



2005 Title V Maternal and Child Health Block Grant Needs Assessment Final Report, Maryland

Executive Summary

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Maryland Department of Health and Mental Hygiene
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I. Introduction

Over the past eighteen months, Maryland's Title V Program has worked to complete its 2005 needs assessment of the state's maternal and child health populations including those with special health care needs. This work has yielded a rich body of information which reveals what we believe are the key health issues and needs affecting women, children and families in Maryland. The goals of this needs assessment were to:

- assess the health status of mothers, infants, children and adolescents including children with special health care needs in Maryland;
- assess MCH preventive, primary and specialty care needs statewide and in the twenty-four jurisdictions of Maryland;
- assess both the Title V Program's and the state's capacity to address maternal and child health needs; and
- provide a summary report of findings to the Maternal and Child Health Bureau.

The Family Health Administration (FHA) within the Maryland Department of Health and Mental Hygiene (DHMH) is the state's recipient of federal Title V MCH Block Grant funds. Funds and program activities are jointly administered by two agencies within FHA: the Center for Maternal and Child Health (CMCH) and the Office for Genetics and Children with Special Health Care Needs (OGCSHCN). These two offices comprise the state's Title V Program and are responsible for conducting the MCH needs assessment, identifying priority MCH needs, assessing state capacity to address needs and ultimately, providing leadership for implementing a plan for addressing identified needs over the next five years.

The mission of Maryland's Title V Program is to protect, promote and improve the health and well-being of women, children, and adolescents, including those with special health care needs. The Title V Program seeks to strengthen the MCH infrastructure and to assure the availability, accessibility, and quality of primary and specialty care services for women, children and adolescents. The MCH offices have continually strived to assess and monitor ongoing and emerging needs of Maryland mothers and children and have incorporated these findings into the annual needs application and, where applicable, these findings have also been used to document needs during this current assessment.

The Title V MCH Block Grant Program is the only federal program solely devoted to improving the health of women, children, adolescents and families. Since 1995, Federal Title V legislation has required states to complete a comprehensive, statewide needs assessment every five years that evaluates the population based needs of mothers and children and the state's capacity to address identified needs. The last comprehensive MCH needs assessment was completed in 2000.

In the interim years between the required five year MCH needs assessment, Maryland's MCH offices continually strive to assess and monitor ongoing and emerging MCH needs and concerns. Findings will continue to be incorporated into the state's annual application to the federal Maternal and Child Health Bureau.

As described below, Maryland's five year needs assessment process involved analysis of both qualitative and quantitative data. Vital statistics, census and other data sources were reviewed to help us better understand the problems of mothers and children in Maryland. Focus groups, interviews and surveys were used to convey the story of those in need. This work was completed by policy/program and epidemiology staff within the Title V Program and with the assistance of over 1,000 MCH stakeholders throughout the state including parents, adolescents, health care and other service providers, state and local agency staff and advocacy groups.

Maryland's assessment process included three phases: (1) a population based assessment of health status and needs; (2) capacity assessment; and (3) identification of priority needs; strategic planning and resource allocation. The work completed in each phase of the needs assessment is summarized in the following sections of this final report:

- Section I. Introduction
- Section II. Needs Assessment Process
- Section III. 2005 Title V MCH Priority Needs
- Section IV. Appendices
 - A. The Health and Health Needs of Women and Children in Maryland
 - B. The Health Needs of Children and Youth with Special Health Care Needs in Maryland
 - C. Results of Maryland's CAST-5 Capacity Assessment Process

II. Needs Assessment Process

Over the past eighteen months, the MCH offices have completed multiple components of the Title V Needs Assessment. The needs assessment unofficially began in late 2002/early 2003 when the Assistant Director of the Center for Maternal and Child Health completed structured face-to-face interviews with key maternal and child health program directors and key staff in each of the state's 24 jurisdictions. The purpose of these interviews was to learn about progress in addressing maternal and child health needs and to identify MCH activities within each jurisdiction. The interview instrument consisted of nine, mostly open-ended questions used to guide discussions. Questions centered on the types of maternal and child health programs initiated, program funding sources, MCH funding priorities, future funding needs, continuing and emerging MCH population based needs, and finally, infrastructure level issues and needs. These key informant interviews were used to structure needs assessment planning and development.

Kick-Off Meeting

The official kick-off of needs assessment activities began with an October 2003 meeting with program directors and staff working MCH issues in some capacity within the Department of Health and Mental Hygiene (DHMH). The meeting had multiple purposes: (1) to inform offices

about the Title V Program and the needs assessment, (2) to gather input on strategies and recommendations for conducting the assessment and information on relevant existing data sources and reports, and (3) identify existing and emerging MCH needs from the perspective of participants. Over 60 DHMH agency staff attended including representatives from Oral Health, Preventive Health Services, WIC, Medicaid, Mental Hygiene, Alcohol and Drug Abuse, Health Promotion and Tobacco Use Prevention as well as data gathering offices including the Vital Statistics Administration and the offices responsible for collecting hospital discharge and BRFSS data. The October 2003 meeting featured two guest speakers, one motivational and the other a researcher who presented an overview of the health of mothers and children in Maryland. Facilitated large group activities and smaller roundtable discussions focused on the needs of MCH specific population groups: (1) pregnant women, mothers and infants, (2) children, (3) adolescents and (4) children with special health care needs were also a part of the agenda.

The meeting presented an excellent opportunity to exchange information about mutually beneficial ongoing and proposed MCH-related initiatives and to identify opportunities for further collaboration. Participants were encouraged to bring reports and other documents of benefit to the needs assessment as well as to share with other participants. The participants brought a wealth of knowledge to the table and reviewed several lessons learned from conducting prior needs assessments. Suggestions included using a comprehensive approach in completing the needs assessment. For example, the group advised the Title V Program to consider rural as well as urban needs since the needs of rural populations are sometimes overlooked. The group also suggested using advisory groups and surveys to gather input from MCH stakeholders. Recommended steps for completing the needs assessment included convening a steering committee, examining and summarizing existing data and reports, evaluating existing programs and reviewing approaches used by other states to identify best practices.

Participants also identified numerous current and emerging MCH issues. Asthma, depression across the life span, other mental health problems, substance abuse, smoking, obesity, health insurance coverage gaps, and lack of access to health care services including oral health care, mental health care, and specialty services were identified as ongoing concerns. Emerging MCH issues of concern included that more Marylanders are losing health insurance coverage even though they are fully employed, rising STD rates, substance use, depression, and child abuse and neglect. The themes and issues, voiced at this initial meeting, many of them linked to families in crisis, reflected what the Title V Program continued to subsequently hear during the eighteen months that MCH issues and needs were examined both quantitatively and qualitatively. Furthermore, this meeting also helped to underscore the importance of comprehensive data gathering and analysis within and across the Family Health Administration offices.

Organizational Structure

The organizational structure for the 2005 Needs Assessment consisted of a Steering Committee to guide overall efforts, four population based Workgroups, a data team, and various consultants hired to conduct much of the qualitative portion of the assessment. Input was sought from various MCH stakeholders including state and local agency staff, advocacy groups, and health care providers on an as needed basis as the work progressed. The data team conducted much of the data collection and analyses in-house with the assistance of two part-time graduate students from

the University of Maryland, Baltimore County. Several consultants were hired through the state's procurement process to conduct qualitative analyses to identify unmet needs and to solicit public comment and input for the needs assessment process. Designated Title V staff were also asked to examine cross-cutting population groups, issues and/or needs (e.g., foster care). Findings were incorporated into the work of the appropriate Workgroup(s). Finally, through an MCHB technical assistance contract, the Johns Hopkins Bloomberg School of Public Health facilitated the CAST-5 process to partially fulfill the requirements for the capacity assessment.

MCH Needs Assessment Steering Committee

Following the October 2003 meeting, an MCH Needs Assessment Steering Committee was convened to oversee development and implementation of the needs assessment. After an initial retreat, the Steering Committee established a timeline and met every six to eight weeks to review progress including updates on Workgroup activities. The state's State Systems Development Initiative (SSDI) Project Director had lead responsibility for day-to-day needs assessment activities and provided staff support to the Steering Committee. The Steering Committee was comprised of the following key Title V directors and staff:

- Bonnie S. Birkel, CRNP, MPH, Director, Center for Maternal and Child Health
- Susan Panny, MD, Director, Office for Genetics and Children with Special Health Care Needs
- Maureen Edwards, MD, MPH, Medical Director, Center for Maternal and Child Health
- Jamie Perry, MD, MPH, Associate Medical Director, Office for Genetics and Children with Special Health Care Needs
- Bernadette Albers, MPH, APRN, BC, Assistant Director, Center for Maternal and Child Health
- Cheryl DePinto, MD, MPH, Medical Director, School and Adolescent Health
- Diana Cheng, MD, Medical Director, Women's Health
- William Adih, DrPH, Senior MCH Epidemiologist
- Debra Perry, MPH, Family Planning Epidemiologist
- Vicki Young, LCSW-C, Chief, Family Planning
- Andrew Hannon, Chief, Community Based Initiatives
- Jeanne Brinkley, MPH, CNM, Nurse Consultant and Chief, MCH Systems Coordination
- Yvette McEachern, MA, SSDI Project Director

MCH Workgroups and the Quantitative Assessment

States are required to assess the needs of the MCH population using Title V indicators, performance measures and other quantitative and qualitative data. At a minimum, states are asked to describe major morbidity, mortality, health problems, gaps and disparities for the MCH population. The anticipated outcome is an identification of specific needs by MCH population group based on analysis of data trends. The needs of special population groups and cross-cutting issues are also to be examined.

Four population - based workgroups were designated to complete this phase of the needs assessment. The four workgroups were each assigned one of four MCH Title V population groups: pregnant women, women of childbearing age and infants; children; adolescents; and CSHCN. Each workgroup had a chairperson and data consultant assigned. The data consultants also comprised a data team to coordinate data activities. Two part-time graduate students were responsible for collecting and summarizing data to assist the MCH Workgroups and the data Team, and for conducting literature and internet searches. The four workgroups were charged to:

- Review the 2000 Needs Assessment and interim needs assessment findings and to note progress;
- Review notes from the October Kick-off meeting and identify subpopulations, emerging issues, and concerns;
- Review recent national reports and data for each population group to determine possible issues/problems to be explored in Maryland;
- Identify major data/indicators (including trends) of health status, access, health needs and health disparities to be included in the assessment for each population group;
- Incorporate other related MCH needs assessment activities (e.g., early childhood; abstinence education);
- Identify areas requiring assistance from vendor(s);
- Complete a resource inventory; and
- Determine stakeholder and public input processes.

The Workgroups were asked to meet at least once monthly. Each Workgroup chairperson was a member of the Steering Committee. Workgroup progress was presented at each Steering Committee meeting to assist with coordination and to minimize duplication of effort. Each Workgroup developed a set of MCH indicators to guide this phase of the work. A summary of the findings for each Workgroup is provided in Appendices A and B which provide data on health issues and needs by population group.

Data Sources - Quantitative Assessment

The workgroups used various data sources and reports to complete the population based quantitative analysis. A brief overview of selected major data sources follows. More detailed information about data sources and limitations is provided in Appendices A and B which contain the reports of health status and health needs by population group.

Vital Statistics Data: Vital statistics reports continue to be a major source of data on the health of pregnant women and infants in Maryland. For the most part, data are available for multiple years for each jurisdiction and by race/ethnicity. This key source also provides mortality data for all population groups, but limited morbidity data children and adolescents.

PRAMS: Since the last needs assessment, Maryland began collecting PRAMS data starting with mothers who delivered live births in 2000. Data and reports covering live births in the years 2001-2003 have been published. PRAMS provides an excellent opportunity for Maryland to obtain previously unavailable information on maternal behaviors and experiences that may be associated with adverse pregnancy outcomes. This CDC sponsored survey includes question related to

pregnancy intendedness, obstetric history, and prenatal care use and health behaviors during pregnancy. The Maryland-specific section of the survey includes questions on assisted reproduction, contraceptive use, depression, oral health, and seatbelt use.

U.S. Census Data for Maryland: The decennial Census and its updates provide the basis for most socio-demographic data on Maryland's population including population estimates by race/ethnicity. The Maryland Department of Planning is the state's Census data clearinghouse.

Surveillance Systems and Registries: MCH related surveillance system data and reports are available in Maryland for asthma, newborn screening and birth defects. Information is also available from the state's various registries and surveillance systems including the state's Communicable Disease, Tuberculosis, Sexually Transmitted Diseases, Lead and Immunization registries. These reports and data systems were consulted for the needs assessment.

Mortality Reviews: Maryland is mandated to conduct maternal (MMR) and child fatality review (CFR) processes. In addition, every county is funded to provide fetal and infant mortality review (FIMR) processes. Mortality review involves the identification of death cases, review of records, maternal interviews (FIMR only), consultation with experts, and the development of recommendations for preventing deaths. The data and information supplied in the statewide and local annual reports for these review processes is useful for assessing MCH population based and systems needs.

DHMH and other State Agency Data and Reports: Various MCH population serving programs have accessible data available in either annual program or legislative reports or by special request. These agencies include the Medicaid Program that publishes annual legislative reports on its Managed Care and Oral Health programs, the WIC Program, the Maryland Family Planning Program, the AIDS Administration, the Maryland Departments of Education, Human Resources, Juvenile Services, and the Environment. Maryland's two Health Care Commissions provide data on hospital discharges and emergency department use.

Local Health Department Funding Proposals and Needs Assessment: Local health departments prepare MCH funding proposals and conduct periodic needs assessment activities. These reports were consulted for the needs assessment.

National and State MCH Reports and Databases: Various state and national MCH reports were reviewed including national and state Kids Count reports. Maryland and national data from the 2003 National Survey of Children's Health (NSCH), a new module of the State and Local Area Integrated Telephone Survey (SLAITS), was also examined. NSCH provides national and state specific prevalence estimates for a number of MCH indicators including overall health status, obesity and socio-emotional health. This new survey examines the physical and emotional health of children ages 0-17 years of age in the U.S. and provides estimates for each state. In addition, the 2001 CSHCN SLAITS Survey was used to provide estimates of the health needs and issues confronting Maryland children and youth with special health care needs.

Qualitative Assessment

The qualitative methods employed in the statewide needs assessment included convening over 50 focus groups, surveying MCH program directors and supervisors in local health departments, and holding meetings to gather input from key MCH serving agency directors, program staff and advisory groups. Consultants were hired through the state's procurement process to conduct most of the focus groups. Focus groups were specifically conducted for the Title V needs assessment with parents of elementary, middle and high school students; adolescents; adolescent service providers, African American women of childbearing age, and parents of children and youth with special health care needs.

Maryland is the recipient of an MCHB Early Childhood Grant. As part of needs assessment activities for this grant, focus groups were conducted with Head Start and child care providers; foster care parents and caseworkers; Hispanic mothers; and pediatricians. (The Maryland Chapter of the American Academy of Pediatrics conducted focus groups with pediatricians around medical home issues). The findings from these focus groups were incorporated into the Title V needs assessment and will be used to guide development of the state's Early Childhood Health Plan.

The various focus group findings are interspersed throughout Appendices A and B. Content analysis was used to organize and integrate the qualitative data into specific themes and concepts. Highlights are provided here according to MCH population group:

Pregnant Women, Women of Childbearing Age and Infants. African American babies continue to die at more than twice the rate of White babies in Maryland. Maryland recently participated in an AMCHP sponsored project initiated in response to recent scientific findings linking higher risks for poor birth outcomes for African American women to social and environmental factors including stress and racism. Focus groups with African American women of childbearing age were held in Baltimore City; and Prince George's, Montgomery and Wicomico counties to ascertain perceptions of the roles of stress and racism in poor birth outcomes for African American women. Many of the focus group participants were surprised to learn that African American babies die at higher rates than Caucasian babies. Participants, particularly in the higher income communities, agreed that stress and racism are daily facts of life for most African Americans and that this probably affects the health of babies both before and following birth in America. The Maryland Perinatal Disparities Workgroup, convened at the impetus of the AMCHP Project, is finalizing a report and plan for addressing perinatal disparities in Maryland.

Children. Thirteen focus groups were held with parents of young children to ascertain health needs and barriers in access to care. Major access barriers and problems identified included a lack of access to mental health and oral health services, particularly for children enrolled in Medicaid. Transportation remained as barrier, particularly in rural areas.

Latino immigrants are one of the state's fastest growing racial/ethnic groups. While this population group has diverse national origins and a wide range of socio-economic and educational backgrounds, many lack English proficiency (LEP), are illiterate in their own native language and are employed in low paying jobs. Three focus groups were held with Latino immigrant mothers of young children living in three jurisdictions with large Latino communities. The purpose was to learn about their experiences in accessing health and related resources for their children. The Latino mothers identified several access barriers to the receipt of health care including ethnic

discrimination in the receipt of health care, and a lack of adequate resources to address LEP issues. A lack of affordable child care was also mentioned as a problem for mothers who needed or wanted to work outside the home.

Several focus groups were held with early and school-aged child care providers. Mental health and behavioral problems were a major concern for these providers. Program staff reported working with increasing numbers of young children with behavioral problems, many of them thought to be related to problems with parent and child bonding or attachment. The providers recommended that more mental health specialists be placed in preschool- and school-based child care and education programs.

Six focus groups were held to solicit parental views on the health needs and issues confronting parents of children in elementary and middle school. Parents from a broad range of socio-economic backgrounds participated in these groups. Most parents indicated that they were very satisfied with their child's experiences in the health care system. However, several access barriers were noted. These included a lack of pediatric providers in rural areas, a lack of insurance assistance for middle income families, provider unwillingness to accept Medicaid, and long waiting times for health appointments. Major health issues and concerns raised by the parent group included rising rates of overweight and obesity. Limited physical activity and poor nutritional choices in schools were credited with contributing to rising obesity. Other issues of concern included school safety issues such as bullying, the over-diagnosis and over-medication of children for ADHD, and the overexposure of children to media with violent and sexually inappropriate messages.

Adolescents. Eight focus groups were held with 78 adolescent service providers including educators, recreation workers, religious leaders and health care providers. Mental health problems including access to mental health services, both inpatient and outpatient, were a major concern. Other mental health related concerns included undiagnosed depression and mental health problems among adolescents, and inadequate levels of school based mental health services. Participants also spoke of witnessing increasing rates of substance abuse among teens and the resultant need for increased prevention and treatment programs. Adolescents were described as having too much unstructured, free time and a lack of quality adult supervision. Quality after-school and recreational programs as well as parenting education programs were mentioned as remedies for these problems. A lack of providers skilled in adolescent health, and a lack of culturally competent providers were identified as systems issues. Finally, nutrition, physical activity, and safety issues were viewed by some to be major concerns.

A second vendor held eight focus groups – four with high school students and four with parents of high school students. The focus group facilitator sought perceptions of barriers in access to care for adolescents, perceptions of unmet health needs and emerging health issues, the identification of resiliency factors, and suggestions for improving the health of adolescents and the health care delivery system. Parents viewed a lack of health insurance coverage as a major concern, particularly for adolescents over the age of 19. Adolescents cited a need for improved access to mental health services as well “someone to talk with about problems.” Teens were concerned about confidentiality issues in relating to their health care provider. Obesity and a lack of physical activity were mentioned as issues.

Both parents and adolescents mentioned that teens receive too many mixed messages related to negative health behaviors. For example, students are taught about sexual abstinence, but are also bombarded with opposing media advertisements about products like condoms and medications targeted to men with erectile dysfunction. Physicians were not readily viewed as a source of information on issues related to high risk or unhealthy behaviors by either parents or adolescents.

Children with Special Health Care Needs. The OGCSHCN worked with a number of partners to gather qualitative information from four separate series of focus groups. The OGCSHCN worked with the Maryland Chapter of the American Academy of Pediatrics on a series of focus groups related to the medical home, with Parent's Place of Maryland and the Georgetown University Center for Child and Human Development on a series of focus groups related to the Maryland Family Access Initiative, and with Louisiana State University Health Sciences Center on a series of focus groups around newborn screening communication. The OGCSHCN also sponsored a series of focus groups on health care transition.

In the medical home focus groups parents and providers identified the lack of communication among providers as a central difficulty. Only approximately half of families reported having a personal doctor or nurse who consistently followed up with the family after referrals and visits to a specialist or after ordering specialized services or equipment. Providers spoke of the need for liaisons between parents, schools, agencies, and medical providers and noted that effective communication and collaboration is extremely difficult to achieve in practice.

The greatest barriers to providing medical homes noted by pediatricians were time and money. Caring for CYSHCN takes more time than caring for a typical child. Much of this time is not reimbursed or inadequately reimbursed by insurance companies. Examples included the time needed for extended visits, making referrals, refilling prescriptions, writing letters of medical necessity, communicating with other providers, and generally coordinating care. They also noted the burden of trying to keep up with the various and changing procedures and provider lists among the many insurance companies that they deal with. This takes so much time and effort that many practices are using a dedicated referral coordinator, but this again is an unreimbursed expense and therefore only possible for larger practices.

A third problem identified by many parent and professionals was that pediatric health care providers are not performing thorough screening for developmental problems. Issues raised were inappropriate or incomplete use of screening tests, amount of time required to administer tests, and lack of reimbursement.

In the Maryland Family Access focus groups, families reported difficulty in accessing needed specialty services. Issues included no appropriate specialist in network and no appropriate specialist in geographic proximity as well as inability to pay for needed services. The providers most frequently noted were mental health providers and dental providers. This was true for both those with Medicaid and those with private insurance. Some pediatric providers do not accept Medicaid or limit the number of patients with Medicaid due to lower reimbursement rates.

However, even families with private insurance reported struggling with out-of-pocket expenses, that depending upon the child's diagnosis, could reach up to \$10,000 per year.

Families with Medicaid as well as those with private insurance identified the lack of information about how to navigate their plans as another major concern. Help with finding information about health care and non-medical services and how to access them was a frequently expressed need.

Care coordination surfaced again as a serious problem. A key issue in care coordination is communication. Sadly, families almost unanimously reported that they were receiving no supports with care coordination and none from their primary health caregivers. Respite care was an almost universal concern. The limited availability of trained respite providers in certain areas of the state as well as lack of education on the part of families regarding respite services were identified as barriers to accessing respite care.

In transition focus groups held with parents and their youth ages 13-21 across the state, very few families reported that their doctors had discussed health care transition with them, and very few had begun the process on their own. While some parents encouraged their children to play a more active role in their health care, they reported that it was often difficult to get their children to take on more responsibility. In fact, in the youth discussion, youth under age 18 expressed little knowledge and interest regarding health care transition.

Families and youth expressed a number of concerns related to finding a new "adult" doctor. One concern was finding a doctor willing to take on their youth with special health care needs. In medically underserved areas of the state, parents felt it was difficult enough to find good doctors for "normal, healthy adults." A second concern was finding providers who were knowledgeable about the youth's particular health condition. Parents were uneasy with the thought of their child being treated by a doctor who did not have knowledge or experience with their child's medical condition, even if the doctor was willing to learn. They also expressed frustration at potentially having to educate a new doctor about their child's condition. Youth generally expressed similar views. Lastly, families had concerns about the nature of the adult health care environment including differences in bedside manner, how individuals are treated, and less accommodating scheduling, office hours, etc.

Health insurance was also a significant area of concern. Families did not understand the various insurance options available to them, many did not understand Medicaid eligibility rules, families reported having to negotiate a number of different agencies and receiving conflicting information, etc. For youths, most who participated knew very little about their health care coverage and had given little thought to how health insurance would be obtained in the future.

Parents were divided as to whether they felt medical providers should play a role in transition in other areas of life such as job training, employment, and finding a place to live, but most agreed that it was probably unrealistic to expect physicians to play an active role in these due to lack of time and knowledge in these areas. Shortly after Maryland expanded its newborn screening panel to include disorders detectable through tandem mass spectrometry, focus groups on communication around newborn screening were conducted separately with new mothers of healthy

infants and with pediatricians. Most mothers indicated that they had very little information about newborn screening. This is despite the fact that all mothers are given a brochure about newborn screening in the hospital and asked to sign a consent form prior to the heel stick. Many mothers remembered seeing the newborn screening brochure in their packet of information, but most did not read it. Mothers whose infants had abnormal screening tests, did remember the brochure and found it answered most of their questions. Mothers and pediatricians felt it was important that parents should have some basic information about newborn screening presented in a simple format, and that they would like to have information presented prenatally as well as after the baby is born.

Capacity Assessment

This phase involved examining the state's capacity to address core MCH functions. Maryland was fortunate to receive technical assistance and funding from the Maternal and Child Health Bureau to participate in the Capacity Assessment for State Title V (CAST-5) process. CAST-5 is a set of self-assessment and planning tools designed for state Title V programs. At the state's request, Ms. Holly Grason and other faculty members of the Women's and Children's Health Policy Center (WCHPC) at Johns Hopkins University facilitated Maryland's CAST-5 process. The decision was made to implement all of the CAST-5 components to obtain a comprehensive picture of the state's capacity to provide essential MCH services.

Given multiple timing considerations, the MCH offices worked with the WPHPC to plan completing the CAST-5 process in an intense, condensed three-day format in May 2005. Throughout the three days, over 35 participants were involved in Maryland's CAST-5 process including staff from multiple programs within CMCH and the OGCSHCN, representatives of programs external to CMCH/OGCSHCN but within the Family Health Administration (e.g., WIC and Health Promotion), representatives of other DHMH administrations (e.g., Medicaid, Mental Hygiene and Addictions), and several local health department MCH program directors. Participants also included representatives of other state agencies including the Department of Education, the Department of Human Resources, and Juvenile Services; as well as several advocacy groups concerned with the health of women, children and families, including the March of Dimes, Advocates for Children and Youth, the Mental Health Association, and Friends of the Family (i.e., a private statewide administrator of family support programs).

The CAST-5 Team identified several priority capacity concerns. These included the need to strengthen the MCH data infrastructure and the supportive environment for data sharing at both the intra- and inter-agency levels. A related issue was the need to improve communication and data translation capabilities to inform MCH stakeholders of MCH needs and policy issues. Progress has been made in each of these areas, but deficiencies remain.

Workforce capacity concerns were identified including the loss of highly skilled and trained public health staff due to retirement and the attraction of better paying positions outside of state government. Another concern voiced was the difficulties involved in recruiting and hiring new staff due to the state's hiring freeze and the state's personnel management system. Finally, participants chose the need for more staff skilled in specific areas such as working with communities (e.g., outreach and education) and managing inter-agency collaborations and

initiatives, as a priority. More details on the results of the CAST-5 assessment can be found in Appendix C.

A cursory review of available MCH services by each level of the MCH pyramid (direct, enabling, population based and infrastructure level services) was also conducted. This phase of the needs assessment is continuing and the state hopes to complete a more thorough analysis of available resources over the course of the next year. This will be completed in collaboration with the environmental scan being conducted for Maryland’s Early Childhood Comprehensive Systems Grant and will be submitted with next year’s Title V application.

Regions

Throughout this report, attempts were made to aggregate the data and discussion according to the following regions:

Region	Jurisdiction (s)
Baltimore City	Baltimore City
Montgomery County	Montgomery County
Prince George’s County	Prince George’s County
Western Maryland	Garrett, Allegany, Washington and Frederick Counties
Central Maryland	Baltimore, Howard, Harford, Carroll, and Anne Arundel Counties
Southern Maryland	Charles, Calvert, and St. Mary’s Counties
Eastern Shore	Cecil, Kent, Queen Anne’s, Caroline, Talbot, Dorchester, Worcester, Wicomico and Somerset Counties

Determination of Priority Needs

Several meetings were held over the course of the past six months to develop the state’s eight priority needs. On April 18, 2005, Ms. Holly Grason of WCHPC facilitated a meeting of 15 DHMH staff and MCH stakeholders to discuss priorities among the needs identified through analysis of population based data sets, key informant interviews, surveys, and focus groups. Following a summary presentation of the available needs assessment data, participants discussed considerations/criteria to be applied in determining priorities, as well as opportunities for “positioning” priority issues in communications with policy makers and with the general public. To complete the prioritization exercise, consideration was given to such factors as (1) the importance of the problem (e.g., size, seriousness, disparities, and consequences of not addressing), (2) the availability of effective interventions (scientific basis for interventions, cost), and (3) the acceptability of intervening (logistical and political feasibility).

An initial list of priorities was derived through a two-step process of 1) sequential naming in three rounds, and 2) summing of individual participant's numeric ratings. Scoring resulted in ranking of 53 MCH issues and needs. Scores for the 53 issues/needs identified ranged from a low of 48.5 (highest priority) to a high of 71.5. Finally, the participants summarized the 53 issues/needs into 14 priority focus areas. These areas are summarized below according to Title V MCH population groups:

Pregnant Women and Infants

- **Unintended Pregnancy** (Emergency Contraception, Male Involvement)
- **Infant Mortality** and Related Factors (Low birth weight, access to prenatal care, undocumented immigrant women, Tobacco use, women's wellness)
- Very Early Identification of **Infants at Risk** (e.g., Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders)

Children and Adolescents

- Environmentally Linked Health Problems (**Lead, Asthma**)
- **Injury Reduction** (Unintentional and Intentional)
- Promotion of **Healthy Youth Development** (Transition services for all adolescents)

Children with Special Health Care Needs

- **Support for Families** (Respite care, Child Care, Medical Day Care)

Cross-Cutting/Other

- **Oral Health** (Access to services, particularly for uninsured and Medicaid enrolled women and children)
- **Obesity** (Healthy nutrition and physical fitness)
- **Mental Health** (Depression across the life span, Suicide, Children at risk for bullying)
- **Substance Abuse**
- **Systems Improvements** (Coordinated care for CYSHCN, Access to health care for all, Children in out-of-home placements, Child abuse and neglect)
- **Male Involvement** and Men's Primary Health Care
- **Infrastructure Development** (Workforce Related Issues, Data Capacity, Health Manpower Shortages/Availability, Limited English Proficiency)

Several crosscutting strategies with multiple utility for addressing the priority needs were also identified. These included decreasing inequities in access to care, home visiting programs, promotion of breastfeeding, provision of economic security, and provision of translation services for persons with limited English proficiency. Participants in the May CAST-5 meeting also prioritized the MCH needs identified at the April meeting. The top five priorities were addressing substance abuse problems, addressing mental health problems, reducing infant mortality, addressing obesity and addressing transition issues for CSHCN.

Next, the MCH offices held two May meetings with over 75 MCH staff in local health departments to gather their final input on MCH priority needs. At these meetings, data was once again presented on available needs assessment findings. Participants were presented with a list of needs, issues and challenges identified through the needs assessment process. The priorities identified at the April 18th meeting were incorporated into this list and the invitees were asked to provide key MCH issues or needs not already identified. Following this discussion, the participants ranked the needs in priority order for each MCH population group: pregnant women and infants; children; adolescents and children with special health care needs. Finally, participants were provided with the summary results of the local health department survey and asked to summarize MCH needs for each of four state regions: Western Maryland, Eastern Shore, Central Maryland, and Southern MD-Washington D.C. Suburbs (Montgomery and Prince George's counties). Local health department priority concerns by population group and region are identified below:

Local Health Grouping of MCH Priority Needs by Population Group

Pregnant Women, Women of Childbearing Age and Infants

- | | |
|--|---|
| 1. Increasing numbers of uninsured and undocumented pregnant women | 2. Substance abuse during pregnancy |
| 3. Infant mortality | 4. Mental health |
| 5. Access to health care (e.g., primary, preconception, and oral health) | 6. Social and family support |
| 7. Unintended pregnancy | 8. Access to prenatal care |
| 9. Breastfeeding | 10. Male involvement |
| 11. Sexually Transmitted Diseases | 12. Early identification of infants at risk |
| 13. Maternal Mortality | 14. Cesarean Deliveries |

Children (Infants to Pre-Teens)

- | | |
|-------------------------------|--|
| 1. Families in crisis/peril | 2. Access to care/services |
| 3. Oral health | 4. Unmet need for mental health services |
| 5. Children ready to learn | 6. Children in out-of-home placements |
| 7. Elevated blood lead levels | 8. Child abuse and neglect |
| 9. Tuberculosis | 10. Asthma |
| | 11. Rising rates of obesity |

Adolescents

- | | |
|---|---|
| 1. Reproductive health and pregnancy | 2. Promote healthy positive youth development |
| 3. Mental health | 4. Substance abuse/addiction |
| 5. Nutrition and physical fitness | 6. Systems issues/access to care |
| 7. Injuries – intentional and unintentional | 8. School health and safety |
| | 9. Out-of-home placements |

Children with Special Health Care Needs

1. Lack of coordinated care
2. Navigating the health care system
3. Inadequate insurance to meet needs
4. Transition to adulthood
5. Need for family support services
6. Mental health problems
7. Screening
8. Data to describe the population

Regional MCH Needs/Issues Expressed by Local Health Departments

Rural Areas

Rural areas of the state in Western Maryland and on the Eastern Shore identified a lack of access to care, particularly for Medicaid and uninsured individuals as a major concern. Access is of concern because of numerous manpower shortages in several specialties including oral health, obstetrical care, pediatric care, mental health care for all and specialty care for CSHCN. Preventive and primary care for services for women, substance abuse treatment services for women and adolescents were also identified as priority needs. The lack of a viable public transportation system remains as a major barrier to care in rural areas.

Indicators of increasing family stress were also evident. Local health departments in these two regions frequently mentioned that family violence, child abuse and neglect, and substance abuse were major problems. These findings were identified in spite of the fact that the Department of Human Resources reports that substantiated child abuse and neglect cases are declining.

Echoing a statewide trend, MCH staff noted that there are increasing numbers of uninsured adults and that fewer employers are offering health insurance coverage. MCH staff reported that health insurance costs have skyrocketed and work hours have been limited by some employers to avoid providing health insurance coverage.

Western Maryland

Western Maryland is a mountainous region of the state that includes four jurisdictions: Allegany, Garrett, Washington and Frederick counties. These four counties represented 8% of the state's total population in 2004. Identified MCH needs and issues for the 2005 needs assessment are highlighted below.

- Some areas in this region are in an economic depression. Related issues: shortage of jobs, limited affordable housing, and an influx of new families from Baltimore area has brought larger pool of unskilled labor in search of jobs and low cost housing. Baltimore families are moving to Western Maryland to be closer to relatives housed at state prisons in the area.
- Rising family stress: There is a greater need for mental health and addiction services; Rates of domestic violence and child abuse and neglect are rising and there is a need for parenting education

“The prenatal care situation is “beyond crisis”: Very few OBs remaining because of the malpractice crisis, women have inadequate access to care and may soon be routinely delivered by ER staff in some areas, increasing numbers of uninsured and undocumented pregnant women”

Local health department
MCH Director

- Uninsured rates are increasing: There are more contractual positions without the benefit of health insurance coverage
- Public health resources are strained: Funds have been transferred to higher priority areas such as bioterrorism.
- There is limited access to specialty, primary care and oral health care overall, but especially for uninsured and Medicaid enrollees; Health manpower shortages exist in several specialties: pediatricians, OBs, dentists; Access barriers: transportation, LEP
- There is a growing disparity between ages of young women and their sexual partners.

Eastern Shore

Caroline, Cecil, Dorchester, Kent, Queen Anne’s, Somerset, Talbot, Wicomico and Worcester counties comprise the nine counties representing the state’s Eastern Shore. These nine jurisdictions represented 7.5% of the state’s total population in 2004. Local department surveys and meetings with MCH directors and staffs identified the following MCH needs and issues for this region:

- Oral health: There is a need for state mandate for oral health screening similar to vision and hearing; lack of sealant/fluoride programs in schools
- Manpower shortages: Ancillary personnel - OT, PT; pediatricians, pediatric subspecialties, primary care, OB/GYNs, care coordinators for CSHCN; nurses; public health staff; language interpreters
- Increasing addictions: There is a lack of access to treatment services, particularly for working poor; need for universal screening of newborns; inadequate number of long term treatment slots
- Access barriers: Transportation, growing LEP population; lack of knowledge about available services or how to navigate the system, HMOs are not sensitive to geographical constraints
- Social factors: There is a lack of affordable, lead free housing; and a lack of affordable child care;
- Rising family stress and breakdown of family unit: young families are experiencing problems meeting basic needs
- Increasing mental health problems including maternal depression
- Children and adolescents: asthma, obesity, lack of parental support and guidance

“Maternal depression is increasing across generations, from moms to grandmothers to great-grandmothers. This translates to lack of parenting skills (e.g., discipline), social isolation, lack of child-parent bonding, lack of commitment, and stress about life – basic life needs, shelter, food ,etc.”

Local health department
meeting participant

Central Maryland

The Central Maryland regions encompasses the jurisdictions of Baltimore City, and Baltimore, Carroll, Harford, Howard, and Anne Arundel. This region represented approximately 47% of the state's total population in 2004. It includes one of the wealthiest jurisdictions in the state and the nation – Howard County, as well as one of the poorest – Baltimore City. The region is majority suburban, but includes the urban area of Baltimore City as well as pockets of rural areas in the outlying jurisdictions. Needs and issues identified for this region through surveys and meetings with local health MCH representatives including:

- A lack of access to care, particularly for low income families, was identified as a priority concern. It affects a number of service areas including primary care, oral health care, family planning, mental health and substance abuse treatment services.
 - In some jurisdictions, there are long waiting times for family planning appointments;
 - Prenatal care access is a problem, particularly for undocumented women;
 - With the exception of Baltimore City, there are limited numbers of federally qualified health centers for uninsured persons;
 - Few medical practices accept Medicaid in some jurisdictions (e.g., Howard County);
 - Barriers to care include few services for persons with limited English proficiency as well as a lack of public transportation in some areas for poor and the disabled; and
 - Lack of insurance coverage or inadequate insurance coverage remains a cross-cutting problem.
- Child health issues and needs include asthma, lead, obesity, injuries, and mental health. Parents were viewed as needing parenting and relationship skills. For parents of infants, there is a need to address safe sleeping issues related to SIDS and SUDIs.
- Adolescent health issues include a lack of supervised after-school and recreational activities, suicide, and smoking.
- CYSHCN needs and issues include a lack of specialty providers, and funding for respite services.
- Cross-cutting issues included increasing rates of violence of all types – domestic, child abuse, community; homelessness, families needing assistance in navigating the health system, a lack of affordable housing and child care, and the need for more male involvement initiatives.
- For women of childbearing age and pregnant women issues and needs included increasing rates of depression, lack of access to prenatal care, increasing rates of smoking, increasing STD rates and a lack of available treatment for maternal substance abuse.

“We need more public relations and media about services at local health departments. Now, they are like stealth agencies.”

Local Health Department MCH
Director

Washington, D.C Suburbs and Southern Maryland

The five jurisdictions in this region – Calvert, Charles, St. Mary's, Montgomery and Prince George's – represented 37% of the state's population in 2004. This region includes the state's two largest jurisdictions in terms of population size – Montgomery and Prince George's – as well as the

state's fastest growing jurisdiction – Calvert County. Montgomery and Prince George's counties are also two of the state's most racially and ethnically diverse jurisdictions.

Below is a summary of needs identified by MCH directors in these two combined regions of the state:

- There were concerns about a lack of parental supervision of children. Parents are absent for long periods due to long working hours. This is contributing to teen sexuality. Children are becoming sexually active at younger ages, some as young as eight. More after-school programs are needed. There were also concerns about teen girls dating older men.
- For women, concerns included depression and other mental health issues, drug use, smoking, relationship issues and domestic violence, obesity, STIs and chronic health conditions such as hypertension.
- Adolescents ages 19 and over are often uninsured.
- A number of access problems were identified including increasing numbers of uninsured women, declining obstetrical resources in some areas leading to more limited access to prenatal care, and lack of access to mental health services, dental care, vision care services.
- There were concerns about the health of men, both reproductive and general.
- Workforce issues surfaced. It was noted that burnout is a problem and that the public health work force is aging.
- Residents are often aware of resources that exist or don't understand how to access the system. The public image of local health departments need to be reshaped, it's not just for STDs. There is "poor use" of family planning services and state insurance programs.
- Health providers need to be better education about asthma control and management.
- Cross-cutting issues included lack of access to affordable housing and childcare, and lack of a "user friendly" transportation system.

"The latch key is contributing to teen sexuality."
Local health department staff person

Determination of Priority Needs

The final determination of the state's priority needs rested with the MCH Needs Assessment Steering Committee. Ms. Holly Grason of the Johns Hopkins School of Public Health facilitated a final meeting of the Steering Committee to finalize the priority needs and to determine the state negotiated performance measures. Eight broad priority needs, one outcome measure and ten state performance measures selected. In determining the priority needs, consideration was given to a multitude of factors including the prioritization exercises described above; analyses of MCH data trends; focus group participant comments; provider surveys and meetings with local health department MCH staff; the CAST – 5 capacity assessment process and finally, input from Title V Program staff and other MCH serving agency staff in DHMH. The eight priority needs and eleven state performance and outcome measures are listed below:

State Priority	Performance Measures
1. Eliminate racial and ethnic disparities in maternal and child health	Percent of local jurisdictions with written plans to address racial/ethnic disparities in MCH
2. Promote healthy pregnancy and healthy pregnancy outcomes	1. Percent of pregnancies that are intended 2. Percent of women using alcohol during pregnancy
3. Promote optimal family functioning	Percent of jurisdictions offering respite care services to families of CSHCN
4. Promote healthy children	1. Emergency department visit rate for asthma 2. Percent of children entering school ready to learn
5. Promote healthy adolescents and young Adults	1. High-school graduation rate 2. Outcome: Mortality Rate, Adolescents and Young Adults ages 15-24
6. Improve systems of care for CSHCN	Percentage of jurisdictions that partner with medical homes to develop and disseminate resource materials.
7. Promote healthy nutrition and physical activity across the lifespan	Percent of infants continuing to be breastfed at six months
8. Improve the infrastructure for supporting systems of care for women, children and families	Number of policy or issue briefs developed per year

Section III. Priority Needs, 2005 Title V MCH Needs Assessment, Maryland

Following completion of the five year needs and capacity assessments, the Maternal and Child Health Bureau requires states to prioritize needs to guide strategic planning, program/activity development and performance measurement. Consideration was given to multiple factors in selecting Maryland's 2005 MCH priority needs. These included findings from a review of data trends and analyses; focus group comments; local health department surveys and meetings; the CAST – 5 capacity assessment and input from Title V Program staff and other MCH serving agency staff in DHMH. Maryland does not view this list as static or complete.

Below are Maryland's priority needs identified, as required, as part of the state's 2005 Needs Assessment process. Please note that while the 2005 priorities are numbered, the assigned numbers do not reflect their importance. All of the priorities are of equal importance and must be considered in relation to each other. An MCH Plan detailing the relationship between the state's priority needs and newly identified state performance measure as well as existing national performance measures and health indicators will be provided at the review meeting in August.

Maryland's eight priority need areas are:

1. To eliminate racial and ethnic disparities in maternal and child health.

Over the past two decades following the publication of national and state reports (e.g., the 1987 Maryland Governor's Commission on Black and Minority Health), awareness has been raised about racial and ethnic disparities in health. Both the Maryland Department of Health and Mental Hygiene and the Title V Program are committed to eliminating health disparities. DHMH was also recently mandated by the state Legislature to create an Office of Minority Health and Health Disparities. Racial and ethnic disparities were identified as a priority area during the last comprehensive needs assessment remain as a priority for the 2005 needs assessment.

The Maryland Title V broadly defines health disparity as proposed by Carter-Pokras and Baquet (2002). A health disparity is defined as a chain of events signified by a difference in the environment, access to, utilization of, and quality of care, health status, or a particular health outcome that deserves scrutiny. Inherent in this definition is the view that health differences that are unfair or unjust (i.e., health inequities) and deserve scrutiny.

Maryland data consistently reveal substantial racial and ethnic disparities on numerous key indicators of health and access to health care including infant and child mortality. The research literature is increasingly recognizing that social factors including poverty, and discrimination contribute significantly to these disparities. Maryland has begun to look at the role of stress and racism as a stressor in poor birth outcomes for African American babies. The role of public health in addressing social issues that normally have been viewed as issues that fall outside of our rubric will be considered over the next five years as Maryland attempts to address persistent, yet amenable disparities within its maternal and child health population. Technical assistance will be provided to local health departments and other MCH serving agencies within DHMH to address this priority.

The selected state performance is the percentage of jurisdictions with written plans to address racial/ethnic disparities in MCH. A related national outcome measure is the ratio of Black infant deaths to white infant deaths. A concerted effort will be undertaken to determine the causative factors of key disparities, including maternal and infant mortality, and asthma morbidity.

2. To promote healthy pregnancies and healthy pregnancy outcomes.

As part of its mission statement, Maryland's Title V Program envisions a future in which all pregnancies are planned, all women reach an optimal level of health and well-being prior to pregnancy, no woman dies or is harmed as a result of being pregnant, and all babies are born healthy. Results of the 2005 Needs Assessment indicate that much work remains to be done if this future is to be realized for all mothers and babies. The majority of babies in our state are born healthy to healthy mothers who experience healthy pregnancies. However, Maryland continues to have one of the nation's highest infant mortality and low birth weight rates. The health disparities identified in priority #1 partially contribute to this finding.

Two state performance measures have been selected to address this priority: (1) Percentage of pregnancies intended, and (2) Percentage of women using alcohol during pregnancy. This priority is directly linked to the infant mortality outcome measure as well as performance measures # 8, 15, 17 and 18.

3. To promote optimal family functioning.

Throughout the five year needs assessment, we heard about the need to support and strengthen families to assure that children remain healthy and thrive. This need for support is cross-cutting and required for all Maryland families, especially socio-economically disadvantaged families. However, the Title V Program also recognizes that families of children with special health care needs are especially vulnerable and in need of services that enhance their ability to care for their children and address their need for supportive services such as respite and child care.

Many Maryland families were anecdotally described as "in crisis or in peril." We heard that families are disconnected; parents are stressed and overwhelmed with the process of parenting as well as accomplishing the tasks of daily living; parents are placing demands on their children to be "successful;" children are being abused and neglected; and parental substance use is a growing problem. Family support can take many forms including parenting classes; affordable quality child care; mental health counseling programs; and substance abuse treatment programs. Over the next five years, the Title V Program will promote optimal family functioning by partnering with other MCH serving agencies, families, and communities to develop and implement policies and programs that promote optimal family functioning for all families.

4. To promote healthy children.

Similar to 2000 needs assessment findings, both qualitative and quantitative data continued to reveal unacceptable levels of morbidity and mortality among children in the early and middle childhood periods. Areas of continuing concern included asthma, overweight and obesity, dental caries, mental health related problems, and child abuse and neglect. This priority

was selected to ensure continued focus on improving the health of children in the early and middle years. For example, asthma currently affects more than 100,000 Maryland children and it is the leading cause of hospitalization for children in the elementary and middle school years as well as leading reason for school absenteeism. Asthma is a controllable disease when properly managed. The use of hospital emergency departments for routine asthma management can be an indicator of poor asthma management. The Maryland Asthma Control Program which is administratively housed in the Center for Maternal and Child Health is implementing a statewide plan to reduce mortality and morbidity from asthma by promoting educational and other to improve asthma management. The *emergency department use rate due to asthma* will be used as one the state performance measures for this priority.

This priority was also chosen because of the relationship between health, school readiness and school performance. The Center for Maternal and Child Health is the recipient of an MCHB funded Early Childhood Comprehensive Systems Grant. This funding is being used to develop a plan for promoting school readiness by improving the health of young children in Maryland through early childhood systems building and collaboration. The second state performance measure for this priority is the *percentage of students entering school ready to learn*.

5. To promote healthy adolescents and young adults.

Adolescence, however it's defined (ages 10 – 19 or 12-19 or 13-24), is a time of tremendous change and growth. This transitional developmental period between childhood and adulthood offers many physical, mental and emotional challenges. Risk taking is the norm during this period. Many adolescents make the transition to adulthood with few problems, others do not fare as well. Focus groups with parents and service providers consistently identified the need to promote healthy, positive youth development by offering adolescents “a sense of future.” The health care system was not viewed as “adolescent friendly” and seen as ill equipped to address growing mental health, psycho-social and emotional problems of teens. Hence, adolescent health promotion was chosen as a priority to highlight the unique needs and issues that affect this often overlooked segment of the MCH population within the public health system.

Data on the health and mental health of Maryland adolescents, beyond traditional vital statistics measures, is limited. The Title V Program has chosen the high school graduation rate as the state performance measure and the adolescent/young adult mortality rate as an outcome measure for this priority. Other national Title V measures linked to this priority include rates of teen births, suicide, juvenile arrests and high school drop-outs.

6. To promote healthy nutrition and physical activity across the lifespan.

Adult and childhood overweight/obesity is increasing at alarming rates in the U.S. and we suspect in Maryland. Data on the prevalence and incidence of childhood overweight is currently limited, but efforts are underway to improve obesity surveillance in Maryland. The latest BRFSS data for adults indicates that almost half were overweight or obese and that these rates have increased over the past decades. Rising rates of childhood overweight and obesity were repeatedly identified as a concern by focus group participants, service providers and local health department staff. Two major factors accounting for the rise obesity rates include unhealthy eating

habits and physical inactivity. Parents in our focus groups expressed concerns about school vending machines that promote unhealthy eating habits, a decline in physical education programs and outdoor recess time in schools, and an increased reliance on sedentary activities such as television viewing and computers for entertainment. Because Maryland currently does not have an obesity/overweight surveillance system for the entire child population, a performance measure will be developed in the interim years as data capabilities in this area improve.

Breastfeeding is recognized as the optimum form of nutrition for infants throughout the first year of life. While breastfeeding initiation rates in Maryland have been improving and are approaching the Healthy People 2010 goal of 75%, few Maryland moms continue to breastfeed beyond the early months. Survey data for 2003 estimate that at six months, two in five mothers continued to breastfeed and less than one in five breastfed exclusively. Because breastfeeding has long term benefits and is viewed as essential to giving infants an optimal nutritional start in life, Maryland has chosen the percentage of infants breastfed at six months as the state performance measure.

7. To improve systems of care for Children with Special Health Care Needs

A persistent problem highlighted in this year's needs assessment by both families and providers is the issue of "navigating the system" or finding out about available services within the community and gaining access to them. This is particularly troublesome for CSHCN and their families who may require not only extensive health care services but multiple family support services. The OGCSHCN has tried to address this problem by funding information and referral mechanisms at the large specialty centers serving Maryland CSHCN, at a Regional Resource Center on the Eastern Shore, and at Parents' Place of Maryland. However, the majority of these centers are located centrally within the state, and getting the word out has been slow. We have also found that not all local jurisdictions are well equipped to assist families with locating needed services, and that parents do not feel that that pediatrician's offices are a good source of information on accessing community resources. Pediatricians agree that they don't typically have this type of information in their offices. There is a need to improve the capacity of local jurisdictions and a child's medical home to quickly and efficiently disseminate information about community resources and to advertise the information and referral mechanisms that already exist. The selected state performance measure for this priority is the *percentage of jurisdictions that partner with medical homes to develop and disseminate resource materials*.

8. Improve the infrastructure for supporting systems of care for women, children and families

This broad priority focuses on infrastructure level issues, namely data, work force and manpower maldistribution issues that impact the state's ability to serve mothers and children. The CAST- 5 process noted that Maryland's Title V Program has recently made substantial process in collecting and analyzing data since the last needs assessment. CMCH now employs both a senior level MCH epidemiologist and a family planning program epidemiologist. The PRAMS data set is now available and YRBS data may be available as early as next summer. However, it was noted that current capacity remains insufficient for undertaking in-depth studies that could provide greater

direction for development of MCH policies and interventions. For example, in the mid-nineties, Maryland had one of the nation's highest early prenatal care rates, but over the past several years, early prenatal care rates have declined significantly. The Program lacks sufficient capacity to fully examine the reasons for this decline. In this instance, staff had the expertise, but not the time to perform this in-depth analysis.

The CAST-5 discussions also revealed that the CMCH process for data analysis is not systematic and that greater understanding of the needs affecting the most vulnerable MCH populations in our state is the goal, then the environment for data sharing will need to be improved, in addition to work force development. The Title V Program plans to address these issues by identifying at least one major issue requiring in-depth study and analysis each program year. This work will be accomplished in partnership with other MCH serving agencies, where appropriate. The initial state performance measure for this priority will be the number of policy briefs developed.

Public health work force and health manpower shortage and development issues were also identified as a subset for this priority. A great deal of concern was expressed throughout the CAST-5 deliberations and in meetings with local health departments about the long term implications of several public health MCH workforce issues. The MCH public health workforce is aging and more than one in four professional staff persons are within five years of retirement. Low civil service salaries, poor working conditions, and negative perceptions of public service and public service workers hamper recruitment of the "best and the brightest" to MCH public health departments. As is the case in other sections of the country, the nursing shortage is also a continuing problem. Workforce recruitment and development is also hindered by a complex, rigid, and outdated personnel management system as well as a state hiring freeze.

Several needs identified through the current assessment related to the availability and maldistribution of health resources, particularly for oral health, mental health and primary health care services. Solutions to the problems of manpower shortages will be considered and discussed in subsequent annual applications.

Appendix A



2005 Maryland Maternal and Child Health Needs Assessment Report: Pregnant Women, Mothers, Infants, Children and Adolescents

Prepared by the
Center for Maternal and Child Health
Maryland Department of Health and Mental Hygiene
July 2005

Needs Assessment Methodology

Conceptual Framework

Appendix A documents the health status and needs of Maryland's women of childbearing age, pregnant women, children and adolescents derived from various primary and secondary data sources. Appendix B discusses the health needs of children and youth with special health care needs. In most cases, the identified health indicators summarize Maryland's progress on Title V performance measures and health status and capacity indicators. Because health disparities are a priority concern of the state and the Title V Program, they are also discussed throughout this report and summarized near the end of this document.

Each of the three maternal and child health Workgroups examined population based needs according to several broad domains. For the Women of Childbearing Age, Pregnant Women and Infant Workgroup, the domains included preconception and reproductive health, maternal and pregnancy characteristics, pregnancy outcomes, mental health/substance abuse and behaviors and practices, access to care and infant health. The Early and Middle Childhood group examined mortality, morbidity and health conditions; education; access to care and mental health, behaviors and practices. Finally, the adolescent group used the following domains to examine the health needs of this population: mortality, morbidity and health conditions, reproductive health, education, access to care, and mental health/substance abuse and behaviors and practices.

The health needs of each of Maryland's MCH population groups are discussed here by domain following a brief review of data sources, and data gaps and limitations.

Quantitative Data Sources

National Reports and Surveys

- National Survey of Children's Health (2003, MCHB)
- National Immunization Survey (CDC, various years)
- National KIDS Count Report (Annie E. Casey Foundation)
- U.S. Census Bureau and Maryland State Data Center (Various reports)

State Reports, Surveys and Databases

- Maryland PRAMS Reports
- Maryland Prenatal Risk Assessment Database

- Annual and Special Maryland Vital Statistics Reports
- Maryland Hospital Discharge Database
- Maryland Behavioral Risk Factor Surveillance System

Program Data

- Maryland Department of Health and Mental Hygiene, Maryland Medicaid Program
- Maryland Department of Health and Mental Hygiene, Maryland WIC Program
- Maryland Department of Health and Mental Hygiene, Alcohol and Drug Abuse Administration
- Maryland Department of Health and Mental Hygiene, AIDS Administration
- Maryland Department of Health and Mental Hygiene, Epidemiology and Disease Control Program
- Maryland Department of Human Resources
- Maryland State Department of Education
- Maryland Department of Juvenile Services

Qualitative Data Sources

- Focus Groups, Parents of Elementary and Middle School Students
- Focus Groups, Parents of Adolescents
- Focus Groups, Adolescents
- Focus Groups, Adolescent Service Providers
- Focus Groups, Pediatricians
- Focus Groups, Child Care Providers – Early and School-based
- Focus Groups, Foster Care Program Case Managers
- Focus Groups, Hispanic mothers of young children
- Meetings, Local Health Departments MCH Directors and Staff
- Meetings, State MCH Serving Agencies
- Surveys, Local Health Departments MCH Directors

Data Limitations and Gaps

Although considerable data is available regarding the health of women, children and adolescents, there still remain areas where data are either unavailable or not readily accessible. The PRAMS database, for example, provides statewide estimates for a number of

MCH indicators, however, it does not allow discernment of estimates at the regional or jurisdictional level. Similarly, health insurance coverage rates for children and adolescents are not available at the jurisdictional level. There is no data on the prevalence of sexual activity or pregnancy rates among Maryland teens. Maryland recently became an YRBS state; however, questions on sexual activity and behaviors will not be addressed. Data on the magnitude of obesity and overweight among Maryland children and adolescents is currently limited, although improving.

Women of Childbearing Age, Pregnant Women and Infants in Maryland

There were approximately 1.2 million women of traditional childbearing age (ages 15-44) living in Maryland in 2003. Women of childbearing age represented 22% of Maryland's total population of 5.5 million. Almost two in five women of childbearing age were members of a racial/ethnic minority group in 2003. Increasing numbers of immigrant women of childbearing age, many undocumented have been settling in Maryland and this trend is beginning to impact Maryland's public maternal and child health service delivery system. As is true for the rest of the population, the majority of the women of childbearing age reside in the two metropolitan areas surrounding Baltimore City and Washington, D. C.

Table 1.
Women of Childbearing Age (ages 15-44), Births and Birth Rates by Race/Ethnicity, 2003

Sources of data on the health status of women of childbearing age in Maryland include vital statistic reports, the BRFSS Survey, and the PRAMS Survey. Data from these sources indicate the following:

- The leading causes of death for young women, ages 15-24, were accidents, homicide and heart disease in 2003.
- The leading causes of death for women, ages 25-44 were cancer, heart disease, and AIDS. AIDS was the leading cause of death for African American women in this age group.
- Between the ages of 25-44, African American women die at more than twice the rate of Caucasian women.
- Most hospitalizations for women under the age of 45 are related to pregnancy followed by infections and major depressive disorders.

	Total	White, Non-Hispanic	African American	Native American Indian	Asian/Pacific Islander	Other/Two+ Races	Hispanic
Women (ages 15-44)							
#	1,201,519	738,388	378,540	4,137	64,433	16,021	64,345
%	100.0%	61.5%	31.5%	0.3%	5.4%	1.3%	5.6%
Births							
#	74,865	43,941	24,244	180	4,343		6,966
%	100.0%	58.8%	32.3%	0.2%	5.8%		9.3%
Birth Rates							
Total	13.6	12.0	15.4				26.6
Adolescent	35.4	24.5	57.6				74.1
% Births to Unmarried Women	34.8%	21.0%	58.8%	50.6%	7.7%	N.A.	46.2%

- The 2004 Maryland BRFSS Survey reported that approximately 19.1% of women of childbearing (age 18-49) were current smokers. White women (22%) were more likely than Black women (17.3%) or Hispanic women (10.2%) to be smokers. That same year, 10.8% of women of childbearing age admitted to binge drinking (5 or more drinks in one setting) within the past month. White women (12.6%) were twice as likely as African American (6.1%) women to report binge drinking.
- With regard to chronic health conditions, 6% of women of childbearing age (ages 18-44) reported being told by a physician that they had diabetes, while 15% reported being told by a physician that they were hypertensive.
- Obesity rates have been increasing among Maryland adults. BMI data calculated by the BRFSS for 2004 indicate that a little less than one half (48%) of women of childbearing age were either obese (22%) at risk for obesity (26%).
- Over one in four (27.3%) of women reported being uninsured just prior to their pregnancy (PRAMS 2003). Other data sources estimate that 14-17% of women of childbearing age are uninsured (e.g., the 2004 BRFSS reports 16%).

Overview – Pregnancy Outcomes in Maryland – Needs and Issues

The best chance for a healthy pregnancy outcome begins with a mother who is healthy before pregnancy, who intends to become pregnancy, who does not use or indulge in unhealthy substances including cigarettes, alcohol or illicit drugs, who seeks and receives adequate prenatal care, who resides in supportive community, and who has the resources necessary to meet her physical, emotional and basic material needs. While the majority of pregnancies in Maryland result in healthy outcomes, too many Maryland infants, children and adolescents fail to reach their optimal health potential. Each year approximately 600 babies die before reaching their first birthday, 2000 are born to young teen moms, 2800 are born to moms receiving late or no prenatal care, and over 6700 are born at low birth weights.

Maryland vital statistics data, local health department surveys and reports, as well as meetings with service providers serve as the basis for needs and issues identified for women during pregnancy and the childbearing years. Local health departments in every region of the state voiced the need to improve access to health care services in just about every service delivery area for women of childbearing age as well as pregnant women. Key informants told consistently told us that a women's wellness status prior to pregnancy is important to assuring the healthiest possible pregnancy outcome.

Just as we heard during the 2000 needs assessment, there remains a need for comprehensive, continual health insurance coverage for women beyond pregnancy. Overall, an estimated one in four women of childbearing age is thought to be uninsured. Uninsured rates are higher for Hispanic and African American women of childbearing age. In spite of the fact that many of the pregnant women with incomes up to 250% of the federal poverty level (FPL) have comprehensive medical and dental coverage

through the Maryland Children's Health Program (MCHP), this coverage does not extend beyond six weeks postpartum. The need for comprehensive, continual health insurance coverage continues to be critical for low income uninsured women including those who are undocumented immigrant and ineligible for publicly funded programs, and well as those who are disenfranchised and in poor health. As more employers exclude health insurance as a benefit, this need is expected to also affect more middle class families.

Substance abuse (i.e., smoking, alcohol and illicit drug use) during pregnancy increases the risk for a poor pregnancy outcome. Smoking rates among pregnant women continued to decline reaching a low of to 7.7% in 2003. However, this percentage continues to exceed the Healthy People 2010 goal of 2%. Smoking remains as severe problem particularly for several counties on the Eastern Shore and in Western Maryland who report significantly higher smoking rates than the statewide average. At least 10 local health departments identified smoking during pregnancy as a major challenge.

Alcohol use during pregnancy is a severe problem in Maryland. Drinking is considered the leading cause of preventable birth defects and mental retardation in the U.S. Prenatal alcohol exposure can result in FASD and FAS as described later in this Section. Data on the prevalence of FAS and FASD is currently unavailable and Maryland has recently began developing a statewide plan to enhance the identification of individuals with FASD and FAS. Local health departments identified alcohol use during pregnancy as a continuing concern. PRAMS data for 2003 indicate that alcohol use during the last three months of pregnancy was reported by 10% of respondents. Similarly, 2004 BRFSS data show that 10.8% of women between the ages of 18-9 engaged in binge drinking in the past month. These percentages fall short when compared to the Healthy People 2010 goal to reduce the rate of alcohol used during pregnancy to 6%. In addition, a recent national report summarized 2000-2001 PRAMS data from eight states and found that Maryland had the second highest rate of alcohol use during pregnancy (CDC, MMWR 2004:53(SS04).

Fewer Maryland women are receiving early prenatal care services. Although prenatal care is not a panacea, babies whose mothers receive quality prenatal care services have better birth outcomes. The declining prenatal care rate threatens to further erode Maryland's ability to address high rates of infant mortality, prematurity and low birth weight births. This may be an indicator of declining health system capacity, increasing rates of uninsurance among adults in Maryland or a lack of obstetrical care providers.

Local health department MCH staff are alarmed by the potential for the state's "malpractice crisis" to further lessen access to obstetrical services, particularly in rural areas of the state. Coupled with this finding is the growing number of uninsured and undocumented pregnant women in Maryland. While this population who are largely Hispanic, tend to have better pregnancy outcomes than most other minorities in the state, local health departments have been increasingly confronted with the need to place a priority on this population. Cultural and language differences serve as barriers to care for this population. This creates an added strain for an already tight public health infrastructure, we were often told, in that providers must struggle to provide translators and bi-lingual staff to address service needs.

Preconception and Reproductive Health

Trends, Progress, Strengths

- Increasing percentages of Maryland adults are participating in physical activity – 77.8% in 2002-2003 (Maryland BRFSS).
- Increasing percentages of Maryland adults are consuming five or more servings of fruit and vegetables daily – 29.3% in 2002-2003 (Maryland BRFSS).

Gaps, Unmet Needs, Challenges

- Approximately two in five of Maryland pregnancies are unintended (i.e., mistimed or unwanted).
- The Guttmacher Institute estimates that there are over 200,000 Maryland women in need of publicly subsidized family planning services.
- Many Maryland women lack access to preventive, primary care and preconception services. Between 15% to as many as one in four Maryland women of childbearing age are uninsured.
- Rates of sexually transmitted infections in Maryland are among the highest in the nation.
- The prevalence of obesity, diabetes, hypertension, and high cholesterol is increasing among Maryland adults (Maryland BRFSS 2002-2003).

Pregnancy Intendedness

Approximately three in five Maryland pregnancies were intended according to the 2003 Maryland PRAMS survey. An intended pregnancy was defined as one that is mistimed or unwanted. African American women, adolescents, and women with less than a high school education are the most likely to have unintended pregnancies. Among mothers with unintended pregnancy, 60% did not use birth control. The most frequently cited reason given by mothers with unintended pregnancies for not using contraception was that they didn't mind becoming pregnant.

Folic Acid Usage

Fewer than one in three women reported taking a multi-vitamin in the month before conception according to the 2003 PRAMS Survey. Multi-vitamins are a source of folic acid which has been documented to prevent neural tube defects. The Healthy People 2010 goal is for 80% of women of childbearing age to take adequate folic acid supplements.

Use of Family Planning Services and Contraceptives

The Title X Maryland Family Planning Program provides access to family planning, preconception health, teen pregnancy prevention, and colposcopy services to women and families in every jurisdiction of the state. The Program serves approximately 70,000 clients annually. Adolescents represented approximately one third of persons served. The Alan Guttmacher estimates that Maryland 's public funded family planning services help to avert 21,600 unintended pregnancies each year.

The Medicaid Program provides continuing coverage for family planning services for women who are no longer eligible for Medicaid following pregnancy. Eligible women are mailed a "purple and white card" to use to receive comprehensive family planning and reproductive health services, including contraceptives. However, few eligible women show evidence of receiving services, less than one in four received a service in FY 2003 according to Medicaid claims files. Family Planning Program staff in several jurisdictions, including Baltimore City indicate that many women are still not aware of their eligibility for Medicaid funded family planning services. This continues to serve as a barrier to accessing services.

Fertility Drugs and Assisted Reproductive Technology

The PRAMS Survey for 2003 indicates that 10% of mothers trying to become pregnant used fertility drugs. Five percent of women used assisted reproductive technologies such as in vitro fertilization. Over 13% of women over age of 40 reportedly used assisted technology.

Sexually Transmitted Infections: Chlamydia, Syphilis and Gonorrhea

Rates of sexually transmitted infections are among the highest in the nation. Syphilis is a sexually transmitted infection (STI) caused by the bacterium *Treponema pallidum*. Untreated syphilis increases the risk for a stillborn birth and can cause cardiovascular disease and blindness (CDC Web site). Syphilis rates have been declining in both the U.S. and Maryland. However, Maryland had the nation's 2nd highest rate of syphilis (2.5 cases per 100,000 population) in 2003. Syphilis rates were higher than the statewide average in three jurisdictions in 2003: Baltimore City, Baltimore County and Prince George's County. The Baltimore County Health Department has identified perinatal infections as a priority area of focus and have convened a Baltimore Metropolitan area Committee to review and implement strategies to reduce infection rates.

There were 8,067 reported cases of Gonorrhea in Maryland in 2003. Among states reporting STIs in 2003, Maryland had the 10th highest rate of gonorrhea (146.4 cases per 100,000 population). Gonorrhea rates were higher than the statewide average in four jurisdictions in 2003: Baltimore City; and Prince George's, Somerset and Wicomico counties.

Chlamydia is a common sexually transmitted infection caused by *Chlamydia trachomatis*. Untreated infections in women can cause pelvic inflammatory disease (PID), leading to chronic pelvic pain, infertility and potentially fatal ectopic pregnancy. In 2003, reported Chlamydia rates per 1,000 women were four times higher for adolescent ages 15-19 (31.5) than for Maryland women ages 20-44 (7.0).

Maternal, Pregnancy and Birth Characteristics

Trends/Progress/Strengths

- Maryland's Medicaid and MCHP Programs provide health insurance coverage for pregnant women with family incomes up to 250% of the federal poverty level.
- The Maryland Medicaid Program is providing health insurance coverage to increasing percentages of pregnant women – approximately 34% in 2004.
- Overall, fewer women are reporting smoking during pregnancy – 7.7% in 2003.
- Pregnant women receive priority status in admission to substance abuse treatment programs.
- The state's congenital syphilis rate is declining.

Gaps, Unmet Needs, and Challenges

- As many as 600 babies may be born each year in Maryland with fetal alcohol spectrum disorder (FASD), a condition that is often under-diagnosed, but has severe, life long effects.
- Mental health (including depression), substance abuse and domestic violence are increasingly being identified as problems for pregnant women and women of childbearing age, particularly in urban and rural areas of the state.

Maryland Births

The numbers of Maryland births have been increasing and birth rates are highest for Hispanic women. In 2003, there were 74,865 live births to Maryland residents; a 2% increase over the number in 2002. Maryland's 2003 birth rate of 13.1 births per 1,000 population was lower than the national average of 14.1. As Table 1 shows, Hispanic women (26.6) had the state's highest birth rate followed by African American women (15.4) and Caucasian women (12.0). The birth rate has been declining for all Maryland racial/ethnic groups with the exception of Hispanics. In 2003, birth rates varied by region and jurisdiction. By region, rates ranged from a low of 11.8 on the Eastern Shore to a high of 15.0 per 1,000 population in Prince George's County.

Births to Unmarried Women

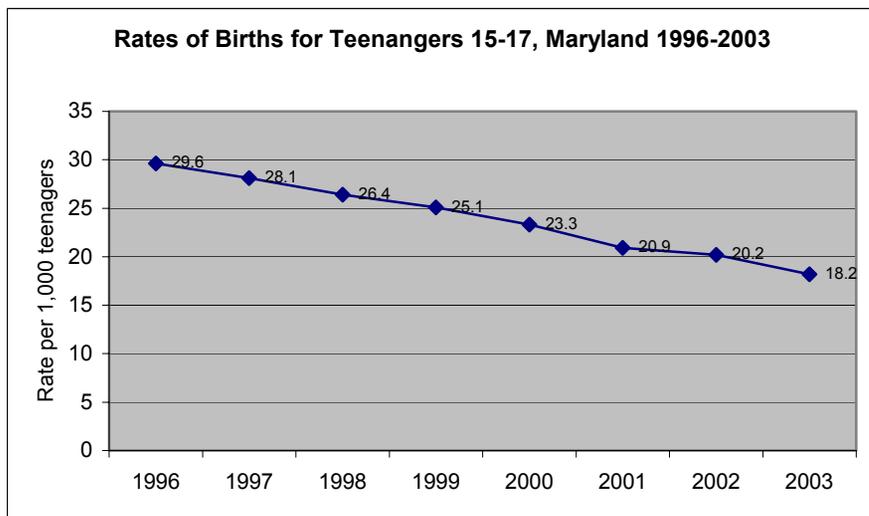
The percentage of births to unmarried women in Maryland continued to increase and stood at 34.8% in 2003. The national percentage in 2003 was 34.6%. In 2002, Maryland ranked 30th nationally on this indicator with a rate that was slightly above the

national average of 34%. The percentage of births to unmarried women by jurisdiction ranged from a high of 68.3% in Baltimore City to a low of 16.1% in Howard County. By race/ethnicity, the percentage ranged from a high of 58.8% for African Americans to a low of 7.7% for Asians. The percentage of births to unmarried women has been increasing for Caucasian women and declining for African American women.

Births to Teens

In 2003, 6,400 adolescent girls (<20) gave birth to 8.5% of babies born in Maryland. This group included 124 girls under the age of 15 and 2,085 girls between the ages of 15 and 17. Maryland PRAMS data for 2003 estimated that 84% of adolescent pregnancies were unintended.

Maryland's teen birth rate declined for the tenth year in a row, falling to a rate of 18.2 per 1,000 teens ages 15-17 in 2003. Rates declined for both Caucasian and African American adolescents but rose for Hispanic adolescents. Births to teens under the age of 18 accounted for three percent of all births in 2003.



The Maryland Vital Statistics Report examines teen births for adolescents ages 15-19 both statewide and by jurisdiction. Adolescent birth rates have been falling steadily over the past decade, particularly among African Americans. The birth rate for adolescents, ages 15-19, dropped to 33.3 per 1,000 live births; a 38.4% decrease over the 1991 rate of 54.1. Nationally, the rate for this age group fell to 41.7.

Paralleling the national trend, Hispanic adolescents, ages 15-19, had the state's highest birth rate, 81 per 1,000 population, in 2003. The Hispanic adolescent birth rate was triple the rate for Caucasians (22.7) and higher than the rate for African Americans (53.0). By jurisdiction, teen birth rates were highest in Baltimore City (71.1); and Dorchester (54.9), Caroline (47.8) and Washington (45.0) counties.

Undocumented Pregnant Women

"Undocumented" or "unauthorized" immigrants as those who did not fit the legal categories of permanent residents, refugees, asylees, or workers and students on temporary visas. Maryland's undocumented immigrant population is increasing. Since 2000, the numbers have increased from 120,000 to approximately 250,000 in 2004 (Pew Hispanic Center, Estimates of the Size and Characteristics of the Undocumented Population). According to a recent Baltimore Sun article, undocumented immigrants are migrating to Maryland because of the availability of jobs in the home construction and landscaping industry. A large percent of undocumented residents are women, and about one in six are children. While nationally, 57% of this population migrates from Mexico, Maryland's Hispanic immigrants are predominantly from Central America and the Caribbean islands.

State Medicaid funds are providing coverage for increasing numbers of emergency deliveries for illegal and ineligible aliens. The numbers tripled from 1,120 deliveries in FY 1999 to 3,479 in FY 2004. Almost three quarters (74%) of these women resided in either Montgomery or Prince George's counties. Other jurisdictions with a hundred or more deliveries included Anne Arundel, Baltimore and Howard counties; and Baltimore City. Beginning in FY 2006, Maryland will no longer provide prenatal care coverage through the Medicaid Program for legal aliens who have immigrated within the past five years. This is being done because as a condition of immigration, the immigrant's sponsor had to agree to cover all their medical expenses. In FY 2004, 823 women received services under this eligibility category. Maryland had been one of three states providing coverage to this population using state dollars.

Medical Complications During Pregnancy

About 2/3 of women reported one or more medical complications during pregnancy in the 2003 PRAMS survey. Complications included preterm labor (27%), nausea, vomiting or dehydration (27%), vaginal bleeding (18.5%), and hypertension (18%). In 2002, approximately one third of deliveries in Maryland resulted in a complication requiring hospitalization. Maryland rates are comparable with national rates but higher than the Healthy People 2010 objective of 24.0 per 100 deliveries. The main labor and delivery complications requiring hospitalization were trauma to perineum and vulva during delivery including damages from instruments and extension of episiotomy (50.4%), abnormality of forces of labor (14.9%), umbilical cord complications (14.8%) and obstructed labor (7.8%).

Obesity and Pregnancy

Obesity is a health risk women both during pregnancy as well as throughout the childbearing years. The Baltimore County FIMR Committee identified rising obesity rates among pregnant women and women of childbearing age as a risk factor for adverse birth outcomes. The March of Dimes Web site cites studies that identifies obesity during pregnancy as risk factors for birth defects, labor and delivery complications, maternal complications (e.g., hypertension, gestational diabetes and preeclampsia) and fetal and neonatal death. There is limited Maryland data on obesity during pregnancy.

Stress and Pregnancy

The research literature is beginning to demonstrate a link between social factors, stress and poor birth outcomes. More than 2/3 of women in the 2003 PRAMS Survey indicated being affected by one or more stressors during the 12 months before giving birth. The top stressors identified were moving to a new address, arguing with partner, inability to pay bills, hospitalization of a family member and the death of someone close.

Smoking during Pregnancy

The picture is mixed on smoking during pregnancy in Maryland. While it appears that smoking rates are declining overall, there are numerous jurisdictions where the smoking rates are more than twice the state average and many local health departments are anecdotally reporting rising rates of cigarette smoking during pregnancy. In addition, work remains to be done to reach the Healthy People 2010 goal of reducing the percent of women smoking during pregnancy to two percent.

Prenatal tobacco use is associated with an increased risk of delivering a low birth weight baby. Both the PRAMS Survey and vital statistics records provide data on smoking behavior during pregnancy. PRAMS also reports on smoking behaviors before and following pregnancy. In addition, the Prenatal Risk Assessment Database (a statewide database comprised of referrals of at risk pregnant women, mainly Medicaid enrollees, to local health departments for care coordination and home visiting services) supplies data on smoking as pregnancy risk factor. In FY 2004, cigarette smoking was identified as a risk factor for 24% of women.

PRAMS data for 2001 to 2003 report that 9.4% to 11.1% of women reported smoking during pregnancy. Smoking percentages varied by socio-demographic factors and were highest for White women and women with less than a high school education. In 2003, 20.6% of women reported smoking in the three-month period prior to pregnancy and 16.4% reported smoking in the postpartum period. This indicates that some women stopped smoking once their pregnancy was determined, however, in 2003 reportedly more than 11% continued to smoke. The overwhelming majority (88%) of PRAMS respondents in 2003 indicated that they were asked about smoking behavior at some time during a prenatal care visit.

Overall, fewer Maryland women report smoking during pregnancy. The Vital Statistics reporting system estimates that 7.7% of women smoked during pregnancy. Percentages varied by region and jurisdiction and were lowest in the more affluent jurisdictions of Montgomery, Prince George's and Howard counties. Jurisdictions with percentages of smokers considerably higher than the statewide average of 7.7% included the Western Maryland counties of Allegany (22.7%), Garrett (16.7%), and Washington (17.5%); the Southern Maryland counties of Calvert (12.2%), Charles (9.4%), and St. Mary's (11.8%), and nine of the eleven Eastern Shore counties including Somerset (19.7%), Cecil (18.9%), and Kent (18.6%). In the Central Maryland area, percentages were highest in Baltimore City (13.4%) and Harford County (11.6%).

By race/ethnicity, the Vital Statistics data for 2003 indicate that American Indian (16.1%) and White (9.4%) women were more likely to report smoking during pregnancy than African American (6.3%), Hispanic (0.9%) or Asian (0.9%) women.

Alcohol Use During Pregnancy and Fetal Alcohol Syndrome (FAS)

Alcohol use during pregnancy is considered the leading cause of preventable birth defects and mental retardation in the U.S. Fetal Alcohol Spectrum Disorders (FASD) encompasses the range of adverse effects that can result from prenatal alcohol exposure. The most severe of these disorders is Fetal Alcohol Syndrome (FAS). FAS is caused by a woman drinking heavily during pregnancy and is characterized by abnormal facial features, growth retardation, and central nervous system problems. The consequences of FASD and FAS are life-long and can include severe problems with learning, developmental disabilities, mental health problems, difficulties in school, inability to live independently and substance abuse. Children and adults with FASD are at high risk for criminal behavior and often become involved in the juvenile or criminal justice systems.

There is currently no data on the prevalence of FASD and FAS in Maryland. FASD is believed to often be unidentified or misdiagnosed. Determining the prevalence of FASD is difficult due to the lack of uniform data sources, significant under-diagnosis and population variability. The CDC and the National Task Force on FAS estimate the prevalence of FAS to be between 0.2 and 2.0 cases per 1,000 live births. Other alcohol related conditions within FASD are thought to occur three times as often as FAS. Applying these rates to vital statistics data, it is estimated that as many as 600 infants may be born with FASD each year in Maryland.

Certain minority groups and disadvantaged populations have higher rates of FAS. This is particularly true for American Indian communities where rates of FAS may be as high as 5 per 1,000 live births. Binge drinking and frequent alcohol use are considered high risk practices for FASD. Women of childbearing age who are binge or frequent drinkers are at highest risk for having an alcohol related pregnancy. Maryland BRFSS data for 2004 indicate that 10.8% of women of childbearing age (ages 18-49) admitted to binge drinking (5 or more drinks in one setting) within the past month.

State level data on alcohol use in pregnancy is available through PRAMS. PRAMS mothers are asked about their drinking behavior both in the three months before pregnancy and during the last three months of pregnancy. In 2003, 10% of women reported using alcohol during the last three months of pregnancy. White women, older women (age 30+), and women at higher educational levels were more likely to report using alcohol during the last three months of pregnancy. Less than one percent of women reported a binge drinking episode (5+ drinks in one sitting) during the last three months of pregnancy. Thirteen percent of women indicated participation in one or more binge drinking episodes during the three month period preceding pregnancy. Binge drinkers were more likely to be White women, women between the ages of 20 to 24, and women with higher educational levels. Seventeen percent of women reported that their health provider never asked about alcohol use during visits for prenatal care.

In addition, the Prenatal Risk Assessment Database supplies data on alcohol use as risk factor during pregnancy. This statewide database is comprised of information on at risk pregnant women, mainly Medicaid enrollees, who are referred to local health departments for care coordination and home visiting services. In FY 2004, alcohol use was identified as a risk factor for 4.4% of women.

Data on alcohol related treatment admissions is available from the Maryland Alcohol and Drug Abuse Administration (ADAA) within DHMH. Pregnant women in Maryland are given priority consideration in admission to substance abuse treatment programs. ADAA identifies alcohol-related admissions as any admission for which alcohol was listed as one of the top three substances of abuse reported. In 2003, there were more than 12,000 alcohol-related treatment admissions for women in Maryland. Close to 3% of these admissions were women who were pregnant at the time of admission. According to ADAA, Maryland has 32% more alcohol related admissions for pregnant women than the national average. The racial distribution of pregnant alcohol related admissions was 50% White, 40% Black and 2% Other in 2003.

Illicit Drug Use During Pregnancy

The Maryland PRAMS Survey does not collect data on illicit drug use during pregnancy nor is there any other source of prevalence data on illicit drug use during pregnancy in Maryland. Nationally, 3% of pregnant women aged 15 to 44 reported using illicit drugs in the past month according to the 2002 National Survey on Drug Use and Health. Illicit drugs include marijuana/hashish, cocaine (including crack), inhalants, hallucinogens, heroin, or any prescription type drugs used non-medically.

One source of drug use as a risk factor during pregnancy is the Maryland Prenatal Risk Assessment Database as described above. In FY 2004, drug use was identified as a risk factor for approximately 1,100 or 7.6% of the 14,000 women identified in the database.

The Maryland Alcohol and Drug Abuse Administration (ADAA) collects data on admissions to substance abuse treatment programs by pregnancy status. ADAA reports that during state fiscal year 2005, 1,142 pregnant women were admitted to treatment facilities (5.3% of all female admissions). Three hundred and twenty nine (28.8%) were reported to still be pregnant at discharge; 374 (32.7%) were no longer pregnant at discharge; and, 439 (38.4%) were still actively involved in treatment. There were 61 cases where women were not reported pregnant at admission but became pregnant while in treatment. ADAA estimates that 6.5% of Marylanders over the age of 14 have substance abuse problems serious enough to require treatment. Less than 30% received treatment during FY 2003.

Since 1997, Maryland has developed and implemented a pilot program in eight jurisdictions for referring babies at delivery with positive toxicology screens for heroin and cocaine (marijuana was recently added) to local departments of social services for assessment and intervention. The state Legislature provides funding for drug treatment services for mothers of children born drug exposed. The Pilot Program is jointly administered by both the Department of Human Resources and ADAA. During FY 2003, there were 370 referrals of drug-exposed newborns to the local department of social services (LDSS) in the eight jurisdictions participating in the pilot program. These infants were born to 362 women.

More than 70 percent of the infants and families in the Pilot Program in FY 2003 were identified in Baltimore City. The Pilot Program's FY 2003 Report to the Legislature notes that "There is no uniform protocol used Statewide by physicians or hospitals to screen women either prenatally or at time of delivery for illicit drugs. According to staff implementing the pilot program, prenatal assessment of substance use is still not routine among providers. There is also a difference in how private versus Medicaid patients are assessed. If a woman does report substance use prenatally, toxicology screening is not always done. Even if a woman reports substance use at time of delivery, some physicians will not order a toxicology screen. This practice has led to racially and socio-economically biased reporting to child welfare." Another treatment related concern for women requiring treatment postpartum is that, unlike pregnant women, postpartum parenting women are not given priority treatment status. This serves as barrier to securing treatment for new mothers in a timely manner.

Physical Abuse During Pregnancy

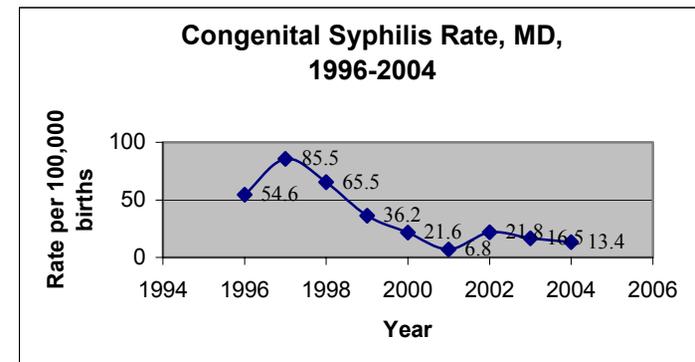
The Maryland PRAMS Survey collects data on physical abuse during pregnancy. In 2003, four percent of mothers reported being physically abused by a husband or partner during pregnancy, and two percent reported being abused by someone else. Although, homicide linked to domestic violence is a leading cause of maternal mortality in Maryland, few women, less than half in 2003, were reportedly asked about physical abuse during prenatal care visits.

Cesarean Deliveries

Many Maryland babies are being born via cesarean section, approximately one in four in 2003. Much work remains to be done to reach the Healthy People 2010 objective of 15%. Cesarean delivery rates have increased steadily in the past decade both nationally and internationally, raising questions about the appropriateness of cases selected for this intervention. Following a declining trend in the early and mid-1990s, due to an increase in the number of vaginal deliveries after a prior cesarean section (VBAC), the rates of cesarean deliveries have increased dramatically rising from 20.5% of all deliveries in 1997 to 28.7% in 2003. Nationally, the percentage stood at 27.6%. In 2003, the highest rates of cesarean deliveries occurred in Wicomico, Somerset and Worcester counties and the lowest rates occurred to women in Allegany, Dorchester and Talbot counties. Rates also varied by race/ethnicity and were highest for African American (31.4%) and American Indian (31.7%) women and lowest for Hispanic (24.4%) women.

Congenital Syphilis

Congenital syphilis is a preventable birth outcome. Congenital syphilis became a state priority following the 2000 Maryland Title V needs assessment when the state saw a spike in the congenital syphilis rate. Between 1996 and 1997 Maryland's congenital syphilis rate increased 57% from 54.6 to 85.5 cases per 100,000 live births. This increase was largely attributable to a rise in the primary and secondary syphilis rate in Baltimore City in both 1996 and 1997. By 2001, the number of congenital cases had declined to 5; down from 60 in 1997. This decrease was largely attributed to increased provider education and outreach to at risk populations such as inmates at correctional facilities and substance abusers.



The number of cases rose again in 2002 to 16 and a rate of 21.8. As a result, congenital syphilis was identified as a case priority for FIMR Teams in FY 2003 efforts. Ten of the sixteen 2002 cases occurred in Baltimore City. The FIMR review found that most cases were presumptive rather than confirmed. The number of cases declined to 13 in 2003 and to 10 in 2004.

In 2003, the CDC reports that Maryland ranked 13 in the rate of congenital syphilis cases. Maryland had the nation's 2nd highest syphilis rate in that year. Maryland's estimated 2004 congenital syphilis rate continues to remain above the Healthy People 2010 goal of 1 case per 100,000 live births.

HIV/AIDS in Infants and Pregnant Women

HIV/AIDS is affecting an increasing percentage of women in Maryland. In 1987, women accounted for 12.7% of diagnosed AIDS cases. By 2003, this proportion had tripled to more than one third. Maryland law requires mandatory counseling and voluntary testing of all pregnant women for HIV/AIDS. However, there are currently no incidence or prevalence rates for HIV/AIDS among pregnant women.

The numbers of pediatric AIDS cases has declined since 1992. Since the start of surveillance, there have been a total of 314 pediatric AIDS cases diagnosed in Maryland and there are currently an estimated 245 Maryland children living with AIDS. The number of babies born to HIV infected women has been decreasing. There were 20 children infected with HIV/AIDS born in 1998, and there were 5 infected children born in 2003 statewide (2004 Maryland HIV/AIDS Report).

HIV/AIDS disproportionately affects African Americans and Baltimore City residents in Maryland. Baltimore City represents 12% of the state's population, but approximately half of the state's HIV/AIDS cases. African Americans represent 28% of the state population, but over 80% of HIV/AIDS cases.

Pregnancy Outcomes

Trends, Progress, Strengths

- For 1998-2002, the average maternal mortality ratio (MMR) was 14.0 per 100,000 live births, higher than the national MMR of 9.4 for this time period, and substantially higher than the Healthy People 2010 goal of 3.3.
- Infant death rates have declined significantly for all racial and ethnic groups over the past 25 years. Between 1994-1998 and 1999-2003, the average statewide infant mortality rate declined by 8.6% falling from 8.6 to 7.9 deaths per 1,000 live births.

Gaps, Unmet Needs, and Challenges

- Maryland's mortality ratio is higher than the national average and has shown very little improvement in recent years. Homicide is the leading cause of pregnancy associated mortality in Maryland.
- Maryland's infant mortality and low birth weight rates are some of the highest in the nation. Maryland's infant mortality rate has historically exceeded the national rate. Much work remains to be done to reach the Healthy People 2010 goal of 4.5 deaths per 1,000 live births.
- African Americans fare far worse than most other racial and ethnic groups on major indicators of perinatal health. In particular, African American babies continue to die two to three times the rate of Caucasian babies in Maryland. The gap widened between 2002 and 2003.
- Almost one in five (18%) Maryland women reported being at moderately or severely depressed following pregnancy.
- In 2002, there were 536 sentinel defects in 491 Maryland and 1,034 non-sentinel defects reported to the state's Birth Defects Surveillance System.

Maternal Mortality

For 1998-2002, Maryland's average maternal mortality ratio (MMR) was 14.0 per 100,000 live births, higher than the national MMR of 9.4 for this time period, and substantially higher than the Healthy People 2010 goal of 3.3. The maternal mortality ratio (the number of maternal deaths per 100,000 live births) for Maryland has shown no improvement in recent years. In 2003, there were 42 pregnancy associated deaths identified by Maryland's legislatively mandated Maternal Mortality Review Committee. Pregnancy associated deaths are defined as the death of a woman while pregnant or within one year of pregnancy conclusion, regardless of the cause of death. Homicide has been identified as the leading cause of pregnancy associated mortality in Maryland. No regional or jurisdictional level data were available.

In the U.S., African American women have a maternal mortality ratio three to four times greater than that for White women. During 1998-2002, Maryland's MMR averaged 20.0 per 100,000 live births for black women compared to 11.4 among White women. The difference between African American and White women is smaller in Maryland because African American women have a lower mortality rate than the U.S. average and White women have a higher rate of death in the United States overall.

Low Birth Weight and Prematurity

In 2003, 8,229 babies (11%) were born prematurely or too early (under 37 weeks gestation). Premature babies are more likely to die within the first year of life than full term babies. Premature babies are also more likely to be born at low birth weights putting them at risk for numerous medical and handicapping conditions. Prematurity and low-birth weight are the leading causes of infant deaths in Maryland. Risk factors for prematurity or low birth weight include medical conditions and complications, behavioral/social factors such as maternal smoking, maternal weight gain and late entry into prenatal care. The Vital Statistics Administration partially attributes the increase in the state's infant mortality rate between 2002 and 2003 to an increase in the number of very low birth weight infants.

In 2003, 6,825 Maryland babies (9.1%) were born at low birth weights (less than 2,500 grams). That same year, 1,440 (1.9%) of babies were born at very low birth weights (less than 1,500 grams). Much work remains to be done in Maryland to reach the Healthy People 2010 goals for low birth weight (5%) and very low birth weight (0.9%).

Maryland's low birth weight rate has consistently been higher than the national average (7.9%) in 2003. The percentage of infants born at low birth weight increased in Maryland and the U.S. throughout the nineties. Factors contributing to the increase include the growth of multiple births, which are more likely to be delivered preterm, and/or at low-birth weight. In 2003, 58.9% of multiple births included babies born at low birth weights as compared to 7.1% of live singleton births. However, low birth weight rates have also been increasing among singleton births.

The low birth weight rates for American Indians and African Americans in 2003 were significantly higher than that of other racial and ethnic group. African American (13.1%) and American Indian (14.4%) babies were approximately twice as likely as Caucasian (7.1%), Hispanic (7.0%) and Asian (8.0%) babies to be born at low birth weights. Low birth weights have been increasing among Caucasian babies in Maryland.

Four jurisdictions had low birth weight rates considerably above the statewide average of 9.1%: Somerset County (14.7%), Baltimore City (13.7%), Garrett County (12%), and Prince George’s County (10.4%).

In 2003, 85.3% of very low birth weight infants born in Maryland were delivered at high-risk facilities. There were no data available for the U.S. or for the various regions in Maryland.

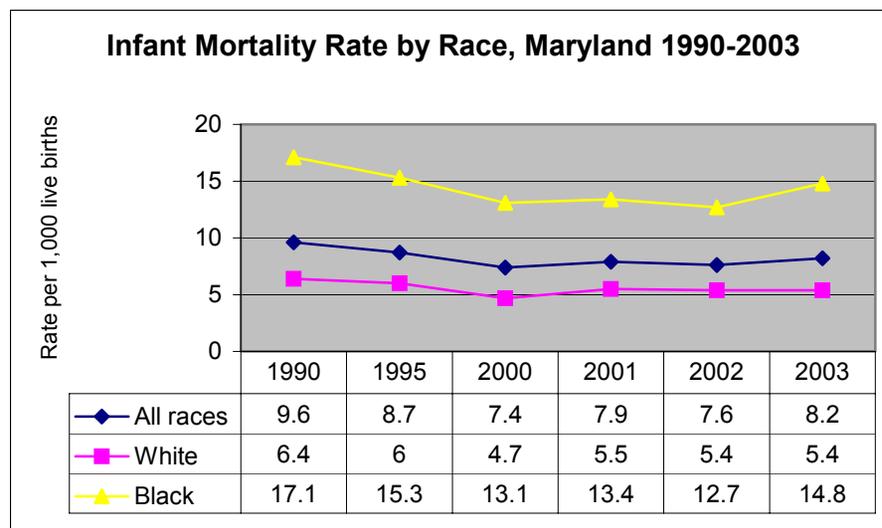
Infant Mortality

Infant mortality, the rate of infant deaths per 1,000 live births, is often used as a health indicator but is also recognized as a measure of the quality of life in a community. Maryland’s infant mortality rate has historically and continues to be higher than the national rate and Healthy People 2010 goal of 4.5 deaths per 1,000 live births. Each year in Maryland, approximately 600 babies die before reaching their first birthday. Major disparities continue to persist.

Infant mortality has declined significantly over the past 50 years and reached a record low of 7.4 deaths per 1,000 live births in 2000. However, between 2002 and 2003, the state’s infant mortality rate increased by 8%, rising from 7.6 to 8.2. The state’s Vital Statistics Administration indicates that the rise in the overall rate was due to a 17% increase in the Black infant mortality rate, which rose from 12.2 in 2002 to 14.8 in 2003.

Infant mortality rates vary by race/ethnicity in Maryland. Lowest infant death rates occur among Asian, Hispanic and Caucasian babies. Death rates have historically been higher for African American and American Indian babies. African American babies are two to three times more likely to die within the first year of life as White babies in Maryland.

Over 75% of infant deaths occur in the five jurisdictions with the state’s highest population levels: Prince’s George’s, Baltimore, Montgomery and Anne Arundel counties; and Baltimore City. Between 1999-2003, the average infant death rates by jurisdiction ranged from a low of 4.0 in Queen Anne’s County to a high of 12.1 in Baltimore City. Jurisdictions with rates above the statewide average for this time frame included Baltimore City; Garrett and Prince George’s counties; and six of



nine Eastern Shore counties: Cecil, Kent, Caroline, Dorchester, Wicomico and Somerset. Statistically significant declines in infant mortality occurred in Montgomery, Prince George's and Queen Anne counties between 1999 and 2003, but rates have either remained the same or increased in other jurisdictions.

The leading causes of infant deaths in 2003 were prematurity/low birth weight, congenital malformations and maternal complications of pregnancy. This was the first time since 1969 that SIDS was not among the three leading causes of death. SIDS, the fourth leading cause of death, represented 9% of all infant deaths and was the leading cause of death in the postneonatal period. The leading causes of infant deaths varied by race in 2003. For Black infants, the leading causes were low birth weight, congenital malformations and SIDS. The leading causes for White infants were congenital malformations, low birth weight and maternal complications of pregnancy.

Neonatal Mortality

Neonatal mortality is defined as the death of a live born infant in the first 28 days of life. The majority (71%) of the 613 infant deaths in Maryland occurred in the neonatal period in 2003. Maryland neonatal mortality rate of 5.9 was higher than the Healthy People 2010 goal of 2.9 in 2003. Risk factors for neonatal mortality include maternal infections, pregnancy and delivery related complications, poor maternal health, and lack of access to prenatal care. In 2003, low birth weight, congenital malformations and maternal complications of pregnancy were leading causes of neonatal deaths in Maryland.

Neonatal mortality rates have generally been declining in Maryland; however, the neonatal mortality rate rose from 5.4 in 2002 to 5.9 in 2003, a 7.4% increase. This increase was the result of a 19.2% increase in the Black neonatal mortality rate, from 8.9 in 2002 to 10.6 in 2003. The White neonatal mortality rate fell by 4.9%, from 4.0 in 2002 to 3.8 in 2003. Black neonatal mortality rates had been falling steadily in Maryland prior to the 2003 increase. In contrast, White neonatal mortality rates have shown little change over the past decade. African American babies were more than twice as likely as White babies to die within the neonatal period over the past decade.

Over one in five neonatal deaths occurred in Prince George's County in 2003. Three of the seven jurisdictions with five or more neonatal deaths had neonatal mortality rates above the state average of 5.9 for 2003: Prince George's County (9.3), Baltimore City (8.7) and St. Mary's County (6.7).

Postneonatal Mortality.

Postneonatal mortality is defined as the death of a live born infant from 29 days through 11 months of life. Twenty nine percent of Maryland's 613 infant deaths occurred in the postneonatal period in 2003. Maryland postneonatal mortality rate of 2.3 was higher than the Healthy People 2010 goal of 1.2 deaths per 1,000 births. Maryland postneonatal mortality rates have been rising since 2000. The reason for the rise is unclear and no single cause of the death appears to be responsible for the increase. Between 2002 and 2003, the rate rose from 2.1 to 2.3, a 9.1% increase. The White postneonatal death rate rose from 1.5 to 1.6, an 11.3% increase, while the Black rate increased from 3.7 to 4.2, an 11.7% increase.

African American babies are approximately twice as likely as White babies to die within the postneonatal period. By jurisdiction, Baltimore City had the state's highest postneonatal mortality rate in 2003. SIDS, congenital malformations and accidents were the leading causes of death in the postneonatal period in 2003.

Fetal Mortality

A fetal death is a death of a fetus at 20 or more weeks gestation. The fetal death rate is the number of reportable fetal deaths (total births plus twenty or more weeks gestation) per 1,000 live births. There were 637 fetal deaths in Maryland according to the Maryland Vital Statistics Administration in 2003. Maryland's fetal mortality rate stood at 8.4 deaths per 1,000 total deliveries (live births plus fetal deaths) in 2003. The African American fetal death rate of 14.0 was more than twice the White rate of 6.1 during this time period. Fetal death rates were highest in Baltimore City and Prince George's County.

Ratio of African American Infant Deaths to White Infant Deaths

Throughout the past several decades, Black babies have died at two to three times the rate of White babies in Maryland. The finding continued in 2003, when the gap widened to an infant death rate that was 2.7 times higher for African American babies as compared to White babies. The magnitude of the disparity varied by region and was highest in the Western Maryland (3.3) and Baltimore Metropolitan area (3.2). The magnitude of the disparity was lowest in Montgomery and Prince George's County, the two jurisdictions that surround the Washington, D.C. area.

Leading Causes of Infant Death

Between 1999 and 2003, there were 2,902 infant deaths. The five leading causes of death were prematurity/low birth weight, congenital malformations, SIDS, maternal complications of pregnancy, and newborn complications. Accidents were the 9th leading cause of death.

Sudden Infant Death Syndrome (SIDS)

SIDS is one of the leading causes of infant deaths in Maryland, ranking third for all infant deaths for the years 1999-2003 and fourth in 2003. In the five year period between 1999 and 2003, SIDS claimed the lives of 273 infants. SIDS is the leading cause of postneonatal deaths. The Maryland Vital Statistics Administration reports that deaths from SIDS declined significantly in Maryland over the past decade. African American babies are three times as likely as White babies to die from SIDS.

Sleep position is a risk factor for SIDS. Infants who are not placed on their backs to sleep are at increased risk for a SIDS death. Maryland PRAMS reports for 2001-2003 indicate that 61 to 63% of infants were most often placed on their backs to sleep. Sixteen percentage were most often placed on their stomachs. African American babies (27%) were twice as likely as Caucasian babies (11%) to be placed on their stomachs to sleep. The Healthy People 2010 goal is for 70% of infants to be placed on their back to sleep.

Postpartum Depression

The mental wellness of pregnant women and mothers are increasingly being recognized as important precursors of healthy child development and well-being. Infants of depressed mothers are more likely than other children to have delays in cognitive and motor development and may develop learning and behavior problems. Depressed mothers are also more likely than other mothers to have poorer parenting skills and may not bond with their babies as well as they should. Women of childbearing age are often at risk for major depression according to the Agency for Health Care Research and Quality's recent report on perinatal depression. Depression is the most common psychiatric diagnosis for which women are hospitalized in Maryland (Health of Maryland Women, 2002).

Maryland is one of several states that collects information on postpartum depression. Postpartum depression is defined a major depression lasting two or more weeks following delivery. Most mothers first notice their symptoms by six weeks after the baby is born. However, postpartum depression may develop from four weeks to 12 months after delivery. It is to be distinguished from the “baby blues” which many women experience after delivery. The 2001 – 2003 PRAMS reports indicate that between 18-22% of Maryland women report being at least moderately depressed in the postpartum period. Approximately 2% report being depressed to the point of needing help. Rates of reported moderate depression were highest for adolescents and lowest for older women in 2003. CMCH is undertaking further studies regarding depression across the life span beginning of maternal depression.

Infant Health

Trends, Progress, Strengths

- More Maryland women are initiating breastfeeding.

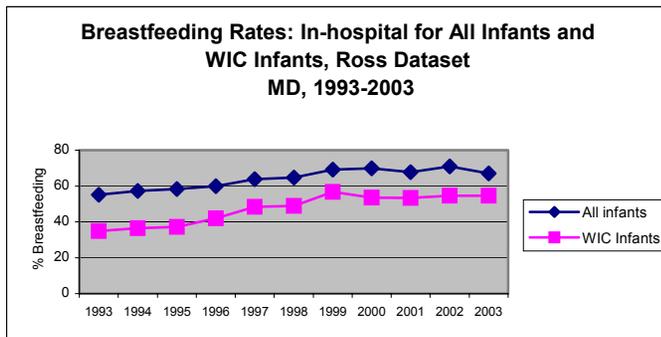
Gaps, Unmet Needs and Challenges

- Only 35-39% of Maryland have continued to breastfeed at six months and only 17% breastfeed exclusively at six months. The Healthy People 2010 goal is for 50% of women to continue breastfeeding for at least six months.
- As many as 600 babies may be born each year with fetal alcohol spectrum disorder (FASD), a condition that is often under-diagnosed, but has severe, life long effects.

Breastfeeding

Breastfeeding is widely recognized as the most optimal and complete form of nutrition for infants. Nutrients in breast milk include protein, fat, minerals, vitamins and digestive enzymes. The American Academy of Pediatrics recommends exclusive breastfeeding as the ideal for the first six months after birth with continued breastfeeding through the first year. Most health

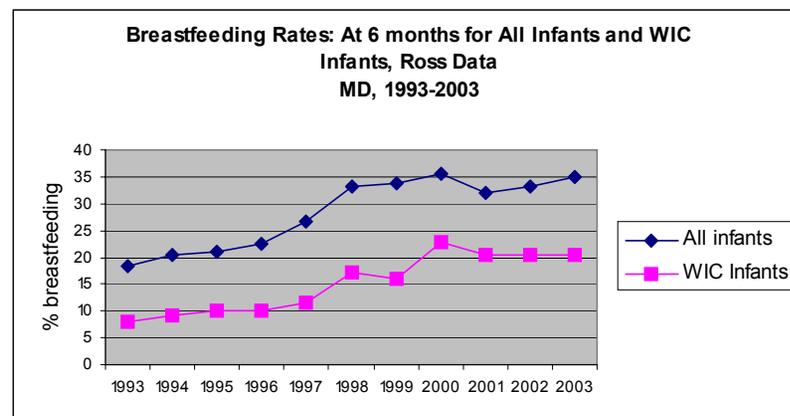
professionals concur that breastfeeding an infant for any length of time is a benefit for the baby. The benefits of breastfeeding are numerous. According to the HHS Blueprint for Action on Breastfeeding released by the Department of Health and Human Services in 2000, breastfeeding not only improves resistance to infectious and chronic diseases among infants, it promotes infants' physical and cognitive development, maternal health, and offers socioeconomic benefits to families and communities.



There are several sources of data for estimating breastfeeding rates among Maryland moms: the National Immunization Survey, the Maryland Newborn Screening Database, the Ross Dataset and the WIC Program. These various databases indicate that increasing percentages of Maryland mothers are initiating breastfeeding, between 61 to 72% in 2003. According to the 2003 National Immunization Survey, 72% of Maryland moms reported ever breastfeeding, 40% reported breastfeeding at six months and 19% reported continuing breastfeed at 12 months.

Breastfeeding rates among new mothers in Maryland have increased steadily over the past decade, rising from 48% in 1991 to 61% in 2003 according Maryland's Newborn Screening Program. Breastfeeding among women enrolled in the Maryland Women, Infants and Children (WIC) Program have improved even more dramatically, increasing from 13.0% in 1991 to 52% in 2004.

Maryland PRAMS and National Immunization Survey data indicate between 72-77% Maryland moms breastfeeding their babies at some point during infancy. In the PRAMS Survey, rates varied from a low of 67% for African American moms to a high of 90% for Hispanic moms. Breastfeeding rates also increased with years of education and age. According to PRAMS, slightly more than half (55%) of moms reported breastfeeding for two or more months.



Breastfeeding rates begin to decline in the months following birth. Factors for this decline include the return to work and school, a lack of environmental, workplace and social supports for lactation, and the belief that exclusive breastfeeding does not provide sufficient nutrition. The Healthy People 2010 goal is for at least 50% of moms to sustain breastfeeding for six months and beyond. An estimated 40% of Maryland moms have reached this goal.

By race/ethnicity, breastfeeding rates in Maryland are lowest for African American women and highest for Asian and Hispanic women. Women living in Baltimore City (49.7%) are less likely to breastfeed as compared to other areas of the State (75.7%). Women over age 20; and those with more than a high school education are more likely than their counterparts to initiate and continue breastfeeding.

Leading Causes of Hospitalizations in Infancy

In 2003, there were 6,500 infant hospital discharges in Maryland, excluding discharges for newborns and neonates. Leading causes of hospitalizations for infants in 2003 included respiratory conditions (e.g., bronchitis, pneumonia and asthma), certain conditions originating in the perinatal period, congenital anomalies, and fluid and electrolyte disorders (e.g., dehydration).

Newborn Metabolic Screening and Disorders

In 2003, the proportion of newborns with at least one screening (PKU, hypothyroidism, galactosemia, hemoglobinopathies) in Maryland met the year 2000 Objective of 100%. Newborn metabolic screening and disorders are discussed in greater detail in the CSCHCN section of the needs assessment report.

Newborn Hearing Screenings

Maryland implemented a universal newborn hearing screening program in 2001. The proportion of newborns with a hearing screen before hospital discharged was 91.2% in 2004 for Maryland. Historically, between 180 to 210 infants are diagnosed with hearing loss each year in Maryland. Appendix B, the Needs Assessment Report for Children with Special Health Needs provides additional data for this area.

Access to Care for Pregnant Women, Mothers and Infants

Trends, Progress, Strengths

- Medicaid provides health insurance coverage for women in families with incomes at up to 250% of the federal poverty level.

Gaps, Unmet Needs, Challenges

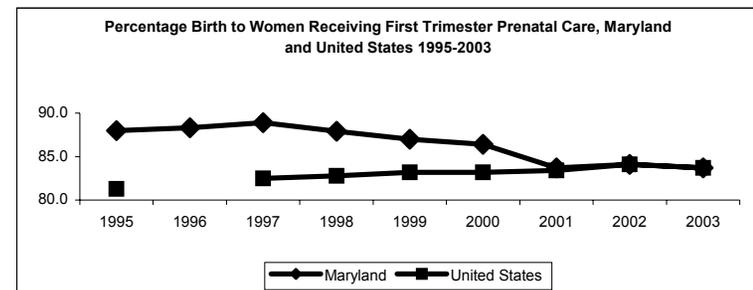
- Up to as many as one in four women of childbearing age in Maryland may be uninsured.
- Fewer Maryland women are receiving early prenatal care services.
- A decline in the number of obstetrical care providers, partially as a result of the state's "malpractice crisis" is perceived as a potential "crisis" by some local health departments, particularly those in rural areas of the state.
- Access to comprehensive health care, including preventive and primary care services, and subsequent referrals for specialty services continues to be a concern of consumers, private providers and public health officials.
- Oral health services are inaccessible for many women before, during and following pregnancy. The problem is particularly acute for uninsured women, women enrolled in Medicaid and women in rural areas.
- Increasing numbers of undocumented uninsured women are seeking health care in Maryland. This is placing a tremendous burden on several local health departments in the state.

Health Insurance Coverage

Lack of health insurance coverage remains a major problem for many Maryland women. Over one in four (27.3%) of women reported being uninsured just prior to their pregnancy (PRAMS 2003). Medicaid covers the cost of approximately one third of Maryland births. Maryland's MCHP Program provides coverage to pregnant women with incomes between 185% to 250% of the poverty level. In FY 2003, this Medicaid expansion Program provided insurance coverage for 533 Maryland women. During FY 2005, any woman receiving MCHP could continue to receive MCHP benefits even if her income status improved, so that continuity of care could be maintained..

Access to Prenatal Care

Women who receive early and adequate prenatal care services are more likely than their counterparts to give birth to healthy, normal weight babies. Since the 1970's, the U. S. prenatal care rates have increased substantially due to such factors as advances in medical knowledge and

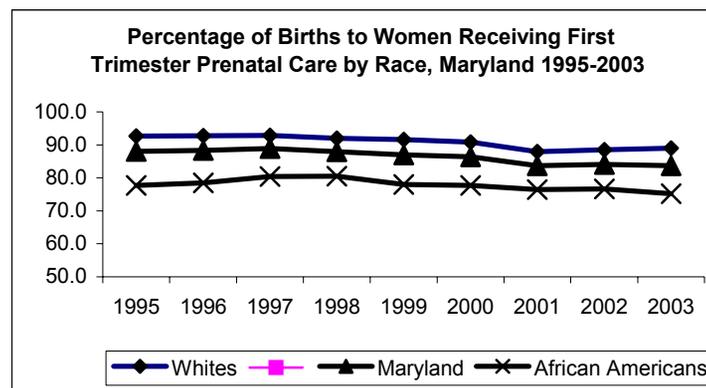


technology, and the expansion of Medicaid coverage for prenatal care. The U.S. Healthy People 2010 Objective is for 90% of women to initiate prenatal care within the first trimester. Barriers to early prenatal care include lack of health insurance coverage, pregnancy unintendedness, long appointment waiting times, and negative attitudes toward the health care system.

Overall, fewer Maryland women are receiving early prenatal care. Maryland’s early prenatal care percentage peaked at 88% and was significantly higher than the national average in 1997. By 2003, the early prenatal care rate had declined to 83.7% and was similar to the national average of 83.7 in 2002. The national trend continues toward rising early use rates.

The reasons for the decline in Maryland remain unclear and are continuing to be investigated. Maryland PRAMS survey respondents indicate the following reasons for not receiving early prenatal care: couldn’t get an earlier appointment or doctor wouldn’t start care earlier (40%); not aware of pregnancy (34.2%), and didn’t have insurance, Medicaid or enough money (34%). In 2003, the overwhelming majority (91.5%) of PRAMS respondents reported confirming their pregnancy within the first trimester even if prenatal care was received later. Hispanic women, adolescents and women with less than a high school education were more likely to report receiving care later than the first trimester.

In 2003, early prenatal care usage rates continued to vary by race/ethnicity and were lowest for Hispanic women (70.1%) followed by African American women (75.2%) and American Indian women (78.9%). The rate for White non-Hispanic women surpassed the Healthy People 2010 goal and stood at 90.9%. Early prenatal care rates improved for Caucasian women and declined for African American women between 1995 and 2003. Hispanic women on the Eastern Shore and in Montgomery and Prince George’s counties as well as African American women in Baltimore City had usage rates at or below 70%. By jurisdiction, early prenatal care rates varied from a low of 73.8% in Baltimore City to a high of 95.9% in Carroll County. Six counties (Anne Arundel, Carroll, Howard, Harford, Cecil, Queen Anne’s) met or surpassed the 2010 goal of 90% in 2003.



Early prenatal care rates in Maryland also vary by type of health insurance coverage. In 2002, an estimated 69.7% of Medicaid women as compared to 90.0% of non-Medicaid women received early prenatal care. Rates of early usage have declined for both these groups since 1998. In the 2003 PRAMS Survey, 68% of women responding indicated that health insurance or an HMO paid for their

prenatal care; while 26% reported that Medicaid or HealthChoice paid for their care. (Approximately one third of the state's 75,000 births were to women enrolled in the Medicaid Program in 2004).

In 2003, over 2,800 women--3.8% of live births--received late or no prenatal care (third trimester or later). The current state trend is toward increasing percentages of women receiving late or no care. African American and Hispanic women were more than twice as likely as Caucasian and Asian women to receive late or no prenatal care. The percentages varied by county and ranged from a low of 0.7% in Carroll County to a high of 7.5% in Prince George's County.

Local health department MCH directors, particularly in rural areas, expected the "state's malpractice crisis" to cause further erosion in access to early prenatal care services. In some areas where obstetrical services were already limited, many of the few available obstetricians are opting to give up their obstetrical practices while maintaining their gynecological practices reportedly because of the high costs of malpractice insurance.

Access to Prenatal Care for Undocumented Women

Several jurisdictions also expressed concerns about the increasing numbers of undocumented women requiring prenatal care services. Most of these women are uninsured, have limited English proficiency and therefore, lack access to care for financial as well as cultural reasons. A July 2005 report issued by the Center for Immigration Studies documents that in 2002, almost one in four births in the US. were to an immigrant mother, the highest level in U.S. history. In 1970, 6 percent of American births were to immigrant mothers (legal or illegal) compared to 23% in 2002. An estimated 42% of births were to illegal alien mothers with births to illegals now accounting for an estimated one of every 10 U.S. births. Nationally, Hispanics represent 44% of immigrant births.

Maryland was identified as one of the 12 states with the most dramatic increase in births to immigrants. Births to immigrant women were estimated to represent 22% of births in the state in 2002. State Medicaid data indicate that the paid deliveries under the eligibility category of X02, emergency coverage for illegal and ineligible aliens, tripled between FY 1999 and FY 2004, rising from 1,120 to 3,479.

Oral Health Care and Pregnancy

There is limited Maryland data on oral health needs and access to oral health care during pregnancy. PRAMS data for 2003 show that less than half (48%) of mothers had a routine dental visit during pregnancy, and 26% reported needing to be seen for a dental problem. Older women, women with a high school education or higher and White women were more likely to report visiting a dentist during their pregnancy.

Several local health departments provide oral health services for pregnant women, however, the majority of the clientele are immigrants. The decision to see pregnant immigrant women is based on the premise that women with Medicaid can access oral health services in the private sector. However, because of the low Medicaid reimbursement rates, these women are often unable to find dentists willing to accept Medicaid or to provide certain types of services.

Cross-Cutting Child and Adolescent Health Indicators and Needs

Maryland's children and adolescents are its most important resource. The Title V needs assessment collected a wealth of available data on the health of children and adolescents in Maryland. This section presents of the health of children adolescents as a population group in Maryland. Later sections review health data for children and adolescents.

Data Sources

Since the last needs assessment, improvements have been in the availability of data for monitoring the health of children and adolescents in Maryland. Surveillance systems for asthma, immunizations have been developed or are well on the way to full implementation. Hospital inpatient and emergency department utilization data is also now available. The 2003 National Children's Health Survey provides statewide estimates for a number of MCH indicators for children, ages 0-17, in Maryland. (During the interim needs assessment years, more detailed analyses of the SLAITS databases will be undertaken for Maryland children).

Focus groups and surveys were also a source of data. Approximately 35 focus groups and meetings were held with parents, services providers and adolescents, health providers, and state and local MCH serving agency staff. In addition, local health departments completed surveys identifying state and local MCH needs. Qualitative findings are integrated here as well.

Socio-Demographic Characteristics

In 2003, there were 1,530,261 million children in Maryland, approximately 38,000 more than counted in the 2000 Census. The Maryland Department of Planning projects that this population group will increase to 1,628,490 by 2030. Children and adolescents, ages 0-19, represented 28% of Maryland's total population of 5.5 million in 2003. By age group, adolescents, ages 12-19, represented a plurality (41.5%) of the state's child and adolescent population. Several recent reports have documented improvements in the health of Maryland's children such as declining teen pregnancy rates and increasing immunization rates. According to the 2004 Kids Count Data Book published by the Annie E. Casey Foundation, Maryland, one of the nation's wealthiest states, ranked 27th on 10 indicators of child well being.

Race/Ethnicity

In 2003, Caucasians represented 60.6% of the state's child and adolescent population, ages 0-19. The state's 40.4% racial minority children included African Americans at 32.1%, Asians at 4.1%, American Indians at < 1%, and Two or More Races at 2.6%. Hispanic children who can be a member of any racial group represented 5.7% of the population. There are approximately 33,400 – 41,750 undocumented children living in Maryland. (Pew Hispanic Center, Estimates of the Size and Characteristics of the Undocumented Population).

In 2003, there were an estimated 677,000 racial and ethnic minority children living in Maryland. The majority of Maryland's racial and ethnic minority children were African American (71.4%), followed by Hispanic (13.2%), Asian (9.2%) and other racial groups (6.1%). Hispanics are the fastest growing ethnic group in the U.S. and in Maryland. Hispanic children represented 13.2% of the minority child and adolescent population and 5.8% of the state's total child and adolescent population in 2003. The majority of the state's Hispanic population is concentrated in the Washington-Baltimore corridor and on the Eastern Shore. Maryland's Hispanic child population as a percentage of the state's child population at 5.8% is one-third the national percentage of 18%. Conversely, Maryland's percentage of African American children as a percentage of the state's total at 31% is twice the national percentage of 15.5%.

Maryland's Racial and Ethnic Minority Children, ages 0-19 2003

Race/Ethnicity	Number	% of Total
Total	677,108	100.0%
African American, Non-Hispanic	483,756	71.4%
American Indian, Non-Hispanic	3,698	0.5%
Asian, Non-Hispanic	62,048	9.2%
Hawaiian, Non-Hispanic	267	0.0%
Hispanic	89,502	13.2%
Two or More Races	37,837	5.6%

Geographic Distribution

The majority (74%) of Maryland's 1.5 million children and adolescents lived in the eight suburban metropolitan area jurisdictions surrounding Baltimore City and Washington, D.C. Children in Baltimore City defined here as the state's urban area represented 11%

of the total child and adolescent health population. The remaining (15%) children lived in the 14 rural jurisdictions defined as Southern Maryland, Western Maryland (excluding Frederick) and the Eastern Shore.

	Total (0-19)	% of Total	0-4	5-9	10-14	15-19
MD	1,530,261	100.0%	364,507	369,378	409,468	386,908
Rural	231,185	15.0%	55,860	59,901	68,350	6,733
Suburban	1,094,456	74.0%	262,955	267,661	292,197	271,643
Urban						
Balto. City	175,955	11.0%	44,009	39,808	46,394	45,744

Family Structure and Living Arrangements

In 2000, 72.3% of children under age 18 lived with two married parents, while 27.7% lived in families headed by a single parent. Living arrangements varied by race with African American children (52.4%) almost three times as likely as White children (17.3%) to live in single parent families. By age group, adolescents were slightly more likely than young children to live in single parent families.

Poverty and Income

Maryland is a wealthy state – the child (0-17) poverty rate – 10.7% in 2000 - was one of the lowest in the nation. Median income household income - \$53,866 was one of the highest in the nation. In 2002, there were an estimated 141,877 children between the ages of 0-17 living in households with incomes below poverty. By jurisdiction, poverty rates in 2000 ranged from a low of 4.1% in Howard County to a high of 24.9% in Baltimore City. While about 11% of all children lived in the City, approximately 28% of poor children lived in Baltimore City in 2000. Sections of the Eastern Shore and Western Maryland also had high rates of poverty. African American and American Indian children were more than three times as likely as Caucasian children to be poor according to the 2000 Census.

Mortality, Morbidity and Health Conditions (All Children and Adolescents)

Trends, Progress, Strengths

- Child and adolescent death rates are declining.
- Fewer Maryland children are reportedly being affected by HIV/AIDS.

Gaps, Unmet Needs, Challenges

Asthma

- Asthma is a leading cause of childhood morbidity in Maryland. Among Maryland children under age 18 years of age, an estimated 153,172 have been diagnosed with asthma at some point during their lifetime, representing 11.1% of children. An estimated 118,673 children (8.6%) currently have asthma. Asthma disproportionately affects African-American children.

Obesity and Overweight

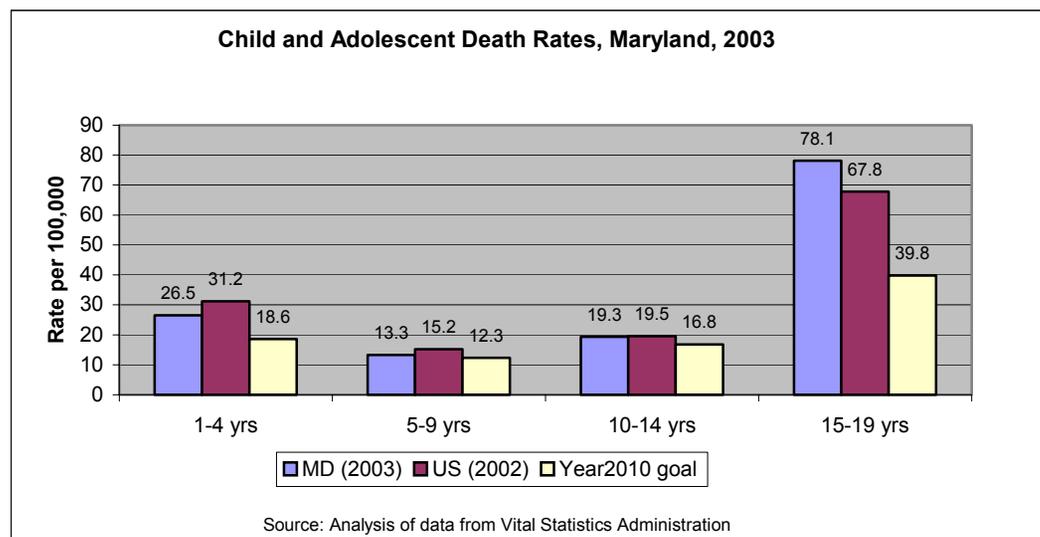
- Obesity and overweight were recognized as an increasing problem for Maryland children and adolescents. National Children's Health Survey data for Maryland estimate that 13.3% of Maryland children and adolescents were overweight in 2003 and another 16.6% were classified as at risk.
- Parents, schools, health professionals and service providers need to be educated on how to promote healthy nutrition and physical activity among children.
- There is a need to address school policies that contribute to the problem of obesity and overweight among children – elimination of physical education classes, curtailment of recess periods, and promotion of unhealthy food choices in vending machines and school cafeterias.

Oral Health

- Inadequate access to oral health services was frequently mentioned as an unmet need in surveys and interviews with local MCH staff. Oral health needs and challenges identified in the state's current five year plan include a lack of dental providers in rural areas, a lack of publicly subsidized dental health programs to serve the uninsured and underinsured and a lack of dental providers accepting Medicaid.

Mortality

Maryland issues an annual Child Death Report to support the work of the state's mandated Child Fatality Review Team. The 2004 Report reviews child deaths between the ages of 0-17. In 2003, there 944 deaths of infants and children under the age of 18 in Maryland. The majority (64.6%) of these deaths occurred in infancy. Injuries were the leading cause of death in children aged 1-17 years in 2003. Unintentional injuries comprised 33 percent of the 334 deaths, followed by homicides, cancer, cardiovascular diseases, congenital malformations and suicides. Overall, childhood deaths have declined during the past decade in Maryland. However, the report notes that considerable progress is required for the state to reach Healthy People 2010 objectives for infants, children and adolescents. For example the 2003 death rate for adolescents ages 15-19 is twice the HP objective at 78.1 and 39.8 deaths per 100,000 population, respectively.



Child death rates for children, ages 1-14, were examined by race and region for 2003. There were a total of 206 deaths. Overall, there were 19.3 deaths per 100,000 population. The Black rate at 28.2 was 46% higher than the White rate of 15.0. for children between the ages of one to four, the Black rate of 39.7 was twice the White rate of 20.2 in 2004. By region, Baltimore City had the highest death rate at 39.7, more than twice the statewide average. The lowest death rates for this age group were in Montgomery County (11.1), and the suburban Baltimore counties (13.4).

Hospitalizations

In 2003, there were 42,137 hospital discharges involving children and adolescent aged 0-19. (Because Maryland's hospital discharge database does not contain unique identifier, the number of discharges is not an unduplicated count). The overall hospital discharge rate per 100,000 was 2,753.6 in 2003. African American children had the highest estimated hospitalization rate at 3,278.4

discharges per 100,000 population, followed by White (2,408.0) and American Indian (2,375.9) children. Asian children had the lowest discharge rate at 1,082.0, about a third of the Black rate. By age group, infants had the highest discharge rate, followed by adolescents and young children ages 1-5. Children in the middle years had the lowest hospitalization rate.

Baltimore City's discharge rate of 5,657.7 was twice the statewide average and the highest of any jurisdiction or region. Higher than statewide average rates were also seen in several rural counties in Western Maryland and on the Eastern Shore. Montgomery and Prince George's County along with the Southern Maryland region had the lowest discharge rates. Lower rates in the D.C. area suburbs of Montgomery and Prince George's County may be reflective of use of hospitals in the neighboring District of Columbia.

Injuries

The Maryland Center for Preventive Health Services publishes an annual report on injuries in Maryland. The report, *Injuries in Maryland*, presents mortality and morbidity data as measured injury related hospitalizations and emergency department visits. In 2003, there were 46 injury related deaths to children under the age of five, 64 deaths to those between the ages of five to 14, and 594 deaths to those between the ages of 15-24. Leading causes of injury related deaths for children under age 15 in 2003 included motor vehicle accidents, suffocations and drownings. Leading causes of injury related deaths for older adolescents included (1) firearms, (2) motor vehicle accidents, and poisonings.

In addition, there were 1,410 injury related hospitalizations to children ages 0-14 and 5,357 to adolescents and young adults ages 15-24. In 2003, emergency department visits totaled 100,295 to children under the age of 15 and 96,778 to adolescents and young adults ages 15-24. The leading causes of injury for children 0-14 as measured by emergency department visits in 2003 were (1) falls, (2) being struck by or against something and (3) motor vehicle accidents. Leading causes of injury related hospitalizations included for this age group included (1) falls, (2) motor vehicle accidents, and (3) poisonings.

The leading causes of injury related emergency department visits in for adolescents/young adults, ages 15-14, in 2003 were (1) motor vehicle accidents, (2) being struck by or against something and (3) cuts or piercings. Leading causes of injury related hospitalizations for this age group included motor vehicle accidents, poisonings and cuts and piercings.

Overall, rates of injury related mortality and morbidity are highest in Baltimore City and in outlying rural areas in Western Maryland and on the Eastern Shore.

Obesity and Physical Activity

There are concerns about growing obesity and overweight because even though obesity is not a chronic health condition, it is a risk factor for four of the ten leading causes of death – heart disease, Type II diabetes, stroke and cancer. Nationally, an estimated 65% of American adults are overweight or obese. The most recent Maryland BRFSS data for the years 2002-2003 indicate that 20.6% of adults were overweight. Nationally, over the past 20 years, the numbers of overweight children and teens, ages 6-19, more than doubled from 5-7% to 16%. National data indicate that prevalence is twice as high for African and American and Hispanic children as it is for Caucasian children.

Data on obesity prevalence as well as the nutrition habits and physical activity among Maryland children is limited, but improving. Several activities are currently underway to improve the availability of data on height/weight, nutrition and physical activity patterns of Maryland children. These include the newly implemented YRBS survey which provide nutrition and physical activity data on teens in grades 9 to 12; parental reports of child height and weight to be obtained through the 2004 BRFSS survey; BMI data collected through a sample of office-based physician offices; and Medicaid EPSDT chart review data.

The 2003 National Children’s Health Survey is the first data source to provide statewide estimates of the percentage of children, ages 10-17, at risk for and currently overweight. This survey estimates that 13.3% of children were overweight and another 16.6% were at risk for being overweight. Maryland’s percentages were slightly lower than the U.S. average of 15% overweight. Black (42%) and Hispanic (32%) children were more likely than White (24%) children to be either overweight or at risk for being overweight. Slightly more than one half of children aged 6-17, reportedly engaged in physical activity for 20 minutes for at least four of the seven days in the prior week according to the survey. Fifteen percent did not engage in physical activity at all in the prior week while one third participated between one to three days.

“Children are not receiving vigorous exercise on a daily basis.”
“Children no longer go outside and play as I did when I was young.”
“I am reluctant to let my children play outside unsupervised”
due to fear of violence, sexual predators, drugs, etc.
Focus group participant comments

BMI data for 2004 from the Maryland WIC Program indicate that 16% of 2 to 5 year old WIC enrollees were overweight. Another 16% were identified as at risk for obesity and 4% were determined to be underweight.

A major theme heard in focus groups with parents of elementary, middle school and high school students was concern about their own overweight children and/or the number of overweight children seen in their communities. Parents expressed concerns about the poor unhealthy, quality food provided to students at school; vending machines in schools that encourage poor nutritional choices;

the reduction in physical education classes; and large portion sizes in restaurants. Several parents stated that they were taking actions to ensure healthier eating habits for their children – cooking more vegetables, only offering desserts on weekends, eating out less, and packing healthy lunches.

Asthma

Asthma is a chronic disease of the airway that affects an individual's ability to breathe, which can cause serious illness and death. However, asthma morbidity and mortality can be prevented. Proper asthma management includes avoiding environmental triggers and taking appropriate medications. Despite known asthma management practices, participants at 2002 Maryland Statewide Asthma Focus Groups told a story of substantial negative life experiences because of asthma:

- “We had to hold our son back in kindergarten because he missed so much school.”
- “I find a problem adhering to the (management) plan because of the time involved in following it. The doctor will tell you to do something 3 times a day or six times a day and it is impossible...”
- “My son gradually gave up soccer and different things (because of his asthma)...”

Asthma is a leading cause of childhood morbidity in Maryland. The Asthma Surveillance System reports that among Maryland children <18 years of age, an estimated 11.1%, or 153,172, have been diagnosed with asthma during their lifetime. Children miss school and parents miss work because of asthma. The direct cost in Maryland is approximately \$69 million annually. Emergency department visits and hospitalizations demonstrate missed opportunities to control asthma properly. In 2003, asthma was a leading cause of hospitalizations for children between 6 and 11 years of age and a leading cause of hospitalizations for younger children and adolescents.

Asthma disproportionately affects African Americans, low-income individuals, and individuals in certain jurisdictions, such as Baltimore City. In 2003, African-Americans Marylanders had nearly three times the mortality and hospitalization rate and four times the emergency department visit rate than Whites.

Oral Health

Oral health is a critical component of the overall health of children and adolescents. Poor oral health is increasingly being recognized as a risk factor for several poor health outcomes including prematurity, low birth weight and heart disease. Former Surgeon David Satcher issued the first Surgeon General's Report on Oral Health in 2000, calling oral disease a silent epidemic. The

report cited significant disparities in oral health status by race/ethnicity, income and insurance status. Inadequate access to oral health services, particularly for uninsured and Medicaid enrolled women and children, was frequently mentioned as an unmet need in surveys and interviews with local MCH staff. The state's most recent five year Oral Health Plan identified the following as oral health access problems: (1) a lack of dental providers in rural areas, (2) a lack of publicly subsidized health programs to serve the uninsured and underinsured, and (3) a lack of dental providers accepting Medical Assistance.

The most recent state surveys of the oral health status and needs of Maryland preschool and school aged children found:

- 42% of school aged children surveyed had untreated decay.
- 53% of children in kindergarten and 3rd grade had untreated decay in their primary teeth.
- The Eastern Shore had the highest percentage of untreated dental decay (54%) followed by the Central Baltimore region (48%). The Southern region had the lowest percentage of untreated dental decay (14%).
- Approximately 55% of Head Start children surveyed had decayed or filled tooth surfaces.
- Hispanic children had significantly more untreated decay than Caucasian children (64% vs. 44%).
- Caucasian children were twice as likely as African American children to have dental sealants (31% vs. 16%).

Limited data is available on the use of dental health services by children and adolescents in Maryland. The 2003 National Survey of Children's Health found that 2/3 of children had received both a preventive medical and preventive dental care visit in the past year. The majority of parents also indicated that their children had received all the dental care was needed in the past year. Hispanic (89.7%) and Black (91.6%) children were less likely than White (97.1%) children to have received all needed dental care.

Medicaid extends coverage of oral health services to eligible children and women enrolled in its managed care program, HealthChoice. Medicaid data files for 2003 indicate that less than one in five pregnant women received dental services. Increasing percentages of Medicaid enrolled children aged 4 through 21, have been receiving dental services, a total of 43.2%. This was more than double the percentage receiving services in 1997. However, only 13.65 of children received restorative services in 2003. The Office of Oral Health and the Medicaid have worked to increase the number of dentists participating in the Program, a total of 330 in 2003. However, it is still recognized that dental provider shortages continues to exist in certain areas and some dentist provide limited services.

Mental Health including Access to Care Mental Health Services

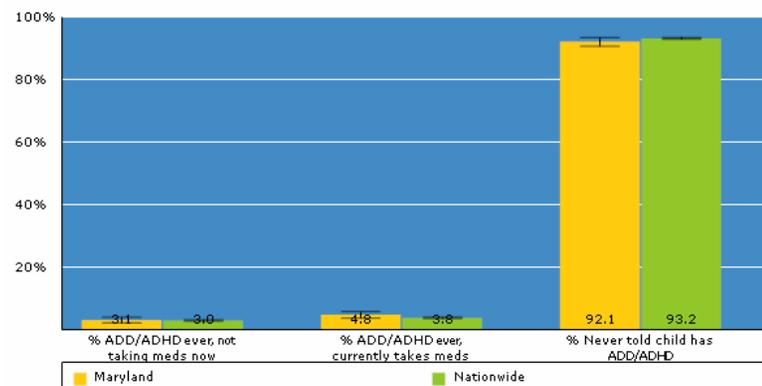
The Surgeon General's Report on Mental Health defined mental health as “the successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and cope with adversity.” Nationally, it is estimated that one in ten children suffer from a mental disorder severe enough to cause some level of impairment.

However, fewer than one in five of these ill children receives treatment. The mental disorders affecting children and adolescents include the following: ADHD, ADD, Autism Spectrum Disorders, bipolar disorder, borderline personality disorder, depression, post-traumatic stress disorder, eating disorders and childhood onset schizophrenia. (Surgeon General’s Report and NIMH Web site). As many as 70 percent of children with diagnosable mental, emotional, or behavioral disorders are not receiving the mental health services they need. (Surgeon General’s Report on Mental Health).

The Maryland Mental Hygiene Administration estimates that between 5-11% of Maryland children and adolescents, ages 0-17, are affected by a serious emotional disturbance. This represents between 69,000 to 151,792 children and adolescents. In 2003, 40,400 children and adolescents received services provided by the Mental Hygiene Administration. The 2003 NSCH found that roughly 10% of children ages 3-17 reportedly had some type of moderate or severe socio-emotional difficulties.

Local health department staff, child health providers and adolescent service providers indicate that increasing numbers of children and adolescents are in need of mental health services and/or are using psychotropic medications. Some evidence of increasing mental health needs of children and adolescents is provided by Maryland Department of Education. Emotional impairment has been identified as a “High Growth Disability” by the Maryland Department of Education. Between 1994 and 2004, the enrollment of students with emotional impairment in Maryland schools increased from 5,638 to 9,776. Increasing numbers of Maryland children are being diagnosed with Autism and related disorders. Autism was also identified as a “High Growth Disability” by the Maryland Department of Education. Between 1994 and 2004, the enrollment of students with autism in Maryland schools increased from 422 to 4,660.

ADHD/ADD is one of the most commonly diagnosed behavior disorders in children. Parents in the focus groups also expressed concerns about what appears to be increasing diagnosis of children with ADD/ADHD. There is fear that many children are being misdiagnosed and inappropriately medicated. A 1998 school survey completed for the Maryland’s Task Force to Study the Use of Ritalin found that approximately 3% of school children received medication for ADHD during the school day. More recent data from the 2003 National Children’s Health Survey for Maryland indicate 4.8% of children ages 2-17 were told that they had ADD/ADHD and were currently using medication, while another 31.% were told that they had ADD/ADHD but were currently not taking medication. There appears to be increased pressure placed on parents to place their children on medications to address behavior disorders such as ADD/ADHD. Teachers and



school administrators sometimes “demand or require” that parents medicate their children so that the child’s behavior is better managed while in school.

Special Populations (All Children and Adolescents)

Children in Foster Care

For the 2005 needs assessment, the Title V Program reviewed reports issued by the Maryland Department of Human Resources on the status of children in Maryland's foster care system as well as the incidence and prevalence of child abuse and neglect cases. In FY 2004, 73% of the 10,738 Maryland children in foster care (out of home placement) entered because of child abuse and neglect (Citizen Review Board Annual Report 2004). The state's Citizen Review Board reports that fewer children are entering care, a smaller proportion of cases are associated with parental substance abuse (63% in FY 2004), the average length of stay is moderating (29 months in FY 2004). The 2004 Report also noted that the state continued to struggle with a child welfare workforce that was substantially below the number needed to protect children in Maryland. In 2005, Governor Ehrlich and the Maryland General Assembly increased funding to the Department of Human Resources to substantially increase the numbers of child welfare workers.

In FY 2004, 3838 children entered Maryland's foster care system. Almost a quarter of children stayed in the system for more than three years. The total number of children in foster care declined from 12,587 in FY 1998 to 10,738 in FY 2004. Factors such as substance abuse epidemics (e.g., crack), rates of homelessness, parental HIV/AIDS cases and parental incarceration rates impact the numbers of admissions to foster care.

African American children are disproportionately represented in Maryland's foster care system. African American children represented 76% of children in out of home placements in FY 2004 while 20% were White and 1% were Hispanic. Geographically, the majority (64 %) lived in Baltimore City. By age group at placement, 37% were under the age of five; 39% were between the ages of five and 11, 24% were between 12 to 18 years old, and 12% were over the age of 18.

Children in foster care are at risk for behavioral and emotional problems and poor educational outcomes. A GAO study found that 12% hadn't received routine care, 34% hadn't received immunizations, and only 10% received services to address developmental delays. Studies indicate that youth who transition are more likely to become teen parents, engage in substance abuse, have lower levels of educational attainment, become homeless and become involved with the criminal justice system.

Child Abuse and Neglect. In FY 2004, there were 6,342 child abuse and neglect investigations with indicated findings. The numbers of indicated cases of child abuse and neglect have been declining since FY 1993 when there were 11,159 cases. The majority of the cases involved neglect (54%), followed by physical abuse (28%), sexual abuse (18%) and mental injury (< 1%). One quarter of the indicated cases occurred in Baltimore City in FY 2004.

Homeless Children and Youth

Poverty, a lack of affordable housing and parental substance abuse are major risk factors for homelessness in Maryland. The Department of Human Resources annually surveys emergency shelters, transitional housing programs and other programs serving homeless persons. The data are published in a legislatively mandated annual report. The FY 2003 Annual Report found that one third of 45,560 persons served lived in families. The 8,713 children ages 0 to 17 counted represented 21% of persons served. Over half lived in Baltimore City, Montgomery or Prince George's counties.

Children of Incarcerated Parents

Children of incarcerated parents are a special population of concern because these children are at risk for mental health, behavioral, psychological, cognitive and educational problems. Data on the health status and needs of children of incarcerated parents in Maryland is limited. National data from the Federal Resource Center of the Child Welfare League of America indicate that there more than 2 million children in American have an incarcerated parent, up from 500,000 in 1991.

A 1998 report on Women in Prison Report commissioned by the Maryland Commission on Women found increasing incarceration rates for Maryland women. In 1998, 868 women were incarcerated in Maryland prison. By 2004, that number had grown to 1,100 women with the primary reason for admission being drug violations. The Commission study found that 20% of the women arrived pregnant and 80% had children, an average of 2.4 children per women. The average age of the women was 29 years, six in ten were African American and most (68%) had lived in Baltimore City prior to incarceration. The Title V Program plans to explore the health needs and issues of children of incarcerated parents during the interim needs assessment years.

Access to Care (All Children and Adolescents)

Trends, Progress, Strengths

- Fewer Maryland children and adolescents were uninsured in 2002-2003 according to the Maryland Health Care Commission. Between 2001-2002 and 2002-2003, the percentage of uninsured Maryland children declined from 10% to 9% and resulted in 10,000 fewer uninsured children. The Maryland Children's Health Program is partially credited with the decline. MCHP provides health insurance coverage to close to 100,000 Maryland children.

Gaps, Unmet Needs and Challenges

- Many Maryland children, adolescents and families, especially those who are uninsured or covered by public insurance programs, lack access to oral health, mental health, substance abuse, and primary health care services. The Title V Program repeatedly heard this from MCH service providers, parents and state and local agency staff.
- Forty-four percent of Maryland children lack access to a medical home as defined by American Academy of Pediatrics.
- Rural areas, in particular, report inadequate access to both general pediatric and pediatric subspecialty care services.
- Lack of transportation, lack of acceptance of public insurance by some providers, and long waiting times for appointment, (particularly in rural areas) remain as barriers to care.

Health Insurance Coverage

Uninsured children are less likely than children with health insurance to have access to preventive and primary care services as well as a medical home or regular source of health care. The lack of access to health care services can adversely affect the health of children if care is not be accessible to address conditions that are amenable to medical intervention such as asthma and middle ear infections.

According to the Maryland Health Care Commission, in 2002-2003, approximately 740,000 Marylanders lacked health insurance coverage. Approximately 140,000 (19%) of the uninsured were children ages 0-18. Employment based coverage is the major source of health insurance in Maryland. Almost three quarters (71%) of Maryland's non-elderly were covered by employer

based insurance as compared to 63% nationwide. Because Maryland is such a wealthy state, relatively speaking, Medicaid covers non-elderly Marylanders (7%) at nearly half the national percentage (12%).

The percentage of uninsured Marylanders increased between 2000-2001 to 2001-2002, and again in 2002-2003, rising from 11.3% to 15%. Maryland's uninsured rate remained below the national average of 17% in 2002-2003. The increase was largely attributed to an increase in the number of uninsured adults due to reductions in employer based coverage. During this time period, the number of uninsured children declined by 10,000 to approximately 140,000.

Approximately 8.5-9.5% of Maryland children were uninsured at some point during 2003. Maryland respondents to the 2003 National Survey of Children's Health for Maryland reported that that 8.5% of children were either currently uninsured or had been uninsured for some period in the past year. The child uninsurance rate for Maryland was substantially lower than the national rate of 14.9%. The Maryland Health Care Commission uses Census Bureau's Current Population Survey Data to estimate uninsurance rates for Maryland.

Health insurance rates varied by race/ethnicity. Hispanic children (24%) had the highest uninsurance rate. Black, non-Hispanic children (13%) and Asian/Other children (11%) were three times as likely as White children (4%) to be uninsured. Hispanic children were disproportionately represented in the uninsured population. Adolescents, ages 13-18, (11%) were more likely than younger children to be uninsured. By income and poverty status, children in the lowest income groups had the highest uninsured rates – (e.g., less than 100% of poverty level: 24% versus 601%+ of poverty: 2%). By family status, uninsured rates were highest for children in families where no parents worked (24%), where adults had less than a high school education (24%), and where the child did not live with either parent (41%).

MCHP, Maryland's State Children's Health Insurance Program, began implementation through the state's Medicaid Program on July 1, 1998. Since its inception, enrollment has increased from 38,000 in FY 1998 to 93,000 in FY 2004. Enrollment reached a peak of 110,000+ in FY 2003, prior to programmatic changes instituted on July 1, 2003. MCHP covers eligible children under the age of 19 in families with incomes up to 300% of the poverty level. Children in families with incomes between 200% and 300% of federal poverty pay a premium to participate. Services are provided through HealthChoice, Medicaid's managed care program.

Children in the Early and Middle Childhood Years

A summary of the major health indicators and needs for children in the early and middle childhood years, ages 1 to 11, with some overlap with infancy and adolescence, is provided below beginning with a look at socio-demographic characteristics. In some instances, the data presented includes an overlap with either infancy or adolescence.

The Early Childhood Years (Young Children)

The early childhood period is a time of tremendous growth and challenges. Age breaks for the early childhood population range from zero to three, to one through five. For the purposes of this needs assessment, Maryland's early childhood population is defined as children between the ages of zero to four. This was done because much of the available data is presented according to this age group. However, there are instances when the data discussed includes five year olds.

Census estimates of the population by age group recently became available for 2004. The Census estimates that 374,578 children were between the ages of zero to four in 2004. This age group represented 24.1% of children and adolescents between the ages of 0 to 19. The majority (72%) of young children live in the suburban, metropolitan areas surrounding Baltimore City and Washington, D.C., while 15% live in the state's 14 counties characterized as rural and the remaining 12% live in Baltimore City. In 2003, four in ten young children were members of a racial minority group: Black, Asian, or American Indian. Seven percent of young children were identified as Hispanic.

The Middle Childhood Years (ages 6-11 or 5-9)

The health literature has traditionally limited its focus on the health of children during the years between early childhood and adolescence – the middle childhood years, ages 6-11. This population group is generally viewed to be healthy and has therefore generally received relatively little attention from researchers and policymakers. The recent publication of the report - The Health Needs of America's Middle Childhood Population – provides a rare look at the health issues affecting this age group. The Report notes the following:

- There are substantial health issues in middle childhood that merit increased commitment.
- The health issues affecting this population group are more likely to be behavioral and social in origin, rather than biomedical.
 - Mental health disorders affect nearly 20%.

- Some unhealthy behaviors of adolescents may have antecedents in middle childhood (e.g., poor nutritional habits, smoking). These behaviors are linked to diseases such as hypertension, diabetes and cancer later in life.
- The middle childhood years provide an opportunity to encourage healthy behaviors to prevent disease later in life.
- Research is sparse for this period of life which is important in and of itself.

For the 2005 Title V Needs Assessment, Maryland attempted to focus attention on the health needs of children during the middle years. There is no consensus on the age definition for middle childhood. Age definitions include five to nine; six to 12 and five to 12. Much of the available data in the literature is reported for the five to nine age group. Where available, data is presented and both six to 11 age group and the five to nine age group.

The Census estimates that Maryland's population included 368,612 children between the ages of five to nine in 2004. Children in this age group represented 23.7% of children and adolescents between ages zero to 19. Sixty percent of this age group was White in 2003 and 40% were a member or one or more racial minority groups. Six percent were Hispanic. Most (72%) lived in the state's suburban-metropolitan areas, while 16% lived in the state's rural areas and 11% resided in Baltimore City.

Mortality, Morbidity, Health Conditions and School Readiness Early and Middle Childhood

Trends, Progress, Strengths

Immunizations

- More Maryland preschoolers are getting fully immunized by age 3. In 2004, an estimated 83.7% of Maryland children, ages 19 to 35 months, were immunized according to the 4:3:1:3:3 series. This represented an increase over the 2000 rate of 75.4%.

Lead

- Fewer Maryland children are being identified with elevated blood levels – 1,719 children in 2002 (2.2% of those screened). The state has a 2010 plan to eliminate childhood lead poisoning.

School Readiness

- More Maryland kindergarteners are entering school ready “fully ready to learn” – 58% in 2004-2005 school year; up from 48% in 2001-02. Maryland has developed a Model for School Readiness that defines early learning standards and indicators. Progress is annually tracked and monitored.
- Head Start and Early Head Start centers serve nearly 12,900 children and 200 pregnant women through 280 sites statewide.

Gaps, Unmet Needs and Challenges

Immunizations

- Work remains to reach the Healthy People 2010 goal of 90% of children ages 19-35 months fully immunized.

Lead

- Lead poisoning continues to disproportionately affect children in several high risk areas –Baltimore City and parts of Western Maryland and the Eastern Shore. Twenty of the state’s 24 jurisdictions have areas of targeted risk. The problem disproportionately affects African American children.

School Readiness and Success

- An estimated 10% of preschoolers have behavior problems that negatively affect their ability to learn.
- Less than 60% of Maryland kindergarteners enter school ready to learn.
- According to the Maryland Department of Education, more Maryland students are being diagnosed with mental health problems (e.g., emotional impairments, autism, ADHD, and depression).

Systems Issues

- There is a need to develop a comprehensive approach to early childhood health that is fully integrated with broader, comprehensive efforts aimed at early childhood development.

Leading Causes of Deaths and Hospitalizations

Injuries are a leading cause of death for this age group. Between 1999 and 2003, there were 485 deaths to children ages 1-5. The leading causes of death were accidents (24%), cancer (9%), homicide (9%), congenital malformations (9%), and cardiovascular diseases (5%). Between 1994 and 2003, the child death rate for this age group declined by 24% from 32.8 deaths per 100,000 persons to 24.8. In 2003, the death rate per 100,000 for Black children between the ages of one to four stood at 39.7 and was twice the rate for White children (20.2).

Asthma and other respiratory related conditions (e.g., pneumonia and bronchitis) were the leading cause of hospitalizations for young children in 2003. Other significant causes of hospitalization included fluid and electrolyte disorders (e.g., dehydration) as well as injuries and poisonings.

Children ages six to 11 have the state's lowest mortality and hospitalization rates when compared with children and adolescents in other age groups. Between 1999 and 2003, 331 deaths occurred to children between the ages of six to 11. The leading causes of death were accidents (31%), cancer (17%), and cardiovascular disease (5%). Between 1994 and 2003, the child death declined by 29% from 18.9 deaths per 100,000 persons to 13.5.

Leading causes of hospitalizations for this age group in 2003 included asthma and other respiratory disorders, injuries and poisonings and mental health disorders.

Immunizations

Immunizations have had a dramatic impact on morbidity and mortality related to vaccine preventable diseases and their complications. Maryland requires immunization for measles, mumps, rubella, diphtheria, tetanus, and polio, varicella and hepatitis B for entry into preschool programs, kindergarten, and grades one through twelve. Pertussis immunization is required for preschool, and kindergarten through the second grade. H. flu type b immunization is required for entry into preschool programs. Since 1994, the National Immunization Survey (NIS) conducted by the CDC has estimated vaccination coverage rates for the U.S, states and selected cities. Title V requires states to monitor coverage for the 4:3:1:3:3 vaccination series (DTP, Polio, MMR Hib, Hep B.)

Immunization rates for Maryland children have been improving. According to the NIS, in 2004, an estimated 83.7% of Maryland children ages 19 to 35 months were fully immunized. Maryland's coverage rate was above than the national rate of 80.5%

in 2004. Data for the 2004-2005 school year indicate that relatively few Maryland children were suspended from school because they were not fully immunized.

Data is currently unavailable by jurisdiction with the exception of Baltimore City. Baltimore City children (78.3%) were less likely to have been immunized as compared with children in other jurisdictions of the state (84.5%). When fully operational, Immunet, Maryland's immunization registry, will track children in need of immunizations and provide data on the immunization status of Maryland children.

Parental perceptions of barriers to immunization include: lack of trust of the medical care system in general; delaying immunization because of mild illness; placing a low priority on immunizations, including the perception they are only necessary for school or daycare entry; a parental perception that some diseases are natural and need not be immunized against; objections for religious reasons; inability to take time off from work; lack of access to well-child care; lack of knowledge regarding the timing of childhood immunizations and misperceptions about the safety of immunizations; and difficulty understanding the complexity of the immunization schedule.

Lead Exposure and Poisoning

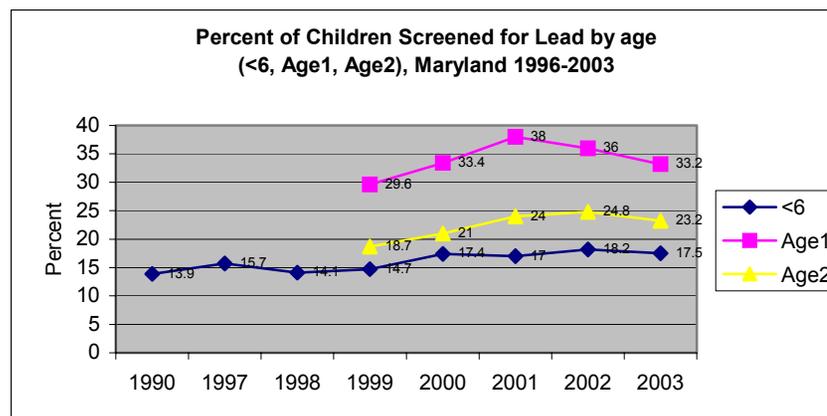
Lead remains as a serious and widespread environmentally linked hazard for young children in Maryland. Major risk factors for lead poisoning include living in high risk housing built before 1950 and poverty. In addition, an increasing immigrant population and increased blood lead testing have led to the discovery that children are being lead poisoned through lead affected pottery, cosmetics and toys. Because of the state's high concentration of older housing, available data suggest a higher prevalence of blood lead elevation among Maryland children than children nationally. Montgomery County is reporting that 50% of poisonings are non-lead paint related.

There has been a steady decline in childhood lead poisoning in Maryland over the past decade at all levels of exposure. The reduction has occurred both statewide and in areas of highest risk such as Baltimore City. The Maryland Department of the Environment cites several lead poisoning prevention efforts as the reason for the decline. These include increased enforcement of lead laws, increased lead awareness among parents, health providers and property owners, improved maintenance of rental housing, and new home starts in high risk areas.

To comply with federal funding requirements, Maryland has developed a Plan to Eliminate Childhood Lead Poisoning by 2010. The goal is to eliminate all but sporadic cases of childhood lead exposure in young children.

High risk areas for lead poisoning in Maryland include Baltimore City, the Lower Eastern Shore and Western Maryland. It is estimated that 4,986 children in Baltimore City and 1,341 children on the Lower Eastern Shore under age six years have blood lead levels above 10 ug/d (Source: Maryland Plan to Eliminate Childhood Lead Poisoning).

Blood lead testing is believed to be the most reliable technique for identifying children with elevated blood lead levels. In 2003, 76,721 Maryland children under the age of six were tested for lead exposure. This represented 17.5% of children in this age group. Blood lead testing increased from 13.9% in 1996 to 18.2% in 2002 and fell to 17.5% in 2003. By jurisdiction, blood lead testing rates range from a low of 7.6% in Howard County (a jurisdiction with low risk) to a high of 37.3% in the Eastern Shore county of Somerset. More than a third (35.2%) of Baltimore City children under the age of six were tested.



School Readiness

In January 2000, the Maryland Subcabinet for Children, Youth and Families submitted a report outlining the need to improve services to young children to prepare them to enter school ready to learn. The report called for the development of a reporting system to monitor progress in this area. Maryland has issued an annual report on school readiness since the school year 2001-02. This report summarizes information on Maryland's Model for School Readiness for the state and each jurisdiction.

The data collection process involves teacher observation and evaluation of student classroom experiences and activities during the first eight weeks of the school year to gain an understanding of what students know, are able to do, and areas required further work to reach full development. Teachers receive training on the assessment tool (Work Sampling System or WSS) that includes 30 performance indicators that are aggregated into seven domains: social and personal development, language and literacy, mathematical thinking, scientific thinking, social studies, the arts and physical development and health. A composite score as well as scores for each of the seven domains are determined. The composite scores are used to derive three levels of readiness - full readiness (consistently demonstrate of skills, behaviors, and abilities to be successful); approaching readiness (inconsistently demonstrate skills, behaviors, and abilities to be successful); and developing readiness (does not demonstrate skills, behaviors, and abilities to be successful).

For the most recent school year, the School Readiness report indicates that more Maryland kindergarteners are entering school fully ready to learn – 58% in 2004-05. This represented a 9% increase over the percent in baseline school year of 2002-02. Improvements also occurred among each Baltimore City continued to lag behind the rest of the state in the percentage of children identified as fully ready – 40%. Other jurisdictions with percentages below the statewide average for the 2004-05 school year included Caroline (42%) and Cecil (43%) counties on the Eastern Shore, and Prince George’ County (48%). Racial and ethnic disparities also exist. Hispanic children (43%) were least likely of all children to be fully ready to learn. This is most likely indicative of language difficulties due to limited English proficiency. Only 37% of children with limited English proficiency were identified as fully ready to learn. Children with disabilities and in need of special education were also less likely to be “fully ready to learn. By prior education care, children previously enrolled in non-public nursery schools scored highest on the composite measures – 75% were deemed fully ready to learn. Conversely, children enrolled in Head Start scored lowest at 47%.

Adolescents

Adolescence is a critical period of life during which individuals make the developmental transition from childhood to adulthood. Adolescence is characterized by marked physical, emotional, and intellectual changes, as well as by changes in social roles, relationships and expectations, all of which provide the foundation for functioning as an adult. Expert opinion varies on the definition of an adolescent. For example, the *Bright Futures* Guidelines defines the age range for adolescents as 11 to 21, and subdivides this period into three stages: early (11-14); middle (15-17); and late (18-21). Others define pre-teens or tweens as 10-12; and adolescents as 13-19. The Maryland Needs Assessment defined adolescents to include youth between the ages of 12-19 and young adults as persons between the ages of 20-24. Because data was often limited for the 12-19 age group; a decision was made to also view adolescents as those between the ages of 10-19.

Census data for 2004 indicate that there were 806,368 youth between the ages of 10 to 19. The majority (71%) of adolescents lived in the suburban areas of Maryland, followed by 17.5% in the state's rural counties and 11.5% in Baltimore City. Five percent of adolescents were Hispanic origin in 2004. Sixty one percent of adolescents were White, 32% were Black, four percent were Asian and less than one percent were American Indian.

Access to Care and Systems Issues

Gaps, Unmet Needs and Challenges

- Focus group participants and local health department MCH program staff remarked that the health services delivery system is not “adolescent friendly” and that there are few trained providers skilled in addressing the unique needs of adolescents.
- There is a need to develop a comprehensive approach to adolescent health that is fully integrated with broader, more comprehensive efforts aimed at youth development.

Health Profile of Maryland Youth -2003 National Survey of Children’s Health

Data from the 2003 National Survey of Children’s Health present the following portrait of adolescents between the ages 12 and 19 in Maryland:

Overall Health:

- The majority of the parents (86.9%) rate the health of their adolescents as excellent/very good; 27% as fair/poor.
- Almost three in four rated the condition of their teeth as excellent/very good; 7% as fair/poor.

Access to Care:

- Less than half were reported to have a medical home as defined by AAP. However, most of them (87.7%) had a usual source of health care. Ninety-eight percent felt that this usual source of care provided all the care that was needed.
- Most adolescents (95%) were insured at the time of the survey; 5% were uninsured. More than nine percent were reportedly uninsured at some point in the past year. Most of them (76.6%) reported private coverage, while 18.4% reported public coverage.

Obesity and Physical Activity

- More than one in ten adolescents (13.3%) were determined to be overweight and another 16.6% were classified as “at risk” for being overweight. African-American teens (20.6%) were more than twice as likely as Caucasian teens to be overweight.
- One in five of those between 12 to 17 years old reported not participating in physical activity for 20 minutes or more during the previous week. Forty four percent reported participating for 4 or more days.

Asthma:

- Fifteen percent of adolescents were affected by asthma. Ten percent reported having asthma with health effects and 5% reported asthma with no health effects.

Mental Health:

- Almost 5% of adolescents had been diagnosed with ADD/ADHD but were not taking medication. Another 6.8% had been diagnosed and were currently taking medication.
- Almost 11% reported moderate or severe socio-emotional difficulties in the area of emotions, concentration, behavior or getting along with others.

Activities

- The majority (82%) participated in organized activities outside of school (e.g. clubs or sports teams).

Focus Groups Findings

The focus groups with adolescents and parents of adolescents yielded the following summary of issues, needs and recommendations:

Parental Influence: Parents realize that they are an enormous influence on their teenage children. They want to be a source of information on negative health behaviors, and to be good role models, but they may need help. Regarding the important issue of sex education, parents want to have some control over what their children learn, but realize that many parents may need to be prompted to broach the subject with their children, and that the messages related to teenage sexual activity need to be discussed at home and reinforced in the school and elsewhere.

Barriers to Health Care for Young Adults: Parents and teenagers do not see the same barriers to health care access for adolescents. Parents, not surprisingly, most often focus on the cost of care, health insurance coverage issues, and confusion over provider networks. Teenagers were clearly most concerned about the confidentiality of the health care services they receive and how the lack of confidentiality leads to real barriers for teenagers who want to access services, but fear the consequences if information is not kept confidential.

Mixed Messages. Both parents and teenagers see an abundance of mixed messages related to negative health behaviors. Students are taught abstinence in sex education classes, but are bombarded with the opposite message in television shows and commercials for products like condoms, birth control pills, and medications for erectile dysfunction; students are taught about the dangers of HIV/AIDS, but advertisements like those featuring Magic Johnson leave the impression that AIDS is not a serious problem; students are told to eat nutritious foods but are offered unhealthy food choices in school cafeterias and have access to vending machines filled with soda and junk food; youths are told to get more exercise, but physical education is not a requirement after 9th grade and guidance counselors and parents stress academics in their class schedules.

Feeling “Connected” to School. An unexpectedly high number of students reported feeling ‘unconnected’ to their schools. While some students did feel very connected (particularly those who are involved in a school sports team), others appeared to be indifferent to their school or even alienated from it. The large number of students at many high schools, violence in the schools, favoritism by teachers and administrators, and uncaring school staff have tended to diminish students’ feelings of connection with their schools. School administrators’ responses to drug use or violence in schools that result in intrusive security measures appear to have further alienated students from their schools.

Physicians as a Resource for Teenagers. Physicians are not seen as a potential source of information about issues related to high-risk or unhealthy behaviors. Neither teenagers nor parents see physicians as having an important role in encouraging positive health behaviors among adolescents. Teenagers do not see physicians in this role because they often do not feel they have a good relationship with their doctors and would not feel comfortable talking to them about these types of issues. Parents do not see physicians in this role because they do not believe physicians have time for these kinds of discussions with teenagers – physician practices are too busy. Some parents even seemed ambivalent about the role physicians could play in these issues, worrying that patient-physician confidentiality requirements might result in doctors keeping important information from parents.

Addressing the Negative Consequences of Lack of Exercise. Teenagers had lots of ideas for how to encourage physical activity among teenagers. They suggested that some type of physical education class be required all four years of high school, and recommended that playing on sports teams, intramural sports, and dance or exercise classes should count toward the requirement. Youths questioned the quality of their current physical education classes and thought students might participate more in class if a wider range of physical activities was included in physical education class (such as break-dancing). Teenagers would like to see the school gym and other facilities like weight rooms available to students when not in use for classes or sports teams, particularly in the late afternoon and early evening. And, most interestingly, students suggested that schools provide support for a broader array of exercise types, including activities like skateboarding. One participant noted that skateboarding is a physical activity that appeals to a “different social group,” which suggests that simply increasing access to traditional sports activities will not necessarily expand the number of students who participate in them.

Mental Health Services. Teenagers would like better access to mental health services. They see school guidance counselors as too busy to provide the services they need. They want more access to people whom they can talk to about their problems, and it is important that this service be confidential. Parents also agree that increased access to mental health services is important.

Health Care-Related Service Misconceptions. Both teenagers and parents seem to have misconceptions about health care-related services, particularly in schools. For example, parents suggested that school guidance counselors do not have appropriate training to

provide advice to students on issues other than class schedules, when they are, in fact, trained in counseling. Students complained that school nurses could not dispense medications under any circumstances, but the fact is they can be given to students if parents sign a permission form and provide the medication in advance. And the question of what physicians must keep confidential from a teenager's office visit was not understood by either parents or students. Given some of the stories teenagers reported, this might not be well understood by physicians, either. Informational campaigns on these topics would be helpful for all constituencies.

Mortality, Morbidity, Injuries and Violence – Adolescents

Trends, Progress, Strengths

- Adolescent mortality rates, including teen violent deaths have been declining in Maryland.
- Overall, fewer adolescents are being arrested for both violent and non-violent crimes in Maryland.

Gaps, Unmet Needs and Challenges

- Preventable injuries – accidents, homicides and suicides – remain as leading causes of adolescent deaths.
- Homicide, the second leading cause of death for Maryland adolescents, resulted in the deaths of 89 teens (ages 15-19) in 2003. African American males die at more than ten times the rate of Caucasian males from homicide in Maryland.
- Suicide which is often linked to depression is the third leading cause of death for Maryland adolescents. Suicide rates for adolescents ages 15-19 have remained stable at approximately 7 deaths per 100,000 adolescents over the past several years. In 2003, 29 adolescents between the ages of 10 and 19 took their own lives.

Leading Causes of Deaths and Hospitalizations

Between 1999 and 2003, there were 1,627 deaths to adolescents between the ages of 12 to 19. The five leading causes of death for 1999-2003 were accidents (including motor vehicle crashes) (31%), homicide (24%), suicide (9%), cancer (5%) and cardiovascular disease (3%). The adolescent mortality rate for ages 12-19 declined by 11% between 1994 and 2003 from 61.7 deaths per 100,000 population to 55.0. Leading causes of hospitalizations for 2003 included pregnancy and childbirth, injuries and poisonings and mental health disorders (including depression).

Unintentional Injuries

Unintentional injuries or accidents are the leading cause of death for adolescents between the ages of 10-19. Over the five year period of 1999-2003, the 592 deaths for this age group represented 29% of all deaths. Motor vehicle accidents were the cause of approximately 70% of these deaths. Other causes included falls, drownings, fire and poisonings. The death rate for older adolescents fluctuated between 24.0 and 29.3 between 1999 and 2003.

In 2003, motor vehicle accidents were the leading cause of accidental deaths for older adolescents (ages 15-19), but represented a lower percentage of death for younger adolescents, 36%. Maryland's average mortality rates from motor vehicle accidents for children and young adults for 2001-2003 were higher than the national rates (2004 CFR Report).

In 2003, the accidental death rate for adolescents aged 10-19 was considerably higher than the statewide average of 15.8 in two regions: Western Maryland (17.1), and the Eastern Shore (28.9). Child Fatality Review committees in several jurisdictions (e.g., Baltimore, Caroline, Prince George's, Montgomery and Howard counties) expressed concerns about motor vehicle related injuries and deaths among teens. Adolescent risk taking behaviors in and around cars, such as drinking, high speed driving, and the non-usage of seat belts were identified as factors in teen deaths and injuries. Rural counties also expressed concerns about the dangers of ATV like vehicles.

Homicide

Homicide is the second leading cause of death for Maryland adolescents aged 10-19, representing 20.5% of the 2036 deaths in this age group. Nationally, homicide ranks third. Between 1999 and 2003, 417 adolescents (ages 10-19) were murdered. The majority of homicides occur to African American males – 89% between 1999 and 2003. Few homicide deaths occurred to adolescents of other racial and ethnic groups in Maryland. The majority of homicides among older adolescents involved firearms (2004 Child Fatality Review Report).

Homicide rates are highest for African American males and lowest for White females. In 2003, the homicide rate for Black males at 110.8 deaths per 100,000 population was more than 22 times the White male rate of 4.8.

Adolescents in Baltimore City represented the majority of homicides by jurisdiction – 59% in 1999 – 2003. Another 24% of death occurred in the D. C. suburban counties of Prince George's and Montgomery. Statewide, the homicide rate has declined slightly from 23.5 deaths per 100,000 in 1999 to 21.5 deaths per 100,000 in 2003. The Healthy People 2010 goal is to reduce the rate of homicide to no more than 3.0 deaths per 100,000 population for all age groups.

Suicide and Depression

Between 1999 and 2003, 157 (7.7% of deaths) Maryland adolescents, ages 10-19, ended their own lives. These suicides disproportionately occurred in rural areas of the state – the Eastern Shore, Western Maryland and Southern Maryland – which represented 21% of the state's adolescents, but 35% of suicides. The Eastern Shore experienced a spike in the numbers of adolescent suicides between 2000 and 2001, but the numbers have since declined.

Focus group participants and local health department staff, anecdotally, repeatedly indicated that depression is rising among adolescents. Suicide, which is often linked to depression, is the the third leading cause of death for Maryland adolescents. Nationally, suicide ranks second. Suicide rates among adolescents aged 15-19 declined by 22.5% between 1999 and 2002, from 8.0 deaths per 100,000 population to 6.2, respectively.

Suicide rates are generally highest for White males and lower for African American females. The suicide rate for Black males increased in the nineties but has since declined. The White male rate fluctuated between 11.1 and 14.1 between 1999 and 2003.

An estimated 10 to 15 percent of the child and adolescent population has some symptoms of depression. The prevalence of major depression among all children ages 9 to 17 has been estimated at 5 percent. (Surgeon General's Report) Mental disorders, including depression, were a leading cause of hospitalizations for Maryland adolescents, ages 12-19 in 2003. At least two county CFR committees mentioned a deepening severity of depression among adolescents as a cause for concern. The committees also identified the need for additional mental health services and voiced concerns about depression and suicide related to sexual identity issues as well as bullying. Parents and service providers in our focus groups echoed these same concerns.

Reproductive Health – Adolescents

Trends, Progress, Strengths

- Fewer Maryland teens are giving birth. Maryland's adolescent birth rate declined for the 10th straight year in 2003. Rates declined for both Caucasian and African American adolescents but rose for Hispanic adolescents.
- Maryland's Healthy Teen and Young Adult Program served ____ Maryland youth in FY 2004.
- The Maryland Abstinence Education and Coordination Program funds after-school programs based on youth development resiliency principles in eleven jurisdictions in FY 2004. The Program held its fifth statewide conference in 2005.

Gaps, Unmet Needs and Challenges

- Some counties are reporting evidence of earlier sexual behavior among children and pre-teens between the ages of 8 to 12 and more adolescents are becoming increasingly involved with older men.
- More than 2,100 babies were born to teen mothers under the age of 18 in 2003. One hundred and twenty four births were to girls under the age of 15. The vast majority (85%) of these pregnancies were unintended according to Maryland PRAMS reports.
- For African American girls (ages 15-19) in Maryland, the teen birth rate of 53.0 per 1,000 live births was more than double the rate of 22.7 for Caucasian girls in 2003, while rates among Hispanic young women (81.0) were more than triple the rates for Caucasians.
- Work remains to be done to reach the Healthy People 2010 goal of 5.1 births per 1,000 teens ages 15-17.
- Adolescents ages 15-19 have the highest Chlamydia and gonorrhea rates of any age group. Among Maryland adolescents ages 15-19, the rates of gonorrhea (659 per 100,000) and Chlamydia (2,169 per 100,000) were substantially above the national rates (443 per 100,000 for gonorrhea and 1,524 per 100,000 for Chlamydia) in 2003.
- There were 72 young people (13-19 years of age) newly diagnosed with HIV in 2003. Young people ages 13-24 accounted for 12% of new HIV cases in Maryland in 2003.

Adolescent Sexuality and Births

Maryland does not collect data on teen sexual activity. National estimates of sexual activity are provided here and derived from YRBS surveys conducted in several states and interpreted by the National Campaign to Prevent Teen Pregnancy. These data indicate that slightly less than half of high school students – 46.7% - reported having sex at least once. Sexual activity increased with

grade level and showed that 62% of twelfth graders reported being sexually active. The data, however, indicate that the trend is toward declining sexual behavior among high school students.

Anecdotally, several local health departments expressed concerns about a trend toward earlier sexual behavior among children and teens. MCH staff reported that children as young as eight were becoming sexually active. The needs assessment team was also told of concerns about teens and multiple sex partners, teens engaging in unprotected sex, young women choosing older male partners and finally, teens and oral sex.

Maryland collects data on teen births, but there is no accurate data on the number of teen pregnancies. Teen births are discussed under the Pregnant Women and Infant section of this report.

Sexually Transmitted Diseases

Adolescents are at high risk for contracting sexually transmitted diseases. Nationally, more than two thirds of all sexually transmitted diseases occur in people younger than age 25. Chlamydia and gonorrhea are the most common sexually transmitted diseases for teens. In 2003, reported Chlamydia rates per 1,000 women were four times higher for adolescent ages 15-19 (31.5) than for Maryland women ages 20-44 (7.0).

Mental Health, Substance Abuse, Behaviors and Practices – Adolescents

Trends, Progress, Strengths

- Overall, fewer adolescents are smoking cigarettes and using illicit drugs.

Gaps, Unmet Needs and Challenges

- Mental health problems among adolescents are said to be increasing in both magnitude and severity including both diagnosed and undiagnosed depression.
- There are insufficient numbers of structured pro-social after-school and weekend programs for adolescents.
- Parents are not spending enough quality time with adolescents.
- The prevalence of obesity among adolescents is unknown, but anecdotal information suggests that rates are rising.

Substance Use – Tobacco, Alcohol and Illicit Drugs

The Maryland Adolescent Survey provides information on the extent of alcohol, tobacco and other drug use among students in grades six, eight, ten and twelve. The Survey is conducted jointly by the Alcohol and Drug Abuse Administration within DHMH and the State Department of Education. The survey is administered bi-annually and was expanded in 2002 (the most recent year for which data is available) to include questions on school and neighborhood safety.

In 2002, fewer students in all grades reporting using cigarettes, alcohol and marijuana (the three most commonly used substances) within the past 30 days. One percent of 6th graders, 10.6% of eight graders, 12.7% of 10th graders and 19.8% of twelfth graders reported smoking cigarettes within the past 30 days in 2002. Five percent of 6th graders, 16.4% of 8th graders, 35% of 10th graders and 44.2% of 12th graders reported drinking some form of alcohol within the past 30 days. Less than one percent of 6th graders, 6.9% of 8th graders, 16.7% of 10th graders and 21% of 12th graders reported using marijuana within the past 30 days in 2002.

Alcohol is the substance most used by Maryland adolescents. Seventy percent of 12th graders have tried some form of alcohol. More than one in four 12th graders (29%) reported binge drinking (5+ drinks in one sitting) within the past 30 days. Beer, wine and

wine coolers were the most frequently used category of alcoholic beverage. One in five 12th graders had tried an alcohol beverage at age 12 or younger. Drinking rates were highest for White students and lowest for African American and Hispanic students.

Cigarettes were the third most used substance by Maryland adolescents. Two in five 12th graders had tried cigarette smoking and almost one third (32%) of 12th graders reported being regular smokers. Thirty four percent of 12th graders who ever smoked started smoking cigarettes at age 12 or younger. Asian and African American 12th graders were less likely to have tried cigarettes than their White and Hispanic peers.

Almost half (47.5%) of 12th graders reported ever using a drug other than alcohol or tobacco. More than one in four indicated using a drug other than alcohol or tobacco within the past 30 days. Between 2001 and 2002, 12th graders reported increases in 30 day usage in some substances including crack and other forms of cocaine, where percentage point increases ranged from 0.8 to 1.1%.

Adolescents Involved with the Department of Juvenile Services

The Maryland Department of Juvenile Services (DJS) is responsible for the health, safety and care of youth entering its system. Services are provided to youth between the ages of 7 and 21; however, youth between the ages of 14 and 18 comprise the majority served.

Case referrals to DJS began decreasing in FY 1998 and between FY 1997 and FY 2003 decreased by 8%. In FY 2004, 35,012 youths were referred to DJS. The majority (71.3%) were males, but females are becoming an increasing percentage of youths referred; 29% in FY 2004. Five percent were under the age of 12. More than half (52.4%) were African American, followed by Caucasians (44%) and other youth (3.3%). Over of 50% of youth referred lived in one of five jurisdictions: Baltimore City (21.1%), Baltimore County (11.9%), Prince George's County (10%) and Anne Arundel County (9.6%).

In FY 2004, 4,223 youth were admitted to secure detention facilities. Twelve percent were females. African-Americans represented 73% of those admitted to secure facilities. The total youth in all out-of-home placements for FY 2004 was 5,127.

DJS provides data on intake cases by type of offense. One in four youth were referred to DJS in FY 2004 for a person to person offense ranging from simple assault (20.7% of total offenses) to murder (28 cases). One in three (34.3%) were referred for a property offense ranging from theft/shoplifting (14.5% of total offenses) to carjacking (24 cases). One in five referrals were for alcohol and drug related offenses ranging from narcotics possession (8.7% of total offenses) to narcotics distribution (6.5% of total offenses). The remaining one in four referrals were for CINS offenses (2.4% of total offenses) and uncategorized offenses (17.8% of

total). CINS offenses include truancy and ungovernable behavior. Uncategorized offenses include such offenses as disturbing the peace, traffic violations, tobacco violations and possession of a deadly weapon. Most referrals are made by police officers.

Upon intake, DJS screens each youth to determine area of educational and health risk. Screening data for the period of January 2003 to March 31, 2004 revealed the following for youths who were formally processed:

- Education: The majority (81.5%) were currently enrolled in school; however, over in four missed at least one day of school per week. Thirty percent had received special education services.
- Physical Health: Most youths (63%) rated their health as fair or poor. The majority (93%) had health insurance coverage. Approximately half were sexually active and 3.4% had a child.
- Mental Health: Thirteen percent of these youths had seriously thought of suicide, and 47% had tried it. Over one in five youths currently was receiving mental health services and 14% needed additional mental health services. Thirty percent admitted that a family member had been imprisoned or on probation within the past three years.
- Substance Abuse: Approximately one third smoked cigarettes and 99% had tried alcohol or other drugs.

Education and School Health

Trends, Progress, Strengths

- Increasing percentages of high school students are completing their high school education within four years – 85% in 2003.

Gaps, Unmet Needs and Challenges

- During the 2003-2004 school year, over 10,000 public high schools (4%) dropped out before completing their studies.
- High school graduation rates vary by jurisdiction and race/ethnicity and are lowest in Baltimore City and for American Indian and African American students.
- The rate of violence related high school suspensions is increasing.
- Adolescent service providers identified limited access to comprehensive school based health education and health services as major barriers in promoting adolescent health.

Several measures of healthy adolescent development involve success in school. Children and adolescents who are not successful in school are at risk for a number of less than optimal outcomes in life including fewer future educational and employment opportunities, teen pregnancy, substance abuse, and crime. Risk factors for poor school success include poverty, family instability, inadequate educational systems, and lack of early educational nurturing.

High School Drop-outs

The Maryland Department of Education collects data on the percentage of students in grades 9 through 12 who drop-out before graduation. In the 2003-2004 school year, statewide, 3.9% of students – 10,610 – dropped out of school. Overall, high school drop-out rates in Maryland have been declining. The percentage of drop-outs varied by jurisdiction and race/ethnicity in 2004. Baltimore City had the state's highest drop-out rate at 11.7%, while Frederick County had the lowest at less than one percent. Statewide, African American, Hispanic, and American Indian students, 5.7%, 4.1%, 4.1%, respectively were most likely to drop-out in 2004. Asian (1.4%) and White (2.8%) students were the least likely to drop-out.

High School Graduates

The high school graduation rate is a measure of the percentage of 12th graders who receive a high school diploma during the reported school year. The state target goal is 90%. In 2004, 84.3% of 12th graders graduated from high school. Asian students had the state's highest graduation rate at 94.5% followed by White students at 88.2%. American Indian (76.7%), African American (77.1%) and Hispanics (82.5%) students had lower graduation rates. By jurisdiction in 2004, high school graduation rates were lowest in Baltimore City where slightly more than half of students of all races, with the exception of Asians, graduated.

School Violence

School violence is one measure of the emotional health of children and adolescents. The 2004 Maryland KIDS Count Report examined violence related school suspensions as a measure of school violence in Maryland. The Report notes that school violence in Maryland has increased by 24% over a seven period since 1993. Violence related suspensions were defined as expulsions resulting from verbal and physical attacks against teachers and students. The majority of these suspensions occurred in high schools.

During this time period, nine jurisdictions saw a decline in their violence related suspensions, while fifteen jurisdictions saw increases. Rates tripled in Baltimore County and doubled in Calvert and Talbot counties. The report cautioned interpretation of the data given the subjective nature of determining who gets suspended and for what cause within each school and school jurisdiction. An examination of updated data on school suspensions for the 2003 and 2004 school years based on what is believed to be the methodology used by KIDS Count determined that school violence rates have continued to climb.

Family Health (Cross-Cutting Issue for All Populations)

Trends, Progress and Strengths

- Maryland is one of the wealthiest states in the nation as measured by per capita, median and mean income.
- Reported cases of child abuse and neglect and the numbers of children in foster care are declining.
- More male involvement initiatives are starting in Maryland.

Gaps, Unmet Needs and Challenges

- The percentage of births to unmarried women continues to increase – nearly 35% in 2003.
- Fewer Maryland children are living in two parent families. Many children live homes and communities where fathers are absent.
- Half of African American men in their 20s in Baltimore City are either incarcerated or under criminal justice supervision. Statewide nearly 10% of African American males are incarcerated (Justice Policy Institute, Washington D.C.).
- Maryland service providers report that many Maryland families lack access to affordable housing and affordable child care. In FY 2004, at least 9,276 children were homeless when the Department of Human Resources conducted its annual survey of shelters. Family members represented 35% of the state's homeless, outside of Baltimore City, this percentage rose to 55%.
- The Alcohol and Drug Abuse Administration reports that an estimated 245,000 Maryland children are dependent upon parents with serious substance abuse problems.
- About 11,000 Maryland children were in foster care in FY 2004.
- More than 30,000 suspected cases of suspected child abuse and neglect were investigated by the Department of Human Resources in FY 2004. For 6,342 of these cases, the Department found credible evidence that abuse or neglect had occurred.
- There is a lack of capacity to meet service needs and demands for family support services including parenting classes and support groups, family support centers, home visiting programs, family therapy, mental health counseling, case management services and respite services.
- Some communities - particularly in Baltimore City, on the Eastern Shore and in Western Maryland – have areas of high concentrations of poverty. These areas are characterized by high unemployment rates, poor and substandard housing, blight, low performing schools, and high crime and violence rates.

Children need safe, nurturing, and healthy home and community environments to reach their full potential. The needs assessment team heard that many families across all racial, ethnic and economic strata are struggling to overcome multiple family stressors that threaten healthy outcomes for our children. Comments from focus group participants, local health department MCH directors, MCH service providers, parents, and state agency staff consistently identified family supported related needs that

traditionally have fallen outside of the purview of public health – social factors. The social determinants of health and access to health care are beginning to receive greater attention in public health. For example, the CDC has a division which focuses on the social determinants of health and has explored such issues as racism. Internationally, the World Health Organization has developed and updated publications on social factors and health – the Solid Facts. The research literature has estimated that medical care factors explain a small percentage of health status – approximately 10%.

Health Disparities (Cross Cutting Issue for All Populations)

Trends/Progress/Strengths

- Maryland's population is becoming more diverse.
- Researchers and funding agencies are beginning to take a closer look at the role of social factors (e.g., income, stress, racism) in health status and health care access.

Gaps, Unmet Needs, and Challenges

- Significant racial and ethnic disparities persist for most maternal and child health indicators.
- With few exceptions (e.g., substance use and suicide), African American mothers, babies, children and adolescents fare far worse than other racial/ethnic groups on most measures of mortality, morbidity, health and social status, and access to health care.
- There is a need for more cultural competence in health care.
- There are inadequate numbers of translators and bi-lingual staff to address the needs of populations with limited English proficiency.
- Hispanic and African American women report experiencing discrimination in the health care and social services delivery system.

The 2005 needs assessment identified (1) the growing racial and ethnic diversity of Maryland's population, (2) the existence of persistent and widespread racial and ethnic disparities in maternal and child health, and (3) the urgent need to systematically address these disparities if the health of women, children and families in Maryland is to improve. Racial and ethnic minority children in Maryland, especially those who are economically disadvantaged, continue to lag behind their White peers on a number of key health indicators. Because the elimination of racial and ethnic disparities in maternal and child health was viewed by the Maryland Team to be of key importance to improving maternal and child health outcomes, a section of the needs assessment report was devoted to summarizing key disparities.

Although the health of most Americans has improved significantly over time, not all racial and ethnic groups have benefited equally. African-Americans and Hispanics, for example, are more likely than whites to suffer from poor health and to die prematurely. Minority and low-income families are more likely to live in substandard housing and polluted communities, increasing their risk of childhood lead poisoning, asthma, and other environmentally related diseases. In addition to being disproportionately affected by disease, minorities often lack adequate insurance and access to health care due to financial and cultural barriers.

Over the past 50 years, the health of Maryland and the U.S. population has improved substantially. Mortality and morbidity rates continue to decline while life expectancy has increased. Unfortunately, racial and ethnic minority children and adults are not experiencing the full benefit of many of these improvements. Maryland data reveal substantial racial and ethnic disparities in many key maternal and child health indicators. In general, African American children in Maryland are faring far worse than White children on just about every indicator where the data are available. Two exceptions are suicide and substance use. For the most part, the state has failed to significantly narrow the racial gap on most of these indicators over the past decade as the magnitude most disparities has been maintained and in some cases has increased.

The statistics are troubling and point to the need for continued data collection and analysis to understand the causes of inequities and well as strategic planning and targeting of funding to implement evidence based approaches proven to reduce disparities. Among the issues to be address to eliminate disparities are cultural competence in providing health care, improving access to care and proportional representation of minorities in the health professions must also be addressed to eliminate disparities.

To a large extent, disparities in health and access to care among minorities reflect disparities in socioeconomic status. Poverty and unemployment rates are two to three times higher for African Americans than Whites. However, other factors socially linked factors such as stress and racial discrimination also play a role.

One of the overarching goals of the national Healthy People 2010 Initiative is to eliminate health disparities by race, ethnicity, income, and other characteristics. Much work remains to be completed if Maryland and the nation are reach this goal. Significant areas of racial and ethnic disparity in maternal and child health are summarized below:

Life Expectancy

The average life expectancy of a baby born in Maryland in 2003 was 77 years. African American men have the lowest life expectancy of all Marylanders: 68.7 years as compared to 76.0 years for White men. Overall life expectancy was 78.5 years for Whites and 72.5 years for Blacks in Maryland for infants born in 2003.

Women of Childbearing Age, Pregnant Women and Infants

There were 74,865 births to Maryland women in 2003. Approximately 53% of these births were to White, non-Hispanic women; about one third to African American women; six percent to Asian women; and less than one percent to American Indian women (180 births). Hispanics represented 9% of births. White, non-Hispanic women, Hispanic women and Asian tend to experience better pregnancy outcomes than African American or Native American women in Maryland. It should be noted that while the data presented here is for 2003, generally the same findings and trends have been observed in prior years.

Unintended Pregnancy

In 2003, African American (57.2%) and Hispanic (54.2%) women were more likely than White women to report that their pregnancy was unintended (Maryland PRAMS Survey 2003).

Preconception Health

Black (76.3%) and Hispanic (85.4%) women were more likely than White women (67.5%) to report daily use of a multivitamin the month before pregnancy (Maryland PRAMS Survey 2003).

Birth Rate

At 26.6 births per 1,000 population, Hispanic women had the state's highest birth rate in 2003, twice the White rate of 12.0 and higher than the African American rate of 15.4. Unlike other racial/ethnic group, the Hispanic birth rate has been climbing.

Births to Unmarried Women

Overall, more Maryland births are occurring to unmarried women, nearly 35% in 2003. African American babies (58%) were more than twice as likely as White, non-Hispanic (21%) babies to be born to an unmarried mothers. Approximately half of American Indian and 46.2% of Hispanic babies were born to unmarried mothers. Only 7.7% of new Asian mothers were unmarried in 2003.

Teen Births

Hispanic teens (ages 15-19) had a birth rate of 81.0 per 1,000 women in 2003; the state's highest teen birth rate. The Hispanic teen birth rate was more than 3 ½ times the rate for White adolescents (22.7). The Black teen birth rate (53.0) was twice the rate for White adolescents. In 2003, there were 2,209 births to adolescents under the age of 18. African American births were disproportionately represented in this total at 58%.

Maternal Mortality

In the U.S., African American women have a maternal mortality ratio three to four times greater than that for White women. During 1998-2002, Maryland's MMR averaged 20.0 per 100,000 live births for black women compared to 11.4 among White women. The difference between African American and White women is smaller in Maryland because African American women in Maryland have a lower mortality rate than the U.S. average and White women in Maryland have a higher rate of death in the United States overall. The numbers are too small to compare women of other races and ethnicities.

Infant Mortality

Infant mortality rates have declined significantly over the past several decades; however, the magnitude of the racial disparity was not significantly affected. In 2003, African American babies continued to die at a rate that was more than two and a half times higher than for White babies. Asian babies had the state's lowest infant mortality rate in 2003 at 3.2 deaths per 1,000 live births. African American babies (14.7) had the state's highest infant death rate, dying at more than twice the rate of White (5.4), Hispanic (6.0) and Asian (3.2) babies in 2003. (Data for American Indian women was not available). African American babies in Maryland are disproportionately affected by infant mortality, especially related to low birth weight, prematurity and SIDS.

Data from the Vital Statistics 1999-2001 linked birth and infant death file indicate that overall women who smoke during pregnancy have a higher mortality rate than women who are nonsmokers, 11.8 and 7.1 deaths per 1,000 live births. However, infants born to Black non-smoking mothers had a 45% higher death rate than babies born to smoking White mothers. The linked file also showed that Black college graduates are nearly three times more likely to experience an infant death than their white counterpart. In addition, Black women with a college degree experience a higher infant death rate than White women with less than a high school education.

The disparity in infant mortality rates for Blacks and Whites is evident in every region and jurisdiction of the state with a significant minority population. In 2003, the magnitude of the disparity was greatest in Western Maryland, where Black babies died at 3.3 times the rate of White babies, and in the Baltimore Metropolitan area where the magnitude was 3.2.

Neonatal, postneonatal and fetal mortality rates are also twice as high for African American babies as compared to White babies. In 2003, Asian babies had the lowest rates of neonatal and postneonatal death and the rates for Hispanics were lower than the statewide average of 5.8 and 2.3, respectively.

Low Birth Weight (LBW) and Prematurity

Hispanic (7%) and White (7.1%) babies had the lowest rates of low birth weight in 2003. American Indian (14.4%) and African American (13.1%) babies had the highest low birth weight rates, followed by Asians at 8%. Similarly, Hispanic (9.1%) and White (9.6%) babies were the least likely to be born prematurely. Prematurity rates were highest for American Indian (14.5%) and Black babies (14.3%). The percentage of African American babies born at LBWs declined slightly over the past decade, while the percentage of White babies born at LBWs increased – a cause for concern. Even so, African American babies continued to be twice as likely as Caucasian babies to be born at low birth weights.

Cesarean Deliveries

African American (31.4%) and American Indian (31.7%) women were more likely than White (27.6%), Asian (27.9%) and Hispanic (24.4%) women to give birth by cesarean section in 2003.

Substance Abuse during Pregnancy

White women (15%) were three times as likely as Black women (5.35) to report smoking during the last three months of pregnancy. (Maryland PRAMS Survey 2003). Data was not available for other racial and ethnic groups. White women (10.4%) were three times as likely as Hispanic women (3.4%) and slightly more likely than Black women (8.3%) to report using alcohol in the last three months of pregnancy (Maryland PRAMS Survey 2003). PRAMS does not collect data on illicit drug use.

Physical Abuse and Pregnancy

Fourteen percent of Hispanic women reported being physically abused by a husband or partner prior to pregnancy, more the four times the rate for White women (3.8%) and twice the rate for Black women (8.8%) (Maryland PRAMS Survey 2003). Eleven percent of Hispanic women reported being physically abused by a husband or partner during pregnancy, more than four times the rate for White women (2.2%) and higher than the rate for Black women (7.1%) (Maryland PRAMS Survey 2003).

Postpartum Depression

Comparable percentages of women reported being at least moderately depressed in the months following delivery – Whites (21.9%), Blacks (23.5%), and Hispanics (20.4%).

Breastfeeding

Black women have the lowest breastfeeding rates, statewide and nationally. In 2003, 95% of Hispanic women and 82% of White women indicated initiation of breastfeeding as compared to only 65% of African American women (Maryland PRAMS Report 2003). Eighty eight percent of Hispanic women reported continuing to breastfeed for four weeks or more in 2003. This compared to slightly more than half (51.3%) of Black women and 69.3% of White women.

SIDS and Infant Sleep Position

Infant sleep position - placing infants on their backs to sleep as opposed to their stomachs – is a major preventive strategy for reducing SIDS deaths. Black women (27.2%) were more than two and half times likely than White women (10.7%) and five times as likely as Hispanic women (4.7%) to report placing their infants on their stomachs to sleep.

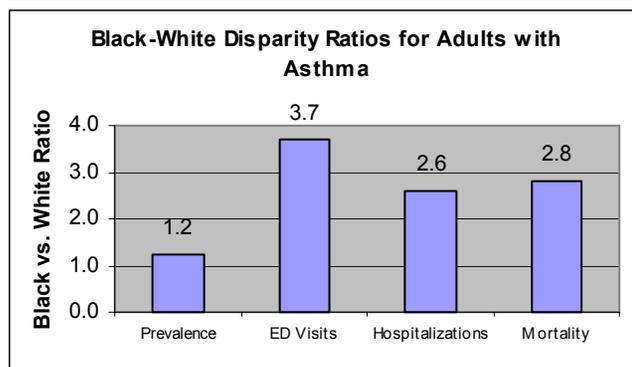
HIV/AIDS

The overall African American HIV/AIDS prevalence rate is 12 times the rate for Whites and 6 times the rate for Hispanics in Maryland. AIDS is the leading cause of death among African American men and women ages 25-44 in Maryland. African American women are representing an increasing proportion of new HIV and AIDS cases each year – 37% in 2003. The overwhelming majority

(81%) of women of childbearing age (13-49 years) living with HIV/AIDS in Maryland are African American. The majority of the estimated 245 Maryland children currently living with HIV/AIDS were born to African American mothers.

Asthma

Health disparities related to asthma exist. Specifically, 9.5 percent of African-American Marylanders have a current prevalence of asthma compared to 7.8 percent of white Marylanders. In 2003, African-Americans Marylanders continued to have nearly three times the hospitalization rate and four times the emergency department visit rate than whites. In order to examine whether increased prevalence of asthma among African-Americans could explain the higher morbidity and mortality, a disparity ratio was examined. The results indicate that the increased asthma morbidity and mortality among African-Americans cannot be fully explained by higher prevalence.



Although these findings are for adults, similar results would be expected for children. Other factors, such as higher asthma severity, poorer asthma control, and/or more limited access to health care may further explain these higher rates of morbidity and mortality for African-American asthmatics.

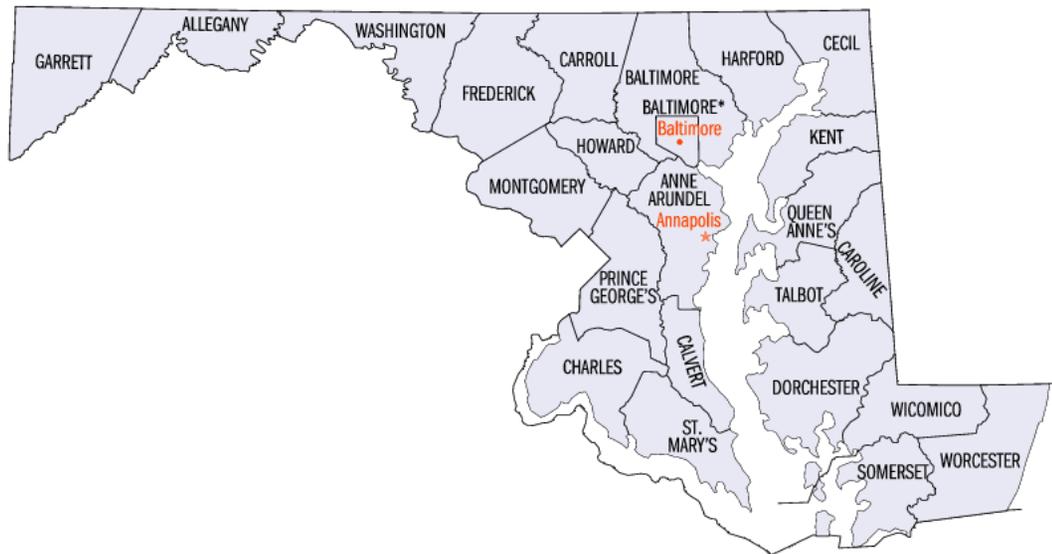
Access to and Utilization of Health Care

Health Insurance Coverage- In 2002/2003, according to the Maryland Health Care Commission, 24% of Hispanic children ages 0-18 were uninsured, six times the rate for White, non-Hispanic children. Asian (15%) and Black (13%) children were more than four times as likely as White children (4%) to be uninsured.

Prenatal Care – Only 70% of Hispanic women received prenatal care within the first trimester in 2003, the lowest rate for any racial/ethnic group. White, non-Hispanic women had the highest rates of early prenatal usage at 90.9%, exceeding the Healthy People 2010 goal of 90%. The comparable rates for African American women, American Indian and Asian women were 75.2%, 78.9% and 86.5%, respectively.

Appendix B

2005 Maryland Title V Needs Assessment Report for Children and Youth with Special Health Care Needs



Prepared by
The Office for Genetics and CSHCN
Maryland Dept. of Health and Mental Hygiene
July 2005

CYSHCN Needs Assessment Methodology

Conceptual Framework

Broad domains for assessing need were chosen by the needs assessment committee based upon the existing national performance measures for CYSHCN as well as the content areas utilized on the 2001 National Survey of CSHCN. The domains chosen were Health Care Needs and Access to Care, Impact on Family, Comprehensive Health Care Through a Medical Home, Adequate Insurance to Pay for Services, Community-Based Services Organized for Easy Use, Family-Professional Partnerships and Satisfaction with Services, Early and Continuous Screening, and Transition to Adult Life. Additional indicators/areas of interest under each of these broad domains were identified based upon input from Title V CSHCN Program staff and informal stakeholder input including families. Data was gathered from both quantitative and qualitative sources in an attempt to create a comprehensive picture of the needs of the CYSHCN population in Maryland.

Quantitative Data Sources

1. National Surveys

- National Survey of Children with Special Health Care Needs (2001, NCHS/MCHB)
- National Survey of Children's Health (2003, NCHS/MCHB)

2. State Surveys

- Needs Assessment of Individuals with Spina Bifida (2004, Chesapeake-Potomac Spina Bifida Association)
- Hemophilia Foundation Needs Assessment (2005, Hemophilia Foundation of Maryland)
- Barriers to Quality Child Care Survey (2003, Maryland Developmental Disabilities Council)
- Medicaid Managed Care Customer Satisfaction Survey (2003, Maryland Dept. of Health and Mental Hygiene)
- Maryland School Health Services Survey (2003, Maryland State Department of Education)
- Survey of Maryland Pediatricians on UNHS Program (2004, Maryland chapter American Academy of Pediatrics)
- Survey of Maryland Licensed Audiologists (2004, Maryland Dept. of Health and Mental Hygiene and Towson University)

3. Program Data

- Program Data, Office for Genetics and CSHCN, Maryland Dept. of Health and Mental Hygiene (Title V CSHCN Program)
- Program Data, Office of Health Services, Maryland Dept. of Health and Mental Hygiene (Maryland Medicaid Program)

- Program Data, Maryland Family Access Initiative/Parents' Place of Maryland
- Program Data, Mental Hygiene Administration, Maryland Dept. of Health and Mental Hygiene
- Program Data, Social Security Administration
- Program Data, Maryland State Department of Education

Qualitative Data Sources

1. Focus Groups

- Focus Groups on Health Care Transition for CYSHCN (2004-5, Maryland Dept. of Health and Mental Hygiene)
- Focus Groups on Medical Home (2005, Maryland chapter American Academy of Pediatrics)
- Focus Groups - Maryland Family Access Initiative (2004, Georgetown University Center for Child and Human Development and Parents' Place of Maryland)
- Focus Groups on Newborn Screening Communication (2004, Maryland Dept. of Health and Mental Hygiene and Louisiana State University Health Sciences Center)

2. Key Informant Interviews

- CSHCN Focused Needs Assessment (2003, Talbot County Health Department)

3. Town Meetings

- Town Meetings on Inclusive Child and After-School Care for CSHCN (2004, Maryland Department of Disability)

4. Mixed Methodology

- Somerset County CSHCN Needs Assessment (2003, Somerset County Health Department)
- Needs Assessment for Special Medical Services for Children (2000, Frederick County Office for Children and Families/Local Management Board)
- A Needs Assessment for CSHCN (2004, Caroline County Health Department)

Gaps in the Data

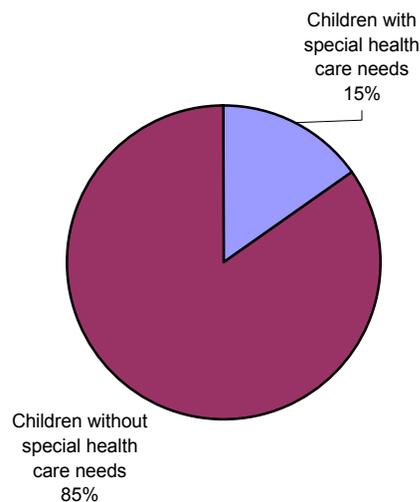
It is very difficult to collect data that is representative of the broadly defined population of CYSHCN on either a quantitative or qualitative basis. Quantitative data on this population outside of the large, national surveys has been generally limited to surveys of

specific condition groups. Qualitative data may be somewhat more representative. Maryland also lacks county-specific data for the CYSHCN population, with the exception of some programmatic data (ex. special education counts). There is also a general lack of data on minority groups, especially the Hispanic population. Content areas where there is a particular need for additional data include quality of life for CYSHCN, barriers to health care transition from the view of adult providers, screening and referral practices of Maryland physicians and scope of screening beyond early childhood, child abuse/neglect in the population of CYSHCN, and reimbursement issues impacting the care of CYSHCN.

Prevalence of Children and Youth with Special Health Care Needs in Maryland

According to the 2001 National Survey of CSHCN, the prevalence of CYSHCN ages 0-17 years in Maryland is 15.2%, corresponding to approximately 209,000 children and youth (see figure 1). This is significantly greater than the national prevalence of 12.8%. Almost one-quarter of all households with children in Maryland have one or more CYSHCN.

Figure 1: Prevalence of Maryland children with special health care needs ages 0-17 years



Newer data from the 2003 National Survey of Children's Health estimates the prevalence of CYSHCN in Maryland at 18.3%, compared with 17.6% nationally.

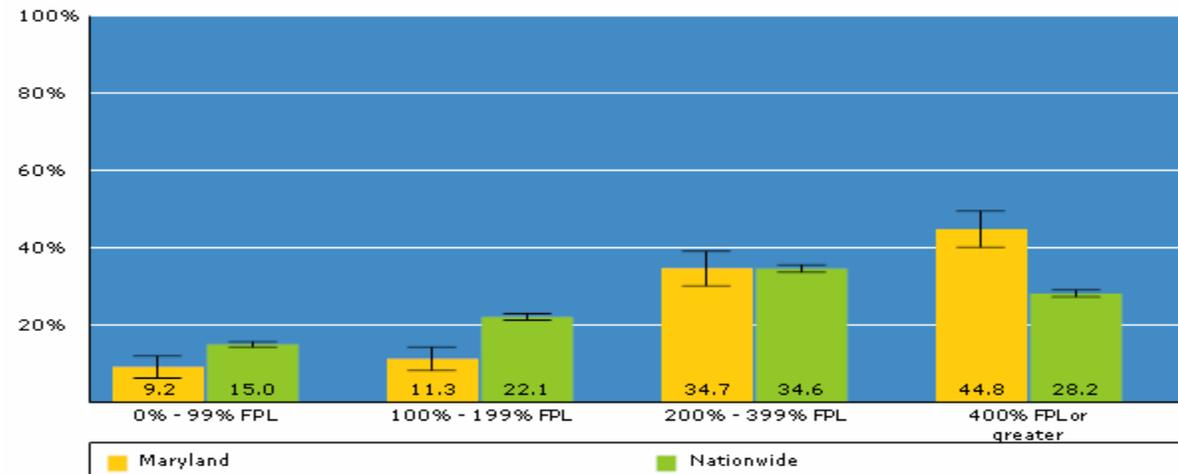
As expected, the prevalence of special needs is greatest in children and youth over the age of 5 years, reaching a high of 18.2% of children and youth between the ages of 12-17 years based on data from the 2001 National Survey of CSHCN. In Maryland, mirroring the nation as a whole, special needs are present more frequently in males than in females (17.9% versus 12.4%), and also appear to be diagnosed more commonly in multi-racial children and youth as well as in non-Hispanic whites. The highest prevalence of special health care needs by race estimated in Maryland was 19.2% for multi-racial children and youth.

Maryland data also suggests that there may be a disparity in prevalence of special needs by income level. The 2001 National Survey of CSHCN estimates that Maryland children at 0-99% FPL are significantly more likely to have special health care needs than children at all higher incomes; this is in contrast with the national as a whole where there is virtually no disparity in the prevalence of special health care needs by income.

Socio-Demographics of Maryland's Children and Youth with Special Health Care Needs

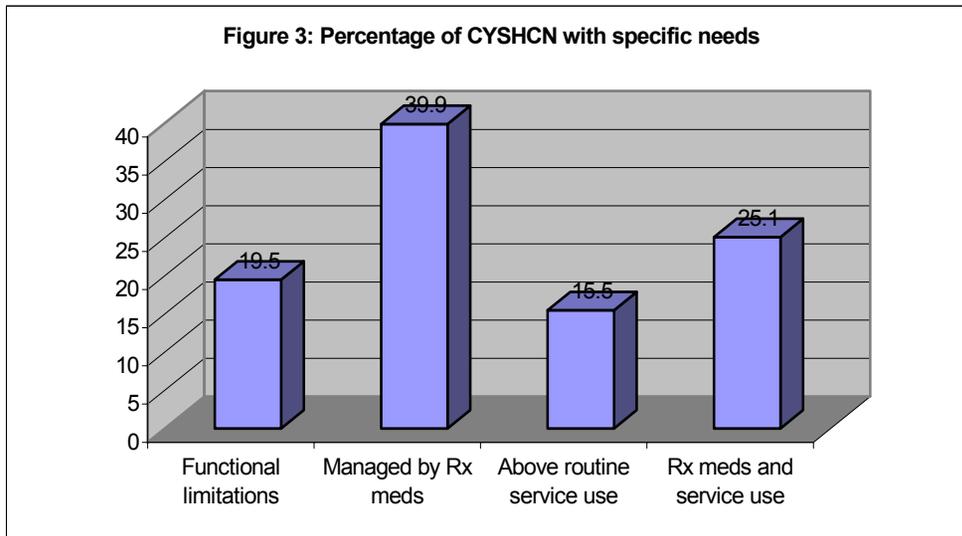
In the population of CYSHCN in Maryland, the majority fall between the ages of 8-14 years of age according to the 2001 National Survey of CSHCN. Over 60% are male and approximately 63% are non-Hispanic whites. Slightly over 9% of CYSHCN in Maryland live in households at 0-99% FPL while almost 45% live in households at 400% FPL or greater. This is quite different from the nation as a whole where more CYSHCN live in the extremes of poverty (15%) and many fewer live in the highest income category (about 28%) as estimated by the 2001 National Survey of CSHCN (see figure 2). This data likely reflects Maryland's status as one of the wealthier states in the nation.

Figure 2:
Prevalence of CYSHCN living in poverty, Maryland vs. nation



Characterizing the Special Health Care Needs Population

The 2001 National Survey of CSHCN classified CYSHCN in a noncategorical fashion by the consequences of their chronic condition including elevated service use, need for prescription medications, and functional limitations. In Maryland, 19.5% of CYSHCN are reported to have functional limitations due to their conditions on the 2001 National Survey of CSHCN. Almost 40% are reported to use prescription medications alone to manage their condition, and over 25% are reported to use prescription medications and have above routine use of services related to their special health care need (see figure 3). About 17% of Maryland CYSHCN require specialized therapies.



Mental health and developmental problems are particularly prevalent in CYSHCN, and may be increasing. According to the 2001 National Survey of CSHCN, over 28% of CYSHCN in Maryland have ongoing emotional, behavioral, or developmental problems; these children and youth are more likely than other CYSHCN to live in the poorest families. More recently on the 2003 National Survey of Children's Health, 31% of CYSHCN ages 3-17 were reported to have moderate or severe difficulties in the areas of emotions, concentration, behavior, or being able to get along with other people.

The 2003 National Survey of Children's Health reported state-specific data on 2 chronic conditions,

asthma and ADHD. In Maryland, 12.8% of respondents reported that their children had asthma, with 9.3% reporting that their child had experienced health effects from their asthma in the past year. Of children 2-17, 7.9% were reported to have ADHD, with 4.8% taking medication at the time of the survey.

Data from a number of programs serving CYSHCN in Maryland can also help characterize this population. In Maryland as of December 2003, there were 13,697 children and youth ages 0-17 years receiving SSI disability. Almost 66% of these children were receiving their SSI disability benefit under the category of mental disorders, which includes mental retardation. Data from the Mental Hygiene Administration, which administers the State funded mental health system, reports that it served 41,362 severely emotionally disturbed children under age 18 in FY03.

Data from the Maryland State Department of Education indicate that as of October 2003, there were 113,865 children ages 3-21 receiving publicly funded special education services in Maryland. This represents 13% of the population of children enrolled in Maryland public schools, a stable figure compared with 1998, and an increase from about 12% in 1993. Looking at the total enrolled population by ethnicity, students of Asian/Pacific Islander descent and Hispanic descent were underrepresented in the population of students receiving special education services. The majority of the children receiving special education services were male (68.5%) and white (52%). Children with specific learning disabilities account for the highest percentage at approximately 36%. There were 4,084 children receiving services under the autism category, about 2.5 times greater number of children than in 1998 and 14.5 times greater

than in 1993. The other high growth disability in Maryland over this time period is children with emotional impairments, increasing steadily from 5669 children in 1993 to 9727 children in 2003.

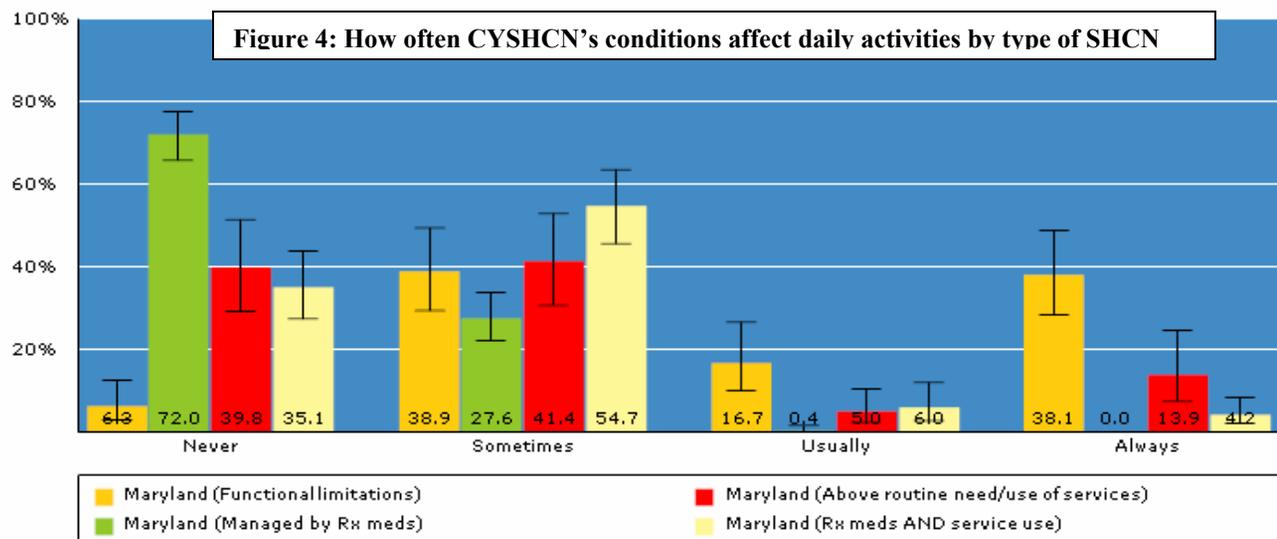
As of October 2004, there were 6,276 children ages 0-3 years receiving services through the Infants and Toddlers program in Maryland.

The Maryland School Health Services Survey completed for the 2002-03 school year reported 109,186 children ages 3-21 in the school system with chronic health conditions; this does not include data from 3 of the largest jurisdictions in the state. Among the conditions reported on the survey were almost 29,000 children with ADHD, over 44,500 children with asthma, 1,434 children with diabetes, 1,939 children with heart problems, and 2,265 children with orthopedic impairments.

Health Status and Quality of Life

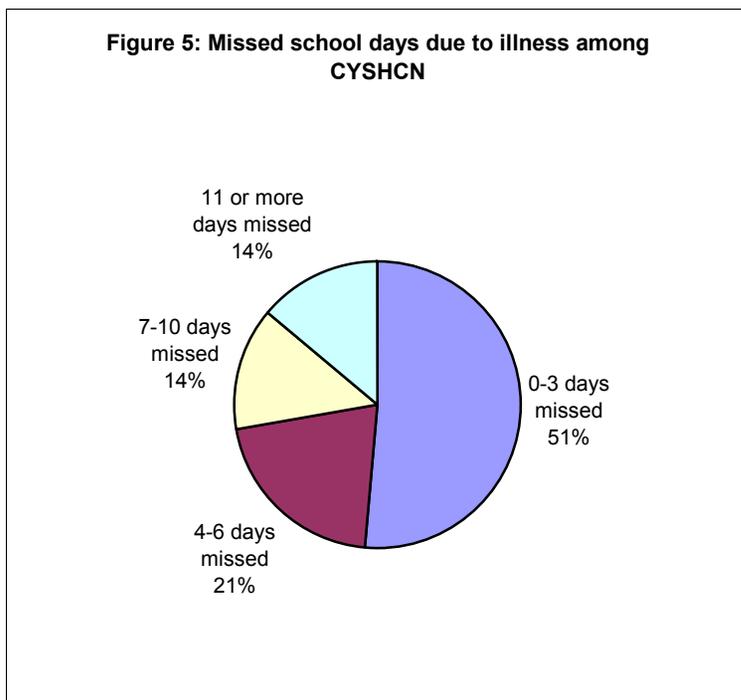
On the 2001 National Survey of CSHCN, almost half (47%) of parents ranked their child's condition as moderate, while about 20% ranked their child's condition as severe or most severe. The remaining 33% ranked their child's condition as mild. Children with functional limitations were most likely to be ranked as severe or very severe by their parents (over 43%), and children just managed by prescription medications were most likely to be ranked as mild (57%). Children at the extremes of poverty were most likely to have their condition ranked as severe or very severe by their parents as compared with children in other income categories.

Over 45% of parents reported that their child's condition never affects his/her daily activities, while about 16% reported that it usually or always does. Children managed by prescription medications alone were least likely to be affected in their daily activities, with 72% reported by parents to never be affected. As



expected, children with functional limitations were most affected in their daily activities, with almost 55% usually or always affected, and another 39% sometimes affected (see figure 4). Once again, children at the extremes of poverty were reported by parents to be most often affected by their conditions.

According to the 2001 National Survey of CSHCN, over half of children (51.5%) missed only 0-3 days of school in the year prior to the survey due to their condition. However, one in 7 CYSHCN were reported to have missed 11 or more school days (see figure 5). Children with functional limitations missed the most school.



The 2003 National Survey of Children’s Health looked at overall health status of children. As might be expected, children without special health care needs were more likely to have their health status reported as excellent or very good than CYSHCN, 91% versus 73%. Of note, on this survey, only 5.5% of CYSHCN had their health status reported as fair or poor.

There is limited data specifically looking at quality of life for CYSHCN. On the 2004 Needs Assessment of Individuals with Spina Bifida conducted by the Chesapeake-Potomac Spina Bifida Association, almost 74% of respondents rated their overall quality of life as excellent or very good.

Health Care Needs and Access to Care

Key Findings

- On the 2001 National Survey of CSHCN, over half of Maryland families reported that their child needed 2-4 different types of health services in the past year, and over 45% needed greater than 5.
- While the majority of CYSHCN received all of the services they needed, about 1 in 6 families reported one or more unmet needs.

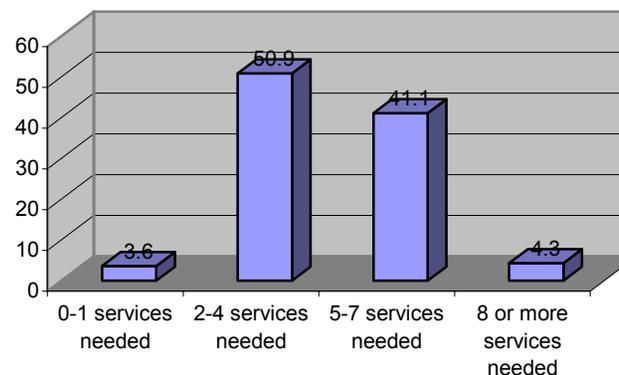
Disparities

- Uninsured CYSHCN and those without adequate insurance were more likely to have one or more unmet needs.
- Hispanic CYSHCN were also more likely to have one or more unmet needs.

Health Care Needs

CYSHCN often require access to a wide range of health and related services. On the 2001 National Survey of CSHCN, slightly over half of Maryland families reported that their CYSHCN required 2-4 services in the past year, while over 45% needed greater than 5. Eight or more services were required by 4.3% of CYSHCN (see figure 6). Children with functional limitations generally required higher levels of services than other CYSHCN. The services required most by CYSHCN were prescription medications (90.4%), routine preventive health care (81.7%), dental care (81%), specialty care (52.6%), vision care or eyeglasses (38%), and mental health care/counseling (27%).

Figure 6: % of CYSHCN reporting need for specific health care services

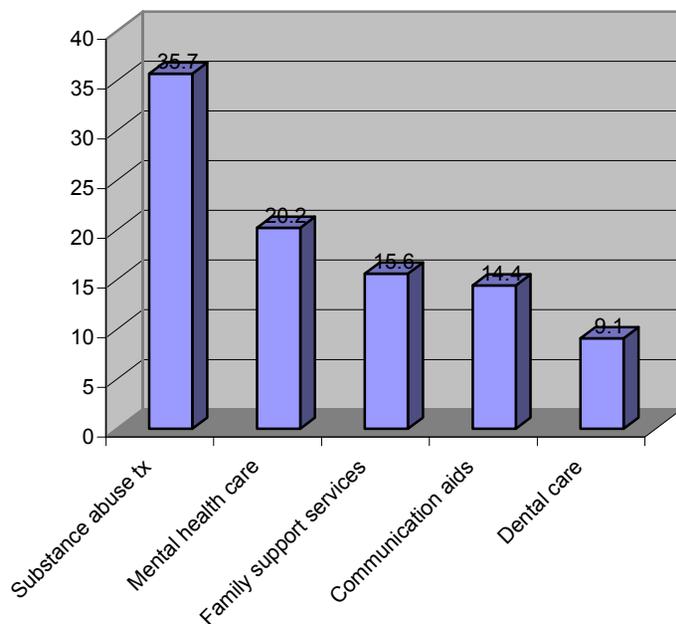


Unmet Need

While the majority of CYSHCN received all of the services that they needed, over 16% had one or more unmet needs for health services in the past year, and 4.5% had 2 or more unmet needs. There were similar findings from the 2004 Needs Assessment of Individuals with Spina Bifida where almost 16% reported unmet need for health and related services. According to the 2001 National

Survey of CSHCN, uninsured CYSHCN, those with inadequate insurance, Hispanic CYSHCN, and CYSHCN without medical homes are more likely to report one or more unmet needs.

Figure 7: % of CYSHCN needing specific services who reported unmet need



Of those families whose child needed specialty care on the 2001 National Survey of CSHCN, almost 27% reported problems getting a referral. Of note, only 3.5% of families reported an unmet need for specialty care. Other services with relatively high unmet need were substance abuse counseling (almost 36% of families whose child needed substance abuse counseling reported unmet need), mental health care or counseling (over 20%), family support services (almost 16%), communication aids or devices (14.4%), and dental care (over 9%, see figure 7). The 2003 National Survey of Children’s Health reported an unmet need for preventive dental care in 6.8% CYSHCN, compared with only 4.1% of children without special health care needs.

On the 2003 Maryland Medicaid Managed Care Customer Satisfaction Survey, the percentage of CSHCN members who were reported to have no problems getting needed care ranged from 67-79% compared with 75-89% for non-CSHCN child members. In addition, only 52-58% of parents of CSHCN members reported on this survey that their child always got care quickly.

Barriers to Care

There are many barriers to needed care for CYSHCN. On the 2001 National Survey of CSHCN, the 5 most frequently cited reasons for delaying or foregoing needed care in descending order were lack of money to pay provider, type of care not covered by health plan, appointments conflicted with other home and work responsibilities, could not get approval from plan/doctor, and could not get appointment soon enough. Further discussion of specific barriers to care for CYSHCN can be found in the corresponding section of the CYSHCN needs assessment report.

Impact on Family

Key Findings

- Mothers of Maryland CYSHCN are significantly less likely to have mental and/or physical health rated as excellent or good than mothers of children without SHCN on the 2003 National Survey of Children's Health.
- Over 27% of families have cut down on work hours to care for their CYSHCN, and over 12% have a member who has stopped working due to their child's condition, according to the 2001 National Survey of CSHCN.
- About 1 in 6 families report that their child's health condition has caused financial problems for their family.

Disparities

- The families most likely to report financial problems due to their child's condition are Hispanic families, families who live at the extremes of poverty, and families whose child has functional limitations.
- The poorest families are also more likely than others to have cut back on work hours or stop working due to their child's condition.

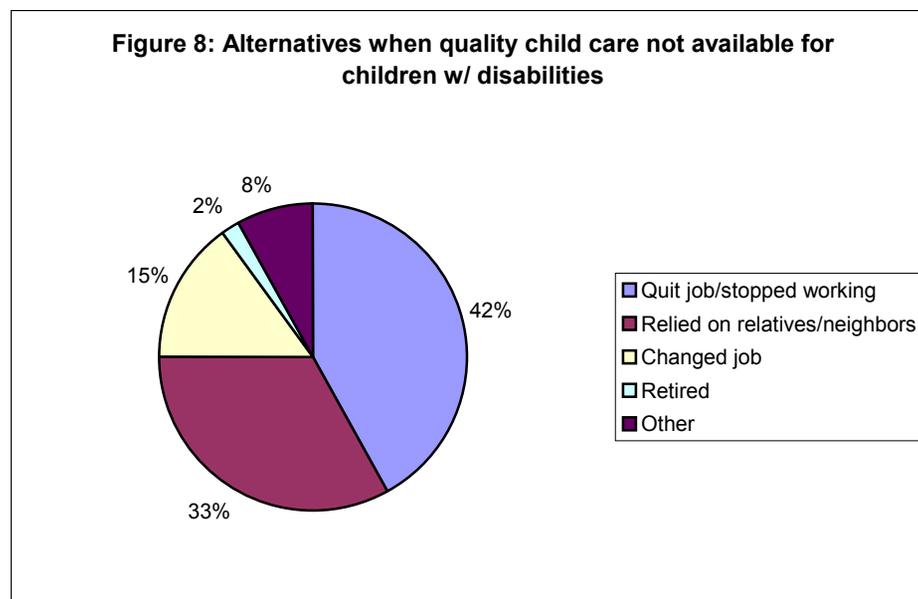
Impact on Employment

Caring for CYSHCN can have a significant impact on families. The needs of CYSHCN can vary greatly. For instance, some children receive care from several providers and have frequent medical appointments. Some are dependent upon technology and may need assistance with basic activities of daily life such as feeding. Others may need to take medications. While the majority of families spend less than one hour per week providing and/or coordinating their child's care, about 1 in 11 families spends 11 or more hours per week doing this, according to the 2001 National Survey of CSHCN. As a result, some families find that it is necessary for a family member to cut back on work hours in order to be able to meet the multiple demands of caregiving. Over 27% of families have cut down on work hours to care for their CYSHCN, and over 12% have a member who has stopped working due to their child's condition, according to the 2001 National Survey of CSHCN. The poorest families are more likely than others to cut back on work hours or to stop working.

Access to Child Care

Lack of quality child care certainly contributes to the impact that having CYSHCN can have on employment. In 2003, the Maryland Disabilities Council surveyed families of children with disabilities about child care issues; 83% of respondents reported difficulties in

finding, obtaining, or keeping child care. When asked what their alternative was when they were unable to find child care, 42% reported that they had stopped working, and 33% had changed jobs to accommodate their lack of child care (see figure 8). The number one barrier to obtaining and/or keeping child care reported on the Developmental Disabilities Council survey was lack of provider willingness to accept the child, presumably based on the child’s disability. Also ranked highly were concerns about quality of care available for their child and lack of provider knowledge about how to meet the child’s special needs. The lack of quality child care for CSHCN is supported by data from the 2003 National Survey of Children’s Health, where almost half of families with CSHCN ages 0-5 reported problems with child care, significantly greater than reported by families whose children did not have special health care needs. Data from the Developmental Disabilities Council as well as from town meetings across the state on Inclusive Child and After School Care also support the need for appropriate after school care programs for CYSHCN.



Financial Impact

Cutting back on work hours or stopping work altogether can significantly impact a family’s finances. In addition, the costs associated with providing care for CYSHCN can be great. About 1 in 11 families reported out-of-pocket health care costs between \$1001-\$5000 per year on the 2001 National Survey of CSHCN. Based on 2004 focus group data from the Maryland Family Access Initiative, depending upon the child’s diagnosis, out-of-pocket expenses could reach up to \$10,000 per year. It is not surprising, therefore, that about 1 in 6 families reported that their child’s health condition has caused financial problems for their family, according to the 2001 National Survey of CSHCN. The families most likely to report financial problems due to their child’s condition were Hispanic families, families who live at the extremes of poverty, and families whose child has functional limitations.

Family Health and Respite

The issues discussed above can put stress on family members of CYSHCN. According to the 2003 National Survey of Children’s Health, mothers of CYSHCN are significantly less likely to have mental and/or physical health rated as excellent or very good than

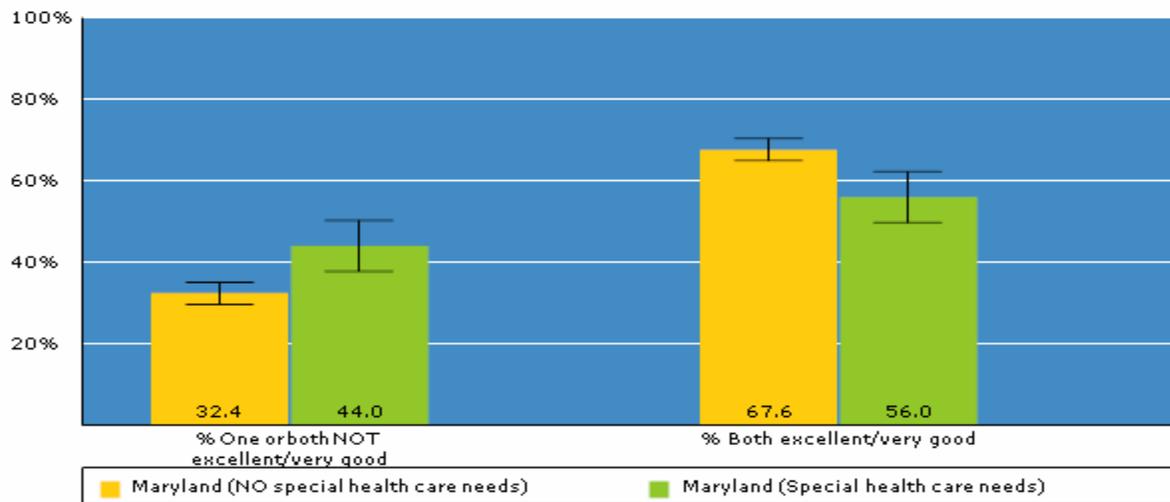


Figure 9: Children & youth w/ mothers whose mental and physical health are BOTH excellent/very good

mothers of children without special health care needs (see figure 9). The need for regular respite activities for families is a recurring theme in all local health department needs assessments. On the 2004 Needs Assessment of Individuals with Spina Bifida, over 20% of respondents reported problems with lack of respite care. According to the 2001 National Survey of CSHCN, about 22% of Maryland families who reported needing respite in the 12 months prior to the survey indicated that they did not receive all of the respite care that was needed. Respite was identified as the 2nd highest area of unmet need in the survey. The limited availability of trained respite providers in certain areas of the state as well as lack of education on the part of families regarding respite services are barriers that have been identified related to accessing respite care.

Comprehensive Health Care Through a Medical Home

Strengths/Assets

- Over 92% of Maryland CYSHCN are reported to have a usual source of care on the 2001 National Survey of CSHCN.
- 90.5% of families feel that their child's health care providers usually or always listen carefully to them, and almost 89% feel that their child's providers spend enough time with them.
- 91% of families reported a personal doctor or nurse who is consistently available when phone advice or urgent care is needed for their child on the 2003 National Survey of Children's Health.

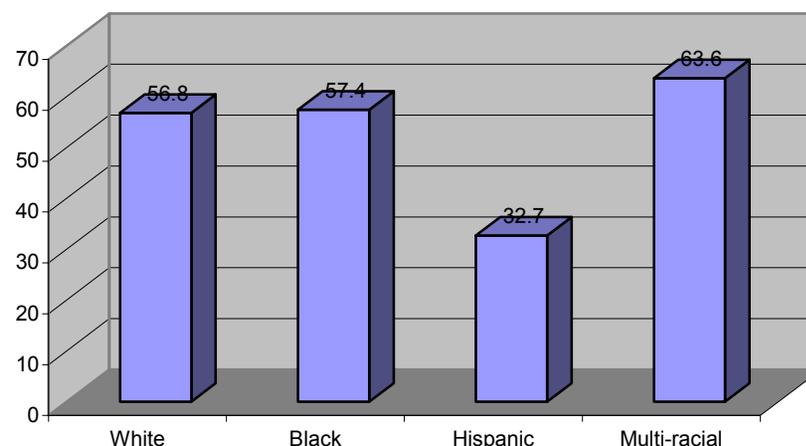
Challenges/Needs

- Just over 56% of Maryland CYSHCN are receiving care that meets all criteria for a medical home according to the 2001 National Survey of CSHCN.
- Only about 35% of families have effective care coordination for their CYSHCN when needed.
- Hispanic CYSHCN, children with functional limitations, and uninsured CYSHCN are the groups least likely to report care consistent with a medical home.

Medical Home Prevalence

While having a medical home is important for all children, CYSHCN in particular need the type of care embodied by this model. According to the 2001 National Survey of CSHCN, just over 56% of Maryland CYSHCN are receiving care that meets criteria for a medical home compared with 52.7% nationally. Hispanic CYSHCN, children with functional limitations, and uninsured CYSHCN are the groups least likely to report care consistent with a medical home (see figure 10). Although the more recent 2003 National Survey of Children's Health measured medical home in a different fashion, similar results were seen for Maryland with just over 51.4% of CYSHCN reporting care consistent with a medical home model. This is compared with 55.8% of children without SHCN reporting care consistent with a medical home.

Figure 10: % of CYSHCN who have medical homes by race/ethnicity



Usual Source of Care

Having a usual source of care is a starting point for a medical home. Over 92% of Maryland CYSHCN are reported to have a usual source of care on the 2001 National Survey of CSHCN. A personal doctor or nurse for their CYSHCN was reported by just over 88% of families on this survey, and almost 94% of families on the 2003 National Survey of Children's Health. This is also reinforced by data from the 2003 Needs Assessment of Individuals with Spina Bifida. This survey found that 94% of respondents reported having a primary care provider. In Maryland, the greater need is to move beyond just having a usual source of care and put a more comprehensive medical home model into practice.

Coordinated Care

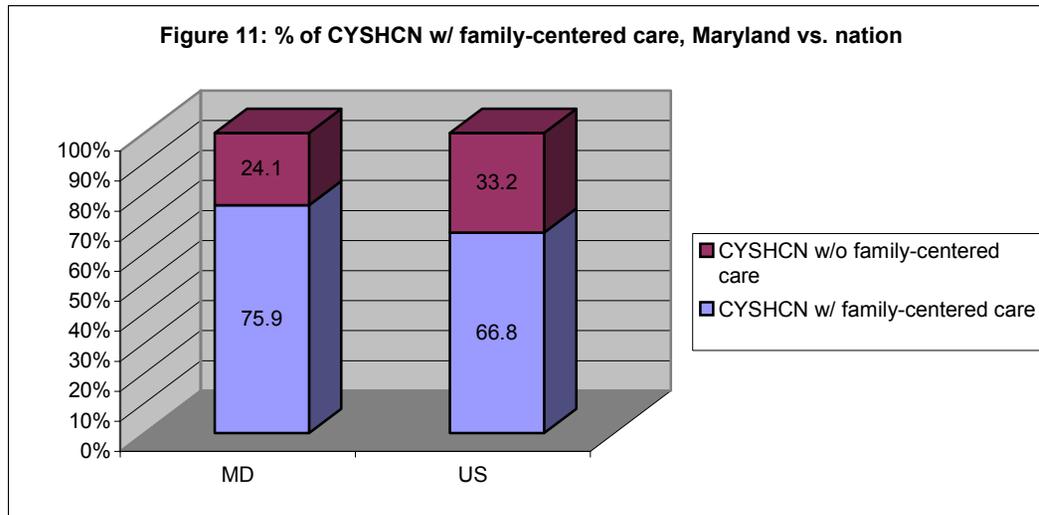
One particular need reported by families is for better coordination of care by health care providers. On the 2001 National Survey of CSHCN, only about 35% of respondents were found to have effective care coordination for their CYSHCN when needed. In a local health department needs assessment in Somerset County (2003), almost all respondents reported that their child's care was sometimes to never coordinated by a professional, and in a series of focus groups conducted by the Maryland Family Access Initiative grant in 2004, families almost unanimously reported that they were receiving no supports with care coordination and none from their primary health caregivers. A key issue in care coordination is communication. On the 2001 National Survey of CSHCN, only 48% of families of CYSHCN who needed care coordination reported that their doctor's communication with other health care providers was excellent or very good, and only 27% reported that their doctor's communication with other programs was excellent or very good. Lack of communication among providers was also a barrier to medical home identified in a series of medical home focus groups held by the Maryland chapter of the American Academy of Pediatrics throughout the state in early 2005. Even providers note that effective communication and collaboration is problematic. For example, in a local health department needs assessment in Talbot County (2003), providers identified a key need for liaisons between parents, schools, agencies, and medical providers.

Accessible Care

Accessibility of care is a critical medical home component. On the 2003 National Survey of Children's Health, 91% of families of CYSHCN reported a personal doctor or nurse who is consistently available when phone advice or urgent care is needed for their child. A more problematic issue involving accessibility is referral to specialty care. On the 2001 National Survey of CSHCN, almost 27% of families who reported that their child needed specialty care had problems getting a referral. The medical home focus groups highlighted a tension between parents and providers about what constitutes an "appropriate" referral. Insurance barriers and availability of specialists also play a role in this issue. An additional problem related to referrals was highlighted on the 2003 National Survey of Children's Health, where only 62.5% of families reported having a personal doctor or nurse who consistently follows up with the family after the CYSHCN sees a specialist or gets specialized services/equipment. A lack of follow-up by physicians after referrals was also noted in the medical home focus groups held by the Maryland chapter of the American Academy of Pediatrics.

Family-Centered Care

Another important pillar of the medical home model is family-centered care. This is a relative strength for Maryland according to the 2001 National Survey of CSHCN, where it was estimated that almost 76% of Maryland CYSHCN receive care that is family-centered,



compared with less than 67% nationwide (see figure 11). The survey estimated that 90.5% of families felt that their child's health care providers usually or always listened carefully to them, almost 89% felt that their child's health care providers spent enough time with them, and over 90% felt that their child's health care providers were sensitive to their families' values and customs. On the 2003 National Survey of Children's Health, 79% of families reported that their CYSHCN had a personal doctor or nurse who consistently spent enough time with them and explained things in a way that parents and the child could understand. In Maryland, family-centered care was found to be less accessible to

CYSHCN who had functional limitations, children who were Hispanic, and children without insurance. Not surprisingly, this is similar to the disparities found for having a medical home as noted previously. One emerging issue of importance that was noted in local health department needs assessments by both parents and providers (Caroline County 2004, Frederick County 2000) was the issue of inadequate resources for communicating appropriately with families with limited English proficiency.

Cost of Care/Reimbursement

The greatest barriers to providing medical homes identified by pediatricians in the medical home focus groups conducted by the Maryland chapter of the American Academy of Pediatrics were time and money. Caring for CYSHCN takes more time than caring for a child without special health care needs, and much of this time is either not reimbursed or inadequately reimbursed by insurance companies. Examples included the time needed for extended visits, making referrals, refilling prescriptions, writing letters of medical necessity, communicating with other providers, and generally coordinating care. They also noted the burden of trying to keep up with the various and changing procedures and provider lists among the many insurance companies that they must deal with. This takes so much time and effort that many practices are resorting to use of a dedicated referral coordinator, but this again is an unreimbursed expense for the practice.

Adequate Insurance to Pay for Services

Strengths/Assets

- On the 2001 National Survey of CSHCN, over 97% of Maryland families of CYSHCN reported having insurance at the time of the interview.
- Over 93% reported no gaps in health insurance coverage in the year prior to the survey, compared with 88.4% nationally.

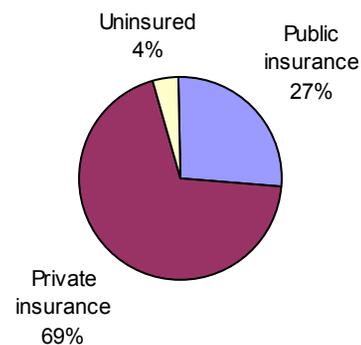
Challenge/Needs

- Almost 1/3 of Maryland CYSHCN do not have adequate insurance, according to the 2001 National Survey of CSHCN.
- CYSHCN from the poorest families are more likely to lack insurance coverage or to have insurance that is not adequate to pay for the services they need.
- Hispanic and multi-racial CYSHCN and those with functional limitations are less likely to have adequate insurance.

Rate of Insurance Coverage

On the 2001 National Survey of CSHCN, over 97% of Maryland families of CYSHCN reported that their child had public or private health insurance at the time of the interview. The national rate of uninsurance was almost double the Maryland rate. In addition, over 93% of Maryland families of CYSHCN reported that their child had no gaps in health insurance in the year prior to the survey, compared with 88.4% nationally. While the overall rate of insurance coverage for Maryland CYSHCN is high, CYSHCN from the poorest families are more likely to lack insurance coverage, with an uninsurance rate estimated at 2.5 times higher for families living at 0-99% FPL than for Maryland CYSHCN as a whole. Although the numbers are small, this data is similar to the trend at the national level. In addition, from Maryland's experience with the Children's Medical Services Program which serves as payer of last resort for specialty care and related services for uninsured and undersinsured CYSHCN, it is known that a significant portion of the uninsured children in Maryland lack coverage due to their citizenship status. This number

Figure 12: Type of health insurance coverage CYSHCN



will increase as of July 1, 2005, when about 3000 Maryland children who are legal immigrants but have lived in the US for less than 5 years will lose their health insurance through Maryland Medicaid.

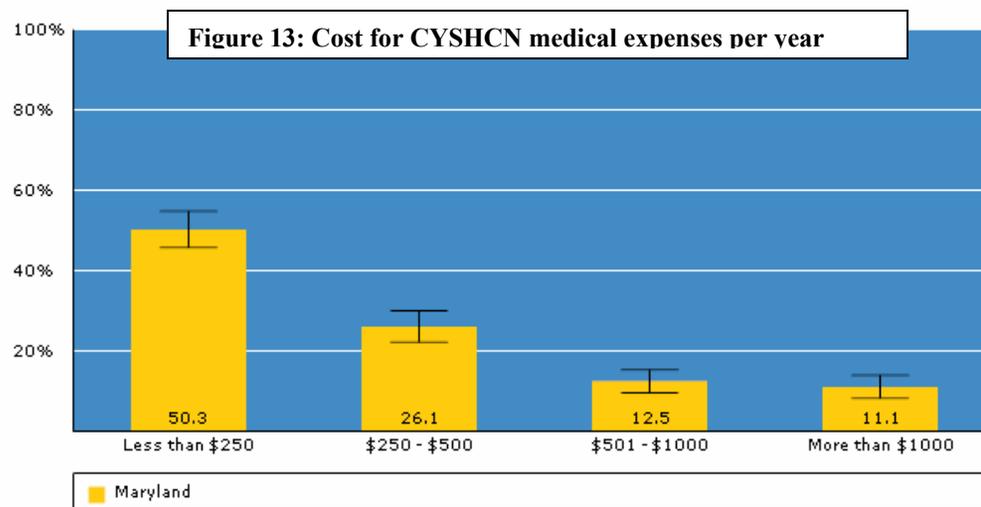
The overall high rate of insurance coverage for CYSHCN in Maryland is supported by more recent data from the 2003 National Survey of Children's Health, where 95.9% of CYSHCN were insured at the time of the survey. Additionally, this survey indicated that the majority of insured CYSHCN are covered by private insurance (over 69%) with less than 27% covered by public insurance (see figure 12).

Adequacy of Insurance

Adequacy of health insurance is the greater challenge in Maryland. According to the 2001 National Survey of CSHCN, almost 1/3 of Maryland CYSHCN do not have insurance that is adequate to pay for the services they need. On the 2004 Needs Assessment of Individuals with Spina Bifida, over half of respondents indicated that getting health care services covered by their insurance was definitely or somewhat of a problem. Similarly, on the 2005 Hemophilia Foundation Needs Assessment, 43% of respondents were concerned about getting services covered by their health insurance. Adequacy of insurance is a greater problem for CYSHCN from the poorest families, for Hispanic and multi-racial CYSHCN, and for CYSHCN who have functional limitations, according to the 2001 National Survey of CSHCN.

Out-of-Pocket Costs

One issue related to insurance adequacy is out-of-pocket costs. On the 2001 National Survey of CSHCN, over 1/4 of families of CYSHCN reported that costs not covered by insurance were never or only sometimes reasonable. In Maryland, families with private insurance tend to incur more out-of-pocket costs than those with other insurance types. About 1 in 9 families reported costs greater than \$1000 per year on the National Survey of CSHCN (see figure 13); families whose child had private insurance were about 3.5 times more likely to report this than those whose child had Medicaid. Based on 2004 focus group data from the Maryland Family Access Initiative, depending upon the child's diagnosis, out-of-pocket expenses could reach up to \$10,000 per year.



Access to Needed Providers

Another critical issue is access to needed providers. On the 2001 National Survey of CSHCN, about 1 in 11 families reported that their child's insurance never or only sometimes allowed them to see needed providers. Focus groups on medical home conducted by the Maryland chapter of the American Academy of Pediatrics in early 2005 highlighted the fact that some pediatric providers do not accept Medicaid or limit the number of patients with Medicaid due to lower reimbursement rates. On the 2003 Maryland Medicaid Managed Care Customer Satisfaction Survey, 21% of child members reported having significant problems seeing needed specialists. Difficulty accessing needed specialists services was also reported in Maryland family Access Initiative focus group findings for both those with Medicaid and those with private insurance, as well as in a number of local health department needs assessments (Talbot County 2003, Somerset County 2003, Caroline County 2004, Frederick County 2000). Issues included no appropriate specialist in network and no appropriate specialist in geographic proximity. The providers most frequently noted were mental health providers and dental providers.

Other Scope of Benefits

Insurance plans may place limitations on coverage for certain types of services that particularly impact CYSHCN. For instance, some plans limit the number of visits per year to mental health providers or limit visits for specialized therapies such as PT, OT and speech. In addition, plans can restrict how frequently durable medical equipment can be purchased and the types of equipment covered. These restrictions translate into out-of-pocket costs as noted above, or families may do without services. While this information is heard not infrequently when discussing insurance issues with families, there was little data from the needs assessment about these specific issues.

Navigating Health Plans

A final issue is the complexity of using health plans and difficulty getting or understanding information about how to use the plan or how to appeal adverse decisions. On the 2003 Maryland Medicaid Managed Care Customer Satisfaction Survey, between 23-38% of respondents with a child with special health care needs reported difficulties with customer service in their plans, compared with 13-25% of child members with no special health care need. Based on statistics tracking family calls to Parents' Place of Maryland through the Maryland Family Access Initiative in 2004 for assistance with insurance issues, the number one concern of callers with either Medicaid or private insurance was lack of information about how to navigate their plans.

Community-Based Services Organized for Easy Use

Strengths/Assets

- Over 70% of Maryland families of CYSHCN report that services are usually or always organized for easy use on the 2001 National Survey of CSHCN.

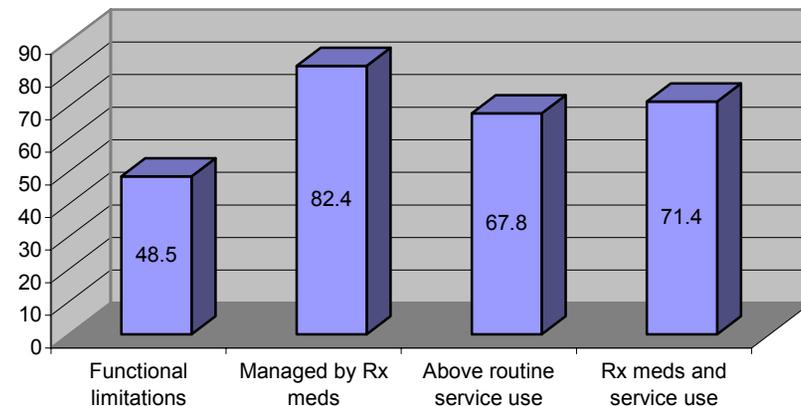
Challenges/Needs

- Less than half of families whose CYSHCN have functional limitations report that services are organized for easy use.
- Only 43% of families of uninsured CYSHCN report that services are organized for easy use.
- Hispanic and multi-racial families of CYSHCN are less likely to report that services are easy to use.

Organization for Easy Use

CYSHCN and their families must often access a number of health-related and family support services to meet their needs. Ideally, all of the services that a child and family require would be easily available and accessible within that child's community. On the 2001 National Survey of CSHCN, over 70% of families of CYSHCN reported that services were usually or always organized for easy use. While this represents the majority of CYSHCN and their families, there is still a significant number who feel that there are problems with how community-based service systems are organized. In particular, a little less than half (48.5%) of families whose CYSHCN have functional limitations report that services are organized for easy use (see figure 14). The survey data suggest that these children are those with more severe health conditions or disabilities, and it is likely that they may require more extensive services than other children with special health care needs. In addition, families whose CYSHCN are uninsured are also much less likely to report that services are organized for easy use. It is not surprising that lack of health insurance presents a barrier to using needed services within the community. Hispanic and multi-racial families of CYSHCN are also less likely to report that services are easy to use. This may in part reflect issues with limited English proficiency and lack of culturally competent service systems.

Figure 14: % of CYSHCN reporting community services organized for easy use, by SHCN type



Navigating the System

Other available data beyond the 2001 National Survey of CSHCN highlight a number of different problems that are perceived by families and providers related to community-based systems of care. A persistent problem is the issue of “navigating the system” or finding out about available services within the community and gaining access to them. On the 2003 Needs Assessment of Individuals with Spina Bifida, 60% of respondents reported a lack of information about available services. Tracking calls to Parents’ Place of Maryland as part of the Maryland Family Access Initiative in 2004, one of the top 3 needs of families was information about health care and non-medical services and how to access them. In addition, multiple local health department needs assessments (Caroline County 2005, Talbot County 2003, Frederick County 2000) indicated a need for information and referral mechanisms, resource coordinators, and “helping families know about services.”

Of note, in the medical home focus groups held by the Maryland chapter of the American Academy of Pediatrics in early 2005, parents did not feel that pediatrician’s offices were a good source of information on accessing community resources. Even pediatricians admitted that they don’t typically have this type of information in their offices, and some had never even thought about this. Most thought that it was a good idea to have information about community resources available to families, but they didn’t feel like they had the time or personnel to put this together for their practice.

Local Access to Services and Transportation

Another barrier to community-based systems of care, particularly in the outlying areas of the state such as the Eastern Shore and Western Maryland, is the limited availability of specialty providers (especially mental health) and dentists within the community. Even when providers are available locally, there may be other problems such as long waiting lists or insurance issues (especially not accepting Medicaid). When providers are not available or accessible within the community, families are forced to travel, sometimes several hours to the large specialty centers, in order to get the care that their child needs. Transportation remains a major barrier for many families, as noted in virtually every local health department needs assessment. Lack of providers for CYSHCN within the community also extends to specialized therapies such as PT, OT and speech/language services in some areas of the state as well as respite, child care, and other family support services. Once again, this forces families to look for these services outside their community or to go without them.

Family-Professional Partnerships and Satisfaction with Services

Strengths/Assets

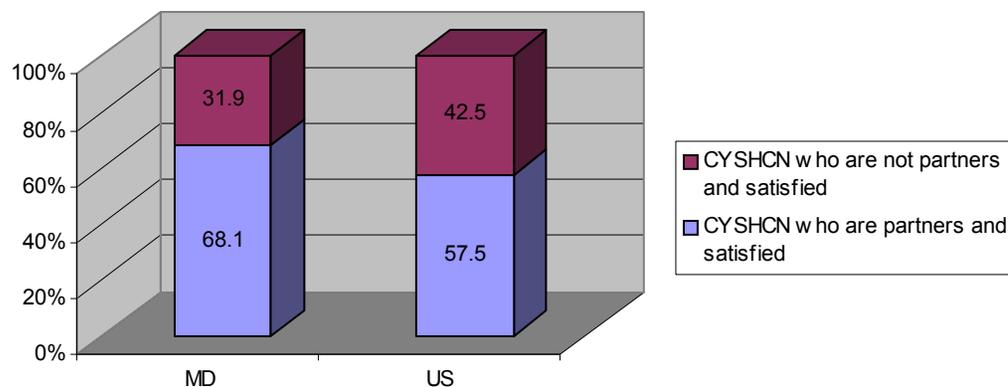
- According to the 2001 National Survey of CSHCN, over 88% of families of Maryland CYSHCN report that their child’s health care providers help them feel like a partner in care.
- Over 70% of Maryland families report that they are very satisfied with services compared with 60% nationally.
- Almost 76% of families of CYSHCN are estimated to receive family-centered care, compared with less than 67% nationwide.

Challenges/Needs

- Hispanic families, uninsured families, and those whose child has a functional limitation are less likely to report feeling like partners and satisfaction with care.
- These same families are also less likely to receive care that is family-centered.

Family-professional partnerships and satisfaction with care are a relative strength for Maryland. According to the 2001 National Survey of CSHCN, over 68% of families of CYSHCN report that they are partners in decision-making and are satisfied with the services they receive, compared with 57.5% nationally (see figure 15).

Figure 15: % of CYSHCN who are partners in care and satisfied w/ services, Maryland vs. nation



Family-Professional Partnerships

Over 88% of families of Maryland CYSHCN report that their child’s health care providers help them feel like a partner in care on the 2001 National Survey of CSHCN. This finding is supported by data from the 2003 Needs Assessment of Individuals with Spina Bifida which found that over 82% of respondents felt that medical personnel have kept them informed and involved in health care decisions.

Satisfaction with Care

Over 70% of Maryland families report that they are very satisfied with services on the 2001

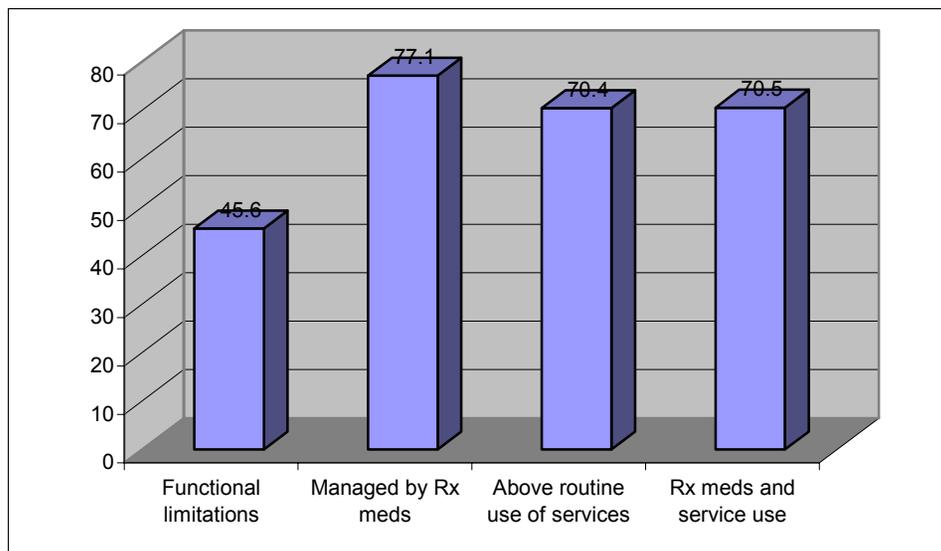
National Survey of CSHCN, compared with only 60.1% nationally. Satisfaction with health care services in Maryland is also indicated by the 2003 Medicaid Managed Care Customer Satisfaction Survey where families of CSHCN members gave their child’s overall health care an average rating of 8.6-8.8 out of 10 and gave their child’s personal doctor or nurse average ratings of 8.8-9.2 out of 10. In addition, on the 2005 Hemophilia Foundation Needs Assessment, 91% of respondents were satisfied with the quality of their health care services.

Family-Centered Care

According to the 2001 National Survey of CSHCN, almost 76% of Maryland families of CYSHCN receive care that is family-centered, compared with less than 67% of families of CYSHCN nationwide. Family-centered care is discussed in detail under the domain “Comprehensive Health Care Through a Medical Home.”

While Maryland does appear to do somewhat better than the nation in regards to family-professional partnerships, satisfaction with services, and family-centered care, there is certainly a good deal of room for improvement. The 2001 National Survey of CSHCN does indicate some areas of disparity, including Hispanic families, uninsured families, and families whose child has functional limitations (see figure 16).

Figure 16:
% of CYSHCN who are partners in care and satisfied w/ services by SHCN type



Early and Continuous Screening

Strengths/Assets

- In Maryland, almost 100% of newborns who are screened and confirmed with conditions receive appropriate follow-up as defined by the State.
- According to FY04 data, 91.2% of newborns were screened for hearing before leaving the hospital.
- Screening of children through EPSDT has been increasing.

Challenges/Needs

- Available data indicate that loss to follow-up at a number of levels is problematic for the UNHS Program.
- The 2003 National Survey of Children's Health estimated that almost 1 in 4 Maryland children is at moderate or high risk for developmental delay
- This survey documented that almost 47% of families of children ages 0-5 reported that they were not asked by their providers if they had concerns about their child's learning, development, or behavior in the past year.

Newborn Metabolic Screening

Screening is an important mechanism for the early identification of special health care needs in children. Institution of early treatment for children identified with certain disorders may prevent serious health and developmental consequences. Through the newborn metabolic screening and follow-up program in Maryland, almost 100% of babies identified with disorders are linked with appropriate medical care and other needed services. In the past several years, only one baby (a child with sickle cell disease) has been lost to follow-up as defined by the State. In FY04, 133 babies with metabolic and hematologic disorders were detected through the newborn metabolic screening and follow-up program.

In Maryland, the most important problem over the past 2-3 years has been the increasing difficulty in maintaining a comprehensive newborn screening program with 2 laboratories in the state licensed to provide newborn screening: the State public health laboratory and a private lab, Pediatrix. There have been a number of obstacles to providing what the OGCSHCN considers appropriate follow-up, particularly related to data sharing with Pediatrix and with comparing the results from several specimens on the same baby when some go to Pediatrix and some go to the State lab (Maryland has a routine 2nd specimen). The problems encountered are becoming increasingly significant as the fraction of Maryland hospitals using Pediatrix increases.

Maryland currently screens for all of the disorders recommended by the American College of Medical Genetics and the March of Dimes except for cystic fibrosis. However, cystic fibrosis will be added in the near future. The recent national attention brought to

newborn screening has created some tension between advocates and the newborn screening program. While new technology continues to make it possible to screen for increasing numbers of disorders, there does not appear to be awareness in the general public that not all conditions may be appropriate for screening. In addition, the resources required to create and support the infrastructure that would be needed for adequately following up individuals identified through a further expanded screening process are lacking.

Shortly after Maryland expanded its newborn screening panel to include disorders detectable through tandem mass spectrometry, focus groups on communication around newborn screening were conducted separately with new mothers of healthy infants and with pediatricians. Most mothers indicated that they had very little information about newborn screening. This is despite the fact that all mothers are given a brochure about newborn screening in the hospital and asked to sign a consent form prior to the heel stick. Many mothers remembered seeing the newborn screening brochure in their packet of information, but most reported receiving little information about it and did not read it. Mothers and pediatricians felt it was important that parents should have some basic information about newborn screening presented in a simple format, and both mothers and pediatricians indicated they would like to have information presented prenatally as well as after the baby is born.

Newborn Hearing Screening

In Maryland's Universal Newborn Hearing Screening (UNHS) Program, most newborns are screened for hearing prior to hospital discharge. This was 91.2% of infants in FY04, down slightly from 93.7% in FY03. Historically, between 180-210 infants are diagnosed with hearing loss each year in Maryland, with the average age at diagnosis 93.7 days in FY03. Nearing the end of its 5th year, the UNHS Program has made great strides in screening Maryland babies, but still experiences loss to follow-up at a number of levels. Recent evaluation of program data identified a number of problem areas. First, there are a disproportionate number of NICU babies lost to follow-up, which is particularly concerning because many of these infants are at a greater risk for hearing loss. In addition, the UNHS Program has noted that the number of infants failing the initial hearing screen who do not receive a rescreen by 6 weeks of age is relatively high. Follow-up specialists in the UNHS Program continue to meet resistance from parents and medical personnel when calling to suggest rescreening. Lastly, there is a lag between rescreen failure and diagnostic evaluation, which it seems may be at least partly due to failure of the audiology community to report diagnostic evaluations to the UNHS Program.

Another identified need of the Program is to raise awareness of the importance of early intervention services for children who are diagnosed with hearing loss. The Chapter Champion of the Maryland chapter of the American Academy of Pediatrics surveyed pediatricians in 2004. While 61.5% of respondents claimed familiarity with early intervention services in their area (i.e. the Infants and Toddlers Program), less than half referred to early intervention. In a survey of licensed audiologists also conducted in 2004 by Towson University Department of Audiology, only 64% of audiologists reported that they refer to the Maryland Infants and Toddlers Program. The UNHS Program also currently lacks the ability to track children's entry into early intervention services as well as the outcomes of intervention over time.

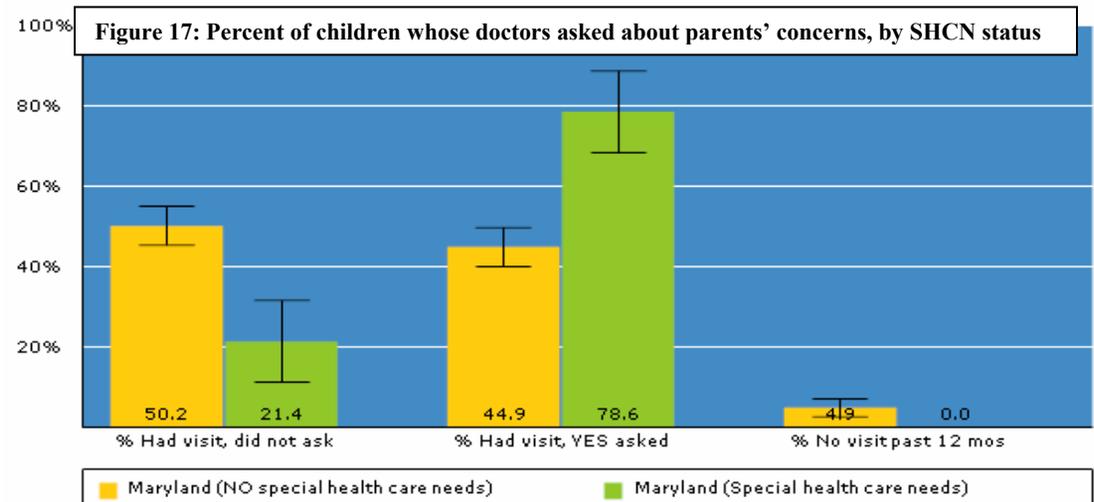
Birth Defects Surveillance

While not a screening program, the Birth Defects Reporting and Information System (BDRIS) seeks to identify children with birth defects as early as possible after birth and link their families with services. Maryland law currently mandates reporting of only 12 sentinel birth defects, with voluntary reporting of others. BDRIS is a passive surveillance system, and must rely upon the reports from providers in addition to reviewing vital records for case ascertainment. This creates a time lag in the program’s ability to accurately report data. The most recent complete statistics are from CY02, during which there were 536 sentinel defects in 491 Maryland babies and 1,034 non-sentinel defects. The rate of defects has been relatively stable over the past few years.

Since the adoption of HIPAA regulations, BDRIS has encountered significant difficulty in obtaining the medical information critical to fulfilling its role. This is due to concerns from health care providers about the extent to which the release of information is legally authorized under HIPAA. A need in Maryland is to pass legislation that will allow BDRIS to collect data on all birth defects, and to give the program clear-cut authority to access medical records for the purpose of identification and characterization of birth defects cases, investigation of birth defects clusters or potentially hazardous trends in the prevalence of birth defects, and investigation of environmental hazards. A bill to this effect was introduced in the 2005 legislative session, but ultimately failed due to unresolved concerns about informed consent issues.

Screening for Developmental and Behavioral Problems

The 2003 National Survey of Children’s Health estimated that almost 1 in 4 Maryland children is at moderate or high risk for developmental delay. However, in terms of screening for developmental and behavioral problems, this survey documented that almost 47% of families of children ages 0-5 reported that they were not asked by their providers if they had concerns about their child’s learning, development, or behavior in the past year. While almost 80% of families with CSHCN were asked about these concerns, less than 45% of families whose children did not have a special health care need were asked (see figure 17). In medical home focus groups held by the Maryland chapter of the American Academy of Pediatrics in



2005, many parent and professional participants felt that pediatric health care providers are not performing thorough screening for developmental problems. Issues raised were inappropriate or incomplete use of screening tests, amount of time required to administer tests, and lack of reimbursement.

Even when screening is accomplished and concerns are identified, there may be barriers to following up on these concerns. Of those families who reported that they were highly concerned about their child's learning, development, or behavior, over 45% reported that they did not get specific information from their doctors to address their concerns. Families with CSHCN were much more likely to report getting specific info than families who had children without special health care needs, almost 74% versus about 41%. In the medical home focus groups, families reported that some pediatricians seem to be reluctant to diagnose certain developmental and mental health problems and may recommend taking a "wait and see" approach rather than refer for specialist evaluation.

EPSDT

The Maryland Medicaid program tracks screening under EPSDT. On the 2003 Annual EPSDT Participation Report, an improvement from the previous year was reported in overall child screening ratio from 72% to 74%. Ratios were .96 for children under age 1 year, 1.13 for children ages 1-2, and .78 for children ages 3-5. Older children were screened at a ratio of .51 or less, which emphasizes the need for "continuous" screening as children get older.

Lead Screening

Elevated blood lead levels remain a serious problem for Maryland. Lead screening will be discussed elsewhere in the Maryland needs assessment report.

Transition to Adult Life

Strengths/Assets

- Available data indicates that some of the important components necessary for successful transition to adult life are occurring for some Maryland CYSHCN.

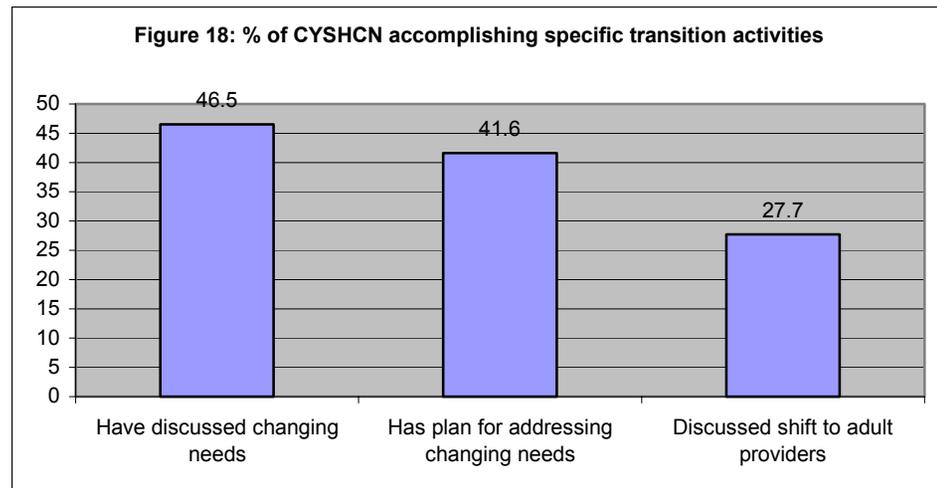
Challenges/Needs

- The 2001 National Survey of CSHCN estimates that the number of Maryland CYSHCN ages 13-17 who receive all the services necessary to make the transition to all aspects of adult life is only 2.7%.
- For the majority of CYSHCN, the data suggest that there is no cohesive plan to assist with transition to adult life and/or there are significant barriers within the current system to address transition needs.

Transition to adult life has emerged as an important issue as more CYSHCN are surviving into adulthood. The 2001 National Survey of CSHCN estimated that the number of Maryland CYSHCN ages 13-17 who receive the services necessary to make the transition to all aspects of adult life is only 2.7%; this is compared with an estimate of 5.8% for the nation as a whole.

Health Care Transition Process

Transition must take place in a number of different arenas. Health care transition is helping young people with special health care needs plan their move from the child-centered health care system to the adult-centered health care system. On the 2001 National Survey of CSHCN, about 47% of families of CYSHCN reported that they had providers who have talked with them about changing needs as an adult, and almost 42% had providers who have developed a plan with the child/youth to address changing needs (see figure 18). The 2005 Hemophilila Foundation Needs Assessment found that for individuals who had already transitioned, only 40% reported that someone had spoken to them about their transition to adult care. In transition focus groups held



with parents and their youth ages 13-21 across the state, very few families reported that their doctors had discussed health care transition with them, and very few had begun the process on their own. In fact, in the youth discussion, youth under age 18 expressed little knowledge and interest regarding health care transition.

Change to Adult Providers

One aspect of health care transition is the change to adult health care providers. On the 2001 National Survey of CSHCN, less than 28% of families of CYSHCN had providers who have discussed the eventual shift to adult providers (see figure 18). The 2004 Needs Assessment of Individuals with Spina Bifida found that a little over 50% of respondents over age 13 had talked with their primary care provider about seeing adult providers. In the transition focus groups, families and youth expressed a number of concerns related to finding a new doctor that takes care of adults. One concern was whether there would be a doctor willing to take on their youth with special health care needs. In medically underserved areas of the state, parents felt it was difficult enough to find good doctors for “normal, healthy adults.” A second concern was finding providers who were knowledgeable about the youth’s particular health condition or disability. Parents expressed that they were uneasy with the thought of their child being treated by doctors who did not have knowledge or experience with their child’s medical condition or disability, even if the doctor was willing to learn. They also expressed frustration at potentially having to educate a new doctor about their child’s condition. Youth generally expressed similar views. Lastly, families had concerns about the nature of the adult health care environment including differences in bedside manner and how individuals are treated, and less accommodating scheduling, office hours, etc.

Assuming Responsibility for Care

Another important component of health care transition is for CYSHCN to learn to take responsibility for their care as developmentally appropriate. In the 2004 Needs Assessment of Individuals with Spina Bifida, over 63% of respondents over age 13 reported that they knew how to manage their health care. In the 2005 Hemophilia Foundation Needs Assessment, parents reported that children as young as 6 years of age were assisting with some aspects of their health care. While some parents in the transition focus groups had already taken a few steps toward encouraging their children to play a more active role in their health care, they reported that it is often difficult to get their children to take on more responsibility. In families where the youth had a condition that significantly interferes with decision-making, a number of parents were wrestling with the issue of obtaining some form of guardianship. However, there was a general lack of information about how and when to obtain guardianship, the benefits and risks involved, and the cost of getting legal help.

Health Insurance

Health insurance was a significant area of concern in the transition focus groups. Families did not understand the various insurance options available to them, many did not understand Medicaid eligibility rules, families reported having to negotiate a number of

different agencies and receiving conflicting information, etc. For youths, most who participated knew very little about their health care coverage and had given little thought to how health insurance would be obtained in the future.

The preceding data on transition suggests that while some of the important components necessary for successful health care transition are occurring for some CYSHCN, for the overwhelming majority, there is no cohesive plan to assist with transition to adult life and/or there are significant barriers (real or perceived) within the current system to address transition needs.

Other Transitions

Transition in other aspects of life also presents challenges for CYSHCN. According to the 2001 National Survey of CSHCN, only about 28% of CYSHCN ages 13-17 had received any vocational or career training. Of respondents ages 14-21 on the 2004 Needs Assessment of Individuals with Spina Bifida, only 36% reported having an Individualized Transition Plan. The result is that of those respondents over 18, only 20% were employed full time and 40% reported being involved in neither work nor school. Several local health department needs assessments (Caroline 2004, Talbot 2003, Somerset 2000) also indicated the need for job training/placement for CYSHCN. In the transition focus groups, parents were divided as to whether they felt medical providers should play a role in transition in other areas of life such as job training, employment, and finding a place to live, but most agreed that it was probably unrealistic to expect physicians to play an active role in these due to lack of time and knowledge in these areas.

Appendix C

**Maryland MCH Program Capacity Assessment Using CAST-5
Summary of Retreat Deliberations May 23, 24, 26, 2005**

**Prepared by the Johns Hopkins Bloomberg School of Public Health
Women's and Children's Health Policy Center**

Maryland MCH Program Capacity Assessment Using CAST-5 Summary of Retreat Deliberations May 23, 24, 26, 2005

Prepared by the

Background

Capacity Assessment for State Title V (CAST-5) is a set of self-assessment and planning tools for state programs responsible for the federal Title V maternal and child health (MCH) services block grant and related programs. Over the past few years since development of CAST-5, about 25 states, including Maryland, have chosen to use some or all of the CAST-5 tools. CAST-5 is framed around the 10 Essential Services for Public MCH Programs, which are a more specific delineation of core public health functions as applied to populations of women, children, and youth, including those with special health care needs. State system performance is self-assessed through a series of indicators that are rated in light of the program's vision, mission and goals; political, social, and economic context; and population health needs. Analyses of strengths, weaknesses, opportunities and threats (SWOT) and specific organizational resource needs related to the 10 Essential Services are identified and form the basis for strategic thinking about capacity building. An action plan for state organizational capacity development is the end product that results from implementation of the CAST-5 process.

Plans to use CAST-5 in Maryland were initiated jointly by the leadership of the Center for Maternal and Child Health (CMCH). The primary impetus for using CAST-5 in Maryland in 2004-2005 was the Title V MCH Block Grant requirement for a comprehensive needs assessment every five years. While CAST-5 is not required, it can be a useful component of this assessment of population needs and systems capacity. The program requested and received federal MCHB support in using CAST-5, specifically from the Johns Hopkins Women's and Children's Health Policy Center (WCHPC). Given that the primary reason for using CAST-5 was to contribute to the comprehensive Title V needs assessment, Maryland leaders chose to implement all of its components to obtain a comprehensive picture of essential services performance and capacity needs.

Given multiple timing considerations, the program worked with the WCHPC to plan for completing CAST 5 in a 3-day condensed timeframe in May 2005. Participants in the Maryland CAST-5 process included staff from multiple programs within CMCH (including the Title V Children with Special Health Care Needs program – CMS), representatives of several programs within the Family and Community Health Administration but external to CMCH (e.g., the WIC Program), representatives of other DHMH administrations (e.g., Medicaid), and several local health department MCH directors. Participants additionally included representatives of other state agencies such as the Department of Education, Department of Human Resources, Juvenile Justice Services, as well as several non-governmental organizations concerned with the health of Maryland's women, children, and families, including the March of Dimes, Advocates for Children and Youth, the Mental Health Association, and Friends of the Family.

What follows is a brief summary of the deliberations transpiring at Maryland's CAST-5 Retreat.

Key Themes in CAST-5 Ratings and Deliberations

Overall, participants identified many areas of traditional (e.g., interagency collaboration), as well as newly-emerging strength (e.g., data). As anticipated, the CAST-5 retreat participants also identified a number of areas for further development (e.g., translation and use of data).

The MCH programs/staff at DHMH are relied on extensively to provide scientific and programmatic and policy expertise, and to provide assistance to other state and local public agencies, and statewide and community-level organizations. Examples include Early Intervention, School Readiness, FAS, health care in the Juvenile Justice system, Special Education, health in child care, and early childhood mental health. Interactions have been established with the Department of Transportation and the Housing Authority and can be built on to achieve additional health programming goals. Program staff provide data and other information for executive and legislative briefings and testimony, and provide technical assistance and support to local health departments in many arenas. CMCH has provided notable leadership for the state's Asthma initiative, and the Committee on Children and Environmental Health.

Retreat participants, however, noted that CMCH briefing communications usually happen as reactive, and not proactive, activity and that there is little/no involvement in high level policy deliberations (e.g., rate setting, budget deliberations, etc.). There was general agreement that CMCH is currently not able to designate staff to be responsible for these kinds of information/public awareness activities as staff roles and responsibilities are already overextended.

Maryland's Title V program has made recent, impressive enhancements in data collection and analysis, data-driven planning, but capacity is insufficient for undertaking in-depth studies that would provide direction for development of interventions. Two epidemiologists are now fully dedicated to MCH program work, and two new data sets -- PRAMS and family planning -- are available. Youth Risk Behavior Survey data will be available in the near future, and CMCH and its agency partners are beginning to attend to the need for data on obesity. CMCH receives excellent assistance from Vital Statistics and benefits from data available from the Governor's Office of Children and Youth.

Participants identified the depth of staff capacity for data analysis as an area of need, particularly given that despite major policy and program efforts to improve access to care, low birth weight and infant mortality persist as problems; and early entry into PNC is decreasing. Moreover, if the programs are to enhance their work with the most vulnerable populations -- children subjected to or at risk for abuse/neglect, children in the juvenile justice system or other out-of-home placements, children with special health care needs, and homeless families -- the environment for data sharing will need to be improved, along with staffing capacity. Discussions revealed that the CMCH process for data analysis not systematic and that it is not always clear to stakeholders who to contact for what data. The State's governmental hiring freeze as well as personnel policies (e.g., definitional and position specification issues related to "MCH epidemiologist") were noted to be of particular concern in regard to data capacity.

With the enhanced data and analytic capacity, MCH and related programs are poised to make better use of data for translation to policy and programs. There was general concurrence that in order to enhance MCH-related communication strategies, both skills development and additional staffing are needed. Retreat participants also noted the need to make better use of alliances with local health departments and with nonprofit groups at the state and local level (e.g., March of Dimes, Advocates for Children and Youth) in order to elevate public and governmental attention to the health concerns of women, children, and families in the state. As in many other states, there is little understanding of the scope and depth of public MCH programming in the general public (and even among public or other governmental entities). CMCH programs provide data and publish informational reports, but not all relevant stakeholders are aware of reports that are produced. Moreover, while data briefs are prepared by program staff, they are rarely produced for proactive use due to capacity limitations; the CSHCN program has been particularly hampered in this regard. Efforts are underway to promote broader and better use of information generated by FIMR and CDR teams, but more can be done..

Extensive efforts and resources are dedicated in Maryland for educating the public and encouraging adoption of positive health behaviors as well as awareness of MCH concerns on a community population level. All of these efforts involved large sums of state funding. Uncertainty was expressed at the retreat, however, regarding the effectiveness of these efforts. Exceptions are the anti-tobacco and teen pregnancy prevention campaigns, SIDS prevention, and the Campaign for Our Children. Special challenges in this arena involve the high mobility of the population that places heavy demands on information/outreach needs, and the constantly evolving nature of processes/methods for information dissemination (e.g., internet); it is hard for staff to keep up. Evaluation of educational interventions outcomes/impacts is expensive and methodologically difficult.

Many efforts are directed towards engaging communities and stakeholders in MCH and related concerns. Children's Medical Services provides resources to Family Voices (Parent's Place) to provide training for CSHCN family advocates and CSHCN family representation on policy initiatives, and funding allocated to MedChi supports training for FIMR action teams. CMCH provides resources to and participates in the MD Coalition to End Childhood Lead Poisoning as well as a number of other important coalitions. A very strong child care advocacy coalition exists in Maryland and has been instrumental in promoting needed policy and service changes. The Title V programs make extensive use of focus groups to solicit constituent information on services and strategies that need to be undertaken.

DHMH MCH staff undertake an array of activities to assure quality health care. Examples include: site visits/audits of Medicaid EPSDT providers and family planning and other service providers (contract performance and monitoring); institution of core performance measures in 2004 for all contractors receiving MCH funds; consumer satisfaction surveying by family planning programs. In specific regard to perinatal-related concerns, FIMRs and CRENSHAW activities are implemented as continuous quality improvement functions at the systems level, wherein gaps and problems are identified and plans to ameliorate these are instituted. Efforts also are underway to evolve an OB scorecard for delivery facilities. While standards were

recently developed for perinatal facilities, there is no CMCH involvement in standards with respect to private insurers.

Despite all the information resources available to the public (hotlines, brochures, radio, DHMH website, etc.), people still frequently report that they cannot access services; there is unmet need for helping people who need services to efficiently and successfully take the steps necessary to navigate the system and actually connect with the services that they need.

Local health departments administer all Medicaid outreach. CMS funds three regional information resource centers for CSHCN (KKI, Parents Place, Eastern Shore Consortium), but the CMS program information line is not well-utilized. The mobility of the population noted above as well as the general impression in the public that government run health services are only for persons who are poor are perceived to exacerbate problems of access.

DHMH efforts to provide education on cultural competence to clinical/program providers were noted by the CAST-5 participants to be very limited and the high expense of translation services was noted to be problematic. Moreover, local health departments are doing outreach and information work, including cultural competency enhancements, on shoestring budgets.

Programs of the CMCH undertake a great deal of activity to ensure that needed services are available to vulnerable populations. Some examples include: model systems of metabolic newborn metabolic and hearing screening and follow-up are in place; perinatal risk screening and Home Visiting interventions for women enrolled in Medicaid are overseen by CMCH. CMS funds are used to support medical day care centers for special needs children and to support specialty care outreach clinics for CSHCN. An interagency agreement between MCH and Medicaid is in place and working well such that there is ongoing consultation and efforts to secure resources (fiscal and provider) and assure quality of care (major e.g., is family planning waiver, community waiver for home and community care for medically fragile children).

Tracking systems for some high risk groups, however, are limited; foster care health, juvenile justice health are areas of great need; LHDs report inadequacies with respect to tracking of high-risk clients to be of significant concern. Efforts to address limitations in tracking children with special health care needs are hampered by the fact that the CMS program has lost some “connections” with LHDs following major systems changes that moved service delivery for this population into the private sector. CAST-5 retreat participants raised broad concerns about public health’s ability to address service delivery gaps given the current economic environment wherein resources to develop and/or expand programs/services are more limited than ever; sources of grant funds are diminishing and there is increasing pressure to constrain growth of the Medicaid budget/program.

Workforce development is primarily supported by CMCH programs through continuing education functions and through sponsoring rotations for preventive medicine residents and medical and allied health services students. Lack of work space for students, however, was noted to be a problem. A good deal of concern was expressed throughout the CAST-5 deliberations about the long-term implications for the public MCH workforce of relatively low civil service salaries and negative perception of public service and public service workers. As is the case across the country, the nursing shortage is a particular problem (e.g., the University of

MD cannot increase enrollment because of the inability to hire qualified faculty). Also similar to other state governments, workforce development is perceived to be hampered by complex, rigid, and outdated personnel management policies that are not implemented with creativity.

Evaluation efforts are few, but have evolved in some regards: evaluation is built into the structure of certain programs (e.g., asthma, Family Planning, and abstinence education), and special studies have been conducted (e.g., CSHCN program evaluated medical day care services). Where program evaluations are undertaken, they ordinarily are stronger on process evaluation than on measuring impact or outcomes. Participants noted that CMCH lacks resources for evaluation and/or research (funding and staffing) but that few requests from LHDs for assistance with evaluation are received.

Identification of Capacity Needs

Participants reviewed a comprehensive list of 28 elements of public MCH programming capacity related to structural resources, data/information systems, organizational relationships, and competencies/skills. Identified below are those elements that participants identified as deficient, particularly in light of their consensus rating of program adequacy in regard to the 10 essential MCH services.

Organizational Resources Needed

1. Authority and Funding, with specific regard to:
 - a. Procurement processes – can't spend money efficiently
 - b. Staff hiring
 - c. Unfunded mandates – e.g., FAS
2. Routine communication channels – have these, but limited by staffing and ability to do on a routine basis (varies from program to program)
 - a. Don't hear about what's going on in within the agency – no formalized, routine mechanism to get information from higher levels of DHMH
 - b. No routine mechanism to hear about consumer experiences
 - c. Could have better communication with university partners
3. Access to up-to-date science, policy and programmatic information -- Have some information, but inefficient access to scientific journals, and legal counsel in particular. Getting programmatic data is a struggle.
4. Workforce capacity -- specific concerns are related to low number of staff and to hiring processes.
5. Mechanisms for accountability and quality improvement – limited/no use of incentives for state workforce; also could look at incentive structure for providers
6. Data Infrastructure and supportive environment for data sharing -- need more communication among agencies to facilitate how data is collected, what data is to be collected, and how best to collaborate; need to improve understanding of how HIPAA works (exaggerated concerns are limiting). Old/incompatible expensive IT systems are problematic.

Organizational Relationships Needed

7. Insurer and insurance oversight stakeholders -- staff experience difficulties negotiating with MCOs.
8. State and local policymakers – limited capacity and channels of access.
9. Businesses – relationships needed to influence policies.

Competencies Needed

10. Communication and data translation skills, especially for
 - a. Learning how to make the public care
 - b. Health educators needed who can make materials and message understandable, culturally appropriate, etc. (some Hispanics speak Spanish but cannot read brochures or pamphlets, even if in Spanish)
 - c. Product placement, marketing in general
 - d. Ability to work effectively with public and private organizations and agencies and constituencies – skill currently developed through “trial by fire” – formal training would be good, as would more “in person” training
11. Ability to influence the policymaking process
 - a. Difference between understanding process and can have influence, and what actual ability to influence process
 - b. Important to look to relationships with advisory councils, and what those members can do that state employees cannot, also involving consumers
12. Experience and expertise in working with and in communities – need to:
 - a. Hire people to work with communities, convene focus groups
 - b. Enhance the functioning (and impacts) of existing coalitions
 - c. Expand staff capacity in Health Promotion unit (don’t have capacity to provide technical assistance to other parts of DHMH)
 - d. Address issues of immigrants (related concerns about increasing gang presence)
13. Management and organizational development skills (and time to manage well)
 - a. Skills related to this area are in silos in job descriptions (programmatic versus management); would be useful for CMCH staff to have cross-over skills.
14. Data and analytic skills – need to expand and enhance overall/in a regards.

Capacity Needs Priorities As Voted by Retreat Participants on May 26

- #1 -- Communication and Data Translation, including routine two-way communication mechanisms with stakeholders at all levels
- #2 – More staff skilled in working with communities (including focus groups)
- #3 (Tie) – More staff skilled in Data Analysis, and improvements in the Environment for Data-sharing
- #3 (Tie) – Enhanced ability of CMCH staff (across all units) in working with organizations, especially skills for leading group/committee work and management of interagency collaborations and initiatives

Additional high priority capacity concerns were related to effective strategies for working through personnel systems, expanded relationships with insurers, and with businesses/the business sector (particularly to influence their health-related policies), and capabilities and capacity to have greater influence, generally, in health policymaking.

Opportunities

A number of creative strategies to address areas of perceived deficiency were noted throughout the three days of the retreat. Model practices and strategies exist that can serve as potential templates for extending program organizational capacity for action in new arenas of MCH improvement. For example, the Asthma Initiative incorporated data strategies, partnership strategies, etc. that could be considered for new areas of endeavor, such as obesity. Other model practices included, Baltimore City Health Department's process for bi-monthly data review, and providing follow-up educational information and/or to the media in follow-up to breaking news stories. Mention was made on previous work at the Secretary level to address data sharing across agencies as something that could be built on to facilitate tracking of individual in certain high-risk groups.

Much effort and many resources have been devoted to FIMR and CDR over recent years, and it was suggested that extensions and enhancements of this area of substantial success (i.e., case review programs) might be good launching points for moving forward in areas of identified weakness (e.g., translating data to policy action, working with communities for problem-solving).

Opportunities to address capacity needs related to data translation and use were noted in newly available data (e.g., Head Start, CSHCN SLAITS data, March of Dimes' Peristats) and the work conducted over the past year to compile the 5-year needs assessment. Potential exists to produce a MCH report formatted as a multi-use document (briefs, pull out components, topic and/or area-specific data sheets, etc.).

As clear throughout the CAST-5 retreat deliberations, CMCH partnerships are many, and could be drawn on to enhance and expand capacity in various important ways. For example, links with ACYF might allow for Kids Count briefings serve as vehicles for raising awareness of CMCH-identified health programming agendas. Current partnerships with Department of Human Resource leaders and managers could provide expanded resources with respect to graphics and publication production and other information dissemination tasks. Interagency partnerships also could be beneficial/efficient for continuing education/training activities (e.g., cultural competence), and outreach efforts. Participants noted that there may be interest in building on successful CMCH work with DJJ. The CSHCN program's need for enhanced focus on CHSCN child care and on transition services could be addressed in part by inclusion on extant task forces that were initiated by the Governor.

The potential for greater use of the Internet was suggested for health education purposes, for getting input from constituents, and for enhanced routine two-way communications with constituent groups (including providers).

Appendix C-1

Maryland CAST-5 Retreat Agenda

Maryland MCH Capacity Assessment Retreat

Agenda

Monday, May 23

- 9am: Welcome, Introductions, Objectives
- 9:30am: CAST-5 Process Overview for the Retreat
- 9:45am: Center for MCH Presentation: Overview of 2005 Needs Assessment Findings
- 10am: Large Group Discuss Needs Priorities and Environmental Context
- 10:45am: Break
- 11am: Large Group Complete Process Indicators & SWOT for EMCHS #5
- 12:30pm: Lunch
- 1:30pm: 3 Working Groups Each Complete Process Indicators & SWOT for a MCHES
- 3:30pm: Adjourn

Tuesday, May 24

- 9:00am: Groups Present Ratings from Monday afternoon, and Discussion
- 9:45am: 3 Working Groups Each Complete Process Indicators & SWOT for a MCHES
- 11:00am: Groups Present Ratings from Morning Session, and Discussion
- Noon: Lunch Break
- 1:00pm: 3 Working Groups Each Complete Process Indicators & SWOT for a MCHES
- 2:45pm: Groups Present Ratings from Afternoon Session, and Discussion
- 3:30pm: Adjourn

Thursday, May 26

- 9:00am: Consolidated SWOT Presented, Themes Discussion
- 10:00am: Capacity Needs Rating, Part I (Structure)
- 10:30am: Capacity Needs Rating; 3 Groups (Data, Relationships, Competencies)
- Noon: Lunch
- 1:00pm: Review Population/Needs Priorities, and Vote on Capacity Needs
- 2:00pm: Vote on Capacity Needs Priorities
- 2:30pm: Break
- 3:00pm: Review voting results; Discuss Themes and Broad Strategies for Action Plan
- 4:00pm: Evaluation and Next Steps

Location -- Johns Hopkins Applied Physics Lab; Columbia, MD

Appendix C-2

Maryland CAST-5 Participant List

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Appendix C-3

Maryland Indicator Ratings for 10 Essential Services

Minimally Adequate	Partially Adequate	Substantially Adequate	Fully Adequate	<p>Process Indicator: Essential Service #1 Assess and monitor maternal and child health status to identify and address problems.</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>1.DU.1 Use public health data sets to prepare basic descriptive analyses related to priority health issues (e.g., PRAMS; BRFSS; YRBS; live birth, fetal death, abortion, linked live birth/infant death data; community health surveys; census data; etc.)</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>1.DU.2 Conduct analyses of public health data sets that go beyond descriptive statistics</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>1.DU.3 Generate and analyze primary data to address state- and local-specific knowledge base gaps</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>1.DU.4 Interpret and report on primary and secondary data analysis for use in policy and program development</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>1.TA.1 Establish framework/template/standards about core data expectations for local health agencies and other MCH providers/programs</p>
<input checked="" type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<p>1.TA.2 Provide training/expertise about the collection and use of MCH data to local health agencies or other constituents for MCH populations</p>
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>1.TA.3 Assist local health agencies in data system development and coordination across geographic areas so that MCH data outputs can be compared</p>

Minimally Adequate	Partially Adequate	Substantially Adequate	Fully Adequate	<p>Process Indicator: Essential Service #2 Diagnose and investigate health problems and health hazards affecting women, children, and youth.</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>2.1 Use epidemiologic methods to respond to MCH issues and sentinel events as they arise</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>2.2 Engage in collaborative investigation and monitoring of environmental hazards (e.g., physical surroundings and other issues of context) in schools, day care facilities, housing, and other domains affecting MCH populations, to identify threats to maternal and child health</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>2.3 Develop and enhance ongoing surveillance systems/population risk surveys and disseminate the results at the state and local levels</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>2.4 Serve as the state's expert resource for interpretation of data related to MCH issues</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>		<p>2.5 Provide leadership in reviews of fetal, infant, child, and maternal deaths and provide direction and technical assistance for state and local systems improvements based on their findings</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>2.6 Use epidemiologic methods to forecast emerging MCH threats that must be addressed in strategic planning</p>

Minimally Adequate	Partially Adequate	Substantially Adequate	Fully Adequate	<p>Process Indicator: Essential Service #3 Inform and educate the public and families about maternal and child health issues.</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>3.IB.1 Utilize a routine mechanism for identifying existing and emerging health education needs and appropriate target audiences</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>3.IB.2 Conduct and/or fund health education programs/services on MCH topics targeted to specific audiences to promote the health of MCH populations</p>
<input checked="" type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<p>3.IB.3 Produce and disseminate evaluative reports on the effectiveness of health promotion and health education programs/campaigns</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>3.PB.1 Utilize a routine mechanism for identifying existing and emerging population-based health information needs</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>3.PB.2 Design and implement public awareness campaigns on specific MCH issues to promote behavior change</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>3.PB.3 Develop, fund, and/or otherwise support the dissemination of MCH information and education resources</p>
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>3.PB.4 Produce and disseminate evaluative reports on the effectiveness of public awareness campaigns and other population-based health information services</p>

Minimally Adequate	Partially Adequate	Substantially Adequate	Fully Adequate	<p>Process Indicator: Essential Service #4 Mobilize community partnerships between policymakers, health care providers, families, the general public, and others to identify and solve maternal and child health problems.</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>4.1 Respond to community MCH concerns as they arise</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>4.2 Specify community geographic boundaries and/or stakeholders for use in targeting interventions and services</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>4.3 Provide trend information to targeted community audiences on state and local MCH status and needs</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>4.4 Actively solicit and use community input about MCH needs</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>4.5 Provide funding and/or technical assistance for community-driven and generated initiatives and partnerships among public and/or private community stakeholders (e.g., MCOs, hospital associations, parent groups)</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>4.6 Convene, stimulate, and/or provide resources (e.g., staffing, funding) for coalitions of agencies and/or constituent professional organizations to develop strategic plans to address health status and health systems issues</p>

Minimally Adequate	Partially Adequate	Substantially Adequate	Fully Adequate	<p>Process Indicator: Essential Service #5 Provide leadership for priority setting, planning, and policy development to support community efforts to assure the health of women, children, youth and their families.</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	5.DD.1 Actively promote the use of the scientific knowledge base in the development, evaluation, and allocation of resources for MCH policies, services, and programs
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	5.DD.2 Support the production and dissemination of an annual state report on MCH status, objectives, and programs, beyond the annual Block Grant submission
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	5.DD.3 Establish and routinely use formal mechanisms to gather stakeholders' guidance on MCH concerns
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	5.DD.4 Use diverse data and perspectives for data-driven planning and priority setting
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	5.PD.1 Participate in and provide consultation to ongoing state initiatives to address MCH issues and coordination needs
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	5.PD.2 Develop, review, and routinely update formal interagency agreements for collaborative roles in established public programs (e.g., WIC, family planning, Medicaid)
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	5.PD.3 Serve as a consultant to, and cultivate collaborative roles in, new state initiatives, through either informal mechanisms or formal interagency agreements
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	5.PD.4 Advocate for programs and policies necessary to promote the health of MCH populations based on the scientific knowledge base/data and community input

Minimally Adequate	Partially Adequate	Substantially Adequate	Fully Adequate	<p>Process Indicator: Essential Service #6 Promote and enforce legal requirements that protect the health and safety of women, children and youth, and ensure public accountability for their well-being.</p>
<input checked="" type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<p>6.LA.1 Periodically review existing state MCH-related legislation to assess adequacy and any inconsistencies in legislative/regulatory mandates across programs serving MCH populations</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>6.LA.2 Monitor proposed legislation that may impact MCH and participate in discussions about its appropriateness and effects</p>
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>6.LA.3 Devise and promote a strategy (specific to state constraints/protocols) for informing elected officials about legislative/regulatory needs for MCH</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>6.LA.4 Initiate legislative proposals and/or lead regulatory efforts (specific to state constraints and protocols) pertaining to MCH concerns when appropriate</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>6.CS.1 Participate in processes led by professional organizations and other state agencies to provide MCH</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>6.CS.2 Provide leadership to develop and promulgate harmonious and complementary standards that promote excellence in quality care for women, infants, and children, in collaboration with professional organizations and other state agencies with regulatory capacity as appropriate</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>6.CS.3 Integrate standards of quality care into third party contracts for Title V-funded services, other publicly-funded services (e.g., Medicaid, SCHIP, WIC, family planning), and/or privately-financed</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>6.CS.4 Develop, enhance, and promote protocols, instruments, and methodologies for use by health plans, insurance agencies, and other relevant state and local agencies that promote MCH quality assurance</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>6.CS.5 Participate in or provide oversight for quality assurance efforts among regional health providers and systems and local health agencies and contribute resources for correcting identified problems</p>

Minimally Adequate	Partially Adequate	Substantially Adequate	Fully Adequate	<p>Process Indicator: Essential Service #7 Link women, children and youth to health and other community and family services, and assure access to comprehensive, quality systems of care.</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>7.AA.1 Develop, publicize and routinely update a toll-free line and other resources for public access to information about health services availability</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>7.AA.2 Provide resources and technical assistance for outreach , improved enrollment procedures, and service delivery methods for hard-to reach populations</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>7.AA.3 Develop and routinely evaluate tracking systems for universal, high risk, and underserved populations</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>7.AA.4 Provide or pay for direct services not otherwise available to CSHCN and other MCH populations (with Title V or other available funding)</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>7.AA.5 Provide resources to strengthen the cultural and linguistic competence of providers and services to enhance their accessibility and effectiveness</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>7.AA.6 Collaborate with other state agencies to identify and obtain resources to expand the capacity of the health and social services systems, and establish interagency agreements for the administration of capacity-expanding initiatives/protocols</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>7.AA.7 Actively participate in public insurers' oversight of health plan/provider enrollment procedures and development of plans for appropriate provision of services for new enrollees</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>7.CC.1 Provide leadership and resources for a system of case management and coordination of services</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>	<p>7.CC.2 Provide leadership and oversight for systems of risk-appropriate perinatal and children's care and care for CSHCN</p>

Minimally Adequate	Partially Adequate	Substantially Adequate	Fully Adequate	<p>Process Indicator: Essential Service #8 Assure the capacity and competency of the public health and personal health workforce to effectively and efficiently address maternal and child health needs.</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<p>8.CP.1 Develop and enhance formal and informal relationships with schools of public health and other professional schools to enhance state and local public agency analytic capacity</p>	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>8.CP.2 Monitor the numbers, types and skills of the MCH labor force available to the state and localities</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>8.CP.3 Monitor facility/institutional provider and program distribution throughout the state</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>8.CP.4 Integrate information on workforce and facility/program availability or distribution with ongoing health status needs assessment in order to address identified gaps and areas of concern</p>
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>8.CP.5 Create financial and other incentives and program strategies to address identified clinical professional and/or public health workforce shortages</p>
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>8.CM.1 Make available and/or support continuing education for targeted professional audiences in public and private provider sectors on clinical and public health skills, emerging MCH issues, and other topics pertaining to MCH populations (e.g., cultural competence, availability of ancillary services and community resources, the community development process)</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>8.CM.2 Play a leadership role in establishing professional competencies for Title V and other MCH programs</p>

Minimally Adequate	Partially Adequate	Substantially Adequate	Fully Adequate	<p>Process Indicator: Essential Service #9 Evaluate the effectiveness, accessibility, and quality of personal health and population-based maternal and child health services.</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9.1 Support and/or assure routine monitoring and structured evaluations of state-funded services and programs
<input checked="" type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	9.2 Provide and/or assure technical assistance to local health agencies in conducting evaluations
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9.3 Provide resources for and/or collaborate with local health or other appropriate agencies in collecting and analyzing data on consumer satisfaction with services/programs and community perceptions of health needs, access issues, and quality of care
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9.4 Perform comparative analyses of programs and services
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9.5 Disseminate information about the effectiveness, accessibility, and quality of personal health and population-based MCH services
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9.6 Utilize data for quality improvement at the state and local levels
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9.7 Assume a leadership role in generating and disseminating information on private sector MCH outcomes

Minimally Adequate	Partially Adequate	Substantially Adequate	Fully Adequate	<p>Process Indicator: Essential Service #10 Support research and demonstrations to gain new insights and innovative solutions to maternal and child health-related problems.</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>10.1 Monitor the progress of state-specific and national MCH research and disseminate results of that research to providers, public health practitioners, and policy makers</p>
<input checked="" type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<p>10.2 Serve as a source for expert consultation to MCH research endeavors in the state</p>
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>10.3 Conduct and/or provide resources for state and local studies of MCH issues/priorities</p>

Appendix C-4

Maryland CAST-5 Detailed SWOT

MCH Capacity Strengths

The MCH programs/staff at DHMH are relied on extensively to provide scientific and programmatic and policy expertise, and to provide assistance to other state and local public agencies, and statewide and community-level organizations. Examples include:

- Early Intervention, School Readiness (including Casey Foundation efforts), FAS, Health Care in the Juvenile Justice system, Special Education, health in child care, early childhood mental health, "Tamar's children" (incarcerated women and parenting concerns), etc.
- Provide data and other information for/prepare legislative testimony
- CMCH led Asthma initiative, and the Medical Director currently Chairs Committee on Children and Environmental Health
- Provide technical assistance and support to LHDs in many arenas, for example for family planning data systems and analyses, other data efforts
- High level of staff participation on interagency coalitions, task forces, etc.
- Data provided to legislature and executive branch on health disparities
- Participate on MD Health Care Commission

Data sources and analytic capacity related to MCH populations and issues have been substantially enhanced in the past several years.

- vital statistics program continues to be strong
- were able to hire an MCH epidemiologist
- have access to hospital discharge and ambulatory visit data
- PRAMS begun and now have two years of data
- now have state-specific CSHCN data through the SLAITS survey
- secured legislative approval to begin the YRBS
- March of Dimes Peri-Stats and Gov. Office of C&Y serve as good sources of data
- have new data system and resources for analysis for family planning programming
- collected information on congenital syphilis
- maintain surveillance systems for asthma, birth defects
- FIMRs are funded in all jurisdictions
- have conducted focus groups
- have conducted special surveys (esp. providers, and LHDs)
- beginning to develop data specific to obesity
- beginning in-depth studies on entry into PNC, Chlamydia and other STD trends, IMR increase

Ability to translate data to information for action is growing (but not yet optimal?)

- staff keep up-to-date on research reports, scientific literature; they share the burden to cover all bases
- have started preparing briefing sheets to facilitate prompt replies to requests for information from the Secretary, Governor, and legislators
- reports prepared on FIMR/CFR
- prepare reports in both print and website postings
- notifications to providers (e.g., Mercury info tear sheets for perinatal providers)
- major contributors to Kids Count, OCYF statewide reports
- send Child Fatality Reports to the legislature
- have many pieces in place for a comprehensive state annual report on MCH populations and issues

Many efforts have been undertaken to provide health education to the public and encourage adoption of healthy behaviors

- Anti-tobacco campaign
- Teen Pregnancy Prevention campaign
- SIDS awareness
- Campaign for Our Children
- Abstinence Education

Efforts are directed towards engaging communities and stakeholders in MCH and related concerns

- Provide resources to MedChi to provide training for FIMR action teams

- Provide resources to Family Voices (Parent's Place) to provide training for CSHCN family advocates and CSHCN family representation on policy initiatives
- Use focus groups to solicit input
- Provide resources to and participate in MD Coalition to End Childhood Lead Poisoning
- collaborate with the very strong child care advocacy coalition that exists in Maryland

DHMH MCH staff undertake an array of activities to assure quality health care. Examples include:

- site visits/audits of Medicaid EPSDT providers and family planning and other service providers (contract performance and monitoring)
- core performance measures instituted last year for all contractors receiving MCH funds
- dissemination of best practices information (e.g., family planning,
- family planning programs conduct consumer satisfaction surveys (as does Medicaid/Health Choice)
- FIMRs and CRENSHAW activities are fundamentally CQI functions at the systems level where gaps and problems are identified and plans to ameliorate these are instituted
- developed standards for perinatal facilities
- evolving an OB scorecard
- share reports with MCOs (e.g., Asthma report)

A wide array of information resources are made available to help the public access services and information, such as

- multiple toll-free hotlines (Medicaid MCH, WIC, Suicide Prevention, CSHCN, Medicaid Enrollee and REEM lines)
- brochures for many programs, and specific services; distributed at many venues, including the State Fair
- website posting of information
- 3 regional information resource centers for CSHCN (KKI, Parents Place, Eastern Shore Consortium)
- LHDs administer Medicaid outreach

Activity to ensure that needed services are available to vulnerable populations includes:

- cultural competence items
- model systems of metabolic newborn screening, and newborn health screening and follow-up in place
- involved in perinatal risk screening and Home Visiting interventions
- support for specialty care outreach clinics for CSHCN has been continued where possible
- CMS provides support for medical day care centers
- an interagency agreement between MCH and Medicaid is in place and working well such that there is ongoing consultation and efforts to secure resources (fiscal and provider) and assure quality of care (major e.g., is family planning waiver, community waiver for home and community care for medically fragile children)
- applications are made for grant funding (when available) to support services (e.g., Depo Provera grant from the Abel Foundation)

Workforce development and support efforts underway or recently completed include:

- creative staffing and technical assistance is implemented to help address nursing shortages
- monitor numbers of available providers in the state for some types of clinicians; geographic monitoring primarily, not quality of care
- contribute to workforce training through sponsoring rotations for preventive medicine residents and medical, and allied health services students
- DHMH staff provide lectures for medical school and public health students in the state
- Perinatal outreach coordination

Evaluation efforts have evolved in some regards:

- Evaluation for some programs is built in- eg asthma, FP, Abstinence education
- Have been evaluations of SIDS awareness for child care workers, CSHCN campaign evaluation will be done
- Campaign for Our Children has been evaluated
- Stronger on process evaluation (vs. outcome)
- CSHCN program evaluated medical day care services
- TA is provided to LHDs on evaluation of family planning programs

MCH Capacity Weaknesses

- Limited/no involvement in high level policy deliberations (e.g., rate setting, budget deliberations, etc.)
- Gov. trying to trim the use of advisory groups
- Briefing communications usually happen as a reactive activity and not proactive (except sometimes in follow-up to news stories)
- Lack of DHMH support/resources for communications work (e.g., graphics, publication)
- Not able to designate staff to be responsible for these kinds of information/public awareness activities (already staff overload)
- Need champions to facilitate and support working to share resources across agencies

- LHDs do not have epidemiology /data-related staff capacity in most jurisdictions
- Abortions are under-reported
- Lack of data for addressing emerging issue(s) (e.g., obesity)
- Data source documentation not compiled/organized all in one place
- Lack of a departmental approach to providing data support (sometimes a problem)
- CMCH process for data analysis not systematic
- Difficult to tease out data duplication for populations
- Other than for newborn screening, don't have systematic data for CSHCN
- Don't always have depth needed for data analysis
- Not all populations captured in available data sets
- Lack of Interagency Agreements on data exchange (e.g., JJ, DHR, MSDE, and DHMH); need both aggregate and case level data
- Difficult to get data on CSHCN from other agencies that is useable/compatible with CMS data
- Some reporting issues in birth defects need to be resolved
- Not all interested stakeholders are aware of reports that are produced

- Sometimes there are time lags in responding to information requests (due to bureaucratic process and capacity limitations)
- Not always clear to stakeholders who to contact for what
- Do not produce data briefs for proactive use (capacity issue)

- Local FIMRs could be doing more to use results to make change

- Don't reach certain populations, including foster care and undocumented children, women in prison, homeless women, children families
- CSHCN unit hasn't done public awareness campaigns; lost opportunity esp. before legislative sessions
- Some folks don't understand scope/depth of what MCH does

- MCH did health systems review/audit
- There is some inconsistency in some standards for licensing, certification for practice of health professionals (e.g., speech pathology, DHMH and MSDE different)
- No involvement in standards with respect to private insurers

- CMS program information line is not well-utilized
- Despite all the information resources available to the public (hotlines, brochures, radio, DHMH website, etc.), people still frequently report that they cannot access services
- There is unmet need for helping people who need services to efficiently and successfully take the steps necessary to navigate the system and connect with the services that they need
- LHDs are doing outreach and information work, including cultural competency enhancements, on a shoestring budget
- DHMH efforts to provide education on cultural competence to clinical/program providers are very limited
- Tracking systems for some high risk groups are limited; foster care health, juvenile justice health areas of particular concern; this is a concern for the LHDs in particular
- CMS program has lost some "connections" with LHDs following major systems changes that put services into the private sector

- Don't examine numbers of public health workers
- Can't enroll as many nurses as would like, because schools are short on nursing faculty, due to pay scale
- Department of Personnel and Management negative structure, lack of creativity
- Relatively low civil service salaries
- Negative perception of public service and public service workers
- Lack physical space/work space for students
- Teaching not seen by DHMH staff as part of job
- Evaluation not required of all programs
- Lack resources for evaluation (funding and staffing)
- Lack capacity, but also do not get requests from LHDs to assist with evaluation
- Need to monitor activities of external groups doing research in the state
- Have limited capacity to generate sufficient/desired number of grant proposals for research and/or for program development

MCH Capacity Opportunities

- Pursue more multivariate analyses so can better understand what interventions to implement
- Head Start data now becoming available; could do more with these data
- March of Dimes Peri-Stats accessible on the website
- Could link VS to FIMR findings
- Possible model for routine data review/discussion, and for getting information out found in Baltimore City's work in this area
- Development of the Asthma Surveillance work as a model for how to proceed in the face of staff reductions and hiring freezes
- Pull data sources together in order to make more readily accessible
- Could look at organizational structure for collection/analysis/use of data
- Work more with LHDs and other partners (e.g., universities, MOD) on data efforts
- Could consider a listserv for LHDs to share best practices
- Could look at/organize data needs relevant to prioritize being identified for '06 needs assessment
- Could benefit from enhanced collaboration activity in some areas
 - Gov interagency TF on Transition (CSHCN not involved)
 - Become involved in child care for CSHCN task force
 - Become more visible for involvement in state-level policy deliberations (e.g. budget)
 - CSHCN task force
- Enhance attention to males <21 years
- Extend health education work through partnerships with schools, developmental screening, providers, child care (e.g., newsletter), DHR graphics resources sharing
- Examine literature about effectiveness, health behavior change methods
- Use multiple media (e.g., water bottles)
- Explore Kids Count briefings as an opportunity for MCH legislative needs dialogue
- Pursue opportunities for state to partner with professional organizations and LHDs who could then connect with advocacy groups and legislators
- Fine-tune the communication processes between state MCH and external partners to improve opportunities for moving policy agendas

- Data on CSHCN is newly available and can be used to contribute to briefing materials/awareness-generating activities
- Students and other links to local universities can help meet capacity needs (e.g., develop briefing materials, fact sheets, etc.)
- Required reports can be structured in ways that they are useful for multiple purposes (e.g., MCH report-briefing sheets)
- Internet potential for education of the public, as well as collecting feedback from constituents, information on needs
- Can build on/expand current efforts to provide briefing materials on MCH science information in follow-up to breaking news stories
- Could do more to promote reports and make them more accessible to constituencies through mechanisms such as list serves, newsletters, executive summaries
- Could do more to promote awareness of MCH expertise and key contacts among constituencies
- Centralized data base for CFR will be operational soon.
- Could seek to better understand reasons why local FIMRs are not achieving change in response to recommendations
- Could create a mechanism to elevate attention and action at the state level for FIMR
- Family Planning program is a part of the OPA-funded project at JHU SPH, will be able to explore data and quality of care issues
- Evolve clinic performance standards
- Explore other state models for consolidated health information lines; all access is local, so LHD should be the focus of new efforts/refinement efforts
- Might pursue the idea of evolving "health and human service navigators" to help people make the links with needed services
- State DHMH might be able to help LHDs with the costs of medical translation
- State level might be able to facilitate county-to-county mentoring and training efforts in a number of arenas (esp. outreach, cultural competency, etc)
- Provide (expand) skills building for providers of "medical homes" to strengthen capabilities for outreach, referral for public/community services, care coordination, etc.
- Partner with other agencies for resources for outreach, for training of joint concern (e.g., cultural competence)
- Focus on recruitment of individuals that will increase diversity in the public health workforce (e.g., even start with high schools).
- FQHC development and new linkages can be explored to enable the MCH system to address special concerns such as asthma, obesity, in addition to primary care and family planning (efforts are underway)
- May be a good time to revisit telemedicine strategies to extend the capacity of CMS to address issues of limited access to specialty care
- Could consider a listserve for LHDs to share best practices
- Information/libraries available from Hopkins, U Maryland, OPA, HRSA
- Could examine public and private workforce numbers/capacity and distribution in more detail
- Create quasi-non profit organizations, as Baltimore City DOH does to extend workforce/program capacity
- Proximity to DC provides access to training sources
- Mentoring training for DHMH employees
- University of Maryland – students doing masters in epidemiology
- Formalize obtaining students, etc.
- Explore contracts with nurse practitioners (practice groups)
- Maximize possibilities found in development of Federally Qualified Health Centers

- Continue to work with JHU and UMD to do research, also Morgan State and UM College Park
- Childcare campaign will be evaluated

MCH Capacity Threats

- Continuity of working relationships across agencies/programs can be compromised with change of staffing, etc. unless interagency agreements are in place
- Sometimes difficult to do minor fixes to legislative, can make vulnerable to changes you don't want
- Variability of data capacity in LHDs
- Hiring for data capacity is complicated by definitional issues as well as specs for government positions (mismatch at times)
- Hiring freeze of particular concern with data capacity
- Difficult to evaluate educational interventions outcomes/impacts: methodology not developed, and is expensive
- Uncertainty persists about whether the health information reaches the right audience – people who seek out health information are probably already more informed than others who might need the information more
- When information is solicited from community groups on their needs, expectations that you will do something about their issues are created -- can't always meet those needs/demands
- In some cases for licensing of health professionals, government employees are not allowed to sit on boards.
- There is aging of the public health workforce, and heavily used MCH clinicians such as nurse midwives.
- The pipeline for public health workforce does not appear to be highly populated; perhaps exacerbated by the trend for people not to go into public service
- A substantial hiring freeze is in place for DHMH
- Population is very mobile; makes heavy demand on information/outreach needs
- The processes/methods for information dissemination are constantly evolving; hard to keep up (e.g., internet)
- General impression in the public that government run health services are just for persons who are poor
- Translation services are very expensive
- Limited evaluation of systems of information and outreach
- Sources of grant funds are diminishing in the current economic environment; resources for funds to develop and/or expand programs/services are more limited than ever. Similarly, there is increasing pressure to constrain growth of the Medicaid budget.
- Submitting proposals for small grants is not effective or cost efficient strategy.
- Funds for use for evaluation and/or research are difficult to come by from state coffers; this is of particular concern related to evaluating systems of information and outreach, and behavior change interventions

Appendix C-5

Maryland CAST-5 Capacity Needs Summary Profile

Maryland CAST-5 Capacity Needs Summary Profile

Capacity Need	Have	Need	If need, for what area(s) of programmatic performance?
Structural Resources			
1) Authority and funding sufficient for functioning at the desired level of performance	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - Cannot mandate best practices. - Minority business processes cumbersome. - Unfunded mandates compromise planning. - Procurement procedures create long delays in moving funds to vendors. - Difficult to hire staff, even when programmatic funds are available.
2) Routine, two-way communication channels or mechanisms with relevant constituencies	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - No formalized or routine mechanism to get information from higher levels in DHMH. - Do not have routine mechanisms to collect consumer perspectives and experiences. - Limited communications with university partners. - What is missing is the "routine" aspect of communication mechanisms; most is ad hoc/"as needed".
3) Access to up-to-date science, policy, and programmatic information	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - Have information, but don't have library at DOH, don't have journals - Programmatic data is a struggle - Legal counsel is a struggle
4) Partnership mechanisms (e.g., collaborative planning processes and community advisory structures)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<ul style="list-style-type: none"> - No regular mechanisms to meet with local health departments <ul style="list-style-type: none"> - suggestion for routine annual meeting between locals and state for planning - used to be a biennial MCH update conference - Family planning has a routine process to meet with regions quarterly – used for communication more than planning - Many points for meeting, but usually the same players attending each meeting
5) Workforce capacity institutionalized through job descriptions, contract language about skills and credentials, training programs, and routine assessments of capacity and training plans	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - Biggest hurdle is personnel hiring process, antiquated job classifications – only ~20 reviewed annually, and there are thousands! - Concern of image of state government workers. - Length of process – if push, can do in 3-4 months, generally 6 months – lose top candidates to the abyss of the process. - Low number of staff.
6) Mechanisms for accountability and quality improvement	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - CSHCN – not as good as some other areas– locals don't do it as well, and state doesn't review as well. - In MCH, not as good incentives for internal/state workforce – Medicaid does have some incentives, but could do better at looking at incentive structure for providers
7) Formal protocols and guidance for all aspects of assessment, planning, and evaluation cycle	<input checked="" type="checkbox"/>	<input type="checkbox"/>	

Data/Information Systems			
8) Access to timely program and population data from relevant public and private sources	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
9) Supportive environment for data sharing	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - Variation in definitions and variables in data, e.g., age range for adolescents. - Need more communication among agencies to facilitate how data is collected, what data is to be collected, and how best to collaborate – needs to be raised to the level of the Secretaries – there have been inter-organizational meetings, items have been codified, but implementation still a problem. - Lack of understanding of how HIPAA works – information is kept very close to the vest now, less sharing even when it is allowed.
10) Adequate data infrastructure	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - Problems with old/incompatible expensive systems.
Organizational Relationships			
11) State health department/agencies/programs	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
12) Other relevant state agencies	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
13) Insurers and insurance oversight stakeholders	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - Big need for the private sector providers. - Difficulties negotiating with MCOs.
14) Local providers of health and other services	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
15) Superstructure of local health operations and state-local linkages	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
16) State and national entities enhancing analytical and programmatic capacity	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
17) National governmental sources of data	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
18) State and local policymakers	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - For example, can't get a legislator on a CSHCN advisory committee when it's mandated. - Also have opposite experience, legislator takes over the process, takes it in a different direction than the rest of the group would have gone.
19) Non-governmental advocates, funders, and resources for state and local public health activities	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
20) Businesses	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - Better at the local level in some counties - programmatic. - Need it to influence policy. - Family planning has commercial relationship, because buying items needed to provide direct clinical services.

Competencies			
21) Communication and data translation skills	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - Learning how to make the public care. - Health educators needed who can make materials and message understandable, culturally appropriate, etc. (some Hispanics speak Spanish but cannot read brochures or pamphlets, even if in Spanish). - Product placement – condoms, STD information accessed more if people can take it anonymously. - Increased focus on social marketing generally – could use it more.
22) Ability to work effectively with public and private organizations/agencies and constituencies	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - Trial by fire – do it, fail, learn from failure – formal training would be good. - Training department has become much more computer and Internet based, not so much in person.
23) Ability to influence the policymaking process	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - Difference between understanding process and can have influence, and what actual ability to influence process. - Important to look to relationships with advisory councils, and what those members can do that state employees cannot, also involving consumers.
24) Experience and expertise in working with and in communities	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - Hire people to work with communities, convene focus groups. - Have coalitions, but don't feel that they work as coalitions. - In health promotion, a lot of those skills are there, but not throughout the agency – don't have capacity to provide technical assistance to other parts of agency. - Need to address issues of immigrants – it's a building population throughout Maryland. - Concerns about increasing gang presence. - Haven't been able to keep up with how the community populations change.
25) Management and organizational development skills	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<ul style="list-style-type: none"> - Need time – talent is there, don't have time to implement. - There was a mentorship-type committee, but it is now defunct under this administration. - Skills are in silos in job descriptions, department of personnel organizational skills, but having cross-over skills are useful – programmatic versus management.
26) Knowledge and understanding of the state context	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
27) Data and analytic skills	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
28) Knowledge of MCH and related content areas	<input checked="" type="checkbox"/>	<input type="checkbox"/>	