



PULSE

A BI-MONTHLY NEWSLETTER FROM THE ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Family Involvement July/August 2013

Table of Contents

From the President	1-2
Family Leadership Development as Part of Workforce and Leadership Development at AMCHP	2-3
Beyond Story Telling: Family Leadership at the National Level	3-4
The Importance of Family Involvement in Title V.....	4-5
The Family Voice: Important Then... Critical Now!	5-6
Families and Advocacy.....	6
Family Leadership Development: A State Snapshot.....	7-8
The Opportunity to Celebrate Dad is Precious.....	9-11

From the President

By Millie Jones, MPH



As many of you know, the future of Title V, the Maternal and Child Health (MCH) Services Block Grant is being discussed as part of the national agenda on health reform. For well over three quarters of a century, Title V has advocated and supported the health and well- being of mothers, children, youth, including those with special health care needs, and families. I propose that the future of Title V is strong and a critical part of our nation’s commitment to the public’s health and well-being.

In the words of a former AMCHP president, Dr. Maxine Hayes, MCH means **Making Change Happen** – and we have a successful track record of making positive changes in the lives of families in this nation. Last week I attended a W.K. Kellogg Foundation sponsored meeting to connect the dots with national and federal initiatives designed to improve birth outcomes. For several years, we have engaged in action learning collaboratives related to birth outcomes.

Making Connections Happen, Making Collaboration Happen, Managing Change (as it) Happens are all examples of the work we are doing at the local, state and national levels as part of our commitment to ensure that families are healthy and functioning at their full capacity. Title V services are coordinated, community-based, and family centered. While those concepts might not mean a lot to some people, we do know that for families it can mean the difference between finding and utilizing services versus fragmented, inaccessible, or, in some cases, no services.

As we confront the future and move forward with health reform, MCH will continue to **Make Community Happen** and **Maintain Community-Based Help**. Families are counting on us to be there with them, for them, working



ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

From the President CONT.

on their behalf, across the life course, so that current and future generations are reflected in healthy children, healthy families and healthy communities.

Let's make our future a **M**ovement (for) **C**hildren's **H**ealth!!!

Feature Family Leadership Development as Part of Workforce and Leadership Development at AMCHP



By Sharron Corle, MS
*Associate Director, MCH
Leadership Development
& Capacity Building, AMCHP*



Jessica Teel, MS, CHES
*Program Manager,
Workforce & Leadership
Development, AMCHP*

Like many segments of the public health workforce, the MCH workforce is experiencing tremendous changes – on-going budget cuts, accreditation, an aging workforce, implementation of health care reform, etc., – bringing about the need for new skills, capacity and practice needs. At AMCHP, the Workforce and Leadership Development (WLD) team is committed to building the MCH leaders of tomorrow! Our team is enthusiastic about working with members and staff to identify and share resources related to succession planning, talent management, and retention; support leadership development; facilitate opportunities for peer exchange; and increase the use of the MCH Leadership Competencies and evidence-based training and development practice within all AMCHP training and development activities.

AMCHP workforce development efforts focus on improving MCH outcomes by supporting and enhancing the skills and competencies of the MCH workforce with a focus on leadership development and mentoring. While our efforts

Feature CONT.

Family Leadership at AMCHP

largely target individuals either employed by state and local government health agencies, we also work to develop family leaders and those individuals that work as part of larger efforts (community, national organizations, health care delivery system level, etc.) to improve maternal and child health.

AMCHP leadership development efforts have focused on two key programs: the New Director Mentor Program (NDMP) and the Family Scholars Program (FSP). NDMP and FSP provide leadership development opportunities for new Title V and family leaders. Both programs are grounded in the MCH Leadership Competencies and are guided by a three-pronged, evidence-based framework consisting of formal and informal learning opportunities, peer-to-peer networking, and mentoring and coaching support. The NDMP pairs a new Title V administrator (MCH, children and youth with special health care needs (CYSHCN), Title V director) who has been in their position three years or less with a more seasoned Title V administrator to develop specific skills and gain knowledge

Table of Contents

Innovation Station Highlight: Practices in Family Leadership Development.....	11, 13
Data and Trends	12
View from Washington	13-14
Real Life Stories.....	14-15
Success Stories	15
Member to Member.....	16-17
Who's New	17
Get Involved	18
Resources	18-20
Board of Directors.....	21
AMCHP Staff	21-22
Calendar.....	22

Feature CONT.

Family Leadership at AMCHP

that will enhance professional and personal growth, including leadership capacity. Likewise, family leaders participating in the FSP are matched with a family mentor and partake in a 10-month leadership development journey geared for family representatives interested in developing their leadership skills, understanding of Title V, network of family leaders, confidence in advocating on behalf of Title V, and how to increase family involvement within Title V programs in their state. AMCHP believes that developing families as leaders is critical to help them understand how to bring about positive change in the lives of their families but also to enable them to ensure that state MCH programs are relevant to the families they serve.

Two AMCHP committees support the WLD program work, the Workforce and Leadership Development Committee (WLDC) and the Family and Youth Leadership Committee (FYLC). The WLDC focuses on issues state Title V programs face in recruiting, training, and retaining staff, and also works toward developing strategies that support and enhance the skills and competencies of the MCH workforce with a focus on leadership development and mentoring. The FYLC provides leadership and guidance to support the development and implementation of effective programs, strategies, and policies that advance family and youth involvement in MCH issues, including CYSHCN, at the local, state, and national levels.

For more information about the AMCHP Workforce and Leadership Development Team, contact [Sharron Corle](#), associate director, MCH leadership development & capacity building at (202) 266-3036, or [Michelle Jarvis](#), program manager, family involvement at (202) 775-1472, or [Jessica Teel](#), program manager, workforce & leadership development at (202) 266-3054.

NOMINATE YOUR PEERS FOR A 2014 AMCHP AWARD

AMCHP recognizes leadership in maternal and child health in several ways, including awards presented to MCH leaders to honor their excellence in the field. These awards will be presented at the 2014 AMCHP Annual Conference, Jan. 25-28 in Washington, DC. **Nominations are due by Sept. 6.** For more information and nomination guidelines, please [click here](#).

Feature

Beyond Story Telling: Family Leadership at the National Level

By **Kris Green**

*Autism and Parent Services
Manager, Division of Public Health,
Alaska Department of Health and
Social Services*



I entered the world of MCH with the birth of two full-term sons followed by the birth of premature twin sons. Years of joys and challenges, beginning at birth, through developmental issues and life events eventually led to a professional paid parent role within a hospital. In the hospital setting, I promoted and implemented family-centered care from the maternity center/ neonatal intensive care unit (NICU) to out-patient subspecialty services, surgery center, emergency room care, and bereavement services. Then an opportunity to work at the community level in a paid parent role on autism-related issues for the state of Alaska Title V program led to the role as a national representative for all MCH experiences. I've had the privilege of representing families, infants and children as one of two Family Representatives to the AMCHP Board of Directors since my election in 2010. AMCHP has a long history of collaborating with families and consumers to ensure family and youth needs are at the forefront in state and territories planning and delivery of meaningful programs and services using Title V dollars.

The critical role of the Family Rep is to represent the needs and interests of families across the country and to provide expert knowledge of the impact of MCH programs and policy developments on families. Keeping a finger on the pulse of how decisions impact families nationally by watching trends, the Family Reps role is to bring those developments to the attention of the board. In addition, a significant role of the AMCHP Family Rep is to identify best practices on family engagement and support programs that increase family involvement at the local, state and national level.

So, just how do Family Reps effectively carry the family voice back to the board? It sure is NOT done in isolation! It is from the thankful letter to the editor talking about how a [MCH] program impacted a child's life, stories from family leaders who advocate for children with special needs in their state, or the story from a family struggling in my home

Feature CONT. Beyond Telling the Story

state. These stories all create a picture leading to better systems of care. Using this collection of stories “from the kitchen table,” I remind fellow board members how organization decisions will impact families.

The Family Rep role of ensuring family engagement is done by monitoring training programs that engage new family leaders. Because of the work of a highly committed group of AMCHP staff and parents leaders, a shared language is emerging that bridges state and territorial Title V staff and parents. Collaboratively, the Family Reps work with the AMCHP Family and Youth Leadership Committee; and partners with Parent to Parent, Family Voices, and Family-to-Family Health Information Centers. As Family Reps, we are strongly influenced by the voices from emerging leaders of AMCHP family delegates, mentors and scholars. These leaders, across agencies and states, are working on competencies that demonstrate the effective transformation of a family’s personal story into a professional message. Collectively, through active listening, open-minded dialogue, strength-based feedback, and respectfully and constructively identifying strengths and gaps, families have become a “technical assistance team” providing meaningful input at the local, state, and national level.

As the family representative, it was not via formal training, but the result of my journey as a parent with the typical hills, valleys, and mountain tops of joys and challenges that bridged my role from local involvement to national impact – what a privilege to bridge my passion for advocacy to the role of carrying forward the voice of all families.

THE ROAD AHEAD:
Challenges, Changes, & Opportunities
for Maternal and Child Health

2014 amchp annual conference
jan. 25-28
washington, dc
AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Feature The Importance of Family Involvement in Title V



By Trish Thomas
Director of Diversity and Outreach, Family Voices



Leslie Carroll
IMPACT Project Director, Family Voices

Families are the core unit of our society and the constants in their children’s lives; as such, they are pivotal in making any system work – whether it is related to staying healthy, having fun, getting an education, eating healthy food, or any other activity that families do!

The system of care found within the Maternal Child Health Bureau (MCHB) is no different; in order to be successful, Title V must involve family members, including parents and families who are representative of culturally diverse communities, and children and youth with special health care needs, in meaningful, ongoing leading roles focused on developing culturally competent systems at all levels of policy, programs, and practice. The involvement of families is a key indicator of systems development.

Having parent/family involvement in the Title V block grant review enables Title V programs in the states to have a “hands-on” opportunity to continually improve the quality of their block grant review process. Family/parent reviewers provide culturally appropriate guidance and direction to Title V program staff, give important and detailed information on the communities and states they live in, and share how to work together to improve outreach strategies, coordination of care, access to care, communication, and strong partnerships.

Life is dynamic and always changing! Staying current with family perspectives and demographics allows Title V to be right on target with serving families and children. Knowing what works is cost effective for all involved, a time saver, and builds trust for Title V programs. Involving families is a win-win for both the families and Title V.

Feature CONT.

Family Involvement in Title V

Trish Thomas from Family Voices has throughout the years worked with MCHB to recruit, mentor and train parents from diverse populations to review the Title V Block grants. Each year a family member is on the review team to lend their expertise in what works for families of children and youth with special health care needs and their families receiving Title V services. This work continues formally today through Project IMPACT (Improving Maternal and Child Health Programs so All Children Thrive), a cooperative agreement between Family Voices and MCHB. Family Voices works with MCHB to recruit and train parents and family representatives so that they can be successful block grant reviewers. Family Voices is creating new, updated training approaches that will allow more parents to become familiar with the block grant review process. A webinar training will be developed in conjunction with MCHB, which will be available in the winter. Already available, a long-time popular and effective handbook called "Getting to Know Title V" is available on the [Family Voices website](#). The handbook is a great resource for families who want to learn the basics about Title V. It describes the Title V mission, history, and services, as well as how families participate in Title V programs and policies.

Trish Thomas, Director of Diversity and Outreach and Leslie Carroll, Director of IMPACT, are available as resources and welcome your calls, questions, and input. In addition to their work with the Title V Block Grant review, Trish works across all Family Voices projects, providing information and resources, review of materials, networking with the MCHB Divisions and other U.S. Department of Health and Human Services (HHS) programs in building partnerships, to highlight the importance of diversity and cultural and linguistic competence and Leslie focuses efforts on activities such as the IMPACT Health and Wellness Initiative, life course, and family leadership tools related to health promotion and chronic disease prevention.

Trish can be reached at tthomas@familyvoices.org or (505) 872-4774 ext. 102/(888) 835-5669 ext. 102.

Leslie can be reached at lcarroll@familyvoices.org or (541) 708-5404.

Feature

The Family Voice: Important Then...Critical Now!

By Bonnie Strickland, PhD
Director, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau



In the summer of 1987, then Surgeon General of the U.S. Public Health Service, Dr. C. Everett Koop, issued the landmark report entitled, *Children with Special Health Care Needs: Campaign '87 – Commitment to Family-Centered, Community Based, Coordinated Care*. That report established the first national agenda to promote quality systems of services for children with special health care needs and their families. It is well worth noting that in the very first, and central, theme of the report Dr. Koop charged families and professionals involved in the care of children with special health care needs with working together to improve the lives of children and their families through a system of family-centered, community-based, coordinated care.

Since that time family professional partnership has been a cornerstone of Title V values, vision and mission. We celebrate a long history of recognizing, embracing, and supporting the principles of family/professional partnership by engaging families as leaders, advisors, and advocates on behalf of children and youth with special health care needs. Twenty years ago, in 1993, with the nation's first attempt at national health care reform, Title V leaders in every state worked closely with family leaders to establish Family Voices, a coordinated national and state network of families whose mission was to work with partners to create a prominent voice in promoting, examining, and responding to the health reform movement of the time on behalf of children and youth with special health care needs. Those early partnerships provided unique and powerful insights into the potential influence and value of the family voice in influencing the design, utility, and impact of the health care system for all children and families.

Fast forward more than 25 years after Dr. Koop's original vision of family/professional partnership, and once again, we are at the threshold of realizing unprecedented change in the nation's health care system. This time around, due in large part to the work of our original and current pioneers, family partnership and shared decision making are recognized as essential elements in nearly

Feature CONT. The Family Voice

every national health care transformation initiative. This is fortunate because, even with unprecedented improvement, the new health care environment includes many important provisions not yet widely tested in the daily lives of children, youth and families with special health care needs. Ensuring that provisions related to essential health benefits, patient navigators, provider networks, and family/patient-centered care are appropriately defined and responsive to the needs of children, youth, and families will continue to pose a challenge. In order to get it right, the vigilance, voice and influence of the family/professional partnership remain as critical as ever. As we envision and articulate the role of Title V in this exciting and historic endeavor, we should remember our history, celebrate and build on what we have learned, and rededicate ourselves to the first and central principle of that original national agenda....working together to improve the lives of children and their families through a system of family-centered, community-based, coordinated care.

Dr. Christina Bethell, director of the MCH Data Resource Center summarized the family/professional partnership quite nicely in an upcoming commentary...."authentically engaging families and patients at all levels draws us into closer alignment with already deeply held values, aspirations, instincts and goals to promote and improve health and health care."

Feature Families and Advocacy



By Carolyn Mullen
Associate Director, Government Affairs, AMCHP

A period of legislative stagnation permeates the air as temperatures rise and approval ratings plummet in Washington, DC. Hundreds of calls, e-mails and meetings were conducted during this period and to no avail. Traditional lobbyists are rubbing swollen feet, nursing bruised egos and raising their collective hands to heaven begging Congress to do

Feature CONT. Families and Advocacy

something, anything productive. What will push these policymakers to the promised land of compromise? Families and their stories.

"What to cut? What to keep?" is a phrase probably running through the mind of a congressional staffer as he or she begins the arduous task of drafting the annual appropriations bills. These numbers in an excel spreadsheet must tell a story: a story about a family who will lose services if a program is cut, a population that will excel if funding is sustained or the promise of a new program being brought to life and the positive impact it will have. Sure these stories can be told by lobbyists, but policymakers prefer to hear directly from their constituents and the families who benefit from these programs.

In the current budgetary environment members hear only the loudest voices above the fray declaring that Congress must reduce the federal deficit by cutting programs. Most members do not understand how the Title V MCH Services Block Grant affects a child with a special health care needs or helps established regionalized systems of care for the most medically fragile infants. The stories from a constituent's perspective are vitally important to any advocacy campaign, adding color and life to data and funding levels. The AMCHP family scholars program affords the opportunity for families to learn more about how to be an effective advocate and share this knowledge base with others.

Together we must work to educate ourselves and the next generation of the maternal and child health workforce about the importance and value of advocacy at the national, state and local levels. Without continued leadership and a voice for maternal and child health, the very programs that we cherish will be demolished by members of Congress who are trying to achieve budget savings. Many policymakers do not fully understand the ramifications of their actions and the impact this will have on their constituents. AMCHP staff stands ready to work to give families touched by the Title V MCH Block Grant the tools and resources necessary to advocate on behalf of millions of women, children and their families.

Feature CONT.

Family Leadership Development: A State Snapshot

There are some really interesting programs and initiatives around family engagement and leadership development happening across the country. We invite you to take a closer look at a few of those here!

Colorado – Colorado Approach to Family Engagement



By Eileen Forlenza
Director, Family Leadership Initiative, Colorado Department of Public Health and Environment, Children and Youth with Special Health Care Needs Unit

It was a single dad in a rural community on the eastern plains of Colorado that anchored my vision

for developing a network of family leaders statewide. His son was a tenacious six year old with Cerebral Palsy, and their father-son bond was strong and inspiring. Raising his young son alone, this dad was dedicated to absorbing all he needed to learn about the system of services. He asked insightful questions, while offering brilliant solutions. He was courageous, smart, resourceful, committed – and he felt isolated. I left that meeting thinking that if only I could harness the wisdom and perseverance of hundreds of families and braid it with core leadership competencies, our state would indeed have an authentic strategy related to quality improvement through family engagement.

Eight years later, the vision has materialized as the Colorado Family and Community Engagement (FACE) Initiative. The cornerstone of the FACE Initiative is our Family Leadership Training Institute (FLTI), a 20-session leadership course offered in seven local communities statewide. Through a partnership with the Connecticut Parent Leadership Training Institute, this curriculum is based on proven adult learning methodology, is grounded in diversity and is relevant across several MCH priority areas.

Colorado currently has more than 400 graduates of the program, and each graduate has completed more than 120 hours of class time and has demonstrated their leadership skills through completion of a personal leadership project. For more information please visit us at coloradofamilyleadership.com or contact me at Eileen.Forlenza@state.co.us.

Indiana – New Online Training Resource Helps Families Develop Leadership Skills



By Rylin Rodgers
Family Leadership Coordinator, Riley Child Development Center

Building Family Leaders, a new Web-based training portal, will empower families to lead, advocate and engage as partners in the systems that serve their children. The initiative is led by staff from

the Riley Child Development Center and Family Voices Indiana in collaboration with the Indiana State Department of Health Title V Maternal and Child Health & Children's Special Health Needs Services.

Families raising children with special health care needs encounter a maze of systems and services as they seek care for their children. Navigating these systems puts them in a great position to provide relevant feedback, but there is often a gap between experience and knowledge of how to make an impact on the systems they access.

Building Family Leaders provides training in the basic skills while also helping families assess their strengths and weaknesses. An online training portal is the perfect solution for busy families, as families can access the portal on their own schedule and work at their own pace.

Families using Building Family Leaders will positively impact quality of life while helping create more effective and efficient service systems for children and families. Building Family Leaders will be available online.

Feature CONT. FLD: A State Snapshot

Wyoming Parent Leadership Training Institute



By Charla Ricciardi
Coordinator, Child and Adolescent Health, Wyoming Department of Health

The MCH program in Wyoming continues to recognize the role of families as equal partners in decision making in order to improve the health and safety of children and the improvement of early childhood systems in Wyoming. Since MCH piloted the Parent Leadership Training Institute (PLTI) in Cheyenne in 2009, they have continued to see it expand in communities including a total of five locations across the state in 2014. In addition to 68 hours of classroom time, each parent leader invests their time and effort into a community project of their choosing. One parent in Albany County is advocating for an increase in curb cuts in the city to create greater access and opportunities for children who require a special mobility device. This same parent was empowered to join a city board that addresses similar needs of adults and children with disabilities. In the frontier county of Hot Springs (total county population of 4,822), a parent is working with the local public health office to bring prenatal classes back to the area. Through PLTI of the Wind River Indian Reservation, the 2012 and 2013 community projects of parent leaders are resulting in positive changes in schools, a mentoring program between grandparents and fourth-grade students, and a cooking class to teach youth about proper nutrition and healthy eating to just name a few.

PLTI graduates are invited to partner with and provide insight to the Wyoming MCH programs. The PLTI of Wyoming continues to impact systems change, increase health equity, and bolster family engagement as parents are empowered to create lasting change on behalf of children.

For more information contact Charla Ricciardi, child health program manager, or Anne Siebert, parent leadership and engagement coordinator.

Oklahoma Family Network



By Joni Bruce
Executive Director, Oklahoma Family Network

Since 2008, the Oklahoma Family Network (OFN) and partners, including state agencies and disability related organizations have held annual family professional partnerships state conferences. Participants have included families of, and individuals with, special health care needs and professionals serving them. Outcomes have included the development of a consumer advisory council at one state agency and changes in policy and family/consumer involvement in organizations that are involved. In 2012, OFN received a grant from the Oklahoma Department of Mental Health and Substance Abuse to provide five regional institutes promoting and building family and consumer involvement across the state. Local planning committees, including a subset of the original committee and partners in the regions, planned and promoted the events. Four of the five institutes were held in rural or frontier areas of the state. Sessions included: The Importance of Family Leadership and Getting Connected, Local Successful Partnerships, Learning to Share on Boards & Committees, Telling Your Story Specific to Your Audience, and Building Relationships with Policymakers. OFN and partners will continue these institutes for four years building a network of consumers and families armed with leadership skills to promote innovative strategies ensuring continued growth of family involvement and voice.



Feature

The Opportunity to Celebrate Dad is Precious

By Greg Schell

Director, Washington State
Fathers Network, Kindering

Malia Corde

Project Coordinator, NJ Parent
to Parent, Statewide Parent
Advocacy Network



In this article, AMCHP highlights two partners that are leading the way in building programs and resources to engage fathers of children with special needs. Historically, family participation and involvement in MCH programs has focused on mothers, children, and adolescents. Today, programs identify the integral and unique role fathers play in advocacy and the health of their family and community. Washington State Fathers Network is an established program with more than 35 years of experience empowering and engaging dads and developing programs and resources to meet the unique needs of fathers of children with special health care needs. New Jersey Parent to Parent is emerging in this work, and in addition to exploring new tools, they recently hosted their first statewide conference for fathers of children with special needs.

Washington State Fathers Network (WSFN)

WSFN, whose heritage reaches back to 1978 when the Father Program was started at the University of Washington, is a statewide nonprofit, nonsectarian program that advocates and provides connection and resources for all fathers, men, and their families with children with special needs. The mission of the network is to promote fathers as crucially important people in the lives of children and families, at the same time celebrating being the father of a child with special needs. WSFN believes men are superb resources for each other, and fathers have unique needs of their own when it comes to caring for and raising a child with a chronic illness or developmental disability. With 16 chapters led by 14 trained and volunteer dads and one mom, WSFN responds to several thousand dads and families across the state and beyond each year. The

[website](#) has as many as 300,000 hits per month and presentation and trainings have been held in 47 states, five foreign countries, and across Washington.

Fathers have unique ways of adjusting to change, just as moms do. Fathers sometimes have a hard time grasping their uniqueness and adjusting to the very confusing, frustrating, and challenging world of disability. When connecting and talking with other dads in this same situation, they discover they have many similarities. For instance, isolation, a very common feeling of many dads, is often paralyzing. They may not believe this before the dialogue begins, but the relief they experience once they make a connection is palpable. They are the first to notice and comment about this major transformation.

Research about WSFN confirms this in a very significant way. The University of Washington-Bothell assessed the outcomes of participating in WSFN, and the results are rather stunning. The cross-sectional design study had 146 members reply to 38 survey questions. The researchers concluded that participation in WSFN had a substantially positive effect, resulting in:

- Anxiety *decreasing* 97 percent
- Enthusiasm towards their child *increasing* 69 percent
- Feelings of joy *increasing* 67 percent
- Family relationships *improving* 77 percent
- Having someone to relate to *increased* 80 percent
- Feelings of hopelessness *decreased* 57 percent

This research is consistent with two previous looks at WSFN, one that occurred in 2003-05. That data was nearly the same but the study population was intentionally quite different. It included inner city African American dads, Latino dads, and Native American dads. The conclusion is quite clear: when dads of all kinds get together, the benefit is substantial and for many, a major turning point in their lives.

A few quotes from the annual state conference last year may provide some insight as to how important connections can be for fathers:

“Just a great day! Been an emotional year with highs and lows. This day helped keep things and life in perspective.”

Feature CONT. Celebrating Dad



Dads at the NJ P2P Statewide Fathers Conference

“Powerful stories from other Dads-I am so much better for my family after attending this day. (My wife loves it!)”

“...the Dads Panel and Open Mic continue to amaze me. But more important, the opportunity to celebrate dad is precious.”

WSFN is a program of Kindering and is supported by Children with Special Health Care Needs Program, Washington Department of Health, other grants, and private donations.

New Jersey Parent to Parent (NJ P2P)

NJ P2P is based on a national model of peer support that connects parents looking for support with trained veteran “support parents.” Support parents offer emotional support, information and resources to families, often at difficult times in their lives. Like most Parent to Parent programs around the country, NJ P2P has primarily supported moms. However, over the years the impact of a child with a disability on each member of the family – not just mothers, but fathers, siblings, and extended family – has become apparent. Then NJ P2P began to develop strategies to support whole families, and not just one parent.

A few years ago, an increase in the number of fathers attending school meetings, doctors’ appointments, workshops and conferences was observed. Fathers who were the primary caregiver for their child(ren) while the mother was working, or due to divorce, was becoming

more prominent. And there wasn’t a lot of support being offered to fathers, nor were they being acknowledged of the great job they were doing raising their children. Then plans to address this gap and need began.

In 2008, a father was hired as the Southern Regional Coordinator to support fathers of children with special needs in a more meaningful way, realizing that fathers should be supported by other fathers. In June 2009, the first teleconference in honor of Father’s Day was hosted,

and soon after, a new column in the quarterly P2P newsletter called the *Fathers Corner* was started. But more could be done. Last year, the first New Jersey statewide conference for fathers of children with special needs was held. It was a big undertaking, in no small part because the budget to put on this type of event was not there. P2P staff invited fathers to participate in a conference call to discuss the need for and value of such an event. The six fathers who participated strongly agreed that the conference would be a wonderful opportunity. A pre-conference survey of fathers throughout the state was created to solicit ideas about the theme and topics of interest. Ten fathers and the seven P2P staff (the conference planning committee) reviewed the feedback and designed the conference.

The first New Jersey Statewide Conference for Fathers of Children with Special Needs: Educating, Empowering & Supporting One Another was held in Freehold, New Jersey on Jun. 1, 2013. This event was a partnership between NJ P2P, the New Jersey Self-Help Group Clearinghouse, and Parents Anonymous New Jersey. Fifty-four fathers attended the conference. The keynote speaker was Robert Naseef, PhD., father of an adult son with autism and a nationally known speaker on topics such as marriage, family, and fatherhood. Presentations during the conference included fathers who spoke about their experiences raising a child with special needs and lessons learned along the way and information on assistive technology and a variety of recreational activities available for children and young adults with special needs. The day ended with a networking lunch for fathers to talk amongst themselves and to meet with the 22 community and state organizations that participated as exhibitors.

Feature CONT. Celebrating Dad

The evaluations from the conference indicated that the conference met the needs of the fathers in attendance.

During the month of June, NJ P2P also worked with fathers on the Essex Family Council to do a series of weekly lunchtime Dad2Dad teleconferences in honor of Father's Day. In the future, the plan is to organize an annual event for fathers and update the P2P section of the Statewide Parent Advocacy Network (SPAN) website to include information and resources specifically for fathers of children with special needs. It is our hope that these activities have started a movement in New Jersey to give fathers more opportunities to come together to share their experiences and to learn from one another.

For more information about SPAN and New Jersey Parent to Parent, go to spanadvocacy.org.

Feature Innovation Station Highlight: Practices in Family Leadership Development



By Kate Taft
*Program Manager, Child Health,
AMCHP*

The AMCHP Innovation Station is any easy way to find emerging, promising and best practices in a wide variety of MCH topics, including family leadership development. Two examples of model practices in family involvement/leadership that

can be found in Innovation Station are the New Jersey Statewide Parent Advocacy Network (SPAN) Parent Leadership Development Project and the Rhode Island Pediatric Practice Enhancement Project (PPEP).

- **SPAN Parent Leadership Development Project:** The New Jersey SPAN Parent Leadership Development activities are aimed at building the capacity of families to advocate on behalf of their children, and partner with health, education, and other professionals. This

Feature CONT. FLD in Practice

statewide program involves more than 500 parents of CYSHCN per year. The program provides intensive leadership development, ongoing peer-to-peer support, and leadership practice opportunities for families; particularly underserved families. The diverse SPAN staff consists of parent leaders who started out needing help to advocate on behalf of their own children and families, and then developed a passion to help others and change systems so that parents would not face the same challenges and barriers. All SPAN programs and activities are based on the input of staff, the volunteer SPAN Resource Parents, and input from the families being served.

The impact of parent participation is reflected in victories such as having their recommendations included in the recommendations of the Governor's Blue Ribbon Panel on Immigrant Affairs Panel and



Do you have an effective program that addresses family involvement or parent leadership development?

Please consider sharing your program through Innovation Station, AMCHP's searchable database of emerging, promising and best practices in maternal and child health. Through this opportunity, you can:

- Share successes with your peers
- Enhance the MCH field
- Contribute to program replication
- Get expert feedback from the Review Panel
- Receive national recognition

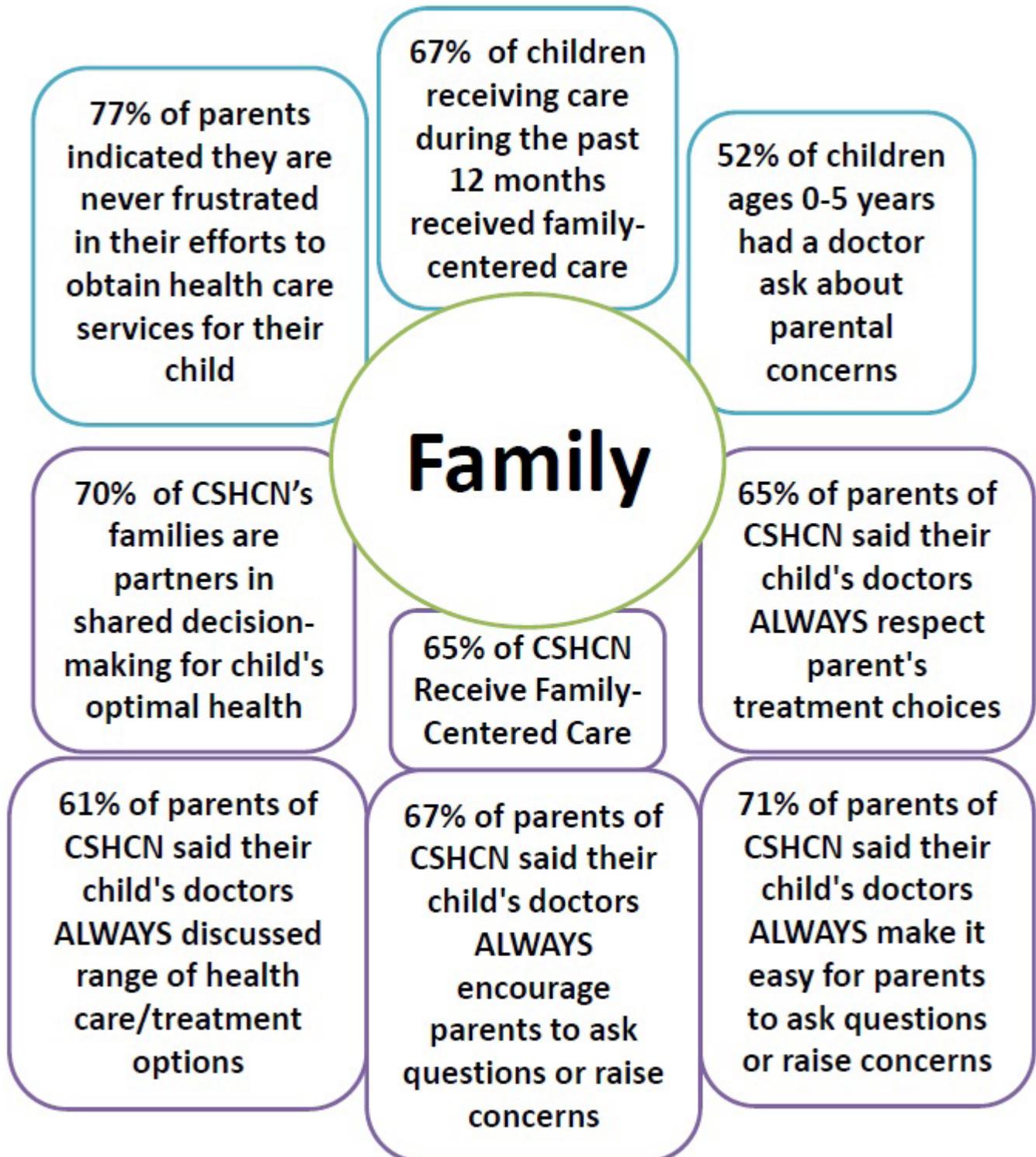
The online submission process is simple and applications are accepted on a rolling basis.

For more information, contact [Kate Taft](mailto:Kate.Taft@amchp.org) at (202) 266-3056 or visit amchp.org/bestpractices.

You can also [click here](#) to refer an innovative MCH program that we should know about!

Data and Trends

Putting Families at the Center of Care: Data from Two National Surveys



Source: National Survey of Children's Health (2011-2012) and National Survey of Children with Special Health Care Needs (2009-2010)

Feature CONT.

FLD in Practice

decision by the state Department of Education to hold additional hearings in multiple locations at more easily accessible times and places. To find out more about SPAN work with parent leadership development, visit spannj.org.

- Pediatric Practice Enhancement Project (PPEP):**
 The Rhode Island PPEP is a cost-effective model of utilizing parents on-site in pediatric primary and specialty care practices to work directly with families identified by the physician as needing assistance with system navigation, resource identification, peer support and education. Developed in 2003, the overall goal of PPEP is to improve short- and long-term health outcomes of CYSHCN.

The project places and supports trained parent consultants in clinical settings to link families with community resources, assist physicians and families in accessing specialty services, and identify systems barriers to coordinated care. The primary role of the parent consultant is to create linkages between the family, pediatric practice, and the community as a whole. The PPEP model demonstrates that utilizing a paraprofessional to reinforce health care messages, perform care coordination, and provide patient education is more cost effective than utilizing a nurse or social worker. Furthermore, they found that a paraprofessional matched culturally and linguistically

is more effective in improving health outcomes. More information about PPEP can be found at: health.ri.gov/family/specialneeds/ppep.php.

By sharing information on successful practices through Innovation Station, AMCHP hopes to encourage replication and spread innovative practices between states to improve health outcomes. For more information about these, as well as other emerging, promising and best practices in maternal and child health, visit amchp.org/innovationstation.

View from Washington

MCH Leadership – 10 Numbers that Will Shape the Future



By Brent Ewig, MHS
Director of Policy, AMCHP

Greetings from Washington where it's hot, sticky, and Congress is on their traditional August recess. This means two main things: 1) most Washingtonians have evacuated our nation's capital to seek solace in the mountains and beaches of this great land and, 2) we once again are facing a completely uncertain budget situation, with no prospect that the appropriations bill funding Title V and most other MCH programs will be passed by the Oct. 1 start of the 2014 fiscal year. At this moment there also is no serious work likely to reverse the second wave of sequestration and little prospect of a grand bargain to address our fiscal woes.

This also means that September will be a critical month to watch how the budget brinksmanship plays out and if a continuing resolution can be passed to sustain funding for critical programs. AMCHP will be monitoring and reporting closely, and may call on MCH leaders to weigh in with elected officials if and when any funding details emerge. In the meantime, I am sharing my list of 10 macro observations that I think will shape our collective future:

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View from Washington CONT.

DEMOGRAPHICS

50.4 percent – number of children younger than one born last year who were Hispanic, Black, Asian American or in other minority groups

BUDGET

\$16.7 trillion – current U.S. debt

\$795 million – current U.S. deficit

\$450 million – estimated combined federal and state reductions to the Title V MCH Services Block Grant in past decade

\$1 billion – estimated hit of sequestration to MCH programs (Title V, WIC, CDC, NIH, etc) for FY 2013

HEALTH REFORM

\$1 trillion – estimated cost of ACA to provide stable insurance coverage, guarantee essential benefits and invest in prevention, home visiting, teen pregnancy prevention, etc over the next 10 years

30 million – estimated number of Americans to gain insurance via ACA. How will this change what Title V does in 2015 and beyond?

WORKFORCE

23 percent – Estimate of public health workers eligible to retire this year

52,000 – Number of public health jobs lost due to budget cuts in past five years

Many – partners that will be needed to sustain MCH programs through this temporary period of contraction

How does this list match your reality? Are there other factors you would like to see added? As always, please let us know what you think and how AMCHP can improve our work to support you. I can be reached at bewig@amchp.org.

Real Life Stories Family Scholars Program Provides a National Perspective



By Lisa Wilson
Parents Let's Unite for Kids

Through my participation in the Family Scholars Program, I learned how the maternal and child health system, including Title V is administered. I gained valuable access to AMCHP resources and the experience of other MCH leaders, including the inspiring family leaders in my cohort. By realizing a national perspective, I also realized new local perspective and began to truly understand how the system in Montana functioned, allowing me to seize opportunities to take a leadership role in developing programs and supports for CYSHCN.

As a member of our Medical Home Advisory Council in Montana, I found myself disillusioned with the state of Pediatric Medical Home implementation in our state. I began to formulate a program to implement family-centered pediatric medical homes in Montana. As a Family Scholar, I felt a responsibility to take a leadership role in designing and implementing the program. With the continuing encouragement of my mentor, I was able to network with several other support organizations and a project started to take shape.

I used the AMCHP best practices and Innovation Station website to research the Pediatric Practice Enhancement Project (PPEP) project from Rhode Island. In an attempt to expand my leadership role, I wrote and submitted a grant to AMCHP for technical assistance to model our new medical home program after PPEP, which our program was

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Real Life Stories CONT.

awarded. In March of 2013, myself and a team of six other people, traveled to Rhode Island for a technical assistance (TA) site visit. The TA afforded us valuable implementation materials, training and accelerated the professional development and education of the new Parent Partners.

With the inclusive vision of parents as equal professionals in public health, I felt ready to approach others as a professional. Montana did not have any interdisciplinary neurodevelopmental clinics at our medical centers and families often complained about needing to wait six to 12 months to be seen at the autism clinic more than eight hours away. I worked with my Utah Regional Leadership Education in Neurodevelopmental Disabilities (URLEND) coordinator and Title V specialty clinic to facilitate meetings aimed at creating such a clinic in Montana. While at the AMCHP conference, I learned about regional MCH TA grants available for states to replicate each other's best practices and thought it might be a way for the providers in Montana who needed help building an interdisciplinary clinic to visit a private, profitable clinic staffed with Leadership Education in Neurodevelopmental Disabilities (LEND) graduates in our region who had been providing phone TA with the help of URLEND. Through AMCHP, I was able to find out which regional MCH professional I should talk with about the grant and eventually ended up working with someone at the Health Resources and Services Administration (HRSA) to decide that it was a good use of funding. I completed the application and my Title V director submitted it for us. We received the MCH TA grant and the clinic in Idaho has agreed to share all of their billing models, intake forms, and approach to care along with the site visit. We expect the clinic in Montana to begin in August and to be privately profitable, requiring no additional ongoing public support.

In addition to these exciting projects, the training and education provided by AMCHP allowed me to advance my systems knowledge and understanding of my role as a leader. With this new breadth of understanding, my role within my organization grew. Along with my professional growth, our organization has grown. We have new statewide and regional partnerships, additional funding, more employees, and are developing more parents as leaders. My participation in the Family Scholars Program had a real and positive impact on myself, my organization, and many other families in my state.

Success Stories Paving the Way for Family Leaders



By Anna Cyr

*Family Consultant, Maine
Parent Federation*

Twenty eight years ago, I gave birth to a beautiful, baby girl. As my husband and I basked in the joy of this new life, the beginning of our family, we had no idea that our lives were about to turn into a roller coaster ride of hospital stays, surgeries, intravenous infusions, and countless sleepless nights. We were told our precious daughter would probably not live to see her second birthday.

Now, looking back, when I think of the time spent actually caring for my daughter, I feel a deep sense of pride and accomplishment. The trauma I experienced had more to do with "navigating the system" and being forced to interact with people who didn't understand our family culture. So, when I was offered the opportunity to be a Family Consultant to the Children with Special Health Needs program, I jumped at the chance to effect change for other families. Little did I know what a huge learning curve lay before me!

The genesis of my journey as a family leader came with no instruction manual, no clear cut activities with which to start. I was making it up as I went along. I discovered that my vision of my role was not shared by others. In fact, pretty much everyone I met had a different idea of what my role should be, and some people did not think I should be there at all! As I began to come in contact with other family leaders from around the country, I realized that the roles vary from state to state and agency to agency. I also began to appreciate the flexibility this gave me to figure out how I could best use my skills and strengths to be most effective.

Today, I believe it will be critical to include genuine family and youth involvement as the Affordable Care Act moves forward and families and youth must navigate new waters. This is a time of great opportunity to have a hand in creating the new health care landscape.

Member to Member

We asked members the following question: What does your role as the family delegate look like in your state?

Connecticut



By Ann Gionet
*Health Program Associate,
Connecticut Department of Public
Health*

The role of the Family Delegate in Connecticut follows closely Webster's definition of the word delegate, as "a person acting for another, as a representative."

My efforts as the Connecticut Family Delegate support families in embracing their own roles as representative of other families during discussions around health care. The family experience happens at many levels including: the family seeking health care solutions having a one-to-one connection with another individual; community-level participation where a person may interact with many families; and the family leader with a systems perspective whose efforts may touch families statewide. As the Connecticut Family Delegate, I work to support families at individual, community, and statewide levels in their efforts to shape health care in Connecticut. Examples of family involvement in CT include taking part in the AMCHP Family Scholars Program; reviewing and commenting on the Title V MCH Block Grant, and participation on the Connecticut Medical Home Advisory Council. Family participation is supported through administrative support including compensation through stipends.

Louisiana



By Angela Durand
*Statewide Parent Consultant,
Louisiana Children's Special
Health Services*

Being chosen as the AMCHP Family Delegate representing Louisiana is a significant personal honor for me. It has helped me tremendously by helping me to lead by example. In my state, my role as a Parent Consultant has always been about working with the parent

component, guiding the parents to be strong parent leaders and offering them information to help them be the voice for families with whom they work with. Being a Delegate has allowed me to attend meetings and speak about what is working and what is not, but also being in the know of the changes impacting our work, it has offered me the opportunity to network with other Family Delegates from various states. It all comes together when we attend the AMCHP conference and meet face to face. Currently, I am networking with other delegates and family members to see how we can enhance the experience of new parents who may be attending AMCHP for the first time. We want to establish a sense of belonging, and hope that they recognize what they bring to the meetings is vital. While it may be overwhelming we want them to gain experience to grow and become a leader for families.

I work closely with the block grant director for Louisiana and write for National Performance Measure #2. Being a Delegate allows me to view and assess the data that comes in and for CYSHCN and look at trends in other states. I have learned so much from my colleagues in other states. We stay in contact throughout the year working on various projects and comparing new ideas. I know that the opportunity to be a Delegate has helped me in seeing the larger picture of health care and how it pertains to lifestyle and environment and even culture. In Louisiana we are known for our unique culture and rich delicious food. We also are looking at healthy eating habits of women and children and children in particular with special health care needs. Being a Delegate has helped me to continue to be a voice for Louisiana and the families we see at Children's Special Health Services. I am currently housed at the Southeast Louisiana Area Health Education Center in Hammond, Louisiana and this agency helps me to keep in contact with trends and health care activities for Louisiana, as well as working in the Children's Special Health Services Program.

New Hampshire

By Martha-Jean Madison
Co-Director, NH Family Voices

In 1988, the New Hampshire Title V, CSHCN Program Special Medical Services, brought together a group of stakeholders, pediatricians,



Member to Member CONT.

specialist, and policymakers to look at service delivery systems for children with special healthcare needs. For the first time an invitation was sent to parents who were utilizing these services. Out of curiosity, a handful of parents responded. I was one of those parents. From the very beginning an air of inclusiveness prevailed and a commitment to parent participation was forged. In 1991, through the opportunity off a Special Projects of Regional and National Significance (SPRANS) grant, Special Medical Services had a parent consultant within their program. I was fortunate to be that parent. There was no real blueprint as to how a parent could be integrated into a system that was medically driven. Over the years there have been many ups and downs, trials and errors, but the commitment to bring the family voices to all levels within systems of care has remained a priority. Today, parents are assisting with rules change, block grant activities, including needs assessment, strategic planning, program design and infrastructure building. As a parent, I applaud the New Hampshire Title V program for its steadfast belief in family-centered care.

Who's New

NEW TITLE V & MCH DIRECTOR

MARYLAND

Ilise Marrazzo
Director, Maternal and Child Health Bureau – Office of Family Planning and Home Visiting, Maryland Department of Health and Mental Hygiene

NEW MCH DIRECTOR

INDIANA

Bob Bowman
Director, Maternal & Child Health Division, Indiana State Department of Health

NEW TITLE V DIRECTOR

NEW MEXICO

Denita Richards
Title V Director, New Mexico Department of Health

Who's New CONT.

NEW CYSHCN DIRECTORS

DISTRICT OF COLUMBIA

Sarah Alleem
CYSHCN Director, DC Department of Health

NEW AMCHP BOARD MEMBER



Rodney Farley

Rodney Farley joins the AMCHP Board of Directors as a Director-At-Large. He is currently a Parent Consultant with DDS, Children Services, the Maternal Child Health Title V Children with Special Health Care Needs program in Arkansas. Rodney is instrumental in establishing Parent Support Groups for families with children who have special health care needs throughout the state.

NEW AMCHP STAFF



Barbara Laur

Barbara Laur, MS, joins AMCHP as the Interim Chief Executive Officer (CEO). Prior to AMCHP, Ms. Laur has served in various interim Executive Director/CEO positions, including AMCHP in 2007. As interim Executive Director/CEO, she provides day-to-day management and leadership during the CEO transition period; analyzes organizational needs; and determine activities that would build a stronger platform for the new executive. Prior to her current role as interim Executive Director/CEO, Ms. Laur served as the Executive Director of Florence Crittenton Services of Greater Washington for approximately nine years from 1993-2002. Florence Crittenton Services of Greater Washington is a nonprofit organization dedicated to empowering teen girls to overcome obstacles, make positive choices, and achieve their goals through programs in schools throughout the greater Washington area. Ms. Laur earned her Master of Science in Music Education from Northwest Missouri State University and completed her Doctorate course work in Adult Education from the University of Nebraska-Lincoln.

Get Involved

AMCHP-CDC Skills-Building Suite: Evidence-Based Practice: Moving Along the Continuum from Selection to Sustainability

Recent years have brought an increased focus on the value and necessity of investing in programs that demonstrate evidence of producing desired outcomes. To provide on-going support for “taking what works and applying it,” AMCHP, in partnership with Community Guide staff at CDC, is thrilled to announce the AMCHP-CDC Skills-Building Suite: Evidence-Based Programs: Moving Along the Continuum from Selection to Sustainability. This three-part virtual workshop is designed to increase state MCH program capacity to better understand evidence-based programs, dialogue about opportunities and challenges in implementing evidence-based programs, understand complexity in fidelity and adaptation, and consider evaluation and sustainability of evidence-based programs. The Skills-Building Suite will be presented via 90-minute virtual sessions over three days, Sept. 5, 10 and 13. [Reserve your seat in the Skills-building Suite today!](#) For more information, contact [Sharron Corle](#).

Advances in Longitudinal Structural Equation Modeling Webinar

This webinar is part of the Research Innovations & Challenges (EnRich) webinar series and is presented by MCH Training and Research Resource Center, with co-funding from MCHB Office of Epidemiology and Research. Tune in Sept. 17 from 2-3:30 p.m. EST with presenter Todd D. Little, Ph.D., professor at the University of Kansas. Dr. Little studies developmental changes in how children's and adolescents' action control processes influence their adjustment and achievement in peer relationships, aggression and their ability to cope with stress and challenges. For more information and to register for this webinar, [click here](#).

Webinar Series: Leading in Changing Times

AMCHP efforts to strengthen the capacity of the MCH community to engage in the leadership process recognize that leadership development is a process, not an event. The Leading in Changing Times Series is an initiative launched by AMCHP as part of our larger efforts to support a diverse, effective and competent workforce in state and territorial MCH programs. The webinar series is a year-long, three-part project, blending principles of key leadership theory with real-world stories from senior-level MCH leaders. These 45-minute leadership “conversations” are designed to share leadership ideas

and inspiration. Part 1 of this series, Great Leaders are Great Decision Makers: The Importance of Decisiveness, is scheduled for Sept. 18 at 3:15 p.m. EST. For more information and to register for this webinar, [click here](#).

Toll-Free Hotline Survey for State Title V Program Staff

Federal Title V legislation requires that state maternal and child health agencies establish and maintain a toll-free hotline for families with information about programs and providers. Because of declining call volumes to the existing line and because of multiple other existing lines with similar purpose/function, Tennessee is in the process of evaluating its toll-free Title V line and asked AMCHP to facilitate a process to gather feedback from other states about their lines. This very brief survey asks about the services offered through the line, who staffs the line, whether call volume is changing, and what alternatives, if any, states are using to meet this requirement. If you have any questions, please contact AMCHP staff [Caroline Stampfel](#). To connect to the survey, [click here](#).

Resources

[AMCHP Family Involvement & Leadership](#): AMCHP focuses its efforts to increase family involvement in Title V programs and leadership/activities by supporting family representatives in all aspects of AMCHP's work and providing resources on family involvement. Activities include supporting family representation on all AMCHP committees and work groups and developing or identifying resources for family involvement. AMCHP provides voting rights in the organization through the Family Delegate position. For more information, contact Michelle Jarvis, program manager, family involvement, at (202) 775-1472 or mjarvis@amchp.org.

- [Family Scholars Program](#): The Family Scholars Program (FSP) represents an opportunity to identify, encourage and train family leaders. This 10 month program strives to provide Family Scholars with the knowledge, tools and resources to enhance their development as family leaders, and to promote policies, programs and systems at the national, state and/or local-level that address important issues impacting the health and well-being of women, children and families, including children and youth with special health care needs.
- [Family Delegates](#): Each Title V program paying dues

Resources CONT.

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'.

- [State Profiles in Comprehensive Family Participation:](#) This issue brief highlights six states with differing levels of family participation and what methods they employ to involve families.

[Boston Public Health Commission Father Friendly Initiative:](#)

FFI provides opportunities for low to no income men living in the Boston area to become responsible members of their families and community. The core principles of FFI are based on the belief that father involvement makes an important impact in the life of a child.

[Center for Family Involvement:](#) With the Partnership for People with Disabilities at the Virginia Commonwealth University, the center works with families to increase their skills as advocates, mentors and leaders in order to support children and youth with special health care needs and their family caregivers.

[Early Steps Southernmost Coast Family Resource Specialists \(FRS\):](#) The FRS is a resource for families served through local state Early Steps and is a community link that supports family centered efforts with each local Early Steps. FRS advocates for families and solicits feedback from families within early intervention programs to ensure quality of programs, policies and the delivery of early intervention services.

[Families, Disability and Culture Guide:](#) This online guide is designed to enhance family-centered and -directed practices and cultural competency at both individual and organizational levels. With the belief that families have a pivotal role as the major influence in the lives of CYSHCN, the guide encourages family-professional collaboration as fundamental to practice and serve children and their families.

[The Family Involvement Center:](#) The mission of the Family Involvement Center is to provide assistance and support for family caregivers while helping policymakers, agencies and providers to transform systems, all to ensure that children and youth with emotional, behavioral or mental health disorders succeed and become productive adults.

[Family Involvement Conference:](#) Based on the belief that

active family involvement in the educational process is the key to effective schools and student achievement, the goal of the conference is to bring together parents and academic professionals in a common forum to address issues that are vital to the well being and success of our youth.

[Family Resource Center Supporting Father Involvement:](#)

The SFI project is a family focused, evidenced-based intervention aimed at effectively engaging fathers as key participants in family support and strengthening. It is also a method of fostering organizational development and growth for agencies and professionals serving at risk families.

[Family Voices:](#) The mission of Family Voices is to achieve family-centered care for all children and youth with special health care needs. They provide families with tools and support in order to make informed decisions, advocate on behalf of CYSHCN for improved public and private policies and serve as a trusted resource on health care.

[Harvard Family Research Project:](#) The Harvard Family Research Project recognizes the growing demand for information on effective ways to support family involvement in early learning and development and is committed to strategies that support children's learning in school, at home and in the community.

[Institute for Patient- and Family-Centered Care \(IFPCC\):](#) IFPCC provides leadership to advance the understanding and practice of patient- and family-centered care. In partnership with patients, families and health care professionals, the institute seeks to integrate these concepts into all aspects of health care.

[Maternal and Child Health Bureau \(MCHB\):](#) MCHB is part of the Health Resources and Services Administration, U.S. Department of Health and Human Services and is responsible for meeting the needs of the MCH populations of the United States and its jurisdictions.

[MCHB Leadership Education in Neurodevelopmental and Other Related Disabilities Program:](#) LEND provides funding to programs within university systems and collaborates with local university hospitals and health care centers. The purpose of the LEND training program is to improve the health of infants, children, and adolescents with disabilities. This is accomplished by preparing trainees from diverse professional disciplines to assume leadership

Resources CONT.

roles in their respective fields and by insuring high levels of interdisciplinary clinical competence.

[MCHB National Center for Family/Professional Partnerships Program](#): NCFPP offers technical assistance to community leaders and partners with key stakeholders in order to provide leadership on implementing the core components of a system for CYSHCN in which families partner in decision making at all levels and are satisfied with the services they receive.

[MCH Library at Georgetown University: Children and Youth with Special Health Care Needs Knowledge Path](#): This knowledge path offers high quality resources and reports on data, effective programs, policy and research aimed at systems of care that are family-centered, community based and culturally competent.

[MCH Organizations Database](#): This database contains contact information for groups concerned with specific illnesses and disorders, genetic services providers, government offices and agencies, national centers for children and youth with special health care needs, networks and support groups for parents, professional associations and providers of services and products.

[MCH Navigator](#): 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.

- [Increasing Meaningful Partnerships between Families and MCH Partnerships](#): the focus of the lesson is on the importance of involving and partnering with families at all levels of programming and leadership in public health organizations – especially organizations that work with children and individuals with special health care needs.
- [Family Advocacy and Involvement in Title V Programs](#): this webcast reviews the role of family advocates in collaborating with Title V program staff.
- [Title V: The Evolution of Family Partnership](#): this section of the MCH Timeline is divided into six modules, and includes a discussion with Merle McPherson, MD, MPH on past Title V programs, as well as personal stories from individual families who struggled prior to Title V reinvention.
- [Every Child Deserves a Medical Home](#): a five-minute introductory video provides an overview of “Every Child

Deserves a Medical Home” and is followed by several short feature narratives presented by pediatricians, other health care providers, and families who – in their own words – describe what “medical home” means to them.

[Minnesota Title V MCH Needs Assessment Fact Sheet: Pregnant Women, Mothers and Infants: Male-Father Involvement in Reproductive Health and Parenting](#) highlights the issues surrounding a lack of male involvement in childbirth, the size and spread of the problem in Minnesota, and the grave outcomes for women and children resulting from such. The fact sheet also provides information on interventions in the state and details their effectiveness.

[National Alliance for Secondary Education and Transition](#): NASET recognizes family involvement in a child’s education as the single most important factor in school success and achievement. NASET promotes family involvement in order to support the social, emotional, physical, academic and occupational growth of children.

[Parent to Parent USA](#): P2P USA presents contact information for statewide parent-to-parent programs. The programs provide emotional support and information to families of children and youth with special health care needs. In particular, the programs match parents seeking support with trained and experienced veteran parents who have shared the experience of disability in the family. P2P USA also offers technical assistance and resources to parents interested in building, improving and evaluating a program.

[Sibling Support Project](#): This national effort is dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental or mental health concerns. The project includes online discussion groups for siblings and for parents of the siblings and presents publications for and about siblings.

[Where is the F in MCH? Father Involvement in African American Families](#): The objective of this study was to review the historical contexts and current profiles of father involvement in African American families, identify barriers to, and supports of, involvement, evaluate the effectiveness of father involvement programs and recommend directions for future research, programs, and public policies.

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Maritza Valenzuela, MPH, CHES, *Program Manager, Adolescent Health*

Karen VanLandeghem, MPH, *Senior Advisor, National Center for Health Reform Implementation*

Sophie Wiley, *Intern, Organizational Performance and Member Services*

Calendar

AMCHP Events

[AMCHP 2014](#)

Jan. 25-28

Washington, DC

Association of Maternal & Child Health Programs

2030 M Street, NW, Suite 350

Washington, DC 20036

(202) 775-0436

www.amchp.org

Calendar CONT.

MCH Events

[ARHP 50th Annual Reproductive Health Meeting](#)

Sept. 19-21

Denver, CO

[2013 Annual Urban Maternal and Child Health Leadership Conference](#)

Sept. 23-25

Savannah, GA

[87th Annual American School Health Association Conference](#)

Oct. 9 - 12

Myrtle Beach, SC

[APHA Scientific Writing for Peer Reviewed Publications for Public Health Professionals Course](#)

Nov. 2

Boston, MA

[2013 American Public Health Association Annual Meeting](#)

Nov. 2-6

Boston, MA

List Your Event on the AMCHP MCH Events Calendar

Do you want to include your listing on the AMCHP MCH Events Calendar? It's easy! Just complete our easy [online submission form](#). You are welcome to submit MCH conferences, webinars, trainings, webcasts and meetings. Thanks for helping us to build our MCH Events Calendar! If you have any questions, please contact [Julio Arguello Jr.](#), Online Media & Information Technology Manager. Please note: All event listings are subject to AMCHP approval.

