



# PULSE

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

## CYSHCN and Systems Building

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## From the President

By Stephanie Birch, RNC, MPH, MS, FNP



One of the core functions of maternal and child health (MCH) and children and youth with special health care needs (CYSHCN) programs is to work with partners and families to develop or enhance systems of care. MCH and CYSHCN staff members are the ideal personnel to lead this effort due to their close working relationships with families and consumers of health care. Systems development that includes coordinated care was initially advocated for by parents of children with special health care needs and more recently has extended into other populations and policies, including the most recent federal legislation under the Affordable Care Act.

Systems of care are now a part of preventative health care, as well as care for all populations especially focused on those with chronic health care issues. Many large health care systems such as Kaiser and United Health Group have demonstrated that care developed in a systems focused manner reduces cost and error rates. Patient satisfaction is increased substantially when care is coordinated and systems focused as well. This issues of *Pulse* shares what states are doing to support this work across agencies and programs. We hope that you will pick up new ideas and apply them to programs you work in.



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## From the CEO

By Michael R. Fraser,  
PhD, CAE



The core functions of public health are familiar to many of us: assessment, assurance and policy development. These three functions take place within a context – a system. Simply defined, a system is a constellation of parts that is held together by a common purpose, communicates and adjusts as needed to move forward toward the shared goal. MCH programs have long taken a “systems” perspective in their work. MCH leaders know that there are many parts and players in the work we do to improve the lives of women, children, fathers and families. No single entity can truly impact MCH outcomes. Instead, we work together to improve and sustain systems that support health. Contemporary public health practice involves “systems building” to address the issues and concerns of MCH. Often, the Title V MCH Services Block Grant is the only source of funding in a state to support cross-cutting, systems-building work. Other funding streams limit the extent to which a program can reach out of its silo to develop and advance shared goals. As such, one of the most valuable aspects of Title V is its flexible, systems-building perspective to meeting state MCH needs.

No one understands the positive and negative aspects of a system better than those who work with and care for CYSHCN. Complex needs require complex care; care that takes a systems perspective by definition. Indeed, quality care involves multiple providers from many different sectors working together to address the health needs of a child and their family. Good care for kids with complex health care needs does not come easily but it makes a huge difference: when caregiving is coordinated and goals are aligned, the child and family do better, providers are more effective, and care is delivered more efficiently. While care for CYSHCN is often held up as the place where “systems of care” are the most important, a systems-based approach to care for all kids is our ultimate aim – what we do for children with complex health care needs also will help improve care for typical children.

This issue of *Pulse* highlights some of the ways that MCH programs take a systems-building perspective in their work. I can think of few other disciplines that are so readily adept

## From the CEO CONT.

at coordinating, collaborating and communicating to reach a shared goal. MCH brings multiple sectors together to leverage and enhance care for many different groups of folks within a community, region or state. I hope this issue encourages your own attempts to build and sustain MCH systems in your work. Use this issue to help guide your efforts, learn from peers and contribute to systems building in your state! You'll be glad you did!

## Feature AMCHP to Convene Stakeholder Work Group to Develop National Consensus Framework for Improving Quality Systems of Care for CYSHCN



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

AMCHP, with funding from the Lucile Packard Foundation, is leading a project to compile, define and reach consensus among key national stakeholders on the desired capacity and performance

of systems of care serving CYSHCN. Creating a comprehensive, quality system of care for CYSHCN has been one of the most challenging and pressing priorities for state health leaders and other stakeholders, such as pediatricians and family physicians, health plans, state Medicaid and Children's Health Insurance Program (CHIP) agencies, and families. The *Patient Protection and Affordable Care Act (ACA)* has further heightened this need as states prepare to extend coverage to millions of uninsured adults and children, design Essential Health Benefits, and implement new quality provisions, among other areas.

Achieving consensus on the desired capacity and performance of systems of care serving CYSHCN is essential to building and strengthening comprehensive, quality systems of care for these children. Over the past two decades, numerous national reports, initiatives, and

## Feature CONT. AMCHP Convenes Stakeholders

research have described frameworks, standards and various measures for such a system. For example, the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) adopted six critical system outcomes for children and youth with special health care needs. The framework serves as an important guide for state CYSHCN programs in developing systems of care. Other related work includes, but is not limited to, the Title V MCH Services Block Grant performance measures and health system capacity indicators, National Committee on Quality Assurance quality standards, the Child Health Insurance Program Reauthorization Act (CHIPRA) Quality Measures, and the Pediatric Managed Care Contracting Purchasing Specifications developed by The George Washington University.

These and other efforts have helped create an important starting point for many states, communities, providers and national organizations to build systems of care for CYSHCN. However, they have not all resulted in states, communities and providers having the specific tools and resources to use and apply a commonly recognized and endorsed national set of standards for systems of care serving CYSHCN to fully measure progress, improve health care quality, and improve health outcomes for this population of children.

This project will compile and synthesize this work into a document that is endorsed or supported by a national group of stakeholders, including AMCHP, the American Academy of Pediatrics, the HRSA/MCHB, Family Voices, and the National Association of State Medicaid Directors. Additional materials, such as a toolkit, that states could use to strengthen their systems of care for CYSHCN also may be developed.

A National Stakeholders Work Group comprised of representatives from state Title V CYSHCN programs, state Medicaid agencies, provider groups, children's hospitals, families, and others will be convened to build and reach consensus on desired capacity and performance of systems of care serving CYSHCN. The work group also will provide guidance to the development of a national consensus document that outlines and describes desired capacity and performance of systems of care serving CYSHCN. For more information about the project, please contact [Karen VanLandeghem](#), senior advisor to AMCHP and project director, or [Treeby Brown](#), associate director, child and adolescent health, AMCHP.

## Feature

### “Moving the Needle” on Systems of Services for CYSHCN

By Bonnie Strickland, PhD

Director, Division of Services for Children with Special Health Needs, MCHB

The Block Grant Review is behind us for another year and, as always, I am struck by the widespread reach and leverage of the state/federal partnership. Over the years, I also have been struck by the observation that the Block Grant Review process provides an excellent opportunity to illustrate how Title V, including CYSHCN programs, addresses the broad CYSHCN population defined in 1998 as, “... those who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.”

The definition of CYSHCN is purposefully broad because it is intended to provide an inclusive, public health perspective on CYSHCN, rather than a treatment-oriented, condition-specific perspective. In fact, most CYSHCN may not receive direct services from the state Title V CYSHCN program at all. A significant proportion of CYSHCN are more likely to be benefiting from the broader MCH program and other service sectors than receiving direct/enabling services from the Title V CYSHCN program. Through the multiple programs and core public health functions of Title V, it is likely that MCH, in some way, touches most, if not all, children and youth included in the definition. With the provisions and imminent implementation of the ACA, the need to clearly articulate the role of Title V in the context of this legislation, and the emergence of the life course perspective as a driver in MCH programs, now seems like a good time to consider, and articulate, exactly how MCH programs work together purposefully, and with partners, to “move the needle” on facilitating the comprehensive system of services for CYSHCN required by the *Omnibus Budget Reconciliation Act of 1989* (OBRA 89).

During the past decade, we have conducted the National Survey of Children with Special Health Care Needs (NS-CSHCN) three times. The survey was the first, and remains the only, survey of its kind designed to utilize the common definition of CYSHCN (minus the “at-risk” component) to provide national and state prevalence estimates, as well as a barometer on how CYSHCN and their families fare in the health care system. The survey has informed thousands

of studies, Healthy People 2010 and 2020 Objectives, and the national performance measures for the Title V Annual Report. Yet, progress toward the “comprehensive system of services” envisioned by OBRA 89 remains slow. The 2009-10 NS-CSHCN indicates that, while many CYSHCN have access to components of a well-functioning system, only a small percentage have access to all six components including: family/professional partnership; access to care through the medical home; adequate financing for needed services; early and continuous screening; organization of services for easy use; and services necessary to transition to adult health care.

“Moving the needle” is certainly not easy. The bar is set intentionally high, and the inclusive definition of CYSHCN, by design, cannot be addressed by a single program. But it can be accomplished with the concerted and coordinated effort across all Title V programs, and deliberate, focused collaboration with partners, including education, child care, health plans, Medicaid, professional organizations, and CYSHCN and families, to name a few. While extensive partnerships are a hallmark of Title V programs, it is not always apparent how these partnerships work together to specifically create the seamless system of services and supports required by the broad population of CYSHCN, as well as those served through the state CYSHCN program. For 2013, I would like to challenge each Title V MCH and CYSHCN program to take another look at the broad definition of CYSHCN and consider the extent to which a clearly articulated system is in place for the broad population of CYSHCN and their families; the extent to



## Feature CONT. Moving the Needle

which the five-year needs assessment process facilitates assessing the gaps for the broad population; and the extent to which the Block Grant application reflects the extent to which Title V programs work together and across programs to ensure an inclusive approach to addressing the needs of the broad population of CYSHCN.

Despite tough economic times, we have seldom had a better opportunity to “move the needle” on access to a well-functioning system of services for CYSHCN and their families. The ACA includes unprecedented opportunities to improve coverage and quality of care; new home visiting programs in almost every state extend the capacity of Title V and partners to directly impact at-risk and vulnerable children and families; significant grant programs provide opportunities to demonstrate and spread models that work; and the science of quality improvement has evolved to a point that we can carefully monitor the impact of our programs. As we move toward realizing the vision established by OBRA 89 of an inclusive and comprehensive system of services for CYSHCN and their families, we have a great opportunity to demonstrate the broad reach of Title V, and the rich legacy of partnership, infrastructure building, and resource leveraging, to advance the system of services for ALL CYSHCN and their families.



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## Feature Adolescent Systems Capacity (ASC) Tool Helps Identify and Implement Organizational Improvements



**By Sharron Crawford Corle, MS**

*Associate Director for MCH Leadership and Capacity Building, AMCHP*

**Maritza Valenzuela, MPH, CHES**

*Adolescent Health Program Manager, AMCHP*

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*Senior Program Analyst, Maternal, Child, and Adolescent Health, NACCHO*

State and local public health departments play an active role in ensuring the health and development of adolescents. In order to do this, maternal, child and adolescent health programs must have the organizational capacity to support adolescent health-focused efforts and improve coordination and integration of adolescent health services and programs. Modeled after Capacity Assessment for State Title V (CAST-5), the Adolescent Health System Capacity Assessment Tool (SCAT) was developed in 2005 as a resource to help state maternal and child health programs assess six key areas of organizational capacity related to adolescent health: commitment to adolescent health; partnerships for adolescent health; program planning and evaluation; surveillance and data systems; education and technical assistance; and policy and advocacy. The ultimate goal of the assessment is to identify areas for organizational improvement and implement strategies to address them.

Since 2005, a number of state health departments have used the SCAT to advance their adolescent health systems and programs. In 2011, recognizing the critical role that local public health plays in improving health outcomes, AMCHP initiated a project with the National Association of County and City Health Officials (NACCHO) to revise the

## Feature CONT. ASC Tool

SCAT to help local public health practitioners assess their organizational capacity to support adolescent health. The first phase of the project was to gather local public health input on the existing tool. To accomplish this, AMCHP and NACCHO brought together a group of local public health practitioners and their key adolescent health partners (i.e., local education agencies) to identify the strengths of the tool, any weaknesses or gaps, and any recommended modifications to the tool to make it better serve local public health practitioners. The revision of the tool was completed in the summer of 2012. Phase two of the project is piloting the revised tool. Through a combination request for applications and invitation process, AMCHP and NACCHO identified six local public health agencies (Chicago Department of Public Health, Illinois; New Britain Health Department, Connecticut; Union County Health Department, Ohio; Deschutes County Health Services, Oregon; Douglas County Health Department, Nebraska; Sedgwick County Health Department, Kansas) interested in piloting the revised tool and brought together the pilot teams for a kick-off meeting in September of 2012. AMCHP and NACCHO are using a concept called collective impact as the framework for the efforts. Collective impact, as defined by the original article *Collective Impact in the Stanford Social Innovation Review*, “*is the commitment of a group of important actors from different sectors to a common agenda for solving a specific...problem.*” We felt that the framework would resonate with public health practitioners who have long recognized that complex societal problems cannot be solved by one organization alone (i.e., the health department) and require collaborative effort across and between organizations. Additionally, the framework was a natural fit given that the five conditions critical for collective impact to work – a common agenda, shared measurement, mutually reinforcing activities, continuous communication and backbone support – are very similar to what the ASC tool is designed to do: *provide a structured process that leads to a common agenda (development of quality improvement plans), shared measurement, continuous communication and mutually reinforcing activities among all participants* to improve adolescent health outcomes.

These efforts can only be realized, however, if the initiative has the infrastructure (time and resources and skills) to effectively support cooperative collaboration. In regard to the collective impact framework, the organization that spearheads the initiative is called the backbone organization. The backbone organization is responsible for

bringing together the right stakeholders to dialogue about current efforts, reach consensus on gaps and priorities, help the group develop appropriate strategies to address them (or identify their particular niche in addressing them), and measure the success of the initiative. Successfully filling the role of the backbone organization requires a specific set of characteristics: a boundary-spanning approach to leadership; an ability to provide strategic direction; the ability to create a sense of urgency and need for a change; and the capacity to communicate effectively, mobilize stakeholders and, most importantly, facilitate productive dialogue. Anyone who has ever been a part of a collaborative effort can understand the critical importance of the ability to facilitate productive dialogue. Recognizing this, AMCHP and NACCHO invested in enhancing the skills of the pilot site teams by requiring attendance at a two-day Technology of Participation (ToP) facilitation training. Created by the Institute of Cultural Affairs, ToP techniques provide a structured process that enables a participatory, inclusive group process. AMCHP and NACCHO also provided some resource support in the form of small pockets of demonstration grants. Our hope, and the underlying theory behind building the capacity of our pilot sites, is that supporting their efforts to be effective backbone organizations will increase the likelihood of a successful initiative. Like any theory, however, the data will ultimately tell the story.

Over the past eight years of using the tool (it was first piloted in 2004), we have found that defining systems capacity can be challenging. What do we mean by systems? And, what do we mean by capacity? Systems are composed of many interconnected systems and subsystems. The adolescent health system, for example, includes many stakeholders outside of the health arena: education, juvenile justice, parks and recreation, and transportation to name a few. System capacity, in regards to adolescent health, is the overall ability of the system to address adolescent health effectively, efficiently and sustainably. Building system capacity requires key stakeholders, agencies, partners, entities, etc., to communicate and collaborate in order to leverage their efforts and maximize their impact on identified outcomes, in this case adolescent health. Effectively working together to achieve common outcomes is at the heart of collective impact. We are eagerly looking forward to seeing some of the change efforts that result from the local public health adolescent health assessments – and will be sharing insights and lessons learned.

## Feature

# AMCHP and National Center for Ease of Use of Community-Based Services Support Focus on Latino Families With CYSHCN

By Myra Rosen-Reynoso, PhD

Research Associate, Institute for Community Inclusion,  
University of Massachusetts Boston

AMCHP and the National Center for Ease of Use of Community-Based Services are partnering to sponsor an action learning collaborative (ALC) focused on addressing state policies and practices that enable ease of use of services for Latino families with CYSHCN. In April 2012, the following four states were selected to participate: Indiana, New Hampshire, New Mexico and Rhode Island. In addition, North Carolina and Oregon were chosen as lead mentoring states. This ALC program links states with

two lead states and provides a tailored technical assistance model around the MCHB Indicator Five for Ease of Use of Community-Based Services for Latino Children and Youth with Special Health Care Needs. The Title V program in each of these states has been working on a specific project with a variety of partners, such as Family-to Family Health Information Centers, the American Academy of Pediatrics, LEND programs, local school districts, Medicaid, Head Start and Latino community-based organizations.

The following is a brief overview of each state project:

*Indiana* has brought together a team, including representatives from numerous Latino community-based organizations and state commissions, to develop and implement a strategic plan for addressing ease of use of services for Latino families with CYSHCN.

## ACT EARLY STATE SYSTEMS GRANTS

In order to support the collaboration of these summit teams, and to further the activities initiated by state teams during the Act Early Summits, AMCHP will award grants to state teams in the amount of up to \$15,000 for a 12-month period. Keeping in mind both the opportunities and limitations associated with this relatively modest amount of funding, the state team will use this funding to build on and complement other state activities as outlined in their state plan, which are designed to strengthen state and community systems for early identification and intervention for children with signs of autism spectrum disorder and other developmental disorders (ASD/DD).

AMCHP will provide ongoing technical assistance, disseminate resource materials, and link grantees to other states and experts in ASD/DD. To access your state materials or find information about the Act Early Regional Summit Project, please refer to the AUCD [website](#).

Grant Funds: Grant funds will be awarded in one award of up to \$15,000. Grant funds cannot be used to pay for salaried employees, equipment, software, individual trainings, conference or course registration, primary research, publications, personnel or indirect expenses.

AMCHP will offer grantees:

- Ongoing technical assistance via a variety of methods, including telephone, e-mail, online discussion boards, and webinars from AMCHP staff and partners
- Structured peer support, a forum to network, share ideas and problem-solve with colleagues nationwide working on similar issues
- Technical expertise and consultation, information from leading national experts in the field of ASD/DD

To access a full copy of the RFA, please [click here](#).

2012 – 2013 State Grantees:

- Arkansas
- California
- Georgia
- Maryland
- Nevada
- New Hampshire
- New Jersey
- Oregon
- Virginia
- Wyoming

## Feature CONT. AMCHP Latino ALC

*New Hampshire* has been working on a health literacy campaign to identify messages and information related to the upcoming mandated changes to New Hampshire Medicaid and Children's Health Insurance Program that need to be effectively communicated to Latino families with CYSHCN.

*New Mexico* has been focusing on making services easier to use for Latino children and youth with diabetes and metabolic disorders.

*Rhode Island* has been working with public school personnel to refer Latino families with CYSHCN to parent leaders with the Latino community and has been training parent leaders to serve as peer navigators.

This month, all of the participating states met in Raleigh, North Carolina with the North Carolina Title V director and staff to learn from one another about building systems of care for Latino CYSHCN, share lessons learned and best practices, and develop action plans. In addition, there were presentations from families, parent leaders and professionals working with Latino families in North Carolina. These presenters included:

Melissa Bailey, Executive Director, North Carolina Field, who shared success stories and challenges in trying to connect farmworker families/children to services.

Mariela Maldonado, Hispanic Affairs Liaison, NC Autism Society, who led a discussion on how the Autism Society has been able to create five support groups across metro areas in the state for Latino families with autistic children.

Debbie Biggerstaff, Innovative Approaches Coordinator, Carbarus County Health Alliance, who shared findings from the Innovative Approaches focus groups with Latino families to improve services for Latino families throughout North Carolina.

Norma Martí, Public Health Minority Outreach Consultant, North Carolina Division of Public Health, who provided extensive information about the systems of care for Latino CYSHCN in North Carolina and local parent Promotora programs.



Key themes that emerged throughout the meeting included: challenges in interpretation and translation for Latino families, renewed commitment to developing partnerships including those external to the MCH programs, embedding family involvement

and promoting family leadership in programming, rigorous evaluation and sustainability. Some resources from this meeting are available on the center website at: [communitybasedservices.org](http://communitybasedservices.org).

On Feb. 9, at the 2013 AMCHP Annual Conference, there will be a pre-conference skills-building session that will include several of the participating ALC states with presenters discussing the importance of partnership and peer learning for improving the ease of use of services for Latino families who have CYSHCN, lessons learned, and how their projects can be implemented in other states.

This ALC is supported by Grant No. U42MC18283 from the Maternal and Child Health Bureau, U.S. Department of Health and Human Services, Division of Services for Children With Special Needs.

## Feature Systems-Level Impact: Using the Collective Impact Framework for Public Health Systems Building

**By Erin Bonzon, MSPH/MSW**  
*Associate Director, Women's & Infant Health, AMCHP*

**Tegan Callahan, MPH**  
*Program Manager, Women's & Infant Health, AMCHP*

Systems-wide progress requires decisions and actions that develop strong partnerships. Partnerships will be at the core of any comprehensive initiative. Yet, partnerships for improving



## Feature CONT.

### Collective Impact

maternal and child health outcomes need to go beyond traditional collaborations and public-private partnerships in order to develop collective impact and influence systems change. The concept of 'collective impact' was introduced in a 2011 article in the Stanford Social Innovation Review (Collective Impact, Kania and Kramer). Collective impact is a structured approach to creating collaborative partnerships with a specific focus on working together to solve complex social and health problems that do not have a single, defined source or solution. Collective impact proposes bringing together people and organizations from across multiple sectors (economic, education, health, housing, environment, business, law enforcement, etc.) to

accomplish a shared set of goals.

In order to make progress on improving systems, public health partnerships should embody a 'collective impact' approach to improving social outcomes. Collective impact is the commitment of a group of important actors from different sectors to a common agenda for solving a specific social problem. Social innovation researchers found that successful collective impact initiatives have five core characteristics:

- **Common Agenda** – a shared vision for change that includes a common understanding of the problem and

#### Improving the System of Services for Children and Youth with Special Health Care Needs Through D70 Implementaion Grants

Improving the System of Services for CYSHCN is the primary goal of the D70 HRSA-funded state implementation grants. A recent webinar presentation and discussion of D70 grants highlighted successes of the grants in various states and their implications for the future of systems of care for CYSHCN. States have used D70 funds in a variety of ways to address systems building.

**Identification of CYSHCN:** North Dakota Integrated Services employs a team, including a primary care physician, care coordinator and two family partners, as the foundation for their systems of care. Other components include regular screening to identify CYSHCN, a comprehensive resource list available to families, care plans, pre-visit calls and information meetings by parent partners.

**Medical Homes:** Pennsylvania has supported medical home implementation and transition services as part of their systems of care for CYSHCN. Partnerships with family and youth play a key role in facilitating this implementation.

**Cultural Competency:** With their D70 grant, Missouri has created sustainable change to support their systems of care for CYSHCN. Their primary focus is improving family centered, coordinated, culturally competent care.

**Child Health Improvement:** New York has aligned CYSHCN program activities with other child health improvement strategies through coordination and quality improvement initiatives. They also have implemented best practice standards for children with autism.

**Family Partnerships:** Navajo Nation (Arizona, New Mexico, Utah) – Diné for our children. This program created a grassroots movement that fostered cultural expansion, cultivated partnerships, empowered teams of parents and CYSHCN to become leaders and tasked families with key project roles and responsibilities.

While numerous states have implemented successful programs, more works needs to be done to move health care for CYSHCN toward an integrated system. Strategies for systems integration that were mentioned include: building, enhancing and maximizing partnerships; engaging family and youth as partners; continuous quality improvement; using data to build capacity and measure impact; and providing technical assistance, resource and support.

## Feature CONT. Collective Impact

a joint approach (i.e., agreed on actions) to solving the problem. In order to reach a common agenda, disagreements and differences in the definition of 'the problem' or 'the goal' must be addressed.

- Shared Measurement Systems – agreed on ways in which success will be measured and reported are aligned and all participating organizations can hold each other accountable and evaluate successes and failures along the way.
- Mutually Reinforcing Activities – the efforts of each stakeholder must fit into an overarching plan of action. Collective impact does not require all stakeholders to do the same thing, rather, each stakeholder should undertake a specific set of activities in which they are apt to excel, which is coordinated with the actions of others.
- Continuous Communication – a shared vocabulary and, eventually, trust will develop through regular meetings. Stakeholders need to have constant contact with one another in order to recognize and appreciate common motivations, see their own interests will be treated fairly, and believe that collective decisions will be made based on the best possible solution to the problem.
- Backbone Support Organizations – collaboration requires a support infrastructure. The most effective examples of collective impact have staff dedicated to the planning, management and support of the

initiative. Staffing requirements for large collective impact initiatives may be as simple as: project manager, data manager and meeting facilitator.

AMCHP is currently using collective impact as a framework to guide initiatives and promote partnerships at the state and national level. Three current AMCHP initiatives that highlight the principles of collective impact and promote a collective impact approach include the Best Babies Zone (BBZ) partnership, the Adolescent Systems Capacity Tool and our new ALC phase for our ongoing project to help state MCH programs Optimize Health Care Reform to Improve Birth Outcomes.

The BBZ is a multisector approach to reducing infant mortality and racial disparities in birth outcomes and improving birth and health outcomes by mobilizing communities to address the social determinants that affect health. The BBZ approach is focused on non-traditional partners (i.e. public health, economic development, community development and education agencies) aligning under a common agenda. The development of a clear and transparent action plan is an important step in implementing BBZ, as well as central to developing a common agenda under a collective impact framework. The BBZ action plan will include a clear model of the overarching initiative framework, and a clear path toward implementing the community assessment and site partnership development and coordination. Also central to the BBZ common agenda are shared evaluation measures, currently under development, that will align the efforts within project sites as the initiative moves forward. Other aspects of collective impact highlighted by the BBZ include continuous communication and backbone support. Communication and trust are key features of the BBZ initiative; project sites are encouraged to set-up regular collaborative meetings with their partners and the overall project will support sites in their efforts to coordinate and facilitate these collective relationships. Finally, the project provides backbone agency support on two levels. Locally, community efforts are supported through an identified backbone agency at within each of the four BBZ pilot communities. In addition, a National Leadership Team provides overall project coordination and backbone support through identifying strategies and providing technical assistance to develop cross-sectoral partnerships and coordinate the collective processes for the BBZ Initiative.

### Feel like you are missing something?

AMCHP Members receive our member-only, bimonthly publication *Member Briefs*. *Member Briefs* is a succinct, easy-to read summary of useful information for MCH leaders. Each issue of *Member Briefs* includes plenty of news you can use including:

- Current News from Washington
- Funding Opportunities for MCH programs
- Our MCH Calendar and Events
- Leadership Lesson and Best Practices from Peers
- Opportunities to Get Involved
- And more!

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### Collective Impact

The Adolescent Systems Capacity Tool was developed in 2005 as a resource to help state maternal and child health programs assess six key areas of organizational capacity related to adolescent health: commitment to adolescent health; partnerships for adolescent health; program planning and evaluation; surveillance and data systems; education and technical assistance; and policy and advocacy. The ultimate goal of the assessment is to identify areas for organizational improvement and implement strategies to address them. In 2011, recognizing the critical role that local public health plays in improving health outcomes, AMCHP initiated a project with NACCHO to revise the SCAT to help local public health practitioners assess their organizational capacity to support adolescent health. AMCHP and NACCHO are using collective impact as the framework for the efforts. A collective impact approach was a natural fit for guiding the redesign of the ASC tool because the five conditions that are critical for collective impact to work are very similar to what the ASC tool is designed to do: provide a structured process that leads to a common agenda (development of quality improvement plans), shared measurement, continuous communication, and mutually reinforcing activities among all participants to improve adolescent health outcomes. (*To learn more, see the article on page 5.*)

Lastly, the new cohort of state teams for the AMCHP Optimizing Health Care Reform to Improve Birth Outcomes project ALC will be provided with direct technical assistance and training on collective impact approaches for state-level initiatives to improve birth outcomes. AMCHP recently redesigned the ALC component of this ongoing project in reaction to multiple, exciting, concurrent national initiatives directed at improving birth outcomes and reducing infant mortality. Some of these initiatives include the MCHB Collaboration and Innovation Network (COIN) in regions IV and VI, the Association of State and Territorial Health Officials Healthy Babies Challenge, and the Center's for Medicaid Services Strong Start Initiative. These initiatives create a current environment of opportunity which provides partners at the state and local levels significant leverage to make coordinated improvements to birth outcomes and, subsequently, overall population health. AMCHP will provide state teams selected for the ALC with direct training on collective impact in order to coordinate participation in multiple initiatives. In particular, the project will offer ALC states:

- Ongoing technical assistance to develop and implement strategies for using a collective impact framework to improve birth outcomes through health reform
- A forum to network, share ideas and problem solve with colleagues nationwide working on improving birth outcomes through health reform
- Information from leading national experts in various fields (i.e., collective impact, improving birth outcomes including preconception health, and health reform)

These three project areas – Best Babies Zone, the Adolescent Systems Capacity Tool and the Optimizing Health Care Reform to Improve Birth Outcomes project ALC – are examples of how AMCHP is actively promoting the principles of collective impact. By thinking about how we collaborate with partners and provide opportunities to members that enhance their ability to coordinate activities across multiple priority areas, AMCHP hopes to enhance our contribution to a collective MCH health system across the country.

## Feature

### Opportunities for Systems Integration Put into Motion with MCH Leadership

**By Carolyn McCoy, MPH**  
*Senior Policy Manager, AMCHP*

**Kate Howe, MPH**  
*Program Manager, Child Health, AMCHP*

Systems integration is an important priority in achieving maximum public health benefit. With most public and private health care insurance and delivery systems historically operating in parallel, there has been little or no coordination among providers or payers. As a result, families often have to navigate complex systems unassisted. Providers are



## Feature CONT.

### System Integration into Motion

often reluctant to refer patients for additional services and supports, such as home visiting and care coordination, from community-based agencies that they know little about, and public and private systems risk duplication of effort. This issue is even more critical for CYSHCN who require level of services beyond other children. Title V programs have long recognized this priority and worked to provide comprehensive, collaborative systems of care for women, children, families and children with special health care needs. Recent efforts at federal, state and local levels have underscored this need. Dr. Michael Lu, associate administrator for maternal and child health at HRSA, has outlined the MCHB approach to integration of the MCH system as one that is “vertical (appropriate levels of care), horizontal (service coordination and systems integration) and longitudinal (the continuum of care across the life course).” This focus, along with other efforts, present important opportunities for state MCH programs to take leadership in systems integration.

The ACA gives states new tools and funding to integrate public and private delivery of health care services. Also at the national level, the Institute of Medicine (IOM) of the National Academies, recently published a framework and recommendations for how primary care systems and public health departments can improve integration. The IOM committee selected health topics that follow the life course perspective, involve mental and behavioral health and there are evident health disparities. One of the selected examples is MCH and within that topic, the Maternal, Infant, Early Childhood Home Visiting Program (MIECHV). The IOM report delineates a set of recommendations on how agencies can work toward systems integration, all of which are functions that Title V programs encompass nationally and have traditionally been the nexus for systems integration of population health and primary care.

State MCH programs are well positioned to optimize the opportunities availed by the ACA through such provisions as MIECHV, Community Transformation Grants and the Centers for Medicare and Medicaid Services (CMS) Strong Start for Newborns and Mothers Initiative and national momentum brought by the IOM report to further integrate public health and primary care. Some of that work has already begun through national and federal efforts. The Commonwealth Fund/AMCHP issue brief and [webinar](#),

[“New Opportunities for Integrating and Improving Health Care for Women, Children and Their Families”](#) highlights the efforts of states to integrate health care services for low-income women and children, especially through state Title V maternal and child health programs. The MCHB-launched the [COIN](#) to reduce infant mortality in the 13 southern states of Regions IV and VI represents another effort to bridge silos across programs and states in order to share practices and innovation to improve birth outcomes. The COIN builds on the success of the Infant Mortality Summit held in January 2012, at which the 13 states in Public Health Regions IV and VI developed plans to reduce infant mortality and improve systems.

In addition to the myriad of opportunities for systems integration presented through home visiting and other MCH programs, Title V programs also are assisting in integrating behavioral health and primary care. The Substance Abuse and Mental Health Services Administration (SAMHSA) is currently convening efforts to promote this integration and has engaged state MCH programs in this work. Title V programs are important partners in this work given the focus on state populations and program design that requires collaboration noted above, as well as efforts to create systems of care for CYSHCN. Additionally, through current initiatives on improving birth outcomes, such as the infant mortality summit and COIN meetings, issues including maternal depression and tobacco use and the harmful impacts on birth outcomes, women’s health and child development have been identified and discussed.

SAMHSA in conjunction with the Region VI U.S. Department of Health and Human Services (HHS) Operating Divisions brought a team of nine individuals from each of the states in Region VI together for the purpose of providing an opportunity to develop state plans to enhance existing efforts of integrating primary care and behavioral health. The meeting was held in Dallas, Texas on Sept. 27-28 at the Department of Health and Human Services, which allowed for the participation of all the federal partners. The state teams consisted of representatives from: primary care association directors, primary care organization directors, maternal and child health directors, state Medicaid directors, provider association directors, recovery oriented association directors, state mental health directors, state substance

## Feature CONT.

### System Integration into Motion

abuse directors, and national prevention network directors. The emphasis on integration was to begin to think of behavioral health issues as a chronic illness with potential for relapse, which requires a chronic disease management model, utilizes a primary preventive approach, and includes strategies for long-term recovery.

In establishing the state teams, it was understood that inclusion of MCH directors was a crucial component to the success of any integrated health model. This is especially salient in Region VI, where geography remains a large deterrent to accessing quality maternal health care and where affordable access to transportation is a challenge for many. This, combined with increased rates of recreational substance use among women of child-bearing age, drove forward the necessity to think of all aspects of health care in any innovative health care models that improve the health outcomes and lives of people in the region.

The meeting also afforded states the opportunity to hear of the evidence-based models for integration and from three existing grantees currently involved in integration efforts within Region VI. One model that was presented for consideration among the state teams is the “4Ps Plus Screening Tool for Perinatal Substance Abuse, Depression and Domestic Violence” (Ira Chasnoff, MD, University of Illinois-Chicago), which has shown success in Louisiana. The “4Ps” provides primary care physicians with a tool to routinely and consistently screen for behavioral health needs, thereby providing an opportunity for targeted intervention in a non-threatening and holistic way. There also were presentations from the Hogg Foundation and the Louisiana Public Health Institute to illustrate the role that philanthropy and foundations can play as partners in integration. There will be follow up calls with each of the state teams, federal partners and the National Council for Behavioral Health to discuss progress on each of the state plans and any technical assistance that might be necessary.

This meeting and subsequent follow up presents a great opportunity for the enhancement of federal, state, private and local partnerships. For MCH/CYSHCN programs, the meeting offered states the opportunity to begin to discuss and identify collaborative strategies to address the behavioral health needs of women and children. If you have any questions about primary and behavioral

health care integration efforts in Region VI, please contact [Michael Duffy](#), SAMHSA regional administrator (Region VI).

Efforts at all levels, federal, state and local, to integrate public health and primary care in the public and private sector have great potential to not only create more efficient, effective systems of care, but also improve the health of our nation. State MCH programs are situated at the crossroads of public health and primary care, have shown to be leaders in systems integration in the past, and can continue to do so in this era of health care reform.

## Real Life Stories

### Louisiana Partners to Improve Early Childhood Systems



**By Amy Zapata**  
*MCH Program Director, Louisiana  
 Office of Public Health*

Louisiana, like most states, has established an early childhood state advisory council to inform policies affecting young children from birth through school entry. The 2007 Head Start reauthorization legislation was the impetus for the formation of State Advisory Councils (SACs) in many jurisdictions. Charged with advising on improvements to quality, accessibility, and coordination of early care and learning programs, legislation required SACs to have representation from the sectors that administer such programs. While broad representation from “health” was not specifically required, Louisiana’s long-standing HRSA-funded Early Childhood Comprehensive Systems (ECCS) grant initiative advisory group came to form the foundation of the state Early Childhood Advisory Council (ECAC). The 29-member Louisiana ECAC includes robust representation from health programs, including the *Individuals with Disabilities Education Act* (IDEA) Part C early intervention program, Medicaid, behavioral health, and the Title V Maternal and Child Health and Children’s Special Health Services programs. For the past year, I have had the opportunity to serve on the ECAC and the smaller executive committee. A major area of focus for the council in Louisiana is supporting state efforts to create greater alignment

## Real Life Stories CONT. Louisiana Partners

across early care and education programs. This work includes refining the quality rating system, developing a unified professional development system for early childhood caregivers and teachers, and the development of an early childhood data system coordinated with the longitudinal system of education. Participation in the work of this priority area of the early childhood system has illuminated many opportunities for Title V and other health partners to inform and support common goals toward improved child outcomes.

The success of early care and education is inherently tied to children's health and well-being from birth through

school entry. Even for preschool programs such as Head Start, the longest-lasting gains have been shown to be among children who were healthy at the start of their lives (2012, Aizer and Cunha). Pregnancy and early childhood are recognized as critical developmental periods that impact an individual's functioning and later health (2010, Halfon, Inkelas, and Hochstein). From improving maternal health and birth outcomes to developmental screening and early intervention, supporting the development of physical and social-emotional health are key. Louisiana's inclusion of health as a partner in the development of a coordinated early childhood system is recognition of the critical role health plays in school readiness and beyond.



**Do you have a successful practice that addresses CYSHCN or systems integration? Let us know about it!**

AMCHP is collecting emerging, promising and best practices in maternal and child health and would like to include programs that address CYSHCN issues such as systems of care, transition, and more.

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 Howe](#) at (202) 266-3056 or visit [amchp.org/bestpractices](http://amchp.org/bestpractices).

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

The recent evaluation of the national ECCS Initiative confirms that multisector systems-building is not simple. The evaluation findings indicate that, "...early childhood systems-building is most dynamic [where states] try to identify the areas where the greatest opportunities exist at a particular point in time and focus efforts on them while maintaining a lesser level of activities in other areas" (2012, Altarum Institute). However, the partnerships established then became a platform for "consolidating gains" as new opportunities emerge. In Louisiana, working with our state early care and education partners has been an invaluable catalyst toward establishing relationships and processes that have resulted in greater interagency coordination. These relationships and a cross-sector framework are essential to realizing true gains for the health and well-being of children.

Charged with supporting the development of health among **all** mothers, children and families, state Title V programs are uniquely positioned to contribute to the development and implementation of a common agenda across agencies. Doing so is a tremendous opportunity to advance Dr. Lu's vision for Title V: to improve the quality, access, accountability and integration of systems to achieve equity in outcomes.



## Real Life Stories

### Colorado 9to25: Partnering with Youth to Build a Statewide System for Young People

**By Anne-Marie Braga**

*Anne-Marie Braga, Population and Community Health Unit Manager, Colorado Department of Public Health and Environment*

**Audra Bishop**

*Youth Health Specialist, Colorado Department of Public Health and Environment*

Lifelong success for young people demands coordination between all those who care for and about them. For years, Colorado has been focused on building a coordinated, comprehensive early childhood system. Using lessons learned and capitalizing on strong public private partnerships, we have recently launched its counterpart for youth – *Colorado 9to25 (CO9to25)*. During the last Colorado MCH needs assessment, “building a comprehensive youth system” was identified by both adults and youth as a top priority. In addition, over the last five years, Colorado has focused on integrating positive youth development across the state. Positive youth development is an approach that promotes the development of skills, opportunities and authentic relationships so that young people reach their full potential. This continues to be the foundation for our adolescent health work, including our youth systems-building effort. Integrating a comprehensive systems approach for youth can provide a cutting edge opportunity to help young people and their families safely navigate the complex biological, behavioral, cognitive and social factors that impact their lives.<sup>1</sup>

Using systems thinking,<sup>2</sup> the socio-ecological model<sup>3</sup> and a positive youth development approach, we partnered with young people, other state and local agencies, and urban and rural community-based organizations to develop a vision and framework for *CO9to25* – a collective, action-oriented network of youth and adults working together to align efforts to achieve positive outcomes for all youth in Colorado. Our vision is that all young people in Colorado are *safe, healthy, educated, connected* and *contributing* so that they can achieve their full potential. In order to reach that vision, *CO9to25* strives to ensure policies, programs and initiatives across Colorado operate as a coordinated,

integrated system. Once the outcomes were agreed on, specific indicators were developed with input from diverse youth and adults. To view these, [click here](#).

Finally, after identifying the outcomes and indicators, the leadership team chose the following five broad strategies to develop a coordinated system:

1. Mobilizing partnerships
2. Raising public awareness
3. Promoting best and promising practices
4. Sharing accountability for results
5. Promoting policy and environmental change

An action plan detailing how each strategy will be implemented is under development, but includes the department hiring two part-time youth advisors to guide and implement this work; adding our indicators to the Healthy Kids Colorado Survey (which includes the CDC annual Youth Risk Behavior Survey); partnering with other state-funded programs to leverage funds to implement local “youth system” teams; and developing and implementing an innovative “certification” system to improve the quality of youth-serving organizations, while helping youth and adults identify organizations that embody the *CO9to25* framework.

We must protect and leverage the current investment in early childhood by continuing this support into adolescence. This will help ensure a sound and healthy workforce, increased civic engagement, and strong leadership among youth, while positively influencing the long-term health trajectories of adults and communities.<sup>4,5</sup>

For more information, visit [colorado9to25.org](http://colorado9to25.org).

1 Bultman, L. (2006) Systems Thinking in a Changing Environment: From Planning to Outcomes. Center for Evaluation and Research, Nemours Health and Prevention Services.

2 Bultman, L. (2006).

3 The socio-ecological model supports the fact that every young person is part of a family, community and policies/systems and that each of these levels must be addressed to truly improve youth outcomes.

4 Knudsen E, Heckman JJ, Cameron JL, & Shonkoff, JP. (2006). Economic, neurobiological, and behavioral perspectives on building America's future workforce. Proceedings of the National Academy of Sciences, USA, 103 (27):10155-62.

5 Cunha F. & Heckman JJ. (2007). The Technology of Skill Formation. Discussion Paper No. 2550. Bonn, Germany: Institute for the Study of Labor.

## Real Life Stories

### A Mother's Struggle Leads to Impassioned Advocacy for Integrated Systems

By **Rylin Rodgers**

*Training Director, Family Leadership Coordinator, Riley Child Development Center*

In the world of maternal and child health, we strive for systems of care: interagency collaboration; individualized, strengths-based care practices; cultural competence; community-based services; accountability; and full participation of families and youth at all levels of the system. My personal and professional roles focus on moving closer to that ideal every day.

Early in my children's lives, our family was immersed in a complex web of sub-specialty pediatric providers, physicians who were treating the complicated needs of Matthew and Laura and attempting to diagnosis the disease, syndrome or genetic issue that was causing their symptoms. I remember this as an overwhelming introduction to the complex world of pediatric medicine.

As I would go from appointment to appointment with a growing list of hypothesized diagnoses and often conflicting treatment plans, I distinctly remember pleading for the doctors to talk with each other and to meet with each other. My frustration hit the boiling point when I learned that the care conference I was requesting was only offered to inpatients, and as practiced did not always include the full team with which my family was interacting. In reality, my husband and I were charged with facilitating our own virtual care conference and getting to a diagnosis and plan of care would be our job alone. My blood pressure rises even now as I think of the existing community resources and programs that we were not connected with in those early years; the missed opportunities are numerous.

For our family, these rocky early experiences quickly empowered us. We knew our children, we knew our family and we would decide which medical advice would best meet their needs. As my children have grown, our family has become better able to navigate systems and services. And now, as adolescents, my children are increasingly the leading advocates in their own care. But,



and the BUT is big, I have never forgotten the difficulty that the lack of coordination created. I instinctively knew it could be different and that it could be better. A system where all members of the sub-specialty team coordinated care would create better care, and likely less work. As fate – and life – would have it, being my children's mom has led me to a life's work focused on improving systems and services for families raising CYSHCN. And this year, over a decade after my first experiences, I find myself deeply involved in an effort at the Indiana University

School of Medicine and the Riley Hospital for Children to cross silos and coordinate care. As a cross-department center slowly forms to support children with neurodevelopmental disabilities, I continually connect to my family's experience and the experience of so many families in similar situations. My involvement is not about my family; instead it is about the systems of care that are needed for all families in our and an example of full participation of families at all levels of the system.

## Success Stories

### Maine Works to Make System Navigation Easier for Children with ASD/DD and their Families

By **Toni Wall**

*Director, Children with Special Health Care Needs Program, Maine Center for Disease Control and Prevention*



**Nancy Cronin, MA**

*ASD Systems Change Coordinator, Maine, Developmental Disabilities Council*



In 2008, Maine began an ASD Systems Change Initiative sponsored by the Commissioners of Education,

## Success Stories CONT.

### Maine Making Navigation Easier

Labor and Health and Human Services. The ASD initiative was charged with analyzing the multiple systems of care that individuals with ASD and their families had to navigate. The work began by analyzing the early identification and early intervention systems, which revealed that it took an average of 32 months from parent concern to actual diagnosis of ASD. Stakeholder recommendations include lowering barriers to reduce the overall time between concern and diagnosis.

Utilizing the HRSA State Implementation Grant for Children and Youth with ASD allowed Maine to improve identification rates of children with ASD by encouraging early childhood professionals, such as Part C IDEA staff, head start staff, public health nurses and physicians, to screen all children at 18 months for an ASD. This initiative also is linked with the state CMS grant, Improving Health Outcomes for Children, which includes routine developmental screening in all well-child visits using the ASQ-SE and ASQ-3 as one of their pediatric quality-improvement projects with follow up with the MCHAD when indicated. Through the HRSA grant, Maine produced a training DVD and curriculum on the administration and scoring of autism screening tools. Hundreds of professionals have received the training and materials. In addition, Maine implemented monetary incentives to encourage professionals to screen for autism. Results have shown steady improvement, with a 98 percent increase in ASD screening at well-child visits over a one-year period.

A second issue is the long wait time to receive a diagnosis due to diagnostician wait-lists. Maine piloted new processes between early education professionals (Part C and Section 619B IDEA) diagnosticians to expedite the time between referral and diagnosis for those suspected of having an ASD. Preliminary results show a 54 percent reduction in time has been achieved. The change is a result of early childhood professionals assisting families with necessary paperwork needed for the first visit. In total, the multiple improved processes have shown a decrease between referral to diagnosis from 11 weeks to nine (19 percent) for children aged three to five years.

## Success Stories

### Mississippi MACSS Project: Changing Systems within a Community Health System of Care

By **Jane Z. Siders, Ed.D.**  
*Co-Director, Institute for Disability Studies*

There are 21 Community Health Centers in Mississippi serving the health care needs of medically underserved and indigent populations, including those living in rural areas. The mission of the Mississippi Community Health Centers is to ensure equal access to quality, comprehensive health care services and the elimination of health disparities in the state. Community health centers play a critical role in the health care of Mississippi children and youth because of the rural nature of the state, the high rates of poverty, and the fact that Mississippi has the highest rate of disability per population in the nation. All 21 Community Health Centers provide developmental screening for young children, but none screen specifically for autism.

Through the HRSA State Implementation Grant for Children and Youth with ASD, the Mississippi Access to Coordinated Systems of Services (MACSS) project has teamed with the Southeast Mississippi Rural Health Initiative (SeMRHI) to develop and implement a screening protocol and algorithm for autism that includes both primary and secondary screens. The screening protocols and algorithm will be replicated at each of the 14 community clinics associated with SeMRHI. A Web portal has been developed for each of the 14 community clinics to report data on the numbers of children screened, the numbers of children who fail a secondary screen, the numbers referred for a full diagnostic assessment, the number of children diagnosed with autism, and information obtained during periodic follow-up.

During the final year of the project, replication information and technical assistance will be available to all 21 community health centers for use in their community clinics. Finally, a special health care clinic for children on the spectrum and those with other disabilities has been established to serve as a medical home at one of the primary SeMRHI clinics that is housed on the campus of a public school.

## Success Stories CONT. Mississippi MACSS Project

Housing a community health clinic on the campus of a public school increases access to a medical home for the large numbers of indigent and uninsured families residing in rural areas of Mississippi. Housing a specialty clinic in collaboration with the community health clinic provides family support and coordination of care that is not readily available with other health care providers. Replication of this specialty clinic across other Community Health Care Centers will ensure that children on the spectrum and those with other disabilities and their families have access to a system of community care that is coordinated across a network of providers.

## Success Stories Vermont Medical Home and Community-Based Teams Collaborate to Improve Services

By Janet Kilburn, LICSW

*Medical Social Worker, Children's Integrated Services Early Intervention, Children with Special Health Needs, Vermont Department of Health*



The goals of the Vermont State Implementation Grant for Improving Services to Children and Youth with ASD/DD include increasing collaboration between the Medical Home and community-based teams. An exciting accomplishment this year is the piloting of care coordination by placing medical social workers, from the Vermont Title V CYSHCN program, in Medical Homes. The mutual experience has produced a practical description of the scope of collaboration needed between Medical Homes and communities, as well as strategies that work to increase understanding of the pediatric system of care and access to community resources. This activity is coordinated with the Vermont Blueprint for Health expansion to pediatric populations, Children's Integrated Services Early Intervention (Part C), and the medical home training projects of the Leadership Education in Neurodevelopmental Disabilities (LEND) program at the University of Vermont (VT-ILEHP).

## Success Stories CONT. Vermont Medical Home

Since the inception of Part C, CYSHCN medical social workers in Vermont have an integrated role in order to ensure streamlined navigation and care coordination for families; they work directly in Child Development Clinics in the evaluation of children with ASD/DD; they provide regionally based care coordination to families of children with a wide range of special health needs; and they also are core members of Part C Early Intervention teams. Participating in care conferences in the Medical Home has further integrated these roles and reduced categorical/programmatic silos and fragmentation.

These care conferences are family-centered meetings, led by the primary care provider (typically lasting one hour), that may include any specialty care providers, community providers, schools, the family and their formal and informal supports (i.e., personal care attendants or grandparents). The purpose is to organize and streamline care for families by facilitating effective communication about strengths, challenges, current services, needs and gaps in services. A coordinated plan of care is developed with goals, resources and action steps. These regular care conferences are an efficient and effective strategy of health care reform, utilizing the expertise of all providers and facilitating creative problem solving that supports the both child and family health. Family success stories to date include: 1) preventing out of home institutional placement of a child with a neurodegenerative syndrome and ASD through creative, multi-agency funding and wrap-around home based services, 2) providing in-home anticipatory bereavement counseling and increased nurse case-management as part of a new pediatric palliative care program, and 3) the recent expansion of the role of CYSHCN Title V care coordination to include not only social workers but psychiatric consultation as well (our Child Development Clinic psychiatrist also is assisting in the Medical Home with medication management, links to community mental health resources, etc.).



Marinell Newton, MSW, the social worker that visits the different pediatric practices as part of this medical home pilot.

## Success Stories CONT.

### Vermont Medical Home

Key outcomes that emerged from this pilot include:

- Increased understanding by physicians, families and community providers of the health care delivery system
- Appropriate referrals and increased access to community-based resources, including psychiatric consultation
- Identifying systems issues and barriers (insurance issues, poverty, lack of psychiatric and mental health services, etc.)
- Increased ease of use and coordination of community-based services for families
- Prevention of duplication of services

This Vermont medical home pilot recently was selected as a case study for research by the National Center for Ease of Use of Community-Based Services, one of six national centers addressing the core outcomes measures for success in serving children with special health care needs.

## Member to Member

**How is your state leveraging home visiting and early childhood comprehensive systems funding to build or increase capacity in early childhood systems?**

### MONTANA



**Dianna Frick, MPH**  
*MCH Epidemiologist, Montana  
Department of Public Health and  
Human Services*

Montana is leveraging Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Development funding and Early Childhood Comprehensive Systems (ECCS)

funding to support early childhood collaboration and systems change at both the state and community levels. Early childhood coalitions, called Best Beginnings councils, are central to the collaboration efforts. The ultimate purpose is for the state and communities to define and develop community-specific early childhood systems that

## Member to Member CONT.

support capable, high-quality organizations and programs that meet the needs of children and families.

The state, through the collaborative efforts of MIECHV- and ECCS-funded staff, provides technical assistance to communities around key elements of collaboration, including:

- Relationship building: among state partners, between the state and communities, among communities, and within communities
- Governance structure: a structure that expects organizations, not individuals, to be engaged in and committed to systems change
- Capacity building and infrastructure development: recognizing and understanding the challenges for organizations and programs in being effective, and supporting the skills and abilities of organizations and programs to address and overcome the obstacles
- Addressing the tangles: acknowledging and dealing with history and barriers that have stopped similar efforts in the past
- Flexibility: for communities to conduct community assessments, define coalition membership and proceed at a pace that is appropriate for them

## View from Washington

**By Brent Ewig, MHS**  
*Director, Public Policy &  
Government Affairs*



The votes have been counted, the balloons have dropped, and the cheering and/or crying is beginning to fade. So as the election dust settles, we can begin to discern some of the key takeaways and potential impacts on maternal and child health programs.

The big headlines are easy: President Obama won a second term. The Democrats retain control of the Senate and the Republicans will continue to lead the House. In short, the balance of power – in terms of chamber control

## View from Washington CONT.

and numbers of Republicans and Democrats - has not changed much. Furthermore, neither side seems able to claim a new overwhelming mandate from the voters. And yet, voters did signal that they want the leaders of both parties to work together to find solutions and forge compromises that move the country forward.

The impact on MCH programs is less clear. Here is how it might play out on two key issues and what AMCHP is doing on your behalf:

**Budget:** Perhaps most pressing post-election question is if and how will Congress address the pending fiscal cliff. As AMCHP has reported at length, the automatic across the board cuts set to go into effect in less than 60 days will cut nearly \$50 million from the Title V MCH Services Block Grant. Total cuts will be close to \$1 billion from the MCH enterprise when you factor in cuts to WIC, Title X Family Planning, the range of vital Centers for Disease Control and Prevention (CDC) programs for moms and kids, and the critical research conducted by the National Institutes of Health.

With the election over and a lame duck Congress convening, AMCHP is monitoring developments closely, working in broad coalitions. In the initial days after the election, House Speaker Boehner seemed to indicate a willingness to put revenues in play but, as always, the details will be key. The president, in a pre-election interview that was originally off the record, expressed his view that a messy grand bargain can be achieved that will make \$2.50 in cuts for every \$1 in new revenue.

Clearly additional cuts are possible, so we continue to press for a balanced approach that rejects further cuts to the battered non-defense discretionary part of the budget, which largely funds public health. Our view is that any deal needs to take into account the cuts public health programs have already contributed to deficit reduction and preserves the tight caps set in law by the Budget Control Act last year.

Time will tell if a deal can be struck before the cliff is reached. There is the potential that a sequestration-avoiding deal could be even worse for public health, so

AMCHP is working to guard against that. In the coming weeks, expect additional updates and alerts on this critical issue.

**Health Reform:** In this case, the election results more clearly signal that the legislative architecture of the Affordable Care Act is likely safe for at least the next few years. While the electorate is clearly still divided on the support for the ACA, the combined reelection of the president and the Supreme Court decision largely upholding the law means that the business of implementation will continue. We do expect there will be continued attacks emanating from the House but, like the past two years, they are not likely to gain traction in the Senate.

The critical question is, will these factors accelerate action in states that to date have been reticent to pursue implementation? Look for movement in the coming weeks as states will make final decisions if they want to operate their own exchanges, allow the federal government to run them in their state or develop a state-federal partnership.

However it plays out, AMCHP continues to develop resources for state Title V programs and their partners to support your work in implementation, which are available on the AMCHP health reform center Web page [here](#).

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AMCHP? DONATE TODAY!**

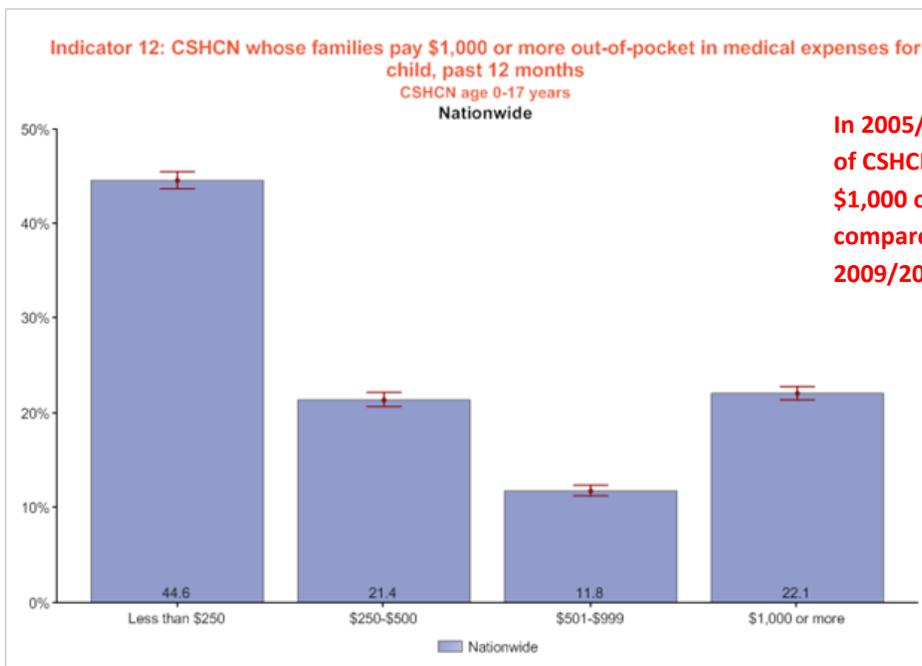


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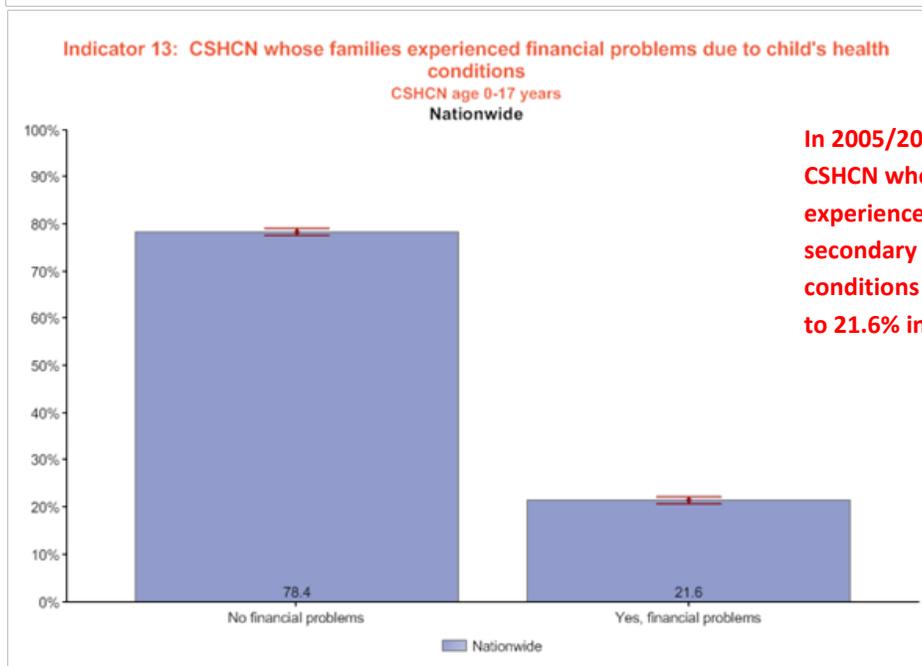
## Data and Trends

### Children and Youth with Special Health Care Needs: Impact on Families

The financial stress on families with Children and Youth with Special Health Care Needs is immense. While insurance companies cover some medical costs of CYSHCN, many times families struggle to provide the financial resources needed to pay for medical services that are not covered. Below is a quantitative summary of the financial impact on families with CYSHCN, as provided by The Data Resource Center for Child and Adolescent Health.



In 2005/2006 the percentage of CSHCN whose families paid \$1,000 or more was 20.0% compared to 22.1% in 2009/2010.



In 2005/2006 the percentage of CSHCN whose families experienced financial problems secondary to the child's health conditions was 18.1% compared to 21.6% in 2009/2010.

\* The Data Resource Center for Child and Adolescent Health: [childhealthdata.org/browse/survey/results?q=1632&r=1&t=1&ta=70](http://childhealthdata.org/browse/survey/results?q=1632&r=1&t=1&ta=70)

## Who's New

### NEW MCH LEADERS

#### MCH AND TITLE V DIRECTOR

##### KANSAS

###### Rachel Berroth, MS

Director, Bureau of Family Health,  
Kansas Department of Health and Environment

#### CYSHCN DIRECTOR

##### TEXAS

###### Manda Hall

Director, Children and Youth with Special Health Care  
Needs, Texas Department of State Health Services

### NEW PARTNERS



**Deborah L. Frazier, RN**  
*Executive Director, National Healthy  
Start Association*

Ms. Frazier spent 30 years of her professional career in the field of maternal and child health. She is a past member of the HHS Secretary's Committee on Infant Mortality (SACIM),

and the former director of the Division of Child and Adolescent Health for the state of Arkansas. Ms. Frazier has long worked with Healthy Start, serving as grantee evaluator, technical advisor to projects, project director for New Orleans Healthy Start, founding member of the association and past board member.

### AMCHP WELCOMES NEW STAFF

###### Sanaa Akbarali

Sanaa is currently a Children and Youth with Special Healthcare Needs intern at AMCHP. She received her BA from the University of Oklahoma in psychology. She is a Master in Public Health Candidate at the George Washington University, with a concentration in maternal and child health.



###### Andria Cornell

Andria is a graduate student at the Johns Hopkins Bloomberg School of Public Health, and joins the AMCHP Women's and Infant Health program team as an intern. She has a BS in Biology with a minor in Business Administration from the George Washington University. She is pursuing a MSPH degree in reproductive, perinatal, and women's health, and a certificate in public health informatics. Prior to beginning her master's program, Andria worked for a DC nonprofit managing federally funded newborn screening education and research grants and coordinating advocacy activities for families of children with rare genetic conditions.



###### Veronica Helms

Veronica graduated from the University of Georgia in May 2011 with a BS in health services and a minor in women's studies. She currently attends the George Washington University School of Public Health and Health Services where she is a MPH candidate with a concentration in maternal and child health. Veronica is currently a CYSHCN intern.



###### Rana Suliman

Rana joins AMCHP as an intern for the organizational performance and member services team. She is currently completing her MPH in maternal and child health at the George Washington University. Prior to beginning her graduate studies, Rana was a Program Manager with Experience Corps, where she provided programmatic oversight, technical assistance, and training to an affiliate network supporting older adult tutors and mentors. She also has worked with healthcare advocacy groups on behalf of underserved communities in the United States and in Sub-Saharan Africa, notably a project working on improving maternal health outcomes in Niger. Rana holds a Bachelors of Arts degree in sociology and spanish from Franklin & Marshall College.



## Get Involved

### AMCHP Technical Assistance Project: Request for Applications

AMCHP, with support from the W.K. Kellogg Foundation, is leading a project to increase the capacity of state MCH programs and other state stakeholders (e.g., Medicaid agencies, providers, local health departments, community health centers) to improve birth outcomes throughout the life course. This project has a specific focus to enhance the capacity of state MCH programs and their partners to maximize the current environment of opportunity by providing state teams with targeted technical assistance on developing a collective impact approach to coordinating the multiple, concurrent efforts and initiatives to improve birth outcomes through health reform. This project will focus on opportunities presented by the Affordable Care Act and other national initiatives to improve birth outcomes and maternal and infant health, with a particular focus on reducing health disparities and assuring racial equity. AMCHP is accepting applications through Dec. 9. For more information, [click here](#).

### AMCHP 2013 Annual Conference Registration Brochure Available

The AMCHP 2013 registration brochure is now available on the AMCHP website. Find out why you should be a part of the largest gathering of state MCH leaders nationwide! [Click here](#) to view the brochure.

### Register Today for AMCHP 2013!

The AMCHP 2013 Annual Conference will be held Feb. 9-12, at the Omni Shoreham Hotel in Washington, DC. To register, visit [regonline.com/amchp2013](http://regonline.com/amchp2013). Don't miss our early-bird registration rates – register now!

### ASTHO Environmental Public Health Tracking Peer-to-Peer Fellowship Opportunity

The Association of State and Territorial Health Officials (ASTHO), with support from the CDC National Center for Environmental Health, has teamed up with Esri to provide fellowships and data visualization training as part of the Environmental Public Health Tracking Peer-to-Peer Fellowship Program. Designed to enhance capacity of states and territories not currently funded as part of CDC's National Tracking Network, the newly upgraded fellowship program now prepares non-funded health agencies with GIS technology to support current initiatives in environmental public health tracking. Fellowship recipients will also visit current CDC grantee sites to learn about

the program, attend a National Tracking Workshop, and develop a pilot project that would help advance efforts to relate health outcomes with environmental hazards of concern. Applications will be accepted through 5 p.m. EST on Dec. 10. For more information on how to apply, please [click here](#).

### MCH Public Health Leadership Institute Applications Now Open

The Maternal and Child Health-Public Health Leadership Institute (MCH PHLI) applications for Cohort IV are now being accepted through Feb. 1, 2013. This year-long leadership development program for the MCH workforce is designed to significantly expand self-awareness and quickly build practical skills for effectively leading, managing people, and building partnerships, to advocate for and create the MCH systems of tomorrow. This unique program improves leadership capacity, teaching tools for creating the kind of culture that engages and motivates others. The program consists of three residential executive-style retreats (10 days of experiential-based training) coupled with a robust and customizable distance-based program. All tuition and lodging charges for this program are grant-supported. For more information and to apply, please [click here](#).

### Conversations that Matter: A How-To Guide for Hosting Discussions about Race, Racism, and Public Health

CityMatCH, the National Organization of Urban MCH Leaders, has released a new guide which was developed through a collaboration with the Lee Institute. The how-to guide serves as a community-empowerment resource, assisting public health professionals in initiating open and honest conversations about racism's impacts. It is intended to help MCH leaders navigate the terrain of talking honestly about race and the impact of historical and contemporary racism on the health of communities. By facilitating honest and effective conversations around race and structural racism, the guide allows for the development of proactive strategies to eliminate racism and promote community healing and health equity. The guide also offers specific suggestions for engaging in one-on-one dialogue, group conversations, or in-house conversations, while remaining general enough to be tailored to fit the needs of different communities. The guide can be [downloaded](#) from the CityMatCH website – hardcopies are available by request at [Rebecca.ramsey@unmc.edu](mailto:Rebecca.ramsey@unmc.edu).

## Resources

[American Academy of Pediatrics \(AAP\)](#) is an organization of pediatricians committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents and young adults. The AAP provides information, policy statements, practice guidelines, child health resources and other publications from leading child health experts.

[The Arc: For People with Intellectual and Developmental Disabilities](#) is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

- [Autism NOW: The National Autism Resource and Information Center](#) is a national initiative of The Arc dedicated to be the central point of quality resources and information for individuals with autism spectrum disorders and other developmental disabilities, their families, and other targeted key stakeholders, including underserved and unserved.

[Association of University Centers on Disabilities \(AUCD\)](#) is a membership organization that supports and promotes a national network of university-based interdisciplinary programs consisting of the University Centers for Excellence in Developmental Disabilities (UCEDD), Leadership Education in Neurodevelopmental Disabilities (LEND) Programs, and the Intellectual and Developmental Disability Research Centers (IDDRC). These programs serve and are located in every U.S. state and territory and are all part of universities or medical centers. They serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change.

- [The Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities \(ITAC\)](#) of AUCD provides technical assistance to interdisciplinary training programs to better train professionals to utilize valid and reliable screening tools to diagnose or rule out and provide evidence-based interventions for children with ASD and other developmental disabilities. The ITAC website provides news, resources, events, funding opportunities and more.

[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.

- [The State Public Health Autism Resource Center \(SPHARC\)](#) is a comprehensive resource center for state Title V programs and others interested in improving systems for children, youth and families with autism spectrum disorders and other developmental disabilities (ASD/DD). The SPHARC website provides informational call recordings and materials, state spotlights/best practices in building systems of care for children and youth with ASD/DD, an expert's corner of key issues facing states, regularly updated resources for families and health care/service providers, and timely announcements for state Title V programs on ASD/DD.

[The Autism Society](#), the nation's leading grassroots autism organization, exists to improve the lives of all affected by autism. The Autism Society website provides information on autism, living with autism, research, news, ways to get involved and more.

[Autism Speaks](#) is the nation's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism, increasing awareness of autism spectrum disorders, and advocating for the needs of individuals with autism and their families. The Autism Speaks website provides information on autism, science, family services, advocacy, ways to give, news, events and more.

[The Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs](#) is dedicated to improving health care coverage and financing for CYSHCN. Visit their website to find publications, products, answers to technical assistance questions, research and resources.

[The Centers for Disease Control and Prevention \(CDC\)](#) is dedicated to protecting health and promoting quality of life through the prevention and control of disease, injury and disability.

- [CDC's National Center for Birth Defects and Developmental Disabilities \(NCBDDD\)](#) works to

## Resources CONT.

promote the health of babies, children and adults and enhance the potential for full, productive living.

- [The CDC Learn the Signs. Act Early. State Plans](#) were developed through the “Act Early” Regional Summit Project. The website allows you to search by regional summit. Click on “State Materials” to access each state’s plan.

[The Data Resource Center for Child and Adolescent Health \(DRC\)](#) works to advance the effective use of public data on the health and health-related services for children, youth and families in the United States. The DRC website provides free, easy access to a variety of national and state level data on children’s health topics, including information about families of children with special health care needs.

[Family Voices](#) aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through their national network, they provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

[Federation for Children with Special Needs \(FCSN\)](#) presents resources for parents and parent organizations working together on behalf of children and youth with special health care needs and their families. FCSN operates a parent center in Massachusetts that offers a variety of services to parents, parent groups, and others who are concerned about children with special health care needs.

[Got Transition?](#) is the National Health Care Transition Center that aims to support optimal transitions from pediatric to adult models of health care for youth with and without special health care needs. The Got Transition website provides information for youth, families, providers and states.

[Health Resources and Services Administration: Maternal, Infant, and Early Childhood Home Visiting Program:](#) This website provides information about the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program, which responds to the diverse needs of children and families in communities at risk, and provides the opportunity for collaboration and partnership at the Federal, State and community levels.

[Interactive Autism Network \(IAN\)](#) is an innovative online project designed to accelerate the pace of autism research by linking researchers and families. Anyone impacted by an Autism Spectrum Disorder (ASD) can become part of IAN’s online community to stay informed about autism research, provide feedback, and make their voices heard.

[The Interagency Autism Coordinating Center \(IACC\)](#) is a Federal advisory committee that coordinates all efforts within the Department of Health and Human Services (HHS) concerning autism spectrum disorder. The IACC website provides information on meetings and events, IACC subcommittees, requests for public comment, news, publications and more.

[Maternal and Child Health Bureau \(MCHB\)](#) 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 maternal and child health populations of the United States and its jurisdictions.

[The MCH Library at Georgetown University: Children and Youth with Special Health Care Needs Knowledge Path](#) offers a selection of current, high-quality resources that analyze data, describe effective programs, and report on policy and research aimed at developing community-based, coordinated, and culturally competent. A separate section lists resources for families. The final part of the knowledge path presents resources that address specific aspects of care and development, such as advocacy, early intervention and special education, financing services, rehabilitation, screening and transition to adulthood.

- [The MCH Library at Georgetown University: Home Visiting Resource Brief](#) provides resources on home visiting.

[The National Center for Children’s Vision and Eye Health advances](#) and promotes children’s vision and eye care, and provides leadership and training to public and private entities.

[The National Center for Cultural Competence](#) works to increase the capacity of health care and mental health care programs to design, implement, and evaluate culturally and linguistically competent service delivery systems to address growing diversity, persistent disparities, and to promote health and mental health equity.

## Resources CONT.

[The National Center for Ease of Use of Community-Based Services](#) works to advance policy and practice solutions that improve the ease of use of community based services by developing a state leadership network, promoting partnerships and recognizing leading communities.

[National Center for Family/Professional Partnerships](#) works to increase leadership capacity and promote knowledge and measurement of family-centered care through the Family-to-Family Health Information Centers and communities of learners.

[National Center on Hearing Assessment and Management](#) works to ensure that all infants and young children with hearing loss are identified as early as possible and provided with timely and appropriate audiological, medical, and educational intervention.

[National Center on Medical Home Implementation](#) works to ensure that all children, including children with special health care needs, have access to a medical home by enhancing and providing resources, tools, technical assistance and support.

[National Center for Project Access](#) provides national leadership on improving access to comprehensive, coordinated health care and other services for children and youth with epilepsy.

[National Consumer Center for Genetic Resources and Services](#) works to enhance access to quality information, the sharing of quality and vetted resources, peer-to-peer partnership, and organizational development resources in order to achieve parity in access and to increase the quality of care.

[National Coordinating Center for Sickle Cell Disease Treatment Demonstration Program](#) provides technical assistance, collects and analyzes data, and implements activities required by the program's authorizing legislation to grantee networks.

[National Newborn Screening and Genetics Resource Center](#) provides State newborn screening programs with expert consultation and technical assistance, resource development, education and training, and collaboration with stakeholders.

[The National Professional Development Center on Autism Spectrum Disorders](#) is a multi-university center to promote the use of evidence-based practice for children and adolescents with autism spectrum disorders.

[Organization for Autism Research \(OAR\)](#) works to apply research to the challenges of autism. The OAR website provides information for family and friends, education and service providers, and professionals.

[Parent to Parent USA \(P2P USA\)](#) is a national nonprofit organization committed to promoting access, quality and leadership in parent to parent support across the country. The P2P USA website provides information on support for parents and organizations. P2P USA also offers technical assistance and resources to parents interested in building, improving and evaluating a program.

[The Pew Center on the States: Home Visiting](#) promotes and advances smart state and federal policies and investments in high-quality, home-based programs for new and expectant families.

[Sickle Cell Disease Newborn Screening Program National Coordinating and Evaluation Center](#) supports grantees in their activities and efforts related to outreach, education and genetic counseling for health care providers, affected individuals across their lifespan, their families, and the general population.

[Traumatic Brain Injury Technical Assistance Center](#) supports the efforts of the Federal Traumatic Brain Injury Program by providing technical assistance and information to grantees and assisting the States as they seek to establish system change.

[U.S. Department of Health and Human Services: Home Visiting Evidence of Effectiveness](#), this website provides information about Home Visiting Evidence of Effectiveness (HomVEE), which was designed to conduct a review of the home visiting research literature and provide an assessment of the evidence of effectiveness for home visiting program models that target families with pregnant women and children from birth to age five.

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## AMCHP Staff

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**Laura Goodwin, Publications and Member Services Manager**

## AMCHP Staff CONT.

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**Rana Suliman**, Intern, Organizational Performance and Member Services

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

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

## Calendar

### AMCHP Events

[AMCHP 2013 Annual Conference](#)

Feb. 9-12  
Washington, DC

### MCH Events

[Teen Distracted Driving Summit](#)

Dec. 1-3  
Washington, DC

[18th Annual MCH EPI Conference Co-hosted with the 2012 CityMatCH Urban MCH Leadership Conference](#)

Dec. 12-14  
San Antonio, TX

Want your event listed on the AMCHP MCH Events Calendar? It's easy! Just complete our [online submission form](#).

## Calendar CONT.

[National Conference on Bullying](#)

Feb. 27-Mar. 1, 2013  
Orlando, FL

[SAHM Annual Meeting: Achieving Healthy Equity for Adolescents & Young Adults](#)

Mar. 13-16, 2013  
Atlanta, GA

[Third Annual Teen Pregnancy Prevention Grantee Conference](#)

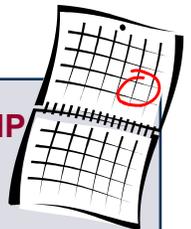
May 20-22, 2013  
National Harbor, MD

[NACCHO Annual 2013](#)

Jul. 10-12, 2013  
Dallas, TX

### 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.*



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