

# AMCHP Fact Sheet

## AMCHP Family Engagement Initiatives

### BACKGROUND

Family engagement plays an essential role in state Title V maternal and child health (MCH) programs. Family members volunteer, advise and/or are employed by state Title V MCH, and/or children and youth with special health care needs (CYSHCN) programs. They bring unique insight and experience, and are prepared to advocate on behalf of MCH. Family engagement refers to a range of activities that engage families in the planning, development, and evaluation of programs and policies at the community, organizational and policy level.

Families contribute invaluable insight and experience to AMCHP programs and policies. Families advise us on the development of publications and programs, serve on committees and advisory workgroups and the board of directors. Families also are a key audience for the AMCHP Annual Conference. In fact, families who attend the annual conference consistently praise the value of the conference as a way to network with other families and Title V programs, and to understand more clearly how Title V makes a difference in the lives of children, youth, families and communities. The purpose of this fact sheet is to highlight the variety of ways that AMCHP is engaging families across programs and policy activities.

### AMCHP ACTIVITIES

AMCHP engages families across the organization. These efforts fall into three main areas: organizational structure, leadership development, and program and policy activities. Throughout these areas, family leaders review and edit content for publications and trainings, provide the perspective of families, give feedback on new initiatives, brainstorm activities, facilitate engagement of other families within their networks, provide tools and resources, serve as content experts, and generally contribute their expertise as a family member or consumer.

### Organizational Structure

Family leaders are a part of critical elements of the infrastructure of the organization.

#### *Family Representatives on the Board of Directors and Committees:*

Families play a key role in shaping AMCHP programs and policies. At AMCHP, families advise on the development of publications and programs by serving on all of our committees and on the Board of Directors. To learn more about our committees and Board members, visit <http://www.amchp.org/AboutAMCHP/board/Pages/default.aspx>.

*Family Leader on Staff:* AMCHP recognizes the unique expertise that family leaders bring to issues affecting them and their loved ones, and support the model of family-professional partnerships. In 2009, AMCHP created a staff position specifically for a family leader. In this position, the family leader on staff acts as a liaison to other family leaders, works to

### About AMCHP

The Association of Maternal & Child Health Programs (AMCHP) is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs.

AMCHP members come from the highest levels of state government and include directors of maternal and child health programs, directors of programs for children with special health care needs, and other public health leaders who work with and support state maternal and child health programs. Our members directly serve all women and children nationwide, and strive to improve the health of all women, infants, children and adolescents, including those with special health care needs, by administering critical public health education and screening services, and coordinating preventive, primary and specialty care. Our membership also includes academic, advocacy and community based family health professionals, as well as families themselves.

AMCHP builds successful programs by disseminating best practices; advocating on our members' behalf in Washington; providing technical assistance; convening leaders to share experiences and ideas; and advising states about involving partners to reach our common goal of healthy children, healthy families, and healthy communities.

help ensure that the family voice is represented throughout AMCHP activities, and serves as one of the family leader representatives on behalf of the organization.

**Family Delegates:** Each Title V program paying dues may designate up to five delegates who have voting rights and the fifth delegate seat must be held by a family liaison to the Title V program. This delegate is called a 'Family Delegate.' The Family Delegate is an active advocate for all families in their state or 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 children and youth with special health care needs and it is the aim to have family representatives from all MCH programs. To learn more about the Family Delegate role, visit <http://www.amchp.org/programsandtopics/family-engagement/Pages/default.aspx>

**Family and Youth Leadership Committee:** The Family and Youth Leadership Committee (FYLC) works to advance the role of families in the design and creation of state, local and national health systems serving women and children, including children and youth with special health care needs. The Family and Youth Leadership Committee envisions that all families will be equipped to be effective leaders, advocates, and partners in health care and in their communities. Members of the FYLC support the work of AMCHP in a variety of ways, including serving as reviewers for family and youth applications and awards, presenting on webinars and virtual trainings for family leaders, writing articles for AMCHP publications, and creating state profiles of parent-led, family-focused, organizations.

## Leadership Development

Developing family leaders and helping them obtain the tools and resources they need to be active participants in the workforce is a main priority of AMCHP.

**Family Leader Support:** In response to direct requests from our members, AMCHP hosts bi-monthly webinars for Family Delegates and all family leaders on various topics identified as important to them through needs assessment data from these groups. Examples of past webinars include: changes and opportunities, adaptive leadership, and advocacy and education of elected officials at the local and national level. The webinars also provide a venue for family leaders to meet and network with each other.

**Leadership Lab, Family Leader Cohort:** For nearly 20 years, AMCHP has supported the development of maternal and child health leaders through formal and informal learning opportunities, experience, dialogue, feedback, peer-to-peer learning, mentoring, coaching, and more. To meet the expanding needs of Title V staff, AMCHP redesigned our approach to leadership development by launching the Leadership Lab. One of the most important aspects of the Leadership Lab is that it contains several cohorts: Directors, Epidemiologists, Next Generation Leaders and Family Leaders. This model builds on our prior Family Scholars program and gives family leaders the benefit of an individualized track to meet their unique needs while also providing integrated learning opportunities with all cohorts for more holistic leadership development. To learn more, visit the Leadership Lab website at <http://www.amchp.org/programsandtopics/WorkforceDevelopment/LeadershipLab/Pages/default.aspx>.

**Family Engagement Survey:** With support from the Lucile Packard Foundation for Children's Health and the Maternal and Child Health Bureau (MCHB), AMCHP launched a Title V family engagement survey in November 2014. The survey, which included an MCH and CYSHCN version, was designed to identify barriers, best practices, and roles of family leaders within Title V programs. Family leaders were involved in determining the elements, design and piloting of the survey. Currently, AMCHP is developing survey reports and case studies as part of a Web-based tool kit based on some of the results of the survey. Family leaders also reviewed and provided feedback on all of these products.

**Family Engagement Community of Practice (CoP):** In October 2015, AMCHP launched a Community of Practice (CoP) on Family Engagement. The goal of the AMCHP Family Engagement CoP is to increase Title V capacity to engage families in their work. The CoP provides a platform to share ideas, innovations, lessons learned, successes and best practices from subject matter experts. MCH and CYSHCN directors who expressed an interest in a CoP in response to the family engagement survey were invited to participate along with family leaders. The CoP officially launched in December 2015 with an orientation webinar.

***Family Engagement and Leadership Web Portal:*** AMCHP redesigned our family engagement Web page into an expanded Web portal for family engagement. The Web portal, which was designed based on requests, review and feedback from family leaders and Title V staff, includes new tabs for important information on family leadership, Family Delegates, state information, and tools and resources. To explore the Web portal, visit <http://www.amchp.org/programsandtopics/family-engagement/Pages/default.aspx>.

## **Program and Policy Activities**

Families are both engaged in the development of, and a target audience for, program and policy activities at AMCHP.

***Alliance for Innovation (AIM) Access:*** AMCHP works with states and a coalition including the American Academy of Pediatrics (AAP), Association of State and Territorial Health Officials (ASTHO), National Academy for State Health Policy (NASHP), National Conference of State Legislatures (NCSL) and National Governors Association (NGA). The focus is on these three areas: 1) Improving continuity of coverage and care for pregnant women and children, 2) Improving systems of care for CYSHCN, and 3) Implementing Bright Futures. With support from MCHB, AMCHP works with Family Voices to actively engage them in thinking on the process and to work with them to write an issue brief on family experiences in gaining access to health insurance in an era of rapid health reform.

***State Public Health Autism Resource Center (SPHARC):*** AMCHP's SPHARC, which is funded by MCHB, ([www.amchp.org/SPHARC](http://www.amchp.org/SPHARC)) is a comprehensive Web-based resource center intended to provide ongoing technical assistance and facilitate cross-state learning to increase the capacity of states, particularly Title V programs and HRSA state autism implementation and planning grantees, in developing and implementing systems of care for children and youth with autism spectrum disorders and other developmental disabilities (ASD/DD). SPHARC engages family leaders in developing and delivering technical assistance to help states improve systems of care through webinars, workshop presentations, peer-to-peer exchanges, etc. Family organizations also are recipients of the state autism grants (MD and NJ).

***The Return on Investment Analytic Action Learning Collaborative (ROI Analytic ALC):*** The ROI Analytic ALC, which is supported by the W.K. Kellogg Foundation, is a project that aims to conduct economic analyses of specific state MCH programs. In order to participate in the ROI Analytic ALC, applicants must assemble a diverse team of MCH program or policy staff, epidemiology staff, community partners, and/or additional state team members based on the MCH program being analyzed. Family leaders are encouraged as an additional state team member in order to provide input on the elements to include and factors to consider for economic analysis. For example, the Kansas state team included a family advisor who played a pivotal role in the survey design and data collection of direct and indirect costs to families for traveling to the seating clinics. To learn more about the ROI Analytic ALC projects, visit the AMCHP [Return on Investment Website](#).

***Action Learning Collaborative for the National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs:*** The overall goal of the *National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs* is to reach consensus among key national stakeholders on standards that would help state leaders transform and improve systems of care for CYSHCN. The second phase of this project focused on promoting the use and implementation of the National Standards to states by convening multidisciplinary state teams. AMCHP, with support from the Lucile Packard Foundation for Children's Health, brought together eight state teams that included representation from families and consumers who were instrumental in informing and guiding technical assistance and trainings to providers, payers, and health plan representatives.

***The AMCHP Every Mother Initiative:*** With support from [Merck for Mothers](#), the AMCHP Every Mother Initiative launched in 2013 to help states take specific and focused steps to reduce maternal mortality and severe morbidity. At its core, the Every Mother Initiative is about peer learning and mentorship. To facilitate this learning, AMCHP hosts 15-month Action Learning Collaboratives (ALCs), or multidisciplinary learning communities that come together to address a common public health issue. Every Mother ALCs aim to strengthen state maternal mortality review (MMR) capacity and support states in taking action based on MMR committee recommendations. States participating in the ALCs include families and consumers in the design and execution of their respective MMR data-to-action translation projects.

**Best Practices Replication Technical Assistance:** As part of an overall strategic goal to improve maternal and child health outcomes by sharing effective and promising practices with state and territorial MCH programs, AMCHP, with support from MCHB, awarded Washington State Department of Health and Minnesota Department of Health technical assistance (TA) awards of \$10,000 each to replicate the Emerging Practice *SPANS: Parent Leadership Development Program*. Award recipients will learn how to tracking trained parents, methods on outreach to underserved families, evaluation methods for training, curricula development, and much more.

**Best Baby Zone:** AMCHP, with support from the W.K. Kellogg Foundation, collaborates with the University of California-Berkeley, CityMatCH, and National Healthy Start Association on the Best Babies Zone (BBZ) Initiative to reduce infant mortality and improve health outcomes in four selected pilot cities in the United States. BBZ uses a comprehensive zonal approach to address four critical sectors – economics, education, health and community – in order to strengthen environments that support healthier outcomes. BBZ engages community members to become leaders in their respective cities and a social movement is cultivated within that city to do whatever it takes to improve birth outcomes in the zone.

**The National MCH Workforce Development Center:** AMCHP, in collaboration with The National MCH Workforce Development Center, has a family engagement workgroup. The group, which includes family leaders, develops and disseminates resources for family leaders to increase their knowledge related to health transformation, improve leadership skills and build a broad and diverse community of family advocates. The group launched Family Leader Action Learning Sets with 30 family leaders at the AMCHP 2015 Annual Conference, created a family leader portal on Transformation Station: <http://www.amchp.org/Transformation-Station/Family-Leaders/Pages/Home.aspx>, developed a three part series on Adaptive Leadership (in partnership with the change management core), developed a Facebook group for family leaders on the AMCHP Facebook page called Family Leader Champions for Title V, and included family leaders as a key participant in the application-based Population Health Symposium (five of thirty-nine participants identified themselves as family leaders).

**Family Engagement for Policy:** AMCHP ensures that family leaders are engaged at all levels in the development and implementation of our policy agenda through several mechanisms. First, family leaders serve on our Legislative and Health Care Finance Committee, which has the primary charge of developing the AMCHP policy agenda and making recommendations for all policy positions taken by the association. Then, AMCHP staff tailor trainings and support for family leaders who are able to make visits to their elected officials during the AMCHP Annual Conference. Finally, on request, AMCHP staff regularly provide policy briefings to the AMCHP Family and Youth Leadership Committee and family leader webinars and/or virtual trainings.

Organizational Structure	Leadership Development	Program and Policy Activities
<ul style="list-style-type: none"> <li>• Family Representatives on the Board of Directors and Committees               <ul style="list-style-type: none"> <li>• Family Leader on Staff</li> <li>• Family Delegates</li> </ul> </li> <li>• Family and Youth Leadership Committee</li> </ul>	<ul style="list-style-type: none"> <li>• Family Leader Support</li> <li>• Leadership Lab, Family Leader Cohort</li> <li>• Family Engagement Survey</li> <li>• Family Engagement Community of Practice (CoP)</li> <li>• Family Engagement and Leadership Web Portal</li> </ul>	<ul style="list-style-type: none"> <li>• Alliance for Innovation (AIM) Access               <ul style="list-style-type: none"> <li>• State Public Health Autism Resource Center (SPHARC)</li> <li>• The Return on Investment Analytic Action Learning Collaborative (ROI Analytic ALC)</li> </ul> </li> <li>• Action Learning Collaborative for the National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs</li> <li>• The AMCHP Every Mother Initiative               <ul style="list-style-type: none"> <li>• Best Practices Replication Technical Assistance                   <ul style="list-style-type: none"> <li>• Best Baby Zone</li> </ul> </li> </ul> </li> <li>• Family Engagement for Policy</li> <li>• Workforce Development Center</li> </ul>

## STAFF CONTACT

**Michelle Jarvis**, Specialist, Family Engagement and Leadership Development; [mjarvis@amchp.org](mailto:mjarvis@amchp.org)

