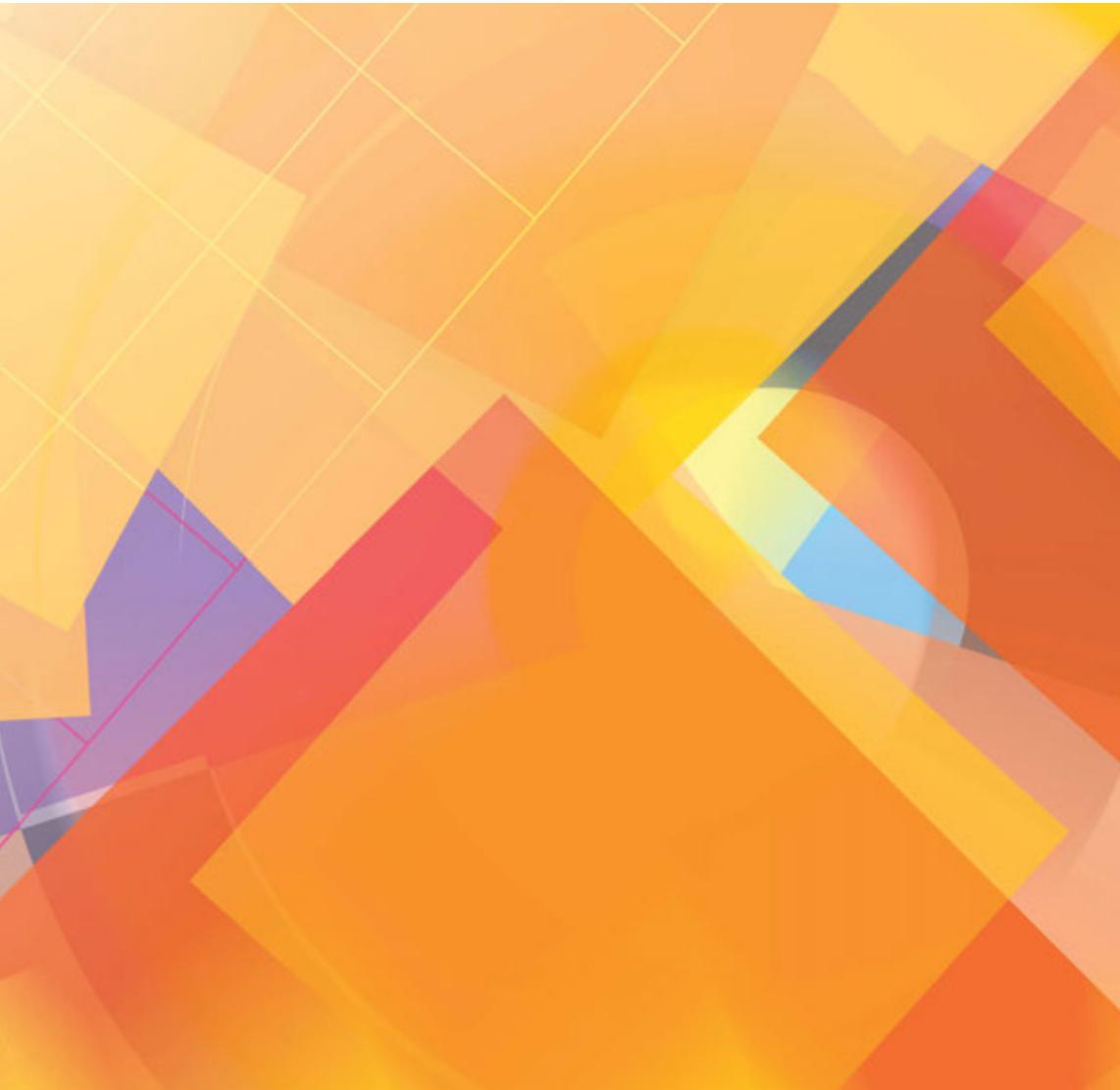




Leading State Maternal and Child Health Programs: A Guide for Senior Managers

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FORWARD

GREETINGS!

I want to thank you and congratulate you on your new leadership role. In the words of a former AMCHP president, Dr. Maxine Hayes, MCH means Making Change Happen – and you have now become a part of the Making Change Happen team.

Managing state programs for maternal and child health (MCH) and children and youth with special health care needs (CYSHCN) can

be challenging. However, always remember you have the most incredible opportunity to make a lasting and positive impact on the health of the women, infants, children, youth, children with special health care needs and their families in your jurisdiction.

One thing you should know is that you are not alone in this new role. There are many people who are here to help you along the way, including your peers across the country, federal Maternal

and Child Health Bureau (MCHB) staff, Association of Maternal & Child Health Programs (AMCHP) members and staff, the National MCH Workforce Development Center, academic and research centers, and informed families, to name just a few. Just come with your questions because we have answers.

Over the past half decade, AMCHP observed significant changes in the landscape of MCH. These include implementation of the Affordable

MCH MEANS MAKING CHANGE HAPPEN

Care Act (ACA), several state agency reorganizations, shrinking state and federal budget resources, and, most recently, the transformation of Title V. With the turnover of state Title V leaders and many retiring, it is important to continue to ensure a “baseline” of maternal and child health services for the next generation of leaders of state MCH and CYSHCN programs. At AMCHP we want to make sure our new generation of MCH leaders will continue to Make Change Happen. Women, children and families are counting on us to be there with them, for them, work on their behalf, across the life course so that current and future generations

are reflected in healthy children, healthy families and healthy communities.

We see this guide as the key to Making Change Happen for MCH leaders in their first six months of the job. We want this to be a tool for you and other new MCH professionals at all levels as it provides a great foundation for working in Title V. We hope you find this guide to be a useful reference as you are learning your role and Making Change Happen in your MCH program.

**Welcome to
the maternal
and child
health
community!**

Millie Jones, MPH
AMCHP President
December 2014

AUTHORS' PREFACE

Leading State Maternal and Child Health Programs: A Guide for Senior Managers is designed to help you succeed at your job. If you are a senior manager in your agency responsible for the oversight or management of all or part of the Title V Maternal and Child Health Services Block Grant, this manual is for you. Titles, duties, and scopes of responsibility for family health related federal and state programs vary between agencies and states, but this guide was written to be adaptable to your situation regardless of your specific position title or responsibilities. It also is useful whether you are from a state where you are the only staff member or from a state having a large number of staff devoted to block grant programs.

As requested by an advisory focus group of state leaders and other experts in the field, AMCHP framed the guide around the major leadership concepts of vision, change and relationships as well as current management concepts including planning. We reviewed conceptualizations of leadership roles by key thinkers whose writings have been used in national public health leadership institutes. These experts include Stephen Covey, Peter Senge,

Edgar Schein, John Kotter and David Campbell. While varying in conceptualization of major leadership roles, this literature makes a clear distinction between leadership and management. Stuart Capper's curriculum "The Mystical Reality of Leadership," part of the MCH Leadership Institute on Systems, includes some concise comparisons of the two roles noting, "management and leadership may be different – but they are not separate." The content for this guide is consistent with Capper's idea, framing the guide around leadership roles as well as providing practical information, tips and resources for senior managers of MCH block grant and related federal and state programs.

In preparing the original guide, we sought the advice of many people across the country. We would especially like to acknowledge with gratitude the following people for their assistance and support:

- [Cathy Hess](#), Health Policy Consultant
- [Kathy Peppe](#), Health Consultant
- [Deborah Dietrich](#), Former Acting Executive Director, AMCHP
- [Stephanie McDaniel](#), Former Director, Center for Best

Practices, AMCHP

- [Meg Booth](#), Former Policy Analyst, AMCHP
- [Lisa Cain](#), Former Director of Center for Membership & Communications, AMCHP
- [Sally Fogerty](#), Former President, AMCHP
- [Members of the focus group listed in Appendix B](#)

In 2013 the AMCHP Workforce and Leadership Develop Committee included the task of revising this guide in their committee work plan. The Workforce and Leadership Development Committee (WDC) is one of the AMCHP organizational committees. The WDC develops strategies that will benefit how Title V staff carries out their daily duties. Some examples include identifying the issues the states are facing with respect to recruitment, training and retaining staff. This committee leverages resources from across the country to assist the Title V staff in addressing common issues such as training, technical assistance, data assessment and professional development. To accomplish this task of revising the guide a subcommittee was established representing committee members



and Title V leaders to work on the revision of the guide. The subcommittee reviewed the guide and identified revisions. Based on subcommittee input the following new sections were recommended.

- ACA Impact on Title V
- Family Engagement
- Data Sources and Techniques
- Workforce Development Resources

The subcommittee and Title V leaders who played a big role in the revision of the guide include.

- Brian Castrucci, Program Director, de Beaumont Foundation
- Eileen Forlenza, Director, Family Leadership Initiative, Colorado Department of Public Health and Environment
- Holly Grason, Director, Women's & Children's Health Policy Center, Johns Hopkins University School of Public Health, MCH

- Donna Petersen, Dean and Professor, College of Public Health, University of South Florida
- Rylin Rodgers, Family Leadership Coordinator, Riley Child Development Center
- Nan Streeter, Deputy Director, Division of Family Health and Preparedness & Title V Director, Utah Department of Health
- Ellen Volpe, Branch Chief, Eastern Region, Maternal and Child Health Bureau

AMCHP staff incorporated the subcommittee recommendations in the latest revisions of the guide in 2014.

Each of these people in the original and revised guide gave freely of their knowledge, skill, expertise and time to make sure this document meets its ultimate goal – passing along to the next generation of state leaders in

family health, MCH and CYSHCN programs the wisdom gained from the perspective of the program's rich history combined with the experience of past and present program leaders. We trust that we have met that expectation.

We enjoyed the challenge presented to us in terms of meeting all of the desired content, format and utility of the guide expressed by those with whom we conferred. We have been mindful that this is a document that must remain somewhat "ageless" in its content; practical in its advice to those newly embarking on leadership positions in family health, MCH and CYSHCN programs in the states, territories or District of Columbia; helpful to the more "seasoned" leaders who may just need a reason to rethink their approach to the job; and inspiring to all senior managers who need to find their own way to do the best job they possibly can. Our bottom line message is: You Can Do It!

GETTING STARTED

ARE YOU A STATE TITLE V LEADER?

If you are a senior manager in a state agency and your responsibilities include components of the MCH Block Grant – also known as Title V of the Social Security Act – yes, you are!

You are:

- Responsible for improving service systems and health outcomes for ALL women, children, youth and families, including those with special needs, consistent with national health goals and state needs assessments
- Part of one of the 59 state/territorial MCH leadership teams in the nation
- Involved with the WIC nutrition program, the Title X family planning program, the Part C early intervention program and various Centers for Disease

Control and Prevention (CDC) programs, Maternal Infant and Early Childhood Home Visiting (MIECHV) program, Early Childhood Comprehensive Systems (ECSS), Special Projects of Regional and National Significance (SPRANS), Community Integrated Service System (CISS) projects, among others. Title V provides a framework for linking these programs to comprehensive strategies

- Working in a state agency called health, public health, human services or many other titles that convey responsibility for ensuring the public's health
- Within a bureau, division or branch called maternal and child health, CYSHCN, family health, community health or something similar
- In a position to make real a longstanding national

commitment to the health of this nation's women, children, youth and families, including those with special needs

Your title, specific duties, position and scope of responsibility may vary from your counterparts across the nation. But the common denominator - responsibility for the Title V MCH Services Block Grant is to improve the health of women, children and families. It is up to you and your colleagues to deliver on a national mission, legacy and promise for improved health of women, children, youth and families. The AMCHP Guide for Senior Managers will help you get started.

YOUR FIRST MONTHS AS A NEW MCH LEADER

Understand the job that you have been hired to do. How has the job been performed in the past and does that impact your ability to do

Dennis Rubino, Former Director, Children with Special Health Care Needs Program, Delaware

“The one common denominator of all MCH/CYSHCN leaders over the many years has been the COMMITMENT to helping the people they serve. That commitment is what makes the MCH family.”

“Given all we have to learn and then put into practice as Title V’ers, having this guidance is one of the best support systems around. If I can’t have one of the seasoned MCH Title V experts in my back pocket, this guidance is the next best thing.”

Millie Jones, Clinical Consultant, Bureau of Community, Wisconsin

the job now? Where do you and the Title V programs fit in the organization of the agency? What authority do you have for decision making? Talk to your, staff, partners, supervisor or agency director about these questions. Access resources that will assist in getting you acquainted to your new role by reviewing last year’s Block Grant application annual report and reviewer comments. Reach out to leaders of other key MCH programs, Medicaid, WIC, Title X. Plan to make personal visits to them if not already known to you. Lastly, become acquainted with your Division of State and Community Health (DSCH) Project Officer.

Ask for briefing documents from program directors under your supervision. Ask that briefings include a description of the program(s), information about current program strengths and needs, budgets and contracts, staffing, statutory requirements,

current performance reports, a schedule of key deadlines, needs assessment, Block Grant annual report, annual report reviewer comments, and data specific to the program area, “hot” issues, pending or proposed legislation, key stakeholders and constituencies, and any other issues that you should know. Request information on important departmental policies (e.g. travel procurement).

Get to know the program staff as quickly as possible and personally meet as many of them as you can. Attend program staff meetings. Obtain a directory of your staff including their work, home, and cell phone numbers and background information on your key staff members.

Read the first two chapters of this guide as soon as you can. They give a sense of the rich history of the nation’s MCH programs and the commitment to family health we all share.

For Further Development: Learning Opportunities from the MCH Navigator

- MCH Orientations (structured trainings for new hires, support staff, mid-level, senior staff, local health department, advisory boards, community and advocacy groups)
<http://www.mchnavigator.org/trainings/orientations/bundle-1.php>

Participate in the AMCHP New Director Mentor program for new Title V leaders. Take advantage of this opportunity to learn from your peers. The AMCHP website also provides many publications, issue papers, fact sheets and other policy documents that you will find helpful.

Seek opportunities for involvement through AMCHP, your national association. Understanding what is happening at the national level helps you to be a strong MCH leader in your state, territory or jurisdiction. The AMCHP annual meeting is an excellent training forum for learning about current issues, discussing federal directives and plans, and expanding your knowledge about managing Title V programs and funds.



CHAPTER 1

The Big Picture: Title V as a Foundation for Ensuring the Health of Women, Children, Including Children with Special Health Care Needs, and Their Families

THE ROOTS AND EVOLUTION OF TITLE V

Back to the future – that's how current public health emphases on assessment and policy might be viewed from a Title V perspective. The roots of Title V of the 1935 Social Security Act date back to the dawn of the 20th century, and it grew from a focus on using data to affect policy.

The **Federal Children's Bureau** was created in 1912 "to investigate and report on the status of children and on their common as well as special needs" and on "the welfare of children and child life among all classes of our people." Establishment of the Bureau was the first effort by the federal government in recognizing its role in promoting the health and well-being of children. The efforts of the early Children's Bureau led to important federal programs and priorities that are still in place today including uniform birth registries, school lunch programs, child labor laws, and infant and maternal mortality reduction.

The **Sheppard-Towner Maternity and Infancy Act of 1921**, provided the first federal grants to states for establishing maternal and child health services. Martha May Eliot, a longtime leader in the Children's Bureau and its chief from 1951-1956 noted that the act "established the national policy that

the people of the United States, through their federal government, share with the states and localities the responsibility for helping to provide community services that children need for a good start in life." In spite of its widespread support among many groups, the act was allowed to expire in 1929, led by opposition from the American Medical Association (AMA), the Catholic Church and the Public Health Service; who deemed the act as encroaching on the role of physicians in the lives of children and their families and as intruding in the lives of families. The American Academy of Pediatrics (AAP) was created in 1930 as a result of pediatricians who disagreed with the AMA position. During the eight years that it was law, the Sheppard-Towner Act fostered creation of child health units in 47 states, many of which remained in place after it was allowed to lapse. Most important, the act was critical to establishing the public health infrastructure for maternal and child health in this country that we now know as Title V.

The **Social Security Act of 1935** included Title V, again authorizing grants to states, this time "for the purpose of enabling each State to extend and improve, as far as practicable under the conditions in such State, services for promoting the health of mothers and children, especially in rural areas and

For Further Development: Learning Opportunities from the MCH Navigator

Drawn from the MCH 101 Bundle:

- MCH Populations, Mission, and Principles
<http://www.mchnavigator.org/trainings/MCH-101-mission.php>
- MCH History and Title V Legislation
<http://www.mchnavigator.org/trainings/results.php?Competencies=1K1>

in areas suffering from severe economic distress, there is hereby authorized to be appropriated for each fiscal year, beginning with the fiscal year ending June 30, 1936, the sum of \$3,800,000. The sums made available under this section shall be used for making payments to States which have submitted, and had approved by the Chief of the Children's Bureau, State plans for such services." The grants targeted MCH, children with special needs (then known as "crippled children"), and child welfare services. While the MCH component continued to focus on prevention, the CYSHCN component introduced grants for medical care. States were funded by formula to establish service units and were required to submit state plans to obtain funding.

Over the next six decades, special program emphases were added to Title V, as the program adapted to identified needs and to the enactment of other federal health programs. Maternity and Infant Care (MIC) and Children and Youth (C&Y) projects developed under Title V in the 1960s to respond to problems of mental retardation and poverty conditions, respectively. These projects proved to be effective comprehensive care models. Projects for neonatal intensive care, family planning and dental care were added by the 1970s.

Later years brought programs on school health, genetic diseases, newborn screening, training and research. All of these made significant contributions in advancing the field of maternal and child health. At the same time, new federal programs, including community health centers and Medicaid, resulted in some loss of influence for the Title V federal and state program.

In 1981, Title V became a Block Grant under the Reagan Administration but retained some key features of the original legislation. The Block Grant shifted responsibility for Title V to the states with few requirements at the time. However many critics, including those in Congress, decried the lack of accountability mechanisms, cited initial reductions

in funding and decreased federal oversight as weakening programs in some states.

The 1989 amendments brought increased accountability for Title V while retaining flexibility. The 1989 amendments were an attempt to retain the historic strength of the program in assessing, planning and responding flexibly to state specific needs, while introducing stronger national accountability. These amendments were enacted under the Omnibus Budget Reconciliation Act of 1989 (OBRA '89). Advocates came together with state MCH programs and AMCHP to urge Congress to seek this balance in the law. These amendments established the groundwork for current aspects of the program, such as the needs assessment. OBRA 1989 also required that Title V coordinate with Medicaid particularly on Early Periodic Screening Diagnosis and Treatment (EPSDT). This is the basis for the Title V role in health reform and partnering with Medicaid, the Children's Health Insurance Program (CHIP) and ACA.

Recent years showed continued tension between flexibility and accountability. Over the course of the 1990s, Congress frequently proposed federal legislation to create more and larger block grants. Some proposals included recommendations to consolidate the MCH Block Grant program

with others, such as WIC, family planning, immunizations and other public health programs. As of 2013, Congress has not enacted any of these proposals. The State Children's Health Insurance Program (SCHIP) was enacted as a capped entitlement to the states, allowing states more flexibility than they have with Medicaid. At the same time, this decade saw passage of the Government Performance and Results Act (GPRA), which was one of the policy forces that drove development of performance measures under Title V. These policy tensions between block grant and categorical programs and flexibility and accountability are likely to continue.

Today, Title V gives states flexibility with accountability for systemic approaches to improve health access and outcomes for ALL women, children, youth and families. Title V has been dubbed the "framework," the "infrastructure" and even the "glue" for overall state and territory strategies, policies and programs. Over the years, many strengths have evolved from Title V: flexibility, adaptability, broad mission focused on national health objectives, responsiveness to state and territory needs, and accountability for performance. While the dollars for Title V may be a relatively small proportion of a total state budget for family health

programs, used effectively they can have a big impact.

MCH TRANSFORMATION OF THE TITLE V BLOCK GRANT

There are changes ahead for the Title V Block Grant. In May 2013, MCHB began working in partnership with the leadership in the state MCH programs as well as with other national MCH leaders and stakeholders like AMCHP to develop and refine a vision for the Transformation of the Title V MCH Block Grant to better meet current and future challenges facing our

nation's mothers and children, including CYSHCN. The details of this transformation will be released in January 2015.

National MCH Mission Statements 2014

...in federal statute

The Title V MCH Services Block Grant statute is authorized to improve the health of all mothers and children consistent with national health objectives to enable each state to provide and assure access to quality maternal and child

health services, reduce mortality, prevent diseases and disabling conditions, promote health, provide services to children and youth with disabilities, and promote family-centered, community-based, coordinated care.

State Title V managers are responsible for:

- Working toward the national mission
- Creating a vision for state systems in improving the health and welfare of families, including CYSHCN



- Using limited Title V resources strategically and mobilizing, leveraging and aligning other resources to achieve the mission and vision
- The list goes on and on and responsibilities vary from state to state

...for AMCHP

To support state maternal and child health programs and provide national leadership on issues affecting women and children.

...for MCHB

To provide leadership, in partnership with key stakeholders, to improve the physical and mental health, safety and well-being of maternal and child health (MCH) population which includes all of the nation's women, infants, children, adolescents, and their families, including fathers and children with special health care needs.

health system in "disarray," IOM recommended that public health agencies focus on strengthening three core functions: assessment, policy development and assurance. As public health agencies worked to rise to the challenges of this report, federal and state agencies came together to flush out these core functions. The result was a set of 10 essential public health services that are used as a framework for a range of public health efforts. In 2002 the report was updated, *The Future of the Public's Health in the 21st Century*, which further reviewed the nation's public health capabilities and identified how federal and state agencies can better ensure the health of communities by:

- Adopting a population health approach that considers the multiple determinants of health
- Strengthening the governmental public health infrastructure, the backbone of the public health system
- Building a new generation of intersectoral partnerships
- Requiring accountability from and among all sectors of the public health system
- Making evidence the foundation of decision making
- Enhancing and facilitating communication within the public health system

Simultaneous to this work, AMCHP, the national organization of state Title V MCH, CYSHCN and family health programs, was working with MCHB to articulate and support future directions and roles for state programs. In 1995, AMCHP partnered with the Child and Adolescent Health Policy Center at Johns Hopkins University to produce the *Public MCH Program Functions Framework: Essential Public Health Services to Promote Maternal and Child Health in America*.

This document, developed by and for state leaders, helped provide a common framework for programs across the country. The content is consistent with broader public health frameworks but is tailored to promoting maternal and child health and serving children with special health care needs. Strong emphasis is placed on ensuring availability, access and quality of health services, as well as on linkages with other systems serving women, children, youth and families.

Because the MCH Essential Services are adapted from the 10 essential public health services framework, they offer an important common language and bridge to broader public health efforts.

CONCEPTUAL FRAMEWORKS FOR TITLE V

ESSENTIAL PUBLIC HEALTH SERVICES

In 1989, the Institute of Medicine (IOM) published *Toward the Future of Public Health: Finding the public*

10 ESSENTIAL PUBLIC HEALTH SERVICES

TO PROMOTE MATERNAL AND CHILD HEALTH IN AMERICA

- 1. Assess and monitor maternal and child health status to identify and address problem**
- 2. Diagnose and investigate health problems and health hazards affecting women, children, and youth**
- 3. Inform and educate the public and families about maternal and child health issues**
- 4. Mobilize community partnerships between policymakers, health care providers, families, the general public, and others to identify and solve maternal and child health problems**
- 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**
- 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**
- 7. Link women, children, and youth to health and other community and family services, and assure access to comprehensive, quality systems of care**
- 8. Assure the capacity and competency of the public health and personal health workforce to effectively address maternal, child health and children and youth with special health care needs**
- 9. Evaluate the effectiveness, accessibility, and quality of personal health and population-based maternal and child health needs**
- 10. Support research and demonstrations to gain new insights and innovative solutions to maternal and child health-related problems**

In the 1990s, the federal MCHB developed a framework for Title V that graphically represents the role of the program as the foundation for the family health system. Now known as the MCH pyramid, this framework is consistent with the essential public health services; they can be mapped onto each other. In 2015, MCHB revised the pyramid as part of the 2015 block grant transformation. The MCH pyramid distills core services into three main categories and, through the graphic of the pyramid, illustrates how each set of services rests on the foundation beneath.

- **Direct Health Care Services** in this framework are directly provided to individuals, by state or local agency staff or by grantees or contractors. Title V programs commonly support prenatal care, well-child and school-based health services, and specialty services for children and youth with special health care needs.
- **Enabling Services** help families access and use health services and are usually targeted to families that have special needs or face specific barriers.
- **Public Health Services and Systems** assess and monitor MCH health status, maintain the public health workforce, develop public health policies and plans, enforce public

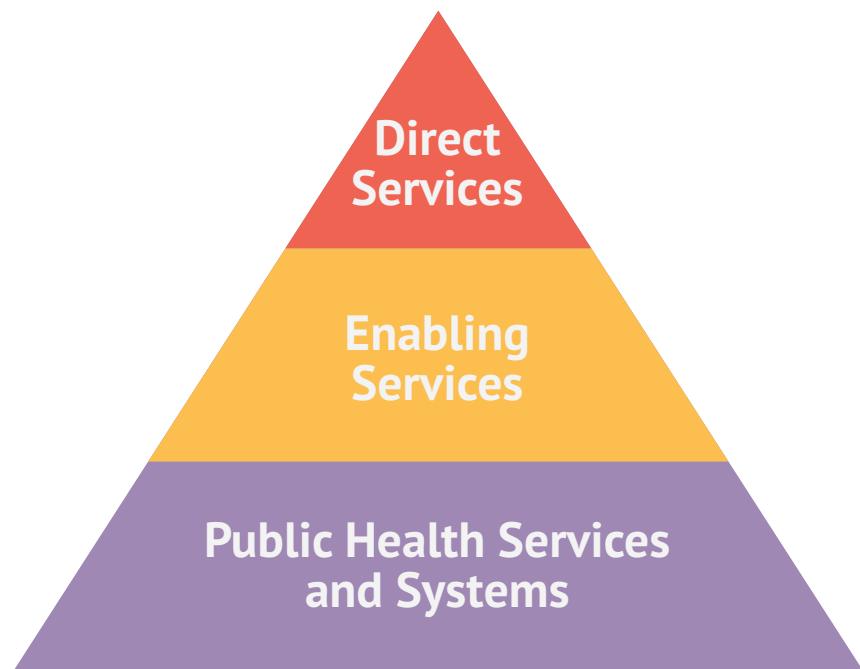
health laws, and ensure quality improvement.

Federal Title V requirements, including applications, annual reports and performance measures, are tied to this framework. It is critical that you be familiar with the pyramid and how your agency Title V activities are classified within this framework.

The pyramid also illustrates the shift that is occurring in the roles of state Title V programs. If you plugged in Title V federal and state expenditures into the appropriate levels of the pyramid, the pyramid might be upside down. Historically, the largest share of state MCH/CYSHCN

funds supported direct provision of health services. As health coverage for women, children and youth expanded, first through Medicaid and later through SCHIP, and as many publicly insured families were served through managed care systems, many state Title V programs reduced their roles and expenditures in direct provision of health care.

The role of Title V has always been to “ensure” services, a role for public health also emphasized in the IOM core public health roles. State leaders can ensure services through multiple mechanisms, including needs assessment, planning and recommendations



Source: MCHB Title V MCH Services Block Grant to States Program Guidance and Forms for the Title V Application/Annual Report, Seventh Edition

A state MCH leader builds systems on the foundation of Title V history, mission and key concepts.

to state policymakers and other agencies to fill gaps. But when no other recourse is available, state leaders use Title V resources to provide access. While this need has not disappeared completely for women, children and youth, it has diminished. States have begun to shift resources down through the pyramid to support enabling, population-based and infrastructure-building services.

As mentioned earlier there are changes ahead for the Title V MCH Services Block Grant and possibly a modified pyramid.

SYSTEMS OF CARE

One response to the needs of children and youth with chronic health conditions and disabilities, over the last several decades the federal MCH Bureau has placed

strong emphasis on systems development. Congress first added language focusing on this Title V role in 1987 and later in the 1989 amendments. While the focus has been on systems for CYSHCN, states also address preventive, primary and specialty care services for all women, children, youth and families.

State systems development for CYSHCN is now incorporated into national health objectives, as well as Title V performance measures. The federal MCHB has developed a national agenda focused on:

- Access to coordinated, quality health services through a “medical home”
- Trained providers
- Adequate insurance coverage
- Family engagement and satisfaction

- Early and continuous screening
- Transition to adult systems

Family health programs strive to develop systems of care that are family centered, comprehensive, coordinated, culturally competent and community based.

To ensure that all families have access to health care that meets their needs, health systems must be culturally competent. Particularly given the health disparities for different racial and ethnic groups, MCH programs must ensure that providers and systems are culturally competent to narrow those gaps. Providing guidance and requiring accountability for cultural competence demands that you, your staff, and your policies embody its attributes. Ongoing training in cultural competence is a key element to the success of your program.



KEY CONCEPTS FOR MATERNAL AND CHILD HEALTH

Social Determinants of Health

Social determinants of health are factors/circumstances that play a big role in a person's current state of health. These factors/circumstances include where one is born, grows up, lives, works and age, and the systems of care available to deal with an illness. There also are bigger factors/circumstances that play a role such as economics, social policies and politics. For the MCH population social determinants of health are an important key

Systems also should be family centered and consumer oriented. Families can and should be involved in all of the core functions of state programs – from needs assessment, through planning and program development, to service delivery and evaluation. As with cultural competence, the MCHB has extensive resources on family-centered approaches.

As Title V leaders you also should be familiar with the MCHB Core Quality Outcomes for CYSHCN.

- Families are partners in decision making at all levels
- Coordinated, ongoing,

comprehensive care within a medical home

- Adequate insurance to cover needed services
- Early and continuous screening for special health care needs
- Community-based service systems are organized for ease of use
- CYSHCN receive services needed for transition to adulthood

A state MCH leader builds systems on the foundation of Title V history, mission and key concepts.



In 2003 MCHB defined its population as “all women, infants, children, adolescents and their families, including fathers and children with special health care needs.”

concept to understand because as a MCH leader your role in your state is to run programs that help reduce health inequality for those who have systematically experienced greater social or economic obstacles to health (e.g., race, socioeconomic status, geographic location, physical disability). AMCHP members are involved in various efforts to improve birth outcomes through a social determinants of health framework, such as the Partnership to Eliminate Disparities in Infant Mortality, the Best Babies Zones project and the Collaborative Improvement and Innovative Network (CoIIN) to reduce infant mortality. State MCH Directors work with various partners in fields such as economics, education, housing, transportation and policy to develop programs and policies that lead to healthier communities.

Life Course

Life course is a theoretical model that takes into consideration the full spectrum of factors that impact an individual's health not just at one state of life (e.g. adolescence), but through all stages of life (e.g. infancy, childhood, adolescence, childbearing age, elderly age). Life course theory shines light on health and diseases patterns – particularly health disparities – across populations and over

time. Life course theory also points to broad social, economic and environmental factors as underlying causes of persistent inequalities in health for a wide range of disease and conditions across population groups. Many MCH programs are implementing a life course approach to address the health of populations by translating the theoretical model to public health practice.

Systems Building

MCH and CYSHCN programs historically have played a strong role in “filling the gaps” or serving as part of a “safety net” for low-income, underserved and special needs populations. Many state programs historically filled this role by directly providing services through state and local clinics. As the nation took action beginning in the late 1980s to improve health care coverage, especially for children and pregnant women, and as Medicaid enrollees are moving to managed care delivery systems, public health programs reexamined their roles.

The need for a strong safety net remains today, and family health programs continue to play a substantial role in supporting it. However, programs are decreasing their role in “direct service” while focusing more on systems building. Title V programs build systems of

care by assessing unmet needs and gaps in services, identifying and developing service provider and funding resources to fill gaps and meet needs, providing training and monitoring to ensure quality services, and measuring system performance and population outcomes. Title V promotes a multidisciplinary approach to health care to address interrelated medical, psychosocial and nutritional needs.

Systems building is a concept that encompasses a range of functions included in the many conceptual frameworks discussed above. A key idea of systems building is a focus on the whole and how its parts interact, not just on the parts. In line with the Title V focus on all women, children, youth and families, and on outcomes for their health, a systems approach is absolutely necessary to achieve results. This systems approach also explains why MCH programs straddle public health, health care, and child and family service arenas. All of these arenas interact with families and communities to affect conditions that impact health and well-being.

Consider, for example, the problem of childhood asthma. Traditionally, public health studied its epidemiology and worked to eliminate or reduce environmental contributors. The

health care system also plays a role to medically manage the condition. Child-care centers and schools need help preventing and managing asthma. A public health, population-based approach to addressing chronic conditions such as childhood asthma considers the social determinants of health, the factors that impact a condition, and strategies to prevent the condition. These are all considered within a systems context recognizing that no one system has responsibility for all aspects of child health in this example. The Title V program leads only some of these components, but it works with the others to ensure that the entire picture is addressed and that the components are linked.

Family/Consumer Partnership

Family/consumer partnership is a guiding principle in state CYSHCN programs across the country, and one on which they must measure their performance. Family/ consumer engagement also is being incorporated into other maternal, child and adolescent health programs. Family/ consumer engagement makes a positive difference in program planning, implementation and outcomes. States have used highly individualized approaches in working with family representatives. Some specific approaches and tips for working with families are detailed in Chapter 6.

Population Based

Like other public health programs, Title V always has focused on entire populations, unrestricted by categorical eligibility requirements. The statutory mission of the program remains to improve the health of all mothers and children (emphasis added). However the boundaries of the “MCH population” have been interpreted more broadly recently and are now the subject of discussion and debate.

The purpose of the MCH Services Block Grant Program is to enable each state:

- To provide and to assure mothers and children (in particular those with low income or with limited availability of health services) access to quality MCH services;
- To reduce infant mortality and the incidence of preventable diseases and handicapping conditions among children, to reduce the need for inpatient and long-term care services, to increase the number of children (especially preschool children) appropriately immunized against disease and the number of low income children receiving health assessments and follow-up diagnostic and treatment services, and otherwise to promote the health of mothers and infants by providing prenatal, delivery, and

postpartum care for low income, at-risk pregnant women, and to promote the health of children by providing preventive and primary care services for low income children;

- To provide rehabilitation services for blind and disabled individuals under the age of 16 receiving benefits under title XVI, to the extent medical assistance for such services is not provided under title XIX; and
- To provide and to promote family-centered, community-based, coordinated care (including care coordination services, as defined in subsection (b)(3)) for children with special health care needs (CSHCN) and to facilitate the development of community-based systems of services for such children and their families.

Adolescents are part of the population of focus in Title V efforts. The Title V statute defines children as individuals under age 22. The federal MCH agency turned attention to this population in the 1960s, and more recently (in the 2000's) to young adults, those individuals under age 26. Today, most state Title V programs have designated adolescent health coordinators, who are organized in the National Network of State Adolescent Health Coordinators

CYSHCN are children who have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

(NNSAHC). NNSAHC and AMCHP have partnered to produce guidance for states, including a conceptual framework for adolescent health.

CYSHCN have always been a major, specific component of Title V programs. Prior to the Block Grant, there were separate funding streams for CYSHCN (“crippled children” as they were then known). For many decades, the programs focused on bringing quality specialty medical care to children with specific diagnoses, at times and in places where such care would not otherwise have been available. With advances in medical care and coverage, the need for the public sector to provide such care diminished, while other needs intensified. Increased specialization and sub-specialization of medical care, along with creation of new human service and education programs, created needs for managing or coordinating care. Medical advances also enhanced survival rates and longevity of infants and children with illnesses or disabilities, challenging system capabilities and family resources. Today, the role of Title V programs in directly providing medical services has decreased, as the programs increasingly work to improve systems, enable access and coordinate care, in partnership with families.



Particularly as we have learned more about the important relationship between preconception health and birth outcomes, state leaders, CDC and MCHB have returned their attention to women's health. As the 21st century begins, these leaders are working to conceptualize and test models for building women's health systems.

The National Initiative on Preconception Health and Health Care (PCHHC) is a public-private partnership that began in 2004. The PCHHC is comprised of a steering committee and five workgroups focusing on the following domains: consumer, clinical, public health, research and surveillance, and policy and finance. The goals of the national initiative are to: Improve the knowledge, attitudes and behaviors of men and women related to preconception health; Create health equity and eliminate disparities in adverse maternal, fetal and infant outcomes; Ensure that all women of birthing age receive preconception care services that will enable them to achieve high levels of wellness, minimize risk and enter any pregnancy they might have in optimal health; Reduce risks among women who had a prior adverse maternal, fetal or infant outcome through interventions during the postpartum and

interconception period.

Although the maternal mortality rate is declining in most countries around the world, it has nearly doubled in the United States since 1990. State leaders, MCHB, CDC and Merck for Mothers have initiated programs that address both maternal deaths as well as severe complications during pregnancy and childbirth.

In 2011, Merck announced a 10-year, \$500 million initiative to reduce maternal mortality. With funding from Merck for Mothers, the AMCHP Every Mother Initiative aims to strengthen state maternal morbidity and mortality surveillance systems and enhance the ability of the states to translate surveillance data into policy and programs that improve health outcomes for women and mothers.

CDC is leading an initiative to develop standards and recommendations to strengthen the maternal death review process. Currently underway, the project is expected to result in a best practice guide for new maternal death reviews; standardized information collection across state review teams to facilitate national analysis and reporting; and a catalog of review findings successfully translated into actions. AMCHP is collaborating with CDC to identify system enhancements and core variables

within the Maternal Mortality Review Data System.

Also the National Maternal Health Initiative has increased the attention being devoted to family health, including the roles and needs of fathers. In 2003 MCHB defined its population as "all women, infants, children, adolescents and their families, including fathers and children with special health care needs." The future promises increased exploration of the population boundaries for programs historically rooted in the health of children and their mothers.

IMPORTANT RESOURCES

ON THE HISTORY OF TITLE V

- Association of Maternal & Child Health Programs. About Title V. Retrieved from <http://www.amchp.org/AboutTitleV/Pages/default.aspx>.
- Brosco, J. P. (2012). Navigating the Future Through the Past: The Enduring Historical Legacy of Federal Children's Health Programs in the United States. *American Journal of Public Health*. 102(10), 1849-1857.
- Health Resources and Services Administration Maternal and Child Health Bureau. Understanding Title V of the Social Security Act. Retrieved from <http://www.amchp.org/AboutTitleV/Documents/UnderstandingTitleV.pdf>.
- Health Resources and Services Administration Maternal and Child Health Bureau. MCH Timeline. Retrieved from <http://mchb.hrsa.gov/timeline/>.
- Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Rethinking MCH: The Life Course Model as an Organizing Framework, Concept Paper, November 2010. Retrieved from <http://mchb.hrsa.gov/lifecourse/rethinkingmchlifecourse.pdf>.
- Hutchins, V. L. (1994). Maternal and Child Health Bureau: Roots. *Pediatrics*. 94, 695-699.
- Lesser, A. J. (1985). The Origin and Development of Maternal and Child Health Programs in the United States. *American Journal of Public Health*. 75(6), 590-598.
- Association of Maternal & Child Health Programs. (2013) MCH 3.0-Advancing the MCH Vision. Retrieved from http://webcast.hrsa.gov/AMCHP_day1_webcast1_skillsbuilding/.
- VanLandeghem, K., Schor, E. L. (2012) New Opportunities for Integrating and Improving Health Care for Women, Children, and Their Families. Retrieved from <http://www.amchp.org/Policy-Advocacy/health-reform/resources/Documents/New%20Opportunities%20for%20Integrating%20and%20Improving%20Health%20Care%20for%20Women,%20Children,%20and%20Their%20Families.pdf>.



CHAPTER 2

The ABCs: Title V at the National and State Levels

AN IMPORTANT TOOL FOR BUILDING STATE SYSTEMS

While more accountability was introduced with the 1989 amendments, the Title V statute today continues to offer significant flexibility to build programs to meet the specific needs of your state and to fit with your state size, systems and cultures. This chapter provides more specific information on the federal and state components of Title V and how they work together.

As a senior manager with responsibility for Title V, it is important that you review the Title V legislation, as well as the current application and report guidance (see Chapter 6 for highlights). All of the requirements for state programs are contained in these documents; there are no regulations specific to Title V. As with every law, there are nuances and aspects that are open to interpretation. In addition to reading the tips included in this guide, talk to your counterparts in other states to learn from their experience. Federal MCH administrators can advise you within the context of the law, the guidance and federal policies.

HOW ARE STATE MCH PROGRAMS ORGANIZED?

Given the flexibility of Title V, there is great variation among MCH

programs across the country. One (mostly) common denominator is that programs by law must be administered by the “state health agency.” The exception to this rule is that a small number of CYSHCN programs are located in other state agencies, usually universities, because the Title V legislation “grandfathered” existing programs.

Even with this common location there is great variety in the structure and hierarchy for state Title V programs. State executive branch agencies vary widely across the country, and their structure and responsibilities can change, especially with new administrations.

The saying goes “when you have seen one MCH program, you have ONLY seen one MCH program.” However there are some commonalities among state health agencies. In 2014 the Association of State and Territorial Health Officials (ASTHO) programs released volume three to their 2007 *Profile of State Public Health*. This profile outlines the various structures of health agencies in the United States. A couple of the key findings of this report include:

- 58 percent of state health agencies are free standing independent agencies, and 42 percent are a unit of a larger umbrella agency
- With regards to state health

For Further Development: Learning Opportunities from the MCH Navigator

Drawn from the MCH 101 Bundle:

- Title V Implementation <http://www.mchnavigator.org/trainings/MCH-101-Title-V.php>
- Services Provided by Title V <http://www.mchnavigator.org/trainings/results.php?Competencies=1K3>
- Accountability <http://www.mchnavigator.org/trainings/results.php?Competencies=Accountability>

agencies relationship with regional /local public health, 14 states reported having centralized or largely centralized governance structure, four states reported shared governance structure, six states reported mixed governance structure and 27 states reported decentralized or largely decentralized structure

Today, MCH leaders usually work within larger public health agencies that include traditional areas such as epidemiology and health statistics, chronic disease prevention, and health promotion. The agency also may include environmental health, substance abuse prevention and treatment, mental health, developmental

disabilities, health facilities management or regulation, and Medicaid. Whether Title V operates within or outside of the same agency, these programs can make a big difference in the ease of communication and coordination of efforts.

The units with direct responsibility for Title V programs may be called MCH, CYSHCN or similar terms or may have a broader scope in family or community health. A fairly common structure is a bureau of family health (aka “big MCH”) overseeing MCH preventive and primary services for women or pregnant women, children and youth (aka “little MCH”), as well as CYSHCN. Related programs may be administered under or alongside these units. A 2006 AMCHP survey (State Title V Workforce Development Survey Program Profiles) found that 96 percent of state health agencies had MCH programs and 86 percent had CYSHCN programs that were considered to be the Title V unit. MCH or family health agencies commonly administer family planning programs and the supplemental food program for Women, Infants and Children (WIC). MCH or CYSHCN may administer the federal early intervention program (Part C) or Medicaid waivers for home- and community-based services. Related state-funded programs, foundation

initiatives and CDC programs – such as lead poisoning prevention, breast and cervical cancer screening, birth defects and developmental disabilities prevention – also often fall under the purview of the Title V unit.

In some states, the scope of Title V programs may be even broader, reaching to adult-oriented programs, primary care or chronic disease prevention. States with broad units often organize, plan and link the programs in a lifespan framework. This approach can ensure specific attention to children and youth needs, while maximizing opportunities for prevention and intervention at appropriate points across the lifespan.

WHAT DO STATE TITLE V PROGRAMS ACTUALLY DO?

Within the broad and flexible scope of Title V, the mix of agency functions and community services varies considerably. Each agency has a unique history in the context of the state political, cultural and socioeconomic characteristics. The state health care delivery and financing systems, including the roles of private and public sectors, add to the variety. Diversity in geography, race, ethnicity, income level and immigrant status are other key

factors affecting family health.

Southern states, often with highly diverse populations and high rates of poverty, historically play active roles in delivering health services through the public sector, often through local health departments. Northern states, especially on the coasts, tend to have high concentrations of academic and medical institutions and play a lesser role in public delivery of care. These states tend to play more of a role in financing and regulating health care. States in the middle of the country tend to have a mix of these roles.

Historically, MCH programs have played a significant role in delivering clinical preventive and primary care services to women, children and youth with state or local health agency staff. Many states provide specialty and therapeutic services for children with special health care needs in medical centers and mobile units. Other states rely on contracting with providers such as community health centers. Historically, Title V programs were involved where services were not available or not accessible due to barriers such as lack of coverage. In 2009 AMCHP was commissioned to write a report by the Lucile Packard Foundation for Children’s Health on the *Models of Care for Children and Youth with Special Health Care Needs: Promising*



Title V programs are charged with ensuring access to preventive, primary and specialty care.

Models for Transforming California's System of Care. This report is a great resource for new Title V leaders in identifying promising models to support the system of care for the CYSHCN population.

As public insurance has expanded in recent decades, it has met more of the fundamental health needs of women, children and youth. In turn, the variation in the roles of MCH programs seems to have increased. Without universal coverage, there are still families who lack insurance, particularly among immigrants. Even with insurance, providers may not be available or accessible, and barriers such as culture, language or transportation may impede access. Title V programs still are

charged with ensuring access to preventive, primary and specialty care. But how programs do this is shifting in most states.

With the shift to managed care systems in the 1990s, many states considerably decreased their roles in delivering care directly with state or local health agency staff. Where gaps in coverage, availability or access persist, more state Title V programs have moved toward grants or contracts to support local agency services. State programs also have looked to influence policy and to leverage other resources to close the gaps. Drawing on assessment and evaluation data, and on population and program expertise, MCH leaders are seeking to work with

Medicaid, SCHIP, managed care organizations, state policymakers and families to identify solutions for gaps in coverage and access.

As more children, youth and women gain access to private medical care, state MCH and CYSHCN programs are working to ensure that they receive comprehensive, multidisciplinary services, often in new ways. Some states have developed models and reimbursable bundles of services to "wrap around" basic medical care provided in office settings. These packages include services such as nutrition, social work, health and parent education, and therapies for special needs children and youth.

Additionally, state Title V programs are revisiting needs assessments

and reviewing evidence-based research to identify unmet needs and opportunities for prevention and intervention. Areas receiving increased attention in the early part of the 21st century include:

- Oral health
- Mental health
- Newborn screening
- Home visiting
- Early childhood development
- Care coordination, especially for children with special health care needs
- School health
- Adolescent health
- Reproductive health
- Women's health
- Transition services to bridge child and adult health systems

State Title V programs are addressing these areas by applying core functions and building the infrastructure for population-based health services. Optimally, starting with a needs assessment and planning that includes stakeholder input and review of evidence-based practice and progress on performance measures, Title V programs determine strategies to meet identified goals and objectives. These strategies may or may not entail extensive use

of Title V resources. Providing data, expertise and assistance to other agencies may help shape a policy or program in another agency's jurisdiction. Funding and evaluating limited demonstration models may result in a new intervention with other funding sources. Title V programs can be leaders and catalysts for systems change.

Although the trend toward major, multiagency restructuring may have accelerated recently, reorganization is a constant in public agencies, and something for which you should be prepared. While there is not one model for organizational structure and placement, some things to consider include:

- The agency mission should support the Title V emphases on prevention, population-based and comprehensive approaches, special needs, and systems development
- Children, youth and women, especially those with special health needs, each have unique needs that should be explicitly addressed in organizational structure
- The agency must be competent in data collection and analysis for needs assessment, planning and evaluation, as well as program development for target populations

MCH leaders agree that it is critical for all states to have a division responsible for ensuring the health of women, children, youth and families.

As with organizational structures, there is considerable variation in the education and experience of your colleagues across the country. MCH programs historically have promoted multidisciplinary teams, at the management as well as the local service level. Previous federal requirements for physicians to lead state programs were eliminated, but many states retain physicians on their senior leadership teams. These doctors, most commonly pediatricians, bring critical expertise, along with an ability to forge relationships with state physician groups that may be more difficult for non-physicians. Nurses, social workers and nutritionists also are commonly found in senior leadership positions. Clinical backgrounds are helpful in policy and program development and evaluation and offer a value often sought after by other agencies. Many clinicians in leadership positions have advanced degrees

You have the flexibility and opportunity under Title V to form a multidisciplinary team to reach your mission and goals.

in public health or other relevant fields. With the growth of MCHB training programs, increasing numbers of Title V leaders have earned graduate degrees in MCH.

Increasingly, people with experience administering other public programs are bringing that experience to bear on family health. Community-based providers from both the public and private sectors are bringing their important ground-level knowledge to the state level.

You have the flexibility and opportunity under Title V to form a multidisciplinary team to reach your mission and goals.

State programs also play a leadership role in workforce development. One of the essential health services – ensuring the capacity and competency of the public health and personal health work force – has become an urgent necessity. Shortages in key areas, particularly nursing, have been well documented. State senior managers can partner with schools of public health, other academic partners, and state and national public health associations to ensure the availability of health workers. It also is important to train your staff in new areas, such as systems development and information technology.

WHAT IS THE ROLE OF THE FEDERAL MCH BUREAU?

As we saw earlier, federal leadership for maternal and child health dates back before Title V to the Children's Bureau. A reorganization in 1969 moved Title V to the Public Health Service. After a number of reorganizations and in response to advocacy led by AAP, and an OBRA 1989 request that an office for MCH be established, the modern day MCH Bureau was established in 1990. Currently, MCHB is one of five bureaus within the Health Resources and Services Administration (HRSA).

The federal-state partnership for maternal and child health also predates Title V. The nuances of that relationship, and particularly the amount of federal oversight, have varied over the past century. The philosophy of the federal administration has a strong influence on the relationship, particularly since Title V became a block grant in 1981. In the 1980s, the Title V statute had very limited accountability provisions and the administration strongly emphasized state flexibility; accordingly there was limited direction from the federal MCH agency. Following the 1989 Title V amendments and with new federal leaders, more emphasis was placed on accountability and on assisting states to develop capacities. The strength of the



federal-state MCH partnership over the past decade is evidenced in the collaborative effort of states and MCHB to develop and implement performance measures into the Title V program.

State Title V programs, through AMCHP, urged that the 1989 amendments address the federal as well as the state role in the Title V program. The result was legislation requiring the secretary to "designate

an identifiable administrative unit with expertise in maternal and child health within the Department of Health and Human Services, which unit shall be responsible for":

- Special Projects of Regional and National Significance (SPRANS) in Title V
- Federal-level coordination of Title V, Medicaid (especially EPSDT), related agriculture and education programs, health block grants, and categorical health programs, such as immunizations
- Information in areas such as preventive services and advances in care and treatment
- Technical assistance, on request, to states in areas such as program planning, establishment of goals and objectives, standards of care, evaluation, and consistent and accurate data collection
- In cooperation (and avoiding duplication with) the National Center for Health Statistics, collection, maintenance and dissemination of information on the health status and needs of mothers and children in the United States
- Preparation of reports to Congress on state Title V activities, accomplishments and information

- Assistance to states for developing care coordination services
- A directory of toll-free information lines established in states under Title V

Like its state counterparts, the federal MCH agency has a broad mission based in Title V but extending beyond the specific provisions of Title V. Over the past decades, the federal agency has taken on a number of related programs including:

- Abstinence education, both Section 509 grants to state programs, as well as federal special project (SPRANS) funds
- Autism
- Community Integrated Service Systems (CISS)
- Congenital Conditions
- Emergency medical services for children (EMSC)
- Family to Family Health Information Centers
- Healthy Start
- Heritable Disorders
- Sickle Cell Service Demonstration Program
- MIECHV Program
- Universal Newborn hearing screening

- Personal Responsibility Education Programs
- Poison control centers
- Traumatic Brain Injury (TBI) service programs
- Women's Health Office
- MCH Workforce Development

AMCHP and MCHB are among the best sources for Title V information, best practices and models.

THE FEDERAL-STATE PARTNERSHIP IN THE 21ST CENTURY

As a result of the new accountability measures incorporated into Title V in the 1990s, one important aspect of the federal-state relationship now revolves around annual applications and reports. The review of Block Grant plans and performance measures provide an opportunity for feedback and identification of state needs. In the last quarter of a century, the review has broadened to include consumers, incorporating the Title V goal of being family centered.

The federal MCH agency responds to needs identified in the block grant process and provides assistance to state programs. This assistance comes in many forms, and like many aspects of this program, has varied over time.

AMCHP and MCHB are among the best sources for Title V information, best practices and models.

State needs, with many specific initiatives State Title V programs and AMCHP have played a critical role in advising the federal agency on developed in response.

Some of the ways MCHB provides assistance to state programs include:

- **Directly from MCHB central or regional offices.** Assistance is limited by numbers of staff, but funds are sometimes available to help states purchase technical assistance.
- **Policy, information and resource centers** funded under the Title V grants for SPRANS. Over time, the federal agency has funded many such centers with a range of programs, which may or may not have state Title V programs as a primary audience.
- **SPRANS grants focused on state identified needs.** The federal agency has flexibility in setting SPRANS priorities, although Congress has come to have strong influence. In response to states and AMCHP identification of needs, the federal agency often has developed specific SPRANS projects, such as MCH research; training grants, genetic disease

testing, counseling, information dissemination; hemophilia diagnostic and treatment centers; and other special MCH improvement projects that support a broad range of innovative strategies.

- **SPRANS grants to assist states at national or regional levels.**

The federal MCH agency has supported much of the AMCHP work in assisting states, specifically through conferences, workshops, publications, consultation and other tools. Other grantees, often university-based, have assisted states in specific regions. Recently funded SPRANS projects include the National Infant Mortality Collaborative Improvement and Innovation Network (CollIN) and the Adolescent and Young Adult Resource Center.

- **Continuing education institutes,** also funded by SPRANS, for senior Title V leaders. These Institutes focus on skill development in the context of Title V programs. One sample program includes the National MCH Workforce Development Center.

- **CISS grants** to assist all states in key program or system areas. CISS grants are another Title V “set-aside” added in 1989. Developed in partnership with the federal Administration

for Children and Families, the initiative helped build state interagency partnerships supporting family preservation goals in child welfare. For example, a national CISS initiative helped all states develop home visiting programs.

RESOURCES

Association of Maternal & Child Health Programs (2008). State Title V Workforce Development Survey Program Profiles. Retrieved from <http://www.amchp.org/programsandtopics/WorkforceDevelopment/Documents/Issue%20Briefs%20Dev.%20Strategies%20web.pdf>.

Association of Maternal & Child Health Programs (2014). State Title V Profiles. Retrieved from <http://www.amchp.org/Policy-Advocacy/MCHAdvocacy/Pages/StateProfiles.aspx>.

Association of Maternal & Child Health Programs (2009). Models of Care for Children and Youth with Special Health Care Needs. Retrieved from <http://www.amchp.org/programsandtopics/CYSHCN/resources/Documents/Models-of-Care-for-CYSHCN.pdf>.

Association of State and Territorial Health Officials (2010). Profile of State Public Health. Retrieved from <http://www.astho.org/Research/Profile-of-State-Public-Health/>.

Health Resources and Services Administration, Maternal and Child Health Bureau. About Us. Retrieved from <http://mchb.hrsa.gov/about/index.html>.



CHAPTER 3

The Big Picture: Leading through Influence to Achieve Change

YOU HAVE POWER AND INFLUENCE!

MCH leaders vary in the degree of power they have by virtue of their positions within state bureaucracies and the magnitude of their budgets and programs. This chapter discusses tools that are available to you, including sources of potential power, statutory leverage, vision, partnerships, advocacy and marketing. Certainly Title V leaders do not have the same kind of power and influence that comes with leading a large state agency or directing a budget as large as Medicaid. It also is critical for state MCH leaders to ensure that your vision is aligned with your agency leadership. But managers responsible for Title V programs have both formal and personal sources of power and influence. The greatest power comes from recognizing potential sources you have and using them strategically and judiciously.

As a Title V leader, you have a number of sources of potential

power and influence, including:

- A rich legacy of MCH leadership
- Your knowledge, skills, expertise and passion
- Your staff knowledge, skills, expertise and passion
- Stature, visibility and direct means of control related to your position
- Budget resources, including the ability to fund agencies and organizations that may be supporters or detractors
- Legislative and regulatory requirements governing your programs that can be used strategically to back up your course of action or requests of others
- Control or influence over contracts, regulations or other legal requirements
- Ability to develop voluntary standards and guidelines, backed by the power of your office and the influence of

For Further Development: Learning Opportunities from the MCH Navigator

- Leadership Training Bundle
<http://www.mchnavigator.org/trainings/leadership.php>
- Communication Training Bundle
<http://www.mchnavigator.org/trainings/communication.php>
- Policy and Advocacy (MCH Leadership Competency 12) Training List
<http://www.mchnavigator.org/trainings/results.php?Competencies=12>.

the stakeholders involved in development

- Data, information and reports needed by others or that can influence others
- Access to other state leaders and managers in your agency, other agencies, the governor's office and the state legislature
- Individuals, organizations and agencies with direct, vested

Joan Wightkin, Former Director, MCH Program, Louisiana

My years of experience in state government have shown me that sometimes people in the highest positions do not see themselves as having power and influence while 'true leaders' at lower levels of the hierarchy assume the leadership role and end up moving mountains.

It's up to you!

interests in your programs, and those with more indirect investments in your mission, at both state and national levels

- A network of colleagues in other states, accessible via AMCHP

WHAT KIND OF LEVERAGE DOES TITLE V PROVIDE?

While statutory requirements for Title V are fairly limited, there are some important tools to exert influence and lead change.

WITHIN TITLE V

- Needs assessment and performance data can draw public and policy attention to unmet needs and insufficient progress. You can use this data to compare your state to the nation, other states or across political jurisdictions within the state.
- Legal requirements to address identified needs can help protect against changing political priorities.
- So called “30/30 earmarks” designate minimum funding for preventive and primary services for children and youth. These earmarks can help ensure continued attention to children’s needs and counteract

mistaken assumptions that Medicaid and SCHIP can or will meet all needs.

- Requirements that Title V services be provided free of charge to those below the poverty line, and using a sliding scale for those above, can help assure that financial barriers are not erected to block access to services.
- Requirements for interagency coordination can be used internally and externally to place priority on interagency efforts and to help gain a “seat at the table.” Requirements for Medicaid coordination are the most detailed and support roles in policy development for EPSDT, outreach and information, including toll-free phone lines.

UNDERSTANDING TITLE V IN OTHER PROGRAM STATUTES

Medicaid

Title V and Medicaid play a critical role in improving access and better health outcomes for children, youth and families. Coordination and partnership between these two programs are important in achieving the goal of Title V. In this relationship Title V programs provide infrastructure and access to services that Medicaid can

in turn build on. Medicaid only works with a specific sub-set of the Title V population. Medicaid relies on Title V programs to provide access to and delivery of health and mental health services. The coordination between these two in states is based off of legislative mandate. This includes a Interagency agreement (IAA) that 1) utilizes Title V agencies (or their grantees) who can provide care and service to Medicaid beneficiaries, 2) make “appropriate” provisions to reimburse Title V agencies (or their grantees) for covered services provided, and 3) provide the sharing of information and education on pediatric vaccinations and delivery of immunization services.

State Children's Health Insurance Plan

Medicaid has authority over SCHIP and legislation requires states to coordinate with maternal and child health programs. Although Title V is not explicitly included in the legislation this is the intent behind the language. SCHIP is a federal-state matching health care block grant program for uninsured low-income children. Children who are eligible for Medicaid are not eligible for SCHIP, however, states can administer SCHIP through their Medicaid programs.

Supplemental Security Income (SSI)

In the Supplemental Security Income (SSI) for disabled children program, reference to Title V has provided the basis for state CYSHCN programs to receive lists of all children enrolled in SSI. These lists have facilitated Title V outreach and follow-up to ensure that these children are linked with needed services. This policy also helped support a Title V role in outreach and recertification efforts following changes in federal eligibility rules in the 1990s. In most states SSI beneficiaries are also eligible for Medicaid.

Healthy Start

Healthy Start is an initiative to reduce the rate of infant mortality and improve perinatal outcomes through grants to project areas with high annual rates of infant mortality. The authorization of federal Health Start programs requires grantees to coordinate their services and activities with state Title V agencies.

Congress enacted most of these provisions in response to recommendations from MCH leaders through AMCHP and its partner organizations. AMCHP continues to seek opportunities to strengthen the statutory basis for effective program coordination.

USE THE “VISION THING”!

One of the most, if not the most, important roles of a leader is to develop, communicate and mobilize others around a vision for the future. If the Title V program previously developed a vision statement, review it and renew or revise it with your internal and external stakeholders. Taking a look at vision statements from AMCHP, MCHB and other states, as well as your agencies, can be useful in this process.

The AMCHP vision is to build a society that values healthy families as the foundation of vital communities.

The MCHB vision is, a future America in which the right to grow to one's full potential is universally assured through attention to the comprehensive physical, psychological and social needs of the maternal and child health population. We strive for a society where children are wanted and born with optimal health, receive quality care and are nurtured lovingly and sensitively as they mature into healthy, productive adults. MCHB seeks a nation where there is equal access for all to quality health care in a supportive, culturally competent, family and community setting.





Knowing and passionately communicating your vision can inspire others to work with you. With a vision to work toward, you can align strategies, plans and budgets to support it.

Communicate your vision frequently. Be able to articulate it in 30-second sound bites that your audience will hear and remember. Your passion can be contagious.

KNOW YOUR KEY STAKEHOLDERS

Stakeholders – those who have or could have a direct interest in your programs – include a wide range of groups, such as:

- Your staff
- Consumers of services your programs directly support (Women, children, youth and families who benefit from population-wide functions)
- Providers of services funded by your programs
- Clinical and health professionals and their organizations
- Other state programs and agencies, especially those with overlapping missions, functions or target populations
- Local health agencies

- Community-based organizations
- Your agency leaders
- Governor, including key staff
- State legislature, especially key committees
- Congressional delegation
- Advocacy and voluntary agencies
- Business community
- Faith community
- Health care providers, including hospitals and community health centers
- Academic institutions, especially schools of public health

A fundamental part of your job as a state leader is to forge relationships with stakeholders, especially those with strategic importance to achieving your vision, mission and goals.

TIPS FOR BUILDING PARTNERSHIPS

- Learn about and actively practice family-centered policies and programs
- Learn about and actively practice cultural competence
- Identify effective committees, associations and other groups

- with similar missions and contribute to their work
- Identify and cultivate potential champions in key stakeholder groups to help carry your vision
- Learn about the mission, goals and agendas of key stakeholders and help them within the context of your mission
- Learn who your program detractors are and why; develop strategies to respond to their concerns
- Form task forces, advisory groups and coalitions when appropriate to achieve specific strategic aims

PEARLS OF WISDOM FROM YOUR COLLEAGUES...

- The more difficult the relationship, the more important it is to meet face-to-face
- Assess what you might do differently, but do not take all difficulties personally
- Some responses may be to past history or the legacy of your predecessor. Find out your key stakeholders' views of your programs and learn from that past history and legacy
- Never, ever burn your bridges!

“Be a good listener, always be willing to meet people halfway, do not be afraid to help someone get their needs met first, and build your reputation as someone who is trustworthy and who honors their commitments.”

Donna Petersen, Dean, University of South Florida, former CYSHCN and family health director

UNDERSTAND YOUR ADVOCACY ROLE

As we saw earlier, public sector advocacy for maternal and child health has roots dating back to the beginning of the 20th century. A dictionary definition of advocacy is “an act of pleading for a cause.” The dictionary definition of the verb to advocate “is to support or urge by argument.” Leaders of Title V programs generally have a commitment to the cause of improving health and well-being. MCH leaders need to lay out a vision and support its achievement, using data and evidence to make the argument for specific programs. So, you are an advocate!

Agency culture. The possibilities for advocacy are numerous. It's important to know the limitations, but often you are not as limited as you may assume. There are several parameters for advocacy as a state employee. First is the extent to which your agency fosters or discourages open discussion and diversity of views. All agencies need their senior staff to support the agency mission and goals, but there are degrees to which

agencies seek total adherence to the “party line.” This political culture affects the degree to which you may be able to argue or discuss disagreements publicly. Observe and ask colleagues about your agency culture. When in doubt, ask. Sometimes an agency culture may appear to discourage advocacy when it is actually allowed.

External communications. Another parameter affecting advocacy is agency policy on communications with the state legislature, the governor's office, congressional delegation or the media. Many times, public employees assume that such communications are not possible, when they may be. Sometimes you need advance approval, which seems like a barrier. Learn what your agency policies are, in statute, written policy and in practice. You can then determine if and how you may use direct communications.

In some states, direct communications with legislators, the governor's office and media may be centralized in the agency. If this is the case in your state,

one of your advocacy roles is to educate the individuals in these central offices about your areas of expertise and the MCH programs. If you become a helpful resource to these offices, they are more likely to represent your programs in their communications or even direct questions to you. In some states, it may be routine for such communications to be routed to you, although you may not be allowed to initiate such contacts. Some states allow both response and initiation of contacts by certain senior managers. In these cases, you can build a reputation as a helpful resource with these key external players. You may want to strategically share AMCHP policy updates and action alerts with your agency government affairs leadership to inform them of opportunities to weigh in on critical decisions.

Education versus lobbying. It is useful to bear in mind the distinctions among education, advocacy and lobbying.

Education, or the provision of information and science-based evidence, is an essential public health service. Education coupled with a call to action is advocacy. This role also is consistent with a core public health service: leadership for priority setting, planning and policy development. Only when advocacy focuses on specific legislation does it become lobbying.

There is no blanket prohibition on lobbying by public employees. Again, if you seek to lobby, to affect specific legislation, it is important to know if you are within permissible parameters for your agency and when in doubt, ask. You also must be sure that any time spent lobbying is not charged to federal funding that prohibits use of those funds for that purpose, such as Title V. Finally, you can lobby as a private citizen on your own time.

There may be some real barriers to lobbying, so how else can you advocate for action?

Lots of ways!

PUBLIC HEALTH TOOLS FOR ADVOCACY

- Sharing newsletters, fact sheets and reports with key stakeholders like advocates and policymakers
- Informational briefings and conferences for advocates and policymakers
- Inviting policymakers to visit programs or attend agency events
- Convening task forces and advisory committees to review information and develop recommendations
- Facilitating or participating in coalitions to stimulate specific action and ensuring that your key stakeholders are aware of the MCH policy updates and advocacy alerts issued by AMCHP

UNDERSTAND THE POLICY PROCESS

A former German chancellor noted, “People who love the law or good sausage should never watch either being made.” However, if you want to educate, advocate or even lobby to influence policy, it is critical to know how public policy is made, both formally through legislation and informally through policymakers.

The governor. The state chief executive is clearly in a position of power and influence. Gubernatorial priorities are in turn influenced by a number of factors, including not only party and ideology but personal background and experiences. Find out as much as you can about these and their potential link to MCH issues. Does the governor have children? Does the governor or his contributors have any strong ties to health groups? What are the governor’s spouse’s interests? Spouses often take on campaigns and initiatives relevant to family health. Find out how the governor’s office is structured, whether there are advisors on health or families, and what their backgrounds and interests are. Be sure to provide them with information relevant to their interests, if appropriate. The governor’s office usually will initiate the state budget, introduce legislation in priority areas and can dictate many aspects of state agency operations.

The state legislature. State legislatures vary tremendously in their composition and operations. Know whether yours is part-time or full-time, paid or volunteer, staffed or not. These characteristics can make a big difference in the timing and information needed to enact legislation. Know which committees in both branches have jurisdiction over budget



and policy matters related to health, children and families, and other areas of importance to you. Committees are the next step after introduction of legislation, and committees have the power to stop or significantly alter legislation before it goes to each branch for a vote and, if passed, to the governor for action. Know the chairs and most influential members of the committees, along with those who are most interested in your issues. Attend committee hearings if possible to learn their styles and interests; observe how others before the committees present testimony and respond to questions. Get to know legislative staff, establishing yourself as a

helpful expert resource – they will remember!

Congressional delegations. Do not forget the federal policy process! While significant power has been devolved to the state level, Congress still exerts strong influence on what states can do. Congress makes decisions on the federal budget and appropriations for specific programs, including Title V. The Labor, Health and Human Services, and Education appropriations committees in both the House and Senate are key to Title V and other programs benefiting women, children, youth and families. Authorized under the Social Security Act, Title V is

under a different Senate committee than programs authorized under the Public Health Service Act. As with your state legislature, knowing the process and the key players in Congress is important to your ability to assist them with information and recommendations. You also need to know your state senators and representatives to Congress and their committees that are relevant to your programs. As with state-level policymakers, it is important to develop relationships with these federal staffs, making yourself known as a good source of information. While having face to face meetings is critical and preferred, touching base with key staff during important times

throughout the year increases the visibility of your programs and your value as a trusted resource for policymakers.

Influential people in your state.

Regardless of the degree of latitude you have to interact directly with policymakers, it is important to know who has influence with them and whether anyone has a connection with your programs. Often, a personal connection to an issue has a strong influence on policies.

USE COMMUNICATIONS AND MARKETING STRATEGIES

Once a dirty word in health and human service circles, marketing has come to be recognized as an important tool in public and nonprofit arenas. At a very basic level, this means thinking beyond the programs to how they are presented and to whom.

SOME SIMPLE TIPS FOR MARKETING

- Write simply, using plain English and short sentences
- Use easy-to-understand state maps, graphs and pie charts to depict data
- If you can, budget for professional printing of

documents that will be disseminated broadly, using colors and plenty of space

- Make your website a priority; keep it up-to-date, interesting and complete with key data, reports, contact information and links, including a link to AMCHP
- Tell stories about your data and programs or, better yet, have families tell stories about the impact of programs

Working with the media. Knowing how to work with the media can do a lot to help you get the word out on your vision, your program accomplishments and resources that are needed to achieve goals. Your state agency public information office can be a resource, and it is well worth your time to inform them about your programs and areas of expertise. That office will be more likely to forward media calls to you or represent your perspectives with the media. Working with this office, you can develop proactive media strategies, using tools like letters to the editor, op-ed columns, press releases and press briefing kits, and human interest pieces profiling local programs and family stories. These tools can get your messages across more powerfully than written reports. As with policymakers, making yourself known as a credible source of information for the media can help

assure balanced coverage of issues concerning the health of women, children, youth and families.

Consider training for yourself and key colleagues if your senior team does not have this expertise.

RESOURCES

Association of Maternal & Child Health Programs . Advocacy.
Retrieved from <http://www.amchp.org/Policy-Advocacy/MCHAdvocacy/Pages/default.aspx>.

Association of Maternal & Child Health Programs . Legislative Alerts.
Retrieved from <http://www.amchp.org/Policy-Advocacy/Leg-Alerts/Pages/default.aspx>.

U.S. Department of Health and Human Services, Health Resources and Services Administration. State-MCH Medicaid Coordination: A Review of Title V and Title XIX Interagency Agreements, 2nd Edition.
Retrieved from <http://mchb.hrsa.gov/pdfs/statemchmedicaid.pdf>.

Johns Hopkins University. The Women's and Children's Health Policy Center. <http://www.jhsph.edu/research/centers-and-institutes/womens-and-childrens-health-policy-center/>.

New England SERVE. Retrieved from <http://www.neserve.org/>.

National Public Health Information Coalition (NPHIC). Retrieved from <http://www.nphic.org>.



CHAPTER 4

The Affordable Care Act

The Patient Protection and Affordable Care Act (ACA), signed into law on Mar. 23, 2010, was designed to achieve three main goals: 1) expand health insurance coverage, 2) shift the focus of the U.S. health care system from diagnosis and treatment to prevention and 3) reduce the costs and improve the efficiency of the health care system.

Embedded within these core goals are numerous programs and funding opportunities for states to improve their health care delivery systems. As MCH experts, Title V staff can engage state leaders in ensuring that women, children, and youth, including those with special health care needs and their families, benefit fully from the law's implementation.

The law is not without controversy. Since its passage, the ACA has survived repeated legislative repeal attempts, a Supreme Court challenge that resulted in fundamental changes to the law, and the 2012 presidential election, which was largely seen as a referendum on the law. Conversely, there also have been constructive efforts to fix components of the law that needed refinement.

As of 2014, most of the major ACA milestones have been implemented and the law is taking root. However, state willingness to fully implement

the ACA varies greatly across the country, and this may determine how MCH programs navigate the health reform landscape. Critical issues that affect MCH populations, such as coverage gaps, underinsurance, benefits design and other concerns, require MCH leaders to have a thorough understanding of the goals of the law and strategies to achieve them.

ACA HEALTH INSURANCE EXPANSION

HEALTH INSURANCE MARKETPLACES

Health insurance marketplaces are where consumers in need of health insurance can shop for coverage. To make health plans affordable, consumers can apply for advance premium tax credits (APTCs) – a subsidy that offsets the cost of health insurance premiums. Tax credits are available to those who earn between 100 percent and 400 percent of the federal poverty level (FPL).¹ States have the option to establish a state-based marketplace, partner with the federal government in the operation of a state-based marketplace, or default to the federally-facilitated marketplace (FFM). Healthcare.gov is the portal that directs consumers to their state marketplace, or allows them to purchase insurance directly from the federally operated website.

For Further Development: Learning Opportunities from the MCH Navigator

- Navigating Your Way through Health Reform and the Affordable Care Act <http://www.mchnavigator.org/trainings/ACA-spotlight.php>
- Children and Youth with Special Health Care Needs Training Spotlight <http://www.mchnavigator.org/trainings/cyshcn.php>

MEDICAID EXPANSION

The ACA expanded Medicaid eligibility for those earning up to 138 percent of FPL. However, the 2012 Supreme Court ruling made participation in the Medicaid expansion optional for states. As of March 2015, 29 states have fully adopted the expansion.² In the remaining non-expansion states, nearly four million adults fall into a "coverage gap," whereby they earn too much for traditional Medicaid but are beneath the 100 percent FPL threshold to qualify for tax credits.³ For children ages six to 19 in families earning up to 138 percent of FPL, the ACA requires all states to transition their coverage to Medicaid, if they are not already in that program.

ACA HEALTH INSURANCE MARKET REFORMS

In addition to coverage expansions, the ACA includes several important insurance market reforms that will benefit all women, particularly pregnant women, as well as children and youth with special health care needs. Prior to the ACA, insurance companies could deny women coverage based on preexisting conditions such as pregnancy, or charge them more based on gender.⁴ The ACA eliminates health plan preexisting condition exclusions, and plans can adjust rates based only on age, family size, state of residence and smoking status. In addition, insurers can no longer deny coverage to children younger than age 19 with special health care needs.⁵ The law also bans lifetime and annual limits on most benefits, requires health insurance companies to publically justify any unreasonable rate hikes, and ensures that most premium dollars are spent on care, not administrative costs.^{6,7}

PREVENTIVE SERVICE BENEFITS IN MARKETPLACE PLANS

Qualified health plans sold in the health insurance marketplace and Medicaid benchmark plans are required to provide a core set of 10 essential health benefits that include preventive services and maternity and newborn care.⁸ These services must be available without



cost sharing (no copayments, deductibles or coinsurance) in plans sold through the health insurance marketplace and individual plans sold outside the marketplace.⁹

Plans are required to cover all preventive services recommended by the U.S. Preventive Services Task Force, the Advisory Committee on Immunization Practices, and the Bright Futures Guidelines recommended by AAP.¹⁰ Included are services for adults (15 services), women (22 services), including pregnant women, and children (26 services). Some of the preventive benefits for the following populations are:

ADULTS (SELECTED)¹¹

- Immunization vaccines for adults
- Obesity screening
- Sexually transmitted infection prevention counseling for adults at higher risk
- Tobacco use screening for all adults and cessation interventions for tobacco users

WOMEN (SELECTED)¹²

- Comprehensive breastfeeding support and counseling, access to breastfeeding supplies
- Folic acid supplements
- Gestational diabetes screening for women 24-28 weeks pregnant
- Contraception
- Anemia screening for pregnant women

- A well-woman visit

CHILDREN (SELECTED)¹³

- Autism screening for children at 18 and 24 months
- Congenital Hypothyroidism screening for newborns
- Developmental screening for children under age three, and surveillance throughout childhood
- Immunization vaccines for children from birth to age 18
- Obesity screening

The women's preventive service requirements are based on recommendations from the Institute of Medicine (IOM) report, *Clinical Preventive Services for Women: Closing the Gaps*. The report underscored the importance of women's health overall and makes several recommendations related to preconception and interconception care. In its report, the IOM recognized that several visits may be needed to obtain all necessary recommended preventive services, depending on a woman's health status, health needs and other risk factors.¹⁴ Additionally, the IOM recommended that the preconception component of the visit include an opportunity for a health care provider to conduct, "evidence-based tests, procedures, and screening for non-pregnant women to optimize reproductive outcomes and prevent or optimize

treatment for chronic conditions, as well as topics for counseling and guidance for preconception health."¹⁵

PREVENTIVE SERVICE BENEFITS IN MEDICAID

Medicaid coverage for women varies widely from state to state. The federal government establishes guidelines for states on required services and what, if any, cost sharing is permitted. States cannot charge fees for services for pregnant women and children or family planning services, in order to lower barriers to access for these populations.¹⁶ In addition, benefits are distinguished as "core" or "optional," which determines what states may cover and receive federal matching funds.¹⁷ Family planning, smoking cessation for pregnant women, and prenatal and postpartum care are included as core benefits, but other preventive services recommended for adults that are not pregnancy related are "optional" benefits.¹⁸ Starting in January 2013, the ACA provided incentives for states to cover preventive services rated "A" or "B" by the U.S. Preventive Services Task Force and vaccines recommended by the Advisory Committee on Immunization Practices without cost sharing, and provides a one percentage point increase in federal matching payments.¹⁹

THE ACA AND....

WOMEN'S HEALTH

Expanded Insurance Coverage

Women's health insurance coverage plays an important role in maternal and infant health. Insured women are more likely to obtain preventive care and other services such as prenatal care. Many women ages 19 to 64 (57 percent) have employer-sponsored insurance or through their spouse. However, these women are less likely than men to be covered through their own job (35 percent vs. 44 percent respectively) and more likely to be covered as dependents (22 percent vs. 13 percent), making them vulnerable to losing insurance if they divorce, their partners lose their jobs or they become widowed.²⁰

A significant proportion of women receive their health insurance coverage through Medicaid, which serves approximately 13 percent of non-elderly.²¹ Medicaid covered nearly 7.3 million women between the ages of 15 and 44 in 2006 – nearly two thirds of all adult women on Medicaid.²² In 2010, Medicaid financed approximately 48 percent of births in the United States.²³ In spite of the scope of Medicaid and its coverage expansions for pregnant women over the past two decades, in 2013, 17 percent of women ages 19-64 are uninsured and many lack access



to care, particularly specialty care.²⁴

Low-income women and women of color, especially Latinas, are at greatest risk of being uninsured.²⁵ Uninsured women consistently report lower rates of screening for high blood pressure, high

cholesterol, obesity and other conditions, compared to their insured counterparts. These conditions are among the key factors known to adversely affect maternal health and birth outcomes.²⁶ The ACA provides states and communities with new



opportunities and resources to develop and improve women's health efforts.

It is important to understand one of the more complicated issues related to the ACA and health insurance coverage for pregnant

women. In August 2013, the Internal Revenue Service (IRS) determined that Medicaid pregnancy-only coverage is not minimum essential coverage (MEC) and therefore women who qualify for both Medicaid pregnancy-only coverage also are eligible for premium tax credits to purchase health insurance in the marketplace.²⁷ Furthermore, the final regulation noted that women with pregnancy-related Medicaid would not be granted hardship exemption from the individual shared responsibility provision.²⁸ Recognizing that this may place hardships on low-income pregnant women in terms of finance and access, the Centers for Medicare and Medicaid Services (CMS) issued a guidance letter to state health officials and state Medicaid directors. According to the letter, the majority of states offer full-scope Medicaid benefits to low-income pregnant women. For those states that do not provide full-scope benefits to low-income pregnant women, HHS plans to review the benefits and coverage offered in the state pregnancy-related services category. If the scope of pregnancy-related services are considered equivalent to full-scope Medicaid benefits, then the plan will be considered to satisfy MEC. In addition, the letter allows women enrolled in coverage that is not MEC to qualify for a hardship exemption.²⁹

Support for Breastfeeding Mothers

As mentioned previously, under the ACA, new private health insurance plans (including those available on the Health Insurance Marketplace) are required to provide coverage for women's preventive health services – including breastfeeding support, supplies and counseling – with no cost sharing (they can no longer charge a patient a copayment, coinsurance or deductible when services are delivered by a network provider).³⁰ These breastfeeding benefits must be provided in conjunction with each birth.

According to CMS, because lactation services are not specifically mentioned in the Medicaid statute or federal Medicaid regulations, not all states separately reimburse lactation services as pregnancy-related services.³¹ Due to the multiple health benefits associated with breastfeeding, however, CMS encourages states to go beyond the requirement of solely coordinating and referring enrollees to WIC and include lactation services as separately reimbursed pregnancy-related services. Per the ACA, coverage of lactation services without cost sharing will be eligible for a one percentage point increase in the federal medical assistance percentages (FMAP) in 2013.³²

In addition to the insurance coverage of breastfeeding support,

the ACA protects the rights of nursing mothers in the workplace. The ACA amends the *Fair Labor Standards Act* (FLSA), also known as the Federal Wage and Hour Law, to require that employers provide reasonable break time for an employee to express breast milk for her nursing child for one year after the birth of the child. The law guarantees the employee break time each time she needs to express milk. In addition, employers are required to provide a private place (i.e., non-bathroom) that is shielded from view and free from intrusion from coworkers and the public for nursing mothers to express breast milk during the workday. As long as nursing employees are completely relieved of their duties during the break time, the law does not require employers to compensate an employee for this time. These requirements, however, do not preempt state laws providing greater protection to employees, such as state laws providing compensated break time. Employers with fewer than 50 employees are not subject to FLSA break-time requirement if compliance with the provision would impose an undue hardship.³³

There remains a need for updated guidance from the U.S. Department of Labor to address more complicated situations (i.e.,

situations where the work place is not in an office building, situations where it may be appropriate to develop a shared space that can be used by employees from multiple employers, and situations where employees are not in a fixed location or where they are hosted by a client throughout their shift).

CHILDREN'S HEALTH INCLUDING CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

STREAMLINED APPLICATION PROCESS

The ACA mandates a simplified application form to screen all applicants for eligibility in the Medicaid and CHIP programs, as well as for premium tax credits through the marketplace. The application can be submitted by mail, telephone, in person or online and will be processed regardless of point of entry, whether it be through Medicaid, CHIP or the marketplace.³⁴

This coordinated application process, also known as "no wrong door," is designed to minimize the administrative burden families of CYSHCN currently experience when applying to multiple programs. This application process helps minimize gaps in coverage and facilitates continuity of care, as family income

or other circumstances change and enrollees move from one program to another. Families whose individual members qualify for different programs should find it easier to maintain their enrollment and access benefits for which they are eligible.³⁵

MAINTENANCE OF EFFORT

The ACA established the “Maintenance of Effort” (MOE) provision, which requires states to maintain their Medicaid and CHIP eligibility criteria that were in place when the ACA was signed into law. States cannot reduce income eligibility for these programs, nor can they make enrollment more difficult. States have the option, however, to raise the income eligibility and/or make enrollment easier. For children’s coverage through Medicaid and CHIP, the MOE ends Oct. 1, 2019. For adults, the MOE ended Jan. 1, 2014, when the health insurance marketplace opened.³⁶

BAN ON PREEXISTING CONDITIONS

Under the ACA, insurance companies are now prohibited from using preexisting conditions as a way to limit their financial responsibility to those they insure. This provision went into effect for children under age 19 on Sept. 23, 2010. It began for adults over age

19 on Jan. 1, 2014 and includes a ban on denial of coverage for claims related to a preexisting condition. This requirement is for both new and existing insurance policies. “Grandfathered” individual policies (policies purchased on or before Mar. 23, 2010 directly from the insurer, not through an employer) are exempt.^{37,38}

REMOVAL OF ANNUAL AND LIFETIME BENEFIT CAPS

The ACA also eliminates annual and lifetime benefit caps for children and adults. Prior to the passage of ACA, private insurance companies could place annual and lifetime benefit caps on coverage. This practice often resulted in children with high medical costs becoming uninsured when they exhausted their benefits, putting families at risk for medical debt and financial hardship. The ACA removal of annual and lifetime dollar limits on essential health benefit services helps families of children with high medical costs maintain their private insurance coverage. This provision applies to employer-sponsored plans, marketplace plans and most individual plans sold outside the marketplace. Insurance companies may still place yearly and lifetime dollar limits on services that are not considered essential health benefits.³⁹ The provision was fully implemented in January 2014.

COVERAGE FOR YOUNG ADULTS

Under the ACA, young adults are eligible for coverage through their parent’s health plan. Any group health plan or plan in the individual market that provides dependent coverage for children is required to make that coverage available for young adults up to age 26, even if the young adult is no longer a student, no longer lives with his or her parents, is not a dependent on a parent’s tax return, is married, or eligible to enroll in an employer plan.⁴⁰ It is estimated that more than three million young adults have been covered by this policy.⁴¹

COVERAGE FOR FORMER CARE FOSTER YOUTH

States are now required to expand Medicaid eligibility for foster care children until they reach the age of 26. To receive continued Medicaid coverage, a youth had to have reached the age of 18 while in foster care, and be enrolled in Medicaid at that time. Similar to adult children covered on their parents’ insurance, former foster care youth are now provided the same opportunity to be covered by insurance up to the age of 26.⁴²

HOSPICE CARE

Currently, children with life-threatening conditions (those with a medically certified life expectancy



of six months or less) enrolled in Medicaid and CHIP programs operating as Medicaid expansions have access to coverage for hospice care, either as an optional benefit or through application of EPSDT. However, their families must decide to end curative care before they can access hospice services. This sometimes means a curative treatment that has palliative benefits is no longer available. It also is a difficult emotional decision for families, which can limit timely access to helpful services through hospice. Section 2302 of the ACA,

also called “Concurrent Care for Children,” allows children to receive both types of care at the same time, including pain and symptom management and family counseling. This provision went into effect on Mar. 23, 2010. It is hoped that removing the requirement to stop curative care will increase the use of hospice services by terminally ill children and their families. States with stand-alone CHIP programs can offer hospice care as an optional benefit but if they choose to, they are required to comply with this provision as well.⁴³

HEALTH HOMES

The ACA offers the opportunity for states to implement a “health home” program for both adult and pediatric populations. States are eligible to receive a higher federal Medicaid match if they amend their state plans to cover health homes services such as care coordination, health promotion, patient and family support, and referrals to community and social services. Health home enrollees must have at least two chronic conditions such as mental illness, substance use disorders, asthma, diabetes,

heart disease or being overweight or have one chronic condition and are at risk for a second or have one serious and persistent mental health condition.⁴⁴ States have the flexibility to determine eligible health home providers and can be a designated provider, a team of health professionals or a health team.⁴⁵

MCHB NATIONAL PERFORMANCE MEASURES AND ACA PROVISIONS

Traditional MCH services complement the coverage expansions and market reforms provided through the ACA. In coming years, state Title V leaders will need to demonstrate how

health reform efforts and ACA implementation are impacting the health status of MCH and CYSHCN populations and the delivery of Title V-supported services. The new Title V national performance measures offer an opportunity to demonstrate the synergy between the Title V programs and the ACA, as indicated in the chart below.

National Performance Measure (NPM) #	NPM	National Performance Priority Areas	Applicable ACA provision
1	Percent of women with a past year preventive visit	Well woman care	<ul style="list-style-type: none"> Health plans are required to cover preventive services with an A or B rating from the USPSTF; there is no cost sharing for those services
2	Percent of cesarean deliveries among low-risk first births	Low risk cesarean deliveries	<ul style="list-style-type: none"> Could be part of the Medicaid core set of quality measures Strong Start for Mothers and Newborns Initiative
3	Percent of VLBW infants born in a hospital with a Level III+ NICU	Perinatal regionalization	<ul style="list-style-type: none"> Coverage of maternity benefits as an essential health benefit (EHB) in market-place plans
4	A) Percent of infants who are ever breastfed; B) Percent of infants breastfed exclusively through six months	Breastfeeding	<ul style="list-style-type: none"> Breastfeeding: coverage of support/counseling and equipment w/o cost sharing under preventive services, Workplace accommodations: Break-time requirement for nursing mothers (place to pump, reasonable time to pump) Prevention and Public Health Fund could be used to support or linked to other activities that promote breastfeeding.
5	Percent of infants placed to sleep on their backs	Safe sleep	<ul style="list-style-type: none"> Coverage of all Bright Futures preventive services without cost sharing
6	Percent of children, ages nine to 71 months, receiving a developmental screening using a parent-completed screening tool	Developmental screening	<ul style="list-style-type: none"> Preventive services for children without cost sharing; Developmental screening up to age three and surveillance throughout childhood
7	Rate of injury-related hospital admissions per population ages zero to 19 years	Injury	<ul style="list-style-type: none"> Violence and injury prevention counseling in Bright Futures guidelines Injury prevention counseling in MIECHV encounters The law allows young adults to stay on parents plans until age 26 Medicaid health home option for states Community-based health teams
8	Percent of children ages six to 11 years and adolescents ages 12-17 years who are physically active at least 60 minutes per day	Physical activity	<ul style="list-style-type: none"> Coverage of Bright Futures guidelines which includes promotion of healthy weight BMI screening covered without cost sharing Prevention and Public Health Fund

RESOURCES

The Affordable Care Act: A Working Guide for MCH Professionals
<http://www.amchp.org/Transformation-Station/Documents/ACA-guide.pdf>

National Performance Measure (NPM) #	NPM	National Performance Priority Areas	Applicable ACA provision
9	Percent of adolescents, ages 12-17 years, who are bullied	Bullying	<ul style="list-style-type: none"> Depression screening for adolescents covered as a preventive service Coverage of Bright Futures guidelines which includes violence and injury prevention, which includes bullying
10	Percent of adolescents with a preventive services visit in the last year	Adolescent well-visit	<ul style="list-style-type: none"> Coverage of Bright Futures with no cost-sharing Young adults coverage on parental plans until age 26 Medicaid medical home option for states Community-based health teams
11	Percent of children with and without special health care needs having a medical home	Medical Home	<ul style="list-style-type: none"> Medicaid health homes Center for Medicare & Medicaid Innovation (CMMI) funding for systems and payment reform Community-based collaborative care network program Pediatric ACO demonstration project Community health center expansion State grants to promote community health teams to support patient-centered medical homes
12	Percent of children with and without special health care needs who received services necessary to make transitions to adult health care	Transition	<ul style="list-style-type: none"> Medicaid health homes
13	A) Percent of women who had a dental visit during pregnancy and B) Percent of infants and children ages ones to six years, who had a preventive dental visit in the last year	Oral health	<ul style="list-style-type: none"> Dental coverage for children is an EHB but not required to purchase; Not having dental coverage for children does not subject families to the tax penalty
14	A) Percent of women who smoke during pregnancy and B) Percent of children who live in households where someone smokes	Smoking	<ul style="list-style-type: none"> Medical Assistance with Smoking and Tobacco Use Cessation measured in the adult core set of Medicaid (voluntarily reported) Covered as part of preventive services without a copayment or co-insurance or meet deductible. This applies only when these services are delivered by a network provider Tobacco use screening and interventions for all adults and cessation for users Tobacco use screening and interventions for all women, and expanded counseling for pregnant tobacco users Prevention and Public Health Fund Strong Start for Mothers and Newborns Initiative
15	Percent of children zero through age 17 years who are adequately insured	Adequate insurance coverage	<ul style="list-style-type: none"> Medicaid eligibility for children raised to minimum of 138 percent FPL Advanced premium tax credits available for purchase of health insurance on the marketplace for families with income of 100 percent FPL to 400 percent FPL Extended presumptive eligibility beyond children and pregnant women and expands the role of hospitals in determining eligibility presumptively

CONCLUSION

State Title V leaders can lend valuable support to the successful implementation of the ACA. MCH leaders are experts in their field.

They understand the health needs of women, particularly pregnant women, CYSHCN and their families, and can offer expertise and guidance to state officials responsible for implementing ACA

provisions. As state health care delivery systems are transformed in the ACA era, Title V can play a leadership role in ensuring that MCH populations receive the care and services they need.



CHAPTER 5

The ABCs: Key Players at the National and State Levels

YA GOTTA HAVE FRIENDS!

It is a truism that no one can succeed alone. MCH leaders have learned this lesson well over the years. Chapter 3 provides more specific information about the legislative process (federal and state), as well as some of the Title V partners that share similar concerns and viewpoints with MCH and CYSHCN programs. Some are federal agency partners and others are advocacy organizations that offer services that you may find useful.

PUBLIC POLICY AT NATIONAL AND STATE LEVELS

The federal government is a key national partner for the Title V program, particularly because the program exists as a result of federal legislation and annual appropriations. For those of you who need a quick reminder, a review of the three branches of government and the federal and state legislative processes may be helpful. If you are already familiar with this information, feel free to skip ahead to the sections on national and state agencies.

THE LEGISLATIVE PROCESS

The business of Congress is to make laws; their work begins with the introduction of a proposal that can take the form of a bill,

a joint resolution, a concurrent resolution or a simple resolution. A bill is the form used for most legislation and can originate either in the House of Representatives or the Senate. The letters "H.R." designate a bill originating in the House of Representatives ("S." is used for bills originating in the Senate), followed by a number that the bill retains throughout its parliamentary stages. Bills are given to the president for action when approved in identical form by both the House and the Senate.

Joint resolutions may originate either in the House or the Senate; there is little practical difference between a bill and a joint resolution as both become law in the same manner (except for a joint resolution proposing an amendment to the Constitution).

Concurrent resolutions are used for matters affecting the operations of both the House and the Senate. On approval by both bodies, they are signed by the clerk of the House and the secretary of the Senate and are not presented to the president for action. A matter concerning the operation of either the House or Senate alone is initiated by a simple resolution that is not presented to the president for action.

Any member of the House or Senate may introduce a bill. An important phase of the legislative process is the action taken by committees that

For Further Development: Learning Opportunities from the MCH Navigator

- Services Through MCH Programs (MCH Leadership Competency 1K3)
Training Brief <http://www.mchnavigator.org/trainings/results.php?Competencies=1K3>
- How Public Health Programs Work Together (MCH Leadership Competency 1K5)
Training Brief <http://www.mchnavigator.org/trainings/results.php?Competencies=1K5>

function similarly in both bodies. It is during committee action that the most intense consideration is given to the proposed measures. Each bill is referred to the committee that has jurisdiction over the area affected by the measure. Usually the first step in the process is a public hearing where committee members hear witnesses representing various viewpoints. After hearings are completed, the bill is considered in a session that is commonly known as the "markup" session where amendments may be offered to the bill, and the committee members vote to accept or reject these changes. Markup can happen in either the subcommittee, full committee or both. At the conclusion, a vote of the committee or subcommittee members decides what action to take. It can be reported, with or

without amendment, or tabled. If the committee approved extensive amendments, they may decide to report a new bill incorporating all the amendments, known as a “clean bill” which also is given a new number. If the committee votes to report a bill, the Committee Report is written to describe the purpose and scope for the measure and the reasons for recommended approval. After the committee has reported a bill, it is generally ready for action by the full House or Senate where debate time is provided to proponents and opponents, and a final vote is held. Once a measure passes the House or Senate, it is sent to the other body for consideration. A bill must pass both bodies in the same form before it can be presented to the president for signature into law. If there are any changes, differences must be resolved, usually by a conference committee appointed with both House and Senate members. This group will resolve differences and report an identical measure back to both bodies for a vote. Final votes may be taken by the electronic voting system that registers each individual member response (although votes in the House may be by voice vote without a record of individual responses). After a bill has passed both the House and the Senate, it is considered “enrolled” and is sent to the president, who may

sign it into law, veto it and return it to Congress, let it become law without signature, or, at the end of a session, pocket-veto it.

The state legislative process.

The legislative process used in most states mirrors that of Congress although there can be some unique differences. Besides understanding the federal legislative process, it is important that the Title V leader be completely familiar with the legislative process for his own state or jurisdiction and to know the relevant committees and their members. Usually the state legislature will print a limited number of legislative directories. If you are unable to obtain a copy of that directory, some advocacy or professional organizations print

and distribute free copies of state legislative rosters, committee assignments, maps of districts, etc. If the state agency has a legislative liaison, meet with that person to establish your interest in all bills and public hearings concerning MCH, CYSHCN and family health issues. There also may be a daily publication or website that provides information about bills introduced, committee assignment for bills, hearing schedules, reports of testimony, and other information. You should scan these publications frequently while your legislature is in session to ensure that you are aware of any proposed bills that impact the Title V program and alert your agency legislative liaison or chain of command about the



YOU SHOULD BE PREPARED FOR THE MANAGEMENT ISSUES THAT ARISE IN YOUR AGENCY WHEN YOUR FEDERAL FUNDING IS DEPENDENT ON A CONTINUING RESOLUTION.

need for possible agency positions, testimony or behind-the-scenes conversations with the sponsors or friendly legislators.

Tips for Success

- Stay well informed about current legislative activity at both the federal and state level. Make sure you are subscribed to the AMCHP Member Briefs newsletter, which provides regular federal policy updates as well as our Legislative Alerts, which let you know when advocacy actions are needed to promote MCH policy.
- Keep one-page, “thumbnail” descriptions of your programs handy as background information to use during bill drafting, hearings, etc.

THE JUDICIAL BRANCH

The U.S. Supreme Court is the highest court in the country and is vested with the judicial powers of the government. There are lower federal courts that have been established by Congress using the power granted from the Constitution. Courts decide arguments about the meaning of laws, how they are applied and whether they violate the Constitution. The judiciary uses its power of judicial review to provide checks and balances on

the legislative and executive branches of government. While not directly involving Title V policy in recent years, the courts system often reviews issues related to the Medicaid program and recently the U.S. Supreme Court has played a minor role in adjudicating challenges to the ACA.

THE EXECUTIVE BRANCH

The Executive Branch of government is responsible for enforcing laws. It is recognized that one person, the president, cannot carry out the duties of the office without advice and assistance. The vice president, department heads (Cabinet members) and heads of independent agencies assist in this capacity; however, their powers are not defined in the Constitution although each has specific powers and functions that have been spelled out in law. Department heads advise the president on policy issues and help to carry out those policies. You will relate most to the agencies and programs within the U.S. Department of Health and Human Services (HHS).

The Federal Budget. The president submits a budget to Congress, typically by Feb. 1 each year. The budget contains estimates of federal government income and spending for the upcoming fiscal year (obtained from the Office of Management and Budget - OMB)

and also recommends funding levels for the federal government. The president's budget is jointly developed and negotiated through the programs and departments, OMB and White House advisors before the president reviews and approves it for submission to Congress. Congress then must pass all appropriations bills based on the president's recommendations and congressional priorities.

There is a congressional budget plan, separate from the president's budget. The Senate Committee on the Budget, along with the House Budget Committee, is responsible for drafting Congress's annual budget plan and monitoring action on the budget for the federal government. The annual budget resolution is an agreement between the House and Senate on a budget plan for the upcoming fiscal year and at least the following four fiscal years. The budget resolution is in the form of a concurrent resolution, so it is not sent to the president for his signature and thus does not become law, but it does provide a framework for subsequent legislative action on the appropriations bills. Additionally, the budget committees have jurisdiction over the Congressional Budget Office (CBO). The CBO provides Congress with objective, timely, nonpartisan analyses needed for economic and budget decisions.

There is a proposed timetable for the consideration of budgetary legislation:

- May 15, annual appropriation bills may be considered in the House
- Jun. 10, House Appropriations Committee reports the last appropriation bill
- Jun. 30, House completes action on annual appropriation bills
- Oct. 1, federal fiscal year begins and all appropriations actions should be completed

Jun. 10 and Jun. 30 serve as target dates. If Congress does not pass all appropriations measures by the start of the fiscal year, it has to enact a continuing resolution to keep the government running. In recent years, Congress has not

been able to complete its work on all of the appropriations bills by the deadline. As a result, there have been multiple continuing resolutions adopted to keep federal agencies open and functioning at the same (i.e., continuing) level of funding. Again, AMCHP will provide you with regular updates about the federal budget process and its impact on Title V funding and the populations you serve.

You should be prepared for the management issues that arise in your agency when your federal funding is dependent on a continuing resolution.

Remember that the congressional budget process involves two separate and distinct parts. First, legislation sets a ceiling for future spending for a specific program,

known as the authorization level. Besides setting a funding ceiling, authorization legislation also lays out the overall policy framework for programs. Currently, the authorization level for the Title V MCH Services Block Grant is \$850 million. Once a program is authorized, Congress can choose to fund the program (or not) in the separate appropriations act process already described above.

Federal Spending. Spending by the federal government is a multistep process in which budget authority is enacted and obligated, and outlays are generated. Budget authority is enacted into law and gives federal agencies the legal basis to incur obligations. Obligations establish the financial liabilities of the federal government and reflect such activities as employing staff

LEADING IN AN ERA OF BUDGET AUSTERITY

One of the central challenges MCH leaders should expect to face is a high degree of uncertainty related to the future allocation of budgetary resources. Concerns about record high federal deficits and increasing federal debt prompted the U.S. Congress to pass a law known as the Budget Control Act of 2011. This law created budget caps and instituted automatic cuts known as sequestration that went into effect in 2013. While Congress has subsequently made adjustments to this law, it has clearly ushered in an era of austerity that will result in tight federal budgets for the foreseeable future. Furthermore, partisan divides within Congress have created a level of dysfunction and delay that result in Congress consistently missing deadlines to finalize annual appropriations bills that are supposed to be completed by the Oct. 1 start date of the federal fiscal year. These bills provide annual funding for the Title V MCH Block Grant and other critical MCH programs. The practical impact on Title V leaders is that you can expect to consistently start each fiscal year with little indication of what level of federal resources will be available, with Congress not finalizing these levels until sometimes as late as March (i.e. six months) into a fiscal year. As your eyes and ears in Washington, AMCHP provides regular updates to all members on the status of federal MCH funding and advocates on your behalf for adequate resources.

and contracting. Outlays are the payments (expenditures) made to honor the obligations.

Budget authority is the specific dollar amount made available for obligation and is provided in appropriations and direct spending legislation. For some programs, however, budget authority is indefinite, providing “such sums as may be necessary” to achieve certain purposes. Budget authority may be enacted for one year, several years or no-year periods. Annual budget authority is available for obligation only during a specific fiscal year, and any unobligated authority expires at the end of that fiscal year. Multiyear authority is available for a period of time longer than one year (the Title V Block Grant has two-year budget authority, which allows funds appropriated in one year’s budget to be spent over a two-year period), and no-year budget authority is available indefinitely. Federal agencies are prohibited by law from obligating more budget authority than was provided by the appropriations act. Adjustments such as a rescission (cut) may be made to cancel or reduce budget authority after it was enacted into law.

The State Budget. The state budget process generally involves only the legislative process for a budget appropriations bill. Usually this

is done annually, although some states have a biannual budget process. Before the governor’s budget is introduced in the state legislature, however, there is a great deal of work that goes into the preparation of that budget. As a Title V leader, you will be involved in the budget preparation process to a greater or lesser degree for the programs under your supervision. Generally, the state office of budget and management (OBM or comparable title) provide budget preparation guidance and a proposed funding ceiling by line item to the agency director and fiscal/budget officer. The programs must then develop justifications for maintaining current funding levels, justifications for increased funding, or adverse impact statements for reduced or eliminated funding. Once the agency responds to the initial proposal from the state budget office, an opportunity might be provided to negotiate and resolve differences between what OBM suggested and the state agency requests.

You should try to participate in meetings with OBM if possible to present strong justification for your program needs. If that is not permitted, be certain that you thoroughly brief the staff who does attend the OBM meeting.

It is common that all of the steps of the budget preparation process are kept confidential until the governor has approved the budget and it has been introduced into the state legislature as a bill. Once the budget bill has been introduced, your agency will likely be expected to support the governor’s budget request. If the budget request is inadequate to meet the program needs, you are in a difficult situation because you cannot publicly criticize your governor’s budget. You will find that program advocates and families are in the best position to press the legislators for additional funds during budget hearings. They may request information from your programs in order to be effective in their advocacy.

Be sure that you completely understand the budget development and adoption process for your specific jurisdiction. In some states, the legislature plays a more prominent role than the governor in making funding decisions. While the nuances may vary depending on your locale, the role you play as the MCH senior manager will remain largely unchanged. Be prepared to respond quickly, efficiently and effectively to information requests when the legislature is giving consideration to the budget. Anything can happen!

KEY FEDERAL PARTNERS

The following is a very limited listing of some of the major federal partners providing direction and funding to Title V programs. This is meant to be only a handy reference for you to use in identifying those agencies and programs within your state that share your interest and concern in family health. You should become familiar with these and other federal programs in your state.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

The U.S. Department of Health and Human Services (HHS) is the U.S. government principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves. HHS is responsible for almost a quarter of all federal outlays and administers more grant dollars than all other federal agencies combined.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

The Health Resources and Services Administration (HRSA), an agency of HHS, is the primary federal agency for improving access to health care by strengthening the health care workforce, building healthy communities and achieving health equity. HRSA's programs

provide health care to people who are geographically isolated, economically or medically vulnerable.

This includes people living with HIV/AIDS, pregnant women, mothers, and their families and those in need of high quality primary health care. HRSA also supports the training of health professionals, the distribution of providers to areas where they are needed most and improvements in health care delivery.

MATERNAL AND CHILD HEALTH BUREAU

MCHB is a division of HRSA which in turn is part of the larger HHS located in Rockville, Maryland, and administers the Title V MCH Services Block Grant. More detailed information about MCHB is found in Chapter 2. Within the MCHB, the Division of State and Community Health (DSCH) is the federal government primary liaison with each of the 59 state and jurisdiction MCH programs. New state Title V leaders and senior managers should meet with their assigned DSCH project officer for an orientation, technical assistance and federal insights into your program areas of strength, as well as those areas needing attention.

OFFICE ON WOMEN'S HEALTH

The Office on Women's Health (OWH) within HHS was established in 1991 to improve the health of American women through health care prevention and service delivery, research, public and health care professional education, and career advancement for women in the health professions and in scientific careers. The office also works with numerous government agencies, nonprofit organizations, consumer groups and associations of health care professionals. Since 1998, OWH has operated a website, the National Women's Health Information Center (NWHIC), for the public, health care professionals, medical researchers, educators and the media.

OFFICE OF ADOLESCENT HEALTH

The Office of Adolescent Health (OAH) was established in the HHS Office of the Assistant Secretary for Health in 2010. OAH coordinates adolescent health promotion and disease prevention programs and initiatives across HHS and works in partnership with other HHS agencies to support evidence-based approaches to improve the health of adolescents. OAH operates grant programs aimed at reducing teen pregnancy (commonly known as TPP grants) and supporting expectant and parenting teens.

(commonly known as Pregnancy Assistance Fund or PAF grants) and maintains an evaluation portfolio associated with these grants. OAH operates a website with extensive resources regarding adolescent health and leads collaborative activities with other federal agencies and national groups that serve adolescents.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

SAMHSA, an agency of HHA, was established in 1992 to improve the lives of people with or at risk for mental and substance abuse disorders. SAMHSA offers discretionary grants and communications initiatives on co-occurring mental and substance abuse disorders, criminal justice, children and families, aging, substance abuse treatment capacity, prevention and early intervention, the New Freedom Initiative, homelessness, disaster response, seclusion and restraint, and HIV/AIDS. SAMHSA supports formula grant programs, primarily the Mental Health and Substance Abuse Prevention and Treatment Block Grant programs. Under both programs, SAMHSA encourages states and territories to address substance abuse prevention, addiction treatment and mental health, both by supporting service

programs and by assessing progress, needs and ongoing activities. Because Title V provides comprehensive health care services to families, it is important to coordinate between these two programs. Title V programs can benefit from learning more about mental health screening in child and adolescent health services and in perinatal care to high-risk women (including those with addictions and substance abuse), appropriate locations for referrals, and data for the Title V needs assessment.

THE CENTERS FOR DISEASE CONTROL AND PREVENTION

The CDC, part of HHS, but located in Atlanta, Georgia is another federal partner important to the Title V program. It is recognized as the lead federal agency for protecting the health and safety of people – at home and abroad. CDC is composed of the following organizations:

- Center for Global Health
- National Institute for Occupational Safety and Health
- Office of State, Tribal, Local and Territorial Support
- Office for Infectious Diseases
 - National Center for Emerging and Zoonotic Infectious Diseases
 - National Center for HIV, STD and TB Prevention
- National Center for Immunization and Respiratory Diseases
- Office of Minority Health and Health Equity
- Office of Noncommunicable Diseases, Injury and Environmental Health
 - National Center for Chronic Disease Prevention and Health Promotion
 - National Center for Environmental Health
 - National Center for Injury Prevention and Control
 - National Center on Birth Defects and Developmental Disabilities
- Office of Public Health Preparedness and Response
- Office of Public Health Science Services
 - Center for Surveillance, Epidemiology and Laboratory Services
 - National Center for Health Statistics
- Office of the Associate Director for Communication
- Office of the Associate Director for Policy
- Office of the Associate Director for Science
- Office of the Chief of Staff
- Office of the Chief Operating Officer

New Title V leaders may want to develop a relationship with several of the CDC organizations because they tie closely to MCH and CYSHCN programs and are potential sources of information (data), technical assistance and funding. For example, the National Center on Birth Defects and Developmental Disabilities funding opportunities include support for expanded surveillance and epidemiology in autism and other developmental disabilities, prevention of birth defects associated with maternal risk factors, fetal alcohol syndrome prevention, newborn screening programs, and reducing disparities in key health indicators (including obesity) among children, youth and adults with disabilities. The National Immunization Program provides ongoing leadership to reduce disability and death resulting from vaccine-preventable diseases. The National Center for Injury Prevention and Control administers the Traumatic Brain Injury (TBI) prevention program. These CDC programs should all relate to and enhance state Title V programs. If CDC funding for these programs is not under your direct span of control, you need to develop a relationship with the manager in your agency responsible for these programs and identify how to enhance coordination.

CENTERS FOR MEDICARE AND MEDICAID SERVICES

On Jul. 1, 2001, the Health Care Financing Administration in Department of Health and Human Services was reorganized into CMS. CMS has seven business centers: the Center for Medicare, Center for Medicaid and CHIP Services, Center for Clinical Standards, Center for Program Integrity, Center for Strategic Planning, Center for Medicare and Medicaid Innovation, and Center for Consumer Information and Insurance Oversight. The Center for Medicare and Medicaid Innovation (CMMI) is the newly created CMS center as it was created in 2010 by the ACA, this center is important to the MCH community for its funding on Strong Start and other public health healthcare integration programs that impact MCH populations. Detailed information about these business centers and their programs are available on the CMS website. There are five major CMS programs with which you should be familiar. You need to develop a working relationship with the state personnel responsible for their implementation, because they have major impact on Title V services and our clients.

- **Medicaid**

Title XIX of the Social Security Act, passed in 1965, established

Medicaid, a federal/state entitlement program that pays for medical assistance for certain individuals and families with low incomes and resources. This program is a cooperative venture jointly funded by the federal and state governments (including the District of Columbia and the territories) to assist states in furnishing medical assistance to eligible needy persons.

Medicaid is the largest source of funding for medical and health-related services for America's poorest people, and the state share of funding to participate in Medicaid is generally the largest item (or close to it) in the state budgets.

Within broad national guidelines established by federal statutes, regulations and policies, each state

- 1) Establishes its own eligibility standards (but limited to individuals who fall into any of 25 specified categories)
- 2) Determines the type, amount, duration and scope of services
- 3) Sets the rate of payment for services
- 4) Administers its own program

Medicaid policies for eligibility, services and payment are complex and vary considerably, even among states of similar size or geographic proximity. A person eligible for

Medicaid in one state may not be eligible in another, and the services provided by one state may differ in amount, duration or scope from services provided in a similar or neighboring state. Certain services must be covered by the states and other services are optional.

Because the Medicaid program is individualized by each state, the relationship between Medicaid and the Title V programs also is highly individualistic. A new Title V leader should meet with the Medicaid director regularly to ensure coordination between the programs for seamless services to clients, timely reimbursement to providers and development of an agenda of mutual concerns, such as oral health services for children.

- **State Child Health Insurance Program**

The Balanced Budget Act of 1997 amended the Social Security Act to add Title XXI, the State Children's Health Insurance Program.

This legislation enables states to initiate and expand health assistance to uninsured, low-income children. The assistance can be provided primarily through two methods:

- 1) A program to obtain health insurance coverage that meets certain requirements relating to the amount, duration and scope of benefits

- 2) Expanded eligibility for children under the state Medicaid program

This program allows each state to offer health insurance plans for children up to age 19 who are not already insured. Families who earn too much to qualify for Medicaid may be able to qualify for SCHIP, a capped entitlement for states. To be eligible for funds, states must submit a State Child Health Plan, including a description of the coordination with Title V programs.

A new Title V leader should meet regularly with the state SCHIP director, because this program has greatly impacted the service delivery system for children. For example, in some states, the CYSHCN population was carved out of the general SCHIP population and the Title V program was assigned to provide their services. In other states, the CYSHCN population was retained in SCHIP and the Title V program sets standards for the services they receive.

Like Medicaid, implementation of SCHIP is highly individualistic in each state, territory and jurisdiction; in some states it may be part of Medicaid. The Title V leader must be on good footing with the SCHIP leader and develop an agenda of mutual interest to assure high quality services for all children in the state.

- **Early Periodic Screening, Diagnosis and Treatment Program**

The EPSDT program is the Medicaid comprehensive and preventive child health program for individuals under the age of 21.

EPSDT was defined by law as part of OBRA 1989 and includes periodic screening, vision, dental and hearing services. In addition, EPSDT requires that any medically necessary health care service listed in the law be provided to an EPSDT recipient even if the service is not available to the rest of the state Medicaid population.

The EPSDT program has two components:

- 1) Ensuring the availability and accessibility of required health care resources
- 2) Helping Medicaid recipients and their parents or guardians effectively use these resources.

The state Medicaid agencies are supposed to manage a comprehensive child health program of prevention and treatment, seek out those who are eligible and inform them of the benefits of prevention and the health services available to them, and help them and their families use health resources effectively. The state Medicaid agency also is supposed to assess the child's

health needs through initial and periodic examinations and ensure that health problems are diagnosed and treated early. With the recent intense focus on Medicaid managed care and the SCHIP program, the EPSDT program has faded into the background somewhat. However, the state Medicaid agencies must still provide annual reports to CMS about the EPSDT activities in the state, so the state is still responsible for carrying out the EPSDT program. The Title V leader needs to be knowledgeable about the coordination between the SCHIP and EPSDT programs and identify ways Title V may be helpful to the clients served by both programs.

- **Health Insurance Portability and Accountability Act (HIPAA)**

HIPAA is the acronym for the Health Insurance Portability and Accountability Act of 1996. CMS is responsible for implementing various unrelated provisions of HIPAA, which may mean different things to different people. Title I protects health insurance coverage for workers and their families when they change or lose their jobs. It lowers the chance of losing existing coverage, eases the ability to switch health plans and helps people buy coverage if they lose an employer's plan and have no other coverage available.

Title II requires HHS to establish national standards for electronic health care transactions and national identifiers for providers, health plans and employers. It also addresses the security and privacy of health data. Title II is critically important to the administration of all health care services including Title V programs.

MCH leaders must ensure that the electronic data systems for patient records, billing and more are in compliance. The Title V leader will need to meet with the Medicaid leadership to discuss the program implications created by compliance in the Medicaid billing system. For example, state specific "dummy" codes have been eliminated. You will need to discuss adequate reimbursement for Title V services with Medicaid leaders.

- **Clinical Laboratory Improvement Amendments (CLIA)**

CMS regulates all laboratory testing (except research) performed on humans in the United States through CLIA. In total CLIA covers about 175,000 laboratories.

The Division of Laboratory Services, within the Survey and Certification Group under the Center for Medicaid and State Operations, has the responsibility for implementing the CLIA program to ensure quality

laboratory testing. Laboratories in clinics and physician offices are generally required to be CLIA-approved to qualify for Medicaid payments.

- **College of American Pathologists (CAP)**

CAP accredits all aspects of medical laboratories. CAP accreditation checklists require more extensive quality and method validation activities than CLIA.

- **Joint Commission on Accreditation of Healthcare Organizations (JCAHO)**

JCAHO accredits all aspects of hospital and other health care organizations such as a free-standing ambulatory care facilities. JCAHO standards take a patient-focused approach and generally follow CLIA.

- **Commission on Office Laboratory Accreditation (COLA)**

COLA accredits many types of laboratories. COLA accreditation standards closely follow CLIA quality control and method validation requirements.

U.S. DEPARTMENT OF EDUCATION, OFFICE OF SPECIAL EDUCATION AND REHABILITATION SERVICES (OSERS)

OSERS is comprised of the Office of the Assistant Secretary and three program components: the Office of Special Education Programs (OSEP), the National Institute on Disability and Rehabilitation Research and the Rehabilitation Services Administration. OSERS supports programs that help educate children and youth with disabilities, provides for the rehabilitation of youth and adults with disabilities, and supports research to improve the lives of individuals with disabilities.

• IDEA '97

OSEP administers the Individuals with Disabilities Education Act (IDEA) including early intervention and preschool programs. OSEP develops and disseminates federal policy and information on early intervention and the education of infants, toddlers, children and youth with disabilities. It also monitors and reports on the implementation of federal early intervention policies and coordinates with other federal agencies, state agencies and others. The IDEA Amendments of 1997 (IDEA '97) represent the first major revision to the act in more than 23 years (since the enactment of P.L. 94-142, the Education of

all Handicapped Children Act of 1975). IDEA '97 retains and strengthens the basic rights and protections under IDEA – including the right to a free appropriate public education (FAPE) for all children with disabilities (including children suspended or expelled from school) and the procedural safeguard rights for these children and their parents. The early intervention program authorized under IDEA '97 is administered by a variety of agencies in the states, typically health (usually the MCH or CYSHCN program), education or mental health. A new Title V leader should quickly identify the agency responsible for the IDEA programs and meet to coordinate between the programs. Generally, early intervention programs need help to complete diagnostic evaluations and arrange health care services for the children in the program.

HEAD START

Head Start and Early Head Start are comprehensive child development programs that serve children from birth to age five, pregnant women and their families. Their goal is to increase the school-readiness of young children in low-income families. The Head Start Bureau, the Administration on Children, Youth and Families (ACYF), Administration for Children and Families (ACF) in HHS administers

the Head Start program. The ACF regional offices and the Head Start Bureau American Indian Alaska Native and Migrant and Seasonal Program branches award grants directly to local public agencies, private organizations, Indian Tribes and school systems for operating Head Start programs at the community level. Participation in Head Start programs requires income eligibility. All Head Start programs must adhere to program performance standards and define the services that they provide to the children and families in accordance with the expectations, requirements, goals and objectives of Head Start. Because Head Start grants are funded directly to local agencies, a new Title V leader will want to meet with the Head Start Directors Association president for your area to identify areas for coordination between the programs. Typically, Head Start programs are interested in health care services, particularly evaluations and immunizations, for enrolled children. Title V programs may be able to provide for health, dental, disabilities and nutrition consultation services to local Head Start programs.

ADMINISTRATION FOR CHILDREN AND FAMILIES

The Administration for Children & Families (ACF) is a division of HHS. ACF promotes the

economic and social well-being of families, children, individuals and communities.

ACF programs aim to:

- Empower families and individuals to increase their economic independence and productivity
- Encourage strong, healthy, supportive communities that have a positive impact on quality of life and the development of children
- Create partnerships with front-line service providers, states, localities and tribal communities to identify and implement solutions that transcend traditional program boundaries
- Improve access to services through planning, reform, and integration
- Address the needs, strengths and abilities of vulnerable populations including people with development disabilities, refugees and migrants

U.S. DEPARTMENT OF AGRICULTURE

The U.S. Department of Agriculture (USDA) provides leadership on food, agriculture, natural resources, rural development, nutrition, and related issues based on sound

public policy, the best available science and efficient management. USDA supports the following two programs relevant to the Title V community.

- Supplemental Nutrition Assistance Program (SNAP)- SNAP provides low income households with electronic benefits they can use like cash at most grocery stores. SNAP is the cornerstone of the federal food assistance programs, and provides crucial support to needy households and to those making transition from welfare to work.
- Women, Infants, and Children (WIC)-WIC provides federal grants to states for supplemental foods, health care referrals, and nutrition education for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, and to infants and children up to age five who are found to be at nutritional risk.

U.S. DEPARTMENT OF EDUCATION

The Department of Education's (ED) mission is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access.

ED was created in 1980 by combining offices from several federal agencies and is dedicated to:

- Establishing policies on federal financial aid for education, and distributing as well as monitoring those funds.
- Collecting data on America's schools and disseminating research.
- Focusing national attention on key educational issues.
- Prohibiting discrimination and ensuring equal access to education.

Example programs within ED include:

- Autism Spectrum Disorders-The purpose of this research grants program is to contribute to the improvement of cognitive, communicative, academic, social, and behavioral outcomes of children identified with autism spectrum disorder (ASD) in preschool through middle school.
- Early Intervention Program for Infants and Toddlers with Disabilities-This grant for infants and families program assist in the implementation of statewide systems of coordinated, comprehensive, multidisciplinary interagency

programs and making early intervention services available to children with disabilities, aged birth through 2, and their families. Under the program, states are responsible for ensuring that appropriate early intervention services are made available to all eligible birth-through-2-years-old with disabilities and their families, including Indian children and families who reside on reservations geographically located in the state.

NATIONAL AND STATE ORGANIZATIONS

Following is a very limited listing of some of the key partners for Title V, especially in the policy arena. Brief descriptions of the organizations, their location and services are included for your information. Some of these organizations have state offices; others have a national presence only but their policy activity frequently affects Title V. This listing is not exhaustive and is meant to be only a beginning point for you to use in identifying organizations in your state that share your interest in family health. You will want to create your own list of organizations that are critical to the success of Title V in your state.

ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS (AMCHP)

AMCHP is your association – the national nonprofit organization representing state public health leaders and others working to improve the health and well-being of women, children, youth and families, including those with special health care needs. It is an affiliate organization of the Association of State and Territorial Health Officials (ASTHO) and maintains its offices in Washington, DC. AMCHP accomplishes its mission through the active participation of its members and vital partnerships with government agencies, families and advocates, health care purchasers and providers, academic and research professionals, and others at the national, state and local levels. AMCHP offers many opportunities for you to formulate health policy at the national level and learn more about the field, such as:

- Participating in the AMCHP mentoring program for new Title V directors or the data training for epidemiologists
- Attending annual meetings that attract more than 800 attendees to educational sessions on cutting-edge topics
- Participating on AMCHP committees or task forces that:
 - Identify best practices for the AMCHP Innovation Station
 - Develop Issue Briefs on State Profiles in Comprehensive Family Participation.
 - Confer with key federal officials from MCHB and CDC
- Supporting national advocacy efforts such as congressional briefings on Title V topics or congressional hearings on proposed legislation or the federal budget
- Running for AMCHP board officer or regional director

AMCHP gives voice to your interests!

Tips for success

- Meet with your AMCHP regional director early in your new job. You will be welcomed, provided with resources helpful to your job performance and informed about current AMCHP activities.
- Talk with your state health agency member(s) of the following national associations about their organization activities relevant to Title V programs.

ACADEMY OF PEDIATRICS (AAP)

AAP is a national and state-level membership organization for pediatricians. It maintains an office in Washington, DC, to ensure that children's health needs are taken into consideration as national legislation and public policy are developed, but headquarters are located in Evanston, Illinois. AAP interests include access to care for low-income children, injury and poison prevention, disabled children, sports medicine, nutrition, child health financing, child safety legislation and Medicaid policies.

Title V leaders should establish a close relationship with the AAP state chapter president. Members of the state chapter are a wonderful resource for draft policy review, consultation about program standards of care, strategic planning, educational programs and other advisory functions. Their testimony and other advocacy activities are usually very helpful during budget hearings, as well as hearings on other bills impacting Title V programs.

AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS (ACOG)

ACOG is a membership organization dedicated to advancing women's health through education, practice,

research and advocacy. ACOG has more than 57,000 member physicians who are specialists in obstetrics and gynecology. Based in Washington, DC, it is a private, voluntary, nonprofit membership organization that also has state chapters. Title V leaders should cultivate a relationship with ACOG for advice on women's health policies, program care standards, strategic planning, educational programs and advocacy.

AMERICAN PUBLIC HEALTH ASSOCIATION (APHA)

APHA members represent more than 50 occupations of public health. Its headquarters are located in Washington, DC, but there is an affiliated chapter in each state, New York City, five territories and the District of Columbia. Its mission is to improve public health for everyone. The basic organizational unit of APHA membership is the 29 discipline-based sections and four Special Primary Interest Groups (SPIGs) that enable members to share knowledge and experience with their peers, develop new techniques and contribute to the growing body of scientific knowledge within their respective fields. APHA sections of particular interest to Title V include maternal and child health, food and nutrition, HIV/AIDS, injury control and emergency health services, and

statistics. The American Journal of Public Health is a publication of APHA.

AMERICAN PUBLIC HUMAN SERVICES ASSOCIATION (APHSA)

APHSA is a nonprofit, bipartisan organization of individuals and agencies concerned with human services. Members include all state and many territorial human service agencies, more than 1,200 local agencies, and several thousand individuals who have an interest in human service programs. APHSA educates members of Congress, the media and the broader public on what is happening in the states around welfare, child welfare, health care reform, and other issues involving families and the elderly. The headquarters is located in Washington, DC, and APHSA has 12 affiliate organizations including the National Association of State Medicaid Directors, National Association of State Child Care Administrators and the National Association of Public Child Welfare Administrators.

ASSOCIATION OF PUBLIC HEALTH LABORATORIES (APHL)

APHL is headquartered in Washington, DC, and represents national, state, city and local

public health, environmental and international laboratories. It is an affiliate organization of ASTHO. The APHL mission is to promote the role of public health laboratories and policies and programs that assure continuous improvement in the quality of laboratory practices. The association links public health laboratories in 50 states and six territories with federal partners, such as CDC, the Environmental Protection Agency, the Department of Homeland Security and the Federal Bureau of Investigation. APHL also houses the Newborn Screening Technical assistance and Evaluation Program (NewSTEPs), which provides quality improvement initiatives, an innovative data repository and technical resources for newborn screening programs.

ASSOCIATION OF STATE AND TERRITORIAL DENTAL DIRECTORS (ASTDD)

ASTDD is a national nonprofit organization representing the directors and staff of state public health agency programs for oral health and is headquartered in Jefferson City, Missouri. ASTDD formulates and promotes the establishment of sound national dental public health policy and assists state dental programs in the development and implementation of programs and policies for the

prevention of oral diseases. It is an affiliate organization of ASTHO.

ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICIALS (ASTHO)

ASTHO is the national nonprofit organization for the states, territories and the District of Columbia public health agencies. ASTHO's members are the chief health officials of these jurisdictions. ASTHO has 20 affiliate organizations, including AMCHP. The ASTHO mission is to transform public health within states and territories to help members dramatically improve health and wellness. ASTHO maintains its headquarters in Arlington, VA and has public policy information related to access, accreditation and performance, branding public health, e-Health, environmental health, evidence-based public health, health equity, health in all policies, health reform, immunization, infectious disease, preparedness, prevention, and workforce and leadership development

ASSOCIATION OF WOMEN'S HEALTH, OBSTETRIC AND NEONATAL NURSES (AWHONN)

AWHONN is a nonprofit membership organization that promotes the health of women

and newborns, headquartered in Washington DC. Their mission is to improve and promote the health of women and newborns and to strengthen the nursing profession through the delivery of superior advocacy, research, education and other professional and clinical resources to nurses and other health care professionals.

CHILDREN'S DEFENSE FUND (CDF)

CDF began in 1973 and is a private, nonprofit organization that lobbies for all American children. Headquarters are in Washington, DC, although a few states also have state CDF organizations. CDF has high quality publications, issue briefs, initiatives and other activities of interest to Title V.

COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS (CSTE)

CSTE is a professional organization of public health epidemiologists. Headquartered in Atlanta, Georgia, CSTE is concerned with the surveillance and epidemiology of infectious diseases, chronic diseases and conditions, and environmental health concerns. It is an affiliate organization of ASTHO. CSTE promotes the effective use of epidemiologic data to guide public health practice and improve



health through effective public health surveillance and good epidemiologic practice through training, capacity development, and peer consultation.

FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS (F2F HIC)

The F2F HIC program funds grants to ensure that families and CYSHCN are able to participate in decision making at all levels and be satisfied with the services they receive. These state family centers: assist families of CSHCN to make informed choices about health care in order to promote good treatment decisions, cost effectiveness and improved health outcomes; provide information regarding the health care needs of and resources available for CSHCN; identify successful health delivery models for CSHCN; develop with representatives of health care providers, managed care organizations, health care purchasers, and appropriate state agencies, a model for collaboration between families of CSHCN and health professionals; provide training and guidance regarding the care of CSHCN.

FAMILIES USA

Families USA is a national, nonprofit, nonpartisan organization dedicated

to the achievement of high quality, affordable health care for all Americans. Working at the national, state and community levels, it is an effective lobbying group for health care consumers. Its headquarters are found in Washington, DC. Families USA produces health policy reports, conducts public information campaigns about the concerns of health care consumers, operates a consumer information clearinghouse, provides training and technical assistance, and collaborates with a wide range of organizations interested in health care.

FAMILY VOICES

Family Voices is a national grassroots network of nearly 40,000 families, friends, professionals and advocates for health care services that are family centered, community based, comprehensive, coordinated and culturally competent for all CYSHCN. Family Voices also is a clearinghouse for information concerning the health care of children with special health needs.

Family Voices is based in Albuquerque, New Mexico, and is represented in every state, the District of Columbia, Puerto Rico and the Virgin Islands. Many state organizations are operated on a volunteer basis, while some are funded. Title V leaders and senior managers should be very

familiar with the Family Voices leaders in their area. See Chapter 5 for a further discussion on the importance of family engagement in Title V programs.

GOT TRANSITION? / CENTER FOR HEALTH CARE TRANSITION IMPROVEMENT

Got Transition and the Center for Health Care Transition Improvement aim to advance access of effective transition support from pediatric to adult health care for all youth; including those with special needs. Got Transition will facilitate the implementation and dissemination of health care transition best practices in pediatric and adult medical homes and specialty settings. Got Transition is a program of the National Alliance to Advance Adolescent Health and is supported by MCHB. Got Transition is headquartered in Washington DC.

NATIONAL ASSOCIATION OF CHRONIC DISEASE DIRECTORS (NACDD)

NACDD is a nonprofit Public Health Organization committed to serve the chronic disease program directors of each state and U.S. jurisdiction based in Atlanta, Georgia. NACDD is recognized as the national leader in mobilizing efforts to reduce chronic diseases and their associated risk factors

through state and community-based prevention strategies.

NATIONAL ASSOCIATION OF PUBLIC HEALTH STATISTICS AND INFORMATION SYSTEMS (NAPHSIS)

NAPHSIS is a national association of state vital records and public health statistics offices and is based in Washington, DC. It is an affiliate organization of ASTHO. The association develops and markets innovative programs and services to promote collaboration among vital records, health statistics and health information systems professionals in providing health information to policymakers and the public.

NATIONAL COALITION OF STD DIRECTORS (NCSD)

NCSD is a nonprofit organization located in Washington DC, that educates federal, state and local policy makers about issues relevant to the control and prevention of STDs and promotes adequate and efficient allocation of resources to the prevention and control of STDs. NCSD is an affiliate organization of ASTHO.

NATIONAL WIC ASSOCIATION (NWA)

NWA is a national association for state and local directors of WIC programs and maintains headquarters in Washington, DC. It provides leadership in

promoting quality nutrition services; advocating for services for all eligible women, infants and children; and assuring sound, responsive management of WIC.

PARENT TO PARENT USA (P2P)

P2P is nonprofit organization headquartered in Washington DC that provides support as a core resource for families with children who have special health care needs. Through a one-to-one “match” experienced support parents provide emotional support to families and assist them in finding information and resources. Parent to Parent programs are committed to listening and learning from families and developing an array of services and supports in response to family identified needs.



MARCH OF DIMES

The March of Dimes is headquartered in White Plains, New York, and has state chapters. The organization public affairs agenda focuses on advocacy for public policies and programs that relate to the foundation mission – improving the health of babies by preventing birth defects and infant mortality – and on issues that pertain to nonprofit organizations. Public affairs efforts are organized into four general categories: access to health care for women of childbearing age, infants and children; research to prevent birth defects and infant mortality; prevention and treatment programs to improve maternal, infant, and child health; and institutional concerns for nonprofit organizations.

NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS AND RELATED INSTITUTIONS (NACHRI)

NACHRI is a nonprofit membership organization of children's hospitals, large pediatric units of medical centers and related health systems, including those that specialize in rehabilitative care of children with serious chronic or congenital illnesses. NACHRI represents more than 220 hospitals and clinics to ensure children's access to health care and the continuing ability of children's hospitals to provide

services needed by children.

NACHRI headquarters are located in Alexandria, Virginia.

NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS (NACCHO)

NACCHO is the national nonprofit organization representing 2700 local public health agencies (including city, county, metro, district and tribal agencies). NACCHO provides education, information, research and technical assistance to local health departments and facilitates partnerships among local, state and federal agencies to promote and strengthen public health. The NACCHO vision is health, equity, and security for all people in their communities through public health policies and services. The NACCHO mission is to be a leader, partner, catalyst, and voice for local health departments in order to ensure the conditions that promote health and equity, combat disease, and improve the quality and length of all lives.

NATIONAL ALLIANCE FOR HISPANIC HEALTH

The National Alliance for Hispanic Health (the Alliance) is the nation's oldest and largest network of Hispanic health and human service providers and is located in Washington, DC. Alliance members

deliver services to more than 15 million people annually. As an action forum for Hispanic health and well-being, the programs of the Alliance inform and mobilize consumers, promote appropriate use of technology, improve the science base for accurate decision-making, and promote philanthropy.

NATIONAL CONFERENCE OF STATE LEGISLATURES (NCSL)

NCSL is a bipartisan organization serving the lawmakers and staffs of the nation's 50 states, commonwealths and territories. It has offices located both in Washington, DC, and Denver, Colorado. It provides a bipartisan, national forum for lawmakers to communicate with one another and share ideas. NCSL represents state lawmaker interests before Congress, the administration and federal agencies. Each state has an NCSL staff liaison to assist the organization membership and meet with legislators and staff. While Title V leaders will not be able to access NCSL materials directly, AMCHP is often able to obtain materials and discuss policies with NCSL.

NATIONAL FAMILY PLANNING AND REPRODUCTIVE HEALTH ASSOCIATION (NFPRHA)

NFPRHA is a national nonprofit membership organization established to ensure access to voluntary, comprehensive and culturally sensitive family planning and reproductive health care services and to support reproductive freedom for all. NFPRHA represents clinicians, administrators, researchers, educators, advocates and consumers. Members include private nonprofit clinics; state, county and local health departments; Planned Parenthood Federation of America affiliates; family planning councils and hospital-based clinics, along with international family planning agencies. NFPRHA members provide reproductive health care at clinics nationwide, to nearly five million low-income women each year. The headquarters is located in Washington, DC. NFPRHA is an advocacy organization and develops a variety of publications, reports and clinically based fact sheets that are helpful to Title V leaders.

NATIONAL GOVERNORS' ASSOCIATION (NGA)

NGA is a bipartisan organization representing the nation's governors and is located in Washington, DC. NGA represents states on Capitol

Hill and before the administration, develops policy reports on innovative state programs and hosts seminars for state executive branch officials. The NGA Center for Best Practices help governors and their staff to learn about emerging issues and develop innovative solutions to governance and policy challenges in their states. The NGA Center tracks, evaluates and disseminates information on issues such as education, health, technology, welfare reform, the environment, energy, social services, trade, transportation, workforce development and homeland security. While Title V directors cannot access NGA materials directly, AMCHP is often able to discuss policy issues affecting Title V programs with NGA staff.

NATIONAL URBAN LEAGUE

The National Urban League is the nation's oldest and largest community-based organization empowering African-Americans to enter the economic and social mainstream. The Urban League is headquartered in New York City, New York and is a nonprofit, nonpartisan, community-based movement. The mission of the Urban League movement is to enable African Americans to secure economic self-reliance, parity and power, and civil rights.

NEW ENGLAND SERVE

New England SERVE is an independent health policy, research and planning organization that promote quality systems of care for children with special health care needs and their families. Headquarters are located in Boston, Massachusetts. This organization produces very high quality publications for programs serving children with special health care needs and also provides technical assistance, needs assessments and other consultative services.

SAFE STATES ALLIANCE

The Safe States Alliance is a national nonprofit organization and professional association located in Atlanta, Georgia whose mission is to strengthen the practice of injury and violence prevention. Their vision is to be the recognized leader and driving force in understanding and preventing injuries and violence. The Safe States Alliance is a affiliate organization of ASTHO.

THE ARC OF THE UNITED STATES

The Arc is the national organization advocating for and serving people with intellectual and developmental disabilities and their families. The Arc seeks to improve supports, services, research and education for people with

developmental disabilities and their families. The Arc is a grassroots organization with 140,000 members who are affiliated through approximately 700 state and local chapters across the nation; national headquarters are located in Washington, DC.

ZERO TO THREE

Zero to Three is a nonprofit organization headquartered in Washington, DC that provides parents, professionals and policymakers the knowledge and know-how to nurture early development. Their mission is to ensure that all babies and toddlers have a strong start in life.

Tips for Success

- Look at these organizations websites and note their activities related to MCH populations. You'll find many helpful publications!
- Make a list of the key agencies and organizations with interest in family health in your state, territory or jurisdiction. Schedule appointments to meet the key representative of each group to identify and discuss mutual concerns.
- There are many other associations sharing common interests with the Title V program or its "family," such as adolescent health coordinators, genetics coordinators, state family planning directors, Council of Churches, etc. What additional groups can you identify for your jurisdiction?

RESOURCES

Association of Maternal & Child Health Programs. (2014). Sequestration: Fiscal Year 2013 and Beyond. Retrieved from <http://www.amchp.org/Policy-Advocacy/health-reform/resources/Documents/sequestration%20Fact%20Sheet%20update%203.13.pdf>.

Council for Exceptional Children. Retrieved from <http://www.cec.sped.org/>.

Department of Health and Human Services, Health Resources and Services Administration. Retrieved from <http://www.hrsa.gov/index.html>.

National Health Law Program. Publications. Retrieved from <http://www.healthlaw.org/publications/browse-all-publications>.

Johns Hopkins University. Women's and Children's Health Policy Center. Selected Federal Programs for Children and Families. Retrieved from http://www.jhsph.edu/research/centers-and-institutes/womens-and-childrens-health-policy-center/resources/federal_MCH.html.

The Library of Congress Thomas. Government Resources. Retrieved from <http://thomas.loc.gov/links/>.



CHAPTER 6

The Importance of Family Centered Care

WHAT IS FAMILY/CONSUMER PARTNERSHIP?

The Title V MCH program expressly seeks to implement family centered, community-based systems of coordinated care for CYSHCN. At its most basic, family centered care is the partnership between families and professionals at all levels working together for the best interest of the child and the family. The Title V Block Grant defines family/consumer partnership as “the intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course. Family engagement reflects a belief in the value of the family leadership at all levels from an individual, community and policy level.” Family/consumer partnership is a myriad of activities that engages families into partnership with systems and services to ensure that they are working in the best interest of the children and families they are intended to reach. All the aims of MCH programs are best met with the involvement of the families impacted by the policies, systems and services they touch. The Latin phrase *Nihil de nobis, sine nobis* (Nothing about us without us), a slogan used by the disability rights and parent leadership movement, touches on the idea that no policy should be decided without the full

and direct participation of those affected by that policy. As MCH professionals we see firsthand the impact of this philosophy through the work of family leaders involved in all levels of MCH.

Including families at all levels is the right thing to do! Successful businesses have known for decades that consumer input is invaluable to developing goods and services that the public will buy. MCH can put those same marketing principles to use in planning services and allocating scarce resources. We can ensure that our services are targeted to best meet family needs without wasting funds on unnecessary frills or errors in judgment about what we think families want and will use. Families can be our program target marketers who know where and how to reach underserved families. Families are better able to use services if they are educated and aware of their options.

A critical part of promoting family centered care is ensuring programs are structured to support and engage families in planning, development and evaluation. The needs assessment, consumer advisory boards and public comment processes that are cornerstones of MCH programs are opportunities for meaningful engagement. In order to ensure that programs reflect the needs of the

For Further Development: Learning Opportunities from the MCH Navigator

- Family Centered Care (MCH Leadership Competency 8) Training List
<http://www.mchnavigator.org/trainings/results.php?Competencies=8>
- Family Engagement Training Brief
<http://www.mchnavigator.org/trainings/family-engagement.php>

populations served, it is imperative to partner with families during the design and implementation phases. While these activities are important, true family/consumer engagement and family centered care cannot be a series of points-in-time contacts with limited representation of families; instead they result from a continuous commitment to partner with families, instead of simply serving families. It is critical that partnership includes the diversity of families served within your state. Programs benefit from diverse geographical, socioeconomic and cultural perspective.

How MCH programs operationalize family/consumer engagement differs significantly from state to state, reflecting the variability of communities. As a part of the commitment to involvement, programs may hire family

The Title V Block Grant defines family/consumer partnership as “the intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course. Family engagement reflects a belief in the value of the family leadership at all levels from an individual, community and policy level.”

representatives on staff. Family professionals are an important part of the MCH workforce, bringing with them diverse backgrounds and expertise. Increasingly, highly trained MCH family leaders are developed both via their lived experience and by volunteer and professional roles in family organizations, education and other systems related to MCH and through existing MCH workforce pipeline programs. Family leaders have much to offer the programs of their organizations in all areas, including CYSHCN, immunization, injury prevention and perinatal health.

HOW TO BUILD FAMILY/CONSUMER ENGAGEMENT IN YOUR STATE

One approach to family/consumer engagement is to develop and engage parent advisory committees. Together, staff and family leaders set meeting agendas and hold meetings on a regular basis. Families can help review new policies, education materials, brochures, literature and reports. The councils may discuss policies that families find

problematic, help develop the strategic plan, participate in the needs assessment, help develop the Block Grant application and provide advice on the budget. Besides policy making, families can participate in outreach work and training activities for both professionals and families.

Meaningful family/consumer engagement should include a clear commitment to be representative. While seasoned family leaders may cultivate significant connections and networks, which allow them to serve as conduits for the input of diverse families, every effort should be made to ensure family partners who possess direct current experience with systems and services provide feedback and inform continuous quality improvement. For example, a workgroup around income eligibility levels would benefit from the perspective of families who have navigated systems that require income eligibility processes. Ensuring this type of involvement takes us beyond a small pool of family leaders and family members of our MCH staff and may require some creativity to meet families in a variety of settings and in various

levels of their leadership skills. Social media, online polling, text input, non-traditional meeting times, and linguistically relevant documents are some of the many strategies used to engage a broader group of families.

For families to be effective in their role as advisors to Title V programs, they – like all those new to MCH – must be provided with education about MCH broadly, and the Title V Block Grant. Take the time to ensure they are oriented completely so they feel comfortable and able to participate fully in Block Grant reporting and/or reviews. A mentoring system whereby seasoned family advisors and professional staff provide training to new family advisors, including introduction to the MCH Leadership Competencies, is an excellent approach to orientation and development of family leaders. As with all partners it is imperative to be committed to the importance of their input. When you hear someone make a great comment at a meeting, tell her or him so.

Another way for families to be engaged is by serving as an AMCHP Family Delegate.

WHAT IS AN AMCHP FAMILY DELEGATE?

Each Title V program paying dues at AMCHP may designate up to five delegates who have voting rights; the fifth delegate seat is reserved for a family liaison to the state or territory Title V program. The Family Delegate is an active advocate for all families in their state/territory, including families with special health care needs, and works within state, territorial, and/or community systems of care to advise, promote, and educate families and program/policy leaders on new and existing policies/programs. Historically, family leaders have represented CYSHCN, and it is the aim to have family representatives from all MCH programs. Choosing a Family Delegate is a vital step toward meaningful family/consumer engagement and connecting families with counterparts across the country. At present, more than 30 states have Family Delegates. AMCHP encourages all states/territories to appoint a Family Delegate but realizes that not all states/territories have the same capacity to involve families.

The ultimate success of any policy or program initiative depends on its ability meet the needs of families. Family Delegates are key stakeholders in their families and children's care and can serve as an invaluable resource to AMCHP, state

and territorial Title V programs, MCHB, and family organizations, such as Family Voices.

Selecting a Family Delegate

Family Delegates can be identified through a variety of mechanisms, including consulting with program directors at the state, territorial and local level; talking to former AMCHP family scholars; contacting parent groups in the state or territory, such as state chapters of Family Voices, Parent to Parent, Healthy Start and Parent-Teacher Organizations; or looking to family members who already serve as paid family representatives or parent consultants to programs. States and territories also may consider rotating families serving as Family Delegates to AMCHP in order to build family engagement and family representative capacity in the jurisdiction.

Ideally, the Family Delegate has a proven track record as an active advocate for families through their assistance to other families and their own personal experiences in their state or territorial system of care.

ROLES/RESPONSIBILITIES OF FAMILY DELEGATES

Family Delegates have important roles and responsibilities at the local and state levels and should be prepared to advocate

for involvement in some of the following activities:

- Policy development and decision-making process to assist management in determining program outcome (performance) measures, block grant review, data-collection systems, care coordination, outreach and evaluation/assessment
- Participation on advisory boards, state committees or program council structures
- Social marketing campaigns and promotional product development (brochures, fliers fact sheets, pamphlets, guides, needs assessment survey, opinion surveys, resource library, center service delivery systems and Web pages) and on review teams (design delivery and evaluation of program goods and services)
- System of care process (advices on "Best Practices" for program and its consumers, participate in a medical home or cultural competency programs)
- Advance the plan Title V program community outreach and professional development efforts (trainings, support group meetings, awareness campaigns, rallies, technical assistance, conferences, focus groups, etc.)
- Development of a peer support system or parent council of Family Delegates (national-state- and local-level support)



- Help build a community stakeholder network
- Technical assistance to the Title V program regarding the implementation of program services, policies, procedures and strategic planning
- Advocacy, support and guidance to families relevant to navigating the Title V program system
- Liaison to families, the Title V program, AMCHP, and family or other health and human services organizations

COMPENSATED KEY PERSONNEL

Rather than isolating agency and family work, include them as key team members of the MCH workforce on projects, agency initiatives and learning collaboratives. Examples include seeking their participation in Action Learning Collaboratives such as Return on Investment; and as team members of project cohorts, etc.

THE VALUE OF FAMILY/ CONSUMER ENGAGEMENT

Expanding family/consumer engagement in your state, engaging families to be members of task forces, advisory board members, program evaluators, co-trainers of pre-service or in-service training sessions, paid program

staff, paid program or policy consultants, mentors for other families and professionals, grant reviewers, participants in the needs assessment process, reviewers of the Block Grant application, and more, can transform your capacity for family centered care.

The capacity to ensure family/consumer engagement requires that programs figure out how to compensate parents for their time. Relying only on the input of families with the resources to volunteer their time severely limits the perspectives represented. In addition, uncompensated participation devalues the role of family as partners. Some states use the agency contracting process to reimburse parents for their expenses. Others need to secure an administrative rule or even special legislative approval to pay parents for their participation in an advisory capacity. Explore avenues within your system that might be used, develop a proposal and get clearance from agency leadership. Contracting with a family leader as a subject matter expert is often the same administrative process a state must follow when securing a contract for specific expertise and/or outcomes.

MCH leadership at the state level has the opportunity to infuse the strength of family/consumer

engagement into all levels of the system. Requests for proposals, funding and programs supported can be required to include family/consumer engagement in all steps and levels. Tying contracts to this not only provides you access to data about family/consumer engagement at the local level, it grows and strengthens the robust network of family-professional partnerships needed to ensure family centered care.

A critical value of parents familiar with the Title V programs is their ability to strongly advocate for programs that serve them well. Parents and organizations who know how to interact with legislators should be your new best friends. The old adage “make your friends before you need them” definitely applies here! Equipping families with firsthand knowledge of the budget and system challenges faced by MCH allows them to be eloquent and powerful advocates. Families who are partners in care at all levels provide a powerful grassroots network.

Tips for Successful Family/ Consumer Engagement

- Identify current programs that involve parents and how they are compensated whether as salaried or contract employees or provided stipends for their time. Meet with these family

leaders to discuss their roles and identify opportunities for expanding family representation throughout the Title V programs.

- Make it your business to find out what parent groups exist in your state and invite all of them to meet with you to discuss their needs and suggestions for increasing family representation.
- Identify and address barriers to family/consumer engagement, such as transportation, travel reimbursement, cost of child care, long distance phone calls, lost wages for time spent attending meetings, etc.
- Identify and address barriers to achieving cultural diversity in family representation.
- Include funds to support family engagement within your budgets, families should receive stipends or other compensation for their contributions to your program.
- Plan how to secure or expand family/consumer engagement, ensuring cultural diversity and outreach to all groups.
- Hold regional meetings with parents, because it is easier for staff to travel to families, especially if your state is large geographically.

RESOURCES

Association of Maternal & Child Health Programs. (2011) *Building Systems of Care for Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities*. Retrieved from http://www.amchp.org/programsandtopics/CYSHCN/resources/Documents/AutismPolicyProfile_10-20-11.pdf.

Association of Maternal & Child Health Programs. AMCHP Fact Sheet, AMCHP Family Delegate Fundamentals. and the AMCHP Issue Brief How to Select a Family Delegate: State Examples Retrieved from <http://www.amchp.org/programsandtopics/family-engagement/Pages/default.aspx>.

Lucile Packard Foundation for Children's Health: A Review of the Literature Pertaining to Family-Centered Care for Children with Special Health Care Needs. Retrieved from <http://lpfch-cshcn.org/publications/research-reports/a-review-of-the-literature-pertaining-to-family-centered-care-for-children-with-special-health-care-needs/>.

Colorado Family Leadership. Retrieved from <http://coloradofamilyleadership.com/>.

Family Voices. Title V. Retrieved from http://www.familyvoices.org/work/title_v.

Florida Institute for Family Involvement and Institute for Child Health Policy (2002). *Making It Work: When Families that Represent a Service Population Become Employees*. Retrieved from <http://collaboration.omni.org/sites/COFED/COFEDDocuments/Making%20It%20Work%20Hiring%20Family%20Members.pdf>.

Institute for Family Centered Care . Retrieved from <http://www.ipfcc.org/>.

Jeppson, E. & Thomas, J. (1994). *Essential Allies: Families as Advisors*. Institute for Family-Centered Care, Bethesda, MD. <http://www.ipfcc.org/resources/index.html>.



CHAPTER 7

The Big Picture: Planning and Managing Resources for Results

If You Don't Know Where You Are Going, You Will End Up Somewhere Else!

"Would you tell me,
please, which way I ought
to go from here?"

That depends a good deal
on where you want to go."

From *Alice's Adventures in Wonderland* by Lewis Carroll

It is crucial that MCH leaders establish and direct the path of service development and delivery in their jurisdictions. And in The Wizard of Oz, Dorothy lamented her fears, "Lions! And tigers! And bears! Oh, my!" Planning and managing resources may seem fearsome, but they don't have to be so overwhelming. This chapter offers basic information about the strategic planning process, leadership, budget administration and strategies for managing scarce resources

FRAMEWORKS FOR STRATEGIC PLANNING AND MANAGEMENT

The primary reason to plan is to have a clear purpose and direction for your program; decide how to use available resources; identify the resources that need to be developed; and translate the plan priorities, goals and performance measures into work assignments for

staff. Planning intends to answer these questions:

1) Where is the organization now?

- Assess whether your state is moving in the right direction.

2) Where does it want to go?

- If your state is not moving in the right direction, what changes are needed?

3) What does it have to do to get to where it wants to go?

- Work with staff in developing a plan to move in the right direction.

Performing the activities needed to answer these questions is a continuous and cyclical process.

There are many types of plans and a host of planning methods. The annual Title V MCH Block Grant application can, and should, be the annual strategic plan for the state Title V programs, but even that needs translation to a more functional work plan for each program, staff member and agency leadership.

A quick review of one type of planning process may be useful to a new Title V leader. There are numerous references available for a more in-depth look at planning strategies. If you are unfamiliar with planning, or your skills are rusty, you may want to spend time refreshing your knowledge in this

For Further Development: Learning Opportunities from the MCH Navigator

- Strategic Planning (MCH Leadership Competency 11S1) Training List <http://www.mchnavigator.org/trainings/results.php?Competencies=11S1>
- Project Management/ Program Development (MCH Leadership Competency 11S6) <http://www.mchnavigator.org/trainings/results.php?Competencies=11S6>
- Management Training Bundle <http://www.mchnavigator.org/trainings/management.php>

area. You also may find that your state has designated employees to help guide managers through a strategic planning process. Also a great resource is to reach out to another state Title V leader who is seasoned to help provide guidance. If you do not know a seasoned director, AMCHP is here to assist in facilitating this connection.

The primary tasks of strategic planning/management are to understand the environment, define organizational goals, identify options, make and implement decisions, and evaluate actual performance and outcomes. Strategic planning aims to take advantage of new opportunities as yet unknown. This type of

planning differs from traditional long-range planning that begins with a thorough analysis of the current situation. As time passes, the process of keeping this status report current is known as monitoring. Monitoring produces the kind of information contained in annual reports – numbers of people served, expenditures, number of staff members, number of diagnoses made or immunizations given, and so on. It provides a history of the program key features up to the current moment. The focus of long-range planning is to project information about the current situation into the future.

The strategic planning process most often consists of six identifiable stages:

- **Environmental scanning** – scan the external environment for driving forces, emerging issues or major influences that might impact the health status of the population. This is a “taking stock” phase and helps to answer the question “Where are we now?”
- **Evaluation of issues** – analyze the current situation, looking for issues that may emerge and assessing their potential impact on the organization. Such as a needs assessment, during this stage, planners may use a strengths, weaknesses,

opportunities, threats, or “SWOT” analysis, an acronym for considering the strengths, weaknesses, opportunities and threats facing the program. This stage ranks the issues according to their importance to operations or needs.

- **Forecasting** – develop an understanding of the expected future for the most important issues and trends, usually by extrapolating from historical data.
- **Goal setting** – define the desired future based on the issue analysis and overall mission of the program. Goals answer the question, “Where do we want to go?” and should build on strengths (to take advantage of opportunities). They should devote attention to building up areas of weakness while warding off threats.
- **Implementation** – implement specific strategies, such as policies and actions, designed to reduce threats and reach the goals. Strategies give consideration to what is practical, affordable and efficient, with a timeframe and leader responsible for implementation. Strategies designate the human and fiscal resources that will be assigned. They answer the question, “What do we have to do to get there?”

- **Monitoring** – monitor the effects of implementation on the achievement of the goals. This requires that the plan be organized and written into a document that is distributed to all staff and other interested parties.

Throughout the planning process, it is important that you keep in mind the overall mission of your program and the vision and values of what your program ideal world will be if you are successful. This will help you to stay focused. If your Title V program does not already have statements of mission, vision and values, then develop them with a group of staff and families.

SELECTED TOOLS FOR PLANNING AND EVALUATION

Strategic planning literature includes a number of planning tools that incorporate accountability into the plan. As the planning process begins, think about how it will be evaluated from the very beginning. What data will be needed to determine the effectiveness and efficiency of the plan and its strategies? Where will you get that data? How will the program be evaluated? Who is responsible for conducting that evaluation? You are responsible for making many of these decisions even though the plan is developed by a larger group. You may find it helpful to use the

As a new leader in the Title V program, you must be completely familiar with the basic rules governing your agency organizational structure, policies and procedures, protocols, assignment of human resources, work environment, and benefits.

following decision-making and evaluation models.

THE LOGIC MODEL

Strategic planning creates clarity that helps establish the critical questions to be addressed in program evaluation. All programs share common elements. A logic model is a diagram of these common elements, showing what the program is supposed to do, with whom and why. For evaluation purposes, a logic model will:

- Assist your “program” to strategize key ways to plan to address needs identified
- Summarize the key elements of your program
- Explain the rationale behind program activities
- Clarify the difference between the activities and intended outcomes of the program
- Show which activities are expected to lead to which outcomes
- Help you identify the critical questions for your evaluation
- Provide the opportunity for program stakeholders to discuss the program and agree on its description

You will find that logic models also are useful for communicating the elements of your strategies/plan to address needs in your state program to policymakers, staff, external funding agencies, the media and colleagues within your agency. The Plan-Do-Study-Act (PDSA), Toyota Lean process, and many other evaluations mechanisms have been developed over the last decade; utilizing a format or approach also utilized by other public health programs in your state or territory may help establish common ground and language that will help advocate the funders to better understand the important role of MCH in public health programming.

DECISION MAKING

Decision making is necessary to the smooth functioning of any organization, because activities involve collective action not just individual action. Models of group or individual decision making can be helpful but cannot prevent or cure bad decisions. Trust yourself to make the decision, either with a group process or individually, and proceed with implementation of the decision. Anticipate consequences and opposition, and proactively work with potential critics to

mitigate implementation problems. Do not let decisions pile up; make them as you go along because a backlog of many little decisions is nearly always more difficult to deal with than a big and complex decision. Consistently being afraid to make a decision or not taking action also will impair the operation of your program and demoralize the staff. Remember that not making a decision is actually a decision to simply not take any action at all on the problem.

MANAGING RESOURCES – YOUR LEADERSHIP STYLE

Take the time to learn about your own leadership style and encourage your staff to do likewise.

AUTHORITY

Your authority is probably governed in your state, territory or jurisdiction by civil service law and regulations, other comparable requirements and federal laws. For jurisdictions in which employees have unionized, contracts also will provide details about the management and non-management roles.

As a new leader in the Title V program, you must be completely familiar with the basic rules governing your agency organizational structure, policies and procedures, protocols, assignment of human resources, work environment, and benefits.

Recognize the difference between the authority or span of control that you hold in the agency organization and the circle of influence that you exert as the state MCH leader. Actively build coalitions with related programs, helping them to share the vision for Title V programs. A good start in building coalitions is to join and actively participate in groups that share similar missions, such as a Medicaid advisory committee, the state interagency coordinating council for the early intervention program, the state developmental disabilities planning council and program advisory boards to schools of public health, to name just a few. Never miss an opportunity to network and influence others in their work on policy and program development.

LEADERSHIP STYLE

Leadership style is impacted by your education, experience, skills, knowledge, and abilities and translates them into a style of directing others that is both unique to you and definable as a leadership model.

Leadership is much broader than “management” in that it entails visioning, motivation of others, team building, and action on vision. Not every “leader” is truly a leader, however, leadership potential can be developed overtime. A leader is less about one’s title or position. An effective leader is someone who engages others; has a clear understanding of who they are, what they know, and what they can do in terms of their area of responsibility. Leadership skills are different than management skills. Management skills are used to plan, organize and coordinate.

Notwithstanding statutes, regulations and union contracts, there are some basic techniques of good management. Mastery of these guidelines will help you take charge of the Title V program. It has been said that an inspired leader has the hearts as well as the minds of her subordinates. To win the “minds” of your staff, you should ensure your agency is organized so that:

- Every function needed to accomplish the strategic plan and performance measures are realistic and assigned to a designated team or employee. This work plan is a written document and is reflected in individual job descriptions, performance standards and

employee performance evaluations, as well as the policies, procedures and other operational documents describing the collective work of the unit.

- Each employee has only one supervisor to whom they report.
- Each supervisor has the authority and time to enable employees to fulfill their responsibilities.
- Responsibilities assigned to each team/staff member are clearly defined, communicated and understood by everyone – through staff meetings where duties are discussed, orientation of new employees, written manuals and procedures, job descriptions that include specific assignments from the work plan, and a written work plan that is drawn from the strategic plan (e.g., Title V MCH Block Grant).



Tips for Success

- Get acquainted with each staff member and learn about how that person fits in the organization. Involve staff in discussions that impact their work i.e., what is their vision of the organization/program; what they would like to see done differently.
- Do not be too anxious to reorganize the staff when you arrive on the scene. Observe what works well currently and what does not. Talk with key advisors before you reorganize to get their perspectives and then make your own decision. Do not institute organizational change because you think that is what you do as a new leader!
- Hire and retain the best staff – exceptional staff help a leader accomplish the vision.
- Do not assign overlapping responsibilities to more than one team. It results in confusion, animosity and wasted effort.
- Discuss your proposals for a new organization with your superiors, as well as your human resources office to ensure that you comply with existing statutes, regulations and union contracts.

BASIC MANAGEMENT SKILLS

As mentioned in the section above, management skills differ from leadership skills. Examples of management skills include:

- Planning
- Directing
- Organizing
- Coordinating
- Communicating
- Delegating
- Evaluating

To illustrate the above points and the effective management of scarce resources, take a close look at the Incident Command System (ICS) developed by the emergency preparedness system. ICS is a management tool consisting of comprehensive procedures for organizing personnel, facilities, equipment and communications at the scene of an emergency, as well as a model tool for the command, control and coordination of resources. It is based on the basic skills that managers and leaders already know, use and trust: planning, directing, organizing, coordinating, communicating, delegating and evaluating. Keep in mind that the ICS recommends that a supervisor can manage effectively three to seven subordinates, with the optimum being five. How does

that compare to the span of control for supervisors in your program?

The “hearts” of your staff are won by gaining their confidence in your skill as a manager and credibility for your expertise. Also taking time to get to know staff and their role is important to success.

Be conscientious in performing your job; respect the talents and knowledge of the “line staff” and supervisory personnel; demonstrate that you are in your position for the “long haul;” constantly strive to integrate all the program components into a cohesive whole; and provide clarity and consistency to the strategic plan and work plan implementation. You can successfully accomplish your agenda when the enthusiasm, energies and creative ideas of the staff are all directed toward the goals spelled out in the strategic plan. This sense of common purpose is a source of power that you can use to keep staff motivated to work toward improvement in maternal and child health, i.e., the “greater good.”

If you work in an agency that has a small staff, it is easier to develop rapport with your staff and to communicate with them regularly, which you should make a conscious effort to do. If you work in an agency that has a large

staff, you may find it easiest to share your views and listen to staff perspectives during staff meetings of smaller units under your purview; ask to attend their team meetings or create other such opportunities to “rub elbows” with your staff. Be accessible to them and think creatively about how to be accessible without losing control of your schedule. For example, you may visit them in district offices, or you might advertise your willingness to meet staff over brown bag lunches. Be sure your staff knows that you want to know them personally and have an open and honest sharing relationship with them. Your administrative assistant or secretary can help you by making time with your staff a priority in your schedule. You can even schedule time to “manage by walking around” a technique that helps you get to know your staff better in their own work environment.

QUALITIES OF A TOP ADMINISTRATOR

Embrace the qualities of a top administrator. Understand your job thoroughly, as well as your power, authority and control, and know how to exercise them wisely. Think on your feet. Cultivate the role of being spokesperson for the women and children in your state as your agency allows. As

you hone your spokesperson role, use your personal skills to your best advantage but always guard and protect your reputation for honesty and credibility. Your ability to influence others depends on these character traits. Practice your networking skills. Be able to field tough questions, identify problems and develop alternate solutions quickly, but be humble enough to seek advice so that you are making informed decisions. It is extremely important for you to be able to articulate the vision for maternal and child health in your state clearly and briefly. In short, become recognized and respected as THE expert on the MCH and CYSHCN programs, both within and outside of your agency. Be the “go to” person for your agency leadership and your staff when there is an issue or question about the program, its budget or services and its needs. To be an effective Title V leader means that you have successfully combined the cachet of your position with your own charismatic leadership traits.

Tips for Success

- Keep yourself healthy! Do not overlook the possibility of burnout and how it can affect you and your staff.
- Take courses to improve your ability to be a public speaker.
- Use project management software to keep you organized and task oriented.
- Do not be intimidated by directors of other programs that have more money or a higher profile or more political agenda. In time, they will look to you for advice and expertise for the maternal and child population in the state.
- Be one of the first to “meet and greet” new key stakeholders. Schedule an appointment to describe your programs and coordination opportunities within their first 60 days on the job. If you wait any longer, they will get too busy and might not view your program as a key stakeholder!

Cultivate the role of being spokesperson for the women and children in your state as your agency allows.

The “hearts” of your staff are won by gaining their confidence in your skill as a manager and credibility for your expertise. Also taking time to get to know staff and their role is important to success.

New MCH leaders can initially be overwhelmed by the scope of the job and the gravity of the responsibility. While there is a lot to learn, no one expects you to know everything in the first few months on the job. There are some suggestions from “seasoned” Title V leaders that can help you get your feet on the ground, begin to get comfortable with your new job and most importantly to be a success in the position.

- Review the activities listed in “Your First Months as a New Title V Senior Manager” found in the front of this guide. Be sure that you have started to address all of them early in your new position. You can continue to work on them as you begin to include the other activities recommended here.
- Recognize that learning is a lifelong process, so never stop seeking new knowledge and information. Seek training opportunities to enhance your skills as an administrator for the Title V program. Do not forget that your staff needs to have their knowledge and skills refreshed regularly as well. A workforce development program is always a good idea and helps recruit and retain

quality personnel. It also builds capacity for succession.

- Know the statutes, operating policies and rules of your agency and the employees’ union contracts if your agency is unionized. If you are unsure of any of them, meet with the appropriate personnel, obtain copies of the policies, rules and contracts, and study them. Ask questions and do not stop until you are sure that you are familiar with these harbingers of your agency “culture” necessary for your success as an administrator.
- Obtain training on all current union contracts. Contracts are the framework for personnel actions such as hiring, firing, layoffs, disciplinary actions, etc. Obtain training on human resource management so that you ensure you are following proper protocol and not violating any rights.
- Review your state ethics and conflict of interest requirements and procedures. Do you need to file disclosure forms? Are you allowed to accept token gifts such as pens or coffee mugs? Meet with your agency legal counsel to be certain that you

understand the requirements, both during your employment and after you leave the job.

- Identify the most controversial issues you might face in your new position and become





well versed in all sides of the issue. Identify the programs, legislation, budgets, staff, stakeholders and constituents who support or oppose the issue and their rationales. Propose an agency “position” to your director if needed.

AGENCY TRANSITION

Agency reorganization happens sooner or later to everyone in public health. It occurs most often with a major change of state, territorial or jurisdictional administration – usually a new governor or a new state health officer. A new administration typically means that people in key leadership positions will leave en masse, usually the agency director, deputy director, chief legal counsel, lobbyist, chief of human resources, chief of staff and others. While it is upsetting for the remaining agency staff to witness this, have confidence that the agency will not be left with a leadership vacuum and prepare for the change in advance. Also look for opportunities to position your program well under the new leaders.

There will be a new group of leaders who arrive with an agenda to implement, generally built around the governor’s campaign platform and policy priorities. They will probably look first and most

critically at the organizational structures, internal and external communication methods, and budgets because these represent the primary resources of any agency. You should anticipate their need for information by preparing program and budget descriptions in advance; put them together into an easy-to-understand briefing document or manual. You can always polish these materials later when the new leadership requests them.

Be confident that you are the expert in the Title V program and remember that your job is to help the leadership integrate their agenda into your program. Maintain a positive outlook and seek opportunities to be involved in the reorganization process. Gaining a seat at the table where agency-wide reorganization is being planned potentially enables you to steer the direction of the reorganization to strengthen your programs and avoid serious harm to the program. It is possible that you may actually find this to be an opportunity to strengthen the Title V program by realignment of related programs, budgets and staff.

If your position is protected under civil service you will not need to worry as much about being removed from employment, although you can be reassigned. However, if your position is one

that “serves at the pleasure of” the agency director, your continued employment may be in some jeopardy with the change of agency leadership. It is important that you remain calm and keep others on your staff in a “business comes first” mode of operation. You can help yourself best by thinking ahead. Schedule a meeting with your new supervisor or the agency director. Provide a copy of your resume, a listing of people who are part of the new administration and respected public health leaders who will vouch for your work, a listing of recent program results achieved during your tenure, and specific ideas about how you as a leader and the Title V program can support the administrations/agency director’s priorities. Always keep in mind that there is an overarching political agenda; be familiar with that agenda and frame your program results accordingly.

If you have been responsible for the administration of certain politically “targeted” programs, however, you may find it necessary to take further action. For example, you may be required to reapply and compete to retain your job. If this does happen, maintain a positive attitude (remember, the requirements are politically based, not personal) but prepare yourself completely for your interview. Read books to motivate yourself for the interview process,

like Knock ‘Em Dead. Garner behind the scenes support from contacts within the new administration and ask them to call your agency director on your behalf. Try to maintain a balance of the calls made on your behalf between those inside the current administration and respected advocates and public health leaders. Do not flood the director with calls; a few well-placed calls are usually more effective than a huge number of calls that lack specifics. Remember that there is no guarantee that these suggestions will succeed, but give it your best shot.

This is definitely not the time to begin cultivating “political capital” – you should have been developing those networks prior to any change in administration on a daily basis as you carry out the interagency collaboration necessary to implement the Title V program. Change of administration is a time where you will find it useful to have some political capital in your pocket waiting to be spent.

RESOURCES

Planning

Daly Peter, Watkins Michael. (2006) The First 90 Days in Government: Critical Success Strategies for New Public Managers at All Levels. Massachusetts: Harvard Business School Publishing.
W.K. Kellogg Foundation. (2006). Logic Model Development Guide. Retrieved from <http://www.wkkf.org/resource-directory/resource/2006/02/wk-kellogg-foundation-logic-model-development-guide>.

Decision Making

Johns Hopkins University. Maternal and Child Health Leadership Skills Development. Module 5: Organizational Change. (2008) Retrieved from <http://www.mchnavigator.org/trainings/MCH-planning-cycle.php>.

National Network of Public Health Institutes. Developing Performance Measures: An Overview & Practical Pointers. (2013). Retrieved from <http://www.mchnavigator.org/trainings/MCH-planning-cycle.php>.

Administration

Association of State and Territorial Health Officials. Profile of State Public Health. Retrieved from <http://www.astho.org/Research/Profile-of-State-Public-Health/>.

Association of State and Territorial Health Officials. First Days: A Guide for New State and Territorial Officials. Retrieved from <http://www.astho.org/Display/AssetDisplay.aspx?id=2456>.

Federal Emergency Management Agency . Overview of the Incidence Command System, October 2013, Emergency Management Institute. Retrieved from <http://training.fema.gov/EMIWeb/IS/courseOverview.aspx?code=is-100.b>.

Martin Yate. Knock ‘Em Dead 2003. Avon, MA: Adams Media Corp. 2003.



CHAPTER 8

Making Data Your Friend

HOW IS THE DATA AND EPIDEMIOLOGY EFFORT CONFIGURED IN YOUR STATE?

Title V has data at its core; to ensure that state Title V dollars are put to their best uses, the Title V program must do a comprehensive needs assessment every five years. This assessment should be driven by your state data on the health status and needs of your MCH populations and your program's capacity to meet those needs. Ultimately you will set priorities and identify performance measures for the next five years using the best available data for your state. In addition to your use of data to identify needs and gaps and assess capacity and services, there are national performance and outcome measures that are reported to maintain funding. Having dedicated analytic staff can make the annual report and five-year needs assessment much easier.

One of the first things you can do to make MCH data your friend is to learn about how epidemiology resources are organized in your state. In some states, there are epidemiologists and data analysts within the Title V program, under your direct (or indirect) supervision. In other states, there is a centralized epidemiology unit where personnel are assigned to support MCH programs. Another model involves

sharing resources across similar programs, such as a joint MCH and chronic disease epidemiologist. Regardless of the configuration of data and epidemiology support in your state, it is important to have a good handle on what resources are available to assist you in making data-driven decisions.

WHAT EPIDEMIOLOGY CAPACITY DO YOU HAVE?

In determining your MCH epidemiology (epi) capacity, you might find that you have staff that identify themselves as MCH epidemiologists. More often than not, however, you will have people who work intensively with MCH data who may not call themselves epidemiologists. Staff with titles such as data analyst, data manager, statistician, demographer and even policy analyst may all be serving in a capacity that contributes to your overall MCH epidemiology capacity. Some MCH epidemiologists are trained through schools of public health and have a masters or PhD from a public health program in epidemiology, and maybe even MCH epidemiology. In other cases, an MCH epidemiologist may be trained in another of the social sciences (psychology, sociology, etc.) or may come from a more clinical background. Whatever the background of your epis, know that there is no single training

For Further Development: Learning Opportunities from the MCH Navigator

- Epidemiology Training Bundles (Basic for “Data Users,” Advanced for “Data Makers,” and trainings on epidemiology software)
<http://www.mchnavigator.org/trainings/epidemiology.php>

program or configuration of MCH epi effort that works for every state. The Council of State and Territorial Epidemiologists (CSTE) has created a set of competencies for epidemiologists (Competencies for Applied Epidemiologists in Governmental Public Health Agencies, also known as the Applied Epidemiology Competencies, or AECs), and they conduct periodic epidemiology capacity assessments for each of the major epidemiology disciplines. Both of these resources can help you figure out your status with MCH epi and where you would like to be in the future.

CSTE Applied Epidemiology

Competencies

<http://www.cste.org/group/CSTECDCAEC>

CSTE Epidemiology Capacity

Assessments

<http://www.cste.org/group/ECA>

BUILDING MCH EPIDEMIOLOGY CAPACITY

There are several mechanisms you can use to build MCH epidemiology capacity in your state. The options depend on the resources you already have, the level of capacity you desire, and your ability to provide a training experience for new epidemiologists.

CDC Assignees: The CDC Maternal and Child Health Epidemiology Program (MCHEP) is a collaborative effort between the CDC and the HRSA MCHB. For more than 25 years, the MCHEP has assigned senior CDC epidemiologists focused on MCH epidemiology capacity building and applied research; more than 35 assignees have served 20 states and six other public health agencies and organizations in the program's history. The CDC assignment is an agreement between the host site and CDC, and there is generally some level of financial commitment from the state. A doctoral level epidemiologist is embedded in the state and is given a leading role in the development of MCH epi capacity. To learn more, visit the CDC MCHEP Web page: <http://www.cdc.gov/Reproductivehealth/MCHePi/index.htm>.

CSTE Applied Epidemiology

Fellows: CSTE and CDC MCHEP work in partnership to support graduate level fellows in states focused on building MCH capacity. A fellow, assigned to a state for two years, may work in a state with a senior MCH epidemiologist or independently under the supervision of state staff. The fellow comes free to the state, but a state must have a PhD-level staff member available to serve as one of two mentors; CSTE fellows come to the program with excellent training, but this is often their first job in a state public health agency, so providing strong mentorship is very important. Fellows will need to fulfill a set of core competencies over the course of their experience. To learn more, visit: <http://www.cste.org/?page=Fellowship>.

GSEP Interns: MCHB sponsors the Graduate Student Epidemiology Program (GSEP) to enhance student skills in data analysis, promote training in MCH epidemiology, and to provide assistance to state and local health agencies with data-related projects. This program provides graduate students with the opportunity to address specific, defined data or analytic issues to assist state and local health agencies in developing their MCH/CYSHCN information systems. The GSEP experience is 12 weeks long, and student interns are paid a

stipend of \$4,000 for the summer. Hosting GSEP interns might be a great way to complete analyses for short-term, self-contained projects.

University Partnerships:

Some Title V programs will not have the resources or infrastructure needed to hire an MCH epidemiologist or be able to access some of the opportunities listed above. Another option that can be explored to boost MCH epi capacity is partnering with a university. The university does not necessarily have to have a school or department of public health, but that can be particularly helpful. Some states have arranged for MCH epidemiology analytic "time" from university professors, and others have contracts that allow a university professor to devote some portion of an full-time employee at the health department. Whatever the configuration, university partnerships can be a great way to boost capacity and open the door to the developing public health workforce; linking with university internship programs can be a great way to get extra help for all MCH program areas while providing students an opportunity to experience governmental public health firsthand.



University partnerships can be a great way to boost capacity and open the door to the developing public health workforce.

States that have utilized university partnerships: Illinois, Louisiana, Maryland. Examples of these partnerships are included below.

Illinois: The University of Illinois Chicago provides epidemiology support to Title V continuously. The university leads the quantitative portion of the Needs Assessment, the epidemiology support for the CoIN to reduce infant mortality, the Perinatal Quality Collaborative, and data analysis for non-medically indicated early deliveries using birth certificate data.

Louisiana: The Tulane University School of Public Health MCH Training programs assist the state with the Life Course Metrics Project. The university worked with a team representing a range of disciplines to develop a list of potential indicators to measure progress using the life course approach to improve maternal and child health.

This process included a literature review, consultative meetings, and discussion of available data sources. This team was co-led by the state Title V director and a Tulane faculty member.

Maryland: Senior faculty from the MCH Training Program at the Johns Hopkins School of Public Health are members of the Epidemiology Working Group for the Maryland Infant Mortality Reduction Initiative. Participation on this committee reflects an ongoing collaboration on data development spanning several decades. In the summer 2012, faculty provided empirical evidence and expert testimony to the state Department of Health and Mental Hygiene in support of the perinatal outcomes indicators identified for a public monitoring and reporting system through which hospital-specific data would be published.

Skills-Building and Training: Even if you already have some stellar MCH epi capacity, it is important that your staff keep their skills sharp and stay on top of new developments in the field. There are numerous opportunities that range from intensive, in-person trainings to one-hour webinars on hot MCH epi topics that your staff can use for professional development. Skills-building and training opportunities such as those hosted prior to the AMCHP, MCH Epidemiology, and CityMatCH conferences and the MCH epi Symposium at the CSTE Annual Meeting are excellent venues for your staff to receive hands-on experience from national experts in MCH epidemiology. While these opportunities do require travel, there are usually travel scholarships available. If travel is not an option, materials from these training opportunities are usually available online and a select few are even video recorded. You can

access the training archives for the pre-conference trainings presented by AMCHP at the link below. Another great resource is the MCH Navigator MCH Planning Cycle section.

Other “virtual” professional development opportunities may be attractive to your staff, including program and policy staff, because so many training events are moving beyond just analytic techniques to strategies for using MCH data for assessment, planning, evaluation, and improvement of public health programs. Some these include the CDC Yearlong Course, MCH epi Grand Rounds webinars, DataSpeak webinars, and AMCHP webinars. The best way to find out about these opportunities is to stay connected to the MCH epi community through listservs. The two most used are listed below.

AMCHP pre-conference skills-building and MCH Epi pre-conference training archive

MCH Navigator, MCH Planning Cycle

Maternal and Child Health Epidemiology Listserv

The listserv includes nearly 600 MCH scientists and program directors, and provides quick peer exchange and technical assistance on “hot topics” and informs participants of upcoming events and opportunities. To be added to the MCH EPI Listserv,

please e-mail us at MCHEPI@cdc.gov. Post new messages and respond to received messages by sending an e-mail to MICHEP@LISTSERV.CDC.GOV (not case sensitive)

MCHB Division of Epidemiology Listserv

This listserv provides information on a number of topics, including:

- The MCHB Epidemiology and Statistics Program
- DataSpeak webinars
- MCHB news and events
- Upcoming and past publications and presentations
- Reminders about upcoming MCH epidemiology training
- Updates on national surveys and chart books:
 - Women’s Health USA
 - Child Health USA
 - The Health and Well-Being of Children: A Portrait of States and the Nation
 - Other National Survey of Children’s Health chart books
 - National Survey of Children with Special Health Care Needs

List members are invited to post announcements to the list (pending approval from the list moderators) regarding MCH Epidemiology and Statistics Program updates, training opportunities, and other

information relevant to the MCH Epidemiology community. To subscribe/unsubscribe from this list or to contact the list moderators with comments, ideas, and potential announcements for posting, please send an e-mail to the address listed below: mch_epidemiology_general-request@list.nih.gov

ACCESS TO DATA

There are numerous data sources in your state that can inform your work and can be used for your Title V MCH Block Grant reporting. Hopefully your staff have access to vital event data, which certified data on births and deaths (including infant deaths, fetal deaths, and induced terminations of pregnancy). State survey data on pregnancy (like the PRAMS survey), youth (the Youth Risk Behavior Surveillance System or YRBSS), and adults (the Behavioral Risk Factor Surveillance System or BRFSS) can help you to better understand the behaviors, health issues, and opportunities for intervention in your population. Your state also may have access to hospital inpatient data (discharges), emergency department data, and surveillance systems for hearing screening, newborn genetic screening, and birth defects. Some states have access to and agreements with other sources of data such as Medicaid eligibility



and claims, WIC participation, foster care, and SNAP utilization. If you find that you do not have access to the data that you need, AMCHP may be able to help connect you with states that have negotiated memoranda of understanding or agreement who can give you some advice. One helpful resource is a webinar archive AMCHP hosted on [The Ins and Outs of Data Sharing with your State Medicaid Agency](#).

In addition to state data, there are national surveys that provide state-level data to inform your work. These include the National Survey of Children's Health, the National Survey of Children with Special Health Care Needs, and the

National Immunization Survey and NIS-Teen, to name a few. Visit the AMCHP Data Resource Portal for links to these and other sources of data. Many national data sources also have web-based query systems that are designed so that the user does not need to have analytic skills to access the information.

Once you have access to state and national sources of data, consider how you will use this information to inform your five-year Title V needs assessment. A few indicator sets you should be aware of include the Core State Preconception Health Indicators and the Life Course Indicators.

AMCHP Data Resource Portal

Core State Preconception Health Indicators

Life Course Indicators

STATE SYSTEMS

DEVELOPMENT INITIATIVE: DATA SUPPORT FOR TITLE V

Because of the intensive focus on data reporting for Title V, a companion grant called the State Systems Development Initiative (SSDI) Program was created to assist state MCH and CYSHCN programs in the building of state and community infrastructure that results in comprehensive, community-based systems of care for all children and their families.

Your state should have an identified SSDI coordinator; this person can help orient you to the Title V data and reporting requirements. States are expected to focus SSDI resources on establishing or improving the data linkages between birth records and 1) infant death certificates, 2) Medicaid eligibility or paid claims files, 3) WIC eligibility files, and 4) newborn screening files. States should give first priority to these four data linkages, and then focus on establishing or improving access to 1) hospital discharge surveys, 2) a birth defects surveillance system, 3) a survey of recent mothers at least every two years, similar to the Pregnancy Risk Assessment Monitoring System (PRAMS), and 4) a survey of adolescent health and behaviors at least every two years, like YRBSS.

HOW ARE WE DOING? EVALUATION AND IMPROVEMENT

As budgets get tighter, accountability, innovation, and improvement are all key concepts for creating and sustaining successful public health programs. You may have staff dedicated to evaluation activities, for specific programs (like Healthy Start) or available across your whole portfolio. By contrast, you may not have any dedicated evaluators; epis

and other data analysts may take on these roles, or your program management staff may have this as part of their duties. Regardless of your evaluation capacity, there are many resources available to assist your staff in the development of logic models, measures of process, outcome, and impact, and using evaluation findings to improve your program. The CDC resource, *Introduction to Program Evaluation for Public Health Programs: A Self-Study Guide*, may be a useful place to start along with pertinent modules on the [MCH Navigator](#) around logic models.

One of the most powerful tools for visualizing health data is mapping. Using a map to show the concentrations of mortality, the distribution of the social determinants of health, and the coverage of programs funded by Title V can be far more compelling than a paragraph or statistical table with the same information. Mapping is a skill that can have a steep learning curve (and requires some expensive software) but provides immense benefits for MCH programs. AMCHP training archives include materials from trainings on using geographic information systems (GIS) programs such as ArcView to map MCH data and perform spatial analysis. If your in-house mapping capacity is limited, it is worthwhile to explore

whether other departments, such as environmental health or HIV surveillance may already have capacity that you can borrow; perhaps your health agency has a stand-alone mapping unit that can assist you. This also may be an opportunity to explore a university partnership, or partnerships with other state agencies.

A final area of consideration as you make MCH data your friend is to consider opportunities for quality improvement (QI). Whether you are a seasoned QI practitioner or PSDA newcomer, consider developing or enhancing capacity in your Title V program to implement QI methodologies. AMCHP has featured QI in several events, including a mini-plenary at the AMCHP 2013 Annual Conference and pre-conference sessions at the MCH Epi 2012 Conference and the AMCHP 2014 Annual Meeting. The training and conference archives can be a great place to start gathering information on how to bring a QI perspective to your MCH activities. Your state also may be part of the National Improvement Partnership Network (NIPN), housed at the University of Vermont and lead by the Vermont Improvement Partnership, the Vermont Child Health Improvement Program (VCHIP).

In addition, through the CDC National Public Health Improvement Initiative, nearly every state and territory hired a performance improvement manager or accreditation manager with expertise in QI and the charge to drive quality improvement and performance management initiatives across the state health agency. This person can be a valuable QI resource and important ally for the MCH program if you help him or her understand the strengths of your MCH work. Many core activities carried out by Title V and other MCH programs can help the states and territories applying for voluntary national accreditation meet the standards and measures set for by the Public Health Accreditation Board (PHAB). If your state is currently in the process of applying for accreditation it is important to make sure Title V is at the table.

AMCHP Annual Conference Archive

MCH Navigator, Quality Improvement

National Improvement Partnership Network (NIPN)

Center for Public Health Quality

Public Health Accreditation Board



CHAPTER 9

The ABCs: State and Federal Grants, Budgets and Accountability

This chapter offers basic information about managing the Maternal and Child Health Block Grant, such as the strategic planning process of the Title V application, accountability, performance measures, budgets and helpful tips from Title V leaders who have “been there, done that.”

PLANNING AND TITLE V

STATE HEALTH IMPROVEMENT PLAN

Most state health agencies have a state health improvement plan that is multi-year and agency-wide in nature and was developed through a strategic planning process. This plan identifies the state’s health priorities, goals and strategies and is generally based on the core public health functions, essential public health services, Healthy People national health objectives and state health needs. It is used to assign the agency’s resources (workforce and fiscal) and may also be used as a public relations document or to develop state budget requests. By virtue of its planning and documentation process, the Title V program is in an excellent position to be a prominent part of the state health plan, and you should welcome opportunities to participate in the development or revision of a state health plan. Starting in 2015 with the transformation of the Title V

Block Grant, states must submit a Five Year Action Plan. This plan serves as a planning tool and assists with aligning your planned Title V program strategies and activities with identified priority needs. Consider using this action plan as a starting point when you are assisting your state in developing the health plan.

TITLE V APPLICATION AND ANNUAL REPORT GUIDANCE

The **Maternal and Child Health Bureau** provides guidance, entitled Title V Maternal and Child Health Block Grant to States Program Application and Annual Report Guidance, for the block grant application and annual report each year. There are also federally mandated performance and outcome measures and health status and systems capacity indicators, based on the Healthy People national objectives and input from a group of MCH and CYSHCN state leaders. The planning process described in the guidance is very similar to the strategic planning process discussed earlier in Chapter 7. A new Title V leader should read and study the federal guidance before embarking on any new planning process for the block grant to ensure that all requirements are included.

KEY MCH BLOCK GRANT REQUIREMENTS FOR STATES

For Further Development: Learning Opportunities from the MCH Navigator

- 30 Trainings to Support MCH 3.0 Training Spotlight <http://www.mchnavigator.org/trainings/MCH-3-spotlight.php>
- Needs Assessment Training Brief <http://www.mchnavigator.org/trainings/needs-assessment.php>
- Performance Measures Training List <http://www.mchnavigator.org/trainings/results.php?Competencies=Performance%20Measures>
- Financial and Budgetary Concerns Training List <http://www.mchnavigator.org/trainings/results.php?Keyword=budget>

- Annual application and report equals plan
- Comprehensive needs assessment every five years, with annual updates
- Annual plan with goals and objectives (consistent with national health objectives) for meeting needs, with service areas, categories and individuals to be served
- National core and state optional performance measures
- “30/30” requirement to spend at least 30 percent of federal Title V funds on preventive

and primary care services for children and youth and 30 percent on services for children with special health care needs

- Match of at least 75 cents for every federal \$1.00
- No more than 10 percent of funds can be used for administering the funds
- Maintenance of effort for level of state funding in place in 1989
- Funds can be used for health services and related activities including planning, administration, education, evaluation and purchase of technical assistance
- Funds cannot be used for inpatient services, except for CYSHCN, high risk pregnant women, or where approved by the secretary of health and human services (HHS); cash payments to intended service recipients; purchase or improvement of land, construction or purchase of major medical equipment; meeting requirements for other federal programs; research or training from for-profit entities; or paying for service of providers excluded by HHS.
- Coordination with Medicaid, including the Early, Periodic Screening, Diagnosis and Treatment (EPSDT) program,

outreach and enrollment

- Toll-free phone lines to help parents find health information and providers
- Coordination with other federal programs, including food and nutrition, education, developmental disability, family planning and other health programs.

The guidance and application forms are available on the [Bureau's website](#). States, territories and jurisdictions must submit the combined application / annual report narrative, forms and budget through HRSA's secure, web-based server.

Title V Maternal and Child Health Services Block Grant to States Program: Guidance and Forms for the Title V Application/Annual Report

[PDF]

ORGANIZING STAFF

Organizing staff to write the combined block grant application and annual report should be done months in advance of the deadline. If you are in a state with a small staff, you may be the best (or the only) person to write the document. Most likely, you will need some assistance from your agency's budget personnel to complete the financial portions, however, and may want to consider seeking

grant writing expertise from other resources, such as schools of public health or private consultants.

In those states with large staff, the task may actually become more complex, because you will probably divide up the preparation and writing of the document to different people. In this case it is crucial to appoint a single person with responsibility for the final preparation of the application – Some states have created manuals to direct employees in preparing the MCH Block Grant for submission. Such manuals break the tasks to be completed into steps, assign responsibilities for each section, provide due dates for each task and specifies the agency's internal clearance process. Regardless of how large or how small your staff, there are some ideas that can make this annual task less of a chore and even more useful as a strategic plan.

Have a master plan. Make a list of all the major steps to prepare the application/annual report, using the Guidance, and put the list into a logical sequence. Lay those steps out onto a "block grant" calendar, working backwards from the MCHB deadline. You do need to plan; don't make it an afterthought or put it off until you have time. Unless you schedule the time for planning, you will not do it until it is too late to do a great job.

States are required to conduct a comprehensive needs assessment every five years and, through that process, examine their capacity to fully carry out the Title V program, identify and select their priorities for the coming five-year period, set targets and identify activities to accomplish the targets, allocate available resources and monitor the progress over the five-year planning cycle.

Checklist for Preparing the Block Grant	
<input checked="" type="checkbox"/>	Study the guidance and make a list of tasks
<input checked="" type="checkbox"/>	Assign one person to be in charge of coordinating the block grant
<input checked="" type="checkbox"/>	Make a master plan Gather documents (e.g., current application, last annual report, data, budget, forms) Assign every task to someone to complete by deadline Identify need for & obtain technical assistance to complete preparation
<input checked="" type="checkbox"/>	Develop a calendar of key assignments, staff assignments and due dates
<input checked="" type="checkbox"/>	Schedule time to read entire document from front to back; edit
<input checked="" type="checkbox"/>	Double check all forms and table
<input checked="" type="checkbox"/>	Obtain public input; insert documentation into application
<input checked="" type="checkbox"/>	Adhere to state agency clearance process and timelines
<input checked="" type="checkbox"/>	Obtain signature of agency director and submit on time to MCHB
<input checked="" type="checkbox"/>	Celebrate a job well done!

Spread out the preparation of the application over at least 6 months (better yet, 9 months!) before it is due to MCHB, so that you ensure adequate time to obtain data, write new sections, write results and provide updates. Try to begin writing the annual report updates in the application by 90 days after the end of the fiscal year upon which you are reporting.

Your agency probably has clearance requirements that must be met.

For example, some state health officers will not sign off on grant applications until they have been read and approved by the agency's chief fiscal officer and deputy director. Some states require the Governor to sign off on the grant which can significantly impact the timeline. Find out your agency's grant clearance requirements and timeframes and build that time into the calendar. You will win friends throughout the agency if you strictly adhere to their timeframes.

Identify those portions of the document that don't change much from one year to the next and complete them first. Read these parts yourself and make note of what updates are needed. Choose the best staff member to prepare the update (it might be you!). For example, the State Overview section (agency capacity, organizational structure, other MCH capacity, and state agency coordination) will probably need very little editing each year if it was comprehensive and well prepared initially, and the agency

organizational structure remained relatively unchanged. Get the easy parts done first and spend more time on the more difficult sections.

If you have assigned work to staff, be clear about the deadlines. Send out reminders a week or two before the deadline. If the materials are not submitted to you by the expected date, immediately remind the staff member that the material is overdue and assign a revised date. Determine if you need to adjust the overall block grant calendar.

Once all portions of the application are complete, make time in your own schedule to read the entire document from beginning to end. You have the “big picture” perspective of the Title V program for your state and only you can identify errors or gaps in information. Edit the document before allowing it to proceed to your state and/or agency’s clearance process or out to the public for comment. Some states put a shortened document out for public comment, such as bullets with proposed strategies for the Performance Measures, etc. so that they can continue to work on other parts of the grant before it has to be reviewed per state policy. By doing so, comments from the public can be reviewed and incorporated as appropriate to the final application.

Double-check the budget forms to be certain that they reflect the true picture of funding for your program and that you understand and are able to answer questions about the budget figures during the grant review.

PUBLIC INPUT

Public input into the block grant application/annual report is required. Think about the best ways to obtain public input for your jurisdiction and build time for public comment into your calendar. You may find it useful to talk with your assigned MCHB project officer about how to achieve public input effectively, and your AMCHP peers in other states may also be helpful. Remember the idea here is to share the plan widely, get input and incorporate the input as appropriate into the final document. State best practices in obtaining public input include the use of press releases, listening sessions, web postings, public notices, distribution through partner newsletters and listservs, focus groups, survey’s via Survey Monkey, and the use of social media (e.g., Facebook and Twitter).

Remember as a Title V professional you understand Title V programs have a large reach supporting women, children, children and youth with special health care needs and families. However does the general public, program consumers or even

state legislatures, have this same understanding? Consider possibly branding your states Title V events, programs and resources to make it easier for state legislatures, the general public and the population Title V programs you serve understand Title V’s reach. By developing a “branding plan” for all of your events this will make it easier for your target population to identify the work of Title V and provide public input each year.

If you have an advisory committee for the MCH Block Grant, encourage them to comment on the draft application. You might have a one-day committee meeting to review your program results (i.e., annual report) and proposed activities (i.e., annual plan). You could use the MCH pyramid as a review tool. You could use the Performance Measures as a review tool, especially for those that were not achieved in the reporting period.

The number and nature of the comments received and how they were addressed in the final Application/Annual Report should be noted for each year.

All comments received should be summarized. Provide notice on your agency’s website about the availability of the draft application. You could post a copy on the website or require them to contact you for a hard copy to track the

“The best thing about the block grant is its flexibility. The worst thing about the block grant is its flexibility.”

Jeanette Shea-Ramirez, Former Chief, Office of Women’s & Children’s Health, Arizona

number of requests. Give a deadline date for comments to be submitted on the draft document. Include a report on the comments received and any actions taken in the application.

You may want to hold public hearings in various locations throughout your state on the block grant application. Generally, however, such hearings are not well attended unless there is a controversial item in the application or there have been major shifts in policies, funding or budget cuts. Public hearings of this nature work best when they are well advertised in advance, copies of the draft document are easily available to the public and adequate advance notice has been provided to key stakeholders.

Dissemination of the grant application

Post the final version of the application on the agency's website and encourage public input throughout the year. Again, maintain a list of the input received and any action in response.

- Provide copies (printed or electronic) of the application/annual report to your state government library each year. This will ensure that legislators and other state agencies have access to the latest version of the document.
- In some states, your agency's legislative liaison may want to personally deliver a copy of the document to key legislators.
- Another way to make the application available to the public is to provide copies to the library system throughout the state, including contact information for public comments. If you use this method, be sure to send the new application/annual report every year.

Provide key “sister” agencies with an annual courtesy copy of the application. You should think about sending the document in printed and electronic form to Medicaid, SCHIP, early intervention and other key programs that you coordinate with throughout the year. Also share

a copy with key programs within your own agency.

COMPREHENSIVE NEEDS ASSESSMENT

A comprehensive needs assessment is recognized as a good public health practice and is a common feature of programs throughout the field. The MCH Block Grant requires a comprehensive state-wide needs assessment every five years, but as updates are required annually, this assessment should be thought of as a continuous and on-going activity. The Needs Assessment identifies the need for: 1) Preventative and primary care services for pregnant women, mothers, and infants up to age one; 2) Preventative and primary care services for children; and 3) Services for children with special health care needs. This process gives you an opportunity to take a fresh look at the needs and accomplishments of the block grant, including program evaluation results, data, measures of health status for MCH populations, priorities and collaborations with other key programs. It also

documents the basis for selecting the state negotiated performance measures that are designed to address the new priorities.

Because it takes considerable time to conduct a comprehensive needs assessment, do not wait until the year it is due to start the process. Obtain a copy of the Maternal and Child Health Services Title V Block Grant Program Guidance and Forms for the Title V Application/Annual Report. Study the chapter that describes the needs assessment process before initiating any planning activities. It provides an excellent overview of strategic planning and spells out the steps in the process. You can look to other literature and resources to elaborate on any of the steps in the planning process. The needs assessment should serve to inform the MCH Block Grant plan development. One good source is the book, *Needs Assessment in Public Health: A Practical Guide for Students and Professionals*, authored by two MCH veterans, Donna Petersen and Greg Alexander.

Make a master plan for conducting a comprehensive needs assessment. Begin by making a list of the major steps you will have to complete. Make a listing of the workforce and fiscal resources you have available to complete this task. Start well in advance – preferably two years

before the needs assessment is due. Make a master calendar for completing the needs assessment. Start with the date the needs assessment is due to MCHB and work backward until you have all steps in the process assigned

both a deadline and a responsible staff member(s). If you have a staff member with expertise in conducting needs assessment, either designate that person as being “in charge” of the entire process, or ask for her guidance.

Checklist for Conducting Needs Assessment

<input checked="" type="checkbox"/>	Study the guidance and make a list of tasks to be completed
<input checked="" type="checkbox"/>	Use consultants as needed
<input checked="" type="checkbox"/>	Put one person in charge of the needs assessment
<input checked="" type="checkbox"/>	Make a master plan Discuss with MCHB project officer; obtain technical assistance if needed Gather existing documents (e.g., last needs assessment, data updates, studies, reports, program evaluations, SLAITS data, etc.) Assign every task to someone to complete by deadline
<input checked="" type="checkbox"/>	Develop a calendar of key assignments and due dates
<input checked="" type="checkbox"/>	Hold a stakeholders meeting for all interested parties to review master plan; periodic meetings thereafter for steering needs assessment activities
<input checked="" type="checkbox"/>	Obtain new data and analyses
<input checked="" type="checkbox"/>	Read draft report from front to back; edit
<input checked="" type="checkbox"/>	Share draft with stakeholders; conduct process to develop list of needs and priorities based on needs assessment findings
<input checked="" type="checkbox"/>	Complete final report
<input checked="" type="checkbox"/>	Share final needs assessment report, including listing of needs and priorities, widely - with state agency leadership, “sister” agencies, advocacy groups, legislature, governor’s office, etc.
<input checked="" type="checkbox"/>	Celebrate a job well done!

Look at what work has been done in the past and all comments from the federal block grant reviewers about the strengths and weaknesses of the previous assessments.

Talk with your assigned MCHB project officer to obtain further information about comparable states that can serve as examples of how to carry out a comprehensive needs assessment. Talk with your AMCHP peers for additional tips on how they planned the needs assessment, the methodology for the assessment and how they overcame problems or obstacles.

Convene a meeting of all staff, family advisors and coordinating programs (both within and outside your agency). Review the master plan with this ad hoc committee and use their advice in refining the plan for the needs assessment. This group can become a “steering committee” for the needs assessment and be convened periodically to provide status updates and to problem solve. In some states, the MCH Block Grant advisory committee could serve this function. In other states, the steering committee may actually assume some of the responsibilities for carrying out the needs assessment. Remember that the more you decentralize the needs assessment process, the more you are going to need a single person to

be on top of the process, someone to know who is doing what and when assignments are due.

Always conduct an environmental scan early in the process to determine what data, program evaluations and other information you have readily available. Identify what information will be more difficult to secure and determine the best method to obtain the information. For example, the data you need might be available from another program such as Medicaid or Vital Statistics. Or perhaps you will need to identify outside consultants to obtain the information you need. Consultants may bring skills such as forecasting or social marketing that are not already available on your staff. The “steering committee” members should be helpful here. If you are not knowledgeable about statistical analyses, ensure that you have someone with expertise to help you identify trends, determine significant changes over time, and deal with hard data issues, such as small incidence or small populations. Also, it is helpful to have someone with expertise in data linking.

Build adequate time into the needs assessment calendar for an advisory group to review the resulting data, trends and other information. You may use a process

such as the Delphi Method or the Nominal Group Process to generate a listing of key MCH issues and some version of voting for the top priorities. Some states determine in advance that those areas included in the Performance Measures will not be included in the list of State priorities as they already are requirements to address that issue. Consider sending out the list of key MCH issues to all major stakeholders (local health commissioners, families, clinic personnel, human service agency directors) throughout the state and ask them to prioritize the issues. The results can be the Title V priorities for the next five years.

Use the new priorities to direct resources toward the block grant efforts by selecting 7-10 state selected highest priority needs. Based on the identified priority needs, the state will select 8 of 15 National Performance measures for programmatic emphasis over the five-year reporting period. Recognize that political realities may demand that the block grant priorities be amended to reflect current political leadership or campaign promises. However, having prepared the priorities without considering political perspectives may enable you to “take the high road” and offer a persuasive argument for keeping the priorities because they were

determined through a fair, inclusive, and comprehensive process.

Combine all of the data and results obtained during the needs assessment process into a written summary that describes the findings, the framework and methodology used, who was involved in the process (stakeholders and other partners), and what the results mean in terms of Title V services. The guidance provides detailed information about what should be included in the needs assessment summary report. While the needs assessment summary is a document that is submitted to MCHB, it can also be useful to advocacy organizations, advisory committees and other agencies in your state. You may want to use it as a marketing tool for the Title V program.

CAST-5

The Capacity Assessment for State Title V (CAST-5) is a set of assessment and planning tools designed to examine state program's capacity to carry out core maternal and child health functions. They are very helpful tools to use during the needs assessment process and fit well into the second stage in the needs assessment process as described in the guidance. The tools can be used collectively for a comprehensive assessment of the Title V capacity

needs, including opportunities for capacity development. Or they can be used individually to assess the specific, narrower scope of the programs.

CAST-5 is meant to answer the strategic planning questions, "What do we have?" and "What do we need to get the job done?" It helps state Title V programs determine what organizational, programmatic and management resources must be developed or enhanced to achieve the program's goals.

Use of CAST-5 is not required by MCHB, but it is recommended by AMCHP because it assures that the needs assessment takes into consideration resources currently available and those needing development. In addition, CAST-5 provides broad guidance on prioritizing program capacity needs and developing strategies for capacity development. CAST-5 is an initiative of AMCHP and the Johns Hopkins University Women's and Children's Health Policy Center, in partnership with the federal MCHB.

OBTAINING DATA

Obtaining data is critical to the success of the needs assessment and MCH Block Grant plan. Some states have comprehensive structures in place to collect and analyze public health data, while other states do not have

the resources (low funding levels) to support a data infrastructure of this nature. Because of this wide variability across the states, MCHB has invested significant resources in data capabilities in recent years, such as the State Systems Development Initiative (SSDI) grants to improve specific data sources. Additionally, MCHB funded a national telephone survey database for the health status of children with special health care needs known as SLAITS (conducted by the National Center for Health Statistics). MCHB plans an expansion of SLAITS to secure information about the preventive and primary care health status of all children.

As you begin the needs assessment process, determine what data sources are available within the state, from MCHB or from other national resources, as well as the limitations of these data. Determine what you can do to improve the quality of data sources with available fiscal and human resources. For example, SLAITS under samples certain populations by design, so you may want to purchase additional sampling for your jurisdiction to target under sampled groups. You should also identify what basic MCH data exists in your state from sources such as Vital Statistics (from birth and death certificates); research



that identifies trends specific to your state or its subpopulations; service data from Title V, WIC, early intervention, public schools, Medicaid, mental health and others; national MCH data from MCHB's Title V Information System (TVIS); and program evaluations. The block grant requires that reliable data be used for the national performance and outcome measures.

PERFORMANCE AND OUTCOME MEASURES

Performance and outcome measures were introduced in 1999 by MCHB in response to the

Government Performance and Results Act (GPRA) of 1993. The purpose of GPRA is "to improve federal program effectiveness and public accountability by promoting a focus on results, service quality and customer satisfaction." Performance measures are tied to a performance-based program budget, and the states are accountable for meeting the performance measures and evaluating their results in all federally funded programs. Use of performance measures is a good public health practice and was also recommended by the Institute of Medicine in its two studies of the

status of public health in America. GPRA also requires comprehensive strategic plans, annual performance plans with measurable goals and objectives, and annual reports on actual performance compared to performance goals. The MCHB guidance fulfills all of the requirements of GPRA and assures that the states meet those requirements through the MCH Block Grant application and annual report. However, the performance and related outcome measures are not a comprehensive representation of the entire scope of the Title V program within any given state. The national performance

and related outcome measures were selected because they are actionable by Title V programs, they relate to existing national data sources, and the program results can be quantified or measured. The state initiated evidence-based or -informed strategy measures allow the state to track progress based on programmatic investments designed to impact selected national performance measures. The state selected state performance and optional outcome measures address a state's unique needs that surface as a result of the needs assessment. A priority in one state may not be a priority in another state; allowing states to identify additional performance and optional outcome measures ensures flexibility. There are a number of systems building activities that the block grant conducts that are difficult to measure - the quality and extent of interagency collaboration, for example. Because the application limits the number of performance and outcome measures that can be submitted, there will always be state programs that will not be included in the application. It is important that you include descriptions of these programs in the report and application narrative to demonstrate the full range of the Title V program.

In early 2015 MCHB released new guidance for the Title V Block Grant. Changes in the nation's public health care systems, population demographics, health care financing systems and information technology have created new opportunities for improving access to health care and delivering quality public health services to the nation's MCH population, which includes women, mothers, infants, children, adolescents, CSHCN and their families. The transformative changes will facilitate an increased alignment of State Title V program efforts with other MCHB investments and to demonstrate the vital leadership role that state Title V programs provide in assuring and advancing public health systems that continually assess and readily respond to changing MCH population needs. With this new guidance the Bureau implemented a transformed national performance measurement framework intended to show more clearly the Title V contributions on health outcomes while still maintaining flexibility for the states. The new national performance measurement framework includes a three-tiered performance measurement system, which includes the following measure categories: National Outcome Measures (NOMs), National Performance Measures (NPMs) and State-initiated Evidence-based or -informed

Strategy Measures (ESMs). This revised framework focuses on a set of population-based measures which use state-level data derived from national data sources and where state Title V programs track prevalence rates and work towards demonstrated impact.

NATIONAL PERFORMANCE MEASURES (NPMs)

There are fifteen NPMs covering six MCH population domains: 1) Women's/Maternal Health; 2) Perinatal/Infant's Health; 3) Child Health; 4) Children with Special Health Care Needs; 5) Adolescent Health; and 6) Cross-cutting or Life Course. In the following table are the fifteen NPMs and the corresponding MCH Population Domains.

Table: National Priority Areas, Performance Measures, and Population Domains

NPM#	National Performance Priority Area (Measure)	MCH Population Domains
1	Well-woman visit (percent of women with a past year preventive medical visit)	Women/ Maternal Health
2	Low-risk cesarean delivery (Percent of cesarean deliveries among low-risk first births)	Women/ Maternal Health
3	Perinatal regionalization (Percent of very low birth weight – VLBW – infants born in a hospital with a Level III+ Neonatal Intensive Care Unit- NICU)	Perinatal/ Infant Health
4	Breastfeeding (A. Percent of infants who are ever breastfed and B. Percent of infants breastfed exclusively through 6 months)	Perinatal/ Infant Health
5	Safe sleep (Percent of infants placed to sleep on their backs)	Perinatal/ Infant Health
6	Developmental screening (Percent of children, ages 10 through 71 months, receiving a developmental screening using a parent-completed screening tool)	Child Health
7	Injury (Rate of hospitalization for non-fatal injury per 100,000 children ages 0 through 9 and adolescents ages 10 through 19)	Child Health and/or Adolescent Health
8	Physical activity (Percent of children ages 6 through 11 and adolescents ages 12 through 17 who are physically active at least 60 minutes per day)	Child Health and/or Adolescent Health
9	Bullying (Percent of adolescents, 12 through 17, who are bullied or who bully others)	Adolescent Health
10	Adolescent well-visit (Percent of adolescents, ages 12 through 17, with a preventive medical visit in the past year)	Adolescent Health
11	Medical home (Percent of children with and without special health care needs having a medical home)	Children with Special Health Care Needs
12	Transition (Percent of adolescents with and without special health care needs who received services necessary to make transitions to adult health care)	Children with Special Health Care Needs
13	Oral health (A. Percent of women who had a dental visit during pregnancy and B. Percent of children, ages 1 through 17, who had a preventive dental visit in the past year)	Cross-cutting/ Life course
14	Smoking (A. Percent of women who smoke during pregnancy and B. Percent of children who live in households where someone smokes)	Cross-cutting/ Life course
15	Adequate insurance coverage (Percent of children ages 0 through 17 who are adequately insured)	Cross-cutting/ Life course

States are required to select eight of the possible fifteen NPMs; selection should be based on priority areas identified in states' needs assessments.⁴⁶ There are no mandatory NPMs; however states must ensure that at least one NPM from each of the six MCH population domains is selected.

NATIONAL OUTCOME MEASURES (NOMS)

Each NPM has one or more corresponding National Outcome Measures (NOMs; for a table that shows which NOMs align with specific NPMs (see pgs. 21-25 in the Appendix of Supporting Documents for the Guidance for the Title V Block Grant). NOMs are included in the measurement framework for population health assessment and should be tracked to understand the MCH population's health. Changes in NOM indicators can be discussed in the appropriate population domain section of the narrative but there is not a reporting requirement for this discussion. Data for NOMs will be pre-populated by MCHB where possible. States do not provide performance objectives for NOMs.

STATE-INITIATED EVIDENCE-BASED OR -INFORMED STRATEGY MEASURES (ESMS)

State initiated evidence-based or -informed strategy measures (ESMs)

are the measures by which states will directly measure their impact on the NPMs. State-specific and actionable, the ESMs seek to track a state Title V program's strategies and activities and to measure evidenced-based or evidenced-informed practices that will impact individual population-based NPMs. The ESMs are developed by the state, and they provide accountability for improving quality and performance related to the NPMs and to the MCH public health issues for which they are intended. States should work closely with family/consumer partnerships as they develop the ESMs for their selected NPMs. The purpose of the ESMs is to identify state Title V program efforts which can contribute to improved performance relative to the selected NPMs. Most issues in MCH are multifactorial; therefore, while states are strongly encouraged to develop multiple strategies with a related ESM for each strategy to impact a selected NPM, states are required to submit at least one ESM for each of the NPMs selected. For the 2015-2020 Title V Block Grant, states and jurisdictions will develop ESMs for submission with their Year 02 Application/Annual Report (i.e., FY 2017/FY 2015) due in July 2016. For assistance in developing evidence-based or -informed strategies, and ESMs, the table below contains technical assistance contacts organized by NPM.

STATE PERFORMANCE MEASURES (SPMS) AND OPTIONAL STATE OUTCOME MEASURES (SOMS)

In addition to the selected NPMs, states will develop between three and five State Performance Measures (SPMs) to address its unique MCH needs to the extent that these needs are not addressed by the national measures and ESMs. Determination of the SPMs should be based on the findings of the Five-year Needs Assessment. States will identify the established three to five SPMs as part of the second year Application/Annual Report (i.e., FY 2017/2015.) In addition, they will establish performance objectives for each of the SPMs. Annual reporting of performance data for the SPMs will begin with the submission of the FY 2016 Annual Report. A state may also develop (but is not required to develop) one or more State Outcome Measures (SOMs) based on the MCH priorities determined as a result of the Five-year Needs Assessment, provided that none of the NOMs address the same priority area for the state. If developed, a SOM should be linked with a performance measure to show the impact of performance on the intended outcome. For any SOMs developed by the state, five-year performance objectives should be established for each of the reporting years.

The new guidance requires reporting on the MCH populations served and the activities provided by level of the MCH pyramid for 8 of the 15 NPMs, ESMs and SPMs and how they address the six MCH population health domains. As part of their first-year Application/Annual Report (i.e. FY2016/FY2014) and in follow-up to the Five-year Needs Assessment, states must develop an interim Five-year Action Plan Table. This table is intended to serve as a planning tool and organizational framework for states in developing a five-year Action Plan that aligns their planned Title V program strategies and activities with the identified priority needs and selected NPMs/SPMs. In the Year 02 Application/Annual Report (i.e., FY 2017/FY 2015), States will refine the objectives and strategies they identified in their interim Five-year Action Plan Table. The identified strategies should guide states in developing ESMs that address their selected NPMs. In

addition to refining their program objectives and strategies, States will insert the ESMs and the SPMs they develop in the Five-year State Action Plan Table that will be included in the second year (i.e., FY 2017/FY 2015) Application/Annual Report. The revised instructions for the state Title V MCH Block Grant Application and reporting process are built on the premise that state priority needs and national MCH priority areas will serve as the “drivers” for state reporting on the Five-year (and ongoing) Needs Assessment findings, the selection of NPMs to address state-identified priorities, the development of evidence-based or –informed strategies with ESMs to address state and national priority areas (as reflected in the NPMs selected for programmatic focus) and the establishment of SPMs to address the state’s unique needs.

The outcome measures should improve over time if the

performance measures and the activities to accomplish the measures were adequate. For public accountability, states must describe their accomplishments, current activities through their Five-year Action Plan in meeting the established performance objectives for each of the NPMs, ESMs and SPMs. It is your job as a Title V leader to ensure that your state’s data, budget and fiscal systems are able to meet these requirements.

Please note that this section of the Guide for Senior Managers represents an overview of the Title V Block Grant Performance and Outcome Measures, but as a Title V leader in your state, there is no adequate substitute for reading and regularly referencing the Title V Maternal and Child Health Services Block Grant To States Program Guidance.

To assist you, the table below contains information on where to find relevant sections in the Guidance:

Table: Performance and Outcome Measures in the Title V MCH Block Grant Guidance

Topic	Section Title in Guidance	Page numbers in Guidance
Overview of National Performance Measure Framework	“National Performance Measure Framework”	4 - 6
Five Year Action Plan Table	“Five Year Action Plan Table”	28-33
Alignment of NOMs with NPMs	“Appendix E: Performance Measure Framework”	21-25 (Appendix of Supporting Documents)
Stratifiers for NPMs	“Appendix E: Performance Measure Framework”	26-29 (Appendix of Supporting Documents)

SECURING ADDITIONAL FUNDS

Securing additional funds from the state budget, other state and federal agencies, SPRANS, CISS (Community Integrated Service Systems grants from MCHB), other federal agencies, foundations and philanthropic groups may be easier once you have a comprehensive needs assessment and priorities listing. You can “shop” some of the priority needs to complement the block grant funding. For example, if your priority listing shows that preschool children are not adequately screened for vision problems, you should talk with the Lions Club or other vision conservation groups about this issue. The result may well be an invitation to submit a grant application for funding a special project. The application should be easier to develop since you have the background information on what services are currently available, the need for new services, a measurable goal (performance measure), and some strategies on how to positively impact the situation. In this way, the MCH Block Grant application, annual plan and annual report are tools you can use to leverage additional funding sources to help you target and impact the state’s priorities.

OTHER THOUGHTS ABOUT SUCCESSFUL PLANNING

The Maternal and Child Health Services Block Grant provides the

opportunity to direct resources (human, fiscal and technical) to significantly improve the health of the target populations. The critical importance of having a thoroughly researched needs assessment and a strategic plan cannot be overemphasized. Without a well-documented plan and assignment of all resources to fulfill that plan, you will be challenged in warding off inappropriate demands and requests for funding unrelated activities. Block grant funds are flexible but only within the parameters previously described in this guide. Because the funds are flexible, they could be targeted to “cover” budget shortfalls in other program areas that are unrelated to the MCH plan. Your best defense against inappropriate use of these funds is to update your strategic plan annually.

- Develop a strong management team to work closely with you in all aspects of block grant administration. An outstanding leader recognizes his shortcomings and recruits team members with expertise in those areas. Spend time developing strong working relationships and teamwork, preferably in off-site retreats. Meet with the management team regularly and listen to their recommendations before making final decisions.

- Visit local health agencies and providers of MCH/CYSHCN services to see the programs in operation and become familiar with their issues.
- Include all stakeholders (staff, advocates, families, other agencies) in the block grant application, needs assessment and strategic planning process from the very beginning. It ensures their buy-in and improves the chances that the block grant will actually become a working document that staff use to guide their daily work.
- Build support for the Title V programs within your home agency as well as with other key stakeholder agencies and organizations. This means that you need to personally meet with and develop close working relationships with the leaders of key programs (e.g., SCHIP, Medicaid, early intervention, bioterrorism and emergency preparedness, prevention and primary care programs). Be sure you understand what other agencies do, and what they expect from Title V programs. Be an effective collaborator.
- Anticipate what the “hot” issues will be and secure the support of your agency’s leadership before the plan is released to the public. State health officers do not like to be blind-

Your best defense against inappropriate use of these funds is to update your strategic plan annually.

- sided. Respect their leadership position and the political environment of public health, and give them the opportunity in advance to have their say about a controversial issue that may surface. Be proactive.
- Distribute the block grant widely. Remember that others don't know what your program

does, and this is one way to share that information. It also helps to remind everyone of their assignments in carrying out the strategies in the plan.

- Be sure that you have built accountability into the plan. Program activities, performance measures and capacity indicators should have time

frames. Be certain that someone is assigned to each activity as well as to conduct a regular review of the plan's status.

- Allow for occasional deviation from the annual plan. Make note of the deviations for use in future annual reports.
- Evaluate the planning process by regularly getting feedback



from those involved in the block grant application. Was the process adequate? What could be improved? Are enough resources being directed toward a performance measure or priority issue? These are all questions that will help you improve the next cycle of planning.

- Celebrate completion of the application and celebrate achievements. It may seem like a simple idea, but ignoring accomplishments can encourage staff apathy, skepticism or cynicism. Don't skip this step—make it fun!

MANAGEMENT OF BUDGET RESOURCES

Mastering the budget may not seem very interesting; however, it is one of the most important aspects of your job. You must master your budget to be a successful MCH leader, administrator and manager. That means that you must be aware of how much funding you have remaining at all times to make adjustments in your spending as necessary throughout the budget year to ensure that you are doing everything possible to meet the MCH/CYSHCN priorities. You will find it helpful to require the budget staff to notify you when programs are either significantly over or under spending on a line item.

If your budget and expenditures don't reflect the needs assessment data and subsequent priorities, then they have not really been made a priority. Your number one priority should be reflected in the budget. The rank order of all data-driven priorities should be obvious when looking at the budget and expenditures.

It may take you a year or more to plan and carry out the realignment of budget items to reflect the newest needs assessment data and priorities. If you find that priorities have changed and you need to shift fiscal resources accordingly, you should make those changes only after providing adequate notice to those who will be impacted directly. Most people will more easily accept a funding cut if given enough time to adjust their services or spending levels so that they can avert their own fiscal crisis. In your job, surprise cuts in funding will nearly always result in major complaints to the agency director, legislators, governor and the media, as well as affected families - in short, a public relations nightmare. When budget realignments are necessary, don't forget to keep the state agency's leaders informed about your plans and obtain approvals as appropriate. Often there is political "fallout" from budget shifts that can be softened with advanced preparation of state agency leaders,

legislators, the governor's office and advocacy groups.

The amount you keep set aside for this purpose will vary based on your past experience and the total amount of funds available. Having unbudgeted funds can avert or soften mid-year program cuts when you have no choice but to meet unplanned demands on your budget caused by emergencies or unforeseen circumstances. Keep in mind that having a cushion of funds has a down side and may work against you when the agency experiences a fiscal crisis and "sweeps up" all unexpended funds. Your duty is to ensure that fulfilling agency demands does not compromise the purpose and intent of the block grant. Keep in mind that the block grant is flexible funding within broad parameters, but there are limitations to the use of these funds that must be maintained and assured. The state's leadership has a right to expect, and will respect, your honest attempts to justify use of block grant funds to meet their special budget demand. But if the funding demand is an inappropriate use of these federal funds, it is your responsibility to share that information with the agency's leaders. NEVER agree to an inappropriate use of funds regardless of who issues the order. To be certain that you have interpreted the block grant

requirements correctly, discuss the proposed use of funds with your federal MCHB project officer first. If you cannot prevent inappropriate use of Title V funds, then at least keep a detailed paper trail in a safe location documenting your efforts to inform the state leadership that the desired use of funds is inappropriate.

As you gain knowledge and experience with the budget processes for your state or jurisdiction, you will become an expert in planning for expected budget cuts, quickly dealing with an unexpected influx of funds needing to be encumbered or expended on a short timeframe, or other fiscal challenges tossed your way. For example, it is possible, albeit complicated, to plan the interplay of your state and federal budgets to soften cuts in either source. Because state and federal funds are normally on different fiscal years, using one fund to shore up the other will only be a temporary “fix” for one budget cycle. And this “fix” will only work if there is either

no restriction on the use of the funds or you have carefully selected the program area to ensure that it is an appropriate expenditure. Simultaneous mid-year cuts in both state and federal funding will wreak havoc with all budget plans. In coping with fiscal crises, ask for help from your staff managers, fiscal officers, agency leaders and even your Title V peers in other states who may have faced similar budget problems. They can help you analyze the impact and various options. Giving careful thought before making your final decision is time well spent. Remember that you are not alone when it comes to managing the fiscal resources of the Title V programs.

Tips for Successful Budget Management

- Meet with the MCH/CYSHCN financial officer and the state health agency budget director. Learn about funding sources, available discretionary funds, and current budget initiatives for MCH programs and the state health agency.
- Meet with the state health agency director and deputy director. Learn where MCH programs fit into overall agency budget priorities and how they support the agency's initiatives.
- Understand the budget process and the budget calendar(s). Learn the key state laws and regulations governing budgeting and expenditures, as well as the state health agency's policies and procedures.
- Learn your agency's financial monitoring system.

“Your budget is your policy statement.”

Eileen Forlenza, Director, Family Leadership Initiative, Colorado Department of Public Health and Environment

- Understand your responsibility for managing the MCH budget from all funding sources throughout the year. You are accountable for implementation of program budgets. Know your state mandated role for budgeting and fiscal management.
- Expect to prepare materials in support of MCH budget requests (including expansions or justification for maintenance of current funding levels, impact of cuts, etc.) for state health agency officials to use in public budget hearings, meetings with state legislative leadership, the governor's office and advocacy groups. Be prepared to attend meetings and offer budget testimony or answer questions if requested.
- Participate in agency meetings where MCH budgets will be discussed with the state health officer, the state budget director, legislative leadership, the governor's office and key advocacy organizations.
- Identify issues that are a high priority to constituencies, the legislature, the governor and the state health agency leaders and address these to the extent possible in accordance with state agency policies in budget requests and justifications.

- Identify partners and outside support for the MCH budget from advocacy groups, other state or federally funded programs, other agencies and professional associations.
- Understand the state fiscal situation (i.e., shortfalls or surplus) and its impact on MCH and CYSHCN programs.
- Understand the impact and extent of federal funding supporting MCH/CYSHCN programs. As the state Title V director, you are responsible for your state's compliance with the block grant requirements. You must be completely familiar with your block grant budget request, any changes to the budget, expenditures and justification for the budget.
- Understand the usefulness of audits.

RESOURCES

Maternal and Child Health Bureau. Title V Information System. Retrieved from <https://perf-data.hrsa.gov/MCHB/TVISReports/>

Maternal and Child Health Bureau. Discretionary Grant Information System. Retrieved from <https://perf-data.hrsa.gov/MCHB/TVISReports/>

Needs Assessments

Association of Maternal and Child Health Programs. (2014). Title V Five Year Needs Assessment Training. Retrieved from https://amchp.adobeconnect.com/_a838359725/p7mr6qk70ds/?launcher=false&fcsContent=true&pbMode=normal

Donna J. Petersen and Greg R. Alexander (2001). *Needs Assessment in Public Health: A Practical Guide for Students and Professionals*. New York, NY: Kluwer Academic/Plenum Publishers.

Maternal and Child Health Bureau. (2009). MCH Needs Assessment Training. Retrieved from <http://webcast.hrsa.gov/conferences/mchb/partnership2009/needs.htm>

Maternal and Child Health Bureau (2006). *From Needs Assessment to Strategic Action: The Important Journey*. Retrieved from <http://webcast.hrsa.gov/conferences/mchb/needs2006/index.htm>



CHAPTER 10

Workforce Development Resources

WHAT IS THE PURPOSE OF WORKFORCE DEVELOPMENT?

The public health system in the United States has undergone major changes over the last several years. Enduring budget cuts, deficits and hiring freezes and implementation of the ACA, in particular, have affected the skills and knowledge needed by the public health workforce to effectively meet the needs of children, families and communities they serve. While the new face of public health certainly brings changes and challenges, it also brings opportunities for MCH programs to strengthen workforce competency. This section identifies resources that are available to states to assist in providing professional development for the MCH workforce. With the transformation of the Title V Block Grant and MCH workforce development capacity now a component of your Block Grant this chapter is a one stop shop for just some of the resources available to you.



NATIONAL MCH WORKFORCE DEVELOPMENT CENTER

The National MCH Workforce Development Center at the University of North Carolina (UNC), Chapel Hill in cooperation with MCHB, and in partnership with AMCHP and national experts in MCH innovation and quality improvement offer state and territorial Title V leaders training, collaborative learning, coaching, and consultation in implementing health reform using a variety of learning platforms. The Center has tools and resources to strengthen MCH capacity and skills in the following four core areas to move from evidence to action:

- Improving access to care
- Using quality improvement tools to drive transformation

- Fostering integration within public health and across sectors including primary care, mental health, early intervention and community based service delivery and financing systems
- Furthering change management, including effective collective action skills that will lead health improvement for MCH populations.

Key features of the Center include:

- Ongoing assessment, monitoring, and forecasting of state and territorial Title V program readiness and implementation status relative to health reform
- Three levels of training and technical assistance

- Universal, for all Title V staff and MCH trainees related to the four core areas
- Targeted, for self-selected Title V staff and partners
- Intensive, for an annual cohort of states/territories
- Virtual training (live and self-paced) using the AMCHP collaborative learning technology with upgraded capacity for online social networks and communities of practice. (www.amchp.org/transformation-station)

Another excellent component of the Center is the Pipeline Program. This program was designed to enhance training and networking opportunities for graduate and undergraduate students in MCH Leadership Training Programs. By providing Pipeline participants with the tools to effectively serve the MCH population within the context of health reform and the ACA, the Center will advance the capacity of the Title V workforce to implement policies, programs, and systems that optimize the health and well-being of women, children and families.

MCH NAVIGATOR

The MCH Navigator at Georgetown University (GU) is funded by MCHB and serves as a learning portal for maternal and child health professionals, students, and others working to improve the health and well-being of women, children and families. This platform provides a searchable Web-based resource inventory of learning opportunities that catalogues the content and skills addressed by each training in the collection. It provides assessment tools and learning guides to assist learners in addressing their strengths and weaknesses in leadership competencies and offers access to trainings to address needs.

The MCH Navigator project was launched by MCHB in early 2010 as a game-changing tool for online, interactive professional development for the MCH workforce. In 2013, Georgetown University was awarded a cooperative agreement from MCHB to continue and expand on this work. At a time of increased training needs and diminished state and local public health budgets, the MCH Navigator is necessary to connect the workforce to online training resources into action. To explore the website please visit www.mchnavigator.org.

HRSA TRAIN

The TrainingFinder Real-time Affiliate Integrated Network (TRAIN) is the nation's premier learning resources for professionals who protect the public's health. TRAIN is comprised of the national www.train.org site and participating TRAIN affiliate sites. Affiliate sites are managed by state public health agencies, academic partners and others. As TRAIN grows, it serves a larger portion of the U.S. public health workforce.

Because all TRAIN sites are connected, TRAIN users can access information about state, local, national or international training available to them through any participating TRAIN site.

Learners can use TRAIN to:

- Search or browse the nationwide database for on-site or distance learning courses
- Sign up for e-mails about new courses
- Create a personal learning record of competency-based training
- Provide and view feedback about courses listed on the site
- Register online for many courses
- Earn CEUs (often at no cost)

Train is a project of the Public Health Foundation with a grant from The Robert Wood Johnson Foundation and funding from CDC.

AMCHP LEADERSHIP PROGRAMS

Leadership Institute for CYSHCN Directors (LICD)

The LICD is a 16-month program (November-February) for CYSHCN directors to help develop leadership skills at the state and national level. The overall goal of the program is to strengthen systems of care serving CYSHCN by establishing a sustainable, connected network of CYSHCN directors. The LICD allows CYSHCN directors to consult each other as they lead and transform CYSHCN programs during health reform.

Program components of the LICD include: two face-to-face CYSHCN directors meetings at two AMCHP Annual Conferences; an invitation-only listserv exclusively for CYSHCN directors; ongoing peer learning and peer coaching; and a series of bi-monthly webinars targeted to the needs of CYSHCN directors.

If you have questions or would like additional information about the program, please contact Treeby Brown at tbrown@amchp.org or Meredith Pyle at mpyle@amchp.org.

New Director Mentor Program (NDMP)

The NDMP is part of the AMCHP workforce and leadership development efforts to support a diverse, effective and competent workforce in state and territorial Title V programs. The AMCHP philosophy for leaders and developing leaders is transparent. AMCHP believes that leaders can be developed by enhancing natural ability with learned skill development – through formal and informal learning opportunities, experience, dialogue, role modeling, feedback, mentoring and coaching, and more. The NDMP requires an 18-month commitment by the participants from February through August. During the program year, participants are matched with a mentor and are charged with crafting an individual development plan, participating in quarterly webinars, an invitation-only listserv, and peer-to-peer calls. The primary audience for the program is new Title V administrators (Title V, MCH or CYSHCN directors or senior reports) who have been serving in this capacity for three years or less. The three primary goals of the NDMP are: 1) Acclimating new directors to their new roles, 2) Connecting new directors with supportive mentors, resources and the broader MCH community, 3) Developing MCH leaders.

If you have questions regarding the program or would like additional information, please contact Jessica Teel at jteel@amchp.org.



APPENDIX A

The Making of this Guide

AMCHP began developing this guide for new state MCH and CYSHCN leaders in March 2003. AMCHP, responding to the increasing turnover of leadership positions in the field, views this guide as complementing other initiatives, such as the AMCHP mentor program for new directors and CAST-5, as well as the federal MCHB New Leaders orientation meeting and Partnership meeting. To author this guide, AMCHP contracted with two senior consultants with state Title V experience. Kathy Peppe, RN, MS, is former director of the Ohio Division of Family and Community Health

Services and past-president of AMCHP. Catherine Hess, MSW, is a former AMCHP executive director and previously was policy director for the Massachusetts Division of Family Health Services. A focus group of newer and more seasoned Title V leaders, academic and family representatives also assisted in developing this guide.

As the first step in developing this guide, the authors contacted 25 associations representing public officials or administrators, primarily at the state level, to determine if they had developed similar guides for their members. The associations

that we contacted included:

- National Governors' Association
- National Conference of State Legislatures
- Association of State and Territorial Health Officials
- 20 associations of state health agency component programs or disciplines (ASTHO affiliates)
- National Association of County and City Health Officials
- American Public Human Services Association that includes welfare, child welfare and Medicaid directors

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- National Association of State Alcohol and Drug Abuse Directors
- National WIC Association
- National Family Planning & Reproductive Health Association (formerly State Family Planning Directors' Association)
- National Network of State Adolescent Health Coordinators (formerly the State Adolescent Health Coordinators Network)

Additionally, we reviewed some of the materials from the two continuing education institutes funded by MCHB to develop the knowledge and skills of state Title V staff – the CYSHCN Continuing Education Institute (ended a number of years ago) and the MCH Leadership Skills Training Institute. The latter continues to provide two institutes annually, one focused on planning and one on systems. Neither of these institutes has produced formal, written material specifically designed to orient new directors to their positions, but they have produced some very relevant resources.

Finding means to orient new personnel in state leadership positions struck a common chord throughout the 25 organizations that we contacted. In addition to AMCHP, 11 of the 25 organizations

responded that they had developed either orientation or mentoring materials or programs for new leaders. Five of these organizations actually have developed formal written materials (ASTHO, SAHCN, NCSL, NGA and the National Association of EMS Directors). One organization (NASADAD) was preparing a written guide for new state substance abuse directors at the time of our contact. Two additional organizations have plans to develop guides in the near future, and two more organizations have prepared informal materials (e.g., case studies) for use during orientation training sessions. Finally, one organization, the Association of State and Territorial Dental Directors, developed a new director mentor program modeled on the AMCHP mentor program. The AMCHP program looks to the mentor and new director to shape specific learning objectives for a two-day site visit using the MCH core functions as a framework.

The scan we made of other similar organizational efforts to orient new state leaders was extremely useful to us in informing the content for this guide. The findings from the half dozen associations that shared written material with us fell into six main categories:

- Understanding the position and what is the same and what varies across states

- Tips on key challenges and issues that arise
- Skills needed for positions
- Content knowledge needed for positions
- Key players and how to work with them
- Resources for further assistance

Generally, materials designed for higher level elected and appointed officials tended to focus on tips, addressing skills and key players at very general levels. Materials for program managers tended to provide more skill and content knowledge and were more specific about key players and resources.

The information gleaned from the first step in the process of developing this guide was shared with a focus group that we invited to participate. Eleven persons agreed to be members of the group, representing a mix of Title V leaders with less than three years experience in the job, Title V leaders with five or more years experience in the job, a family representative and two academic representatives with previous state Title V experience and AMCHP leadership experience. Besides the 11 able to participate in a meeting, three new Title V leaders agreed to provide feedback through electronic communication. The final list of participants provided a nice

mix of representation from MCH, CSCHN, many of the HHS regions, and the AMCHP Board of Directors. A list of focus group participants is in the appendices of this guide.

We conducted a focus group meeting in Scottsdale, Arizona, on Apr. 29, 2003. All 11 focus group members and a staff member from AMCHP attended the one-day meeting. The purpose of the meeting was to discuss the need for a guide for new state Title V leaders, its possible use and format, and potential content. Prior to the meeting in Scottsdale, we shared a copy of the results of our analysis of all similar guides obtained from other associations. Participants were asked to read this material prior to attending the focus group meeting. We also shared hard copies and presentations of materials from other organizations with focus group participants during the meeting.

During its meeting, the focus group reached consensus on the target audience for the guide, the primary uses of what it decided to call a “toolbox,” the major content categories, and related suggestions for MCHB and AMCHP. The group recommended that:

- The target audience consist of the senior managers responsible for Title V MCH and CYSHCN, which will vary state by state

- The material be conceptualized as a “toolbox” that might be part of a “leadership library” that MCHB or AMCHP might consider building
- The material be disseminated and marketed not just at completion of the tool, but on an ongoing basis through existing channels such as MCHB and AMCHP meetings and regional structures
- The content be organized around major leadership roles. Some major leadership roles were suggested with the understanding that we would investigate common categories used in the leadership literature

The focus group confirmed and validated the perceived need and value of this tool for new leaders in Title V. A number of participants in the group commented that the meeting led them to rethink how they approached their positions and had generated new energy for tackling the challenges at home.

Following the focus group meeting, the authors prepared a draft document that was shared with AMCHP staff and the focus group members. On Sept. 4, 2003, a conference call was conducted to review the draft document and receive suggestions for improving the final product. Additionally, tips and quotes were obtained from

focus group members to sprinkle throughout the text of this guide. We have purposefully kept the tone of the document informal and friendly because we wanted to impart to the reader the feeling that this guide is friendly advice from those who have walked the same path. Most of all, we wish the new senior managers of the Title V Maternal and Child Health Services Block Grant great success in their mission to wisely administer these vital public health programs.

Catherine Hess, MSW

Kathy Peppe, RN, MS

February 2004

APPENDIX B

Revisions of Guide

In 2013, the AMCHP Workforce and Leadership Develop Committee included the task of revising this guide in their Committee work plan. The Workforce and Leadership Development Committee (WDC) is one of the AMCHP organizational committees. The WDC develops strategies that will benefit how Title V staff carry out their daily duties. Some examples include identifying the issues the states are facing with respect to recruitment, training, and retaining staff. This committee leverages resources from across the country to assist the Title V staff in addressing common issues such as training, technical assistance, data assessment and professional development. To

accomplish this task of revising the guide a subcommittee was established representing committee members and Title V leaders to work on the revisions to the guide. The subcommittee reviewed the guide and identified the revisions. Based on subcommittee input the following new sections were recommended.

- ACA Impact on Title V
- Family/Consumer Engagement
- Data Sources and Techniques
- Workforce Development Resources

AMCHP staff incorporated the subcommittee recommendations in the latest revisions of the guide.

APPENDIX C

Focus Group Meeting for Development of a Manual for New Title V Directors

APRIL 29, 2003 - SCOTTSDALE, AZ

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APPENDIX D

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APPENDIX E

Work Cited

¹ U.S. Department of Health and Human Services. *Will I qualify for lower costs on monthly premiums?* <https://www.healthcare.gov/will-i-qualify-to-save-on-monthly-premiums/>.

² Henry J. Kaiser Family Foundation. *Status of State Action on the Medicaid Expansion Decision.* <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/>. Accessed March 16, 2015

³ Henry J. Kaiser Family Foundation. *The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid – An Update.* <http://kff.org/health-reform/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid-an-update/> Accessed March 16, 2015

⁴ Kaiser Family Foundation. *Women's Health Insurance Coverage.* Dec. 10, 2014. <http://kff.org/womens-health-policy/fact-sheet/womens-health-insurance-coverage-fact-sheet/> (Accessed March 17, 2015).

⁵ The U.S. Department of Health and Human Services. *About the Law: Children's Preexisting Conditions.* (accessed Mar. 16, 2015) <http://www.hhs.gov/healthcare/rights/pre-existing/pre-existing-conditions.html>.

⁶ The U.S. Department of Health and Human Services. *About the Law.* (Accessed Mar. 26, 2015) <http://www.hhs.gov/healthcare/rights/limits/>

⁷ The U.S. Department of Health and Human Services. *About the Law.* <http://www.hhs.gov/healthcare/insurance/premiums/rate-review.html>

⁸ U.S. Department of Health and Human Services. Centers for Medicare and Medicaid Services. *Benefits.* (Accessed Mar. 22, 2015) <http://www.medicaid.gov/AffordableCareAct/Provisions/Benefits.html>.

⁹ U.S. Department of Health and Human Services. *Preventive Health Services for Adults* (Accessed Mar. 23, 2015) <https://www.healthcare.gov/what-are-my-preventive-care-benefits/>.

¹⁰ U.S. Department of Health and Human Services. *About the Law. Preventive Services Covered under the Affordable Care Act.* (Accessed Mar. 23, 2015). <http://www.hhs.gov/healthcare/factsheets/2010/07/preventive-services-list.html>.

¹¹ U.S. Department of Health and Human Services. *About the Law. Preventive Health Services for Adults.* (Accessed Mar. 23, 2015) <https://www.healthcare.gov/what-are-my-preventive-care-benefits/>.

¹² U.S. Department of Health and Human Services. About the Law. Preventive Services Covered under the Affordable Care Act. (Accessed Mar. 23, 2015) <http://www.hhs.gov/healthcare/facts/factsheets/2010/07/preventive-services-list.html>.

¹³ Ibid

¹⁴ Clinical Preventive Services for Women: Closing the Gaps. Washington, DC: Institute of Medicine. July 2011.

¹⁵ Ibid

¹⁶ Henry J. Kaiser Family Foundation. State Coverage of Preventive Services for Women under Medicaid: findings from a State-Level Survey. November 2012 <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8330.pdf> (Accessed March. 23, 2015).

¹⁷ Ibid

¹⁸ Ibid

¹⁹ Ibid

²⁰ Kaiser Family Foundation. Women's Health Insurance Coverage. December 2014. <http://files.kff.org/attachment/fact-sheet-womens-health-insurance-coverage> Accessed Mar. 23, 2015.

²¹ Ibid

²² Kaiser Women's Health Survey. Washington, DC: Henry J. Kaiser Family Foundation. May 2011.

²³ Anne Rossier Markus, Ellie Andres, Kristina D. West, Nicole Garro, Cynthia Pellegrini. Medicaid Covered Births, 2008 Through 2010, in the Context of the Implementation of Health Reform. *Women's Health Issues* - September 2013 (Vol. 23, Issue 5, Pages e273-e280, DOI: 10.1016/j.whi.2013.06.006).

²⁴ Kaiser Family Foundation. Women's Health Insurance Coverage. December 2014. <http://files.kff.org/attachment/fact-sheet-womens-health-insurance-coverage> Accessed Mar. 23, 2015.

²⁵ Kaiser Family Foundation. Women's Health Insurance Coverage. December 2014. <http://files.kff.org/attachment/fact-sheet-womens-health-insurance-coverage> Accessed Mar. 23, 2015.

²⁶ Kaiser Family Foundation. Women's Health Survey. Washington, DC. May 2011.

²⁷ Ibid

²⁸ Federal Register. (August 2013). Shared Responsibility Payment for Not Maintaining Minimum Essential Coverage. Retrieved from: <https://www.federalregister.gov/articles/2013/08/30/2013-21157/shared-responsibility-payment-for-not-maintaining-minimum-essential-coverage#h-20>

²⁹ Centers for Medicare and Medicaid Services. (November 2014). Letter to State Health Officials & Medicaid Directors, Re: Minimum Essential Coverage. Retrieved from: <http://www.medicaid.gov/federal-policy-guidance/downloads/sho-14-002.pdf>

³⁰ United States. Department of Health and Human Services Health Resources and Services Administration. *Women's Preventive Services Guideline* Health Resources and Services Administration. (accessed March 23, 2015)<http://www.hrsa.gov/womensguidelines/> .

³¹ United States. Department of Health and Human Services Centers for Medicaid and CHIP Services. *Medicaid Coverage of Lactation Services*. Web. September 2013.

³² Ibid

³³ U.S. Department of Labor. Wage and Hour Division. *Break Time for Nursing Mothers*. <http://www.dol.gov/whd/nursingmothers/> (Accessed Mar. 23, 2015).

³⁴ U.S. Department of Health and Human Services. Center for Medicaid and CHIP Services. *Model Eligibility Application and Guidance on State Alternative Applications*. (accessed March 23, 2015) <http://www.medicaid.gov/federal-policy-guidance/downloads/CIB-04-30-2013.pdf> .

³⁵ Ibid

³⁶ Families USA. *Maintenance of Effort Requirements Under Health Reform*. March 2010. (Accessed Mar. 23, 2015) http://familiesusa.org/sites/default/files/product_documents/maintenance-of-effort.pdf.

³⁷ U.S. Department of Health and Human Services. Healthcare.gov. *Coverage for Pre-existing Conditions*. (Accessed Mar. 25, 2014) <https://www.healthcare.gov/what-if-i-have-a-pre-existing-health-condition/> .

APPENDIX E

³⁸ U.S. Federal Registry. Federal Register Volume 75, Number 123 (Monday, Jun. 28, 2010)] (Accessed Mar. 23, 2015) <http://www.gpo.gov/fdsys/pkg/FR-2010-06-28/html/2010-15278.htm>.

³⁹ U.S. Department of Health and Human Services. Healthcare.gov. *Rights & Protections*. (Accessed Mar. 23, 2015) <https://www.healthcare.gov/how-does-the-health-care-law-protect-me/#part=9>.

⁴⁰ United States Department of Health and Human Services. Healthcare.gov. *Health Coverage for Children under 26* <https://www.healthcare.gov/can-i-keep-my-child-on-my-insurance-until-age-26/> (Accessed Dec. 3, 2013).

⁴¹ Kaiser Family Foundation. *Women's Health Insurance Coverage*. Dec. 10, 2014. <http://kff.org/womens-health-policy/fact-sheet/womens-health-insurance-coverage-fact-sheet/> (Accessed March. 23, 2015).

⁴² Georgetown Center for Children and Families. *Foster Care Children and the Affordable Care Act*. July 2012. (Accessed Mar. 23, 2015) <http://ccf.georgetown.edu/all/foster-care-children-the-affordable-care-act-report-ccf-community-atalyst/>.

⁴³ The Catalyst Center. *The Affordable Care Act A Side-by-Side Comparison of Major Provisions and the Implications for Children and Youth with Special Health Care Needs*. <http://hdwg.org/sites/default/files/ACASidebyside-catalystctr.pdf> (Accessed Mar. 23, 2015).

⁴⁴ U.S. Department of Health and Human Services. Centers for Medicare and Medicaid Services. *Health Homes*. (Accessed Mar. 23, 2015) <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Integrating-Care/Health-Homes/Health-Homes.html>

⁴⁵ Ibid

⁴⁶ MCHB Title V MCH Services Block Grant to States Program Guidance and Forms for the Title V Application/ Annual Report, Seventh Edition (pg 26-27)

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