rate of West Virginia and the United States 1998-2005. West Virginia is above average overall in the rate of SIDS/SUID, as well as by infant race; both White and Black are much higher in the State compared to the national average.



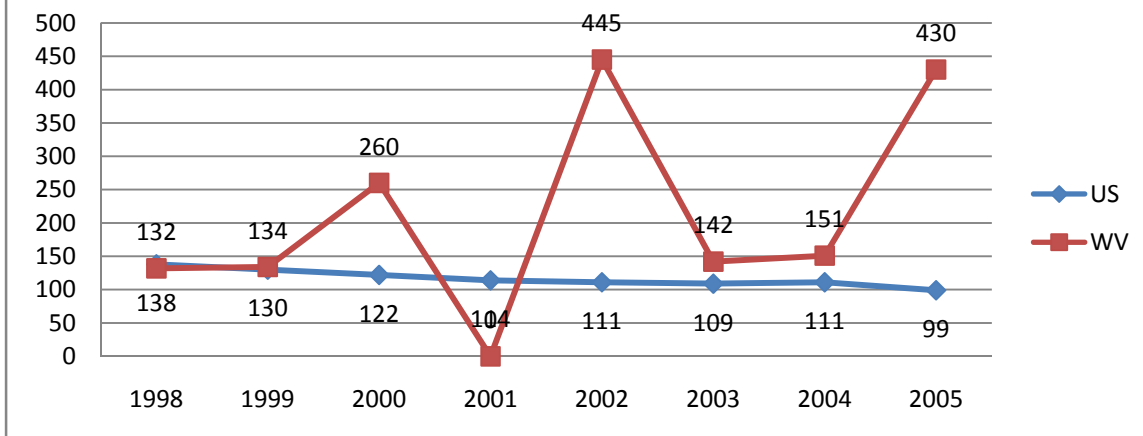
With the small population of minorities in West Virginia, specifically Blacks, it is hard to directly relate SIDS/SUID deaths to a particular race. Although Blacks make up just over 3% of the overall population in the State, 6% of SIDS/SUID deaths are within this population.



### US and WV SIDS/SUID Rates by Race - White per 100,000



### US and WV SIDS/SUID Rates by Race - Black per 100,000



As is expected, the number of SIDS/SUID infant deaths occur before age one, with the majority of deaths (76%) occurring within the first three months after birth. Preterm infants are considered to be at high risk for SIDS/SUID but only make up 19% of WV infant SIDS/SUID deaths and low birthweight infants are also considered to be at higher risk for SIDS/SUID but only make up 18% of infant SIDS/SUID deaths. More than 70% of the deaths of infants to SIDS/SUID were identified as co-sleeping/bedsharing at the time of death.

Sixty-nine percent (69%) of SIDS/SUID deaths were identified as mother entering prenatal care in the first trimester. Smoking, both by the mother and others in the

household, including before and after delivery can have negative effects on infants. Nearly 62% of the SIDS/SUID deaths identified smoking as a risk factor at time of infant death. The national “Back to Sleep” campaign reduced the rate of SIDS significantly, however nearly 31% of WV SIDS/SUID deaths were identified as sleeping on their stomach at time of death with 41% identified as sleeping on their back at time of death. Any type of improper sleep surface, including the use of pillows, blankets, comforters, soft mattress and toys in the infant sleeping area is considered high-risk bedding. High-risk bedding was reported in 54% of the infant SIDS/SUID deaths.

#### Strengths:

In order to address the SIDS/SUID infant death rate in WV, several measures have been put in place to help reduce the number of SIDS/SUID in the State by educating parents and caregivers on the modifiable risk factors associated with SIDS/SUID. Each month the Office of Maternal, Child and Family Health mails postcards to new parents with bulleted information regarding safe sleep for infants. The State Perinatal Program, Right From The Start, discusses during home visitations education on SIDS/SUID, crib safety, co-sleeping/bed-sharing and avoidance of soft bedding. Our Babies: Safe and Sound is an educational campaign that provides parents and other caregivers of infants under the age of one, as well as expectant parents and professionals, with information and tips on ways to keep babies safe while sleeping and also addresses information/skills needed on how to respond to crying babies in order to reduce risk of abuse.

#### **Teen Birth Rate:**

For more than a decade the births to West Virginia teens had consistently declined, and between 1991 and 2004 teen births had dropped by 24%. Then, in 2006, the rate of teen childbearing in the State increased, with alarming social and economic costs. In 2003, West Virginia’s teen birth rate was higher than the National average but it was the birth rate to older teens ages 18 – 19 that accounted for the rate increase. West Virginia was below the National average in births to younger teens ages 15 – 17.

According to the National Campaign to Prevent Teen and Unplanned Pregnancy, young mothers and their children are more vulnerable to adverse social, economic, and health conditions. Teen mothers are less likely to graduate from high school and more likely to live in poverty, and their children are more likely to suffer from low birthweight, low literacy, neglect, greater health problems, a 33% higher risk of becoming a teen parent themselves, and 13% higher risk of becoming incarcerated. The costs of teen childbearing are not only felt by teen mothers and their children, but by society at large. Analysis by the National Campaign to Prevent Teen Pregnancy finds that teen childbearing costs West Virginia taxpayers nearly \$38 million annually, including \$14 million for child welfare and \$4 million for incarceration. Given such evidence,

policymakers, program providers, and the general public share a keen interest in preventing early motherhood. Across the Country, the estimated proportion of females who will become teen mothers decreased from 25 percent in 1991 to 18 percent in 2006.

West Virginia and United States Percentage of Teenage Births		
Year		Percentage
2005	West Virginia	11.9%
	United States	10.2 %
2006	West Virginia	12.4%
	United States	10.4%
2007	West Virginia	12.4%
	United States	10.5%

According to the National Vital Statistics Reports 2007, the final data for 2005 indicates that teens in the United States are more at-risk for unintended pregnancy than in any other industrialized country. The most recent data shows that West Virginia’s teen birth rate of 43.4 births per 1,000 women is higher than the National average of 40.5, with 18-19 year olds in West Virginia accounting for the higher rate. The current rate for girls ages 18-19 is 77 in West Virginia, compared to 70 nationally. While the teen birth rate decreased 34% nationally between 1991 and 2005, it decreased only 25% in WV during the same period.

According to the Centers for Disease Control and Prevention, positive indicators regarding high school teens’ sexual behavior and contraceptive use across the Country are reversing. Presently, more than one-third of teens are sexually active, with less than two-thirds of them reporting using a condom the last time they had sex, indicating a 2% increase of sexual activity between 2005 and 2007 and a 2% decrease of condom use during the same time period.

These trends that the Centers for Disease Control and Prevention call “more sex, less contraception” are especially relevant in light of the fact that the teen birth rate has recently increased – the first increase in fifteen years. A survey of West Virginia high school students shows a higher rate of sexual activity than the National average – 53% vs. 47%. Reported condom use for this group matches the National average at 61% using a condom at last intercourse.

### Strengths

West Virginia’s education policies require that public schools teach some form of sex education, as it relates to HIV/AIDS prevention. Abstinence-based education is primarily stressed and contraception may be covered as part of basic sexual education.



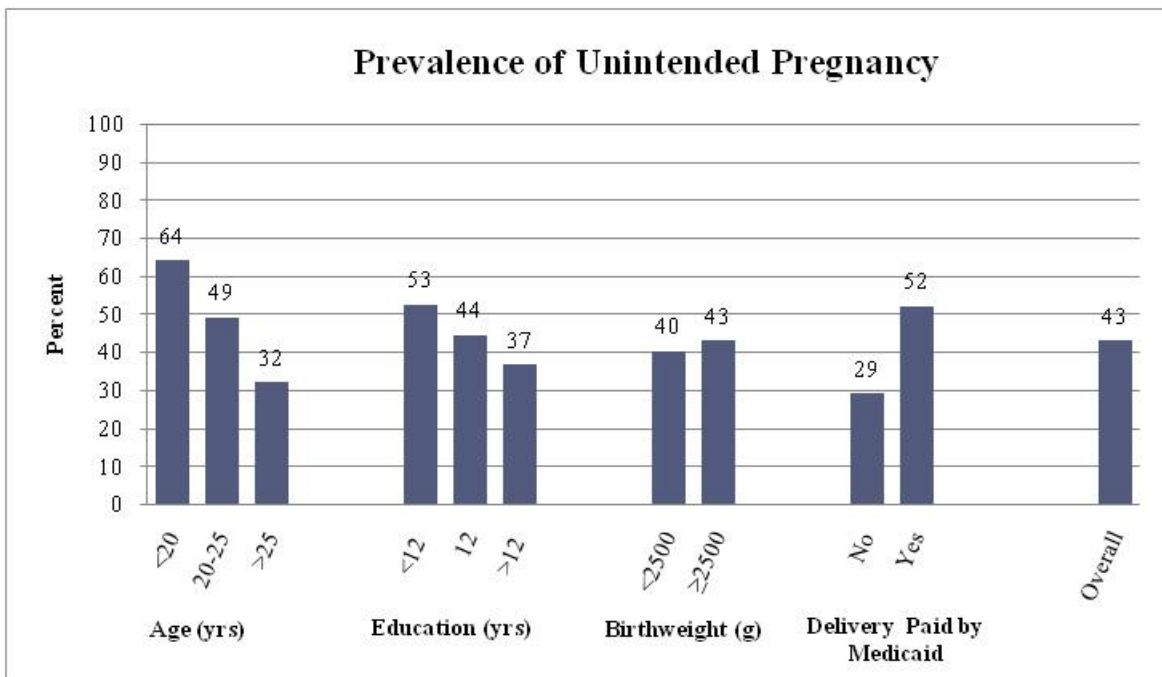
It is important to stress that the West Virginia Board of Education policies indicate a broader approach to sexual education than what actually may be in effect throughout the State.

A State program with a broader approach to sexuality education is the West Virginia Department of Health and Human Resources' Adolescent Pregnancy Prevention Initiative, housed within the Office of Maternal, Child and Family Health. This program includes abstinence and family planning education and is driven by a group of youth advocates including religious leaders, social workers, teachers and school nurses. Another program, the Adolescent Pregnancy Prevention Task Force, is a voluntary network of individual and group programs that addresses adolescent pregnancy prevention, sexuality and reproduction, decision-making and risk reduction.

The West Virginia Department of Health Human Resources Family Planning Program, housed within the Office of Maternal, Child and Family Health, despite limited funding, has been ranked sixth nationally in service availability. Services are available confidentially at low or no cost at 145 clinics through the State. Any female or male capable of becoming or causing pregnancy whose income is at or below 250% federal poverty level is eligible to receive services. No one is denied services because of inability to pay. Family planning clinics help women plan and space their pregnancies and avoid mistimed, unwanted or unintended pregnancies, reduce the number of abortions, lower rates of sexually transmitted diseases, and significantly improve the health of women, children and families.

#### Unintended Pregnancies

The Healthy People 2010 goal is to increase the rate of intended pregnancies to 70%. West Virginia's overall rate of intended pregnancy was 57%, or 43% for unintended pregnancy (*unintended rate is reported for easier comparison with other PRAMS data, see chart below*). The prevalence of unintended pregnancies was highest among those mothers who were less than 20 years old, had less than a high school education, and were on Medicaid at the time of delivery.



According to an article written by L.B. Finer and S.K. Henshaw, *Perspectives on Sexual and Reproductive Health, 2006*, nearly half of pregnancies among American women are unintended, and four in 10 of these are terminated by abortion. The West Virginia Health Statistics Center collects information on all abortions performed in the State. However, this data is problematic because it does not account for women traveling out of state to procure services. The Health Statistics Center reports that after years of a decline in the abortion rate, there was an increase in 2006.

There is a shortage of abortion providers in West Virginia. In 2005, there were 4 abortion providers in the State. This represents a 33% increase from 2000, when there were 3 abortion providers. In 2005, 96% of West Virginia counties had no abortion provider, where 84% of West Virginia women live. The only two clinics that currently provide elective abortion care are located in Charleston.

West Virginia law mandates that a minor must inform a parent or guardian twenty-four hours before having an abortion. This can be a barrier for teens who need confidential services, as some young women cannot involve their parents due to physical or emotional abuse at home or because their pregnancy is a result of incest.

#### Strengths:

Obviously, improving intendedness of pregnancy along with a woman's pre-pregnancy health is critical to improving pregnancy outcomes and infant wellbeing. West Virginia uses every opportunity to address risk behavior(s) reduction in discussion with teens

using the Adolescent Pregnancy Prevention team and with any and all persons participating in family planning services.

WV Medicaid will pay for pregnancy termination upon certification by the physician that a) a general medical necessity exists for the pregnant women related to the following conditions: physical, emotional, psychological, familial, or age, or because of a combination of the above relative to the well being of the patient; or b) a specific medical necessity condition exists such as rape, incest or endangerment of the woman's life if the fetus is carried to full term.

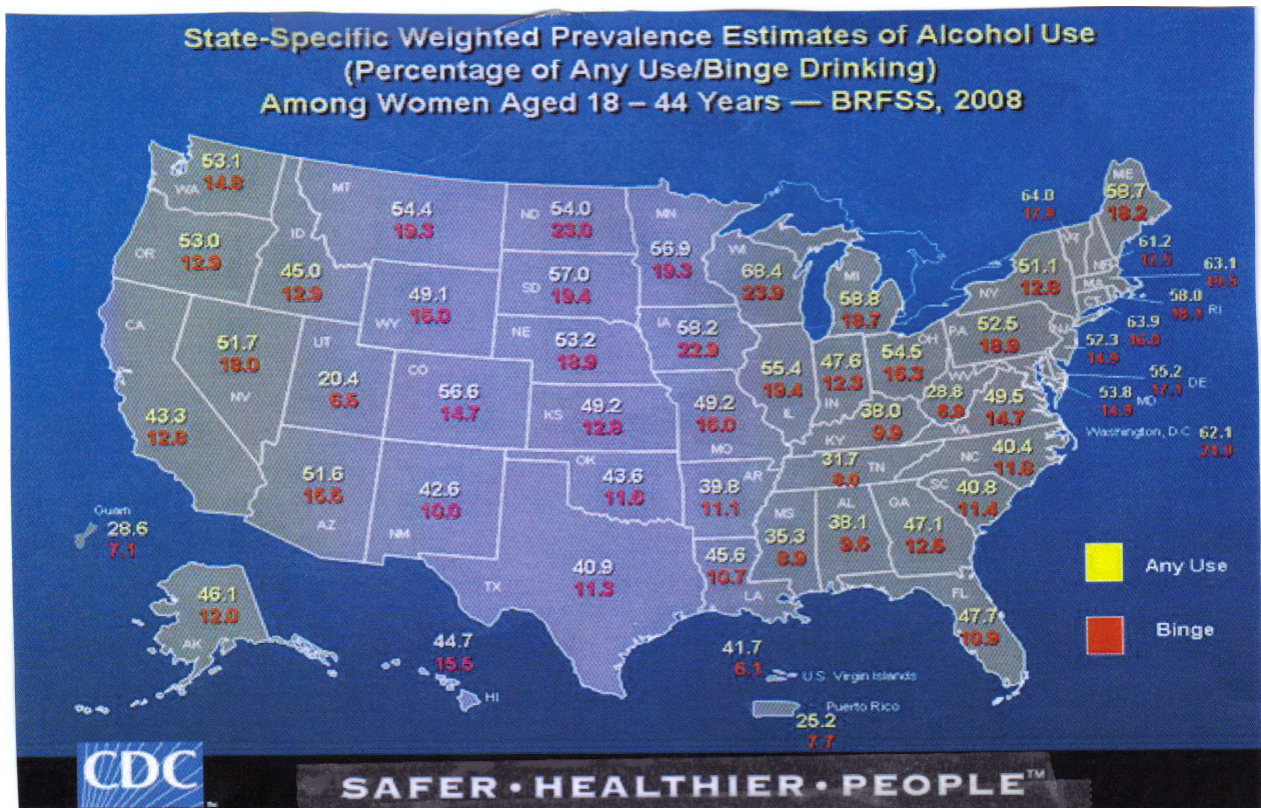
### **Alcohol Use During Pregnancy**

Fetal Alcohol Spectrum Disorders (FASDs) are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. These effects can include physical problems and problems with behavior and learning. Often, a person with FASD has a mix of these problems.

To prevent FASDs, a woman should not drink alcohol while she is pregnant, or even when she might get pregnant. This is because a woman can get pregnant and not know for weeks or more. In the United States half of all pregnancies are unplanned and in West Virginia 43% of women responding to the PRAMS survey in 2006 indicated their pregnancy was unintended.

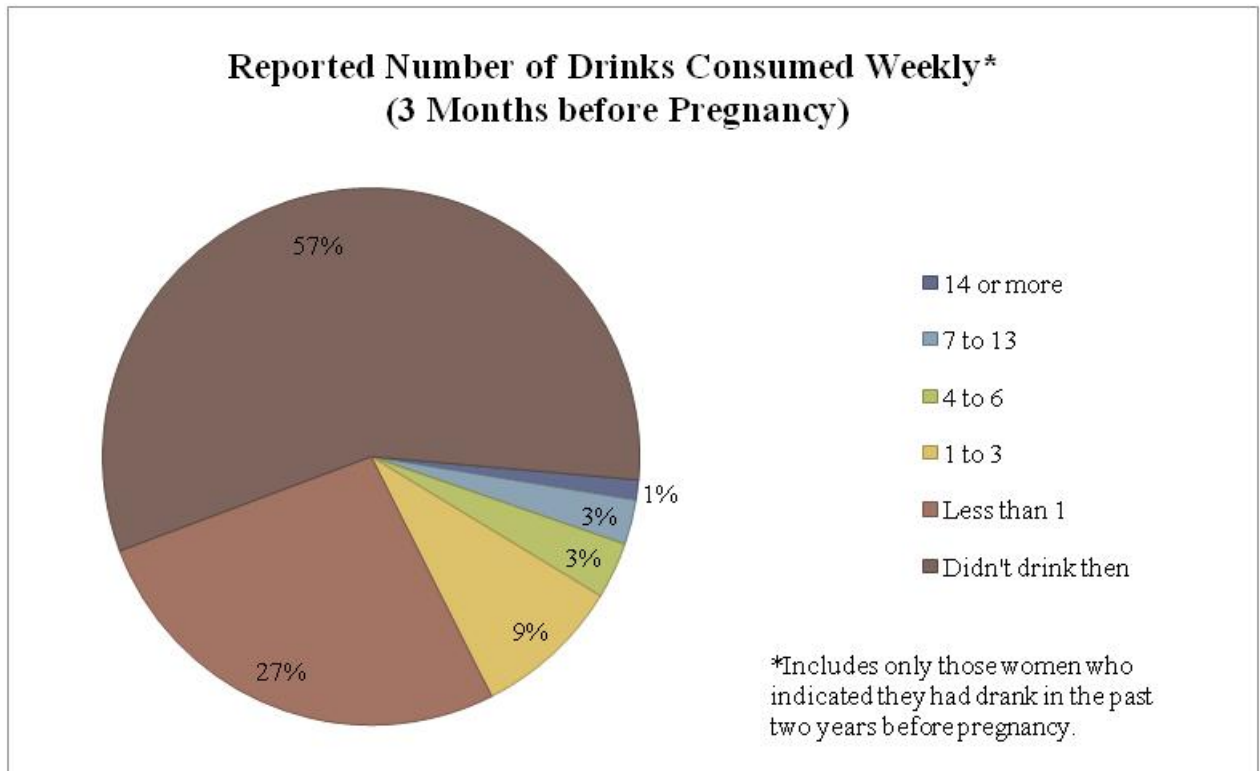
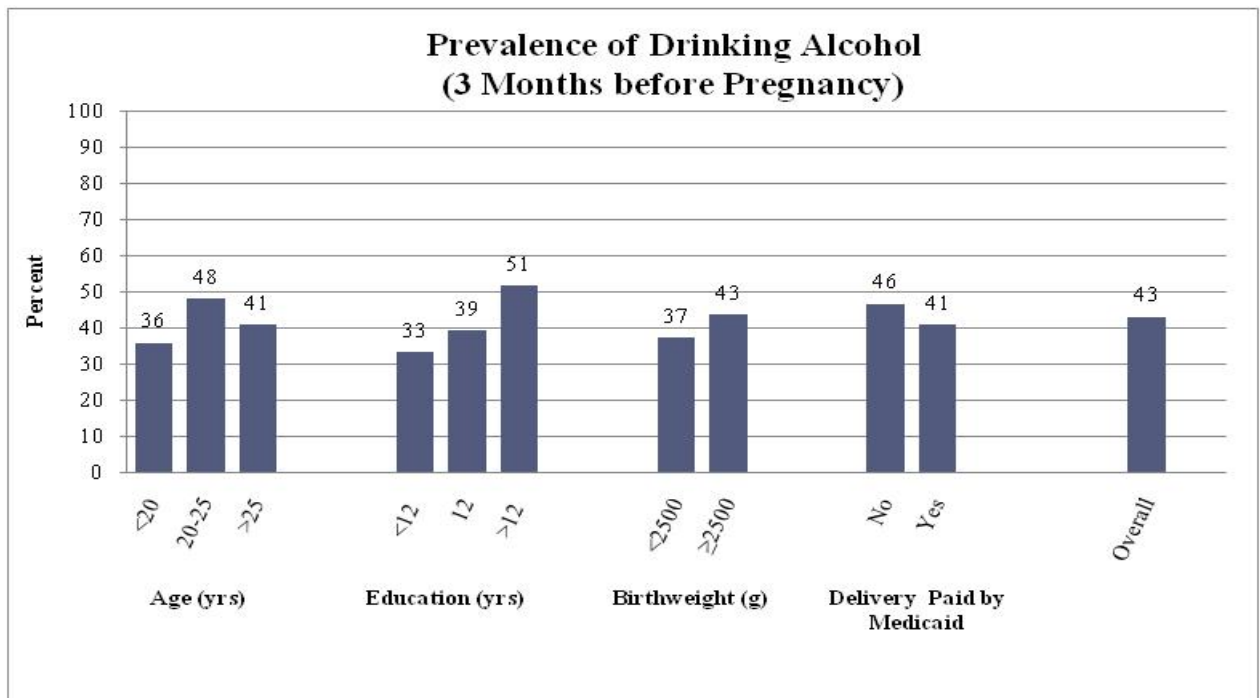
PRAMS asked mothers how they felt about becoming pregnant with their most recent baby. Those mothers who reported they wanted to be pregnant "later" or "didn't want to be pregnant at any time in the future" were grouped as having an unintended pregnancy. Only those mothers who had live births were included in the survey.

CDC monitors alcohol use among women of childbearing age in the United States. These data are important to help reduce alcohol exposed pregnancies by indentifying groups of women at increased risk and discussing prevention programs. The data are collected using this Behavioral Risk Factor Surveillance System (BRFSS). The BRFSS is an on-going, State-based, random digit dialed telephone survey. To determine the potential number of women at risk for alcohol exposed pregnancy, data from the BRFSS are analyzed for women age 18-44 years in all fifty states. Women are asked about their use of alcohol during the thirty (30) days before the survey. Please note BFRSS excludes households without landline telephones, so the results might not be representative of certain segments of the United States population.



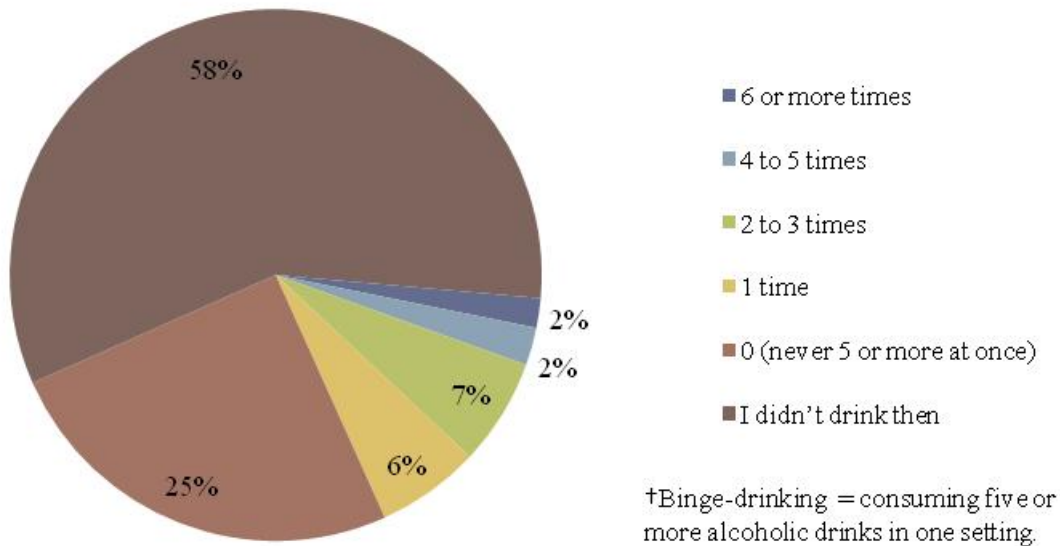
West Virginia PRAMS also asks participants if they had consumed any alcoholic beverages over the past two years. Those mothers who reported they had drunk in that time period are asked additional questions concerning their drinking habits before and during their pregnancy. PRAMS also asked these women how many drinks they consumed per sitting in order to establish binge-drinking habits (consuming five or more drinks in one sitting) during pregnancy.

The Healthy People 2010 goal is to increase the prevalence of alcohol abstinence during pregnancy to 94% and eliminate the prevalence of binge-drinking during pregnancy. Among West Virginia women, 43% responded that they had consumed some quantity of alcohol three months before their pregnancy. However, this rate had reduced to 5% during the last three months of pregnancy. Likewise, the prevalence of binge-drinking reduced during pregnancy. The survey indicated that 17% of women participated in binge-drinking 3 months before pregnancy, but only 1% of those women reported they engaged in binge-drinking during the last three months of pregnancy. West Virginia PRAMS survey responses are depicted in the next five graphs.

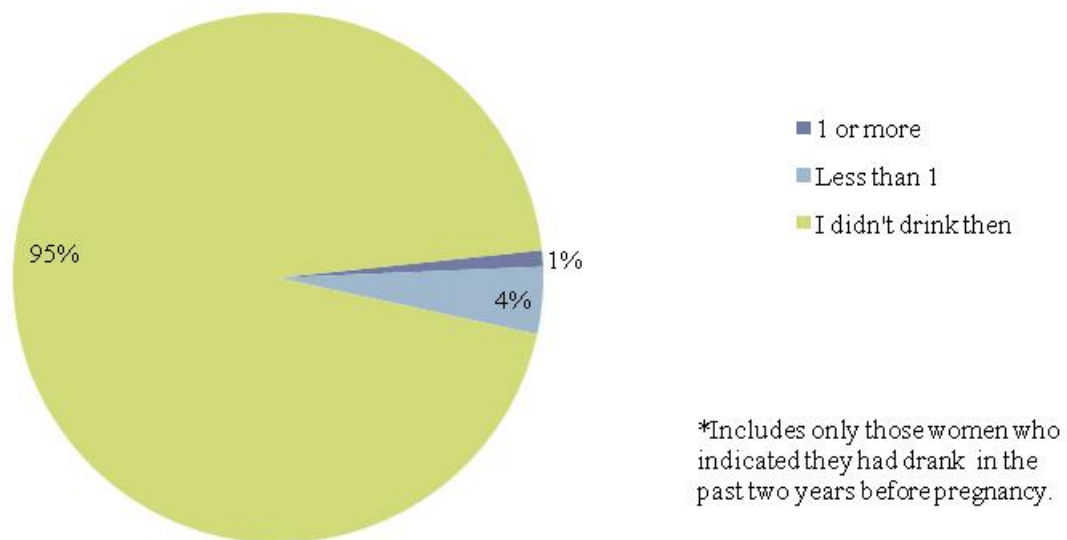




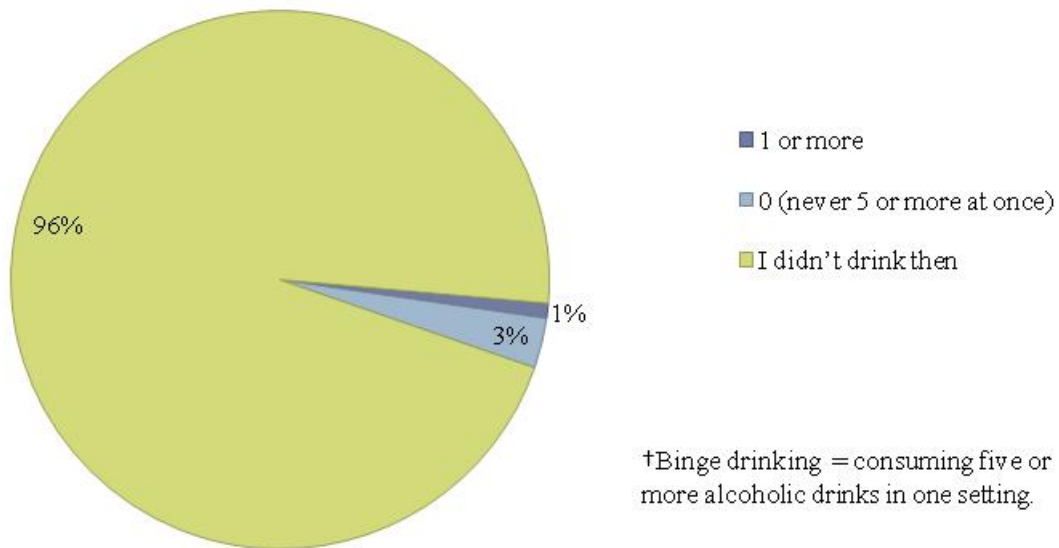
### Prevalence of Binge-Drinking† (3 Months before Pregnancy)



### Reported Number of Drinks Consumed Weekly\* (Last 3 Months of Pregnancy)



### Prevalence of Binge-Drinking† (Last 3 Months of Pregnancy)



#### Strengths:

The Office of Maternal, Child and Family Health and its many partners work to prevent alcohol-exposed pregnancies by educating families, professionals, and the public, and by identifying and providing support for women who report alcohol use during pregnancy. Current risk screening of pregnant women includes questions about alcohol use, but the importance of preconception dialogue is clearly the most critical juncture for these discussions, particularly in government sponsored family planning sites.

Prevention efforts in West Virginia have been successful in raising awareness. The ARC of the Mid-Ohio Valley in West Virginia presents workshops, using modules developed by the ARC of the United States, addressing general information about FAS and related disorders, components of care for children, and advocating for service and support. The Office of Maternal, Child and Family Health workforce serving perinatal populations have all participated in these workshop offerings.

#### Maternal Substance Use and Smoking

Most statistics rank WV lower than the U.S. average on the rates of the use of alcohol and other illicit drugs by pregnant women. Because data must rely on self report and there is not a good system in place to accurately determine the true rate of infants born

with fetal alcohol syndrome, fetal alcohol and other drug affects, it is felt that these rates are highly underestimated. In small, rural WV hospitals, obstetricians and pediatricians have expressed concern about this issue because their facilities are not prepared to treat drug addicted infants. Often there is no disclosure of prenatal substance abuse and it is discovered only when the infant has signs and symptoms of withdrawal after birth. This creates a serious dilemma for unprepared birthing facilities and for physicians who provide pediatric care in rural areas of WV.

According to Vital Statistics, WV has the highest smoking rate for pregnant women in the United States. The rate of smoking during pregnancy in WV for 2007 was 26.9% compared to the National rate of 10.7% in 2005 (last available national information). Alarming rates of these pregnant smokers were Medicaid insured (40.6%). Non-Medicaid insured women accounted for 12.4% of WV pregnant smokers.

The RFTS Program obtained 2008 data from the Birth Score Office which showed that many counties in WV have a self-reported rate of 21% to 68% among Medicaid mothers who smoked during pregnancy. Data derived from the RFTS Electronic Data System revealed a self reported smoking rate of 38% during pregnancy among Program participants. This creates an enormous health problem for the State of WV which affects not only the developing infant but the pregnant woman, her children, and other exposed family and friends, as well as the health care community.

Martha Mullett, Medical Director, WV Birth Score Office provided a Power Point presentation which revealed the following data and provided several recommendations. For the time period July 11, 2007-July 11, 2008, 17,349 WV resident newborns were screened for Birth Score. Of that number, 816 (5%) mothers reported they used one or more addictive drugs or alcohol during their current pregnancy. Of the drugs reportedly used by pregnant women, the drug used most often was reported to be marijuana (59%).

The use of alcohol by pregnant women in WV has never been reported in any significant numbers on the birth certificate, although the question has consistently been asked for several decades. The WV Birth Score report shows that of the pregnant women using addictive substances, 22.6% reported using alcohol. This represents just about one (1) percent of total WV resident births within this study.

Methadone was reported most often next at 17.5%, cocaine at 13.5%, methamphetamine at 3.5% and heroin was reportedly used by 2.6% of the women using drugs during pregnancy. Of WV women who reported using addictive drugs or alcohol during pregnancy, 78% also reported using tobacco. Of women reporting using one or more drugs or alcohol during pregnancy, 83% were covered by Medicaid. This represents about 7% of women covered by Medicaid during that same time period.



From the WV Birth Score report, Dr. Mullett noted that of the 816 women reporting use of one or more drugs during pregnancy, 103 infants were transferred to the NICU after birth. The cost estimate for this care is \$4,306,954. Utilizing data included in the Marshall University Center for Business and Economic Research (CBER) report, "Mean Cost and Potential Savings Associated With Infant Transfers to NICU", a twelve (12) month 20% reduction in infant transfers due to drug/alcohol exposure in utero would reduce the transfers by 20.6 infants and the associated cost would decline by \$861,389.

One cost factor reviewed was that associated with care of an infant transferred to a NICU for care. The economic impact analysis for 2008 is made using the Birth Score Data Study report that identifies the number of infants born whose mothers used addictive substances during pregnancy and the CBER cost savings estimates related to NICU care. The NICU care costs estimates are based on ICD-9 designations for certain conditions such as short-gestation and low birth weight. The CBER study found that these conditions resulted in an average sixteen (16) day stay in the NICU at an estimated cost of \$41,815 per stay.

In 2009 a "Cord Blood Drug Study" was sponsored by the WV DHHR, BPH, Office of Maternal, Child and Family Health (OMCFH) using federal Maternal and Child Health Block Grant funds. (This study was previously referenced in the Methodology section).

According to the principal investigators at Marshall University School of Medicine who conducted the study, the prevalence of drug use in pregnancy appears to be increasing based on increasing numbers of infants diagnosed with neonatal abstinence syndrome (NAS), the number of cases at Cabell-Huntington Hospital tripling from 2003 (25) to 2007 (70).

As the average cost of infants diagnosed with NAS is \$36,000 as opposed to \$2,000, this represents a fiscal as well as medical and social nightmare. This study supports the fact that WV has a serious problem among women who are abusing an alarming amount of drugs and/or alcohol during pregnancy.

#### Strengths:

The WV Perinatal Partnership recommended continued study of the problem of substance abuse during early pregnancy and referral for treatment. They also recommended statewide obstetrical provider training, and the development of guidelines needed to assure pregnant addicted women receive adequate and timely prenatal care and addiction treatment beginning early in pregnancy.

The Committee recommended legislation prohibiting retribution of any kind for pregnant addicted women and prohibiting criminal prosecution based solely on medical records. The Committee recommended that WV mandate drug screening in pregnancy, that women have protection from termination of State benefits (Medicaid, CHIP, etc.), and

that providers be granted immunity from prosecution if a woman refuses treatment after a positive screening.

Related to the care of newborns, the WV Perinatal Partnership recommended the State establish recommended guidelines for screening and testing of delivering women for addictive substances, design hospital guidelines and tools needed to identify addicted neonates and establish recommended treatment guidelines for infants in addiction withdrawal. The Partnership recommended enumeration of the current situation of services provided for detoxification of newborns, to study and report the economic impact of detoxification of newborns compromised by drug addiction as compared to normal newborn care, and to design and conduct educational opportunities for hospital nurses, physicians, and other personnel regarding the use of recommended guidelines and tools.

In 2007, the WV Birth Score Developmental Risk/Newborn Hearing Screen Instrument was revised and questions were added pertaining to the mother's oral health and substance abuse during pregnancy. The numerical Birth Score was changed so that the newborn is considered High Birth Score if the score is 99 or greater. All WV birthing sites implemented the new Birth Scoring System, effective August 1, 2007. All WV Medicaid eligible High Birth Score infants continue to be referred to the RFTS Program for care coordination from birth through age one year.

Prenatal substance abuse screening is being completed in all eight (8) counties participating in the WV Healthy Start/Helping Appalachian Parents and Infants (HAPI) Project. A total of fifteen (15) physician offices within the HAPI region have been provided training and educational materials for substance abuse screening (with assistance of a March of Dimes Grant funded in CY 2006). Comprehensive substance abuse training was provided for all RFTS designated care coordinators (DCCs), and the community. Attendance included RFTS/HAPI DCCs, mental health/substance abuse providers, DHHR/CPS staff, OB/GYN nurses, NICU nurses, Early Head Start, and HAPI and RFTS administration. The training included how to use the screening and educational tools, and a discussion with two women who were currently in substance abuse treatment who had used substances during their pregnancies. The discussion was intended for participants to hear the types of interventions that may have helped during the prenatal period and to increase the comfort level of providers in asking questions about substance use. This "consumer perspective" has been added to all new DCC in-service trainings to increase staff comfort level with the screening process. The HAPI Project staff has worked closely with the physician providing high risk medical care at WVU to establish consultation services if needed for community physicians if a pregnant woman is identified as using substances during pregnancy. As of December 2007, this physician, Dr. Michael Stitely, assumed the role of Principal Investigator for the HAPI Project.

To address the high rate of smoking in pregnancy in WV, the RFTS Program adopted an intense smoking cessation initiative, Smoking Cessation and Reduction in Pregnancy Treatment (SCRIPT), which was implemented statewide in January 2002, through the OMCFH and incorporated as protocol into the RFTS Program in October 2003. The RFTS SCRIPT initiative uses the existing home visitation network of DCCs and protocols established by the RFTS Program.

SCRIPT methods and protocols, developed by Dr. Richard Windsor, MS, PhD, MPH, Professor, Department of Prevention and Community Health, School of Public Health and Health Services, George Washington University (GWU) Medical Center, Washington, D.C, are nationally recognized and evidenced-based. RFTS SCRIPT uses the 5 A's (Ask, Assess, Advise, Assist, Arrange) best practice method for smoking cessation education with pregnant women which is supported by the *Treating Tobacco Use and Dependence: Clinical Practice Guideline, Agency for Healthcare Research and Quality* and by the *American College of Obstetricians and Gynecologists Bulletins, 2000, 2005*.

Collaborative efforts continue with Dr. Richard Windsor and WV agencies that have interest in smoking cessation among pregnant women. Dr. Windsor received notification in October 2007 of a grant award from the National Institutes for Health, National Cancer Institute for 2007-2011. The GWU Institutional Review Board approved the project and is using RFTS as a model of a system of care for evidenced based interventions for pregnant Medicaid smokers. One of the primary objectives of the grant is to institutionalize the intervention with staff during/after the grant and evaluation is completed.

The WV RFTS SCRIPT has used grant funding provided to the OMCFH from tobacco settlement dollars to purchase carbon monoxide (CO) Smokerlyzers for providers to use in participants' homes. Standard RFTS protocol requires all DCCs to analyze the smoking status of every pregnant participant and offer best practice methods for cessation and/or reduction. The CO Smokerlyzers have provided a valuable tool that allows women to visualize the results of their cessation/reduction efforts immediately.

### **Mental Health Issues**

RFTS Program participants are routinely screened for depression using the Edinburgh Postnatal Depression Screen (EPDS). There were 1,894 women screened in the prenatal period and 994 women screened in the postpartum period. A significant percentage of prenatal clients had positive EPDS levels and the data are as follows:

In 2008 4,394 RFTS Project participants were screened for depression using the EPDS. There were 2,731 women screened in the prenatal period and 1,663 women screened in the postpartum period. A significant percentage of prenatal clients had positive EPDS levels and the data are as follows:

To date, a total of 2,002 women participating in the WV Healthy Start/Helping Appalachian Parents and Infants (HAPI) Project received case management services during the postpartum-interconceptional period. From 7/1/01 to 10/31/08, a total of 2,432 postpartum risk assessments were completed, 13,407 postpartum home visits were made, 5,088 referrals to other services were made, and 5,444 units of additional postpartum case management were provided (in addition to the home visiting case management, and case management provided through the infant services during the first year postpartum). For CY 2008 (to 10/31/08), there were 525 risk assessments, 1,145 home visits, 1,517 referrals to other services, and 608 additional units of case management provided.

From 6/01/07 to 1/18/08, 98.5% of WV Healthy Start/HAPI prenatal women were screened for depression (395 out of 401), 76 were at risk (19.2%), 34 women were referred (45%) and 15 women completed a referral (44%). There were 450 out of 455 (99%) postpartum/interconceptual women screened for depression, with 101 (22%) at risk, 84 (83%) referred, and 45 (54%) completed referrals. Since inception, the HAPI Project has screened 2,681 postpartum women (95%), 2,632 prenatal women (97.7%), and 32 preconception women (76%).

<b>Right From The Start Prenatal and Postpartum Scores 2007-2008</b>		
<b>Total Number of Women Screened</b>	<b>2007 (N=2888)</b>	<b>2008 (N=4,394)</b>
<b>Prenatal Scores</b>	(N=1,894)	(N=2731)
0-7	59%	61%
8-11	21%	19%
≥12	20%	30%
<b>Postpartum Scores</b>	(N=994)	(N=1,663)
0-7	67%	72%
8-11	17%	15%
≥12	16%	13%

## Strengths:

The WV RFTS Project continues to partner with the WV Healthy Start/HAPI Project which further addresses mental health issues including postpartum depression. The HAPI Project, which now delivers services to eight (8) WV counties, uses the existing network of RFTS DCCs to assess needs and deliver services to at-risk women and infants following discharge from the RFTS Program at sixty days (60) postpartum. Included in the services provided through the HAPI Project are assessment, referral, and funding for the treatment of postpartum depression.

All prenatal and postpartum WV Healthy Start/HAPI participants are provided health education in relation to the signs and symptoms of perinatal depression and available treatment options through written materials, one-on-one health education/discussion, and screenings.

## Maternal Mortality

Maternal mortality is a key indicator of health worldwide and reflects the ability of women to secure not only maternal health care services but also other health care services. The maternal mortality ratio (MMR) in the United States is 13.1 deaths per 100,000 live births, with Black women facing a much higher risk than White women of dying from pregnancy-related conditions. According to World Health Organization estimates, over 20 countries have lower maternal mortality levels than the U.S.

According to the National Women's Law Center, National Report Card on Women's Health benchmark is the Healthy People 2010 goal of reducing the maternal mortality rate to no more than 3.3 per 100,000 live births [*Healthy People 2010* Objective 16-4].

Maternal mortality data from the Centers for Disease Control and Prevention's *National Center for Health Statistics*, was aggregated from 1999 through 2004 to control for the unreliability of the small values. For 22 states, the number of maternal deaths over the period from 1999 through 2004 was less than 20. The maternal mortality ratio is not based on the total population, but rather on deaths per 100,000 live-born infants. For those years, WV ranked 34<sup>th</sup> in the U.S. with 11.4 deaths per 100,000 live births.<sup>1</sup>

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<sup>1</sup> *National Center for Health Statistics*, "Compressed Mortality File 1999-2004," CDC WONDER On-line Database, compiled from Compressed Mortality File 1999-2004 Series 20 No. 2J, 2007, available at <http://wonder.cdc.gov/cmfi-icd10.html>, analyzed by Quality Resource Systems, Inc. Data for live births from 1999 through 2002 also come from the CDC Wonder on-line site. *National Center for Health Statistics*, Division of Vital Statistics, "Natality public-use data 1995-2002," on CDC WONDER On-line Database, November 2005, available at <http://wonder.cdc.gov/natality.html>, analyzed by Quality Resource Systems, Inc. The 2003 live birth data come from Joyce A. Martin and others. "Births: Final data for 2003," *National Vital Statistics Reports 54* (2005). The 2004 live birth data come from Joyce A. Martin and others, "Births: Final data for 2004," *National Vital Statistics Reports 55* (2006)

Nationally the U.S. Maternal Mortality Rate increased to 13.1 in 2006 from 8.2 in 2002. In California, the MMR more than doubled in that time period, up to 16.9 in 2006. With the overall cesarean rate reaching over 30% nationally, there is concern that increases in maternal mortality and morbidity will occur.

Women who receive no prenatal care are up to four (4) times less likely to die from complications from pregnancy than women who received no prenatal care. Many women experience some degree of emotional liability in the postpartum period, which warrants a follow-up visit; they also need personalized care during this time to hasten the development of a healthy mother-infant relationship and a sense of maternal confidence.

The death of women from pregnancy-related causes remains a threat to national maternal and child health. Maternal deaths as persistent, albeit rare occurrences are overlooked if vital registration systems are relied on to report such deaths. In a study of WV data for 1985-1989, live birth records were matched with death records for women of reproductive age to detect if a woman died within one (1) year of delivery. The data for potential cases were reviewed by committee and classified as maternal and non-maternal deaths. Of all linked birth-death records, 32% were related to pregnancy: Eighty-one percent (81%) were directly related to pregnancy and nineteen percent (19%) were indirectly related to pregnancy. The most frequent causes of death were hemorrhage and embolism. Thirty-eight percent (38%) of the women were transferred to tertiary hospitals before death. The case ascertainment through this study improved maternal death detection by 100% over official vital statistics. Therefore, it was concluded that enhanced maternal mortality surveillance increased the detection of maternal death in WV. Case review of these deaths yielded important information useful in shaping the state's perinatal system.<sup>2</sup>

#### Strengths:

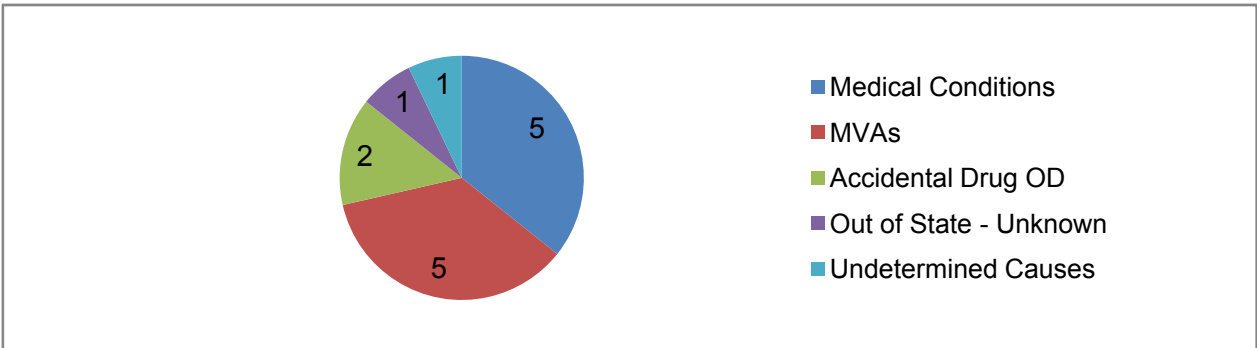
The WV Legislature determined a need to study the State's causes of maternal deaths believing that maternal mortalities are more extensive than first appear on death certificates. The WV Legislature found that more extensive studies would enable a more fully developed plan. In 2009, the WV Legislature signed into law the establishment of a Maternal Mortality Review Team whose responsibility is to review maternal mortalities including all deaths of women who die during pregnancy, at the time of birth or within one year of the birth of a child; establish the trends, patterns and risk factors; provide statistical analysis regarding the causes of maternal fatalities in WV; and promote public awareness of the incidence and causes of maternal fatalities,

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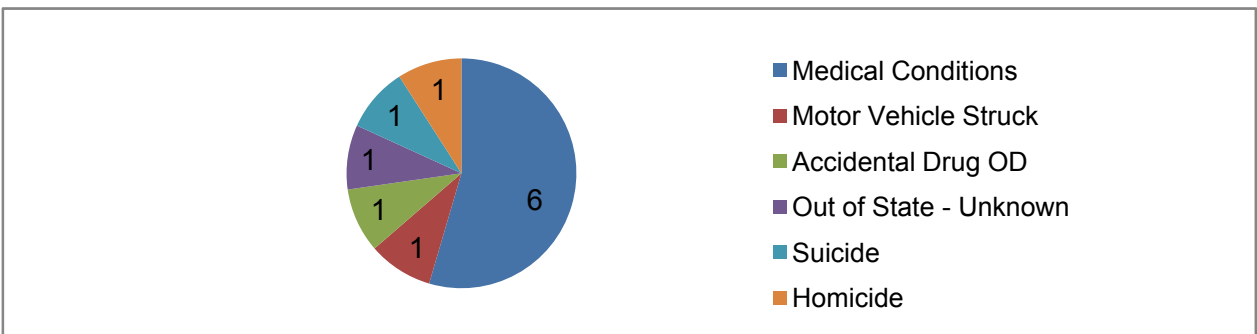
<sup>2</sup> [Am J Public Health](http://www.ncbi.nlm.nih.gov/pubmed/1442960). 2005 Mar;95(3):478-82. PMID: 1442960 [PubMed - indexed for MEDLINE] <http://www.ncbi.nlm.nih.gov/pubmed/1442960>

including recommendations for their reduction and how to avoid these deaths in the future. The review of the 2007 and 2008 maternal deaths have been completed.

2007 WV Maternal Deaths  
14 mothers died in 2007



2008 WV Maternal Deaths  
11 mothers died in 2008



In 2009, the WV Uniform Maternal Screening Act (Senate Bill 307, signed into law 5/29/09), provided a more comprehensive and uniform approach to maternal risk screening by requiring development and use of a standardized tool to alert OB providers of the need for further evaluation and assessment of high-risk pregnant women. The Bill established an Advisory Committee on maternal risk screening within the WV Office of Maternal, Child and Family Health (OMCFH). Selection and appointment of the initial Maternal Risk Screening Advisory Committee was completed in late 2009 and two Advisory meetings have taken place developing the tool. Implementation is scheduled for January 1, 2011.

## **Access to Health Care**

Medicaid is a major source of financing health care services provided to pregnant women, infants and children. Due to economic circumstances in WV, the percentage of Medicaid eligible families has continued to increase. On average from 2001-2007, 55.1% of WV births were funded by Medicaid (WV Vital Statistics).

Providers have expressed the need to address ways to prevent the erosion of Medicaid in WV. West Virginia experienced crises in the number of available providers in the 1980's, 1990s, and is now seeing another crisis due to low physician reimbursement from WV Medicaid. Since the Right From The Start (RFTS) Program is a partnership between the WV Office of Maternal, Child and Family Health (OMCFH) and Medicaid to provide access to early and adequate prenatal care to low income pregnant women and infants, the low Medicaid reimbursement rates have adversely affected the ability of RFTS providers to deliver services. Several RFTS providers have discontinued their agreements to continue service provision because of inadequate reimbursement and others are considering discontinuation. The RFTS administration staff and RFTS providers have requested that the WV Bureau for Medical Services conduct a review of the reimbursement rates. The outcome of the request remains pending.

Because of the rural nature of the State, many families do not have access to public transportation and must rely on friends, neighbors and/or family members to transport them to appointments. Many families depend on the Bureau for Medical Service's Non-Emergency Medical Transportation reimbursement to purchase gasoline, bus fare, or taxi fare to their next medical appointment. It is often difficult for clients to pay for the transportation initially and then complete the forms for reimbursement.

Data collected from the RFTS Prenatal Risk Screening Instrument (PRSI) from 2006 to 2008 continues to report that access to health care for pregnant women is one of the top 5 risk factors. The RFTS Program has as one of its primary objectives to ensure access to early and adequate prenatal care. Although the rate of access to first trimester care for pregnant women in WV is now about 82%, the rate has declined since 2003 when it was 86%.

The rural nature of WV and the vast mileage between many RFTS clients' homes make it very difficult for DCC providers to continue to deliver cost effective services. Agencies have found it very expensive to continue to provide staff for home visits without some type of reimbursement to the agency for mileage expenses.

### **Strengths:**

The RFTS Maternity Care Services Program also provides some coverage for prenatal and delivery care to WV pregnant women who are uninsured or underinsured and are above the income guidelines for Medicaid. These pregnant women may qualify for



some assistance for their prenatal care if they are a WV resident, fall between 150-185% of the federal poverty level, are a pregnant teen age 19 or under or a non-citizen.

Between 2004 and 2008, WV funded a portion of the cost of prenatal care for approximately 500 women annually under the Maternity Services Program within the RFTS Project. Under this Title V funded program, women who have no funding source for prenatal care coverage or have not yet been approved for coverage can receive assistance with payment of their first prenatal visit, an ultrasound and routine laboratory procedures if ordered on the first visit.

	CY 2004	CY 2005	CY 2006	CY 2007	CY 2008
<b>MA</b>	102	106	154	166	178
<b>MM</b>	74	47	70	66	71
<b>MX</b>	311	218	222	217	216
<b>SM</b>	43	12	4	3	6
<b>PM</b>	168	43	0	0	19
<b>DENIALS</b>	Data not available	160	318	320	226
<b>Total Received Services</b>	698	426	450	453	490
<b>Total Applicants</b>	Data not available	586	768	773	716

MA=Non-Citizen, MM=Teen ages 19 and under, MX=Women over age 19, SM=Coverage backdated to date of positive pregnancy test (Medicaid did not cover) PM=Presumptive Eligibility (payment for 1<sup>st</sup> office visit, one ultrasound, prenatal labs associated with 1<sup>st</sup> prenatal visit)

## Oral Health of Pregnant Women

According to the Centers for Disease Control, the second leading cause of infant mortality is the combination of premature birth and low birth-weight. These two factors are also the most significant predictors of infant health and survival. Over the past twenty five (25) years there has been a growing body of research supporting an association between poor oral health/chronic oral infection to the increased incidence of preterm labor and low birth-weight babies. Dental maladies ranging from bleeding gums to dental-related abscesses have special significance during pregnancy. Other factors contributing to poor oral health status during pregnancy include changes in diet and oral hygiene directly resulting in higher decay (cavity) rates, tooth erosion from esophageal reflux and vomiting, and pregnancy gingivitis. According to the National Institutes of Health, “as many as 18 percent of the 250,000 premature low birthweight infants born in the United States each year may be attributed to infectious oral disease.”

For many women under the age of 21 in WV, pregnancy is the only time that they will have medical and dental coverage. West Virginia Medicaid currently covers women up

to age 21, who financially qualify, for full dental benefits. This period of time is also when women are more receptive to modifying or changing behaviors that result in better health outcomes for themselves and their unborn children. This window of opportunity affords healthcare professionals with a unique vantage point in providing education and treatment to improve the oral health status for women and ultimately their children.

Further compounding the problem of oral health services for pregnant women, WV Medicaid fees for dental services are at or below the 10th percentile in the Nation according to a report of the American Dental Association. Data from the WV Health Care Authority shows that less than 25 percent of Medicaid-covered pregnant women under 21 years of age received oral health services during the three (3) years reviewed.

A critical issue identified by the Oral Health Committee of the WV Perinatal Partnership was the need to educate health care professionals in recognizing the direct correlation between oral health and overall health. Current research shows sufficient evidence to recommend appropriate oral health care for pregnant women. Recent studies have shown that women with periodontal disease are at 3-5 times greater risk of a preterm birth than those who are periodontally healthy. It's suspected that bacteria and toxins from periodontal disease enter the bloodstream and cause an inflammation that triggers premature labor. It has been shown that this situation can be aggravated if periodontal disease in pregnant women becomes worse during pregnancy.

While most pregnant women know that smoking and drinking alcohol can be harmful to their babies, they may not know that taking care of their oral health is very important as well. Periodontal disease/dental caries can be prevented and treated.

The RFTS Project compiled dental service utilization data from 2003-2005 on Medicaid clients served by the Project. The average utilization of oral health services was around 18%.

#### Strengths:

Working to improve the oral health status, thus improving the overall health of Medicaid pregnant women in WV, is an ongoing process. The process requires a partnership of many agencies, community groups and health care professionals. The WV initiatives include the following activities:

- Right From The Start educates the health care professionals on the importance of good oral health and its potential impact on positive birth outcomes
- The WV Birth Score tool, maintained by WVU School of Medicine, was revised in 2007 to include questions pertaining to oral health. These data are collected and reported, and can monitor changes in the use of oral health services over the next few years

- To educate new mothers on the value of oral health care, delivering hospitals provided each new mother with a newly-developed perinatal oral health brochure
- RFTS continues an initiative to educate and monitor client utilization of oral health services, with identification of barriers to care
- To educate legislators on potential policy initiatives that can improve the oral health of our citizens, the Perinatal Partnership made presentations to the special WV legislative committee on oral health during the 2007 interim sessions.

The WV Perinatal Partnership made the following recommendations:

- Encourage and support a broad partnership of health professionals to work together to assure that all health care providers are aware of the association between oral health and overall health, therefore recognizing the correlation between infectious oral disease and unfavorable birth outcomes.
- Encourage and support programs working with families to promote oral care before, during, and after pregnancy as a key strategy to improve maternal health, fetal development, infant health, and birth outcomes.
- The Bureau for Medical Services should review the reimbursement rates for Medicaid covered dental services and evaluate the positive impact of preventable dental services for all women of childbearing age. Dental care for all pregnant women may result in an overall cost savings by reducing the number of PT/LBW incidences.<sup>3</sup>

In 2005, the WV Healthy Start/HAPI Project implemented an oral health initiative for pregnant women in eight (8) WV counties using the RFTS provider network. Developed in response to the identified need within the prenatal population, the initiative partnered with the WVU School of Dentistry Department of Rural Outreach. The components of the oral health initiative include:

RFTS Designated Care Coordinator (DCC) education on the importance of prenatal and infant oral health;

- A health education component for prenatal women and their infants and children;
- Dental screenings and cleanings for all prenatals;
- Distribution of Sonicare toothbrushes for all prenatal participants to support continued good oral health habits (through a partnership with Sonicare);

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<sup>3</sup> *The Blueprint to Improve West Virginia Perinatal Health*

*Accomplishments – 2007, Page 60*

- Data collection of participant use of toothbrush (to be linked to the WV Birth Score Office/Vital Statistics birth outcomes data);
- A community consortium-driven petition to WV Medicaid to support oral health coverage for adults (particularly pregnant women) as well as appropriate reimbursement rates for oral health services;
- Evaluation of services implemented; and
- A supply of toothpaste and mouthwash.

The RFTS DCCs are provided comprehensive oral health education by a dental hygienist, as well as a “train the trainers” session with Philips Oral Healthcare on how to instruct clients on proper use of the toothbrush. The service component includes education of the client, scheduling and completing the initial dental appointment cleaning and Periodontal Screening and Recording (PSR), distribution of the toothbrush, monthly follow-up on the use of the toothbrush, and a follow-up PSR postpartum. Additional services are being provided through the WVU School of Dentistry for those women identified as needing additional (more intensive) services based on the PSR at a reduced rate of reimbursement.

These services were developed through a partnership with WVU School of Dentistry and have led to additional partnerships with rural health dentists, Philips Oral Health Care, and Crest. Dental offices agree to provide a dental cleaning and PSR, reinforce education about oral health, and a follow-up PSR after birth. Efforts continue to focus on recruiting dental providers as needed, refining oral health service delivery, and increasing client participation.

A total of twenty-nine (29) dental offices (with multiple providers) located in eight (8) counties are participating in the HAPI Project. Philips Oral Healthcare provides Sonicare toothbrushes for all prenatal clients participating in the oral health component of services, as well as replacement brush heads as incentives to complete the follow-up PSR. To further increase the participation in the follow-up PSR, Philips Oral Healthcare is considering offering baby items from another division of their company. The HAPI Project provides infant toothbrushes, a baby bib with oral health reminders, as well as infant oral health education upon the completion of the follow-up PSR. Crest provides a monthly supply of toothpaste for all participating prenatal women as well. The WVU School of Dentistry has also provided age appropriate toothbrushes for distribution to all family members, including significant others/fathers, grandparents, and all other children in the home. As of June 30, 2008, 1,147 women received oral health education, 781 completed the initial PSR, 791 received a brush, and 269 completed the follow-up PSR.

In order for DCCs to provide effective health education to clients, the HAPI Project provides ongoing training. Topics of trainings provided included HIV/AIDS, Home Visiting, Infant Care, Smoking Cessation, Community Resources, Substance Abuse

Screening, Education and Referral, SIDS Risk Reduction Training, Breastfeeding Café, A Community-Wide Approach, Service Protocol and Documentation, Postpartum Depression, Domestic Violence, Oral Health, Prematurity Summit (MOD), Fetal Alcohol Syndrome, Cultural Sensitivity/Poverty, Mental Health and Confidentiality, and Health Literacy and Health Education.

The WV Birth Score Office, in collaboration with the WV School of Dentistry developed and distributed an oral health brochure which is distributed by birthing hospitals to parents of infants born in WV. A total of 70,000 brochures were printed: 24,000 were distributed to the WV Dental Association for distribution to dentists across the State, 20,000 were forwarded to RFTS, and 500 were distributed to the WVU School of Dentistry-*Oral Health Promotion during Pregnancy Project*. The remaining brochures were distributed to participating birthing sites. In 2008, 20,300 additional dental brochures were provided to WV hospitals for distribution.

In 2008 and 2009, free dental care was provided in WV through the “Mission of Mercy (MOM)” initiative. All M.O.M services are provided by volunteers and every event requires a variety of volunteers including: dental professionals (dentists, dental assistants, hygienists, and dental students), medical professionals, and community volunteers who assist with set-up and clean-up, volunteer registration, translation, parking and helping patients through the process. The first clinic in WV was held in 2008 and had to be closed within two hours because 1195 people attended to access dental care. Two (2) day events were held in Hedgesville in June 2009, and in Parkersburg in July 2009.

## **Domestic Violence**

The problem of domestic violence in WV is serious and affects all population groups. During the 2007-08 fiscal year, the local licensed domestic violence programs in WV offered services to over 18,000 women, men and children. This included both shelter and non-shelter services. While many cases of domestic violence often go unreported, the majority of reported cases of domestic violence in WV are due to intimate partner violence. Additionally, during 2004-2005, domestic violence victims averaged 17.4% of all crime victims known to police.<sup>4</sup>

Domestic violence is a precursor of child abuse and neglect. Spousal domestic violence is more prevalent during the time that a couple experiences pregnancy. The support for women who are at risk for or experience domestic violence during pregnancy is significant for prematurity prevention. Women need access to resources

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<sup>4</sup> Lester, T.K., Haas, S.M., Turley, E., 2007. *Official Reports of Domestic Violence Victimization in WV: 2000-2005*. Criminal Justice Statistical Analysis Center; 2007

for protection and most often seek support from those providers with whom they have established a trusting relationship.

In 2005, a total of 13,661 domestic violence allegations or incidents were reported in WV, with thirty-three (33) of the incidents resulting in death. WV Uniform Crime Reports consistently show that approximately 33% of all homicides in the State are related to domestic violence. An average of two (2) domestic violence homicides occur each month in WV, an average that has held steady since the late 1970's.

For the first time in Right From The Start data collection, domestic violence surfaced in 2006 as one of the top four (4) risk factors, suggesting that Designated Care Coordinators (DCCs), registered nurses and licensed social workers, establish trusting relationships with women enabling disclosure of this sensitive issue. In calendar years 2007/2008, domestic violence was reported by RFTS participants as the fifth top risk factor. DCCs are experienced in recognizing signs and symptoms of domestic violence among pregnant women and are trained on how to interview in a safe environment as well as how to refer to community resources when indicated.

RFTS data for 2007 show 64% of enrolled pregnant women qualify for Intensive Level of Care. According to protocol for assigning levels of care, triggers qualifying a pregnant woman for "Intensive Level" include great conflict with significant other, a history of family violence/physical abuse and lacking a support system in times of stress. RFTS data collected between June 2007 and June 2008 also reveal out of 4,404 Initial Assessments, 444 women reported physical, verbal, sexual or some other type of abuse.

#### Strengths:

Domestic violence has an adverse impact on individuals, families and communities in WV. For this reason, the WV Department of Health and Human Resources (DHHR), through the Bureau for Public Health, convened a DHHR Domestic Violence Workgroup. The workgroup is comprised of members from various DHHR programs and from the WV Coalition Against Domestic Violence. The workgroup was formed to provide expertise and assistance in assessing ways to promote better health and safety practices in order to alleviate domestic violence within the State. It is to this end that the workgroup wrote *the State Plan to Reduce the Incidence of Domestic Violence, WV, 2009*, providing recommendations for accomplishing the work through DHHR and allied agencies. The *State Plan* will guide the method of implementation in carrying out the work.

The Director of Perinatal Programs participates on this Domestic Violence Workgroup. The workgroup continues to explore development of a statewide tool to be used to screen for domestic violence. The RFTS Project screening tool, the Initial Client Assessment, was shared with the workgroup. The tool includes questions that are used

to screen RFTS pregnant women for domestic violence during home visits. For the second year in a row, in 2008, the fifth top risk factor disclosed by RFTS Project participants was domestic violence indicating that the tool was successful in eliciting disclosure. This also indicates the trust relationship which exists between RFTS DCC and client.

Domestic violence survivors and their families have a variety of resources that are available to them in WV. There are fourteen (14) local licensed domestic violence programs in the State. Each of the fourteen (14) is responsible for a specific set of counties, so that all fifty-five (55) of the counties in the State are covered by one of the licensed programs. All services are free and confidential and, while shelter is available if needed, a person is not required to be in the shelter to receive help. The majority of victims who seek help never go to a shelter. The work of assisting survivors is not done solely by the licensed programs, but in partnership with their community-based agencies who offer non-domestic violence advocacy help to victims. These allied agencies may include other social service providers, legal aid, health and mental health providers, skills development programs and others.

## **Cancer**

For more than half a century, cancer has been the second leading cause of death in West Virginia. If current cancer trends continue, epidemiologists predict that by 2016 cancer will be the leading cause of death in the State. Breast and cervical cancers are among the leading causes of cancer-related illness and death among West Virginia women.

### **Breast Cancer in West Virginia**

Breast cancer continues to be the most commonly diagnosed cancer among West Virginia women. The West Virginia Cancer Registry estimates that four women were diagnosed with invasive breast cancer each day from 2002-2006. Data from the West Virginia Health Statistics Center estimates that 1,300 women were diagnosed with breast cancer annually during this same timeframe. According to the 2008 Behavioral Risk Factor Surveillance System (BRFSS), more than one-fourth of West Virginia women aged forty and older had not had a mammogram in the past two years. Furthermore, the likelihood of receiving a mammogram increased with a woman's education. Approximately 43% of women who make \$15,000 or less annually and 40% of women who did not graduate high school have not had mammograms in the past two years.

Breast cancer is a leading cause of cancer-related deaths among West Virginia women. An estimated 300 women died yearly from breast cancer between 2002 and 2006.

### **Breast Cancer Incidence and Mortality in West Virginia (WV) 2002-2006**

	# Diagnosed Annually (WV)	# Deaths Annually (WV)
2002-2006	1,300	300

\*West Virginia Health Statistics Center

## Trends

While cancer continues to be a problem in West Virginia, hope remains. According to United States Cancer Statistics (USCS), in 2005 West Virginia ranked 37<sup>th</sup> nationally in terms of invasive breast cancer incidence. The age-adjusted rate for West Virginia was 115.6 (117.7 U.S.). Mortality data for West Virginia indicated that in 2005, the State ranked 5<sup>th</sup> in the Nation for invasive breast cancer mortality. The age-adjusted mortality rate was 26.9 (24.0 U.S.).

### West Virginia Invasive Breast Cancer Incidence Trends, 2001-2005

	U.S. Incidence Rate	WV Incidence Rate
2001	129.5	118.4
2002	124.9	109.0
2003	120.7	115.2
2004	119.0	115.8
2005	117.7	114.4

### West Virginia Invasive Breast Cancer Mortality Trends, 2001-2005

	U.S. Mortality Rate	WV Mortality Rate
2001	26.0	25.6
2002	25.6	22.8
2003	25.2	25.4
2004	24.4	24.7
2005	24.0	26.9

\* U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2005 Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2009. Available at: [www.cdc.gov/uscs](http://www.cdc.gov/uscs).



## U.S. Preventive Services Task Force New Recommendations for Mammography

In November 2009, the U.S. Preventive Services Task Force released new recommendations regarding breast cancer screening. The new guidelines are as follows:

- Recommend women 50-74 years of age to have a mammogram every 2 years (this is a change from the previous recommendation that mammography be performed yearly for this age group)
- States that there is insufficient evidence to recommend for or against mammography for women aged 75 and older
- Recommends against routine screening for women ages 40-49
- Strongly recommends that clinicians not teach younger women breast self examination

In the midst of the current controversy surrounding these recommendations, the Centers for Disease Control and Prevention (CDC) have recommended that grantees of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) continue to follow Program guidelines for coverage of breast cancer screening among participants. Therefore, the West Virginia Breast and Cervical Cancer Screening Program (WVBCCSP) will continue to prioritize screening for women aged 50-64 years and provide mammography every 1-2 years for this group. The Program will continue to encourage women to talk with their healthcare provider regarding their individual need for screening, based on their health history.

### Cervical Cancer in West Virginia

Approximately ninety-three West Virginia women were diagnosed with invasive cervical cancer each year from 2002-2006. When detected early, cervical cancer is nearly 100% curable, yet West Virginia's women continue to die each year from this disease. An estimated thirty-four women died annually from invasive cervical cancer from 2002-2006.

#### Cervical Cancer Incidence and Mortality in West Virginia (WV) 2002-2006

	# Diagnosed Annually (WV)	# Deaths Annually (WV)
2002-2006	93	34

\*West Virginia Health Statistics Center

## Trends

West Virginia ranks 2<sup>nd</sup> in the Nation in terms of both invasive cervical cancer incidence and mortality. During 2005, the incidence rate of cervical cancer was 10.5 (8.1 U.S.) and the mortality rate was 3.5 (2.4 U.S.).

### West Virginia Invasive Cervical Cancer Incidence Trends, 2001-2005

	U.S. Incidence Rate	WV Incidence Rate
2001	9.1	12.3
2002	8.7	9.3
2003	8.3	9.4
2004	8.1	9.4
2005	8.1	10.5

\* U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2005 Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2009. Available at: [www.cdc.gov/uscs](http://www.cdc.gov/uscs).

### West Virginia Invasive Cervical Cancer Mortality Trends, 2001-2005

	U.S. Mortality Rate	WV Mortality Rate
2001	2.7	4.1
2002	2.5	3.1
2003	2.5	4.1
2004	2.2	3.0
2005	2.4	3.5

\* U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2005 Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2009. Available at: [www.cdc.gov/uscs](http://www.cdc.gov/uscs).

## Screening Barriers

West Virginia is the only State that lies entirely within Appalachia. West Virginia, like much of Appalachia, has its share of health disparities and screening barriers. To better understand these barriers, it is important to understand the culture and demographics of the State. West Virginia is predominantly rural and racially and ethnically homogenous. The State is characterized by high poverty rates, low educational levels, and an aging

population. Geographically, the land lends itself to isolate residents both physically and culturally. Many rural West Virginians will never move further than thirty minutes from their birthplace. Religion is an important part in the lives of many West Virginians and as such, can play an important role in determining healthcare behavior.

The following breast and cervical cancer screening barriers come from two major sources – focus groups conducted in June 2005 by the WVCCSP and published literature.

**Income:** According to the U.S. Census Bureau 2005 American Community Survey, the median household income in West Virginia is \$33,452 compared to the National median of \$46,242. The median income for a female who works full-time, year-round in West Virginia earns an estimated \$24,956 annually. West Virginians also fare worse than their national counterparts in terms of poverty. Approximately 18.0% of individuals live in poverty (13.3% U.S.) and 14.0% of families (10.2% U.S.). Of families with female householders and no husband present, 38.8% live in poverty. That rate increases if children are present in the household; 61.2% of female headed households with children under the age of five live in poverty and 53.6% with children aged eighteen and younger. West Virginia is ranked 5<sup>th</sup> in the Nation for residents living in poverty.

**Cost of healthcare/lack of health insurance:** Both the cost of healthcare and lack of insurance are dominant concerns among West Virginia women, specifically low-income, underserved, and uninsured populations. Many women cannot afford to pay for health insurance if their employers do not provide it. Often caught between providing for their families or paying out-of-pocket for preventive care, most women choose to take the risk and forego screening in favor of providing their family with the much needed necessities.

**Education:** Educating women about the importance of screening and early detection can be a challenge, considering West Virginia ranks 43<sup>rd</sup> in the Nation for high school graduates and 51<sup>st</sup> for college graduates. Only 81.2% of residents aged 25 and older has a high school diploma or equivalent (84.2% U.S.) and 16.9% have a college degree (27.2% U.S.).

**Emotions:** Emotions can also cause a woman not to be screened for breast and cervical cancer. Underserved West Virginia women noted that fear is a major barrier to receiving a mammogram (“fear of finding cancer”, “fear of the unknown”, “fear of pain”). Not surprisingly, embarrassment during a Pap test was a major hindrance to cervical screening (“How much more vulnerable can you get when you are lying on your back with your legs in stirrups?”).

**Culture and Religion:** Culturally, West Virginians have core values and beliefs such as self-reliance, familism, personalism, traditionalism, fatalism, and religious fundamentalism. These values, while preserving strong ties to family and tradition can

also negatively impact healthcare by reflecting the willingness of some residents to use folk medicine, participate in detrimental health behaviors, feel the effects of conservative religion on medical care use, and feel alienated from national society.

**Geography and Transportation:** Geographically, the region is characterized as having a rolling topography with rugged ridges and hilltops reaching upwards of 4,000 feet with remote valleys in between. The valleys often feel isolated and separated from the urbanized areas. While the landscape is beautiful, it can also be treacherous and impassable, causing a major barrier in accessing healthcare. Narrow, winding roads, inclement weather conditions in the winter months, and absence of public transportation outside of urbanized areas compounds the problem of healthcare access.

**Health Professional Shortage:** If all other barriers are overcome, it still may be difficult for a woman to receive screening services due to the healthcare provider shortage that the State is currently experiencing. Sixteen of West Virginia's fifty-five counties are designated health professional shortage areas and thirty-six are federally designated as medically underserved.

#### • Children

According to the National Center for Children in Poverty WV experienced the following characteristics in 2008.

- In West Virginia, there are 233,939 families, with 387,602 children
- Twenty-two percent (22%) or 86,593 children live in poor families (National: 19%), defined as income below 100% of the federal poverty level. For 2009, the federal poverty level is \$22,050 for a family of four. But research suggests that, on average, families need an income of about twice the federal poverty level to meet their basic needs
- Twenty-four percent (24%) of children live in families between 100-200% of the federal poverty level
- Nineteen percent (19%) or 16,881 children in poor families (below 100% of the federal poverty level) have at least one parent who is employed full-time, year-round
- Thirty-six percent (36%) or 31,030 children in poor families have at least one parent who is employed either part-year or part-time
- Forty-five percent (45%) or 38,682 children in poor families do not have an employed parent

- Sixty-three percent (63%) or 54,763 children in poor families live with a single parent
- Twenty percent (20%) or 61,394 children in not poor families live with a single parent
- Twenty-three percent (23%) or 30,233 children, under age 6, live in poor families
- Twenty-two percent (22%) or 56,360 children, age 6 or older, live in poor families
- Forty-six percent (46%) or 39,837 children in poor families live in owner-occupied housing
- Eighty-two percent (82%) or 247,228 children in not poor families live in owner-occupied housing

## **Health Coverage**

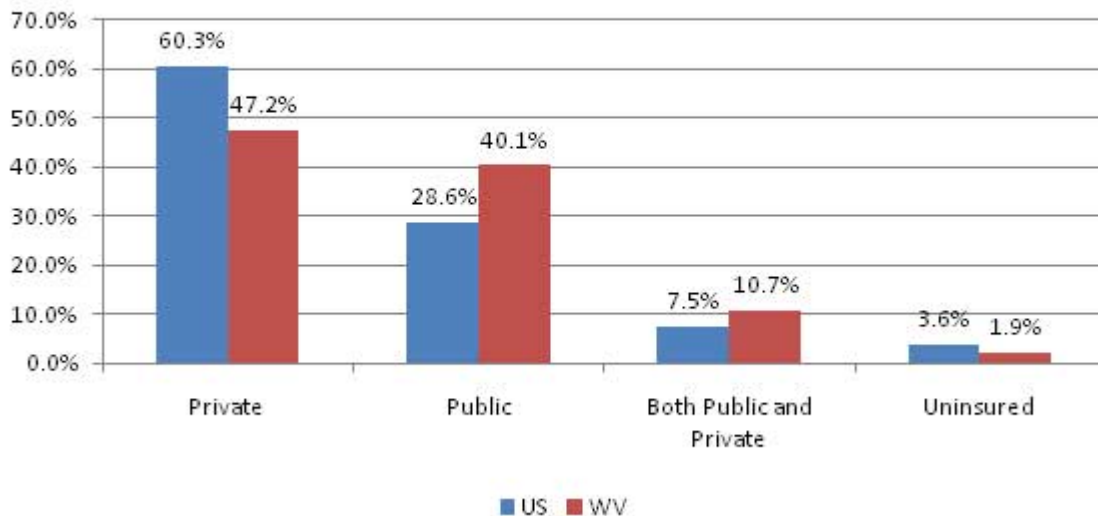
States are required to cover all children under age 19 whose family income is below the federal poverty level (\$19,350 for a family of four in 2005) and all children under age 6 whose family income is 33 percent above poverty. Many states opt to cover additional children; however, West Virginia's expanded coverage is limited to newborns to age one at 150% FPL and pregnant women.

- Medicaid pays for over one-third of all U.S. births, making the program the single largest insurer of prenatal, delivery, and newborn care, including neonatal intensive care
- Medicaid covers 30% of infants and young children, making it the largest insurer of well-baby care and preventive services for healthy development
- Medicaid enrolls over 70% of all poor children
- Children make up 50% or more of the Medicaid population in most states

Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program offers the Nation's most comprehensive coverage for children. Many enrollees have low income; qualify through Medicaid's special "spend down" program for medically needy persons; or qualify through the home and community care waiver program, which states use for children of any income level who have serious disabilities.

Like all children, those in Medicaid range from healthy children with modest needs to children with serious conditions and greater health needs in early childhood. Children with special health care needs have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and require services beyond those required by children generally.

**Percentage of Children with Special Health Care Needs by Type of Insurance - 2005/2006**

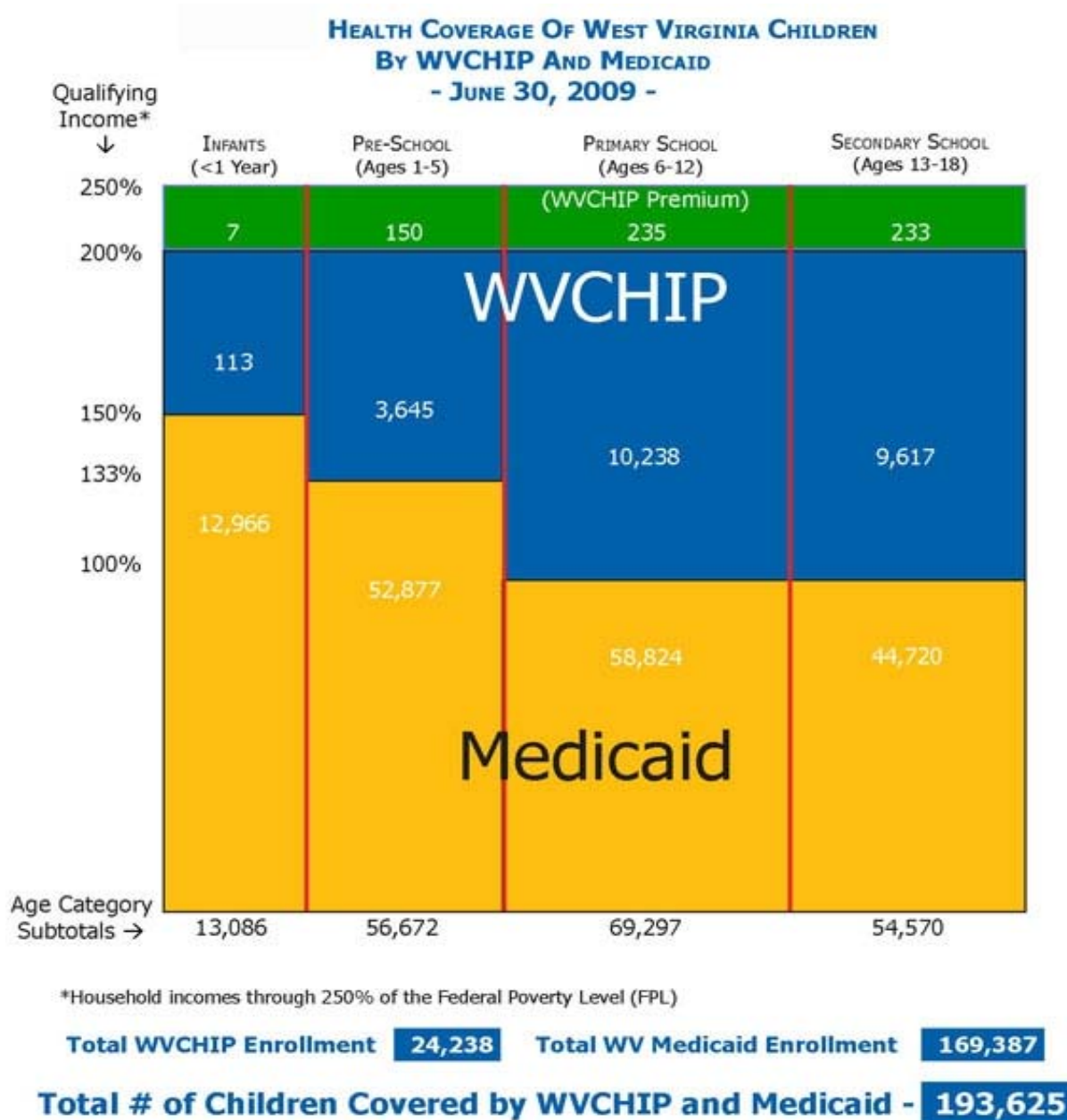


Nationally, 13.9 percent of children are considered to have special needs. These children depend on a combination of federal, state, and local programs to meet their needs. In West Virginia, Medicaid plays a critical role in support of services to children with developmental delays. While the Individuals with Disabilities Education Act (IDEA) establishes the broad parameters for this population of youngsters birth through age five, Medicaid’s ability to pay for services in non-traditional settings, including schools, is limited.

In any given year more than 6.7 million children received IDEA services in the U.S. In West Virginia, in any given year, IDEA/Part C serves 5,700 children and families and local systems serve as many as 4,000.

The U.S. Census Bureau’s Current Population Survey, 2007 to 2009 Annual Social and Economic Supplements, show that the numbers and rates of uninsured children have steadily decreased over the last couple of years. The 2006 survey estimated that 20,000 West Virginia children, or 4.8%, were uninsured. These estimates decreased to 11,000, or 2.8%, on the 2008 survey – reflecting that even though the economy was in decline, children did keep coverage. This stands in contrast to the rate of un-insurance for adults which grew from 16.4% in 2007 to 17.8% in 2009.

The following table from the CHIP Annual Report shows the number of WV children that were enrolled in WV CHIP and/or Medicaid as of June 30, 2009.



On February 4, 2009, President Obama signed into law the Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA). To most, this law simply meant an extension of federal funding of their state’s public health insurance program for children of working families for another 4 years, and also the changing of a flawed federal

funding formula to one which provided greater predictability and stability for growth to cover all children. The CHIPRA legislation itself had numerous provisions: additional coverage options to cover expanded child populations, pregnant women, legal immigrants, assurance of minimum dental and mental health benefits, administrative streamlining of enrollment and re-enrollment practices, new outreach funding, and a performance bonus to help offset the costs of increased enrollment that often impacts state's Medicaid programs more than it does their CHIP. The Act also contained a number of provisions that emphasize quality care and demonstration funding to be determined in the coming year.

#### Strengths:

In January 2009, WVCHIP expanded its income eligibility limit to allow for program participation by families with household incomes up to a new maximum of 250% FPL. Now families of four with gross incomes up to \$55,125 can participate under the WVCHIP Premium plan. While it was a modest expansion, it could not have come at a better time for average families who found they could no longer afford even the employee's share of an employer sponsored plan (a comprehensive family plan now averaging \$13,375 a year). In some cases the expansion had more significance to those families who lost not only health care coverage, but also jobs during this difficult economic period. They are still able to take their children to see a doctor or fill their prescriptions as needed.

As of December 31, 2009, there were 25,053 children enrolled in CHIP (an increase of 138 children over November) and 160,950 children enrolled in Medicaid (an increase of 1,378 children over November).

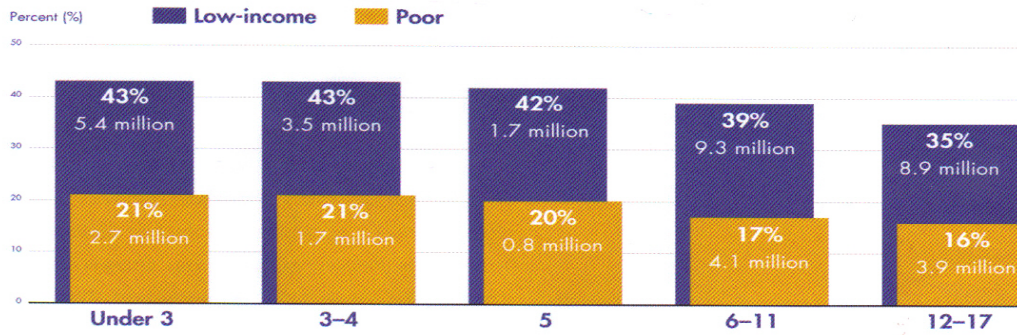
#### Poverty

Early childhood (from birth to age 5) is a period that is critical to a child's cognitive, behavioral and social development, as well as long life economic prospects.

The stress of poverty in the early years can put children at risk. Economic hardship can impede a child's cognitive development and ability to learn. Living in poverty has been shown to increase levels of stress hormones in young children and impair blood supply to their brains, *Source; The Economics' of Human Development: The Technology of Skill Formation, American Economics' Review, 1999.* The graph below depicts the number of U.S. children living in families whose earnings are less than 200% of the poverty threshold, the minimal level of income families need to make ends meet.



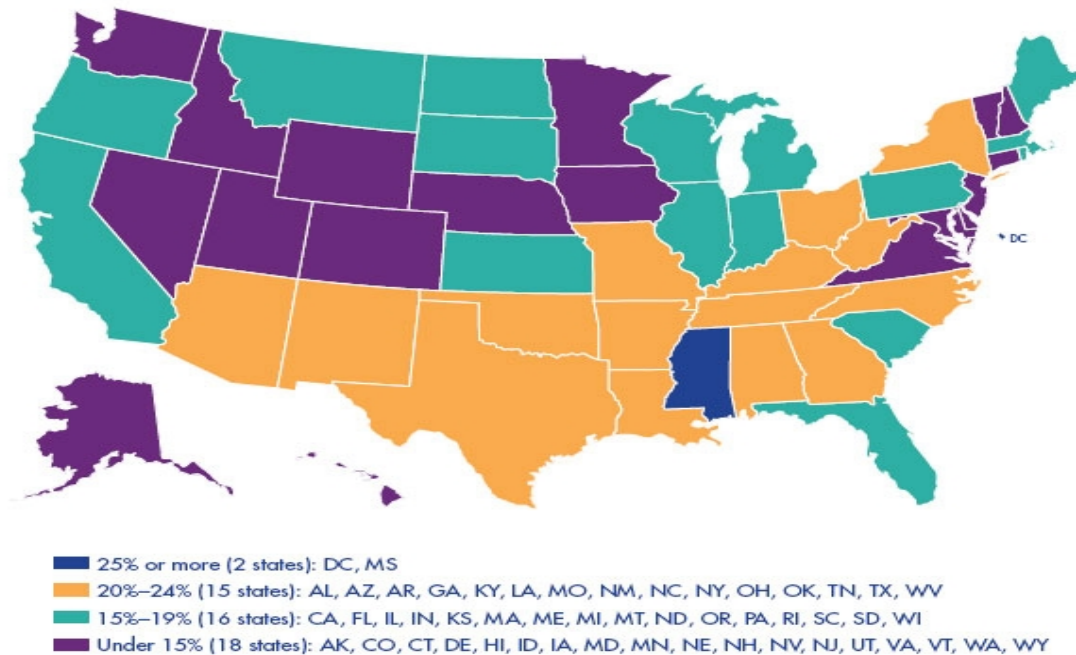
## U. S. Children Living In Low-Income and Poor Families, By Age Group, 2007



Source: Douglas-Hall, Ayana; Chau, Michelle. 2008. *Basic Facts About Low-income Children: Birth to Age 18*. New York, NY: National Center for Children in Poverty, Columbia University, Mailman School of Public Health.

West Virginia's child poverty rate is 20% or more, as depicted below:

Child poverty rates across the states, 2008



© National Center for Children in Poverty ([www.nccp.org](http://www.nccp.org))  
Who Are America's Poor Children?: The Official Story

While the State has done a remarkable job of providing health coverage for children, their families struggle with the high cost of basic necessities, childcare, housing, and

food. Economic hardships faced by children in West Virginia include food insecurity and inadequate housing. It is important to note that many of these low-income families are low-income workers who lack access to benefits that higher-wage earners take for granted, such as health insurance and paid sick days.

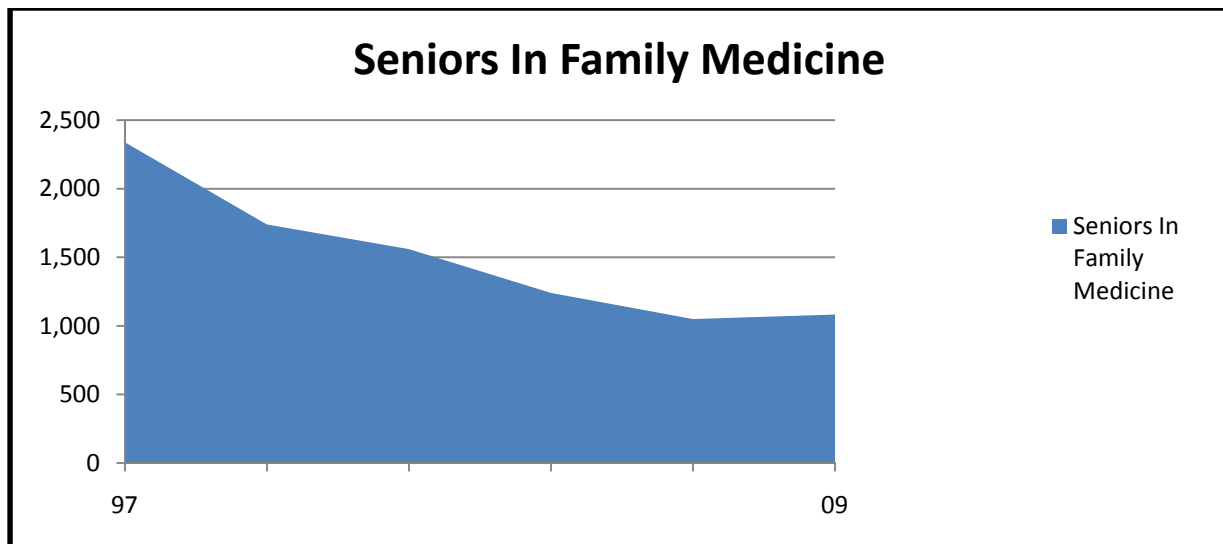
#### Strengths:

To address these challenges, the Office of Maternal, Child and Family Health and its partners encourage the use of community health centers by low-income uninsured adults where free or sliding fee payment is available.

West Virginia is largely dependent on the community health center network, with their core of family physicians to serve not only medically underserved geographical areas but the uninsured as well, as reflected in the payer profile provided above as an example. Regardless of health reform effort outcomes, the number of U.S. medical school students going into primary care has dropped 51.8% since 1997, according to the American Academy of Family Physicians (AAFP). Considering it takes ten (10) to eleven (11) years to educate a doctor, the reduction in Family Practice physicians is a big concern to West Virginia public health. The need for family physicians is critical for the CHC's and necessary to meet the demand for care which is expected to spike nationally in 2020. Since Congress passed health care legislation that extends coverage to the 47 million who lacked insurance, the need for even more doctors escalated. While universal health care financing is an absolute necessity, the infrastructure to address the increase of patients presents a challenge to West Virginia and states across the Country.

#### Students Not Opting for Family Medicine

The percentage of Seniors graduating from U.S. medical schools and choosing residency spots in Family Medicine has declined 53.7% from 1997. As shown on the graph below; seniors in Family Medicine:



West Virginia has, for more than twenty years, supported loan repayment for medical school graduates, and has provided the same opportunities for occupational, speech, and physical therapists and mid level practitioners in an effort to improve health care access. However, since the competition for medical practitioners will increase with practitioner shortage and more patients needing medical care attributable to health care reform, the issue will have to be aggressively addressed by Congress.

- Encourage persons of childbearing age to utilize the OMCFH, family planning provider network, which can provide free or low cost contraceptives
- Routinely distribute information on how to access food stamps and WIC, when appropriate
- OMCFH handles payment for prenatal care, delivery and limited inpatient coverage for low-income, medically indigent pregnant women ineligible for Medicaid
- Referrals are made for low-income energy assistance programs, HUD for rent subsidizes and public housing
- OMCFH works with local food banks, and community service organizations to address food scarcity. The OMCFH team also provides regular donations to these operations. In 2008, the OMCFH donated over 800 items to the local food bank at Christmas

### Education

According to the *2009 West Virginia KIDS COUNT Data Book*, eight of the twelve key indicators of child well-being have shown solid improvement since the start of the new millennium. The most dramatic improvements have been in the percent of eligible children served by Head Start (a 23.4% improvement) and the juvenile delinquency case rate (an 18.2% improvement). However, according to the *KIDS COUNT* report,

three important indicators of child well-being have gotten worse. The percent of low birthweight babies increased from 8.4% in 2000 to 9.6% in 2007, a worsening of 13.7%. The percent of children approved for free and reduced price school meals increased from 49.5% in 2000 to 53.6% in 2007, a worsening of 8.4% and evidence of increasing child poverty. And, the percent of high school dropouts increased from 16.4% in 2000 to 17.0% in 2007, a worsening of 3.7%.

In a review of the State Department of Education, auditors recalculated the State graduation rate for 2007-2008 using a new federal standard and found the State school system is doing worse than previously reported at producing high school graduates. The education department had reported the graduation rate as about 85 percent. Under the new calculations by the auditors, it was likely about 75 percent.

From studies done as recently as 2009, one in every 10 dropouts is in jail; 75% of State prison inmates are dropouts as are 59% of those in federal penitentiaries. The average high school dropout costs this Nation an estimated \$292,000 in lower tax revenues and incarceration costs. For every three dropouts, there is nearly a million dollars in cost to society.

#### Strengths:

During the 2010 Legislative session, a bill was introduced in the Senate to increase the compulsory school attendance age from 16 to 18. Right now, 13 states require teenagers to attend school until they're 18-including neighboring Ohio and Virginia.

Since 2003, a school in Keyser, WV adopted a mission statement of "Success For All Students: No Exceptions, No Excuses". The graduation rate has averaged 91.8% between 2004 and 2008 with the lowest percentage during that period being 89.1% in 2004 and the highest percentage during that period of time being 96.15% in 2008.

In the 2010 Legislative session, WV Governor Joe Manchin III proposed legislation to create new charter schools or convert an existing school into one if 80% of the employees vote by secret ballot to do so. The education proposals come from recommendations by the State Board of Education and were meant to help West Virginia gain up to \$75 million in the next round of federal election spending, dubbed "Race to the Top". H.B.104 did not pass during regular session and was reintroduced during a special session, but still did not pass.

#### **Public Health and Education**

Collaboration between health and education could revitalize service systems designed for a different time. This collaborative, called Coordinated School and Public Health Partnership (CSPHP) in West Virginia, represents a fundamental change in the way education and the health system think about, identify, and meet the needs of children,

youth, and families. It means looking at children beyond the classroom door as he/she lives within a family and community.

Ultimately, this collaboration must be systemic. While education and public health may serve as the catalyst, social services, churches, housing, transportation, and many others must also become engaged.

The first step in the CSPHP was to move from agreement to action by creating a shared vision. Integrating the collaborative in the schools' and communities' activities required the identification of community agencies or service inventory that extended beyond the school's physical plant, as seen below. Another action step has been to provide initial and on-going professional development, since cross-agency training was necessary to foster understanding agency cultures and responsibilities.

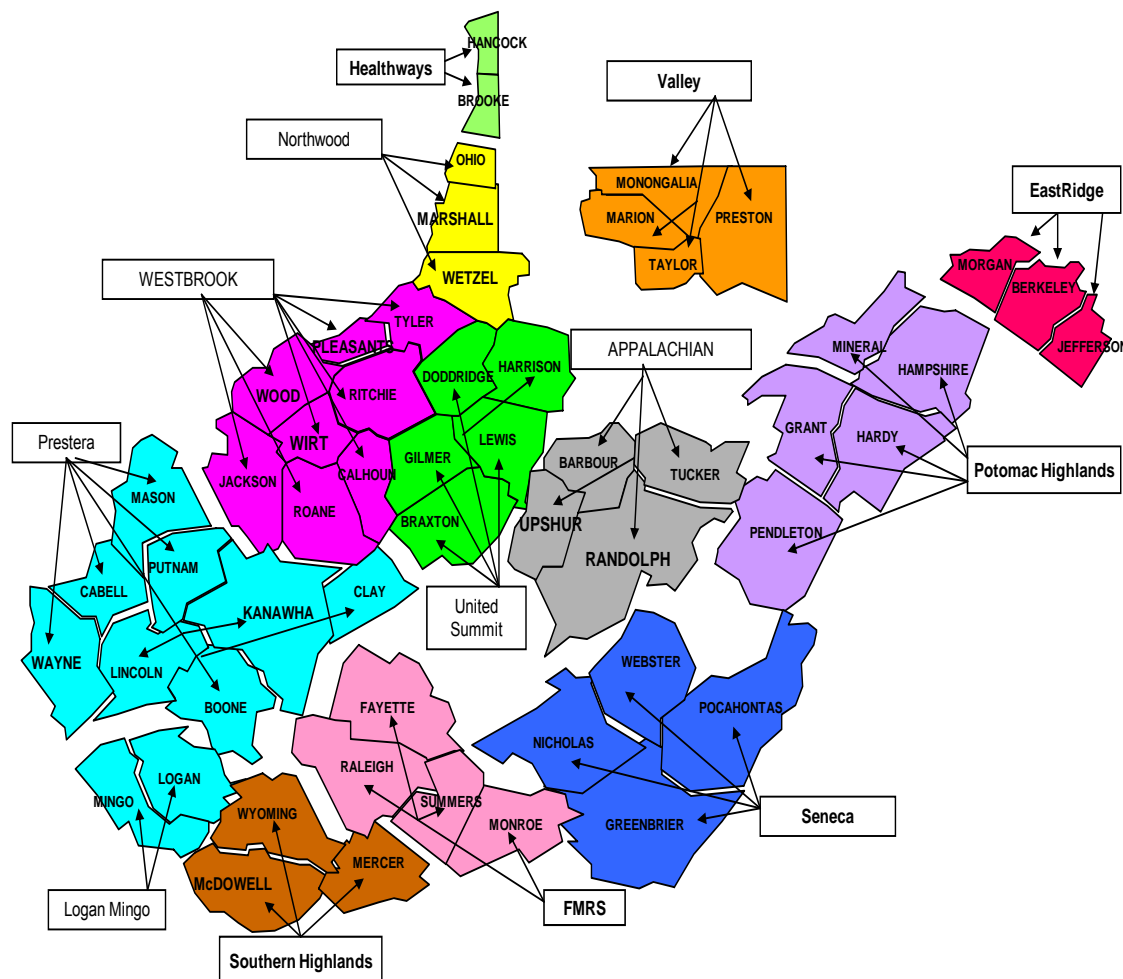
### **Mental Health**

Access to specialized health services, especially mental health is vital to child well-being. Mental health services are a huge system gap in West Virginia, not just because of the financial and social burden imposed on families, but rather the lack of available community-based providers. While West Virginia does have thirteen comprehensive behavioral health centers financed with state and federal resources, these public offerings are stressed and unable to meet the service demand.



## West Virginia Community Mental Health Centers

### CATCHMENT AREAS



According to a U.S. Department of Health and Human Services report, 12 to 22 percent of youth under age 18 are in need of services for mental, emotional, or behavioral problems. The U.S. Department of Health and Human Services also projects that by 2020, neuropsychiatric disorders (mental and behavioral) are projected to become one of the top five causes of mortality, morbidity, and disability among children.

While nationally there has been some success in using the physical location within the school for School Based Health Centers to offer mental health services, the growth of mental health offerings in West Virginia schools have been slow in progressing. The OMCFH sentiment is that the system should use skills and resources within the schools to identify children early who are displaying problematic behavior. Early identification and referral are critical to influencing change. As data is collected about need, both met and unmet, this documentation can be used to advocate for increased attention to

mental health service availability. Currently, it is well known that private practitioners of mental health services are reluctant providers of care for certain populations of children, citing low reimbursement and benefit packages that are not reflective of the individualized patient need.

A U.S. Department of Health and Human Services, Administration for Children and Families, Children's Bureau evaluation of child and family services in West Virginia (2002) identified concerns about the State's difficulty in meeting children's mental health needs. The case review process found that "children did not receive complete mental health assessments or all the services recommended addressing mental health problems." This area identified by the federal government as needing improvement also reflected information from a statewide assessment of stakeholders which corroborates the lack of available behavioral health providers.

#### Strengths:

In negotiation with the Bureau for Children and Families, Public Health/OMCFH/CSHCN agreed to provide care management for children entering the foster care system. While this does not represent all children in the West Virginia Child Welfare system, this agreement will result in the following:

- Comprehensive health assessment at entry into foster care;
- Early identification of children with chronic, debilitating conditions and their medical management;
- Attention to and documentation of health issues and follow-up treatment, when indicated; and
- Ability for medical recordings/reportings that will accompany child regardless of placement (improved documentation)

Unfortunately, while the collaborative may improve many facets of child health for the discrete populations entering foster care, State resources are still insufficient to address all mental health findings.

#### **Child Abuse**

According to *Child Maltreatment 2007*, in 2006 there were 15 child fatalities due to maltreatment, 6 of which were in the child file as Child Protective Services (CPS) cases in WV. This represented a rate of 3.86 deaths per 100,000 children ages 0-17. The national average for 2006 was 2.05. In WV in 2007 there were 12 child fatalities due to maltreatment of which 8 were in the child file as CPS cases. For WV this represented a rate of 3.10 deaths per 100,000 children ages 0-17. Also according to *Child Maltreatment 2007*, in 2007, WV had a total of 7,109 victims of reported child maltreatment. Of these, 973 or 13.7% were removed from the home. There were a total

of 42,248 non-victims in the homes of which 700 or 1.7% were removed from the home. In total there were 1,673 children removed from their home in 2007. Of the 7,109 children reported as victims of maltreatment 639 or 9% were children with disabilities. Of the 639, 74% were children with a behavior problem and 33% were children who were emotionally disturbed (percentage does not equal 100% as some children had both disabilities).

On Absence of Maltreatment Recurrence between 2004-2007, WV typically stayed around 88% each year with the National standard set at 94.6%. In 2004, 17 states met the National standard and in 2007 24 states met the National standard. Only 5 states were in the high eighties percent range, which included WV, while the rest of the reporting states were in the nineties.

#### Strengths:

The West Virginia Department of Health and Human Resources, Bureau for Children and Families, oversees West Virginia's community based child abuse awareness and prevention grants, which are administered according to the guidelines of the federal CBCAP Program Instructions. Child abuse awareness and prevention grants are monitored by Program Specialists in the Division of Early Care and Education and Children and Adult Services.

West Virginia funds four program areas:

- Family Leadership First
- In Home Family Education
- Partners in Prevention
- Starting Point Centers

#### **Obesity**

The increasing rates of childhood obesity nation-wide and the prevalence of adult risk factors for cardiovascular disease at earlier ages, reflect a public health crisis that schools, agencies, and allied health professionals are attempting to address with intervention programs and information campaigns. Recently, even First Lady Michelle Obama announced that she intends to launch a significant childhood obesity awareness campaign nation-wide.

Recognizing that the critical issues related to childhood obesity and the consequences of non-action should be part of any awareness campaign, it is equally important that public health professionals identify the root cause of the culture of obese children. Some have been quick to blame the fast food industry; others blame media or



advertising; schools have been a primary target of blame; still others say that parents are responsible for the fattening of our children.

While childhood obesity is influenced by multiple complex social forces, many would agree that fitness levels of children are low, and obesity rates are high, as a direct consequence of decisions that adults make on behalf of children. All adults share a collective responsibility for the current status of child health in America because it is the adults who make policy; adults purchase convenience food and convenience products; adults decide what receives funding; adults take recess time away in public schools; adults serve processed non-food to their families; adults make marketing and advertising decisions as company executives; and hundreds of other commercial, educational, or parenting decisions that impact the context features of childhood.

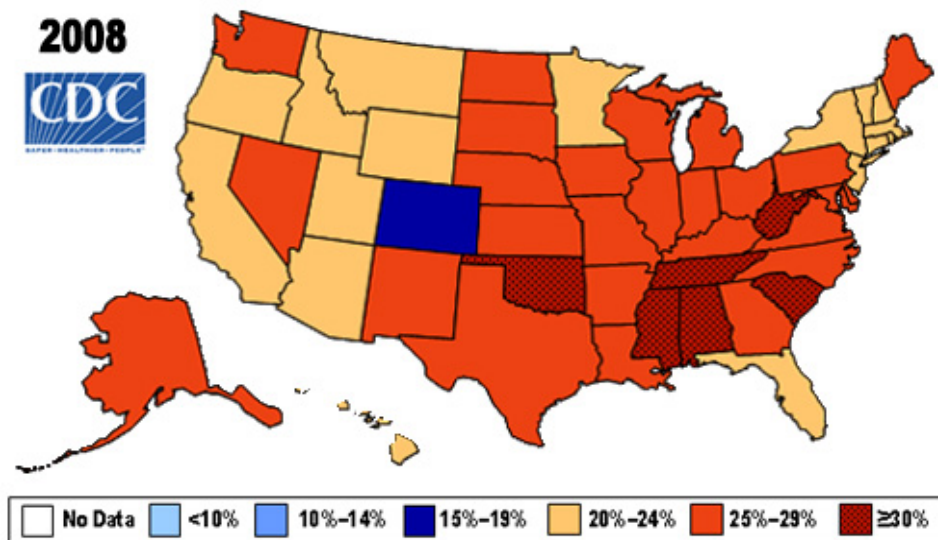
Young children are designed to move. Recently published guidelines (NASPE, 2009) recommend that preschool children be provided sixty minutes of accumulated physical activity, which is structured for them by an informed adult. In addition to structured physical activity, preschool children should have at least sixty minutes (and up to several hours) of unstructured, self-selected free play that is supervised by an informed adult. Likewise, children this young should not be sedentary for more than sixty minutes at a time (except when sleeping). The recommendations note that physical activity needs to be experienced indoors and outdoors, and that preschool children also need to have competence in basic motor skills. And finally, the recommendations state that both parents and teachers need to be more informed about the guidelines so that they can value and facilitate the physical activity and movement experiences of young children. These guidelines remind that, for normal growth and development, young children need to be physically active in short bouts throughout the routines of the day, plus they need ample and appropriate opportunities to practice their emerging motor skills.

Child nutrition experts across the board agree that childhood obesity poses the greatest threats to the Nation's physical and financial health. Today, one-third of U.S. children and adolescents, (about 25 million), are obese or overweight. Child nutrition programs provide children with access to low-cost, nutritious food to support healthy growth and development.

West Virginia has the third highest rate of adult obesity in the Nation, at 31.1 percent and the eighth highest of overweight youths (ages 10-17) at 35.5 percent, according to a new report by Trust for America's Health (TFAH) and the Robert Wood Johnson Foundation (RWJF).

The rate of obese adults remained consistent in the State in the past year. Adult obesity rates increased in 23 states and did not decrease in a single state in the past year, according to the *F as in Fat: How Obesity Policies Are Failing in America 2009*. In

addition, the percentage of obese and overweight children is at or above 30 percent in 30 states. Four states now have rates above 30 percent, including Mississippi, Alabama (31.2 percent), West Virginia (31.1 percent) and Tennessee (30.2 percent).



#### Strengths:

West Virginia has initiated several activities to combat the growing obesity problem within its borders. Among them is 1) Camp New You @ WVU an innovative program designed to help youth and their parents identify and practice lifestyle changes that will assist in reducing unhealthy body weight through increased physical activity and good nutrition. The program focuses on goal setting and decision-making and emphasizes the importance of family participation in helping to create home environments that provide regular opportunities for moderate-to-vigorous physical activity and healthy eating. The signature features of the program include the following: a) interdisciplinary advisory board; b) qualified camp staff; c) access to state-of-the-art facilities; d) focus on behavior change through enhanced self-efficacy, behavioral skills, behavioral capability, and social networking; e) unique summer residency program with a variety of educational sessions for children and parents, developmentally appropriate activities, group counseling, and enrichment activities; and f) structured 12-month follow-up intervention designed to provide continued support for families as the targeted behavior change becomes habitual (periodic weekend retreats, regular telephone coaching, individualized physical activity program design, personal accountability mechanisms); 2) West Virginia does have nutritional standards for competitive foods sold a la carte, in vending machines, in school stores or in school bake sales; 3) The West Virginia Board

of Education increased the school nutrition standards; 4) The West Virginia Legislature established the Healthy Lifestyles Act in 2005 that mandates schools to administer fitness and health education assessments, to offer a certain number of minutes of physical education each week, and to measure the body mass index (BMI) to serve as an indicator of progress; and 5) **Choose Healthy Options Often & Start Young (Choosy)** was designed by WVU, Department of Physical Education, to help adults be reminded of the health messages that will promote the development of healthy preferences early in life, especially when preferences are first being formed.

Many Head Start programs have been introduced to Choosy as an example of a character role model in the award winning obesity prevention initiative launched by Office of Healthy Schools, *I Am Moving I Am Learning* (IMIL). The strategies used in IMIL are not unique to Head Start classrooms. Several states included child care providers in their IMIL training events, and in January 2010, the federal Child Care Bureau launched the Region I Pilot of IMIL in Child Care using the IMIL materials and strategies.

Recently, 50 child care centers in West Virginia received a Be Choosy kit provided by WV DHHR and produced by Lakeshore Learning Materials. This pilot program will focus on the “healthy by design” principles just discussed. Children will be introduced to the Choosy movement vocabulary, practice motor skills, and learn about healthy eating. In addition, they will experience a variety of movement challenges included in the Be Choosy kit. The purpose of the project is to demonstrate that with a little bit of training and some new resources, centers can apply strategies that modify or create healthier preferences for food and physical activity.

Choosy is a role model. If healthy preferences are fostered early in life, children in middle school and older can demonstrate selecting healthy choices when presented with the many options available to them in this sedentary culture. Choice is empowering and choosing from among several healthy options (rather than making a choice between an apple and a doughnut) sets the stage for healthy preference development. Children cannot make healthy decisions unless the adults in their lives do the same.

With a grant from the Robert Wood Johnson Foundation, West Virginia University Health Research Center, West Virginia Office of Healthy Lifestyles and the Office of Healthy Schools partnered to complete a study on “Parent and Health Care Provider Views on the Use of the Terms Overweight and Obese to Describe Children”. The following chart depicts the methods, results and conclusions of the Study.



# Parent and Health Care Provider Views on the Use of the Terms Overweight and Obese to Describe Children

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<sup>1</sup>Health Research Center, West Virginia University; <sup>2</sup>West Virginia Office of Healthy Lifestyles; <sup>3</sup>West Virginia Office of Healthy Schools.

## Background

- 2007 Expert Committee guidelines<sup>1</sup> for the prevention and treatment of childhood obesity recommended:
  - Use of the term *overweight*, rather than at risk for overweight, when BMI is between the 85<sup>th</sup> to 94<sup>th</sup> percentiles.
  - Use of the term *obese*, rather than overweight, when BMI  $\geq$  95<sup>th</sup> percentile.
  - The terms *overweight* and *obese* be used for clinical documentation and risk assessment, but other terms be used during the office visit to "avoid an inference of judgment or repugnance."<sup>1</sup>
- Previous research has suggested that adult and adolescent patients do not view terms such as obesity and body mass index favorably.<sup>2,3</sup>
- This raises questions such as: how parents are to learn about their child's weight status if the appropriate terms are not used by health care providers how public health warnings about obesity risks can be effective in a "don't tell" environment, and whether a parent's rights to know their child's weight status conflicts with the right to respectful treatment.

## Objectives

- Determine parent interest in being told if their child was overweight or obese.
- Determine to what degree parents would be offended by the use of the terms overweight and obese by a health care provider in relation to their child.
- Examine health care provider beliefs about informing parents when children are assessed as overweight or obese.

## Method

- The parent interviews and health care provider surveys were completed in conjunction with a multi-method, multi-informant evaluation of West Virginia's childhood obesity legislation, The Healthy Lifestyles Act. The evaluation was funded through a grant from the Robert Wood Johnson Foundation®.
- Parents**
  - A multi-stage, stratified random sample of 1500 parents of West Virginia students in kindergarten, 2nd, 4th, 5th, 7th, and 9th grade were interviewed (n = 250/grade).
  - Interviews were conducted in all of West Virginia's 55 counties.
- The following questions from the Parent survey were included in this study:
  - In the past 2 years, has your child's pediatrician or primary health care provider discussed your child's weight with you?
  - Were you told your child was: *underweight, normal, at risk for overweight, overweight, or obese*?
  - If your doctor measured your child and found that he or she was overweight or obese, would you want to be told?
  - If your doctor told you your child was overweight/obese, how offended would you be?

## Method

### Health Care Providers

A random sample of more than 600 West Virginia health care providers was contacted electronically or by mail using state listings of providers; surveys were received from 22%, and a final sample of 124 were used in this study.

The following questions from the Health Care Provider survey were included in this study:

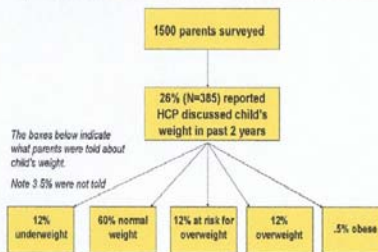
- Do you calculate the child's BMI percentile when height and weight are measured?
- Do you discuss the child's BMI percentile with parents?
- Parents should be informed if their children are obese?

**Analysis:** Descriptive statistics were calculated using SPSS 16.0

## Results

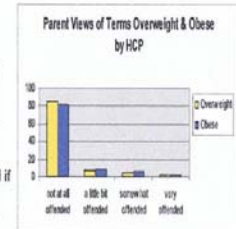
Demographic characteristics of parents and health care providers are presented in Table 1.

Parent		Health Care Provider	
<b>Gender</b>		<b>Gender</b>	
Male	26%	Male	49%
Female	74%	Female	51%
<b>Age</b>	Mean = 41 Range = 24-73	<b>Age</b>	Mean = 41 Range = 25-68
<b>Race</b>	White 95% Black 2% Other 3%	<b>Length of Practice</b>	Less than 1 year 5% 1-5 years 25% 6-10 years 15% 11-15 years 20% Greater than 15 years 35%
<b>Marital Status</b>	Married 80% Not Married 10%	<b>Medical Specialty</b>	Family practice 47% Pediatrics 43% Other (e.g., Internal Medicine) 10%
<b>Education</b>	High School Graduate 49% College Graduate 46%		



## Results

- 99% of parents reported they would want to be told if HCP measured their child and found they were overweight or obese.
- Majority of parents would not be offended if told their child was overweight or obese.



### Health Care Provider

- 99% of providers believed that parents should be told if their child was obese.
- One third of health care providers said they rarely or never calculate BMI percentiles.

## Conclusions

Parents and health care providers overwhelmingly endorsed the importance of telling parents when a child is overweight or obese. These findings are in conflict with the Expert Committee's recommendations regarding conveying child weight status information to parents. Although a small minority of parents will be offended by the terms overweight and obese when applied to their children, parents have the right to this information and should be informed in order to take appropriate action to address this serious health risk. Unless health care providers routinely calculate BMI percentiles and parents are told the child's weight status, the obesity epidemic will always be someone else's problem.

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## Support

- Support for this project was provided by a grant from the Robert Wood Johnson Foundation®

In another study, completed by the same group, designed as part of a state-wide evaluation of WV's obesity legislation, the Healthy Lifestyles Act, all school nurses in WV (n=240) were asked to participate in a survey regarding their role in school-based obesity prevention efforts, 214 responded.

The results indicated that school nurses were a common point of contact for students and parents regarding nutrition, physical activity, and weight management. For example, 85% of nurses reported receiving questions from students about diet and nutrition and nearly half received questions on physical activity and weight loss methods. The majority of nurses (86%) had also been contacted by parents about their

child's diet and nutrition behaviors, 45% received questions about ways to increase child physical activity, and approximately half of the nurses received questions from parents about child weight loss methods. In addition, 61% of school nurses provided counseling to students for weight or body image, and 47% made referrals to health care providers for students with weight problems.

In 2005, the Healthy Lifestyles Act (House Bill 2816) was passed to help address the rising prevalence of overweight and obesity among youth and adults in West Virginia. Implementation of the Act's school-based components, which provide policy direction for physical education, health education assessments, fitness assessments, body mass index (BMI) assessments and the availability of vended beverages in schools, began in August 2006. As prescribed by the Act, leaders from the State's education, public health, and health care sectors are working together to address West Virginia's obesity epidemic, alleviate the related health and economic consequences, and lessen the burden on the State's health care infrastructure.

During the 2008-2009 school year, West Virginia revised the nutritional guidelines for all foods made available to students in schools. These standards are based on the recommendations made by the Institute of Medicine in their 2007 report, *Nutrition Standards for Foods in Schools: Leading the way toward Healthier Youth*. West Virginia was the first state to implement these standards.

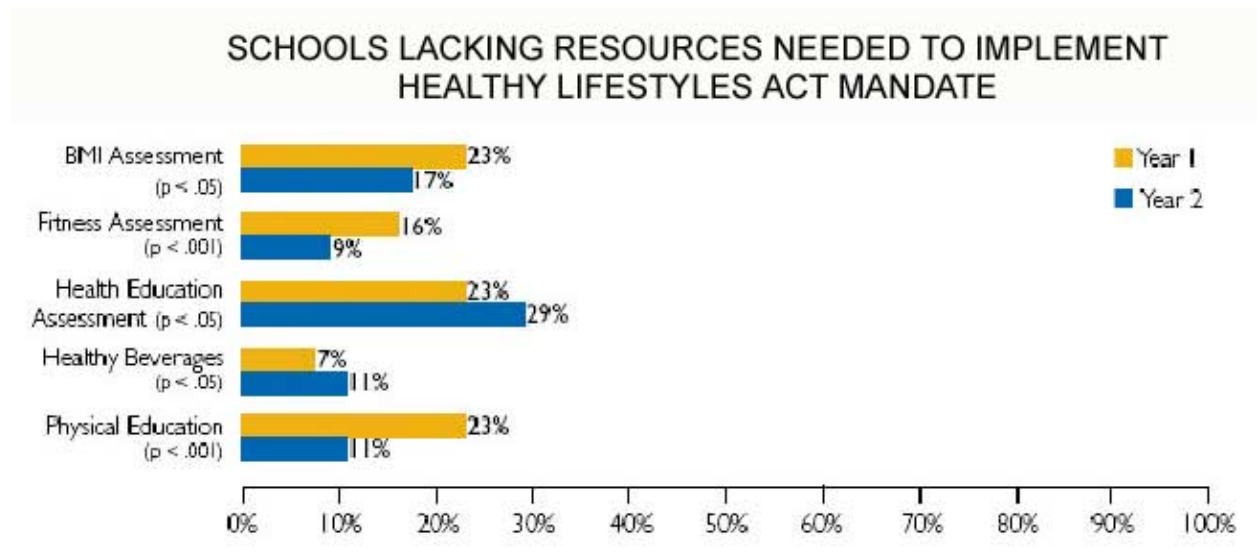
A Year 1 and Year 2 evaluation, covering school years 2007-08 and 2008-09, of the Healthy Lifestyles Act was conducted by a team of university-based researchers and staff from the State health and education agencies responsible for overseeing implementation of the Act.

Superintendents, principals, physical education teachers, health teachers and school nurses were surveyed regarding their perceptions of the implementation of the Healthy Lifestyles Act, its impact on students and schools, and current nutrition and physical activity policies. A mixed picture emerged in the 2<sup>nd</sup> year evaluation. There was marked improvement in school nutrition and progress implementing local wellness policies, but significant challenges prevented progress in areas such as physical education and student fitness.

Schools had difficulty implementing the mandates of the Healthy Lifestyles Act lacking resources related to BMI assessments, fitness assessments and physical education. However, significantly more schools lacked the resources to implement mandates related to healthy beverages, and health education and assessments. In Year 2, 40 percent of schools lacked the resources necessary to implement one or more of the Act's mandates, which is not significantly different from Year 1. Improvements were made in implementing the Health Education Assessment Project (HEAP), but school



staff continued to report significant challenges and overall student scores remained below the state proficiency level.



**OVERALL STUDENT HEAP SCORES FOR NUTRITION AND PHYSICAL ACTIVITY**

	Nutrition		Physical Activity	
	2007-08	2008-09	2007-08	2008-09
Grade 6	66%	65%	77%	76%
Grade 8	61%	62%	79%	77%
High School	73%	71%	65%	64%

### Oral Health

Oral diseases are progressive and cumulative and become more complex over time affecting the ability to eat, appearance as well as communication. These diseases can affect economic productivity and compromise the ability to work at home, at school, or on the job. Many children and adults lack dental insurance and financial resources limiting the ability to seek regular dental services. The following are highlights of oral health data for children as reported from the 2003 U.S. Department of Health and Human Services, National Call to Action to Promote Oral Health and the 2009 National Center for Chronic Disease Prevention and Health Promotion.

- Dental caries (tooth decay) is the single most common chronic childhood disease – 5 times more common than asthma and 7 times more common than hay fever

- Tooth decay affects more than one-fourth of U.S. children aged 2-5 and half of those age 12-15. About half of all children and two-thirds of children aged 12-19 from low income families have had decay
- Tobacco-related oral lesions are prevalent in adolescents who use smokeless (spit) tobacco
- Unintentional injuries, many of which include head, mouth, and neck injuries, are common in children
- Intentional injuries commonly affect the craniofacial tissues
- Professional care is necessary for maintaining oral health, yet 25 percent of poor children have not seen a dentist before entering kindergarten
- Medical insurance is a strong predictor of access to dental care. Uninsured children are 2.5 times less likely than insured children to receive dental care. Children from families without dental insurance are 3 times more likely to have dental needs than children with either public or private insurance. For each child without medical insurance, there are at least 2.6 children without dental insurance
- Children and adolescents of some racial and ethnic groups and those of lower income experience more untreated decay. For example, 40% of Mexican-American children aged 6-8 have untreated decay, compared with 25% of non-Hispanic whites. Twenty percent of all adolescents 12-19 years currently have untreated tooth decay. (In WV, approximately 41% of children receiving Medicaid receive at least one dental service)

Parental awareness, public and private dental coverage, and availability of dental providers, especially for children receiving Medicaid, are critical factors in children obtaining needed dental care. Even though children enrolled in Medicaid are individually entitled under the law to comprehensive preventive and restorative dental services, dental care utilization for this population is low. The reasons for low utilization are many, but a lack of dental providers who participate in Medicaid is a key factor. Few dentists participate in Medicaid – less than half of all active private dentists in some areas. Low reimbursement rates, patient no-shows for appointments, complex forms and burdensome administrative requirements are commonly cited by dentists as reasons for not participating in Medicaid.

State policymakers are increasingly focused on children's oral health as a major policy issue, spurred in part by the *2000 U.S. Surgeon General's Report on Oral Health*, the high profile death of a child from consequences of a preventable dental infection, and expanded dental provisions in the reauthorization of the Children's Health Insurance Program (CHIP). This heightened focus on children's oral health is reflected in new legislation, press coverage, and efforts by state and local oral health coalitions to advance improvements in children's oral health policies and programs. Policy activity has resulted in both successes and frustrations as oral health competes for scarce

resources and the costs of both appropriate and inappropriate dental care continue to escalate. Efforts to reform health care present a significant opportunity to address the resurgence of childhood tooth decay among key populations of children.

Children's oral health is essential to child development and optimal overall health and wellbeing – a critical part of achieving key developmental milestones and function including eating, speaking, and attaining normal social and emotional development. Tooth decay, despite being preventable, remains the single most common chronic disease of U.S. children, affecting 26% of preschoolers, 44% of kindergarteners, and half of all teens. Low-income and minority children are particularly affected as they experience the highest rates of this disease yet have the lowest rates of dental care. Poor oral health can have significant effects on overall health, particularly in adulthood, and has been associated with heart and lung diseases, stroke, and low weight births. In fact, the legacy of poor oral health in childhood is reflected in the health of young people entering the military. The Department of Defense reports that 42% of new Army recruits could not be deployed until their dental problems were addressed.

Dental caries – the disease process that causes cavities – is largely preventable, highly manageable, and chronic. It is a complex disease process involving the interplay of diet, fluoride, and genetics that results in individual levels of risk for cavities. A family history of dental caries, lack of appropriate fluoride exposure, and frequent sugar intake are among the key risk factors for tooth decay.

The decline in dental caries among children has mainly been due to successful, well-established public health strategies that include community water fluoridation, dental sealant programs, and public education and awareness campaigns. Long-standing, community-based public health strategies also have been successful in providing a return on public investment for those who are at the greatest risk. Cost savings include the following:

- Dental costs for children enrolled in Medicaid for five continuous years who have their first preventive dental visit by age one are nearly 40% less (\$263 compared to \$447) than for children who receive their first dental visit after age one
- For every \$1 invested in community water fluoridation, \$38 in dental treatment costs is saved
- School-based dental sealant programs save costs when they are delivered to children at high-risk for tooth decay

When children lack dental coverage and access to regular check-ups, dental care frequently waits until symptoms such as a toothache are severe and facial abscesses occur. In these cases, care is often sought in an emergency department where it is



costly and likely to be limited to treating the immediate symptoms but not the underlying problem.

Dental sealants - plastic coatings applied to the chewing surfaces of the back teeth where most decay occurs - are a safe, effective way to prevent cavities. Yet, only about one-third of children aged 6-19 years have sealants. And, although children from lower income families are almost twice as likely to have decay as those from higher income families, they are only half as likely to have sealants.

According to the 2008 WV CMS 416 (EPSDT Participation Report) there were 206,729 Medicaid eligible persons between the ages of 0 - 20. For a four year period between 2005 and including 2008, only 41% of this population received any dental service within each year. The only fluctuation was in 2006 when there was a spike of 55.69%. For this same time period and age group, only 35% received any preventive dental service within each year and for participants receiving treatment services, the percentage remained in the 41% range for that four year period.

### **CMS-416 Dental EPSDT Participation Report 2005-2008**

Year	Total Eligibles Ages 0-20	Total Eligibles Receiving Dental Services	Percentage Eligibles Receiving Dental Services	Total Eligibles Receiving Preventive Services	Percentage Eligibles Receiving Preventive Services	Total Eligibles Receiving Dental Treatment Services	Percentage Eligibles Receiving Dental Treatment Services
2005	210,974	86,244	40.87%	72,973	34.58%	82,201	40.38%
2006	210,181	117,070	55.69%	73,893	35.15%	85,676	40.76%
2007	207,606	85,108	40.99%	73,012	35.16%	84,711	40.80%
2008	206,729	86,250	41.72%	74,326	35.95%	85,866	41.53%
2009	213,390	92,701	43.44%	81,199	38.05%	92,530	43.36%

### **Opportunities to Address Dental Caries under CHIP Reauthorization Act (CHIPRA)**

On February 4, 2009, President Obama signed into law the reauthorization of the Children’s Health Insurance Program (CHIP). Included in the bill are eight major dental provisions that range from mandating dental coverage to encouraging primary preventive care. The new CHIP provisions include the following:

- Requires that states provide dental coverage for CHIP beneficiaries
- Allows states to provide dental coverage that “wraps” around commercial medical coverage for children who are otherwise eligible for CHIP (they may have private medical, but no dental insurance)

- Requires that states report on CHIP dental program performance
- Establishes a requirement that parents of newborns be informed of risks for early childhood caries and its prevention

The following 1998 prevalence of tooth decay and sealants data for WV children is the latest data available. Oral health data collection, and surveillance systems has been almost non-existent for the past decade. There is currently contract with Marshall University for oral health data collection with reporting due out by spring of 2011.

### 1998 Prevalence of dental caries and dental sealants in West Virginia

<b>Dental caries (tooth decay) experience*</b>	Percentage
Children, aged 8 years	65.6
Adolescents, aged 15 years	66
<b>Untreated caries (tooth decay)*</b>	
Children, aged 6–8 years	35.5
Adolescents, aged 15 years	32.9
<b>Dental sealants *</b>	
Children, aged 8 years (1st molars)	36.7
Adolescents (1st and 2nd molars) aged 14 years	34.6

\*1998 Baseline data taken from WV Healthy People 2010

According to the above data, 65.6% of WV children aged 8 have experienced tooth decay as well as 66% of adolescents aged 15. Thirty-five and a half percent of children aged 6-8 years have untreated caries along with 32.9% of adolescents aged 15. Only 36.7% of children aged 8 and 34.6% of adolescents aged 14 have dental sealants. Data for children’s dental care is not current and difficult to find for WV children.

#### Strengths:

There are several significant changes in the new law that are designed to improve the health care that children receive in CHIP and impact the current benefit structure for WVCHIP. In compliance with CHIPRA’s requirements, the current dental benefit for coverage over 200% FPL needs to be changed. Currently, dental services for this

group are limited to preventive services and subject to a maximum of \$150 per year. The new dental benefit will include both preventive and restoration services. Restoration services will include a co-payment of \$25 per service.

Between January 1, 2008 and December 31, 2008, WVCHIP, using HEDIS-Type Data, estimated that of the 8,675 children 2 to 18 years of age, who were continuously enrolled for the whole year, 8,380 or 96.60% had at least one dental visit during the year. Previous percentages were 96.06% for 2007 and 95.84% for 2006.

#### HEDIS-Type Data

January 1, 2009 to December 31, 2008

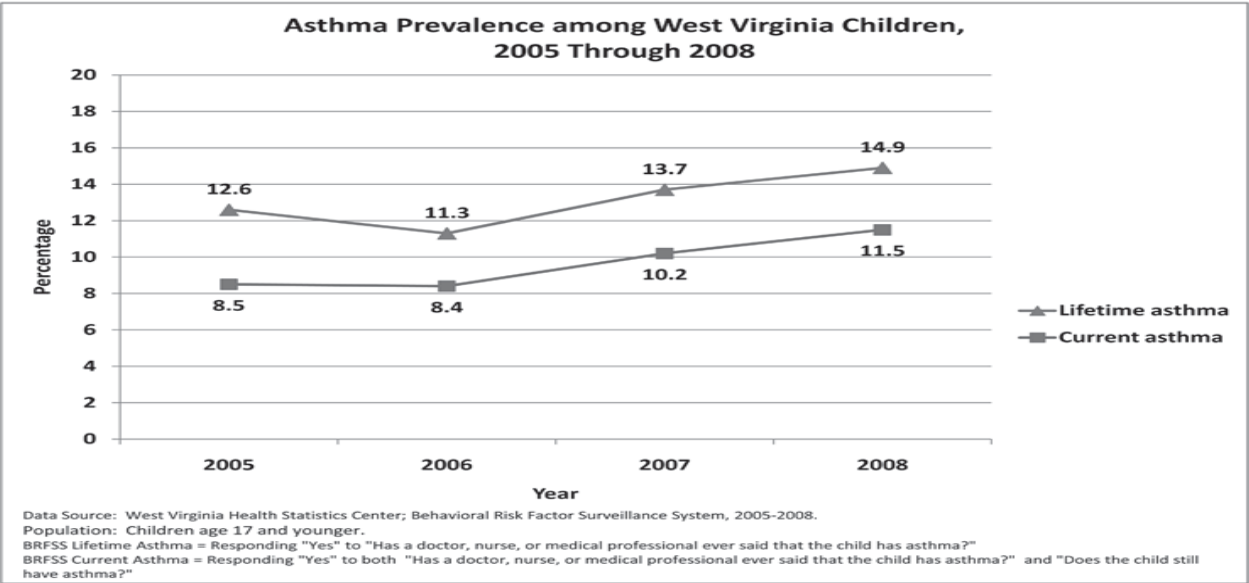
This measure estimates the number of children enrolled for the entire 2008 calendar year, age 2 through 18, that had at least one dental visit during the year.

Age Group	Number of Continuously Enrolled Children	Number Having Dental Checkup Visit	% Year 08	% Prior Year 07	% Prior Year 06
2 to 3 Years	474	458	96.62%	97.54%	96.33%
4 to 6 Years	888	869	97.86%	97.58%	97.51%
7 to 10 Years	2,448	2,377	97.10%	97.24%	96.70%
11 to 14 Years	2,917	2,826	96.88%	96.23%	95.52%
15 to 18 Years	2,422	2,308	95.29%	94.17%	94.72%
<b>TOTAL</b>	<b>8,675</b>	<b>8,380</b>	<b>96.60%</b>	<b>96.06%</b>	<b>95.84%</b>

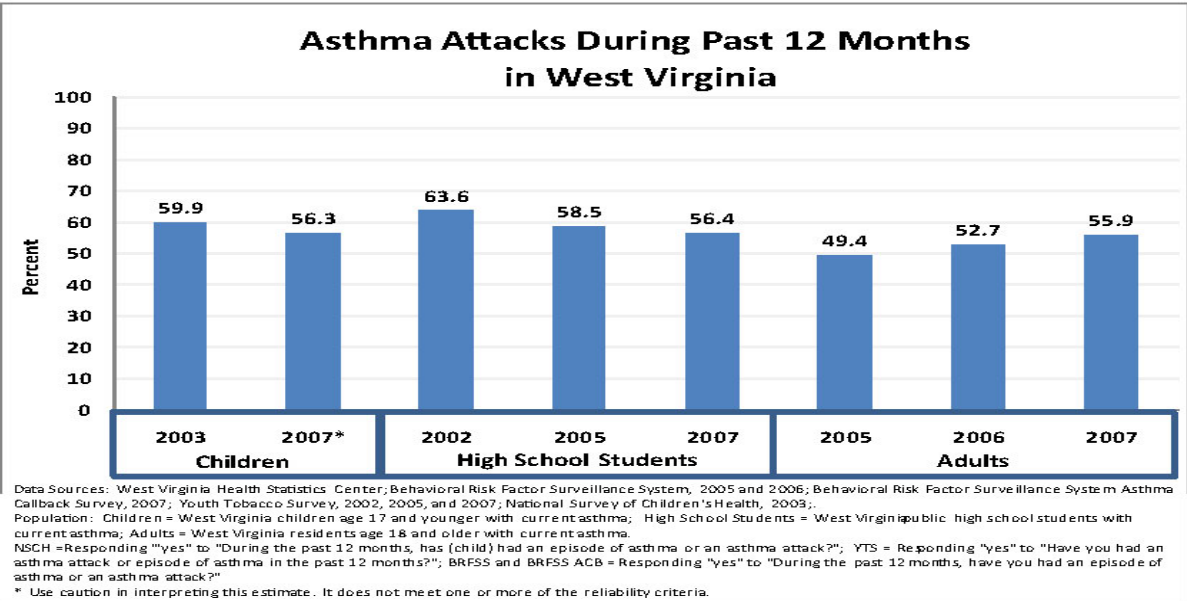
## Asthma

Asthma is a chronic lung disease that causes inflammation and narrowing of the airways. It manifests by episodes of wheezing, coughing, shortness of breath, and chest tightness. These symptoms occur when the airways react causing muscles around the airways to tighten. Mucus is commonly produced, furthering the narrowing and allowing very little air to pass through the bronchial tubes.

Good data can lead to meaningful plans for action. Physicians are critical partners when it comes to actions that will make a difference in addressing the burden of asthma. Asthma is a serious, sometimes life-threatening respiratory disease that affects the quality of life for millions of Americans. According to the 2008 Behavioral Risk Factor Surveillance System (BRFSS), an estimated 9.6% (138,000) of adults and 11.5% (43,000) of children in West Virginia currently have asthma.



West Virginians with asthma experience symptoms and complications that result in decreased quality of life, emergency room visits, hospitalizations, and even death. In fact, the next graph shows that just over half of the adults and children in West Virginia with asthma had an asthma attack in the past 12 months. Between 1996 and 2005, there was an average of nearly 2,600 hospitalizations with a primary diagnosis of asthma each year in West Virginia. In 2004 and 2005, the annual rate of hospitalizations in West Virginia rose slightly higher than the U.S. Between 2000 and 2006, 189 West Virginians have died from asthma, an average annual rate of 1.5 per 100,000 population.



The burden of asthma differs by demographic, geographic, and socioeconomic characteristics. Four populations in West Virginia at highest risk for asthma complications have been identified:

- Children: Children under the age of 15 are more likely to be hospitalized due to asthma than West Virginians aged 15-44 and 45-64
- Seniors: Adults aged 65 and older have the highest asthma hospitalization and mortality rates in West Virginia. The rate of asthma hospitalizations has more than doubled among seniors since 1996
- Adult Women: West Virginia adult females are nearly twice as likely to have asthma, twice as likely to be hospitalized for asthma and are significantly more likely to die from asthma than males. In fact, West Virginia women are just as likely to have asthma as they are to have diabetes, and asthma is more common among women than coronary heart disease, heart attack, and stroke
- West Virginians of low socioeconomic status: Adults with low socioeconomic status (those without a high school diploma and with an annual household income less than \$25,000) are significantly more likely to have asthma

#### Strengths:

The West Virginia Health Statistics Center (HSC), in collaboration with the Centers for Disease Control (CDC), maintains the BRFSS, a state-based system of health surveys that collects information on health risk behaviors and health conditions. In the past, only limited data on asthma in adults ages 18 years and older have been available through BRFSS. In order to increase the data available on asthma, the CDC converted the National Asthma Survey to a call-back survey administered nationally as part of BRFSS in 2005. HSC began conducting the BRFSS Adult and Child Asthma Follow-up Surveys annually in 2007. These surveys better define the burden of asthma in West Virginia by providing new information on asthma, such as demographics, recent asthma history, symptoms and episodes, health care utilization, knowledge of asthma management, modification to environment, medications, cost of care, work/school related asthma, and alternative therapies.

Prior to 2007, the only data available for children with asthma in West Virginia was the BRFSS Child Prevalence Module. The module only provided prevalence numbers for children with asthma in West Virginia. Using the data available in this new survey, the West Virginia Asthma Education and Prevention Program (WVAEPP) has developed A

*Strategic Plan for Addressing Asthma in West Virginia, 2010-2014* available online at: <http://www.wvasthma.org/>

This plan not only targets reducing the burden of asthma in adults, but also in children. A major goal in this plan is to teach West Virginians with asthma to self-manage symptoms effectively. Data from the 2007 and 2008 BRFSS Child Asthma Call-back Surveys were used for planning interventions that would increase self-management in West Virginians with asthma. Regular visits to a health care professional are essential in asthma control, however, only 64% of children with asthma reported visiting their healthcare provider at least twice in the past 12 months. The National Heart, Lung, and Blood Institute (NHLBI) recommends the use of a spacer/holding chamber when taking inhaler medication, but in West Virginia only 45% of children reported using a spacer with their inhaler medication. Another recommendation of the NHLBI is annual flu vaccine regardless of asthma severity, however, less than half of West Virginia children reported receiving their annual flu vaccine in the past 12 months. This and other data available in the BRFSS Asthma Call-back Surveys can be used to help WVAEPP, physicians, and others determine what is needed to help children with asthma breathe easier in West Virginia.

The West Virginia Bureau for Public Health has received funding from the U.S. Centers for Disease Control and Prevention for asthma statewide efforts since 2001. The West Virginia Asthma Education and Prevention Program (WV-AEPP) was first established as part of the West Virginia Tobacco Prevention Program but was organizationally moved to the Division of Health Promotion and Chronic Disease in 2003. This move created collaborative programs between other chronic disease programs as well as continuing coordinated efforts with the Division of Tobacco Prevention.

Since 2001, WV-AEPP has developed State capacity to address asthma for State residents. By partnering with the American Lung Association of West Virginia, a statewide network of partners, the West Virginia Asthma Coalition, has been established. This coalition has a membership totaling 76 active members and is governed by an elected Chairperson and Vice-Chair. Also, five subcommittee chairpersons are selected to facilitate the following topical areas:

- Data Sharing
- Community Education and Outreach
- Asthma Management
- Environment
- Schools and Pediatrics

The Goals of WVAC are to:

- Educate patients with asthma, health care professionals, and the general public about the seriousness of asthma
- Promote/ensure the appropriate diagnosis and management of asthma by health care professionals
- Encourage patients with asthma to enter into the continuum of care by facilitating access to care
- Encourage partnerships between patients with asthma and health care providers through modern treatment and education, in the interest of improving the quality of life for patients with asthma
- Provide the latest information on asthma health, medication and medical treatment through educational activities, printed materials, and an internet website

The WVAC subcommittees have been integral to the development of the first strategic plan. Through the work of the subcommittees several initiatives have taken place: WVAC took a leading role in advocating student “access to inhaler” policy changes at the State Board of Education level, and in the 2004 West Virginia Legislative Session was successful in pursuing commensurate legislation.

The school bus idle free zone policy, a combined effort between the WV Department of Education and the Department of Environmental Protection, Policy 4336, is an outreach project targeted at reducing diesel emissions from school buses that also includes exhaust emissions from passenger vehicles and delivery trucks on school property. The pollutants from diesel and regular gas vehicles are a common trigger of asthma attacks. This environmental air policy is being supported and promoted by WV-AEPP and the WVAC in multiple capacities. The policy was written to minimize idling and offer a smart, effective, and immediate way to reduce diesel emissions at little or no cost. In junction with providing a smart way to reduce bus emissions, all news buses purchased in 2009 have an electronic shut-off of the motor after 10 minutes of idling. The Department of Environmental Protection is offering free signs that remind all people not to let their vehicles idle for extended periods. To date, 54 county public school systems (of 55 counties), as well as a few private schools, are participating in West Virginia.

Asthma Awareness Day at the State Capitol during the Legislative Session has been an ongoing event since 2005. The most recent was held on February 19, 2009, where 18 groups were in attendance. This event is in support of increasing improved asthma friendly legislation and education for West Virginians by bringing AEPP advocates and partners in direct contact with the State delegates and other legislative staff. For the next Asthma Awareness Day activities, contact the WV-AEPP at 304-558-0644.

Open Airways in Schools, an asthma management program for youth developed by the American Lung Association, was implemented in 15 schools and reached a total of 106 students with asthma in 2006-2007. The takeACTION! Interactive CD ROM for addressing Asthma and Diabetes in West Virginia Schools was developed by a partnership with the West Virginia Board of Education, the Schools and Pediatrics Subcommittee of the West Virginia Asthma Coalition, and WV-AEPP. This interactive program was given to all educators and school nurses throughout West Virginia. This CD ROM allowed for individuals to obtain Continuing Education Units after completing the program. The takeACTION! CD ROM is also accessible online at <http://wvde.state.wv.us/osshp/section6/TRAINING.htm>.

WV-AEPP partnered with the WVU Office of Health Services Research (WVU-OHSR) to implement asthma chronic disease registries in community health centers in West Virginia. This project is ongoing and WVAEPP and WVU-OHSR continue to add to the number of participating community health centers and other facilities that have an asthma registry system. To view the current mapping and list of participating clinics: [www.hsc.wvu.edu/som/cmed/ohsr/index.htm](http://www.hsc.wvu.edu/som/cmed/ohsr/index.htm).

WV-AEPP partnered with WVU Office of Health Services Research to sponsor a Summit on Addressing Asthma in WV Community Health Centers. This two day event featured presentations about The Statewide Asthma Initiative in West Virginia, the CDEMS Program, The Role of the WV Primary Care Association, and offered time for group discussions.

WV-AEPP developed a project with CAMC Health Education and Research Institute, Inc. (CAMC Institute) to develop a Self-Care Management Program for Seniors with Asthma and other chronic lung diseases. CAMC Institute is a part of the CAMC health system which is the largest not-for-profit health system in West Virginia and is the organization responsible for research, continuing education, and oversight of external funding. CAMC Institute is applying for funds on behalf of the CAMC Pulmonary Rehabilitation Program who is in charge of the core development of the program - a self-care management program for seniors with asthma.

A Pulmonary Asthma Handbook for patients is currently being developed as well as a complete education curriculum and follow-up policy. CAMC is also creating an Asthma Database to track their patients. The goal of this program is to reduce the burden of asthma in Southern West Virginia and with the senior population.

WV-AEPP in partnership with the West Virginia Hospital Association and two in-state hospitals, Camden-Clark Hospital and United Hospital, developed the ED Pilot Project. A group collaborative was created to organize an effort to implement a pilot project aimed at reducing asthma-related hospitalizations among patients who receive



treatment for asthma in Emergency Departments and to track these patients effectively. The main objectives of the ED Pilot Project were to: implement the pilot asthma intervention in one hospital Emergency Department in West Virginia, with the intent to achieve a significant positive change from baseline for each of the asthma indicators; and secondly, to evaluate the pilot asthma intervention by measuring the total number of primary asthma admissions through the ED during the pilot, the total number of asthma-related ED visits, and develop a system to identify individuals who return to the ED for asthma-related problems.

An on-line education program is provided by the CAMC Hospital Corporation titled: *Asthma Education for Primary Care Providers*. This web-based curriculum has been a method for accomplishing the newest NHLBI guidelines. CEU's and CRCE's are available to various healthcare providers upon completion of this course. The course is available at [www.camcinstitute.org](http://www.camcinstitute.org)

The WV-AEPP developed a quick reference resource trifold guide for health care providers that contain the 2007 NHLBI Guidelines for the Diagnosis and Treatment of Asthma Expert Panel 3 Report in a condensed version – available by contacting the WV-AEPP at 304-558-0296 or view online at [www.wvasthma.org](http://www.wvasthma.org).

In celebration of World Asthma Day, WV-AEPP staff and respiratory therapists from Charleston Area Medical Center gathered at The Appalachian Power Baseball Park in June 2008 distributing educational materials on asthma and providing free spirometry testing analyzed by a pulmonologist on site. For the next World Asthma Day Celebration activities contact the WV-AEPP at 304-558-0644.

WV-AEPP in partnership with the Division of Tobacco Prevention (DTP) developed two commercials addressing cigarette smoke as a trigger for asthma. The commercials are 30 seconds in length and reference the WV-AEPP website, [www.wvasthma.org](http://www.wvasthma.org), for information on asthma. The Division of Tobacco Prevention references the free Quit line as a resource to stop smoking. The commercials aired for approximately three months in the Mid-Ohio Valley Region. The commercials can be viewed at [www.wvdtpp.org](http://www.wvdtpp.org).

A brochure describing tobacco use and asthma risks titled, *Tobacco Use & Asthma* – was developed by WV-AEPP in cooperation with the WV Division of Tobacco Prevention. This brochure promotes asthma awareness, smoking risks and the WV Quit line. This brochure is available upon request by contacting the WV-AEPP Program at 304-558-0644 or by viewing it on the website at [www.wvasthma.org](http://www.wvasthma.org).

The *Asthma Quarterly* Report, formerly known as *Breathe in the Mountains*, was first published and distributed in the Fall of 2005. There have been a total of five additional newsletters since then and it is now distributed electronically quarterly. The Asthma

Report is a great source for the latest asthma research, medical advances, legislation, asthma activities, and other general information. The *Asthma Quarterly* Report and other publications are available to view on-line at [www.wvasthma.org](http://www.wvasthma.org) or to be added to the emailing list, contact the WV-AEPP Program at 304-558-0644.

WV-AEPP will continue to use the public health approach to address the needs of West Virginians with asthma. This approach involves defining and measuring the problem, determining the cause or risk factors for the problem, determining how to prevent or ameliorate the problem, and implementing effective strategies on a larger scale.

### **Unintentional Injuries/Major Causes of Death**

Unintentional injuries and violence are the leading causes of death, hospitalization, and disability for children ages 1-18 nationally.

- Unintentional injuries (908) were the leading cause of death for children and youth ages 1-24 in WV during the period 2002-2006
- Suicide (171) was the second leading cause of death for youth ages 15-24 in West Virginia during the period 2002-2006
- Suicide (11) was the third leading cause of death for youth ages 10-14 in West Virginia during the period 2002-2006
- Homicide was the third leading cause of death for children ages 1-9 (15) and for youth ages 15-24 (74) in West Virginia during the period 2002-2006
- Unintentional suffocation (11) was the leading cause of injury death for children under age 1 in West Virginia during the period 2002-2006
- Unintentional motor vehicle traffic crashes (553) were the leading cause of injury death for children and youth ages 1-24 in West Virginia during the period 2002-2006
- Unintentional poisoning (150) was the second leading cause of injury death for youth ages 15-24 in West Virginia during the period 2002-2006

Understanding injury rankings among other causes of death is important in determining their physical and economic role in each state. Although injuries are the leading cause of death for ages 1-34, knowing what types of injuries cause the majority of deaths and hospitalizations can influence program planning and development efforts. Tables below

show the top 5 causes of death by age group in the state and the top 5 causes of injury death by age group in the State.

### Leading Causes and Total 5-Year Incidence of Deaths by Age Group, West Virginia, 2002-2006

Age Groups								
Rank	<1	1 - 4	5 - 9		10 - 14	15-24	All Ages	
1	Congenital Anomalies 137	Unintentional Injury 47	Unintentional Injury 42		Unintentional Injury 50	Unintentional Injury 769	Heart Disease 28,898	
2	SIDS 124	Congenital Anomalies 10	Malignant Neoplasms 21		Malignant Neoplasms 16	Suicide 171	Malignant Neoplasms 23,186	
3	Short Gestation 84	Homicide 9	Homicide 6		Suicide 11	Homicide 74	Chronic Low. Respiratory Disease 6,366	
4	Maternal Pregnancy Comp. 52	Malignant Neoplasms 8	Benign Neoplasms 2	Congenital Anomalies 2	Congenital Anomalies 5	Homicide 5	Malignant Neoplasms 51	Cerebrovascular 5,970
5	Placenta Cord Membranes 31	Heart Disease 4	Eight Tied* 1		Heart Disease 3	Heart Disease 38	Unintentional Injury 5,187	

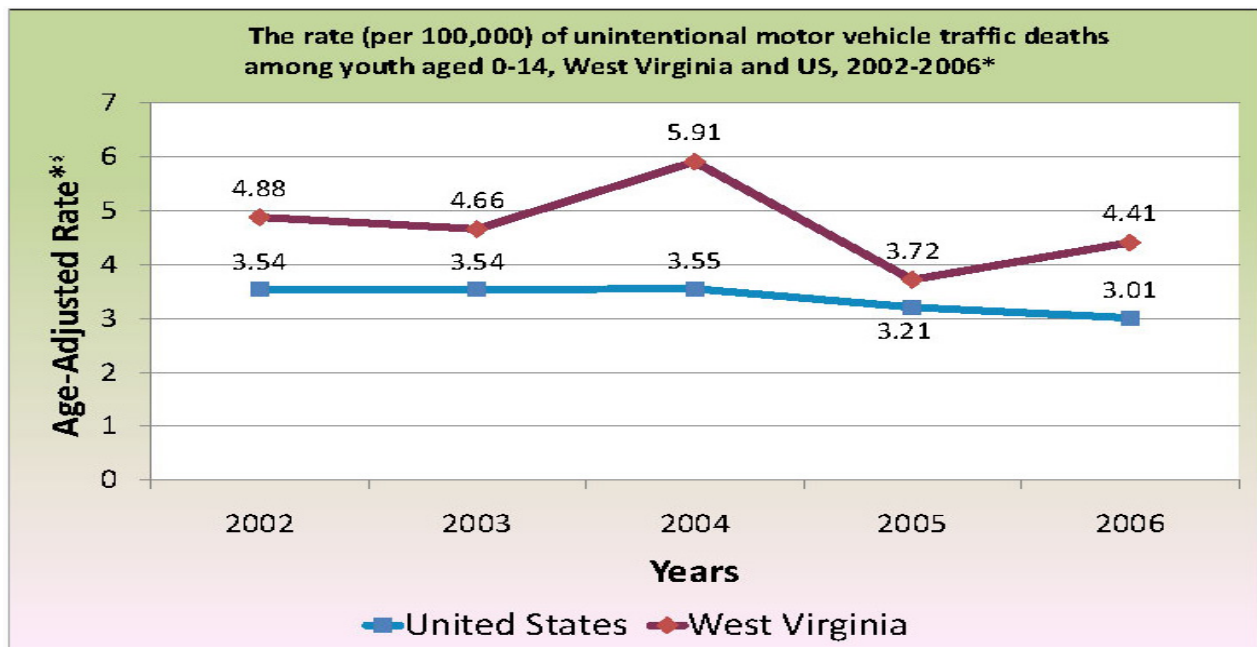
\*Eight mechanisms were tied for the fifth ranking among children aged 5-9 including *Cerebrovascular, Heart Disease, Influenza & Pneumonia, Meningitis, Nephritis, Perinatal Period, Septicemia, and Viral Encephalitis*. Each of these mechanisms had a single death.

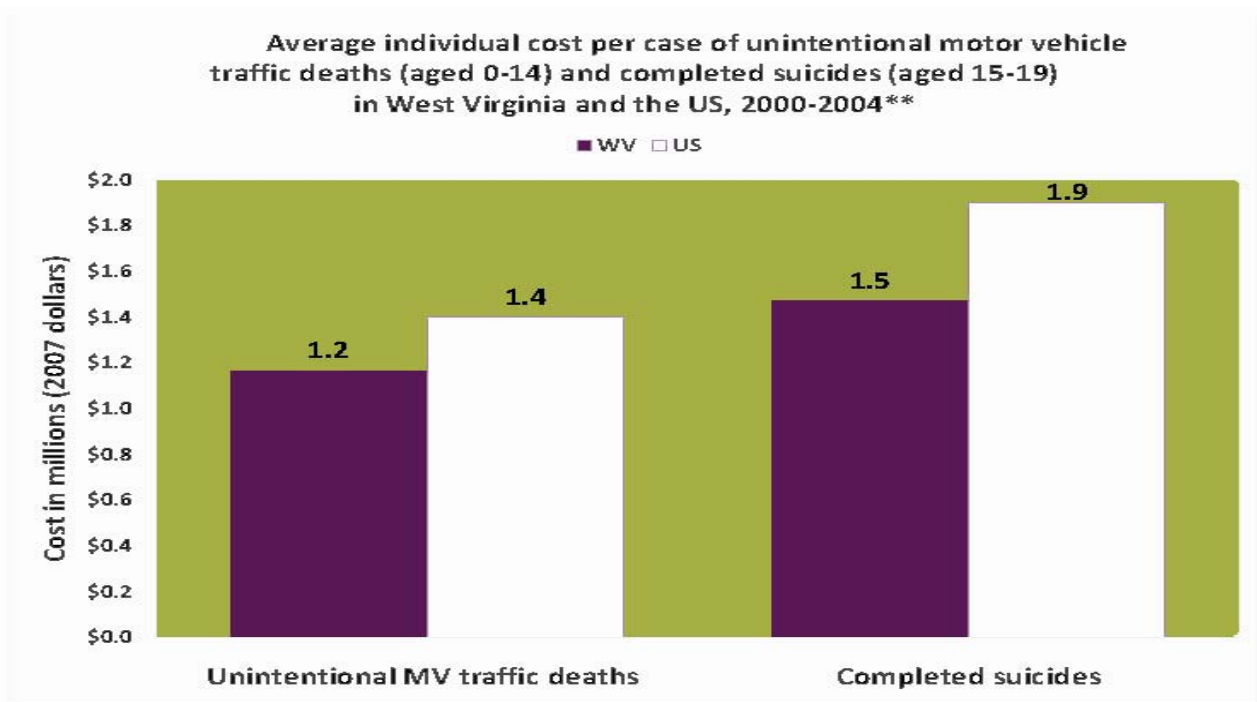
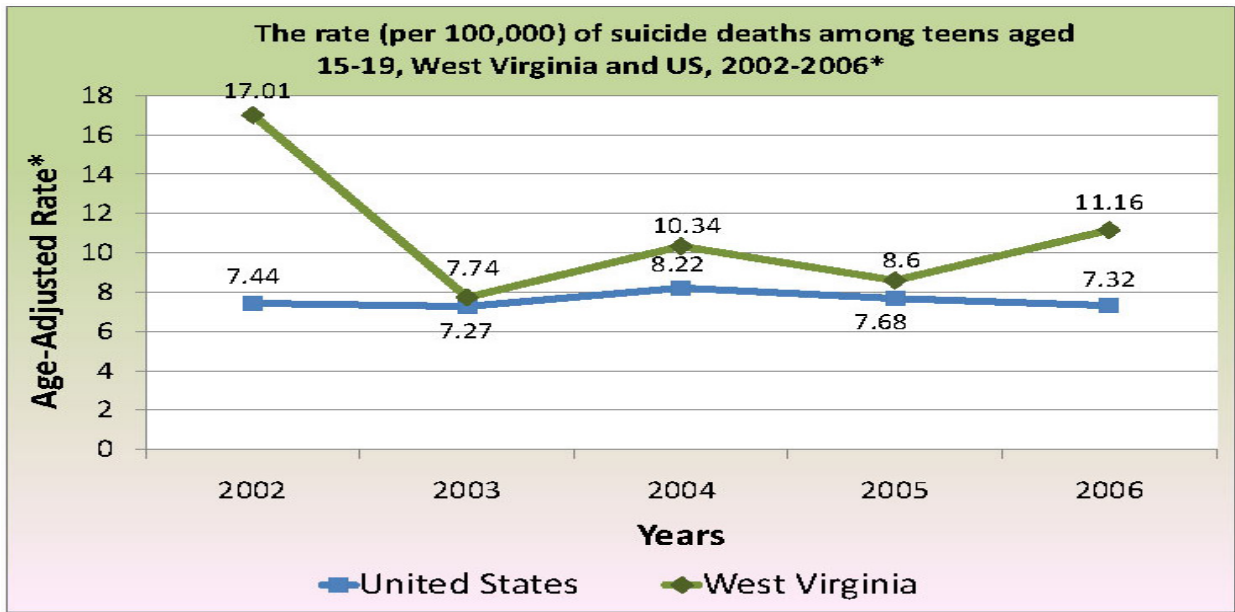
## Leading Causes and Total 5-Year Incidence of Injury Deaths by Age Group, West Virginia, 2002-2006

		Age Groups							
Rank	<1	1 - 4		5 - 9	10 - 14		15-24	All Ages	
1	Unintentional Suffocation 11	Unintentional MV Traffic 15		Unintentional MV Traffic 22	Unintentional MV Traffic 35		Unintentional MV Traffic 481	Unintentional MV Traffic 1,922	
2	Homicide Other Spec., Classifiable 6	Unintentional Drowning 10	Unintentional Fire/burn 10	Unintentional Fire/burn 7	Suicide Suffocation 6		Unintentional Poisoning 150	Unintentional Poisoning 1,160	
3	Unintentional MV Traffic 4	Unintentional Suffocation 5		Homicide Firearm 4	Suicide Firearm 4	Undetermined Fire/burn 4	Suicide Firearm 108	Suicide Firearm 938	
4	Homicide Unspecified 2	Undetermined Suffocation 2	Homicide Other Spec., Classifiable 3	Homicide Unspecified 3	Unintentional Drowning 3	Unintentional Fire/burn 3	Unintentional Other Land Transport 3	Homicide Firearm 55	Unintentional Fall 665
5	Six Tied* 1	Three Tied** 2		Unintentional Other Land Transport 2	Five Tied*** 2		Suicide Suffocation 45	Homicide Firearm 292	

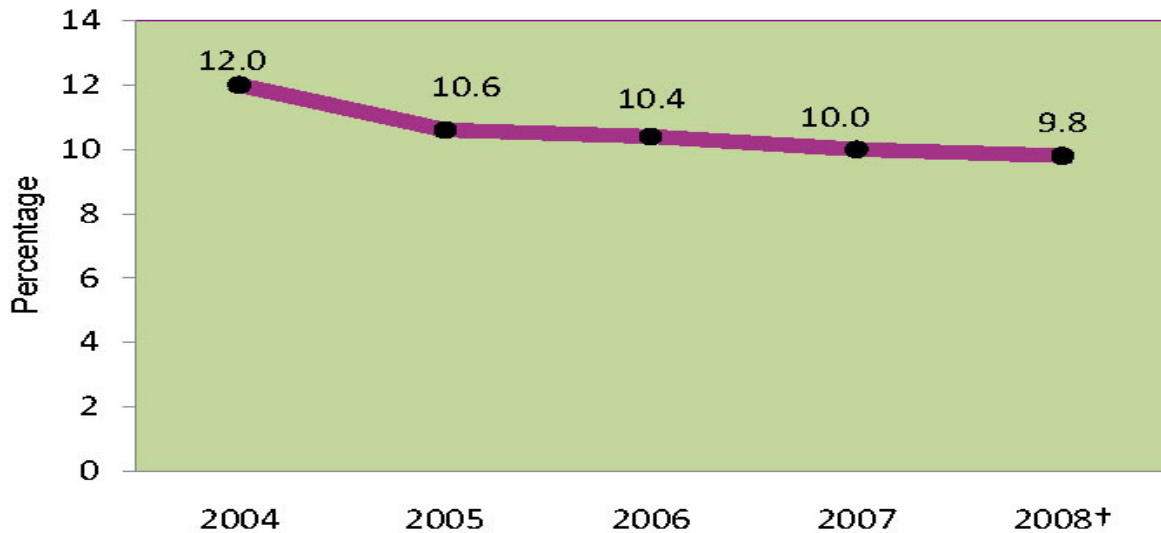
NEC = Not Elsewhere Classifiable. \*Six mechanisms were tied for the fifth ranking among infants younger than 1 including *Homicide Other Spec., NEC, Homicide Suffocation, Undetermined Drowning, Unintentional Fire/burn, Unintentional Other Spec., Classifiable, and Unintentional Unspecified*. Each mechanism had a single death. \*\*Three mechanisms were tied for the fifth ranking among children aged 1-4 including *Homicide Firearm, Undetermined Fire/burn, and Unintentional Pedestrian, Other*. Each mechanism had two deaths. \*\*\*Five mechanisms were tied for the fifth ranking among adolescents and teens aged 10-14 including *Homicide Firearm, Homicide Suffocation, Undetermined Poisoning, Unintentional Fall, and Unintentional Other Spec., Classifiable*. Each mechanism had two deaths.

The federal Maternal and Child Health Bureau Block Grant program requires State MCH programs to report on 18 National Performance Measures (NPM), two of which directly address injuries. The following figures show the trend in the rate of deaths for children aged 14 years and younger caused by motor vehicle crashes, the trend in the rate of suicide deaths among youths aged 15-19, and the cost per individual case between the State and the United States for childhood MV traffic deaths and youth suicides.

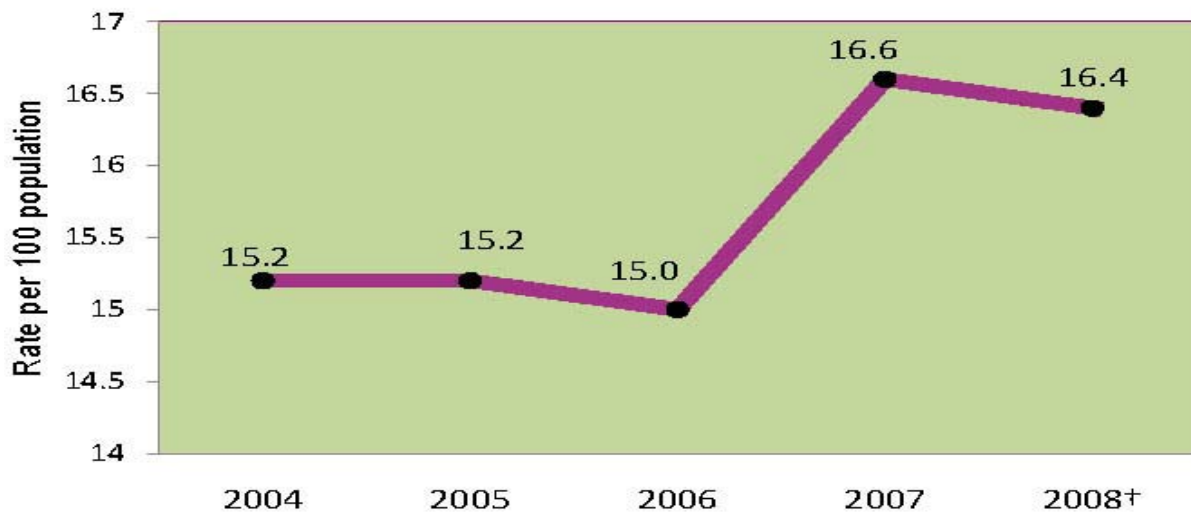




The West Virginia State MCH program reports on two State Performance Measures (SPM) that address injury and violence. The following figures show the trend in efforts to decrease the percentage of high school students who drink alcohol and drive and the trend in efforts to decrease the rate of high school students who never or rarely wear a seatbelt when riding in a car driven by someone else.



The percentage of high school students who drink alcohol and drive, 2004-2008\*



The rate of high school students (per 100) who never or rarely wear a seatbelt when riding in a car driven by someone else, 2004-2008\*

**Strengths:**

West Virginia continues to develop traffic safety materials targeted at young people. Through collaboration, the Department of Education's school-based health education is being improved to incorporate information on health-related decision making. The State's Division of Highways will implement plans for the Strategic Highway Safety Plan.



The West Virginia Council for the Prevention of Suicide is working to reduce the stigma associated with seeking and receiving mental health services, reduce access to lethal means, provide support to suicide survivors, promote support for suicide prevention among providers, and improve public awareness and understanding of suicide.

• **Children with Special Health Care Needs**

**National Survey**

The National Survey of Children with Special Health Care Needs, sponsored by the Health Resources and Services Administration (HRSA), in 2005-2006 produced national and state estimates of prevalence and impact of special health care needs among children 0–17 years of age. Following are the results for West Virginia:

**WEST VIRGINIA**

**NOTE:** All Statistics are based on parental reports.

**Estimate of Number of Self-Reported Children with Special Health Care Needs: 69,567**

**PREVALENCE STATISTICS**

-	<b>State %</b>	<b>National %</b>
Percent of Children with Special Health Care Needs	18.3	13.9
<b>Prevalence By Age:</b>	<b>State %</b>	<b>National %</b>
Children 0-5 years of age	11.4	8.8
Children 6-11 years of age	20.5	16.0
Children 12-17 years of age	22.1	16.8
<b>Prevalence by Sex:</b>	<b>State %</b>	<b>National %</b>
Male	20.4	16.1
Female	16.0	11.6
<b>Prevalence By Poverty Level:</b>	<b>State %</b>	<b>National %</b>
0%-99% FPL	23.6	13.9
100%-199% FPL	19.4	14.0
200%-399% FPL	15.6	13.6
400% FPL or greater	14.9	14.0
<b>Prevalence By Race/Ethnicity:</b>	<b>State %</b>	<b>National %</b>
Non - Hispanic	18.1	15.0
White	17.9	15.5
Black	14.2	15.0
Asian	----	6.3
Native American/Alaskan Native	----	14.5
Native Hawaiian/Pacific Islander	----	11.5
Multiple Races	30.2	17.9
Hispanic	19.6	8.3
Hispanic, Spanish language household	**	4.6
Hispanic, English language household	20.2	13.1

## INDICATOR

<b>Child Health:</b>	<b>State %</b>	<b>National %</b>
Percent of Children with Special Health Care Needs whose conditions affect their activities usually, always, or a great deal.	26.9	24.0
Percent of Children with Special Health Care Needs with 11 or more days of school absences due to illness.	22.3	14.3
<b>Health Insurance Coverage:</b>	<b>State %</b>	<b>National %</b>
Percent of Children with Special Health Care Needs without insurance at some point in the past year.	6.8	8.8
Percent of Children with Special Health Care Needs currently uninsured.	1.9	3.5
Percent of currently insured Children with Special Health Care needs with insurance that is not adequate.	31.7	33.1
<b>Access to Care:</b>	<b>State %</b>	<b>National %</b>
Percent of Children with Special Health Care Needs with any unmet need for specific health care services.	14.0	16.1
Percent of Children with Special Health Care Needs with any unmet need for family support services.	4.5	4.9
Percent of Children with Special Health Care Needs needing specialty care who had difficulty getting a referral.	19.7	21.1
Percent of Children with Special Health Care Needs without a usual source of care (or who rely on the emergency room).	5.4	5.7
Percent of Children with Special Health Care Needs without a personal doctor or nurse.	3.5	6.5
<b>Family Centered Care:</b>	<b>State %</b>	<b>National %</b>
Percent of Children with Special Health Care Needs without family centered care.	31.6	34.5
<b>Impact on Family:</b>	<b>State %</b>	<b>National %</b>
Percent of Children with Special Health Care Needs whose families pay \$1,000 or more in medical expenses per year.	18.00	20.0
Percent of Children with Special Health Care Needs whose condition caused financial problems for the family.	18.2	18.1
Percent of Children with Special Health Care Needs whose families spend 11 or more hours per week providing or coordinating care.	14.3	9.7
Percent of Children with Special Health Care Needs whose condition affected the employment of family members.	21.1	23.8

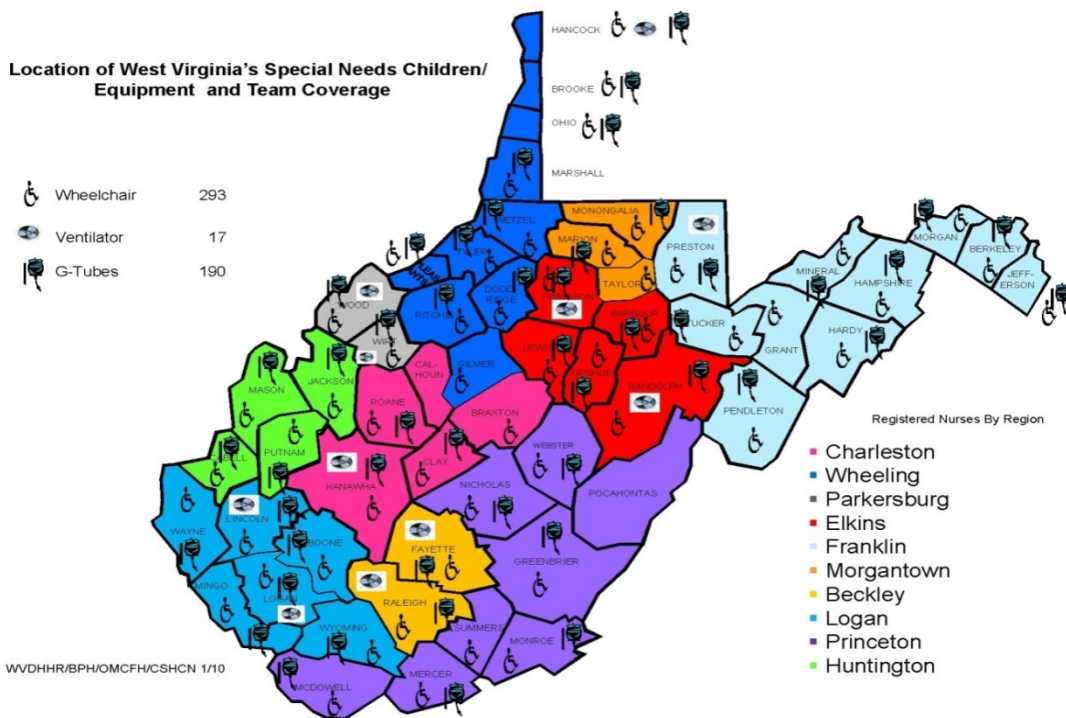
The above statistics set the stage for much of the needs assessment of the children with special needs in West Virginia.

### **Access to Quality Health Care**

The question asked of consumers, providers, and other friends of Title V is, “What is the most critical need you and/or your child have related to health?” Families and providers alike responded, “Access to comprehensive, affordable health care”

In response to this, the CSHCN Program increased clinical capacity, offering clinic care at locations where demand can support, an increased payer mix, and have designed child and family assessment to account for both medical and psycho-social need.





Monitoring outcomes for children with special health care needs poses problems:

- Treatment of chronic conditions is only partially effective. Most of these children will never be cured, so the presence of a condition cannot be used as an outcome measure
- Many external factors are important to successful outcomes but are not easily measured. The presence of the family and community supports is hard to measure yet everyone agrees they have positive implications for patient well-being

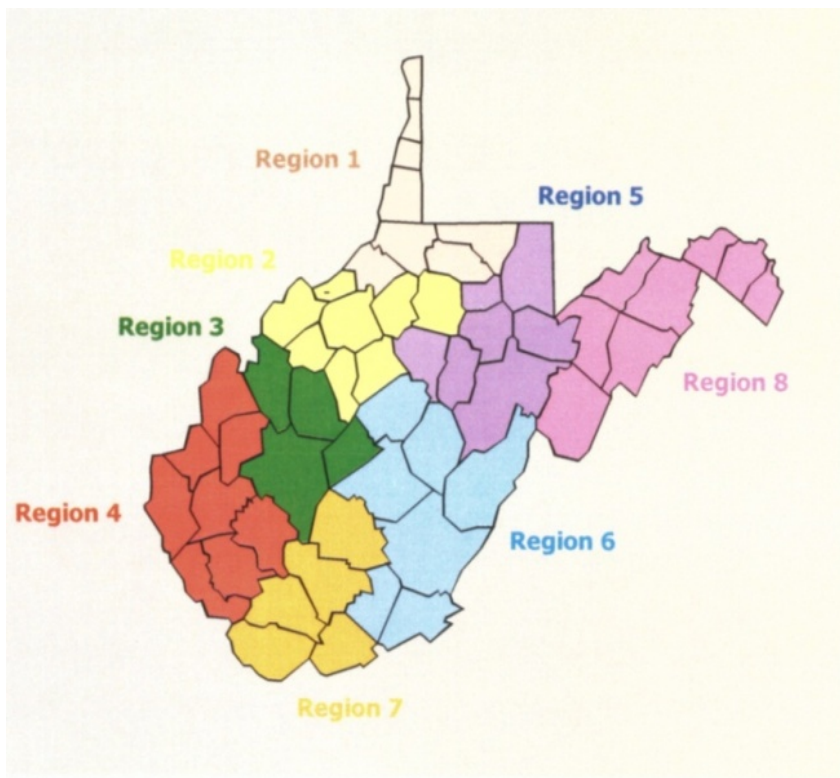
West Virginia Birth to Three (WV BTT) is a comprehensive system of services and supports for families and their infants and toddlers with disabilities, developmental delays, or those at risk of developmental delays. In West Virginia, the WV BTT system is administered by the Office of Maternal, Child and Family Health (OMCFH), Bureau for Public Health (BPH) at the West Virginia Department of Health and Human Resources (DHHR) in conjunction with the West Virginia Early Intervention Interagency Coordinating Council (WVEIICC/ICC). The WVEIICC is appointed by the Governor to advise and assist the lead agency in planning early intervention services. The State Legislature, public agencies (including child care, Head Start, and education), public and private service providers, and parents are represented on the Council. The WVEIICC's vision is to optimize the health and development of young children with special needs. The Council believes that early intervention services should:

- be family-centered
- support and enhance the capacity of families to fully participate in their communities
- support and enhance the capacity of communities to include families
- have adequate and flexible resources and funding
- be accountable, responsive and meaningful for families
- ensure an individualized, integrated and coordinated team approach to service planning and delivery
- ensure the development and retention of sufficient numbers of qualified personnel
- be collaborative, seamless and comprehensive in order to provide service options for children with special needs ages birth to five and their families in settings and activities which are available for their typical age peers in natural environments within their community

Specialized services to infants and toddlers in West Virginia were provided beginning in the early 1970s under federal child development grants. By the mid-1980s, services for infants and toddlers with special needs were available throughout the State by a group of designated providers. However, adequate funding for these services was not available; therefore, waiting lists and lack of specialty services were common. The passage of the Education of All Handicapped Children Act Amendments of 1986 (Public Law 99-457) provided needed support for the State to plan a comprehensive early intervention system. In 1991, the State of West Virginia entered full implementation of Part C of the Act. Twelve providers served as the points of entry into the system, coordinating and delivering services in accordance with federal and state policies and regulations.

West Virginia conducted a comprehensive system evaluation of the State's early intervention system beginning in 1999. The purpose of the evaluation was to determine what was working well and what needed to be revised as the WV BTT system approached its ten-year implementation mark. This evaluation resulted in recommendations for improvements. Several recommendations for improving the State's infrastructure were made including increasing the capacity of the BTT State system to implement, monitor and provide a comprehensive statewide system of services, improving the training and technical supports provided to personnel, assuring adequate financial support, and streamlining the financing and data system. The evaluation also found that there was a critical need to increase the numbers of qualified personnel available to provide services at the local level. This recommendation resulted in the decision to access practitioners through an open vendor system rather than a dedicated provider system, thus allowing more early intervention service options for both families and providers.

In the dedicated provider system, WV BTT contracted with one agency in each of the 12 geographic areas. These agencies served as the single point of entry for BTT in their region, accepting referrals, assuring procedural safeguards, determining eligibility, and provided needed services in addition to the dedicated provider functions such as child find, development of interagency agreements, maintenance of the BTT data system, and quality assurance. As WV BTT increased interagency participation and began to enroll additional agencies and individuals to provide services for children and families, the system continued to contract with local lead agencies, referred to as Regional Administrative Units (RAUs).



Through a grant process, the OMCFH identified eight Regional Administrative Units, depicted in the above map, which are responsible for assuring the local administration of the early intervention system within a specific region of the State. These administrative responsibilities include assuring local comprehensive child find activities, providing access to a central directory of community resources, participating in interagency collaborative efforts, and coordinating local quality assurance activities. Within the child find duties, one of the most important functions performed by the RAU is to inform physicians, families, therapists, and other referral sources about the two-day referral requirement. Federal regulations require any referral source believing that an

infant or toddler needs early intervention services to refer that child to the early intervention system within two (2) working days.

The RAU is also responsible for helping families link to other family support resources in the community. Families are linked to other families of children with special needs as well as family leadership and educational opportunities. The RAU employs a parent or parents in the role of Parent Partners to facilitate linkages with other family support services in the region. The RAU serves as the system point of entry for families within the region. In that role, the RAU is responsible for practitioner recruitment, child referral, coordination of evaluation and assessment activities, eligibility determination, Individual Family Service Plan (IFSP) development, procedural safeguards, and on-going record maintenance.

### Family-Centered Philosophy Underlying Part C

Part C of the IDEA specifies family involvement in establishing outcomes for children within the context of each unique family system, designing strategies for intervention and determining progress on a routine basis. Family involvement is achieved through a family-centered service philosophy in early intervention. In a family-centered system, the needs identified by the family to help them enhance their child's growth and development guide all aspects of the decision-making process. At its core, this philosophy has four main ideals. First, family-centered service provision involves a partnership negotiated between the family and professionals with shared responsibilities for designing and implementing individualized support plans. Second, a shared understanding of and respect for one another's perspective in relation to past experience and future hopes and dreams for the child are an important aspect of family-guided services. Third, information sharing is a critical component of family-guided services. Information sharing occurs when both the professionals and the family share information needed to assist the family in making an informed decision about services and supports. Fourth, professionals must respect the family's abilities to make informed decisions about their children within the context of each unique family structure.

### Guiding Principles for Supporting Young Children and Their Families

The seven guiding principles of a foundation for the vision of effective early intervention services and supports (the Colorado Service Coordination Training [2001]).

- All children have the right to belong, to be welcomed, and to participate fully in the typical places and activities of their communities
- Families are the primary decision-makers
- Children grow and develop in the context of relationships with their families and other caregivers
- All children are unique with their individual strengths and talents. The presence of a disability or special need is not the defining characteristic of any child

- The lives of families are enhanced when they are successful in maintaining everyday lives and relationships
- Everyday routines, activities, and places offer countless opportunities for children to learn and develop
- Children with and without special needs learn important things from one another

### Service Coordination in Birth to Three

Service coordination is the foundation of the early intervention system. Service coordination is an active, on-going process which assists families in accessing and receiving the services, resources, and supports they need to enhance their child's development. All children eligible for WV BTT services are provided with service coordination. This service coordination assures that children and their families receive their rights, procedural safeguards, and services authorized through federal regulations and state policies. Of course, service coordination needs vary from family to family. For example, service coordination needs are often more substantial during the family's entry into the system, at annual IFSP meetings, at critical developmental or health junctures, and then again at transition out of the system.

The WV BTT system makes a distinction between interim and on-going service coordination providers. Beginning with referral to the WV BTT system through the initial Individualized Family Service Plan (IFSP), a family receives interim service coordination through the RAU. The interim service coordinator is responsible for initially interviewing and gathering information from the family. At the initial IFSP, an on-going service coordinator is assigned to work with the family and child. Because the RAU has administrative functions such as assisting with the quality assurance activities, the on-going service coordinator cannot be associated with the RAU.

Under the federal special education law, the service coordinator's responsibilities can be broken into four broad categories. First, the service coordinator is responsible for coordinating all early intervention and other services identified in the Individualized Family Service Plan. In this role, the service coordinator identifies the formal and informal supports the child and family have prior to entering the early intervention system to make sure that early intervention services coordinate with, not replace, these existing services.

Second, the service coordinator serves as the single point of contact to help families in obtaining the services and assistance they need. In addition to identifying specialty services, the service coordinator may assist the family in identifying and securing resources to ensure a healthy and safe living environment for the entire family such as WIC (nutrition and food subsidies), HUD (housing subsidies), and CHIP (subsidized health insurance).

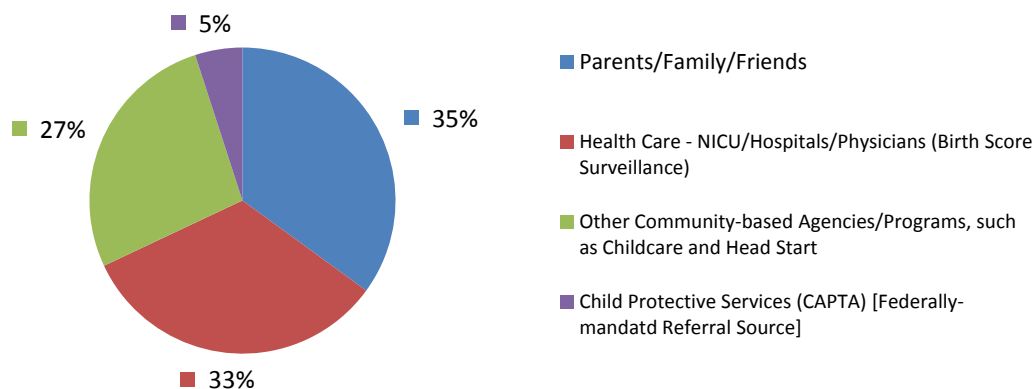
The timely delivery of available services is the third primary responsibility of the service coordinator. Finally, the service coordinator is responsible for assuring that each family is informed as to its rights, options, and roles within the early intervention system.

Additionally, the federal special education law requires that service coordinators carry out the following specific activities for each child and family:

- identifying the family’s concerns related to their child’s unique needs
- coordinating the performance of evaluations and assessments
- facilitating and participating in the development, review, and evaluation of IFSPs
- assisting families in identifying available service practitioners
- coordinating and monitoring the delivery of available services
- informing families of the availability of advocacy services
- coordinating with medical and health providers
- facilitating access to financial resources
- facilitating the development of a transition plan into, within, or from preschool, or other services, as appropriate

Under the federal regulations of the Individuals with Disabilities Education Act (IDEA), each state’s lead agency must assure that all potentially eligible infants and toddlers with developmental delays under the age of three are identified and provided with appropriate developmental services as identified on the child and family’s IFSP. States are not allowed to have waiting lists for services. Eligibility for IFSP services is not based on income – a family of any educational or income level may have a child with developmental delay. Eligibility is based on the child having a developmental delay in the areas of cognition, fine or gross motor skills, language, social/emotional, or adaptive skills.

### Referral Sources for Children in WV Birth to Three Between 7/01/06 and 6/30/07



Public health surveillance systems play a major role in early identification of infants with developmental delay who are referred to BTT/IDEA Part C. This includes the universal Birth Score surveillance completed by all West Virginia licensed birthing facilities which identify developmental delay, documents hearing screening, and identifies infants at risk of post-neonatal mortality. These infants all receive “special handling” by a cadre of providers who work in partnership with OMCFH, see details in Right From The Start, the State’s perinatal program.

### Child Outcomes

West Virginia BTT measures performance outcomes for infants and toddlers and their families who receive Part C early intervention services, using nationally established criteria.

National Child and Family Outcomes for Part C of IDEA were developed through a multi-year, broad-based stakeholder process that was facilitated by the national Early Childhood Outcomes Center (ECO). The U.S. Department of Education then charged each state with establishing systems to measure and report on the percentage of children who received WV BTT services and achieved the following outcomes:

- positive social emotional skills (including positive social relationships)
- acquisition and use of knowledge and skills (including early language/communication)
- use of appropriate behaviors to meet their needs

Baseline data has been gathered via a phase-in process and was initially reported to the Office of Special Education Programs (OSEP) in 2008. West Virginia BTT tracks three Child Outcome Indicators, as indicated on the graph below:

<b>Measurable and Rigorous Targets for Child Outcomes</b>			
<b>Summary Statements</b>	<b>Baseline Data 2008</b>	<b>Targets for FFY 2009 (% of Children)</b>	<b>Targets for FFY 2010 (% of Children)</b>
<b>Outcome A. Positive social-emotional skills (including social relationships)</b>			
1. Of those children who entered the program below age expectations, the percent that substantially increased their rate of growth in this outcome area by the time they exited the program.	71.0%	71.0%	71.05%
2. The percent of children who were functioning within age expectations in this outcome area by the time they exited			

the program.	77.5%	77.5%	77.55%
<b>Outcome B. Acquisition and use of knowledge and skills (including early language/communication)</b>			
1. Of those children who entered the program below age expectations, the percent that substantially increased their rate of growth in this outcome area by the time they exited the program.	78.7%	78.7%	78.75%
2. The percent of children who were functioning within age expectations in this outcome area by the time they exited the program.	70.0%	70.0%	70.05%
<b>Outcome C. Use of appropriate behaviors to meet their needs</b>			
1. Of those children who entered the program below age expectations, the percent that substantially increased their rate of growth in this outcome area by the time they exited the program.	82.3 %	82.3%	82.35%
2. The percent of children who were functioning within age expectations in this outcome area by the time they exited the program.	80.2%	80.2%	80.25%

## Family Outcomes

All states providing early intervention services under Part C of the IDEA must have a system in place to measure three family outcomes identified by the U.S. Department of Education.

### Strengths:

West Virginia Birth to Three uses a nationally developed family survey to measure the benefits that families experience as a result of their involvement in the WV BTT early intervention system. Surveys are sent to the family of each child that exits WV BTT. National outcomes for families that receive Part C/West Virginia Birth to Three services:

- Families know their rights and effectively communicate their children's needs
- Families understand their children's strengths, abilities, and special needs
- Families help their children develop and learn

The following data is reported for responding to families whose children exited the WV Birth to Three system during the FFY 2008.



Measurement	Percent Response At or Above Standard
A. Percent of families participating in Part C who report that early intervention services have helped the family know their rights.	82.4% strongly or very strongly agree (380)
B. Percent of families participating in Part C who report that early intervention services have helped the family effectively communicate their children's needs.	79.6% strongly or very strongly agree (367)
C. Percent of families participating in Part C who report that early intervention services have helped the family help their children develop and learn.	89.2% strongly or very strongly agree (411)

### CSHCN Program

The Children with Special Health Care Needs (CSHCN) Program administered by the Office of Maternal Child and Family offers medical and care coordination services to children and their families, if the child has chronic medical diagnosis.

The WV Children with Special Health Care Needs Program continued a strong commitment to family-centered, community-based, direct services during calendar year 2009. During calendar year 2009, 1,352 children and youth were served through a network of 28 CSHCN community-based specialty care clinics, and through private specialty physicians' offices state wide. Of the 1,352 visits provided through the clinic system, 519 visits were for initial diagnostic evaluations. During this period, 98% of children participating in CSHCN were also Medicaid beneficiaries. This increase over the year 2008 percentage is attributed to the continuing commitment of CSHCN to assist families in obtaining health care financing by assisting with SSI and/or CHIP/Medicaid applications. As of December 2008, there were 9,233 children in WV under the age of 18 receiving SSI benefits. During CY 2009, 748 children ages 0-18 received both SSI and CSHCN benefits. This indicates that the CSHCN Program served 8.2% of WV children under the age of 18 who receive SSI benefits.

### SSI Beneficiaries/Child by Age for West Virginia

West Virginia	Total	Age			Amount of Payments (in Thousands)
		Under 5	5-12	13-17	
Total	9,223	1,243	4,392	3,598	39,546

Source: Social Security Administration

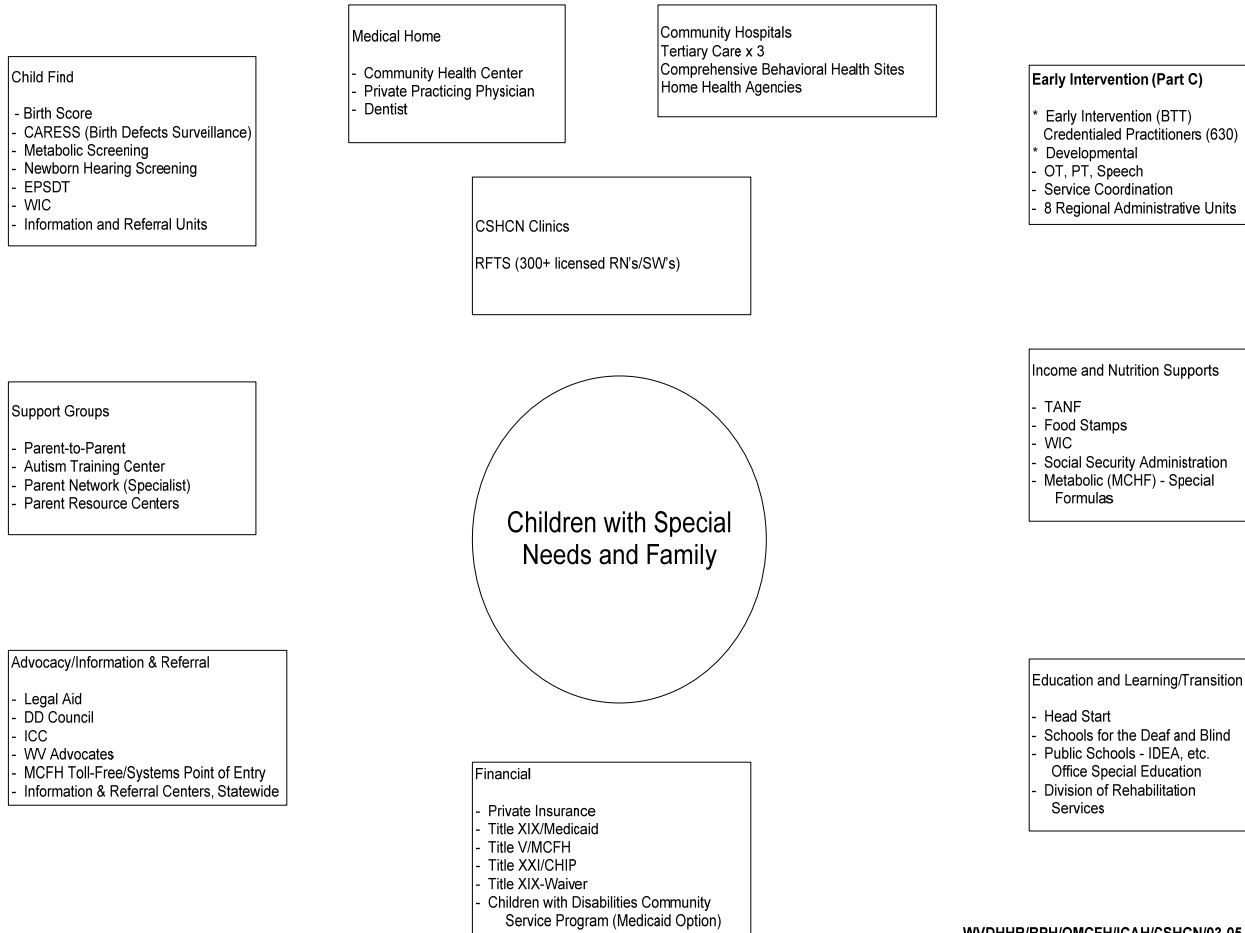
Multi-disciplinary teams provide care-planning and care-coordination to children with special health care needs and their families. The multi-disciplinary team includes the child/parent, physicians, nurses, social workers, therapists, school personnel, vendors and community services who are providing care for the child. Team members, led by the CSHCN nurse and/or social worker, collaborate with the child/family in developing an appropriate, comprehensive care plan for the child. During CY 2009, 1,649 Patient Care Plans were completed to assure a continuum of comprehensive medical care and transition to adult care as appropriate.

The care coordination teams continue to hold weekly planning meetings to better coordinate their work and to discuss responsibilities for tasks within the group. This assists with setting and meeting work priorities, and serves as an opportunity for review of program policies and procedures.

Efforts are made to coordinate the CSHCN specialty care with the child's medical home, and to keep the primary care physician informed of treatment plans. CSHCN strives to provide service in a manner that is accessible, family-centered, and coordinated. CSHCN coverage is provided throughout the State either in a specialty care physician's office or in face to face contacts at a CSHCN clinic site closest to the child's home. Medical transportation costs for appointments are reimbursed at the DHHR Medicaid established rate. The child and the principal care givers are informed of treatment options and involved in development of the Patient Care Plan for the child. Services are continued until the child's 21<sup>st</sup> birthday with transition services available to prepare for adult medical care. Through the Patient/Family Assessment and Patient Care Plan development process, families are linked to medical, educational, and community-based services.

The following model represents the WV OMCFH Continuum of Care for CSHCN and their families.

## Continuum of Services for CSHCN and Their Families



WVDHHR/BPH/OMCFH/ICAH/CSHCN/03-05

### **WEST VIRGINIA CHILDREN WITH SPECIAL HEALTH CARE NEEDS PROGRAM FAMILY SURVEY April 2006**

With the assistance of the Parent Network Specialists from West Virginia University (WVU) Center for Excellence in Disabilities (CED), all parents of children enrolled in the Children with Special Health Care Needs Program were sent surveys in early 2006.

#### Survey Objectives

- To determine the overall satisfaction with services provided by the CSHCN Program
- To ascertain the medical and social service needs of the participants and families served by the CSHCN Program
- To help define the scope of services offered by the CSHCN Program in the future

## Results Relating to Medical Care

- 93% of the respondents were satisfied with the services they receive from the CSHCN Program
- 96% of the respondents reported having a medical home or PCP
- When asked where they would like to receive medical care, respondents preferring CSHCN clinics were approximately equal to those preferring a private physician's office. Less than 8% of the respondents indicated a preference for out of state care and about 1% indicated that they would like to receive care in medical school clinics
- 80% of the respondents felt clinic services were average or above
- 96% expressed satisfaction with services received in private physician's offices
- 90% of respondents were pleased with the DME and supplies they received

## Results Relating to Care Coordination Services

- 89% of respondents felt they received average to above average services regarding referrals to local or community resources
- With regard to transition services provided by CSHCN, 89% of respondents indicated a rating of average or above
- 89% would like more information about medical power of attorney and guardianship issues
- Respondents overwhelmingly listed money as the most significant problem facing them when providing care for their child, followed by transportation problems and a need for respite care

## Conclusions/Recommendations

- The CSHCN Family Survey indicates that the majority of respondents are satisfied with the services they receive from the CSHCN Program
- The CSHCN Program provides a comprehensive care coordination service that Medicaid, CHIP or private insurance companies cannot
- The survey indicates a need for an increased emphasis on care coordination services for the entire family, including educating families about the benefits of these services
- The survey also indicates a need for an increase in transition services, including assistance with guardianship, conservatorship, wills and financial planning

## Nutrition Services

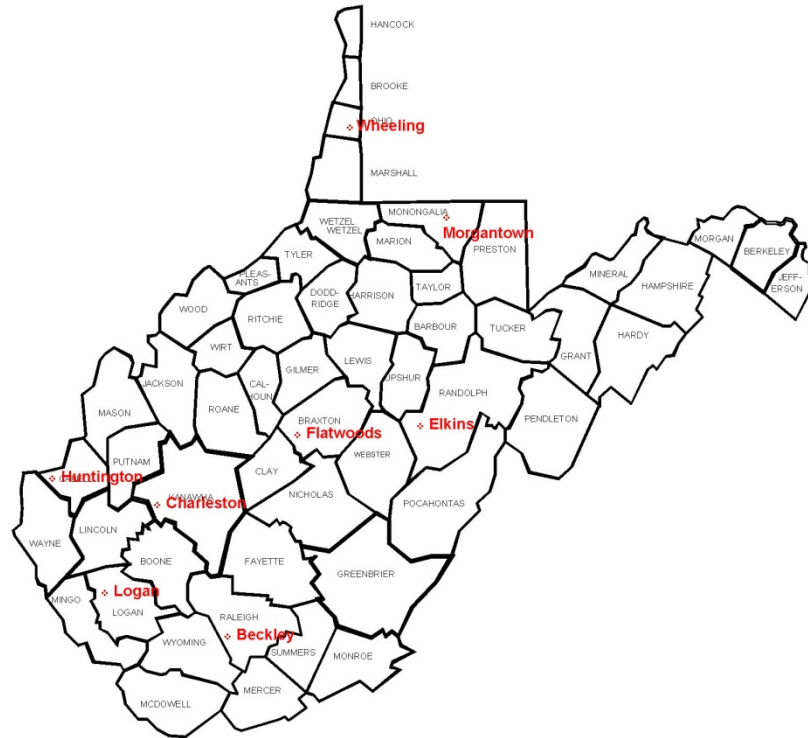
To assure nutritional assessments and consultations OMCFH established a grant with the Center for Excellence in Disabilities at West Virginia University. During CY 2009, a total of 320 children were assessed for nutritional concerns through thirty eight nutrition clinics, telephone consults, or home visits. A nutritional screening tool was developed by the CED nutritionist to identify children at special risk for feeding or nutritional problems. Each CSHCN nurse is charged with using the screening tool with children in his/her region for nutritional needs, and for holding at least two nutritional assessment clinics each year in conjunction with the CED nutritionist. These clinics allow children to be assessed locally without the need to travel long distances, and increases the efficiency of delivery of nutritional services offered by CSHCN.

In discussions with parents of children served by the CSHCN Program, two specific nutrition needs were identified: (1) information on how to add calories for underweight children and (2) information on how to cut calories for overweight children. In order to address this need on a large scale, the CED nutritionist developed three newsletters, including two for children and one for adults, with nutrition information, tips and simple recipes. The newsletters were provided to CSHCN care coordinators who then distributed to children and families in CSHCN clinics.

CSHCN collaborated with the Bureau for Public Health, Office of Nutrition's Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) to review the new WIC food packages that became available October 1, 2009. Additionally, WIC representatives agreed to provide a presentation on the new healthy food options at the CSHCN all staff meeting in September 2009. In doing so, CSHCN staff learned about the changes in WIC and was able to spread the same clear messages about the healthy new food options.

WIC has the potential to reach the caregivers of one half of all infants and one quarter of all preschoolers in West Virginia, as well as one third of all expectant mothers, and support them in maintaining healthy lifestyles. The reach and focus of the WIC program offers a unique opportunity to reduce and prevent childhood obesity in the Mountain state. There are approximately 52,000 women, infants and children in West Virginia who are benefiting from the multiple services offered by WIC, such as nutrition education, health care referrals and food to those who qualify.

## Nutrition (Satellite) Clinics



## Parent Network Specialists

The OMCFH also supports a network of parents who are employed by the Center for Excellence in Disabilities (CED) at West Virginia University. These Parent Network Specialists offer parent-to-parent support for families with children who have disabilities. The specialists attend CSHCN clinics, family support meetings and other meetings where they share information with families. In discussions with parents, one of the needs identified was support from other parents of children with similar special health care needs. In order to address that need, the Parent Network Specialists received training on organizing support groups and have linked interested families in their regional areas.

<b>Parent Network Specialists July 2007 – December 2009</b>	
Number of Clients – CSHCN – 3 Years	1340
Clinic Sessions Attended	146
Information and Referrals	680
IEP's Attended	41
Presentations	22
Total Product Dissemination	9,247
Care Notebooks Disseminated	412
Direct Client Contacts – CSHCN	364
Direct Client Activities	165

### **Dental Special Needs**

Access to dental care for children with special needs continues to be a problem in West Virginia. Because their special needs add to the complexity of their dental treatment, these children have a higher rate of unmet dental care compared to children without special needs. While a survey was conducted by the West Virginia Department of Health and Human Resources in 2002 on the Attitudes of West Virginia Dentists toward Children with Special Health Care Needs, no study had evaluated their needs from the parents' perspective.

In order to assess this issue from the parents' perspective, the West Virginia University (WVU) Department of Dentistry partnered with the WVU Center for Excellence in Disabilities to conduct a survey. An IRB-approved survey consisting of ten questions and demographic information was sent out to 650 parents in 30 West Virginia counties by the Parent Network Specialists of CED. Parents/guardians were asked to list any improvements or suggestions that could be made for their child's access to dental care. The surveys were returned without any personal identifiable information to CED and then given to the investigators.

#### **Results:**

A total of 183 surveys were returned from the 650 distributed, a 28% return.

#### **Results of parents/guardians showed that:**

- 99.5% believe their child should visit the dentist at least once per year
- 98.9% believe that oral health affects medical health
- 82.5% believe that their child should visit the dentist by/around age one
- 89.1% believe that a child should be weaned from the bottle and nursing by 12-24 months of age to prevent early childhood dental decay
- 23.0% believe that Sippy cups with juice do not cause cavities

- 58.5% agree that parents should start using fluoride-containing toothpaste to clean their child's teeth as soon as the first tooth is erupted
- 74.2% said their child has a regular dentist
- the number one problem experienced when trying to find dental care is lack of insurance (27.6%), followed by dentist not capable of treating child due to their disability (23.0%), long wait for the dental appointment (18.4%), dentist is too far away (17.2%), lack of transportation (10.3%), and lastly cannot afford to take the time off work (3.5%)
- 15.4% said that they do need help transitioning their adult child from the Children with Special Health Care Needs Program
- 35% of parents feel that their child's dental needs are not being met.
- The highest percentage of respondents had children between ten and twelve and a half years of age

### **Conclusion:**

Under the scope of this study it was concluded that even though 65% of parents/guardians of children with disabilities state that their children's needs are being met, there are still 35% that are not.

The results of the study showed that while a majority of parents/guardians have been educated about preventive dental care for their child, 10% of parents have not.

To overcome these obstacles, dental health care professionals must continue to expand their own knowledge through education concerning treatment of patients with special needs, and provide parents/guardians with a higher level of understanding of their role in providing dental care to their child.

### **Fostering Healthy Kids (FHK) Project**

In CY 2009, the Office of Maternal, Child and Family Health (OMCFH), within the Bureau for Public Health (BPH), saw a need for care coordination and medical records tracking for children in the Foster Care system. As a result of identifying this need, OMCFH offered a proposal to the Bureau for Children and Families (BCF) to provide health care coordination for children placed in the Foster Care system in West Virginia. The project would be coordinated by programs within the Division of Infant Child and Adolescent Health, including HealthCheck, Systems Point of Entry and the Children with Special Health Care Needs (CSHCN) Program.

Children placed within the Foster Care system have a unique set of barriers to continuity of medical care. Some of these are: frequent placement changes; lack of medical history and need for families (birth, foster, relative, and adoptive) to receive individualized training on how to care for children who have chronic or complex medical needs.



Working on this premise, staff members from BPH and BCF developed a plan to work collaboratively to meet the needs of these children and their families. This plan begins with the HealthCheck liaisons faxing the HealthCheck Screening Form to Systems Point of Entry (SPE) for review of the child's medical needs. If the child has no chronic health conditions, SPE staff will contact the family and assess potential needs, making appropriate referrals.

If the child has a chronic health diagnosis, the case will be referred to the Children with Special Health Care Needs Program for care coordination. The care coordination will consist of working with the foster care families to provide initial screening and on-going comprehensive health assessment. Additionally, the care coordinators will manage and track medical care received (coordination) through the BCF FACTS program. This will assure that current health information will follow the child while in the custody of the state.

Ultimately, this process should provide the framework for the child's health care and development to improve through comprehensive medical care coordination. The families will be educated on the child's health care diagnoses and medical records and follow-up reports will accompany him/her regardless of status, i.e., foster care, emancipation, return to natural/birth family, etc.

### **Kids First Hearing Project**

A need for West Virginia children to obtain hearing amplification has long been identified as a goal by public health officials. The need to hear appropriately is vital for optimal growth and development. The early identification and referral of children in need of amplification is essential. The lack of funding for hearing services is a large service gap identified within the state. Most third party insurers do not provide coverage for hearing examinations or hearing aids. The financial burden for these services has been placed on families who are unable to meet the demand. Often times, the child is left without appropriate amplification, impacting education and all areas of life.

To help address the need, the Office of Maternal, Child and Family Health (OMCFH) entered into a cooperative agreement with Mountain State Blue Cross and Blue Shield. This project, funded by Mountain State Blue Cross/Blue Shield and Title V, is administered by OMCFH. The Kids First Hearing Project purchases hearing services for those WV residents who lack insurance coverage or do not have credible coverage for this benefit. The benefits are paid at the established WV Medicaid rate and include hearing evaluations, hearing aid(s), ear molds, a two year warranty and a six-month supply of batteries. Children from birth up to age eighteen are eligible.

## **CSHCN Transition Services**

Transition services for youth and young adults served by the CSHCN Program continued to be a high priority during CY 2009. During this period, 1,072 transition services were provided to youth, ages 14, 16, 18 and 20 years. Training of nurses and social workers about adolescent transition services continued through the annual all staff meeting. Written policy concerning delivery of transition services was revised and released to the staff in the CSHCN Policy Manual in July 2007. There were 413 Transition Screening Tools completed and updated with adolescents ages 14, 16, and 17 and with young adults ages 18 and 20 in preparation for aging out of the program.

A primary role of the CSHCN Program nurse and social worker is to link youth and their families to community, medical and educational resources to assist in preparation for independent living as adults. One way to obtain this goal is in partnership with the Division of Rehabilitation Service. The Division of Rehabilitation Services offers school to work transition services for adolescents and young adults with disabilities. In CY 2009, 267 referrals were made to the Division of Rehabilitation Services by the CSHCN Program.

In CY 2010, the CSHCN Program, in collaboration with Marshall University Pediatrics, will begin providing care coordination services in a monthly transition clinic. The transition clinic will be held in a pediatrician's office in Barboursville, West Virginia and will serve young adults (14 – 21) with chronic medical conditions. The goal, as stated above, is to assist with planning and linkage to resources to prepare the youth for independent living.

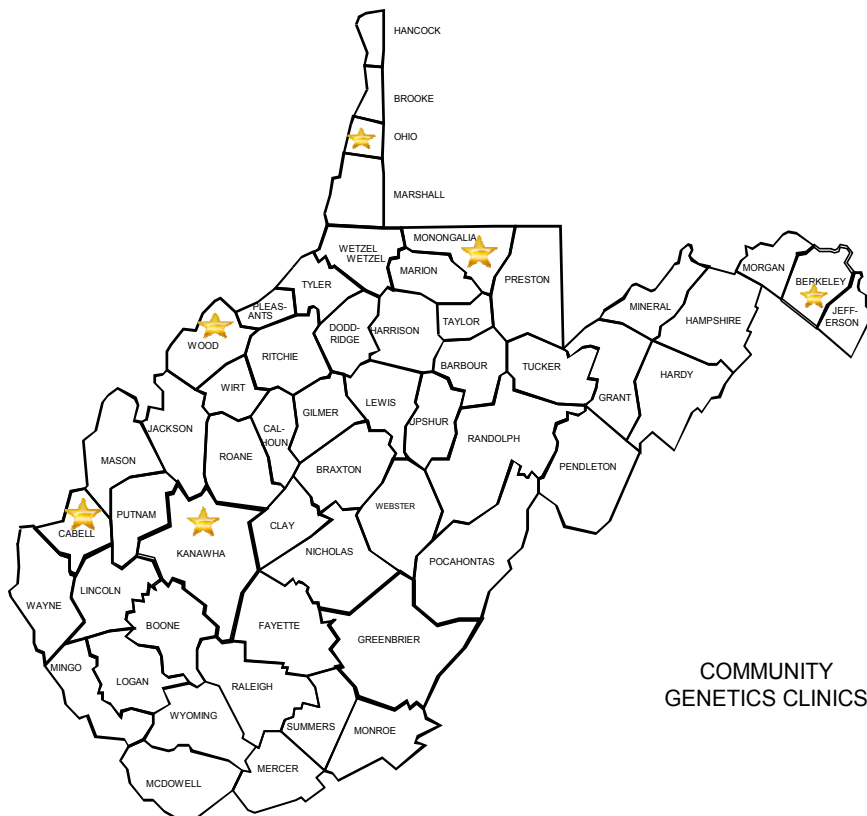
In addition to transition training for CSHCN staff, the Program administrators sought training for all nurses and social workers in the area of guardianship, conservatorship, wills and financial planning. This has been a welcome benefit to families and clients served by the CSHCN Program.

## **CSHCN Community/Genetics Clinics**

To expand services to all West Virginia children and youth with special health care needs, the CSHCN Program partners with community-based professional and medical facilities. The CSHCN Program provides support to those clinics through the provision of social work and nursing services. The professional partners are responsible for clinic operation, staffing, billing and record keeping. In the community/genetics clinics, the CSHCN social worker and nurse provide care coordination to children and families in a familiar, community based setting.

The CSHCN social worker and nurse work cooperatively with clinic staff to provide optimal health care and social services to the clients and their families. They provide transition counseling, as well as resource and contact information relating to health care

and social service needs identified by the client, family or clinic staff. In CY 2009 CSHCN staff provided services in 173 community clinics. Currently the CSHCN Program is providing services in community clinics in Charleston and in Morgantown with the West Virginia University Physician Office Center. Social work services are also provided with the Community Genetics Clinics held throughout the state: (See the map below for locations of the Genetics Clinics):



Following are the cross cutting strengths and needs across the West Virginia MCH Population.

**Cross Cutting Strengths and Needs:**

Culturally Competent Care

Racial disparities in health status, health care, and mortality are well documented. In the United States, African Americans are more likely than non-Hispanic Whites to have diabetes or hypertension, to be overweight or obese, and to be uninsured. In addition, infant mortality, cardiovascular disease mortality, and cervical and breast cancer mortality are all higher among African Americans than Whites.

Measuring health-related racial disparities in West Virginia is challenging due to the small population of racial minorities in the State. For most available data sources, racial

and ethnic minority groups must be combined and multiple years of data must be aggregated to obtain reliable estimates and rates for non-White groups. Nonetheless, *Minority Health in West Virginia*, published by the Bureau for Public Health in April 2007, identifies racial disparities in this State related to STD infection, birth outcomes, and mortality.

A major goal of *West Virginia Healthy People 2010*, the State's disease prevention and health promotion agenda, is to reduce racial disparities in health and mortality. The following summary describes racial disparities in cigarette smoking and outlines progress toward reaching the *Healthy People 2010* goal to reduce cigarette smoking among African Americans in West Virginia.

Although historically the prevalence of smoking has not been higher among African Americans than Whites, it is important to target tobacco prevention efforts toward African Americans for many reasons, including:

- Smoking related illnesses are the number one cause of death among African Americans, surpassing all other causes of death, including AIDS, homicide, diabetes, and accidents
- Although African Americans tend to smoke fewer cigarettes per day and begin smoking later in life than Whites, their smoking-related disease mortality is significantly higher
- African Americans are more likely to develop and die from cancer than persons of any other racial or ethnic group. Lung cancer kills more African-Americans than any other type of cancer
- Research indicates that tobacco companies have more aggressively marketed their products toward African Americans and other minority groups

Historically, West Virginia has had one of the highest rates of cigarette smoking in the Nation. In fact, in seven of the past nine years, West Virginia's prevalence of adult smoking has ranked in the top three among the 50 states and D.C. During this same time period, the prevalence of adult cigarette smoking has been significantly higher in West Virginia than the United States. In 2006, more than 1 out of 4 adults were current cigarette smokers.

Recent tobacco prevention efforts in West Virginia have been successful in reducing the prevalence of youth cigarette smoking. Between 2000 and 2005, the percentage of public high school students who had never tried a cigarette significantly increased, while

the prevalence of current cigarette smokers significantly decreased. However, the same successes have not been achieved for adults. While the adult smoking rate has declined for four consecutive years for the first time since the 1980's, there has been no statistically significant decrease in cigarette smoking among West Virginia adults. Nationwide, the prevalence of adult smokers significantly declined between 1998 and 2004 (from 22.9% to 20.8%) and again between 2004 and 2006 (from 20.8% to 19.7%).

Like other health conditions and risk behaviors, cigarette smoking differs by socio-demographic characteristics. In West Virginia, cigarette smoking is inversely associated with age, education, and income. According to the 2006 West Virginia Behavioral Risk Factor Survey, the prevalence of cigarette smoking was approximately three times higher among 1) adults aged 18-24 than those aged 65 or older, 2) adults without a high school diploma or G.E.D. than college graduates, and 3) adults with an income less than \$15,000 than adults with an annual household income of \$75,000 or more.

The collection of race in the Behavioral Risk Factor Surveillance System (BRFSS) has changed over time. Prior to 2001, respondents were asked to report one race. Since 2001, respondents have been given the option to choose more than one race. Those respondents reporting multiple races are then asked to identify one race as their preferred race. The preferred race classification is used when comparing racial estimates from 2001-2006 to racial estimates prior to 2001.

In the years 1998-2000, there was no significant racial disparity in cigarette smoking among adults in West Virginia. Approximately 32% of African Americans, 27% of Whites, and 17% of adults of other races were current cigarette smokers (see Figure 2). *West Virginia Healthy People 2010* objective 27.20 aims to reduce the prevalence of cigarette smoking among African American adults to 20%.

Although there have been no significant declines in cigarette smoking among the total adult population in West Virginia, comparing estimates of cigarette smoking by preferred race indicates that there has been a significant decrease in the percentage of African Americans who are current smokers. Between 1998-2000 and 2004-2006 the prevalence of smoking among African Americans significantly declined from 31.8% to 18.3%. However, the prevalence of cigarette smoking among Whites has remained stable and the percentage of adults of other races who are current cigarette smokers has increased, although the increase was not significant.

The most recent data indicate that significant racial disparities in cigarette smoking now exist. Cigarette smoking is highest among adults who report more than one race. In 2004-2006, 34.5% of multiracial West Virginians were current smokers, compared with 26.3% of Whites and 19.0% of African Americans. In addition, estimates of cigarette smoking using both the preferred race and multiple race classification indicate that the

prevalence of current smoking was significantly higher among Whites than African Americans in 2004-2006.

#### Conclusions:

Recent BRFSS estimates indicate that racial disparities in cigarette smoking now exist. Whereas there were no significant racial differences in the prevalence of current smokers in the years 1998-2000, data from 2004-2006 indicate that West Virginia adults who are multiracial are significantly more likely than Whites and African Americans to be current cigarette smokers. In addition, African Americans are significantly less likely to be current smokers than Whites. The emergence of racial disparities is due to 1) a significant decline in smoking among African Americans and 2) the ability to collect data and produce estimates among individuals of multiple races (this disparity could not be measured prior to 2001).

A declining trend in smoking among African Americans is not observed nationwide. In West Virginia, African Americans are the only racial group that has experienced a significant decline in cigarette smoking, whereas in the United States they are the only racial group that has not experienced a smoking decrease. Although there have been no significant declines in cigarette smoking among the total population of adults in West Virginia, these results provide encouragement that tobacco prevention efforts are working. This information also suggests that the *West Virginia Healthy People 2010* objective to reduce the prevalence of cigarette smoking among African American adults to 20% has been met.

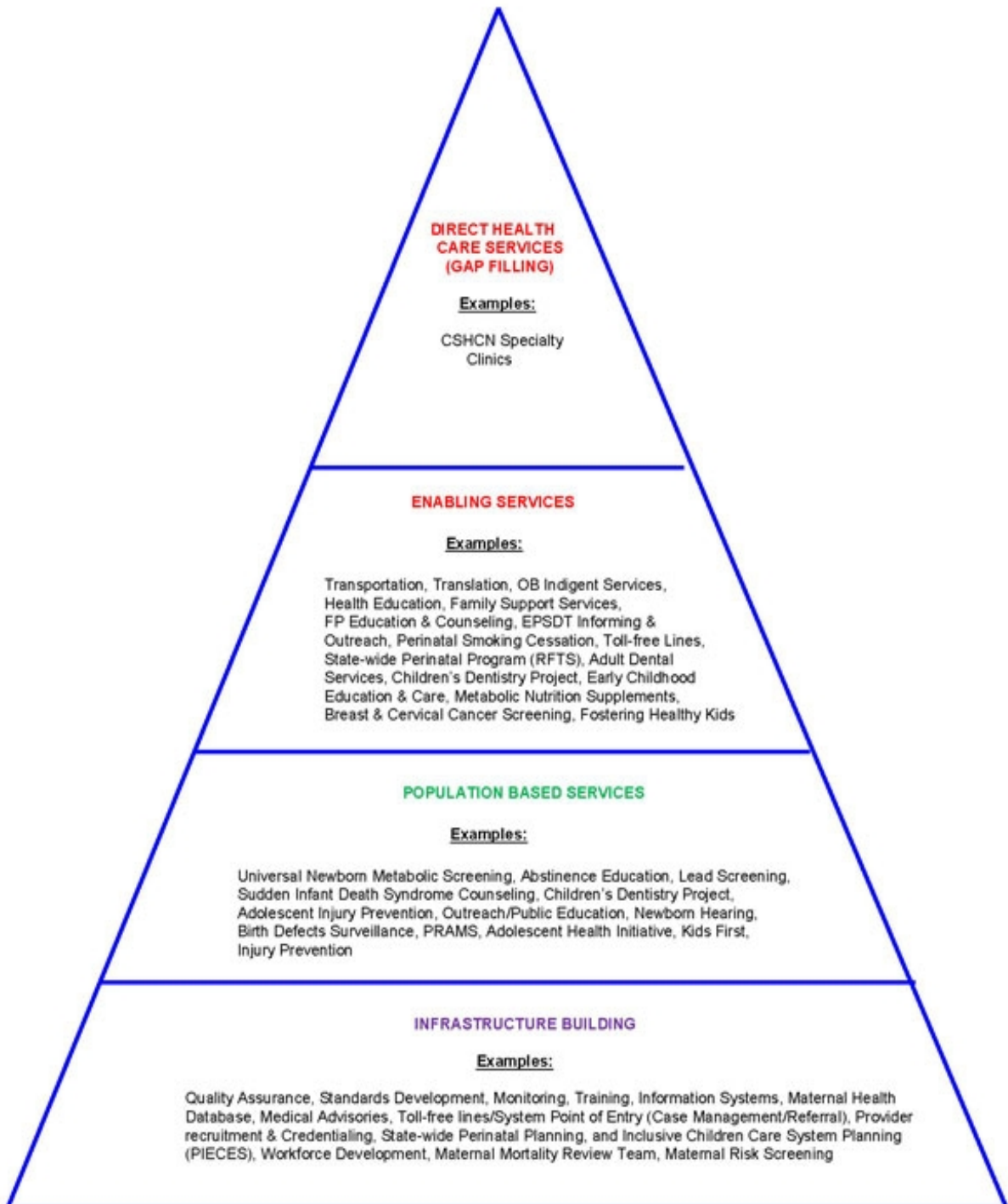
## **SECTION 4**

### **MCH Program Capacity by Pyramid Levels**

The following Pyramid shows the Programs that are offered through or by the WV OMCFH.

Programs that have been added within the OMCFH since the last Five-Year Needs Assessment are:

- Newborn Metabolic Screening of the nationally recommended 29 disorders
- Kids First Screening Initiative
- Fostering Healthy Kids Project
- Maternal Mortality Review Team
- Universal Maternal Risk Screening





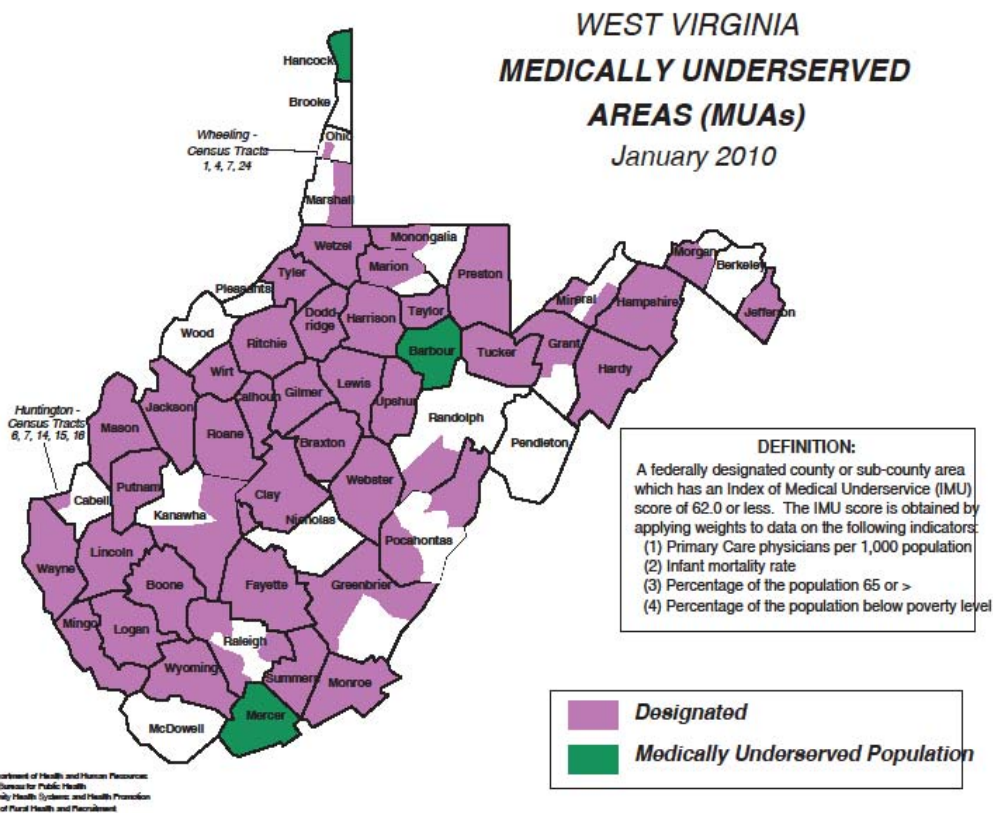
**a. Direct Health Care Services**

West Virginia is surrounded by Pennsylvania, Maryland, Virginia, Ohio, and Kentucky and is commonly referred to as a South Atlantic state. The Appalachian Mountains extend through the eastern portion of the State, giving West Virginia the highest elevation of any state east of the Mississippi River. The second most rural state in the Nation, 20 of West Virginia's 55 counties are 100% rural according to the Census Bureau definition, with an additional 14 more than 75% rural. West Virginia is the only state that lies entirely in the Appalachian Region. Even so, West Virginia is located within 500 miles of 60% of the Nation's population. The State is traversed by two north/south and one east/west interstates that connect its major population centers. In addition, I-68, which ends at Morgantown, where West Virginia University is located, provides access to Washington, D.C. and Baltimore, MD. Interstate 68 also connects with Interstate 79 providing access to Charleston, WV, our State capitol. Winding secondary roads connect the majority of the State's population, with little to no public transportation available between many of the small, isolated towns. Therein lays the single most often cited issue with access to health care for many of the State's residents.

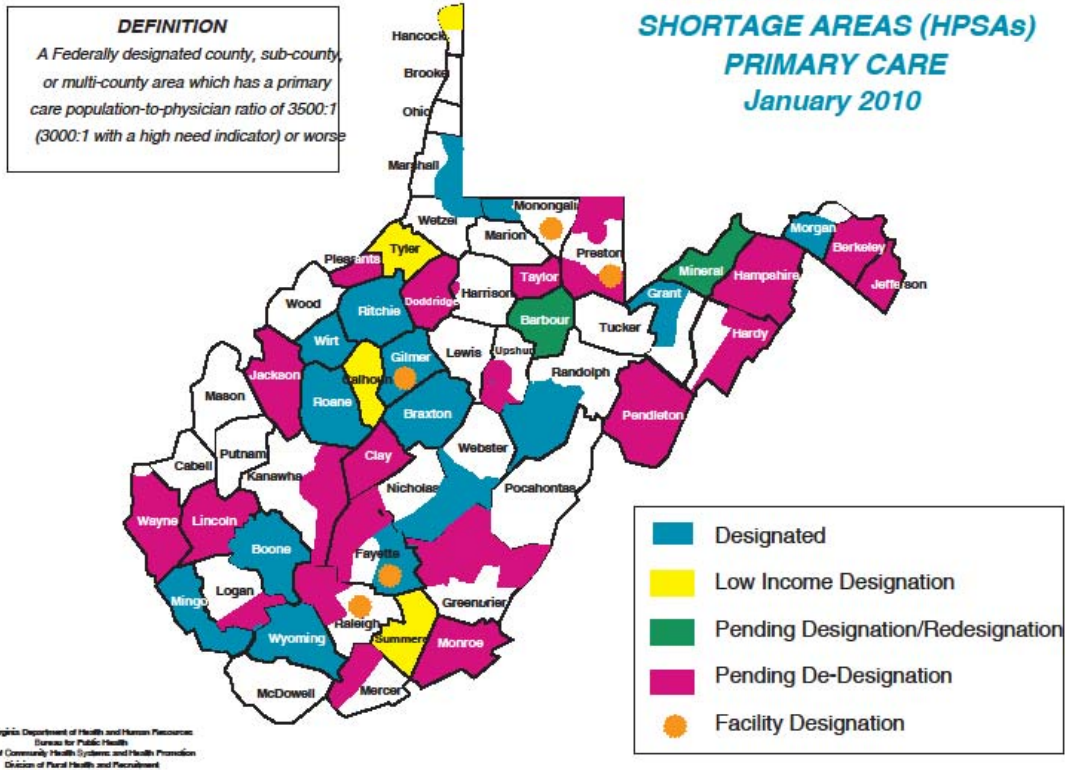
The chart below outlines health care issues by group that affect health outcomes of WV residents:

<b>Infants</b>	<b>Children</b>	<b>Adolescents</b>	<b>Women of Childbearing Age</b>	<b>Women</b>
Prematurity Birthweight Birth Defects Newborn Screening Mortality - SIDS/SUID Insurance/Access Immunizations Well Baby Check ups Early ID/CSHCN Healthcare Financing Family Planning Healthcare Providers Early Prenatal Care Birth Score - How Used - New Data Collected	Immunizations Lead Poisoning Education Early Childhood Oral Health Physical Health Poverty Insurance/Access Well Child Visits Child Care Child Abuse/CPS Issues Two Parent Families CSHCN Birth to Three	Risk Behaviors - Smoking - Car Accidents - Drugs/Alcohol - Seat Belts - Suicide - Sexual Behaviors Mental Health Education - Complete HS - Drop Out Rate - College Attendance Pregnancy Immunizations - HPV STDs Insurance/Access CSHCN School Based Health	Domestic Violence Folic Acid Pregnancy - Intended - Unintended Prenatal Care Postpartum Depression Alcohol/Drug Use STDs Family Planning Mother's Education - Impact on Childrearing Insurance/Access Fertility Sites Pregnancy & Marital Status (2 parent vs single)	Mammograms Cervical Exams Employment Insurance/Access

As of January 2010, 36 of WV's 55 counties were classified as medically underserved areas with an additional 13 counties classified as partially underserved. Only six counties in the entire State were considered to have adequate medical manpower to meet the population need. This is, however, an increase of three counties from 2005. The WV Board of Medicine, in 2009, reported that the current number of licensed physicians in WV is 5,705. Of this 5,705, some, while licensed, are not actively practicing. Ultimately the number of practicing physicians across the entire State is 3,739. The Board of Medicine also reports that there are 553 physician assistants. West Virginia has one School of Osteopathic Medicine and historically their physicians have established practices in our State. The Board of Osteopathy reported in May 2009, 746 D.O.s were in active practice.



**WEST VIRGINIA  
HEALTH PROFESSIONAL  
SHORTAGE AREAS (HPSAs)  
PRIMARY CARE  
January 2010**



The Division of Rural Health and Recruitment Office, of Community Health Systems and Health Promotion, Bureau for Public Health, provides two loan repayment programs for medical professionals throughout the State of West Virginia.

The State Loan Repayment Program (SLRP) is a federally-funded program with matching dollars paid from the State General Revenue Fund. There is a total budget of \$300,000 providing loan repayment to approximately 10 physicians, nurse practitioners, dentists and physician assistants in return for their obligation to work in rural West Virginia. The facility where they work has to have a federal Health Professional Shortage Area designation. When a medical professional receives his or her first award, usually in the amount of \$40,000, he/she will agree to work for a period of two years. At the end of the two years, he/she is eligible to apply for an additional \$25,000 for a one year commitment. This can be done for two one year periods.

The Recruitment and Retention Community Project (RRCP) is a mirrored program of the State Loan Repayment Program, funded entirely by the General Revenue Funds

from the State of West Virginia. This program has a few qualifications to make it more available to providers around the state. Unlike the SLRP, the RRCP only requires the facility be located in a federally designated Medically Underserved Area. The RRCP awards up to \$10,000 for a one year commitment from the medical provider, with the facility matching the award, for a total of \$20,000 per year. The medical provider may apply and receive this award for a total of four years.

In both of these programs, the medical professional must be a U.S. citizen, agree to work 40 hours per week for 45 weeks per year, must agree to see patients regardless of their ability to pay, and must not be in default of any federally funded program, including but not limited to child support payments.

During fiscal year 2008-2009 these two programs provided loan payment assistance to over 70 medical professionals in various parts of the State. These providers saw over 175,000 patients in the office and over 9,500 patients admitted to the hospital. They saw over 34,000 Medicare patients and over 70,000 Medicaid patients.

The WV Perinatal Partnership, which includes representatives from the OMCFH, has reported that the availability of OB/GYNs and other practitioners that do prenatal care and delivery continues to be problematic. Not every county has sufficient births to justify labor and delivery at local hospitals making it necessary for WV women to be served outside the boundaries of the State. The Board of Medicine, in 2009, reports that there are 159 M.D.s and another 23 D.O.s delivering infants across our State. In 2008, there were 21,443 occurrence births in WV which is one physician for every 118 pregnant women.

Community health centers have played a critical role in improving access to health care for all populations across WV. The community health center network is supported with State appropriations and there are multiple centers that actually receive both state and federal resources. Historically, community health center networks have received only \$150,000 per year for construction activities. OMCFH is working with the community health centers on this issue in hopes that the physical expansion of the facility will allow them to recruit dental health practitioners. The lack of available oral health services for adult persons in the State is a critical problem. Also \$1,000,000 was spent on oral health equipment for community health centers during the 2010 fiscal year. This equipment will be ready for use July 1, 2010.

Over the last year, the WV Virginia Perinatal Partnership conducted quarterly meetings via WEBEX with providers in high need areas of the State. The providers explored ways to collaborate to enhance perinatal service and share resources such as physicians. FamilyCare has expanded their perinatal services to three (3) new sites by scheduling an OB/GYN physician on a rotation to the various sites once a month, while

a nurse midwife or nurse practitioner follows the patient locally more frequently if needed. Wirt County Health Association is expanding perinatal services in the Jackson County area using a nurse midwife who is developing practice arrangements with local physicians to support this service. The current issues surrounding expansion of perinatal care in the targeted areas rest upon the supply of skilled practitioners and a willing, available medical provider that can close the gap regarding a collaborative practice agreement. There is an extreme shortage of both professional types in the most rural areas.

The WV Perinatal Partnership has been working with Schools of Nursing in WV to encourage a nurse midwifery program so vacancies created by retirements of Certified Nurse Midwives can be filled. Marshall University School of Nursing will begin a MSN with emphasis in Midwifery program this fall. The Midwifery Program is being offered in conjunction with the Division of Nursing - Midwifery Program Shenandoah University, Winchester, Virginia.

The OMCFH has been a strong supporter of the evolving community health center network dating back to the early 1980's. The networks at that point were struggling, and beginning in the '80's to this date, OMCHF used the community health centers to provide patient care for maternal and child health populations and used MCH Block Grant resources to offset the cost on a fee-for-service basis. Actually the community health centers and OMCFH have a symbiotic relationship that works to the mutual benefit of all, the patient, the health center and the Office. For example, the largest provider of family planning services are the community health centers.

Availability of services for West Virginia's OMCFH population has increased dramatically, however, there remain areas of the State that continue to lack medical practitioners. In addition, meeting the needs of chronic or disabled populations is impaired by the lack of medical sub-specialty providers, such as occupational therapists, physical therapists, speech pathologists, dentists; and as is typical with most states, pediatric sub-specialties are mostly available at tertiary care sites. To attend to these problems, the Bureau for Public Health, in collaboration with the West Virginia University School of Medicine, sponsors a rural practice rotation for physicians, social workers, dentists and other specialty providers, with the intent of encouraging the establishment of rural practices, as well as expanding immediate service capability, since these practitioners render hands-on care.

The community health center network operates more than 106 health care sites across the State which includes school-based health centers and multiple free clinics. The purpose of the School-Based Health Center Program is to provide easy access to preventive and primary health care for school-age children at their local elementary, middle, or high school. These centers are operated and administered by a community-

based healthcare clinic in their area. Each center is located within the school building, or on the school campus. When the school is closed, the student may seek care at the healthcare clinic which operates their school's center. Currently, funding is provided through the Division of Primary Care to 36 school-based health centers serving 45 schools in 18 counties, making health services available to over 25,000 students. Also, funding is provided to one more primary care organization which supplies referrals to the students at 3 high schools in their county. Additional school based health centers are planned.

Each student receiving services at a school-based health center must be enrolled with written parental permission. Follow-up with the parent/guardian is conducted at the time of service, or immediately following.

Services which may be provided by a school-based health center include:

- Preventive education
- Yearly physicals
- Immunizations
- Chronic disease management
- Check-ups
- Acute and intermediate care
- Oral health
- Mental health
- Counseling
- Ancillary and enabling services

## Capacity Assessment Across MCH Essential Services

### West Virginia – Maternal, Child and Family Health

DIRECT SERVICES	
Goals	Strengths/Weaknesses/Needs
<p>Children with Special Health Care Needs is administered by the Office of Maternal, Child and Family Health on behalf of multiple payers, including Title XXI, Title XIX, Title V, and insurance.</p> <p>Definition:</p> <p style="padding-left: 40px;">Children, birth to age 21, with certain chronic, debilitating medical conditions.</p> <p style="padding-left: 40px;">Service includes medical care management, social service, and community supports, including adult transition planning.</p>	
<p>1. Adequate Funding</p>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• OMCFH works diligently to secure a source of health care financing for every child. This has resulted in 93% or more of the children becoming Medicaid or CHIP beneficiaries.</li> <li>• Medicaid and public health share in the administrative cost of the Program.</li> <li>• Medical practitioners provide services at a rate less than routine and customary.</li> </ul> <p><b>Weaknesses/Needs</b></p> <ul style="list-style-type: none"> <li>• Not every chronic disease is a Children with Special Health Care Needs covered condition because of insufficient funding for Title V.</li> </ul>
<p>2. Assuring the capacity and competency of the public and personal workforce.</p>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• The in-house workforce are licensed social workers and nurses.</li> <li>• The West Virginia University Health System has been a strong resource to the Program for 30+ years, providing medical expertise, as well as medical guidance on policy.</li> <li>• Medical providers are board certified Staff are all trained on People First Language, and leadership participates on the Developmental Disabilities Council, Family Voices, Deaf and Hard of Hearing Commission, Social Security Administration- Title V Workgroup, etc.</li> <li>• Parents and consumers participate on the CSHCN Advisory.</li> <li>• Parents, hired through a Title V agreement with the UAP/University Center for Excellence in Disabilities participate in Program policy development, brochure and public informing material development, etc.</li> </ul>

DIRECT SERVICES	
Goals	Strengths/Weaknesses/Needs
	<ul style="list-style-type: none"> <li>• Staff and practitioners are trained in confidentiality law and practice.</li> </ul>
3. Assessment of maternal and child health status using data.	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• Integrated data systems support program reporting.</li> <li>• Claims are handled by one vendor, and each payer pays their part based on the enrolled beneficiary.</li> <li>• Information from data and population-based surveillance systems are used to link children to specialized care.</li> <li>• Staff have access to on-line databases for literature searches.</li> <li>• Staff have access to Medicaid/CHIP eligibility files.</li> </ul>
4. Link women, children and youth to health and other family services and assure access to comprehensive quality systems of care.	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• Specialty/multidisciplinary clinics are held throughout the State.</li> <li>• Medical practitioners and State staff travel to sites in the community to offer medical care that would otherwise be unavailable.</li> <li>• Toll-free responders and social workers respond to health and human service queries.</li> <li>• Individual, client-directed care plans are completed on all participants.</li> </ul> <p><b>Weaknesses</b></p> <ul style="list-style-type: none"> <li>• Lack of respite care services for families who care for special needs persons.</li> </ul>

### Children With Special Health Care Needs

The Children with Special Health Care Needs (CSHCN) Program administered by the Office of Maternal, Child and Family Health offers medical and care coordination services to children and their families, if the child has a chronic medical diagnosis.

The WV Children with Special Health Care Needs Program continued a strong commitment to family-centered, community-based, direct services during calendar year 2009. During calendar year 2009, 1,352 children and youth were served through a network of 28 CSHCN community-based specialty care clinics, and through private specialty physicians' offices statewide. Of the 1,352 visits provided through the clinic system, 519 visits were for initial diagnostic evaluations. During this period, 98% of children participating in CSHCN were also Medicaid beneficiaries. This increase over the year 2008 percentage is attributed to the continuing commitment of CSHCN to



assist families in obtaining health care financing by assisting with SSI and/or CHIP/Medicaid applications. As of December 2008, there were 9,233 children in WV under the age of 18 receiving SSI benefits. During CY 2009, 748 children ages 0-18 received both SSI and CSHCN benefits. This indicates that the CSHCN program served 8.2% of WV children under the age of 18 who receive SSI benefits.

### SSI Beneficiaries/Child by Age for West Virginia

West Virginia	Total	Age			Amount of Payments (in Thousands)
		Under 5	5-12	13-17	
Total	9,223	1,243	4,392	3,598	39,546

Source: Social Security Administration

### Capacity to Address Needs:

Multi-disciplinary teams provide care-planning and care-coordination to children with special health care needs and their families. The multi-disciplinary team includes the child/parent, physicians, nurses, social workers, therapists, school personnel, vendors and community services who are providing care for the child. Team members, led by the CSHCN nurse and/or social worker, collaborate with the child/family in developing an appropriate, comprehensive care plan for the child. During CY 2009, 1,649 Patient Care Plans were completed to assure a continuum of comprehensive medical care and transition to adult care as appropriate.

The care coordination teams continue to hold weekly planning meetings to better coordinate their work and to discuss responsibilities for tasks within the group. This assists with setting and meeting work priorities, and serves as an opportunity for review of program policies and procedures.

Efforts are made to coordinate the CSHCN specialty care with the child's medical home, and to keep the primary care physician informed of treatment plans. CSHCN strives to provide service in a manner that is accessible, family-centered, and coordinated. CSHCN coverage is provided throughout the state either in a specialty care physician's office or in face to face contacts at a CSHCN clinic site closest to the child's home. Medical transportation costs for appointments are reimbursed at the DHHR Medicaid established rate. The child and the principal care givers are informed of treatment options and involved in development of the Patient Care Plan for the child. Services are continued until the child's 21<sup>st</sup> birthday with transition services available to prepare for

adult medical care. Through the Patient/Family Assessment and Patient Care Plan development process, families are linked to medical, educational, and community-based services.

### **Adequate Insurance**

While 98% of CSHCN Program participants have Medicaid, the coverage is a result of aggressive action by the Office of Maternal, Child and Family Health.

#### *Capacity to Address Needs:*

Given this charge, CSHCN has: established an assessment process that assures all health financing resources are explored. This includes eligibility determination for Medicaid (Title XIX) and CHIP (Title XXI). Children who are ineligible for either source of health care financing but have chronic, debilitating conditions covered by CSHCN have their care financed by Title V, if their income is at or below 200% FPL.

Children who do not meet any of the above eligibility requirements are offered care management through Systems Point of Entry (SPOE), in an effort to secure health financing. SPOE works with the Bureau for Medical Services to determine if the child is eligible for an optional Medicaid program called the Children with Disabilities Community Service Program (CDCSP) which serves severely disabled children who would not otherwise be eligible for Title XIX/Medicaid coverage. This program waives parental income to assure access to health care financing.

- All persons who are uninsured or underinsured are provided information on how to access Title XIX or Title XXI. Obviously, having health care financing is the best vehicle for assuring children receive on-going comprehensive care.
- Children who are diagnosed with chronic, debilitating conditions are obviously a priority for CSHCN, but we've also secured a similar commitment from the Social Security Administration Disability Determination Section to assure the populations identified by us receive priority handling.

Children who have a chronic medical condition, including those covered by CHIP, Medicaid, private insurance or Title V, are eligible for care coordination services through the Children with Special Health Care Needs Program. This is an adaptation designed to support the needs of children and families since health care professionals are so very busy and cannot cover office/clinic operational expenses when serving a disproportionate number of government sponsored patients. The end result is that children with special needs require more visits and more time per visit at a time when the clinical community cannot accommodate.

## **Care Coordination with the Medical Home**

In an ongoing effort to offer care coordination to all children and youth with special health care needs in West Virginia, the CSHCN Program plans to expand services in the medical home. Many children with chronic diagnoses receive follow up care through their medical home, whether that be with a pediatrician, a family practitioner or in a primary care center. Not all children and families are aware of CSHCN services and the benefits of care coordination. With that in mind, the CSHCN administrative team has developed two separate marketing tools, each with a different target audience.

The first tool is a Physician's Fact Sheet with information about the benefits of offering care coordination within the medical home. The fact sheet provides a summary of care coordination services that CSHCN could offer, as well as the benefits for the medical practice, child and family. The second tool is a Care Coordination brochure, designed for use by clients and families. The brochure offers information to clients and families, explaining the value of care coordination and citing examples of the benefits offered. CSHCN staff will be trained to present the concept to primary care physicians within their regions, touting the benefits of care coordination in the medical home. Administrative staff will also promote the idea to community and state partners. By partnering with the medical home to provide care coordination to children and youth with special health care needs, the child will receive comprehensive, family centered care within their community – a benefit to all.

## **Chronic Disease Management**

With plans to expand care coordination services through the Fostering Healthy Kids Project and within the medical home, CSHCN staff will be encountering chronic disease diagnoses that they may have little experience with. In order to be prepared for that, OMCFH began a training process to familiarize nurses and social workers with medical conditions that they may have limited knowledge of.

In CY 2009, OMCFH sought the assistance of Mary Beth Hummel, MD, geneticist at West Virginia University. Dr. Hummel provided training to CSHCN staff on a variety of genetic conditions, apprising staff of some of the special needs for both the clients and families. This was very beneficial to staff as they began working with clients in Dr. Hummel's genetics clinics across the State.

The CSHCN administrative team plans to seek training on a variety of other chronic diseases/medical conditions so that Program staff will be well prepared when meeting with children and families. To that end, the Program Director has contacted the Director of the Division of Health Promotion & Chronic Disease, within the Bureau for Public Health, to secure additional training information and ideas.

## **Family Support**

Family Support initiatives are social interventions designed to promote the flow of resources and supports to families in ways that strengthen the functioning and enhance the growth and development of individual family members and family units.

Family support initiatives for person's with disabilities and their families, spurred by PL 100-146, the Developmental Disabilities Assistance and Bill of Rights Act of 1987, exists in West Virginia Legislation, and is a recognized statewide program used to increase resources, and services to families as a part of other human services programs. The Family Support Program has historically received only modest State Legislative appropriation, approximately \$1,000,000, ranking WV 46.5. However, when federal community-based MR/DD dollars are accounted for, West Virginia performs a little better ranking 16 among the states.

### **b. Enabling Services**

West Virginia's plans to expand its Medicaid program for adults were modified when Congress passed health care reform legislation. Governor Joe Manchin's proposal to expand Medicaid coverage for adults earning up to 50 percent of the federal poverty level, or \$10,830 for individuals, would have increased State spending, an increasingly difficult course of action as the bad economy saps revenue. About 271,000 of West Virginia's 1.8 million residents lack health insurance. This year, Governor Joe Manchin III proposed allowing more adults to participate in Medicaid to help bring that number down. Very few adults are allowed to participate in Medicaid in West Virginia. Currently, it's available to parents earning up to 35 percent of the federal poverty level, which is \$22,050 for a family of four. Manchin's proposal would have increased that to 50 percent, and would have allowed adults without children to enroll. Based on revenue collections so far this year, administration officials now estimate West Virginia will have a \$100 million budget shortfall by the end of the fiscal year on June 30, 2010. Governor Joe Manchin III opted to wait for Federal healthcare reform before moving forward.

Although WV has many health care issues such as smoking among pregnant women, infants born prematurely, infants born with low birth weight, obesity and asthma, the WV Office of Maternal, Child and Family Health (WV OMCFH), the administrative entity for the Family Planning Program, Breast and Cervical Cancer Screening Program, EPSDT, Early Intervention/Part C, Kids First Screening Initiative and the CSHCN Program, among others, has woven together funding streams to create a system of care for women, infants, and children, including adolescents and those with special health care needs. The WV OMCFH has developed strong partnerships across the State with the medical community, private sector, as well as community health centers and local health departments, all in an effort to assure access.

## Capacity Assessment Across MCH Essential Services

### West Virginia – Maternal, Child and Family Health

<b>ENABLING SERVICES</b>	
<b>Goals</b>	<b>Strengths/Weaknesses</b>
<p>Arrange care for government sponsored obstetrical populations and children up to age 1 (Title V, Title XIX, Title XXI) that meet pre-established medical criteria. State staff has responsibility for care protocol development and dissemination, provider recruitment, and system development that assures patient access to quality, comprehensive, timely care. RFTS services are provided through a community-based network of nurses, social workers, and physicians.</p>	
<p>1. Adequate Funding</p>	<p><b>Insufficient Funding</b></p> <p><b>Weaknesses</b></p> <ul style="list-style-type: none"> <li>• RFTS (perinatal services), especially those related to case management and behavior risk reduction, such as smoking cessation and parenting education, have been negatively affected by health care cost inflation; see Attachment (<i>RFTS service reimbursement chart</i>).</li> <li>• OMCFH has tried unsuccessfully to persuade insurers to purchase case management and other enabling services for their pregnant and newborn beneficiaries.</li> </ul> <p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• However, nurse liaisons from insurers participate in RFTS skill-building and program meetings.</li> </ul>
<p>2. Assuring the capacity and competency of the workforce.</p>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• All medical practitioners serving RFTS enrollees must have formal working agreements with OMCFH establishing the expectation that patient care will be provided in accordance with ACOG standards; that the OMCFH Quality Assurance team will be given access to patient files for chart reviews, etc.</li> <li>• OMCFH maintains a master listing of providers to facilitate patient choice of medical practitioners.</li> <li>• All nurses and social workers serving as RFTS practitioners are required to: (a) show proof of licensure and (b) must routinely participate in training/skill-building.</li> </ul>

ENABLING SERVICES	
Goals	Strengths/Weaknesses
	<ul style="list-style-type: none"> <li>• Trainings offered by OMCFH are evaluated by participants so process changes to better meet participant need are addressed.</li> <li>• Every year approximately 1/3 of the RFTS practitioner workforce is monitored, and 100% receive a plan of correction if indicated.</li> <li>• Perinatal and Women’s Health maintains a medical advisory to assure expert medical guidance is provided the Office. Membership is statewide and multiple disciplines participate.</li> <li>• Programs facilitate the working relationship agreement between family practice physicians to assure the availability of obstetrical and/or surgical back-up in the event of patient care need. The formalization of these arrangements is to improve patient care and ease transfer of care.</li> <li>• State program leadership participates in tertiary hospital(s) grand rounds to educate new practitioners about available community resources.</li> </ul>
3. Adequate Funding	<p><b>Insufficient Funding</b></p> <p><b>Weaknesses</b></p> <ul style="list-style-type: none"> <li>• RFTS (perinatal services), especially those related to case management and behavior risk reduction, such as smoking cessation and parenting education, have been negatively affected by health care cost inflation; see Attachment (<i>RFTS service reimbursement chart</i>).</li> <li>• OMCFH has tried unsuccessfully to persuade insurers to purchase case management and other enabling services for their pregnant and newborn beneficiaries.</li> </ul> <p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• However, nurse liaisons from insurers participate in RFTS skill-building and program meetings.</li> </ul>
4. Assuring the capacity and competency of the workforce.	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• All medical practitioners serving RFTS enrollees must have formal working agreements with OMCFH establishing the expectation that patient care will be provided in accordance with ACOG standards; that the OMCFH Quality Assurance team will be given access to patient files for chart reviews, etc.</li> </ul>

ENABLING SERVICES	
Goals	Strengths/Weaknesses
	<ul style="list-style-type: none"> <li>• OMCFH maintains a master listing of providers to facilitate patient choice of medical practitioners.</li> <li>• All nurses and social workers serving as RFTS practitioners are required to: (a) show proof of licensure and (b) must routinely participate in training/skill-building.</li> <li>• Trainings offered by OMCFH are evaluated by participants so process changes to better meet participant need are addressed.</li> <li>• Every year approximately 1/3 of the RFTS practitioner workforce is monitored, and 100% receive a plan of correction if indicated.</li> <li>• Perinatal and Women's Health maintains a medical advisory to assure expert medical guidance is provided the Office. Membership is statewide and multiple disciplines participate.</li> <li>• Programs facilitate the working relationship agreement between family practice physicians to assure the availability of obstetrical and/or surgical back-up in the event of patient care need. The formalization of these arrangements is to improve patient care and ease transfer of care.</li> <li>• State program leadership participates in tertiary hospital(s) grand rounds to educate new practitioners about available community resources.</li> </ul>
5. Assessment Using Data	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• Patient data systems are linked with vital statistics.</li> <li>• OMCFH/Title V funds the assessment at birth of <u>all</u> West Virginia newborns. This includes identification of infants at risk of post-neonatal death, developmental delay, and/or newborn hearing. All this information is used by OMCFH/RFTS/Newborn Hearing to assure support and intervention occurs for "at risk" infants.</li> <li>• Technology capacity and personnel to maintain and upgrade computer infrastructure is in place.</li> <li>• Adequate computer hardware, support and training are available for the local administration of the RFTS Program (8 Regional Lead Agencies statewide).</li> </ul>

<b>ENABLING SERVICES</b>	
<b>Goals</b>	<b>Strengths/Weaknesses</b>
<p>6. Link women, children, and youth to health and other services to assure access to comprehensive, quality systems of care.</p>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• Women who receive pregnancy tests at any of the 153 Family Planning sites are provided pregnancy counseling options. Those women electing to carry the pregnancy who are without insurance are given a shortened Medicaid eligibility form and a confirmation of pregnancy that is mailed to local DHHR offices to apply for health coverage.</li> <li>• Systems Point of Entry and toll-free responders all have access to a statewide community resource guide that is on-line and portrays health and human services, which improves referral efforts.</li> <li>• As referenced earlier, standards of care are established by OMCFH/RFTS and application of these standards is applied to government sponsored patients (Title V/Title XIX). See earlier comments on this subject.</li> <li>• Participates in local and state chapter meetings of ACOG.</li> <li>• All direct service practitioners, called Designated Care Coordinators, are charged with securing health care financing for newborns. Other units in OMCFH are charged with assuring provider availability.</li> </ul>

**Perinatal Services**

West Virginia’s RFTS was started in 1989 as a partnership between OMCFH and West Virginia Medicaid to provide access to early and adequate prenatal care to low-income pregnant women and infants. Currently, RFTS provides comprehensive perinatal home visitation services to low-income women up to sixty days postpartum and care coordination for Medicaid eligible infants up to one year of age. RFTS also provides direct financial assistance for obstetrical care for West Virginia pregnant women who are uninsured or underinsured and are above income guidelines for Medicaid coverage. These pregnant women may qualify for assistance for prenatal care if they are a West Virginia resident, have income between 150%-185% of the FPL, are a pregnant teen age 19 or under, or are a non-citizen. Under this Title V funded service, women who have no funding source for prenatal care coverage or have not yet been approved for coverage can receive assistance for payment of their first prenatal visit, ultrasound, and routine laboratory procedures if ordered on their first visit.



## **Family Planning Program**

For more than three decades, the WV Family Planning Program (FPP) has been an integral component of the public health system, providing high-quality reproductive health services and other preventive health care to low-income or uninsured individuals who may otherwise lack access to health care. FPP provides an array of confidential preventive health services for low-income women, men and adolescents through a community-based provider network of 151 locations. Sites include county health departments, primary care centers, hospital outpatient centers, private providers, free clinics and university health sites. FPP services include contraceptives; health histories; gynecological exams; pregnancy testing; screening for cervical and breast cancer; screening for high blood pressure, anemia, and diabetes; screening for STDs, including HIV; basic infertility services; health education and counseling; and referrals for other health and social services.

Subsidized medical care provided by Family Planning Program clinics prevents unintended pregnancies, reduces the need for abortion, lowers rates of sexually transmitted diseases, including HIV, detects breast and cervical cancer at its earliest stages and improves the overall health of women, children and families. Free or low cost pregnancy testing is offered to enable early identification of pregnancy and timely referral into prenatal care.

In West Virginia, 28,260 of the 372,890 women of childbearing age become pregnant each year. Seventy-four percent (74%) of these pregnancies result in live births, 10% in abortion, and the remainder end in miscarriage. It is estimated that 177,300 women are in need of contraceptive services and supplies. Of these, 106,240 women need publicly supported contraceptive services because they have incomes below 250% of the federal poverty level (77,880) or are sexually active teenagers (28,360). The publicly funded Family Planning Program clinics provided contraceptive care to 58,004 women and men – including 15,617 sexually active teenagers in CY 2009.

Any female or male capable of becoming pregnant or causing pregnancy whose income is at or below 250% of the federal poverty level is income eligible to receive free or low-cost clinical examinations and free contraceptives through the Family Planning Program. Among the 50 states and the District of Columbia, West Virginia ranked 6<sup>th</sup> in the availability of publicly funded contraceptive services. These publicly funded clinics help women prevent 13,800 unintended pregnancies each year.

## **Unplanned Pregnancies**

An unplanned pregnancy can be a barrier to obtaining timely prenatal care because it may take weeks or months for a woman to realize or accept she is pregnant. The

consequences of unintended pregnancy can be serious, even life altering, particularly for women who are young or unmarried, have just recently given birth or already have the number of children they want. Lack of prenatal care, along with poor birth spacing, or giving birth before or after one's childbearing prime can pose health risks for the woman and her newborn.

The Family Planning Program participated in a nationwide "Learning Tour" conducted by the National Campaign to Prevent Teen and Unintended Pregnancy (NCPTUP) in April 2008. The West Virginia Perinatal Partnership partnered with NCPTUP to study unplanned pregnancy in the 19-29 year age group, the causes and potential remedies in West Virginia. The "Learning Tour" spoke with professionals, policy makers and young adults recording their thoughts on unplanned pregnancy. The NCPTUP completed a report on the West Virginia findings. The Perinatal Partnership received funding to explore unplanned pregnancies, based upon the findings of the study. A Statewide Advisory Committee was organized to help develop goals and strategies for reducing unplanned pregnancies in West Virginia. The goal is to strengthen women by providing them with the information needed to make healthy decisions regarding pregnancy.

Agency partners recruited in-home educators to participate by incorporating "Planning for a Healthy Pregnancy" into the health education curriculum they currently use with clients. In-home educators received protocols in February and began incorporating the advanced education in the in-home program. The project continued until August 31, 2009. The target groups of women served by the project were women in the third trimester of pregnancy and postpartum women. At the end of the six (6) month project period, a total of 591 women were served, of whom 412 were in the target age group of 19-29 years of age. A summary of project outcome data shows that of the 466 postpartum clients, 95% reported using some type of contraceptive method.

- Birth control pill or patch – 31%
- IUD, implant or injections – 23%
- Tubal Ligation – 18%
- Other – 10%
- None – 5%

The FPP purchased tools to assist Right From The Start, Designated Care Coordinators (DCCs) and Partners in Community Outreach (PICO), home visitors in providing in-home education. These tools included educational DVDs, brochures and wallet cards stressing the importance of spacing and planning for a healthy pregnancy. FPP also made it possible for the RFTS, Regional Lead Agencies (RLAs) and PICO to become "Special Agreement Sites" for family planning services. The RLAs and PICOs can order

spermicide and condoms to offer to clients during home visits. Databases for FPP and RFTS link and share required data elements for a non-medical user visit in FPP. PICO workers will submit data forms monthly to FPP.

### **Preconceptual Services**

Preconception care is a critical component of health care for women of reproductive age. The primary goal of preconception care is to provide health promotion, screening, and interventions for women of reproductive age to reduce risk factors that might affect future pregnancies. Preconception health care is critical because several risk behaviors and exposures affect fetal development and subsequent outcomes.

Family Planning Program clinics offer counseling and referral for patients regarding future planned pregnancies, management of current pregnancies, or other individual concerns (i.e., nutrition, sexual concerns, substance use and abuse, sexual abuse, domestic violence, or genetic issues). In CY 2009, all FPP providers received brochures and wallet cards with information pertaining to planning a healthy pregnancy and preconception checklist to use with all clients of childbearing age. FPP clients seeking pregnancy or planning a pregnancy in the future are offered prenatal multi-vitamins with folic acid as part of their pre-conceptual counseling. Clients in need of enhanced preconception counseling or genetics testing are referred to tertiary care facilities or specialty providers for additional assessment.

### **Insurance**

FPP has been an integral component of the public health care system, providing high-quality reproductive health services and other preventive health care to low-income or uninsured individuals who may otherwise lack access to health care. Subsidized preventive and reproductive medical care provided by FPP clinics prevents unintended pregnancies, reduces the need for abortion, lowers rates of sexually transmitted diseases (STDs), including HIV, detects breast and cervical cancer at its earliest stages, and improves the health of women, children and families. As the cost of health insurance continues to increase, women face challenges affording coverage because they are disproportionately low-income and can have limited access to employer-based insurance.

In 2005, the WV State Legislature passed a contraceptive equity law which required private insurers to cover all FDA-approved contraceptives in plans that cover prescription drugs; however, there is an exemption for employers with a limited number of employees and/or employers with moral or religious objections.

Public Employees Insurance Agency (PEIA) medical insurance coverage of dependants does not include contraceptives or prenatal care/birth of a dependant's child. This attributes to the total number of unintended births in WV each year. The WV Perinatal Partnership requested a study of the economic cost of mandatory contraceptive coverage for dependent minor by health insurers in West Virginia. The study was conducted by Center for Business and Economic Research, Marshall University. The results of the study were presented to the Legislative Oversight Commission on Health and Human Resources Accountability (LOCRHA) in December 2009.

### **Adolescent Pregnancy Prevention Initiative**

The Adolescent Pregnancy Prevention Initiative (APPI) provides development, oversight and coordination of statewide adolescent pregnancy prevention activities. As a focus area of the Family Planning Program, the goal of the Adolescent Pregnancy Prevention Initiative is to reduce the number of pregnancies among adolescents through improved decision-making skills, abstinence, and/or access to contraceptive services.

The Adolescent Pregnancy Prevention Initiative (APPI) is made up of 5 full-time employees: 1 Coordinator and 4 Adolescent Pregnancy Prevention Specialists, who conduct community education and outreach activities on a regional/local level. These 4 Adolescent Pregnancy Prevention Specialists work to increase public awareness of problems associated with early sexual activity and childbearing and collaborate with existing community organizations to promote local activities for adolescent pregnancy prevention. APPI offers abstinence based education but includes information about contraceptives and access to family planning services.

Adolescent childbearing in West Virginia cost taxpayers (federal, state, and local) at least \$38 million in 2004. The average annual cost of adolescent childbearing is \$1,010 per teen birth. The cost is much greater with a child born to a mother 17 and younger. The average annual cost for a birth to a younger teen is \$3,480. These costs are broken down into:

- \$11 million for public health care (Medicaid and CHIP), due to having more health problems at birth
- \$14 million for child welfare, due to increase in child abuse and neglect and because daughters of teen parents are more likely to become teen mothers themselves

- \$4 million for incarceration, because sons of teen parents are more likely to become incarcerated
- \$16 million in lost tax revenue, due to decreased earnings and spending

Most of the costs of births to adolescents are associated with negative consequences for the children of adolescent parents. West Virginia has made progress in reducing adolescent childbearing. The teen birth rate declined 24 percent between 1991 and 2004 saving taxpayers an estimated \$20 million in 2004 alone. Birth rates for teens 15-17 decreased 30% from 1991-2002.

Confidential access to Family Planning Program services is crucial in helping sexually active teenagers obtain timely medical advice and appropriate medical care to continue the decline in teen pregnancy and childbearing. Minor clients seeking reproductive health care can only be assured of confidential services by a Title X-funded Family Planning Program network provider. Current research documents show that fewer teens will seek preventive reproductive health services if confidential care, without parental consent, is not available.

### **Sexual Behavior of Youth**

The Youth Risk Behavior Survey (YRBS) was developed by the Division of Adolescent and School Health, National Center for Chronic Disease Prevention, Centers for Disease Control and Prevention (CDC). In collaboration with the WV Department of Education, the 2007 YRBS was designed to monitor priority health-risk behaviors that contribute to leading causes of disease, death, and social problems among youth. Research indicates that these behaviors and the resulting health problems are largely preventable. The students who participated in the survey are representative of students in WV. The results can be used to make references concerning the health risk behaviors of all WV public high school students in grades 9 through 12.

The following results of the 2007 YRBS illustrate sexual behaviors that result in HIV infection, other sexually transmitted diseases (STDs), and unintended pregnancy that place our youth at risk:

- 52% of WV high school students reported they had ever had sexual intercourse. This reflects a statistically significant improvement in the health risk behavior of sexual activity. Data from 1990-2005 indicated a downward trend in the number of students who had ever engaged in sexual intercourse
- The number of students who reported being currently sexually active (had sexual intercourse during the three month period prior to the survey) also decreased

- According to YRBS data, nearly half (46%) of all U.S. high school teenagers have had sexual intercourse at least once

Contrary to popular belief that teens are experiencing their first sexual intercourse during the after school hours, recent data from the 2000 wave of the National Longitudinal Survey of Youth, 1997 cohort, show that the most common time period that teens between the ages of 16 and 18 first have sex is at night (10pm to 7am), and the most common places are their family home or their partner's family home. Although health risk behaviors of teen sexual activity is improving, this data offers additional insight that may aid parents, teachers, community youth leaders, and others when considering and planning youth activities.

### **Cytology Services**

The Family Planning Program (FPP) and the Breast and Cervical Cancer Screening Program (BCCSP) are required by State purchasing guidelines to evaluate the purchase of cytology services on an annual basis. During the fall of 2006, quotations were solicited for cytology services for both programs and the contract was awarded to Pennsylvania Cytology Services (PCS). The contract was awarded January 2010 with services beginning February 1, 2010. The transition in cytology vendor services was non-eventful. Cytology screening for pap test using liquid based pap test and HPV/DNA test (high-risk only) are available.

### **Sexually Transmitted Diseases**

FPP continued to offer basic STD counseling, education, screening, diagnosis, and treatment activities. Testing and treatment of Chlamydia, gonorrhea, and syphilis are available for established Family Planning clients. For STD services, the *WV Family Planning Program Guidelines* reference the *Sexually Transmitted Diseases (STD) Treatment Guidelines*, published by the Centers for Disease Control and Prevention, as recommended STD screening and treatment protocols. FPP continues to collaborate with the Division of STD/HIV/AIDS and Hepatitis and the WV Office of Laboratory Services in the Region III Infertility Prevention Project (IPP).

FPP, Division of STD/HIV/AIDS and Hepatitis and the WV Office of Laboratory Services jointly received a grant to conduct a pilot project, *Urine Based Chlamydia Screening for Women*. The pilot project targets women under the age of 25 requesting a urine pregnancy test. The objective of the pilot project is to assist in determining the positivity rate in women not typically screened. Many women coming to a Family Planning Program provider for a urine pregnancy test may not be due for an annual exam for several months and may not keep her scheduled annual exam appointment. These women are offered a urine Chlamydia and gonorrhea screening along with the urine

pregnancy test. The pilot project began in September 2007 and has a target of 1,800 tests. Although the target number of tests has been exceeded, the positivity rate at those sites has been significant enough to warrant continued testing. Currently, clients within this population are showing 6.8% positivity. Their male partners are referred to a STD clinic for follow-up and treatment. Once the pilot project is completed, an analysis will be conducted and the findings forwarded to each participating agency. Data will be used to determine the feasibility of continued urine screening to identify positivity in women not typically screened.

In CY 2007, 3,193 cases (rate of 176.2) of Chlamydia infections were reported in WV, representing a 10.6 percent increase compared to 2,888 in CY 2006 (159.7). Of the 3,193 cases, 1,386 (43.4) were reported by the Office of Laboratory Services (OLS) and 1,807 (56.6%) were reported by private providers and laboratories. The OLS performed 37,461 tests for Chlamydia, regardless of the patient's state of residence, of which 1,499 (4.0) were positive.

The number of reported cases of Chlamydia has steadily increased in the last five years (24 percent since CY 2003), with the exception of CY 2006 in which a 2.3% decrease was observed. It is thought that the overall increase is primarily due to increased efforts focusing on education and screening of women and other high risk populations and availability of a less invasive test method (urine based versus vaginal/cervical and urethral swabs). During the first half of 2008, 1,569 cases of infections were reported, compared to 1,598 cases reported during the same time period in 2007.

Women accounted for 76.5% (2,443 cases) of all reported infections in WV in CY 2007. The case rate for women (264.2) was more than three times higher than that of men (84.4). Chlamydia infections in WV disproportionately affect women in the early reproductive state of life. In CY 2007, 60% (1,923 cases) of all reported infections occurred in women between the ages of 15-24. CY 2007 data indicates that 31% (992 cases) of all reported infections occurred in women between ages 20-24 years, closely followed by women ages 15-19 years, which accounted for 29% (931 cases) of all reported infections. Women ages 25-29 years ranked third with 10.2% (325 cases) closely followed by men ages 20-24 years with 9.9% (315 cases).

Since CY 2003, Chlamydia infections have occurred in all races and in all ethnic groups in WV; however, African Americans have consistently been disproportionately affected. African Americans, despite accounting for approximately 3.5% of the State's population, represented 19.3% (617) cases of the infections reported in CY 2007. The rate of infections for African American men (748.0) was 15.9 times that of Caucasian men (47.1) and 7.4 times that of Hispanic men(100.8).

Gonorrhea is the second most frequently reported infectious disease in WV with 42 of the 55 counties reporting at least one case in 2007. The number of reported cases of

gonorrhea in CY 2007 declined for only the second time in the last five years. In CY 2007, 934 cases (rate of 51.5) were reported, which is less than .07 percent decrease compared to 941 cases in CY 2006. WV had an overall increase (13.3%) in gonorrhea infections as compared to CY 2003.

Women accounted for 54.1% (505 cases) of all reported gonorrhea infections in WV in CY 2007. The case rate for women (54.6) was not significantly different than that of men (48.4) and this has remained consistent since CY 2003.

Syphilitic infections account for a much smaller proportion of reportable infections disease cases in WV. During CY 2007, six counties in WV each reported a case of primary or secondary (P&S) syphilis. Since CY 2003 to CY 2007, 15 counties have reported a total of 26 P&S cases. Significantly, nine of the 15 counties are considered border counties, and all of the counties form concentrated areas of disease in the northern corner, the eastern panhandle and the southwestern part of the State.

The number of reported cases of early syphilis Primary, Secondary and Early Latent (EL) in WV has increased 67% since CY2003. However, during CY 2007 six cases of P&S and nine cases of EL syphilis were reported, which represents an 11.8% percent decrease from the 17 cases (11 cases of P&S and six cases of EL syphilis) reported in 2006.

Human Papilloma Virus (HPV) is the most common sexually transmitted virus in the United States. The FPP provided educational posters and brochures for providers and public education. In collaboration with the Infectious Disease Epidemiology Program, Immunization Program, all FPP providers were given information on the quadrivalent Human Papilloma Virus Vaccine.

## **Domestic Violence**

Screening for Domestic and Intimate Partner Violence continues to be monitored by the Family Planning Program. Family Planning Program Specialists inquire about screening and availability of resources for victims at annual site visits. Findings are documented in their reports and entered in a data base. All Family Planning Program providers (100%) provide resources on site for services to those who are victims of domestic or intimate partner violence.

A *Domestic Violence Intervention Guide* was developed within the FPP for use by clinicians. A poster was also created to be placed in the restrooms with tear-off safety-plans for victims to take with them. The intervention guides and posters with tear-off safety plans were mailed to all FPP provider sites and are available by request.



## **Contraceptive Consistency**

Use of highly effective contraceptive methods does not compensate for inconsistent use. Most teens vary their levels of contraceptive consistency across relationships. Teens may use contraception every time that they have sex with one partner, but may use contraception only sometimes or never with a different partner. Teens that inconsistently used hormonal contraceptive methods were more than three times as likely to have a teen birth as teens that consistently used a less effective method, such as a condom. Newer contraceptive methods, such as Depo Provera, NuvaRing (vaginal ring), Ortho Evra (the contraceptive patch) and NuvaRing (implant) combine effectiveness and efficiency and should help prevent unintended pregnancies. This data indicates a continued need for enhanced contraceptive counseling and education for adolescent clients.

## **Pregnancy Intendedness**

In 2006, of women living in WV and delivering a live infant, 57% were intended pregnancies and 43% were unintended. This represents a decrease in the number of unintended pregnancies.

### **Maternal Age**

In 2006, of women living in WV and delivering a live infant, 13% were to women less than or equal to 19 years of age, 39% were to women older than 19 but less than or equal to 25 years of age, and 48% were to women greater than 25 years of age.

### **Birth Control Use**

In 2006, of women living in WV and delivering a live infant, 42% were using some form of birth control when they became pregnant and 58% were not; 85% were using some form of birth control postpartum and 15% were not.

## **High Priority Populations**

WV FPP clinics primarily serve low-income and uninsured women, men and adolescents who do not qualify for Medicaid but earn too little to afford private health insurance. Over ninety percent (90.4%) of FPP clients have incomes below the FPL and receive services at no cost and less than ten percent (9.5%) of clients have incomes below 250% of the FPL and receive services at discounted rates. In CY 2009, only 6.2% of FPP clients (3,640 individuals) were Medicaid enrollees.

## **Statewide or Community Resources for Reproductive Health**

Subsidized medical care is the only health resource for many WV residents, in particular those seeking women's reproductive health care. The economic status of the State has dramatically influenced the availability of adequate health care for many families.

Many private practitioners (not participating in the Family Planning Program) provide contraceptive and basic reproductive health services for Medicaid clients or insured clients. However, It is difficult for these private practitioners to adequately serve low-income, uninsured clients, due to the inability of clients to pay for the medical care and to purchase expensive contraceptive medications, supplies and devices from pharmacies. WV has only one (1) Planned Parenthood affiliate, Planned Parenthood of WV, which recently agreed to participate in the Title X Family Planning Program.

In addition to Family Planning Program and Medicaid Program coverage for contraceptive services and reproductive health care, the WV Children's Health Insurance Program (CHIP Phase II) is yet another resource to assist with financial coverage for care provided to children ages 6 to 19 years with family income between 100% - 150% FPL. Implemented in early 1999, WV CHIP Phase II is administered by the Public Employees Insurance Agency (PEIA) and pays for services provided by WV health care providers. Phase II is a fee-for-service (vs managed care) plan. There is no charge to the family for any services included in the plan - no premiums, deductibles or co-payments. Health care providers are reimbursed at the prevailing PEIA rate for CHIP Phase II services.

CHIP Phase II provides excellent coverage for family planning office visits, annual pap smears, general labs (STD screening services), and prescription drug benefits, which cover oral contraceptives and estrogens/progestins (Depo-Provera injections). The only identified drawback to CHIP Phase II is the inability of providers to offer confidential family planning services for sexually active adolescents, as this is permissible only by Title X regulation or State law (which WV does not have). The Family Planning Program will continue to monitor teens' utilization of family planning services, including those funded under CHIP Phase III.

In March 2006, WV Governor Joe Manchin III signed legislation to expand State Children's Health Insurance Program (SCHIP) eligibility up to 300 percent of the federal poverty level, and on January 1, 2007, the State began a phased-in expansion by enrolling children in SCHIP with family incomes up to 220 percent of the federal poverty level. Adoption of this change is estimated to provide comprehensive health care coverage to approximately 400 uninsured children of working families during the first year of implementation. When SCHIP expands to 300% of the federal poverty level, 4,000 children are expected to be eligible.

## Unmet Family Planning Needs

In 2006, the Alan Guttmacher Institute (AGI) published a report, *Contraception Counts*, highlighting contraceptive services state by state. Among the 50 states and the District of Columbia, WV ranked 6<sup>th</sup> in service availability. WV documented 177,300 women were in need of contraceptive services and supplies. Of these, 106,240 women need publicly supported contraceptive services because they have incomes below 250% of the federal poverty level (77,880) or are sexually active teenagers (28,360). Of the women aged 15-44, 18% have incomes below the federal poverty level, and 23% of all women in this age group are uninsured (i.e. do not have private health insurance or Medicaid coverage). In this same age group, 13% are enrolled in Medicaid.

The CY 2006 Family Planning Program Annual Need Met Report provided information on the percent of the need met for each county in WV. With the exclusion of non-WV residents, in CY 2006, 53,448 unduplicated women, men and teens with incomes less than 250% of the federal poverty level received subsidized services, representing 50.4% need met of the at risk population of 106,240. Family Planning Program clinics serve 56% of all women in need of publicly supported contraceptive services and 60% of teenagers in need. Publicly funded family planning clinics in WV help women prevent 13,800 unintended pregnancies each year.

WV's efforts to improve the health status of women has been successful over time as evidenced by broadened medical coverage, streamlined medical eligibility processes, shared government funding for targeted populations, targeted outreach, risk reduction education, and development of comprehensive programs that address both medical and behavioral issues.

Many conditions such as maternal death or ill health decrease when women have births that are adequately spaced, giving their bodies' sufficient time to regain strength. Babies born less than two years after a prior birth are much more likely than those born after a longer interval to be premature or low birth weight. Increased use of Family Planning Program (FPP) services enables women to reduce closely spaced births and limit childbearing to their 20's and 30's, which may greatly reduce the infant mortality rate.

Medicaid and Family Planning share a common commitment to the goal of ensuring healthy births, reducing the incidence of low birth weight, and improving the health status of WV's children. These agencies also recognize the importance of maximizing scarce fiscal resources and the benefit of collaborative efforts in the development of programs that support shared goals. For this reason, the Family Planning Program proposed a Medicaid Waiver Project (MWP) for low income WV women who received Medicaid for prenatal care and delivery services. If a Waiver Project is approved, FPP

services could extend from the usual eligibility period that normally ends at sixty (60) days postpartum, until two (2) years postpartum. Over a five (5) year project period, this Waiver Project plans to document sufficient success in reducing the incidence of closely spaced pregnancies and unintended pregnancy among low income women to institutionalize the project. This success will lead to healthier pregnancies, better birth outcomes and improved child health. It is projected that providing preventive family planning services to eligible low-income women until two (2) years postpartum will cost the State and federal governments less than the cost of prenatal care, delivery, and infant health care.

### **State Reporting Laws**

Provider agencies are monitored for compliance with State reporting laws by the OMCFH Quality Assurance Monitoring Team (QAMT). Family Planning Program provider agencies must adhere to the State requirement for reporting of suspected child abuse of minor children. WV's child abuse reporting laws require reporting only when the harm is suspected to have been done by the child's parents, guardians, or custodians. According to WV Code §49-6A-1 through §49-A-8, this does not include harm to a child by a person who is not a parent, guardian or custodian (WV Code §49-6A, Child Welfare: Reports of Children Suspected to be Abused or Neglected).

### **Monitoring of Sub-recipient Agencies**

Provider agencies are reviewed periodically by the OMCFH QAMT. Providers must agree to on-site reviews from OMCFH QAMT and/or federal personnel of all client records and program information. The OMCFH QAMT or federal personnel must be given access to all information related to FPP services to insure that client care is provided in accordance with current practice standards.

To insure compliance with Section 1008 of the Title X Statute, the FPP prohibits abortion as a method of family planning. Women requesting information and counseling on pregnancy termination are provided neutral, factual information, non-directive counseling and referral services upon request. No Title X funds are used for abortion services.

Title X funds are allocated to participating providers on an annual sub-recipient Memorandum of Understanding (MOU) (July - June of each year). The following information and data are used in determining allocations:

- Prior year(s) FP client utilization
- Projected expenditures against existing contract
- Past growth in number of FP clients served

- Estimates of potential growth

Using the above factors, the WV Family Planning Program determines tentative allocations for next contract year. WV State Purchasing policies do not require that medical services be competitively bid.

### **Schedule of Discounts/Sliding Fee Scale**

No patient below 100% of FPL income may be charged for services provided as a result of Title X, Public Health Service funding. Client fees are collected beginning at 100% of the income scale and in 25% increments, reaching full payment for the cost of medical care at 250% of FPLI income. The sliding fee scale is revised annually pending receipt of the updated U.S. Department of Health and Human Services poverty guidelines.

### **Privacy of Personal Health Information**

Every provider agency must assure client confidentiality and provide safeguards for individuals against the invasion of personal privacy, as required by the Privacy Act. No information obtained by the staff about individuals receiving services may be disclosed without the individual's written consent, except as required by law or as necessary to provide services to the individual, with appropriate safeguards for confidentiality. Information may otherwise be disclosed in summary statistical or other form that does not identify the individual.

### **Internal Compliance Reviews**

The FPP receives monthly reports outlining the current status of MOU expenditures (year to date and remaining balances). The reports are annualized to determine if expenditures for clinical services remain on target. In addition a detailed monthly expenditure report, generated from the WV Financial Information Management System (FIMS), is reviewed to monitor overall expenditures in comparison to the established budget. For information on medical audit and protocols, refer to Section VII, Evaluation, Quality Assessment and Assurance.

### **Continuing Education and/or Training**

Staffs of participating delegate agencies and clinical service sites are provided on-going in-services, skills development, and continuing education opportunities. Through continuing participation with the Region III training contractor (TRAINING 3) and the Region III Training Advisory Committee (RTAC), the Family Planning Program offers a minimum of four workshops for contracted providers each year. Additional workshops are sponsored by the Family Planning Program for targeted populations or to support

special projects. Selection of topics is based on an annual assessment of training needs, conducted either by TRAINING 3 or the Family Planning Program. On request, new delegate agency and clinic staff are provided a copy of a training manual “*Orientation to Family Planning: Acquiring Knowledge in Reproductive Health Care*”, a self-instructional module which provides general information regarding reproductive health, contraceptive services, sexually transmitted diseases, and counseling and education services, among other topics. Family Planning Program Specialists are available on request for on-site comprehensive orientation and training for new delegate agency and clinic site staff.

## **Bilingual Services**

A need for bilingual or interpreter services in Family Planning Program clinics has not been identified, with the exception of an occasional seasonal demand. Non-English speaking migrant farm workers have occasionally sought services in community health centers in the eastern panhandle of the State. As these situations arise, the individual health centers have interpreters available to assist with communications needs. A policy, Communication with Limited English Proficient Clients, was added to the *Family Planning Program Guidelines*, so all contracted providers would establish procedures in the event that non-English clients presented for Family Planning Program services. FPP providers reported 180 limited English proficient clients receiving FPP services in CY 2008. Over 350 pieces of literature have been distributed 1/1/09 -11/30/09. FPP also partnered with the Bureau for Public Health (BPH) and conducted an in-service on using a new phone-in language resource, *Fluent Language Solutions*, to provide interpreter services as needed without advanced scheduling or additional cost.

## **Breast and Cervical Cancer Screening Program**

The West Virginia Breast and Cervical Cancer Screening Program (WVBCCSP) is a comprehensive public health program that assists uninsured/underinsured, low income women (at or below 200% of the Federal Poverty Level) between the ages of 25 and 64 in receiving quality breast and cervical cancer screening services. These services are offered through a statewide network of over 300 screening and referral providers. The WVBCCSP is funded through a federal cooperative agreement with the Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program (NBCCEDP). West Virginia was one of the original eight states received funding to implement this program in 1991. Today, the NBCCEDP spans all fifty states and the District of Columbia, five U.S. territories, and twelve American Indian/Alaska Native organizations.

Since its inception, the WVBCCSP has enrolled over 110,000 women into the Program and provided more than 141,500 mammograms, 208,500 clinical breast exams, and

218,000 Pap tests. Annually, the Program screens over 16,000 women. However, the Program does more than simply screen women. There are several core components of the WVBCCSPP including: Program Management; Screening, Tracking and Follow-up; Surveillance/Data Management; Quality Assurance and Improvement; Professional Development; Recruitment; Partnerships; and Evaluation.

West Virginia's WISEWOMAN Program is a comprehensive public health program that works with the West Virginia Breast and Cervical Cancer Screening Program (WVBCCSPP) to provide women access to screening services to determine their risk of heart disease and stroke. WISEWOMAN is directed at low-income, uninsured/underinsured women aged 40-64 years. As part of a WVBCCSPP eligible woman's routine breast and cervical cancer screening exam, she will be provided blood pressure readings, total and HDL cholesterol screening, blood glucose measurements, calculation of body mass index, assessment of smoking status, and evaluation of personal and family medical history. As follow-up to her screening exam, she will be offered risk reduction counseling and lifestyle interventions that will address nutrition, physical activity and tobacco use.

Contracted providers and WISEWOMAN staff ensure that women with abnormal screenings receive timely follow-up through the active monitoring of Program data. The WISEWOMAN grant provides \$750,000 in funds. The majority of provider sites are community health centers, since their federal assignment is assuring health access, and this provides an opportunity to be identified as the woman's health home.

In 1996, the West Virginia Legislature enacted House Bill 4181, establishing the Breast and Cervical Cancer Diagnostic and Treatment Fund for the purpose of assisting medically indigent patients with certain diagnostic and treatment costs for breast and cervical cancer. The Fund provides resources to offset the cost of diagnostic care not otherwise available to the WVBCCSPP through the federal cooperative agreement.

To assist NBCCEDPs in providing treatment to women diagnosed with breast and/or cervical cancer, the 2000 Congress gave states the option to provide medical assistance for treatment through Medicaid as a part of the passage of the Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA). West Virginia was one of the first states to take advantage of this opportunity. This means that when an uninsured woman under the age of 65 is diagnosed with breast and/or cervical cancer and/or certain precancerous conditions, she is eligible for a Medicaid card. The card will pay for all her health care services that are included in the Medicaid State Plan, not just those to treat the cancer diagnosis.

### **WISEWOMAN Program**

West Virginia's WISEWOMAN program is integrated with the West Virginia Breast and Cervical Cancer Screening Program (WVBCCSP) and provides eligible women with chronic disease risk factor screening, lifestyle intervention, and referral services in an effort to prevent cardiovascular disease. WISEWOMAN is provided to WVBCCSP participants aged 40-64 years. WISEWOMAN services are offered as part of the WVBCCSP's routine breast and cervical cancer screening exam and includes blood pressure readings, total and HDL cholesterol screening, blood glucose measurements, calculation of body mass index, assessment of smoking status, and evaluation of personal and family medical history. During WISEWOMAN follow-up exams, risk reduction counseling and lifestyle interventions that will address nutrition, physical activity and tobacco use are offered.

### ***Disease Burden and Need***

Like the rest of the Nation, cardiovascular disease (CVD), is a leading cause of death for both West Virginia men and women from all racial and ethnic backgrounds. Using Data from the Behavioral Risk Factor Surveillance System (BRFSS) participants in 2006, the Centers for Disease Control's Chronic Disease Indicators provide the following: West Virginia has the fourth highest mortality rate for CVD in the country. The mortality rate for CVD in West Virginia is 344.5 per 100,000 residents (288.0 U.S.), making it the leading cause of death and a major cause of disability. Stroke, a condition that occurs when the blood supply to part of the brain is blocked or when a blood vessel bursts, affects 3.4% of West Virginians (as compared to the U.S. rate of 2.6%).

### ***Cardiovascular Disease in West Virginia Women***

Cardiovascular disease (CVD) refers to major disorders of the heart and blood vessels supplying the heart, brain and peripheral tissues. According to the WV Health Statistics Center, heart disease (primarily coronary heart disease) and stroke were the first and third leading causes of death, respectively, among women in West Virginia in 2006. CVD accounted for 35.1% of total deaths among White women in that year and 37.7% of total deaths among African American women. Misperceptions still exist, however, that women have less to fear from CVD than men, although it is estimated that 1 in 2 women will eventually die of heart disease or stroke, compared with 1 in 25 who will eventually die of breast cancer. According to the American Heart Association, 38% of women will die within one year after a heart attack, compared with 25% of men.

Among BRFSS participants in 2006, the age-adjusted rate of heart disease mortality among women in West Virginia was 193.8 deaths per 100,000 population; the comparable rate in the United States in 2005 was 172.3. In 2006, the age-adjusted rate of stroke mortality among women in West Virginia was 48.8 deaths per 100,000 population; the comparable rate in the United States in 2005 was 45.6.



*Heart Disease Mortality Rates among Women  
West Virginia and United States, 1997-2006*

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
<b>WV</b>	268.1	262	278.6	253.8	245.6	240.7	238.4	217.7	206.8	193.8
<b>US</b>	226.5	222.4	219.5	210.9	204.2	197.8	190.4	177.3	172.3	NA

*Stroke Mortality Rates among Women  
West Virginia and United States, 1997-2006*

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
<b>WV</b>	52.4	49	64.3	57.4	57.3	57.6	58	56.2	56.3	48.8
<b>US</b>	59.3	58.2	60.1	59.1	56.5	55.4	52.3	48.9	45.6	NA

Stroke affects an estimated 700,000 Americans each year. Approximately 71% of strokes occur in new victims, while 28.6% occur among previous stroke victims. Stroke can occur at any age, but nearly one fourth afflict people under the age of 65. The southeastern United States has the highest rate of stroke in the country; however, researchers have not been able to determine the factors that might cause this region to have higher incidence and mortality.

Risk factors for CVD include high blood pressure, smoking, high blood cholesterol, obesity, physical inactivity, diabetes, dental disease, a diet high in saturated fat and low in dietary fiber, and a family history of heart disease or stroke. West Virginia's women do not fare well in any of these categories, often ranking as some of the worst in the Nation in terms of these health indicators.

According to the 2007 BRFSS, 31.6% of adult women in West Virginia were told they had high blood pressure, a markedly higher percentage than the U.S. median of 26.6%. (West Virginia has the second highest rate in the U.S.) Roughly 40.0% of West Virginia women have high cholesterol (34.2% U.S. females). West Virginians have the second highest rate of diabetes; more than one out of every ten women is diabetic. Statistics also reveal that women in West Virginia need to take better care of themselves by eating more balanced diets and participating in physical activity. In addition, 75.9% (2007 BRFSS) of women did not consume five or more servings of fruits and vegetables daily and 57.9% (2007 BRFSS) do not partake in moderate or vigorous physical activity. More than 62.5% (2008 BRFSS) of women are classified as overweight or obese.

Tobacco use is ingrained in the culture of West Virginia residents. The 2005 West Virginia Breast and Cervical Cancer Screening Program (WVBCCSP) reports that 41% of new enrollees aged 40-64 are current smokers, (significantly higher than both the State and National average). This data demonstrates the need to specifically offer tobacco cessation services to this disparate group of women. The 2005 Adult Tobacco Survey shows that 50.1% of West Virginia's female smokers are seriously considering quitting within the next six months, which provides the WISEWOMAN Program with a unique opportunity to help this high risk group of women to quit tobacco.

Risk factors for heart disease and stroke generally increase with age, lower educational levels, and lower incomes. According to the U.S. Census Bureau, West Virginia's median age was 38.9 in 2000, 40.3 in 2004, and 40.7 years in 2006 which indicates that West Virginia's population is aging. With regard to education, an estimated 81.0% of residents are high school graduates (84.1% U.S.) and only 16.5% have a Bachelor's degree or higher (27.0% U.S.). Poverty and low per capita income also plagues West Virginians. The 2006 inflation-adjusted per capita income in West Virginia is only \$19,417 as compared to the U.S. rate of \$25,267. This means that an estimated 12.7% (9.8% U.S.) of all families and 17.3% (13.3% U.S.) of individuals live in poverty. All of these factors are precursors to poorer health.

West Virginia's poor health is not only costing the State lives, but also billions of dollars each year in decreased work productivity and medical expenses. According to the American Heart Association, coronary heart disease in America is expected to cost \$156.4 billion in 2008, while the direct and indirect cost of stroke is an estimated \$65.5 billion. Risk factors for heart disease are also economic burdens. The direct and indirect cost of high blood pressure is estimated at \$69.4 billion, \$76.6 billion for physical inactivity, \$167 billion for smoking (including loss of work productivity), and \$132 billion for overweight and obesity.

### **Identification of Areas in Need of WISEWOMAN Services**

As a whole, West Virginia lags behind the Nation with regard to health indicators, education, and economics. However, the southern coal fields and mountain regions are in poorer health and utilize available health services less than other areas of the State. According to the Centers for Disease Control and Prevention's (CDC's) Division for Heart Disease and Stroke Prevention, the counties in West Virginia with highest prevalence of heart disease or stroke include Braxton, Cabell, Calhoun, Doddridge, Gilmer, Hardy, Logan, Mason, McDowell, Mercer, Mingo, Pendleton, Putnam, Wayne, and Wyoming. Internal WVBCCSP data shows correlations with these areas as counties of need. However, a number of these counties lack the infrastructure to implement screening services as outlined by the national WISEWOMAN Program.

Since the entire State demonstrates a significant need for the WISEWOMAN Program, West Virginia's program targets all interested counties that have the capacity to implement services.

### **Division of Infant, Child and Adolescent Health**

The goal of this Division is to promote parent/professional collaboration through parent participation on advisories; develop and issue medical care protocols in collaboration with the medical community to ensure provision of quality community-based services for child populations; and develop patient education and outreach strategies to encourage use of preventive health care.

#### **Adolescent Health Initiative (AHI)**

This program, originally financed solely by Title V, to address the most prevalent health risks facing adolescents today, has become a part of a larger initiative within OMCFH financed by TANF resources. The primary goal of the AHI is to improve the health status, health related behavior, and availability/utilization of preventative, acute, and chronic care services among the adolescent population of WV and promote risk resiliency and strengthen youth's personal assets.

Formal work with the Adolescent Health Initiative (AHI) began in 1988. Introduction of the developmental asset principles of Search Institute brought about a change in the mission in 1993. The Search Institute has identified 40 positive experiences and qualities everyone can bring into the lives of youth, called the developmental assets. Organized training opportunities are provided by a workforce hired from the community they serve and offered in the community that the youth live. This workforce, called Adolescent Health Coordinators, is located in each of the eight regions of the State. These Coordinators offer young people, parents, and other significant adults in a child's life skill building sessions on conflict resolution, communication, increased awareness of harmful consequences of substance use, and strategies to develop self-reliance and improve responsible decision making.

#### **The West Virginia Abstinence Education Project (AEP)**

Since the inception of the federal abstinence education funding, West Virginia has been at the forefront of administering these grant dollars by providing long-term, intensive programs in an asset development framework in public schools and community organizations. Abstinence education is primary health prevention that teaches youth the physical, emotional, social, intellectual, spiritual and financial benefits of abstaining from sexual activity. Abstinence Only Education funds have been reinitiated by Congress.

## Early Periodic Screening, Diagnosis and Treatment (EPSDT)

HealthCheck is the Office of Maternal, Child, and Family Health Program responsible for administering the federally mandated Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) for 20,443 “categorically needy” West Virginia children and youth (e.g., children who have poverty-level income, receive Supplemental Security Income, or receive federal foster care or adoption assistance) not enrolled in a Managed Care Organization (MCO). While nationally 29.7 percent of children ages 0-18 are covered by Medicaid, 37.4 percent of children ages 0-18 living in West Virginia receive coverage through Medicaid.<sup>5</sup> Low-income children covered through public insurance are more likely to be born at low birth weight, which enhances the risk for lifelong disability.<sup>6</sup> Low socioeconomic status carries with it many side-effects: poor nutrition, fewer educational opportunities, greater exposure to environmental hazards, and inadequate housing, to name just a few. All of these difficulties increase the probability that a poor child will be in poor health. Undeniably, children living in poverty, particularly children of color, are more likely than other children to suffer from ill health, including vision, hearing and speech problems, dental problems, elevated lead blood levels, behavioral problems, anemia, asthma, and pneumonia.<sup>7</sup>

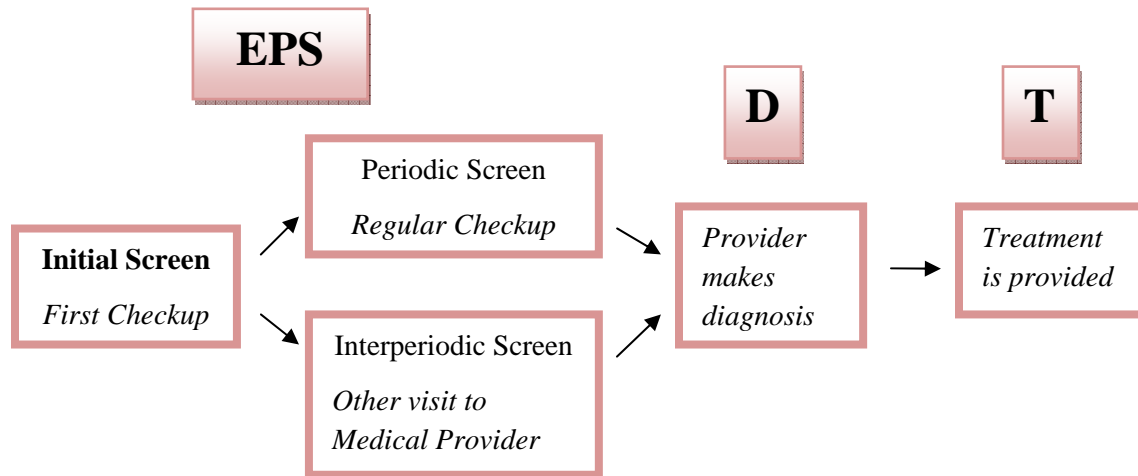
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<sup>5</sup> Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau's March 2008 and 2009 Current Population Survey (CPS: Annual Social and Economic Supplements).

<sup>6</sup> Hack M, Taylor HG, Drotar D, Schluchter M, Cartar L, Andreias L, Wilson-Costello D, & Klein N, 2005. Chronic Conditions, Functional Limitations, and Special Health Care Needs of School-Aged Children Born with Extremely Low-Birth-Weight in the 1990s. *JAMA* 294:3 p. 318-325.

<sup>7</sup> Edward L. Schor et al., Medicaid: Health Promotion and Disease Prevention for School Readiness, 26 *HEALTH AFFAIRS* 420, 423 and n. 21 (Mar.-Apr. 2007) (noting that 39% of young children on Medicaid are at risk of developmental, behavioral, or social delay); Paul Newacheck et al., The Effect on Children of Curtailing Medicaid Spending, 274 *JAMA* 1468 (Nov. 8, 1995).

## Summary of the EPSDT Process



EPSDT establishes a broad scope of benefits and a uniform medical necessity definition – services needed to correct or ameliorate the child’s physical or mental conditions. The EPSDT assurance to children eligible for Medicaid is the provision of preventive health exams and treatment of all medical conditions discovered during the exam, even if the service is not a part of the Medicaid State Plan.<sup>8</sup> EPSDT’s special rules reflect the greater health needs of low-income children, as well as children whose special health needs qualify them for assistance.

State child welfare programs, acting *in loco parentis*, use Medicaid and EPSDT to finance the frequently significant levels of health care used by children in the child welfare system, given the limited funding for child welfare programs and prohibitions under federal child welfare laws against use of federal financing, under child welfare statutes for medical care services. Thus, Medicaid payments are predominate in health care financing for children receiving child welfare services.<sup>9</sup> Moreover, children in such situations typically have acute and urgent physical and mental health needs at the time of entry into care. These children are significantly more likely to experience chronic, underlying physical or mental health conditions, which in turn have been shown to precipitate emergency department visits shortly after entry or around placement changes.<sup>10</sup>

<sup>8</sup> 42 CFR 441.61

<sup>9</sup> Rubin D, Halfon N, Raghavan R, Rosenbaum S, Johnson K. The Deficit Reduction Act of 2005: Implications for Children Receiving Child Welfare Services. Casey Family Programs, Washington DC. December 2006

<sup>10</sup> Rubin D.M., Alessandrini E.A., Feudtner C., Localio A.R., Hadley T. Placement changes and emergency department visits in the first year of foster care. *Pediatrics* 2004;114(3):e354-e360.

In West Virginia, enrollment and participation in the EPSDT Program is a requirement for every child in foster care.<sup>11</sup> Guaranteeing all foster children receive the full benefits of EPSDT services is the shared responsibility of the following DHHR Bureaus:

- Bureau for Children and Families (BCF) – due to their legal guardianship of foster children
- Bureau for Medical Services (BMS) – due to their responsibility to provide health coverage for children in foster care
- The Bureau for Public Health (BPH)/Office of Maternal, Child, and Family Health (OMCFH) – due to their administration of the EPSDT Program and system infrastructure to provide tracking

Currently, more than 3,900 West Virginia children are in DHHR foster placements. The OMCFH provides the initial outreach (identifying, informing and assisting) necessary to establish regular health supervision plans for this targeted population. Once the foster child receives his/her initial EPSDT examination, the child's DHHR social worker assumes responsibility for coordinating care. If additional healthcare is needed, the DHHR social worker must assure that the child receives the needed service(s). Furthermore, the DHHR social worker must assure that all periodic and needed interperiodic examinations are scheduled and subsequently kept. This presents a significant challenge, as communication and information exchanges between the medical practitioner, DHHR social worker, and foster family is often fragmented or incomplete. Hence, BCF and OMCFH have launched the Fostering Healthy Kids Initiative to assure the availability of high quality medical care for all foster children in Kinship Relative Care and Foster/Adoptive Family Care. Theoretically, this initiative will ensure that children in Kinship Relative Care and Foster/Adoptive Family Care placements receive the same levels of healthcare coordination as foster children in Specialized Foster Care, Group Care, Specialized Family Care (Medley), Psychiatric Residential Treatment Facility Care, and Emergency Shelter Facility Care.

#### Children's Dentistry Project

This Project works in concert with other Office of Maternal, Child and Family Health programs, Head Start and the public schools to promote awareness and availability of dental health services as an integral part of preventive, primary health services through educational instruction. Oral health efforts are funded from Title V and State appropriation. The Program conducts needs assessments, provides fiscal resources to local communities to support learning opportunities for children and adolescents which encourage behavioral change; i.e., regular check-ups, brushing/flossing and use of mouth guards during sports activities. OMCFH has contracts with local health

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<sup>11</sup> WVDHHR/BC&F General Foster Care Policy Section 13

departments, primary care facilities and oral health care professionals to provide educational services and materials to all 55 counties in West Virginia. These local health departments and contracted dental hygienists are responsible for oral health education efforts that include working with the public school system. The Office has developed education modules approved by the WV Dental Association, and utilizes oral health supplies and education materials that are used in public school instruction. This Program also supports fluoridation and sealant efforts in the community, in addition to providing oral health supplies and education materials requested by various partners throughout the State.

**c. Population-Based Services**

Population-based services for which OMCFH is directly responsible include newborn metabolic and hearing screening, SIDS/SUID surveillance and prevention education, childhood lead poisoning surveillance and prevention efforts, Pregnancy Risk Assessment Monitoring System (PRAMS), and birth defects surveillance. These early identification services ensure that infants and children are screened early and referred for appropriate medical care and follow-up.

**Capacity Assessment Across MCH Essential Services**

**West Virginia – Maternal, Child and Family Health**

<b>POPULATION-BASED SERVICES</b>	
<b>Goals</b>	<b>Strengths/Weaknesses</b>
The Office of Maternal, Child and Family Health has in place many systems that contribute to the early identification of persons potentially eligible for services. These population based systems include birth score (administered by WVU), birth defect registry, newborn metabolic screening, childhood blood lead level screening, and newborn hearing screening. In addition, because we administer the EPSDT Program, children who have conditions that may be debilitating and/or chronic diseases, are referred to the CSHCN Program for further evaluation.	
1. Adequate funding in all critical areas.	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• Passage of Fee-for-Service rule for newborn metabolic screening enabling the State to charge for this function.</li> <li>• Passage of legislation and rules to increase newborn metabolic screening to the nationally recommended 29 disorders with payment being secured from each birthing facility for each birth. Legislation also allows the addition of new disorders when nationally recommended without having to open up the legislation each time.</li> </ul>

<b>POPULATION-BASED SERVICES</b>	
<b>Goals</b>	<b>Strengths/Weaknesses</b>
<p>2. Assuring the capacity and competency of the public and personal health workforce.</p>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• Public Health surveillance systems are in place that allow OMCFH to monitor, diagnose and secure intervention/treatment.</li> <li>• These population-based services are evaluated using data.</li> <li>• State Lab serves as a sole source for metabolic screening and follow-up occurs as a Title V service by nurses.</li> <li>• Trained community-based workforce is in place to assure additional assessment and intervention occurs.</li> <li>• Practitioners, audiologists, ENTs receive additional training paid for by Title V to enhance services to newborns.</li> <li>• Title V monies have been used to purchase diagnostic hearing equipment for use at strategic locations where access to service was non-existent.</li> <li>• All licensed birthing facilities are trained to complete and report the birth score and other screening processes.</li> <li>• Population-based public health screening activities under the leadership of OMCFH have been codified.</li> </ul>
<p>3. Assessment of maternal and child health status using data.</p>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• All newborns, including those birthed at home, are screened for risk (birth score), hearing and metabolic. These processes are tracked using data.</li> <li>• Data collection is timely.</li> <li>• Data from vital records transfers to OMCFH and is used to engage families in the health care system, especially those related to birth defects.</li> </ul>
<p>4. Link maternal and child health populations to services and assure access to comprehensive, quality systems of care.</p>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• Children who are identified with metabolic disorders, hearing loss, birth defects and/or developmental delay are all linked to appropriate community and medical resources.</li> <li>• There are 240-280 practitioners available to provide care for children who are identified as “at risk” using the birth score, or assure children receive diagnostic and treatment follow-up when the child failed a hearing screen.</li> <li>• There are 600+ practitioners to offer services to infants/toddlers who are developmentally</li> </ul>



POPULATION-BASED SERVICES	
Goals	Strengths/Weaknesses
	<p>delayed. Enrolled practitioners are required to have state-provided curriculum training in addition to a license in a discipline such as OT, PT or speech.</p> <ul style="list-style-type: none"> <li>• Families electing to participate in RFTS, which serves at risk moms and kids, or Birth to Three (infants diagnosed with developmental delay) <u>select</u> service practitioners.</li> <li>• OMCFH actively recruits practitioners to offer direct care, with attention to medically underserved areas.</li> </ul>

**Newborn Metabolic Screening:**

All infants born in WV are screened for 29 nationally recommended disorders including hearing loss. The OMCFH provides PKU special foodstuffs and other medically needed supplements for diagnosed disorders not covered under insurance. Children who are positive are referred to Children with Special Health Care Needs for support services. The OMCFH supports WVU Pediatrics for Genetic services and has offered additional assistance to increase geneticist capacity. WVU is interviewing for an additional geneticist to assist the sole WV genetic specialist physician. The State is able to generate revenue for the Newborn Screening Program by billing the hospitals for each infant who receives a newborn screen. The revenue funds the services and equipment at the State Lab for newborn screening, the OMCFH’s two nurses who provide follow-up for abnormal results, part of a billing person and 50% of the Genetics Program. Screening for all 29 disorders began in February 2009, and by December 31, 2009 two confirmed disorders were identified using the new laboratory method of MS/MS.

**Newborn Hearing**

All children born in WV are screened at birth for hearing loss at the hospital before discharge. Children who fail the screen are followed and assisted in obtaining further diagnostic care to assure that children with a loss receive appropriate medical intervention. Newborn screening is captured under the DRG for the newborn nursery charges and paid for by payors. A HRSA grant supports follow-up and public awareness activities, training of the RFTS care coordinators who provide follow-up services, a program coordinator and literature to provide to the public. The grant also supports loaner hearing testing equipment, housed at the Bureau for Public Health’s warehouse and shipped to the hospital when equipment has malfunctioned.

## **Birth Score**

Population-based surveillance activity administered by WVU in partnership with OMCFH to identify infants at risk of post-neonatal death in the first year of life and to provide appropriate interventions for those determined at risk. This program is supported with OMCFH Title V funds. The Birth Score Office also collects the newborn hearing screening results on the same collection tool as the birth score. Abnormal results or high risk results are sent to the RFTS Regional Lead Agencies who assign a care coordinator based on the infant's area of residence.

## **Childhood Lead Poisoning Prevention Project**

This Project is a collaborative effort between two Offices in the Bureau for Public Health, OMCFH and the Office of Environmental Health Services, funded in-part by the Centers for Disease Control. An advisory guides the operation of the Project, assisting the State with determining the extent of childhood lead poisoning in WV. To this end, extensive data gathering and analysis are routinely distributed. The Office of Environmental Health Services provides assessment of home and environment for residences of children with elevated blood lead levels, based on a priority need.

## **Birth Defects Surveillance**

This system tracks the incidence of specific diagnostic codes using the birth files, death files and hospital monthly reports. All infants identified with a birth defect are referred to CSHCN for services and referrals. A CDC grant funded active case ascertainment in 2004 and 2005, but loss of that funding meant the closure of actively obtaining information from the medical record of the infant and mother. Birthing facilities now send in monthly reports of identified infants with birth defects.

## **d. Infrastructure-Building Services**

Infrastructure building services are the foundation for delivering a well organized, adequate system of care to pregnant women and infants, children and children with special health care needs.

**Capacity Assessment across MCH Essential Services  
West Virginia – Maternal, Child and Family Health**

<b>INFRASTRUCTURE BUILDING</b>	
<b>Goals</b>	<b>Strengths/Weaknesses</b>
<p>Medical-Consumer Advisories are in place for all OMCFH programs, CSHCN, Perinatal and Women’s Health, Pediatrics, BCCSP, etc.</p> <p>All direct providers of services for OMCFH populations (Family Planning, EPSDT, CSHCN, Part C IDEA/Birth to Three, BCCSP, etc.) receive on-site quality assurance monitoring that includes chart review for compliance with national/state level performance expectations.</p>	
<p>1. Adequate funding in all critical MCFH areas/programs</p>	<p><b>Weaknesses</b></p> <p>Insufficient funding in all areas, especially:</p> <ul style="list-style-type: none"> <li>• Perinatal Program, RFTS (Title V/State Appropriation)</li> <li>• Childhood Lead Poisoning</li> <li>• Surveillance of Birth Defects</li> <li>• Oral Health</li> </ul> <p><b>Strengths</b></p> <p>Authority to accept and award grants, establish priorities, rate setting and policy development.</p> <p>Efficient use of all fiscal resources to support OMCH programs; i.e., CHIP, Medicaid, insurances are all payors.</p>
<p>2. Assuring the capacity and competency of the public and personal health workforce</p>	<p><b>Strengths</b></p> <p>WV public and private agencies that finance and/or provide health and social services to OMCFH populations:</p> <ul style="list-style-type: none"> <li>• CHIP</li> <li>• Medicaid</li> <li>• Child Care Agencies</li> <li>• Information/Referral Agencies</li> <li>• University Health Systems</li> <li>• Community Health Centers</li> <li>• Hospitals</li> <li>• Private Practice Physicians</li> <li>• Local Health Departments</li> </ul>

INFRASTRUCTURE BUILDING	
Goals	Strengths/Weaknesses
	<ul style="list-style-type: none"> <li>• UAP (UCED)</li> </ul> <p>Organizational relationships are strong and formalized</p> <ul style="list-style-type: none"> <li>• AAP State Chapter</li> <li>• ACOG State Chapter</li> <li>• NASW</li> <li>• WV Primary Care Association</li> <li>• WV PEIA</li> <li>• Coalition for WV Children</li> <li>• WV Family Alliance</li> <li>• Developmental Disabilities Council</li> <li>• Commission for the Deaf and Hard of Hearing</li> <li>• WV Chapter MOD</li> <li>• WV Hospital Association</li> <li>• WV Insurance Commission</li> <li>• WV Dental Association</li> <li>• WV Family Voices</li> <li>• Association of Local Health Departments</li> </ul>
3. Assessment of Maternal and Child Status using Data	<p><b>Strengths</b></p> <p>Integrated data systems, including direct link to vital statistics (birth/death records, etc.).</p> <p>Technology capacity and personnel to maintain and upgrade computer infrastructure.</p> <p>Capability of on-line data at local service area (RFTS, BCCSP).</p> <p>Data collection systems that are able to feed timely data to programs; for example, birth defect information used by CSHCN for outreach.</p> <p>Access to on-line databases for literature searches.</p> <p>Adequate computer hardware and support personnel.</p>

<b>INFRASTRUCTURE BUILDING</b>	
<b>Goals</b>	<b>Strengths/Weaknesses</b>
<p>4. Link women, children, and youth to health and other family services and assure access to comprehensive, quality systems of care.</p>	<p><b>Strengths</b></p> <p>Teaming is routinely offered for staff to develop understanding of legislative process.</p> <p>Families/consumers are provided financial support to participate in the Fairshake Network to learn the legislative process and advocacy skills.</p> <p>OMCFH toll-free lines and Systems Point of Entry personnel maintain information about programs and services statewide related to health and human services.</p> <p>OMCFH out-stationed staff participates in community driven activities such as the Family Resource Network to provide awareness about public health/OMCFH (Title V).</p>

Infrastructure building services are the foundation for delivering a well-organized adequate system of care to pregnant women and infants, children and children with special health care needs.

The West Virginia Office of Maternal Child and Family Health (OMCFH) has been instrumental in building systems of care for the MCH population for more than 30 years. The OMCFH has purchased and/or arranged for health services for low income persons, including those who have health care financed under Title XIX (Medicaid). The Medicaid expansion of the 1980's resulted in health financing improvements, but it was Title V energy that developed obstetrical risk scoring instruments and recruited physicians to serve mothers and children, including those with special health care needs. It was also Title V that established standards of care, and developed formalized mechanisms for on-site quality assurance reviews

The OMCFH monitoring team is a 29 year old established on-site clinical review process with protocols based on nationally recognized standards by ACOG, AAP, etc., federal standards and regulation, and State policies and procedures. It is a proven effective management review system that addresses the need for quality assurance and improvement. Analysis of outcome and utilization does not concentrate on the individual, but on the trend established by monitoring a series of events. The primary focus of this analysis is cost reduction and quality improvement.

The Office of Maternal, Child and Family Health (OMCFH) establishes partnerships with federally qualified health centers, private practicing physicians, local health departments and hospital-based clinics to ensure access to acceptable and available medical services for all West Virginians. The OMCFH has not provided direct services for more than 30+ years except in the case of children with special health care needs. The Office does, however, recruit and train practitioners, and establish care guidelines to ensure use of nationally approved medical standards for multiple programs. The provider networks are strong, and resources from Title V, Title X and state appropriation support the purchase of health services for more than 57,000 persons of childbearing age yearly. The OMCFH has established guidelines for care of specific populations, including children eligible for the EPSDT program and pregnant women.

The OMCFH partners with WV's Schools of Medicine including WVU, Marshall University and the Osteopathic School located in Lewisburg, WV. As an example of sharing resources, the Joan C. Edwards School of Medicine at Marshall University wanted to know how many WV women were using drugs and alcohol during pregnancy as opposed to what is self reported by the patient on assessments. The OMCFH agreed to fund a cord-blood study that Marshall University physicians, in particular, Drs. Chaffin and Nerhood wanted to research. The physicians were able to obtain participation agreements from most of the major hospitals throughout WV. The results were stunning. WV pregnant women and those who have recently delivered infants

self-reported only 4% use of drugs and alcohol during pregnancy, while the cord blood study showed that of the hospitals that participated in the month of August 2009, 19% had used drugs and alcohol. This information was presented to the 2010 Legislature for the purpose of funding and planning for interventions to address the incidence. More information about this study was included in the methodology section.

The Office of Maternal, Child and Family Health, since the 1980's, has contracted for the provision of direct health care. These contractual relationships include private sector physicians, university-medical school partners, hospitals, community health centers, and local health departments. All services are formally contracted with established performance standards portrayed in the written provider-OMCFH agreements. The exception to this format is CSHCN, which was, until the late 1980's, administered by the former Human Services arm of the now Department of Health and Human Resources organization. This unit has maintained its direct service responsibility because of the scarcity of pediatric and pediatric sub-specialty providers in certain geographical areas of the State. The Program receives referrals from multiple sources. However, as the State has developed and improved population-based surveillance systems, more and more youngsters have been referred. It is also important to note that the State's universal risk scoring of infants, called Birth Score, was modified several years ago to assure the identification of infants with or at risk of developmental delay. These children are referred to the OMCFH administered Birth to Three Program/Part C/IDEA. In addition, OMCFH administers EPSDT, again with direct care through community provider partnerships, but the Office does have access to information on each child, enabling the ability to identify youngsters with chronic or disabling conditions for referral to CSHCN. The primary care physicians are encouraged to refer children to CSHCN, and are routinely visited by Pediatric field staff employed by EPSDT, who serves as technical resources to the medical community. The West Virginia Office of Maternal, Child and Family Health, in collaboration with multiple agencies, family groups, and individuals, has determined several needs across the service system.

Families of children with special health care needs require the same sorts of support as do families with children who do not have special needs; that is to say, they require basic health care, education, recreation, socialization, transportation, and other systems to support them in their roles as family members and to help them raise children to be healthy, responsible, competent adults. All families need these systems to be available, accessible, and responsive to their needs.

Causes of infant death, low birthweight and maternal smoking must continue to be addressed. Within the infrastructure building category, recruitment and retention of qualified medical and other service delivery personnel in WV must receive priority attention in the future. Moreover, insurance systems within the State infrastructure require modification to better accommodate children and families in WV. Recognition of

CSHCN services to include reimbursement for non-traditional services such as intervention by licensed developmental specialists and other professionals must also become a priority.

Children who are placed in foster care are often children who need increased medical and mental health attention as the result of abuse and/or neglect. Because children often move within the foster care system it is important to track services and ensure that the child has a medical home who can manage the child's health plan. OMCFH has partnered with the Bureau for Children and Families to allow the CSHCN Program to case manage the health needs of those children who have been placed in foster care.

Although West Virginia has many health care issues such as smoking among pregnant women, infants born prematurely, infants born with low birth weight, obesity and asthma, the OMCFH has woven together funding streams to create a system of care for women, infants, and children, including adolescents and those with special health care needs. The OMCFH has developed strong partnerships across the State with the medical community, private sector, as well as community health centers and local health departments, all in an effort to assure access. Medicaid has purchased services for their beneficiaries at the request of Title V but they, too, are struggling to finance the health care needed by WV low-income residents.

As a consequence of the increased demand for health care services, the OMCFH has looked for every opportunity to seek non-traditional funding streams to support services for maternal and child health populations. For example, because there was a need to expand newborn metabolic screening, and the support of medical practitioners across the State, the Legislature and the Perinatal Task Force existed, the Office knew that ultimately the barrier would be money. Subsequently, a plan was designed that would allow the OMCFH to bill every birthing hospital for live births at a rate established for metabolic screening services that included the work of the State Laboratory, the tracking and follow-up services of the nurses within the OMCFH, and the involvement of WVU Genetics and other medical system supports. In addition, because of the acknowledgement in WV's previous five year needs assessment, there was recognition that resources for Family Planning had not kept pace with the demand for service. It was also recognized that without resources for Family Planning the lack of this preventive health opportunity would have negative implication for birth outcomes. To maximize resources, WV is now participating in the 340B Prime Vendor Purchasing Cooperative which allows support of the Family Planning formulary at a reduced cost. Through State appropriations in 2009, the Family Planning Program now receives 1.4 million dollars to help defray costs for services. The expansion of Title XXI/CHIP and the availability of Medicaid for the State's children have also allowed the ability to dedicate more Office resources to population-based tracking and surveillance systems that provide for early identification of children most at risk including those at risk of death in



the first year of life that is determined by the statewide operation of the Birth Score system; details of the Birth Score system is elsewhere in this document.

The WVOMCFH has in place many provider agreements that serve the MCH population. It is with these agreements that service is able to be provided in many parts of the State that would otherwise not be available. The following matrix depicts some of these agreements and program service area.

BCCSP = Breast and Cervical Cancer Screening  
RFTS = Right From The Start, the State's Perinatal Program  
BTT = Birth To Three, Early Intervention/Part C  
CSHCN = Children With Special Health Care Needs

OFFICE OF MATERNAL, CHILD and FAMILY HEALTH		
GRANTEE	SPENDING UNIT/REGION	AMOUNT
Beckley-Raleigh Co Board of Health	Oral Health	\$6,500.00
Eastern Areal Health Education Center (WVU)	Oral Health	\$10,000.00
Grant County Health Department	Oral Health	\$7,311.00
Kanawha Dental Health Council	Oral Health	\$38,000.00
Marshall County Health Department	Oral Health	\$11,000.00
Mid Ohio Valley Health Department	Oral Health	\$10,000.00
Monongalia County Health Department	Oral Health	\$15,000.00
Ohio County Board of Education	Oral Health	\$10,900.00
Putnam County Dental Health Council	Oral Health	\$7,500.00
Valley Health Systems	Oral Health	\$4,000.00
Bureau for Medical Services (BMS)	BCCSP	\$55,255.00
Clay County Health Department	BCCSP	\$65,000.00
Marshall University Research Corp.	BCCSP	\$65,000.00
Rainelle Medical Center, Inc.	BCCSP	\$65,000.00
Randolph Elkins Health Dept.	BCCSP	\$124,000.00
Wheeling Ohio Health Dept.	BCCSP	\$65,000.00
WVU Research Corp.	BCCSP	\$406,998.00
WVU Health Sciences Center	Perinatal Programs	\$250,000.00
CAMC Health Education & Research Institute	RFTS	\$184,671.00
Community Action of SE WV (Region I and IV)	RFTS	\$398,788.00
Catholic Charities WV Inc.	RFTS	\$119,203.00
Children's Home Society of WV	RFTS	\$167,309.00
Family Options Providers Inc. (Reg.II)	RFTS	\$173,700.00
Grant County Health Department	RFTS	\$145,686.00
Bureau for Medical Services	RFTS	\$108,212.00
Marshall Univ. Research Corp.	RFTS	\$62,078.00
WVU Research Corp.	Birth Score	\$328,862.00
ARC of Mid Ohio Valley, Inc.	BTT RAU	\$125,620.00
Catholic Charities of WV Inc.	BTT RAU	\$122,525.00
Mtn. Heart Comm. Services, Inc. (Region V)	BTT RAU	\$117,415.00
Mtn. Heart Comm. Services, Inc. (Region VI)	BTT RAU	\$117,226.00
Mtn. Heart Comm. Services, Inc. (Region VII)	BTT RAU	\$110,213.00
RESA VII	BTT RAU	\$128,905.00
River Valley Child Devel. Services (Region III)	BTT RAU	\$136,178.00
River Valley Child Devel. Services (Region IV)	BTT RAU	\$620,000.00
River Valley Child Devel.	BTT RAU	\$494,000.00
Marshall County FRN	Adolescent Health	\$72,500.00
New River Health Assn.	Adolescent Health	\$72,500.00
Pendleton Community Care	Adolescent Health	\$72,500.00
RESA I	Adolescent Health	\$72,500.00
RESA V	Adolescent Health	\$72,500.00
RESA VII	Adolescent Health	\$92,500.00
United Way of Central WV	Adolescent Health	\$72,500.00
Valley Health Systems, Inc.	Adolescent Health	\$72,500.00
WVU Research Corporation	WISEWOMAN	\$349,627.00
WVU Research Corp. (Cnt. For Excellence in Disab.)	CSHCN-CED	\$345,337.00
WVU Research Corp. (Genetics)	CSHCN-Genetics	\$500,190.00
WVU Special Olympics	CSHCN	\$5,750.00
Marshall University Research Corp. (C.A.R.E.S.)	CSHCN	\$36,000.00
Telecom Pioneers of America-WV Int'l. Sports	CSHCN	\$3,000.00
River Valley Child Development Services	CSHCN	\$19,420.00
Bureau for Medical Services	CSHCN	\$650,000.00
<b>TOTAL</b>		<b>\$7,386,379.00</b>

The Office of Maternal, Child and Family Health has in place systems that contribute to the early identification of persons potentially eligible for services. These population based systems include birth score (administered by WVU), birth defect registry, newborn metabolic screening, childhood blood lead level screening, and newborn hearing screening. In addition, because OMCFH administers the EPSDT Program, children who have conditions that may be debilitating and/or chronic diseases, are referred to the CSHCN Program for further evaluation. This connection with EPSDT, which targets some 200,000 eligible children yearly, provides public health with a vehicle for identifying youngsters with problems, knowing that economically disadvantaged children are at increased risk. OMCFH, in an effort to increase public awareness, routinely participates in health fairs and community events. The toll-free lines established in 1980, average over 1,000 calls per month. Each caller receives individualized follow-up from the Systems Point of Entry staff to assure referrals and pertinent information related to the request met their need. OMCFH toll-free lines always receive accolades. Evaluation materials are on file and available if desired.

West Virginia's Office of Maternal, Child and Family Health is known for its positive partnerships with the medical community, the University Affiliated Programs, the State Department of Education, and the March of Dimes Chapter, among others. These partnerships have resulted in shared initiatives. One initiative is the folic acid campaign, a national March of Dimes assignment, used in West Virginia to advocate for the distribution of this supplement preconceptually to reduce the incidence of neural tube defects. Another initiative made possible was the Richard Windsor smoking cessation program in partnership with the Office of Epidemiology and Health Promotion, who contributed tobacco funds for the purchase of CO monitors for the 233 care coordinators for use with pregnant women statewide. A recent initiative is school enterer screening using the EPSDT (HealthCheck) protocol, called Kids First. The objectives of the initiative are: to establish a medical home for the child, to allow school systems to focus on providing needed services for children with identified deficits, to assist families in finding treatment resources, and to promote healthy lifestyle activities. The focus of the screening will be on the domains of oral health, vision, hearing, speech and language, and behavior/development. Kids First is an example of high-level collaboration in government. Three Cabinet level agencies, the Department of Education, the Department of Health and Human Resources and the Department of Administration, are working closely together to bring this project to the families of West Virginia. All insurers agreed to pay for the services. Another initiative is the West Virginia Perinatal Wellness Partnership that includes stakeholders from across the State. Stakeholders include obstetrical and neonatal physicians, Medicaid, private insurance providers, OMCFH, Vital Statistics staff, the Hospital Association and the March of Dimes to mention a few. The 2007 work plan of the Partnership includes the following: 1. Establish a statewide perinatal transport system, 2. Identify and address obstetrical provider shortage areas, 3. Address the lack of oral health care in

pregnancy, 4. Identify costly medical procedures associated with poor birth outcomes, 5. Develop an approach to identifying and treating drug use during pregnancy, 6. Promote perinatal worksite wellness, and 7. Support and promote breast feeding.

For West Virginia's Early Childhood Comprehensive Systems (ECCS) project, the primary collaborative platform is PIECES, Partners Implementing an Early Care and Education System. In 2002, the West Virginia State Legislature mandated a partnership between the Department of Education and the Department of Health and Human Resources to design and implement universal Pre-K education for West Virginia's four year olds by 2012.

The PIECES collaborative also includes representatives from other State and local programs, the advocacy community, child care providers and parents. The vision initially adopted by PIECES was for all children and families in West Virginia to have access to high quality early care and education programs that provide a foundation for academic success and lifelong learning while supporting parents' ability to work. However, all stakeholders understood the need to address more than simply Pre-K education for West Virginia's young children to be ready to learn and to later become healthy, productive adults. Five focus areas were designated: collaboration, professional development, quality initiatives and curriculum, regulations and standards, and child well-being. The realization of the need for a stronger health component led to the Office of Maternal, Child and Family Health (OMCFH) being asked to take on this assignment. Considering other key programs, within OMCFH and that OMCFH has been involved with PIECES since its inception, this was a perfect fit. Accordingly, West Virginia designed its Early Childhood Care System project to fill that role (rather than duplicate parts of the system that are working well) and named it the Early Childhood Health Project (ECH).

The WV OMCFH has two projects that target adolescents; 1) the Adolescent Pregnancy Prevention Initiative (APPI) focuses primarily on educational classroom presentations for adolescents related to pregnancy prevention, contraception, delaying sexual activity and prevention of sexually transmitted infections. Visits to schools provide an opportunity for school personnel to share concerns about student behavior and areas they would like to see curriculum focused and 2) the Adolescent Health Initiative (AHI) addresses the most prevalent health risks facing adolescents and has become part of a larger initiative within the OMCFH financed by Temporary Assistance to Needy Families through the Bureau for Children and Families resources. The primary goal of the AHI is to improve the health status, health related behavior, and availability/utilization of preventative, acute, and chronic care services among the adolescent population in WV and promote risk resiliency and strengthen youths' personal assets. Organized training opportunities are provided by a workforce hired from the community they serve and offered in the community that the youth live. This workforce, called Adolescent Health

Coordinators, offer young people, parents, and other significant adults in a child's life skill building sessions on conflict resolution, communication, increased awareness of harmful consequences of substance use, and strategies to develop self-reliance and improve responsible decision making.

The WV OMCFH provided abstinence education using federal funds until June 30, 2009 when the funds expired. The Abstinence Education Project hopes to resume programming beginning October 1, 2010 when funds again become available.

The Birth to Three/Part C Program partners with a multitude of agencies to assist with child find efforts and to ensure needed services are arranged. WV Birth to Three has institutionalized a variety of strategies for the early identification of infants and toddlers with developmental delay or significant risk factors. WV Birth to Three's interagency agreements with Title V, CHIP, Bureau for Children and Families, Head Start, and Medicaid assist in the early identification and referral of potentially eligible children. West Virginia finds that coordination with primary health care providers and other community partners is important to assure that children potentially in need of early intervention services are identified as early as possible.

WV Birth to Three continues coordination with Title V/CSHCN, Newborn Hearing, and Right From The Start programs to assure that infants failing the newborn hearing screen receive diagnostics and referral to Part C and Ski \*Hi when hearing loss is confirmed. The Birth Score universal newborn screening, conducted on all children born in West Virginia, identifies infants who are born with conditions that may make them at risk for developmental delay. Referrals are made directly to the appropriate Birth to Three Regional Administrative Unit (RAU). Public awareness and child find activities are conducted collaboratively with interagency partners, including Part B preschool, Child Care and Head Start. Examples of this collaboration include the publication and distribution of a quarterly magazine, annual calendars, and developmental wheels to county schools, physicians, Family Resource Networks, medical clinics, early childhood providers, and higher education faculty. The publications include information about how to make a referral to Part C, Part B, Head Start and/or child care. The WV Birth to Three Public Information Coordinator has worked closely with WV CHIP to develop parent educational and child find materials, to be distributed collaboratively. The WV Birth to Three Public Information Coordinator has participated in faith based planning initiatives coordinated through WV CHIP to provide information about WV Birth to Three as a resource for families.

Child find strategies have also included coordination with the Right From The Start and HealthCheck Programs coordinated through the Office of Maternal, Child and Family Health. Local Right From The Start personnel who work directly with high risk mothers and infants are able to identify those children who may be in need of early intervention services. Program Specialists within the HealthCheck Program, in their work with

physicians, are able to provide information about the criteria and requirements, and importance of identifying children who may be in need of early intervention services. Recent policy direction by the AAP to its members encouraging early screening for developmental delays and subsequent referral to Part C have also contributed to increases in the number of children served by the Program.

WV Birth to Three staff have coordinated with the Bureau for Children and Families, Child Protective Services, in the development of procedures to assure the referral of children who have experienced substantiated abuse and/or neglect. Training is provided to WV Birth to Three service coordinators and practitioners related to the requirements and coordination with Child Protective Services and Foster Care, as required by the Federal Child Abuse Prevention and Treatment Act (CAPTA)

The Children with Special Health Care Needs (CSHCN) Program administered by the Office of Maternal, Child and Family Health offers medical and care coordination services to children and their families, if the child has a chronic medical diagnosis.

The WV Children with Special Health Care Needs Program continued a strong commitment to family-centered, community-based, direct services during calendar year 2009. During calendar year 2009, 1,352 children and youth were served through a network of 28 CSHCN community-based specialty care clinics, and through private specialty physicians' offices statewide. Of the 1,352 visits provided through the clinic system, 519 visits were for initial diagnostic evaluations. During this period, 98% of children participating in CSHCN were also Medicaid beneficiaries. This increase over the year 2008 percentage is attributed to the continuing commitment of CSHCN to assist families in obtaining health care financing by assisting with SSI and/or CHIP/Medicaid applications. As of December 2008, there were 9,233 children in WV under the age of 18 receiving SSI benefits. During CY 2009, 748 children ages 0-18 received both SSI and CSHCN benefits. This indicates that the CSHCN program served 8.2% of WV children under the age of 18 who receive SSI benefits.

While 98% of CSHCN program participants have Medicaid, the coverage is a result of aggressive action by Maternal, Child and Family Health.

Given this charge, CSHCN has: (a) established an assessment process that assures all health financing resources are explored. This includes eligibility determination for Medicaid (Title XIX) and CHIP (Title XXI). Children who are ineligible for either source of health care financing but have chronic, debilitating conditions covered by CSHCN have their care financed by Title V, if their income is at or below 200% FPL.

Children who do not meet any of the above eligibility requirements are offered care management through Systems Point of Entry (SPOE), in an effort to secure health financing. SPOE works with the Bureau for Medical Services to determine if the child is eligible for an optional Medicaid program called the Children with Disabilities

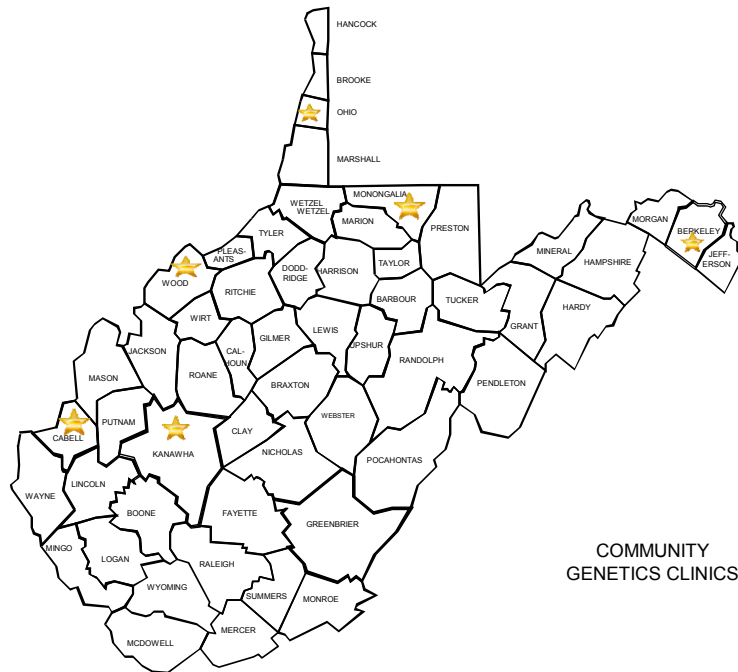
Community Service Program (CDCSP) which serves severely disabled children who would not otherwise be eligible for Title XIX/Medicaid coverage. This program waives parental income to assure access to health care financing.

- All persons who are uninsured or underinsured are provided information on how to access Title XIX or Title XXI. Obviously, having health care financing is the best vehicle for assuring children receive on-going comprehensive care.
- Children who are diagnosed with chronic, debilitating conditions are obviously a priority for CSHCN, but OMCFH also secured a similar commitment from the Social Security Administration Disability Determination Section to assure the populations identified receive priority handling.

Children who have a chronic medical condition, including those covered by CHIP, Medicaid, private insurance or Title V, are eligible for care coordination services through the Children with Special Health Care Needs Program. This is an adaptation designed to support the needs of children and families since health care professionals are so very busy and cannot cover office/clinic operational expenses when serving a disproportionate number of government sponsored patients. The end result is that children with special needs require more visits and more time per visit at a time when the clinical community cannot accommodate.

To expand services to all West Virginia children and youth with special health care needs, the CSHCN Program partners with community-based professional and medical facilities. The CSHCN Program provides support to those clinics through the provision of social work and nursing services. The professional partners are responsible for clinic operation, staffing, billing and record keeping. In the community/genetics clinics, the CSHCN social worker and nurse provide care coordination to children and families in a familiar, community based setting.

The CSHCN social worker and nurse work cooperatively with clinic staff to provide optimal health care and social services to the clients and their families. They provide transition counseling, as well as resource and contact information relating to health care and social service needs indentified by the client, family or clinic staff. In CY 2009 CSHCN staff provided services in 173 community clinics. Currently the CSHCN Program is providing services in community clinics in Charleston and in Morgantown with the West Virginia University Physicians Office Center. OMCFH is also providing social work services with the Community Genetics Clinics held throughout the State: See the map below for locations of the Genetics Clinics:



Family support initiatives are social interventions designed to promote the flow of resources and supports to families in ways that strengthen the functioning and enhance the growth and development of individual family members and family units.

The West Virginia OMCFH also supports a network of parents who are employed by the Center for Excellence in Disabilities (CED) at West Virginia University. These Parent Network Specialists offer parent-to-parent support for families with children who have disabilities. The Specialists attend CSHCN clinics, family support meetings and other meetings where they share information with families. In discussions with parents, one of the needs identified was support from other parents of children with similar special health care needs. In order to address that need, the Parent Network Specialists received training on organizing support groups and have linked interested families in their regional areas.

With the assistance of the Parent Network Specialists from West Virginia University (WVU) Center for Excellence in Disabilities (CED), all parents of children enrolled in the Children with Special Health Care Needs Program were sent surveys in early 2006.

Results of the survey indicated the following:

- The CSHCN Family Survey indicates that the majority of respondents are satisfied with the services they receive from the CSHCN Program.



- The CSHCN Program provides a service that Medicaid, CHIP or private insurance companies cannot, comprehensive care coordination.
- The survey indicates a need for an increased emphasis on care coordination services for the entire family, including educating families about the benefits of these services.
- The survey also indicates a need for an increase in transition services, including assistance with guardianship, conservatorship, wills and financial planning.

Transition services for youth and young adults served by the CSHCN Program continued to be a high priority during CY 2009. During this period, 1,072 transition services were provided to youth, ages 14, 16, 18 and 20 years of age. Training of nurses and social workers about adolescent transition services continued through the annual all staff meeting. Written policy concerning delivery of transition services was revised and released to the staff in the CSHCN Policy Manual in July 2007. There were 413 Transition Screening Tools completed and updated with adolescents ages 14, 16, and 17 and with young adults ages 18 and 20 in preparation for aging out of the program.

A primary role of the CSHCN Program nurse and social worker is to link youth and their families to community, medical and educational resources to assist in preparation for independent living as adults. One way to obtain this goal is in partnership with the Division of Rehabilitation Services. The Division of Rehabilitation Services offers school to work transition services for adolescents and young adults with disabilities. In CY 2009, 267 referrals were made to the Division of Rehabilitation Services by the CSHCN Program.

In CY 2010, the CSHCN Program, in collaboration with Marshall University Pediatrics, will begin providing care coordination services in a monthly transition clinic. The transition clinic will be held in a pediatrician's office in Barboursville, West Virginia and will serve young adults (14 – 21) with chronic medical conditions. The goal, as stated above, is to assist with planning and linkage to resources to prepare the youth for independent living.

In addition to transition training for CSHCN staff, the program administrators sought training for all nurses and social workers in the area of guardianship, conservatorship, wills and financial planning. This has been a welcome benefit to families and clients served by the CSHCN Program.

To assure nutritional assessments and consultations, the OMCFH established a grant with the Center for Excellence in Disabilities at West Virginia University. During CY

2009, a total of 320 children were assessed for nutritional concerns through thirty eight nutrition clinics, telephone consults, or home visits. A nutritional screening tool was developed by the CED nutritionist to identify children at special risk for feeding or nutritional problems. Each CSHCN nurse is charged with using the screening tool with children in his/her region for nutritional needs, and for holding at least two nutritional assessment clinics each year in conjunction with the CED nutritionist. These clinics allow children to be assessed locally without the need to travel long distances, and increases the efficiency of delivery of nutritional services offered by CSHCN.

In discussions with parents of children served by the CSHCN Program, two specific nutrition needs were identified: (1) information on how to add calories for underweight children and (2) information on how to cut calories for overweight children. In order to address this need on a large scale, the CED nutritionist developed three newsletters, including two for children and one for adults, with nutrition information, tips and simple recipes. The newsletters were provided to CSHCN care coordinators who then distributed to children and families in CSHCN clinics.

CSHCN collaborated with the Bureau for Public Health, Office of Nutrition's Special Supplemental Nutrition Program for Women, Infant, and Children (WIC) to review the new WIC food packages that became available October 1, 2009. Additionally, WIC representatives agreed to provide a presentation on the new healthy food options at the CSHCN all staff meeting in September 2009. In doing so, CSHCN staff learned about the changes in WIC and was able to spread the same clear messages about the healthy new food options.

WIC has the potential to reach the caregivers of one half of all infants and one quarter of all preschoolers in West Virginia, as well as one third of all expectant mothers, and support them in maintaining healthy lifestyles. The reach and focus of the WIC program offers a unique opportunity to reduce and prevent childhood obesity in the mountain state. There are approximately 52,000 women, infants and children in West Virginia who are benefiting from the multiple services offered by WIC, such as nutrition education, health care referrals and food to those who qualify.

The Research, Evaluation and Planning Division within OMCFH not only responsible for development and submission of the Title V Application, Progress Report and Needs Assessment, but is responsible for epidemiological and other research activities including all programmatic data generation and program/project evaluation endeavors. This Division ensures that the OMCFH's planning efforts are data driven. The Division houses four epidemiologists and five programmer analysts to develop and maintain the OMCFH databases and applications and provide statistical analysis. All State System Development Initiatives (SSDI) are administered within this Division and has resulted in successful and continued improvements in data collection, matching and linkage ability across the OMCFH programs and projects. Also, housed within this Division are the

population-based programs and surveillance systems; PRAMS, newborn metabolic screening, birth defects surveillance, the childhood lead poisoning prevention project and maternal mortality review.

## **Section 5 Selection of State Priority Needs**

West Virginia health care professionals voiced a strong desire to participate in the process to improve perinatal care. They indicated that although many elements of a cohesive system were present in the State, a move towards a statewide system rather than a fractured regional approach was necessary. The need to utilize new methods of communication, provide better support for medical professionals in rural areas, better utilize our intellectual resources, and more fully implement parent support and education programs was emphasized. The West Virginia Perinatal Partnership was born of these desires and in 2010 continues to remain a strong community partnership.

### **Pregnant Women and Infants**

Concerns that respondents of the WV Key Informant Survey administered by the WV Perinatal Partnership, parent surveys, community groups and OMCFH advisories had are as follows:

#### **Tobacco Use**

- Tobacco use by pregnant women and in-home smoking by family members
- Medical providers advising pregnant women that just “cutting down” on tobacco use and alcohol use is “ok”
- Patient lack of compliance with medical advice

Discussion:

Because smoking continues to be a significant health concern in WV, two State performance measures were chosen to address the issue. **1) Decrease the percentage of high school students who smoke cigarettes daily and 2) Decrease the percentage of pregnant women who smoke within the last three (3) months of pregnancy.** (Last three (3) months of pregnancy was chosen, because PRAMS data will be used and that is how the survey question reads). The Perinatal Partnership is addressing the education of medical providers who only advise their patients to cut down on tobacco and alcohol use during pregnancy.

West Virginia has among the highest smoking rate for pregnant women in the U.S. 2008 data from the WV Health Statistics Center show that the rate of smoking during pregnancy in WV was 27.0% compared to the National rate of 10.7% in 2005 (last available National information). Alarming rates of these were that 40.7% of Medicaid insured mothers reported smoking while only 11.7% of the non-Medicaid insured women reported smoking during pregnancy.

The State's home visiting perinatal program, Right From The Start (RFTS), provides services to Medicaid insured pregnant women. To address the smoking during pregnancy concern, RFTS continues to implement the intense smoking cessation initiative, called SCRIPT, in partnership with George Washington University Medical Center, Department of Prevention and Community Health. Education tools such as videos, carbon monoxide breathalyzers and smoking cessation guides are funded through the WV Division of Tobacco Prevention and are available for use during home visits. A DVD player has been assigned to each home visiting nurse or social worker to use during home visiting sessions for education purposes. RFTS sees approximately one-third of the Medicaid population.

RFTS collaborates with the WV Tobacco Quitline. The Quitline offers nicotine replacement therapy (NRT) options, free of charge, to pregnant women, with a physician's order. NRT products are also available to family members living in the home of the pregnant woman.

### **Drug Use**

- The growing use of legal and illegal drugs by women during and after pregnancy  
The most frequently mentioned drugs used were cocaine, methamphetamine, heroine, and methadone
- Health professionals, especially pediatricians, frequently correlated child neglect with drug use in the home
- Pregnant women treated with methadone and not weaned off prior to delivery.
- Lack of a standard medical protocol, taking into account legal and medical implications, for drug/alcohol testing and referring for treatment during pregnancy

### **Discussion:**

Drug use, especially during pregnancy, is a growing concern as presented in the Cord Blood Study. However, the WV OMCFH has not chosen this issue for a performance measure because the Cord Blood Study was a one-time effort and the data identified does not support the self-reported rate of drug use during pregnancy. The self-reported rate is 3%, while the Cord Blood Study for women who delivered in August 2009 in select hospitals was 19%. The OMCFH has no means of collecting measurable data other than self-report at this time.

The RFTS perinatal home visiting program does screen for drug and alcohol abuse during assessment of risk factors and if identified makes appropriate referrals.

The Perinatal Partnership has as one of its 2010 Work Plan goals to "Develop an Approach to Identify and Treat Drug Use During Pregnancy."

## **Nutrition and Breastfeeding**

- Poor maternal nutrition and a lack of nutrition education
- The rise in obesity, gestational diabetes, type II diabetes, and pre-eclampsia.
- Lack of breastfeeding and lack of support for continued breastfeeding
- Not all hospitals in state adhere to guidelines of American Academy of Pediatrics regarding support for establishing breastfeeding, both for healthy newborns and for high-risk newborns

### **Discussion:**

A low percentage of WV women choose to breastfeed their infants. This should not be taken as an indication of little effort on the part of the State's Bureau for Public Health. All pregnant women participating in the Right From The Start Program receive information about the benefits of breastfeeding their infants. The RFTS Program collaborates with the WIC Program to provide continuity of care and due to a renewed relationship has resulted in increased referrals to the RFTS Program.

WIC goals include providing additional funds to local agencies that will allow breastfeeding peer counselors to visit local hospitals and physician practices in order to provide breastfeeding support and guidance. WIC has received additional financial resources to increase personnel dedicated to breastfeeding encouragement.

WV chose not to keep this measure because the OMCFH provides support and education to one third of the pregnant women whose care is paid for by Medicaid. While it is important to have an impact on even one woman, the number of women who choose to breastfeed through the RFTS Program will not have an overall impact on the percentage of all women who breastfeed. The RFTS will continue to educate women served on the importance of breastfeeding, partner with WIC to encourage breastfeeding, track the percentage of women who breastfeed that are enrolled in the RFTS Program and also track breastfeeding percentages for all women who recently delivered, using PRAMS data.

## **Teen Pregnancy and Single Mothers**

- Insufficient sex education in the schools to help prevent pregnancy.
- Lack of education regarding contraception resulting in closely spaced pregnancies.
- Inadequate parenting skills, especially among teens and single women.
- Poor hygiene among pregnant teens and single women.

- Poor dentition, lack of access to dental care, lack of insurance coverage for dental care.
- Teen pregnancy is still part of our rural culture.
- Lack of self-esteem in young women.
- Lack of desire for education. The two largest determinants of child health in the U.S. are poverty level and parental education.

#### Discussion:

For more than a decade births to West Virginia teens have consistently declined, and between 1991 and 2004 teen births had dropped by 24%. Then, in 2006, the rate of teen child bearing in the State increased. According to the WV Health Statistics Center, the number of births to teenage mothers (ages 10-19) increased by 44 (1.6%), from 2,737 in 2007 to 2,781 in 2008. The percentage of total births represented by teenage births was higher in 2008 than 2007 (12.9% vs. 12.4%). The significantly lower fertility rate among older women, however, resulted in teenage births continuing to constitute a higher proportion of total births than was found nationally.

In 2006 and 2007 the increase in teen births occurred specifically among the 18-19 year-old age group. Births to West Virginia resident teens ages 15-17 continued a decline during the same time period with a slight one-year increase in 2006, going from 20.0 per 1,000 females in 2005 to 20.9 in 2006, but declining again in 2007 to 20.2 births per 1,000 females of the age group. Teen girls ages 18-19 have the highest proportion of teen pregnancies. They also have a higher teen pregnancy rate as compared to 15-17 year-olds in the State.

The Adolescent Health Initiative (AHI), housed within OMCFH, facilitates educational opportunities for adolescents and other community members on preventing pregnancy, delaying sexual activity and other risk behaviors. Trainings promote positive decision making and support asset-building targeting both traditional and non-traditional partners.

The AHI partners with the Adolescent Pregnancy Prevention Initiative and community-based non-profits to secure evidence-based pregnancy prevention funding for West Virginia.

The Adolescent Pregnancy Prevention Initiative, also housed within OMCFH, continues to partner with local community groups in order to provide programming that addresses risky adolescent behavior that may result in unplanned pregnancy. Specialists work with community teen institutes and summer camps providing activities such as Mythbusters, a game that counters untrue beliefs about sex that are common among

adolescents. Specialists are partnering with community groups to plan healthy events that will interest teens and utilize the increased free time of summer. These events include awareness pool parties, self-esteem workshops and responsibility training.

The Adolescent Pregnancy Prevention Initiative continues to focus primarily on education classroom presentations for adolescents related to pregnancy prevention, contraception, delaying sexual activity and prevention of sexually transmitted infections (STIs).

The OMCFH did not choose this as a performance measure because a national performance measure is already in existence.

### **Obstetrical-Neonatal Systems Barriers**

- Lack of adequate high-risk obstetrical services to refer high-risk pregnant women
- Lack of a fully operational statewide perinatal care program for high-risk mothers and infants needing referral and/or transport to high-risk care
- Lack of certain newborn screening testing
- Lack of high-risk newborn follow-up in the home (especially in rural areas)
- Lack of consistent standards for the induction and delivery of late preterm infants (34-37 weeks)
- Voluntarily inducing labor that produces preterm infants was identified as a major provider issue that contributes to higher use of NICU beds and infant mortality
- Voluntarily inducing labor of first time mothers, resulting in higher rates of caesarian sections for this group
- The “malpractice crisis” and cost of liability coverage
- Insufficient high-risk support from tertiary care facilities to community hospitals, the loss of community hospital based continuing education on high-risk care
- No standard protocol for transferring high-risk pregnant women and infants
- The lack of availability of NICU beds in the State when needing to transfer
- Providers not adhering to recommended standards of the American College of Obstetricians and Gynecologists
- Private insurance carriers do not cover in-home follow up of high-risk infants (such as RFTS services) as Medicaid does

### **Discussion:**

Most of the issues cited above have been discussed throughout the Needs Assessment document. Two of the issues have been implemented: expansion of newborn metabolic screening and an increase in the availability of NICU beds. The Perinatal Partnership 2010 Work Plan addresses obstetrical provider shortage areas, the high rate of elective



and c-section deliveries within the State, perinatal outreach educational activities, and seeking support from the WV Legislature and State Government on developing legislation that addresses several areas.

No State performance measures were developed from the concerns because the issues are so broadly focused. OMCFH leadership staff continues active participation on multiple committees of the Perinatal Partnership that are developing plans of action.

### **Education and Support Programs**

- Poor parenting skills and a lack of parenting education and in-home support programs
- Child neglect by parents identified as contributing to infant mortality
- Physicians not referring early enough to the Right From The Start Program (RFTS)
- Increased advertisement and marketing to medical providers and pregnant women for referral to the RFTS Program Discussion:

OMCFH is serving as the catalyst for driving the application process for developing a perinatal system of in-home visiting care. While RFTS is based on a medical model there are additional home visitation programs/models throughout WV such as Parents as Teachers, Maternal Infant Health Outreach Workers (MIHOW) and Healthy Families America, who provide education and support to pregnant women, infants and families, but do not have service capacity throughout the entire State. The application for use of the Patient Protection and Affordable Care Act funds, and for home visitation, education and support services is being submitted to increase home visiting capacity.

OMCFH did not choose a State performance measure to address education and support programs because the issues are very broad at this time and performance measures will be chosen for the Home Visitation Program State Plan.

## **Late Entry, No Entry, and Poor Prenatal Care**

- Many physicians are still reporting concerns over late entry to care as a major concern
- Pregnant women are waiting to have their insurance card or Medicaid in hand prior to making their first appointment for care
- Not enough obstetrical health providers in areas accessible to many women
- In some areas, once a woman calls for the first prenatal appointment there may be several weeks before providers' schedules can fit in a new patient

### Discussion

Although the OMCFH has assured medical providers that the Office will cover the pregnant woman's first visits for prenatal care while she applies for Medicaid and in case she is not eligible, women are either not knowledgeable, Medicaid workers are not telling women to go ahead and seek medical care or physicians are not encouraging women to schedule appointments while they wait for Medicaid coverage. The OMCFH, using Title V dollars, covers women who are not eligible for Medicaid coverage up to 185% of the Federal Poverty Level.

Late entry into prenatal care was not chosen as a State performance measure, because a national performance level exists.

## **Prematurity, Low Birthweight and Infant Mortality**

An examination of West Virginia birth certificate data showed a marked increase since 1993 in the rate of births occurring at 34 through 36 weeks of gestation. The rate of Cesarean delivery among late-preterm births increased at a faster pace than that among other births over the study period. The birth certificate data confirm a growing problem of late-preterm birth in West Virginia, pointing to a need for a more comprehensive examination of these births. The Perinatal Partnership has made recommendations that elective c-sections should not occur before 39 weeks if not medically indicated.

The number one cause of infant death in WV is Sudden Unexplained Infant Syndrome. In 2006, there were 46 SUIDs that accounted for 29.7 percent of the infant deaths. In 2007, there were 29 SUIDs that accounted for 17.8 percent of the infant deaths and in 2008 there were 35 SUIDs accounting for 21 percent of the infant deaths.

## Discussion

Although WV continues to be slightly above average in these areas of measuring infant health, the OMCFH has chosen a new performance measure that addresses the number of SIDS/SUID deaths that will impact the infant mortality rate, ***“Decrease the number of SIDS/SUID deaths”***. National measures already exist to measure prematurity, low birthweight and infant mortality.

### **Children/Adolescents**

Concerns that respondents had and data indicated are as follows:

#### **Tobacco use**

The 2009 YRBS shows that the percentage of students who ever smoked cigarettes daily, which is, at least one cigarette every day for 30 days has decreased slightly to 17.7%, however, the 2009 YRBS also shows that smoking within the last 30 days has decreased from 38.5% in 2000 to 21.8% in 2009. The percentage who reported they have never smoked cigarettes rose from 25.7% to 44.8% from 2000 to 2009.

The Adolescent Health Initiative (AHI) and the Abstinence Education Project (AEP), housed within the OMCFH Division of Infant, Child and Adolescent Health, educate youth about the consequences of tobacco use and encourage responsible behavior. Both programs partner with RAZE, the statewide teen-led, teen-implemented anti-tobacco movement, and other prevention programs to facilitate community-based activities and events promoting awareness.

RAZE is coordinated by the Youth Empowerment Team (YET). YET members include representatives from the Division of Tobacco Prevention, the West Virginia Department of Education’s Office of Student Services and Health Promotion, the American Lung Association of West Virginia and the West Virginia Youth Tobacco Prevention Campaign. There are currently 187 RAZE crews in the State’s schools.

West Virginia’s youth-led tobacco prevention initiative is moving beyond the school system to reach more teens. Initially, the program revolved around the WV Department of Education and funding was routed through schools, where crews were organized. Now, annual \$1,000 grants to form crews are available for community groups as well.

West Virginia is aggressively addressing this problem by implementing evidence-based comprehensive tobacco control programs. The comprehensive plan focuses on four goals: 1) Prevent the initiation of tobacco products among young people; 2) Eliminate exposure to secondhand smoke; 3) Promote quitting among adults and young people; and 4) Eliminate tobacco-related disparities among different population groups.

As of January 2009, all 55 counties have clean indoor air regulations. The WV OMCFH has chosen to keep, **Decrease the percentage of high school students who smoke cigarettes daily** as a state performance measure.

### Oral Health

Following a presentation on the need for a current oral health plan by representatives from the WVDHHR Oral Health Advisory Board, the audience was given opportunity to provide input and feedback from their respected regions. At the conclusion of the meeting, a West Virginia State Oral Health Plan Survey was provided to collect information and identify key priorities that need to be addressed to improve the status of oral health in West Virginia. Participants were asked to rank (1-9) various issues with the most important barriers ranked first.

The following table is a summary of the information collected from the regional community meeting participants.

Priorities at a Glance	Issues Listed According to Rank as Identified by Participants
1	Disease <b>Treatment</b> and Prevention – <i>Direct services, prevention vs restorative, cost and, by whom, etc.</i>
2	Public <b>Education</b> and Outreach – <i>Social marketing of the importance of good oral health.</i>
3	Funding/ <b>Reimbursement</b> – <i>Insurance coverage, Medicaid, PEIA as well as federal funding opportunities.</i>
4	<b>School Based</b> Education and Service Delivery – <i>Services provided at a school or school related site.</i>
5	Oral Health <b>Promotion</b> across the lifespan – <i>Looking at the oral health from perinatal, children and adults through seniors.</i>
6	<b>Workforce</b> – <i>Scope of practice, shortage of dental providers, recruitment and retention.</i>
7	Water <b>Fluoridation</b> and Fluoride Programs – <i>Water treatment plants, fluoride rinse programs, etc.</i>
8	<b>Data</b> Collection and Surveillance – <i>On going monitoring of the status of oral health in West Virginia.</i>
9	<b>Burden of Disease</b> and Documentation – <i>An encompassing report on the current status of oral health in West Virginia.</i>

### Discussion

The West Virginia Department of Health and Human Resources Oral Health Advisory, spearheaded by the OMCFH, worked cohesively to develop the West Virginia Oral Health Plan 2010-2015 which was released in March 2010. The Oral Health Advisory

will be involved in shaping oral health goals, identifying process improvements and legislative awareness.

The Children's Dentistry Project, (CDP) housed within the OMCFH, in partnership with county school systems, Marshall University, Head Start Agencies, WIC, 4-H, school-based health centers and other community children's programs, are working together to offer a sealant and fluoride rinse program within schools. Payments from existing insurance sources are sufficient to cover operational costs and ultimately improve oral health access. This project was initially offered only to students in one targeted county, but the CDP continues to work with partners to expand this service to students in three additional counties. The CDP provides portable dental equipment to ten primary care facilities for the purpose of offering school-based dental services, including sealant applications, in eight counties.

The Oral Health Program is working with Marshall University to establish a surveillance system for school based oral health activities. Currently, school based oral health centers serve 61 schools in 24 West Virginia counties.

The OMCFH administers the Bureau for Children and Families' Pre-employment Services Dental/Vision Project that supports services to assist persons transitioning from welfare to work. In FY 2009, \$1,305,961 was spent serving 1,926 persons for dental benefits.

The OMCFH has chosen to add a State performance measure, "***Increase the percentage of the State's children  $\leq$  18 who are Medicaid beneficiaries who have at least one oral health preventive visit in a 12 month period***".

## **Obesity**

The increasing rates of childhood obesity nation-wide and the prevalence of adult risk factors for cardiovascular disease at earlier ages, reflect a public health crisis that schools, agencies, and allied health professionals in West Virginia are attempting to address with intervention programs and information campaigns. West Virginia has one of the highest obesity rates in the Nation for children and adults.

### Discussion

Because of the multitude of initiatives being offered to combat the obesity crisis in West Virginia, the OMCFH will continue to keep two performance measures identified from the last Needs Assessment, "***Decrease the percentage of high school students in grades 9-12 who are overweight or obese***" and "***Increase the percentage of high school students who participate in physical activity for at least 20 minutes a day, 3 days a week***". Data will be collected using the YRBS.

## Injuries

Unintentional injuries were the leading cause of death for children and youth ages 1-24 in WV during the period 2002-2006. Suicide was the second leading cause of death for youth ages 15-24 in West Virginia during the period 2002-2006. Understanding injury rankings among other causes of death is important in determining their physical and economic role in each state.

### Discussion

The federal Maternal and Child Health Bureau Block Grant program requires State MCH programs to report on 18 National Performance Measures (NPM), two of which directly address injuries, “The rate of deaths for children aged 14 years and younger caused by motor vehicle crashes” and the “rate of suicide deaths among youths aged 15-19”. In the United States, the average rate of unintentional motor vehicle (MV) deaths for children aged 0-14 during 2006 is 3.01 per 100,000 population and in WV for the same year it is 4.41.

The West Virginia State MCH program reports on two current state performance measures that address injury and violence. “**Decrease the percentage of high school students who drink alcohol and drive**” and “**Decrease the rate of high school students who never or rarely wear a seatbelt when riding in a car driven by someone else**”. WV has made progress in these two measures, but is planning on keeping them since they are still above the National rate.

West Virginia continues to develop traffic safety materials targeted at young people. Through collaboration, the Department of Education’s school-based health education is being improved to incorporate information on health-related decision making. The State’s Division of Highways will implement plans for the Strategic Highway Safety Plan.

The West Virginia Council for the Prevention of Suicide is working to reduce the stigma associated with seeking and receiving mental health services, reduce cases to lethal means, provide support to suicide survivors, promote support for suicide prevention among providers, and improve public awareness and understanding of suicide.

## Racial Disparities

In February 2010, *Legacy of Inequality: Racial and Economic Disparities in West Virginia* was published as a joint project of Partnership of African American Churches, West Virginia Center on Budget and Policy, West Virginia Economic Justice Project of the American Friends Service Committee. The report briefly chronicles the experience of African Americans in West Virginia and presents a data analysis of disparities,

causes and suggested policy initiatives. The recommended policy improvements cover five key areas: jobs and economic development; education; family economic security; criminal justice; and planning and evaluation. The recommendations are as follows:

#### Jobs and Economic Development

- Appropriate \$3 million to the West Virginia Economic Development Authority to fund Senate Bill 573 in order to support economic development projects in heavily populated African American communities.
- Appropriate \$2 million dollars to continue funding the Neighborhood Housing and Economic Stabilization Program in minority neighborhoods. This Program has the potential to have a tremendous impact in using housing rehab, new construction and weatherization as an economic development driver and an employment and training initiative in low-income communities around the State.
- Use Temporary Assistance to Needy Families (TANF) Emergency Funds to allow the State or another entity to create a subsidized employment program that specifically targets low-income communities. For instance, the State of New York used the funds to create a “Green Jobs Corp” program that provides public assistance recipients and other low income individuals with employment opportunities in “green jobs.”

#### Education

- Reauthorize HB4669, which created Professional Development Schools (PDSs) in ten counties with high minority and low-socioeconomic populations, and include the following changes: (1) Require the formation of a PDS Team in each county that would include strong community involvement, at least quarterly meetings, and a structure of accountability; (2) Appropriate at least \$100,000 per county to fund the community and parent mobilization training and engagement component of the PDS School Initiative; and (3) Appropriate at least \$200,000 per county to support community tutoring and mentoring programs to support the PDSs.

#### Family Economic Security

- Enact a State Earned Income Tax Credit. At the federal level, the Earned Income Tax Credit (EITC) has been one of the most successful anti-poverty and pro-work policies ever enacted. Each year the federal EITC pulls thousands of families in West Virginia out of poverty. West Virginia could build on the success of the national EITC by joining the 24 other states that have adopted a state EITC. A state EITC would further remedy the problem by supplementing income and improving tax fairness.
- Extend Unemployment Insurance to workers who are presently excluded. West Virginia is eligible for \$33.2 million under the American Recovery and

Reinvestment Act if the State adopts at least three reforms. The Legislature approved the first improvement last year when it adopted a more inclusive method for calculating benefits. To receive the remaining two-thirds of the funds, the State must adopt at least two additional improvements specified in the Recovery Act, such as covering part-time workers and workers with compelling family reasons for leaving their jobs.

### Criminal Justice

- Enact legislation and appropriate \$1 million to fund a Demonstration Re-Entry Project in Kanawha County, which would be administered by community and faith-based organizations to help the over 250 ex-offenders returning to Kanawha County each year successfully transition back to the community. One of the keys to reducing the over representation of African Americans in the State's juvenile justice and adult corrections systems is effective community-based programs. West Virginia's Community Correction Centers are having some success in reducing regional jail costs, but are having no measurable impact on reducing the over representation of African Americans in the system.

### Planning and Evaluation

- Improve data collection. There is not one single data-gathering agency that collects scientifically significant data on the State's African American population. The Department of Health and Human Resources should oversample those counties that contain substantial African American residents so that current data is always available on this minority population.
- Create a State Office of Minority Affairs charged with reviewing information and coordinating agency-level programs across state government to eliminate the racial disparities identified in this report. Efforts to address these issues at the individual agency level are sporadic at best and in many instances nonexistent.

### Discussion

West Virginia is racially homogenous with 94% White, 4% Black and 2% Other. Measuring health-related racial disparities in West Virginia is challenging due to the small population of racial minorities in the State. For most available data sources, racial and ethnic minority groups must be combined and multiple years of data must be aggregated to obtain reliable estimates and rates for non-White groups.

West Virginia has one of the highest rates of poverty in the Nation. While both Whites and African Americans have poverty rates above the National average, there still exist disparities among the two groups. According to 2006-2008 American Community



Survey 28.5% of African Americans are in poverty compared to 16.5 percent of Whites. African American children under age five are more than twice as likely as White children to be poor, with 58 percent living below the poverty line. African American adults also experience significantly higher poverty levels, including one in four working-age adults and one in five seniors.

Based on information gathered for the Needs Assessment, the OMCFH is partnering with the Perinatal Partnership to co-sponsor a WV Perinatal Summit on November 11-12, 2010 to address perinatal health issues and disparities. The Keynote Address is titled "Overcoming Disparities: Collaborating for Equality in Birth Outcomes". This program has been designed to bring together multiple disciplines that provide perinatal healthcare through clinical practice, community programs and professional and patient education. Local and regionally recognized faculty will encourage participants to consider collaborative, innovative strategies when faced with challenges in perinatal healthcare delivery and education. An overall objective of this conference is to collaborate to increase favorable birth outcomes, decreasing health disparities and risks for the underserved. A film to be shown at lunch titled "*Crib: Saving Our Nation's Babies*", a documentary by Tonya Lewis Lee focuses on maternal and infant health in the African American community was developed as part of the U.S. Office of Minority Health's "*A Healthy Baby Begins With You*" campaign.

Other initiatives that the OMCFH is involved with include: 1) participation of the OMCFH WISEWOMAN Project Director in the quarterly Black Medical Society of West Virginia meetings, a nonprofit organization created to bring healthcare professionals together to end health disparities affecting WV's African American communities; 2) participation in discussions with the Advisory Council of the WV Diabetes Control Program on the social determinants of health equity; 3) participation in discussions with REACH WV staff and members of the Kanawha County REACH coalition to discuss local efforts to reduce the disparate impact of diabetes and other chronic diseases on African Americans in Kanawha County; 4) OMCFH has also been invited to participate on the State's nutrition coalition and tobacco prevention coalition which both have initiatives in place to address disparities in WV; and 5) a focus group project that is slated to occur in November 2010 focusing on knowledge of contraceptive methods and prevailing attitudes in the 18-25 year old age group, will include discussion about disparities and; 6) an OMCFH epidemiologist serves on the Minority Health and Disparities Advisory.

The OMCFH did not choose a performance measure in this area because a National Outcome Measure exists (number 2); the ratio of the black infant mortality rate to the white infant mortality rate. The WV OMCFH has reported each year on the National Outcome Measures, although reporting is not required, and will continue to do so to monitor outcomes. This outcome has decreased over the last three years starting in 2006 at 3.3 to 3.2 in 2007 and 2.9 in 2008.

## **Children with Special Health Care Needs**

### ***WEST VIRGINIA CHILDREN WITH SPECIAL HEALTH CARE NEEDS PROGRAM FAMILY SURVEY April 2006***

With the assistance of the Parent Network Specialists from West Virginia University (WVU) Center for Excellence in Disabilities (CED), all parents of children enrolled in the Children with Special Health Care Needs Program were sent surveys in early 2006.

Survey objectives were, to determine the overall satisfaction with services provided by the CSHCN Program, to ascertain the medical and social service needs of the participants and families served by the CSHCN Program and to help define the scope of services offered by the CSHCN Program in the future.

#### **Results Relating to Medical Care**

- 93% of the respondents were satisfied with the services they receive from the CSHCN Program
- 96% of the respondents reported having a medical home or PCP
- When asked where they would like to receive medical care, respondents preferring CSHCN clinics were approximately equal to those preferring a private physician's office. Less than 8% of the respondents indicated a preference for out of state care and about 1% indicated that they would like to receive care in medical school clinics
- 80% of the respondents felt clinic services were average or above
- 96% expressed satisfaction with services received in private physicians' offices
- 90% of respondents were pleased with the DME and supplies they received

#### **Results Relating to Care Coordination Services**

- 89% of respondents felt they received average to above average services regarding referrals to local or community resources
- With regard to transition services provided by CSHCN, 89% of respondents indicated a rating of average or above
- 89% would like more information about medical power of attorney and guardianship issues
- Respondents overwhelmingly listed money as the most significant problem facing them when providing care for their child, followed by transportation problems and a need for respite care

## Conclusions/Recommendations

- The CSHCN Family Survey indicates that the majority of respondents are satisfied with the services they receive from the CSHCN Program.
- The CSHCN Program provides comprehensive care coordination that Medicaid, CHIP or private insurance companies cannot.
- The survey indicates a need for an increased emphasis on care coordination services for the entire family, including educating families about the benefits of these services.
- The survey also indicates a need for an increase in transition services, including assistance with guardianship, conservatorship, wills and financial planning.

As a result of multiple surveys and public forums, several overall system needs became apparent. Within the Direct Health and Enabling Services category, West Virginia is severely lacking in respite services. Respite services are almost non-existent, even for high need, targeted population groups like Medley class members who were previously institutional residents.

## Discussion

The State CSHCN Program has worked diligently to expand care coordination services to a larger population of children with special health care needs, including those who are not enrolled in the CSHCN Program. One of the major accomplishments in 2009 was a collaborative effort between the CSHCN Program and the WVU School of Medicine/Physician's Office Center (POC). The POC began managing several specialty care clinics that were previously managed by the CSHCN Program. In assuming management of the clinics, the POC can schedule clients who are not enrolled in the CSHCN Program, but are in need of care coordination services. The CSHCN Program provides a nurse and social worker to offer care coordination services in each of these clinics that will provide continuity of care to a broader population of children with special health care needs.

Similar efforts are under way with Marshall University/Joan C. Edwards School of Medicine in Huntington, WV. The CSHCN Program also works in collaboration with the Cystic Fibrosis clinic offered through Charleston Area Medical Center's (CAMC) Women and Children's Hospital in Charleston, WV. Medical management and genetic counseling is provided by CAMC, while the CSHCN Program provides the nursing and social service components of the care coordination.

## Summary:

Eight state performance measures were chosen from the list of concerns discussed throughout the Needs Assessment that were not national performance measures. These state performance measures were chosen with the help of the Perinatal Partnership, OMCFH advisories and parents and are listed below in order of priority as they were chosen from the various groups. Priorities were chosen based on slower improvement in those specific areas and the need to increase efforts within these areas.

State priorities have been summarized and listed below:

### A. Pregnant women, women of childbearing age, mothers and infants

1. Decrease smoking among pregnant women
2. Reduce the incidence of prematurity and low birth weight
3. Reduce the infant mortality rate, focusing efforts on black infants and Sudden Unexplained causes

### B. Children and Adolescents

1. Assure that children and adolescents access preventive dental services
2. Reduce smoking among adolescents
3. Reduce obesity among the state's population
4. Decrease the incidence of fatal accidents caused by drinking and driving
5. Increase the percentage of adolescents who wear seat belts
6. Reduce accidental deaths among youth 24 years of age or younger

### C. Children with Special Health Care Needs

1. Maintain and/or increase the number of specialty providers in health shortage areas
2. Increase respite options for caregivers of children with special needs

From the 11 state priorities, eight measures were chosen that will incorporate the priority needs and that are not already national performance or outcome measures.

- 1) Decrease the percentage of pregnant women who smoke within the last three (3) months of pregnancy.
- 2) Increase the percentage of the state's children <18 who are Medicaid beneficiaries who have at least one preventive dental service in a 12 month period.
- 3) Decrease the number of infant deaths due to SIDS/SUID.
- 4) Decrease the percentage of high school students in grades 9-12 who are overweight or obese.
- 5) Increase the percentage of high school students who participate in physical activity for at least 20 minutes a day, 3 days a week.
- 6) Decrease the percentage of high school students who smoke cigarettes daily.
- 7) Decrease the percentage of high school students who drink alcohol and drive.
- 8) Decrease the number of high school students who never or rarely wear a seatbelt when riding in a car driven by someone else.

## **SECTION 6**

### **Outcome Measures - Federal and State**

The relationship between West Virginia OMCFH program activities and the National and State Performance Measures are tightly intertwined and has been discussed previously in detail throughout the Needs Assessment. Each activity for both National and State Performance Measures is specifically aimed at addressing these measures and to ultimately have a positive impact on the outcome. So, when asked “Why does West Virginia undertake its chosen MCH program activities?” the collective response is to impact the entire Title V population with positive outcomes.

To address the National Outcome Measures of infant, neonatal, post neonatal and perinatal mortality rates, WV has implemented activities relating to National and State Performance Measures regarding newborn metabolic screening, immunizations, maternal smoking, birthing facilities delivering high risk infants and neonates, and first trimester prenatal care. Specific activities include:

- The expansion of the newborn metabolic screening to include 29 disorders and case management of all abnormal results.
- West Virginia does not allow for non-medical exemptions for immunizations; EPSDT/HealthCheck and RFTS encourage providers to include immunization education as part of health care.
- State government maintains tobacco quit lines, information about negative effects of smoking during pregnancy are distributed, and smoking cessation programs are offered to all pregnant women.
- OMCFH advocates that all pregnant women be screened for medical risk conditions so that high risk patient care can be planned; new Universal Maternal Risk Screening to be implemented by year’s end will address this issue.
- Early prenatal care is strongly encouraged and supported through all family planning efforts, OMCFH partners with the local health departments to encourage referral of pregnant women who are denied Medicaid coverage for OMCFH obstetrical care service coverage.

To address the State Outcome Measures of infant low birthweight and prematurity, WV has implemented activities relating to National and State Performance Measures

regarding teenage births, maternal smoking, birthing facilities delivering high risk infants and neonates, and first trimester prenatal care. Specific activities include:

- State government maintains tobacco quit lines, information about negative effects of smoking during pregnancy are distributed, and smoking cessation programs are offered to all pregnant women.
- OMCFH advocates that all pregnant women be screened for medical risk conditions so that high risk patient care can be planned. New Universal Maternal Risk Screening is to be implemented by year's end will address this issue.
- Early prenatal care is strongly encouraged and supported through all family planning efforts, OMCFH partners with the local health departments to encourage referral of pregnant women who are denied Medicaid coverage for OMCFH obstetrical care service coverage.
- Perinatal Partnership has encouraged obstetrical providers to not perform elective c-section deliveries after 39 weeks if no medical condition exists.
- Adolescent Pregnancy Prevention Specialists conduct community education and outreach activities on a regional/local level, conduct school and community event presentations, recognize and promote National Teen Pregnancy Prevention Month and Let's Talk Month.

To address the State Outcome Measures of smoking among the total population, WV has implemented activities relating to National and State Performance Measures specifically targeting pregnant women and high school students. Specific activities include:

- State government maintains tobacco quit lines, information about negative effects of smoking during pregnancy are distributed, and smoking cessation programs are offered to all pregnant women.
- Department of Health and Human Resources and Department of Education have strong anti-tobacco programs which include a brand and promotional campaign; RAZE is West Virginia's teen led anti-tobacco movement.
- Smoking bans in government buildings and public access facilities and as of January 2009, all 55 counties have clean indoor air regulations.

To address the State Outcome Measure of deaths to 15-24 year olds due to motor vehicle accidents WV has implemented activities relating to National and State

Performance Measures regarding high school students' use of seatbelts and alcohol and driving. Specific activities include:

- State government alcohol distribution policy protects youth, Department of Education promotes no alcohol policy, Adolescent Health Initiative promotes healthy decision making, and Students Against Destructive Decisions (SADD) works with communities to establish local chapters.
- State law requires seat belt use, Department of Transportation promotes seat belt use and Department of Public Safety sponsors "Click It or Ticket" campaign and puts an emphasis on enforcement of seat belt use.

Of the National and State Performance Measures used to address Outcome Measures there is a mix of those measures that have been met, those measures that are close to being met, and those measures not met. The percentage of screen positive newborns who receive timely follow up to definitive diagnosis and clinical management for conditions mandated by the State Newborn Screening Program has been met with 100% of all infants needing follow up receiving case management. Motor vehicle deaths to those 14 years and younger has also been met in 2008 and future numbers have been adjusted to reflect an even lower rate for following years. The percentage of high school students who smoke cigarettes daily measure has been met as well. From 2007 to 2009 this percentage has dropped from 19.4% to 9.2%. The final measure that has been met that addresses Outcome Measures is the percentage of high school students who drink alcohol and drive. From 2007 to 2009 this percentage dropped from 9.8% to 7.5%.

There are two measures that are very close to being met: the percentage of very low birthweight infants delivered at facilities for high risk deliveries and neonates and percentage of high school students who never or rarely wear a seatbelt when riding in a car driven by someone else. The percentage of very low birthweight infants delivered at facilities for high risk deliveries and neonates increased slightly from 2007 to 2008 and the percentages for future years have been adjusted to reflect this increase. The percentage of high school students who never or rarely wear a seatbelt when riding in a car driven by someone else has decreased from 16.4% in 2007 to 14% in 2009 nearly reaching our target of 13.5%.

Those measures that have not been met and are actually moving in the wrong direction include: percentage of 19 to 35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B; the rate of births for teenagers aged 15 through 17 years; percentage of women who smoke in the last three months of pregnancy; and the percentage of infants born to pregnant women receiving

prenatal care beginning in the first trimester. Immunizations for 19 to 35 month olds decreased from 93.3% in 2008 to 91.5% in 2009. The birth rate for teenagers aged 15 through 17 increased from 20.7 in 2007 to 23.2 in 2009. The percentage of mothers who smoked during pregnancy has been increasing since 2005 and stands at 30% in 2007. The percentage of pregnant women receiving prenatal care beginning in the first trimester has also been decreasing, from 82% in 2007 to 79.1% in 2008.