



PULSE

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

CYSHCN/Systems Building & Home Visiting July/August 2011

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From the President

Systems of Care Development

By Stephanie Birch, RNC, MPH, MS, FNP



With the advances in science, genetics, technology and medicine, increasing numbers of children are being identified and diagnosed with special conditions such as autism, genetic and metabolic conditions, developmental delays, chronic medical issues and other physical conditions. Diagnosis during the prenatal period of a variety of special health conditions is not uncommon as well. This poses major challenges to state Title V MCH and CYSCHN programs to develop systems of care to meet the complex health and culturally diverse social needs of women, infants, all children and adolescents. Developing and implementing systems of care has been the core work of state Title V MCH and CYSCHN programs. This work is a part of the legislative mandates of Section 501 of the Social Security Administration Act and the outcomes are reflected in states' reporting of their national and state performance measures.

Section 2951 of the Patient Protection and Affordable Care Act of 2010 created the landmark Maternal, Infant and Early Childhood Home Visiting Program and was designed to strengthen and improve systems of care for pregnant women, infants and young children. This legislation is focused on programs and activities implemented under the Title V MCH Block Grant and are intended to provide and improve coordination of services for families who reside in at risk or high risk communities. Other funding streams such as those for expanded newborn metabolic screening and the Combating Autism Act also focus on developing

From the President CONT. Systems of Care Development

systems of care. Systems of care development can be a lot of work! It requires partnership, consensus decision making, exquisite communication, program development, implementation and evaluation and data collection and analysis. State Maternal Child Health programs are well poised to lead this challenging and rewarding effort! In this edition of *Pulse*, you will have an opportunity to hear examples of the work done in states in support of systems of care as well as the technical assistance provided by AMCHP staff in support of states' work.

From the CEO Systems Building

By Michael R. Fraser, Ph.D., CAE



Like putting the pieces of a puzzle together to form a complete image, systems building involves putting MCH services together within a state or community to create a unified whole of services geared toward protecting and promoting the health of women, children and families. Systems building is one of the unique features of the Title V MCH Services Block Grant. Unlike other funding streams with specific approaches and guidelines, the Title V MCH Block Grant allows states to tailor their programs to support state specific needs and create a system that works for that state. As such, the MCH system in one state may look very different from the MCH system in another. However, at the core of all state MCH programs, is the goal of improving the lives of women, children and families including children and youth with special health care needs and creating systems that effectively and efficiently provide needed services and programs.

When I first came to AMCHP, systems building was a term that I heard a lot. I remember a meeting I attended with Holly Grason from Johns Hopkins University. Holly provided a definition of a system that I still rely on today. In the definition she shared with me, systems have three components: focus on a shared goal, interrelated parts to meet that goal, and communication between the parts to assure that the shared goal is reached.

Focus on a Shared Goal

Every system has a goal, and for MCH programs that goal is very clear: develop systems that protect and promote health for women, children and families. A major role for MCH leaders within a state is to develop a shared goal that can bring together different kinds of programs and links diverse services providers. Getting agreement on a shared goal is an essential, though often difficult, role for Title V programs. I would posit that getting all MCH players within a state to contribute to a shared goal is one of the hardest parts of a Title V Director's job! However, it is also one of the most important: without a shared goal, how do partners

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From the CEO CONT. Systems Building

and collaborators fit their work into the larger MCH system within a state? What are all the players working toward?

Interrelated Parts

One of the challenges of systems building is getting the various components involved in the system to see themselves as collaborators and partners in the work rather than individual entities providing specific services to segments of the population without the need to link to one another. A task for many MCH leaders is “herding cats” – getting various independent groups to work together toward the shared goal of improving the lives of women, children and families. For a system to function, interrelated parts must work together seamlessly and contribute to the shared goal.

Communication to Ensure Components Meet the Shared Goal

Communication is a constant challenge, and communications between components in an MCH system is no exception. How many meetings, e-mails, and phone calls take place between different organizations to assure that each is helping move forward the shared goal? In my experience there is rarely enough communication between entities – this is an area for continued growth and development for almost all of us! But communication is essential to getting our work accomplished efficiently and effectively. How else do we know what each of us is going to meet our larger, shared goal and coordinate our work?

As you can see the elements of a system are straightforward, but the work of assuring that the system is functioning takes some effort! As you work to build systems in your state, especially for children and youth with special health care needs and the new opportunities presented by the Maternal, Infant, and Early Childhood Home Visitation Program, keep this definition of system in mind. Let me know what else you think contributes to systems building in your state and how AMCHP may be of assistance moving your work forward.

Feature Developing the Maternal, Infant and Early Childhood Home Visiting Updated State Plan

By Catherine J. Bodkin, LCSW, MSHA
Director, Virginia MIECHV Project
Virginia Department of Health

Developing the Updated Home Visiting State Plan, which was required by the Affordable Care Act Maternal, Infant and Early Childhood Home Visiting (MIECHV) Grant, presented opportunities and challenges for each state.

For Virginia, the grant provided a major opportunity to expand local services and initiate a link between the home visiting data and the state’s early childhood education data system. The Memorandum of Concurrence grant requirement resulted in conversations that increased understanding about home visiting as a component in the early childhood system among high-level administrators and the Early Childhood Advisory Council

Conversely, the major challenge for Virginia involved identifying communities at risk for poor health and developmental outcomes for children and families. Virginia met this challenge through a new level of teamwork and creative thinking by building on the existence of an interagency coalition — the Home Visiting Consortium (HVC), which has been existence since 2007 — to develop a formula for selecting at-risk communities. Using combined data from all HVC agencies resulted in community rankings at variance with the usual high-priority list a single partner agency might have compiled. The MIECHV benchmark measures being defined as rates resulted in the HVC ranking small communities at higher risk. Assisted by the Title V Maternal and Child Health Services epidemiology team’s analysis and data presentations, the HVC was able to determine needs and gaps, consider how the quality of data might influence decisions, and discuss the interaction between risk factors. Under the HVC’s at-risk communities selection process, each of the 134 cities and counties received a score for two domains: “individual factors” and “community factors.” Individual factors were indicators that home visiting interventions would potentially impact. Community factors were indicators that home visitors would have to contend with while working in a community. For each factor, a community received a point if its rate was above the overall state rate. Small communities (i.e., populations less than

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Developing MIECHV State Plan

50,000) and large communities were separated. Twenty-eight small and ten large communities were identified as high risk by the domain scores being cross-tabulated on a two-factor table. With HRSA's approval, Virginia included a provision for neighborhoods to present data that would qualify them as high risk by this method.

To determine which at-risk communities would be included for funding in the Updated State Plan, Virginia used the Request for Proposal (RFP) process with the eligible communities. The state RFP mirrored the federal requirements, including a local Memorandum of Concurrence and the justification of a program model selection as required elements. To ensure quality applications, the HVC used a variety of methods (i.e., webinars, web site postings, e-mail, regional meetings, and conference calls) to provide information and technical assistance statewide. A beneficial outcome of the Updated State Plan process was the increased discussion among community partners about steps to improve local referral systems. The challenge for Virginia in the future will be maintaining its efforts to develop a state system with a continuum of accessible, quality home visiting services in all communities while simultaneously implementing the MIECHV project with its specialized focus on at-risk communities.

Pew Study Details State Investments in Home Visiting

By Brent Ewig, MHS

Director, Public Policy & Government Affairs, AMCHP

The Pew Center on the States recently surveyed state agency leaders in all 50 states and the District of Columbia, creating a new inventory of state home visiting programs, models, funding and policies for fiscal year 2009-2010.



The following are key findings:

- [State home visiting programs](#): 46 states and the District of Columbia have some level of investment in home visiting

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Pew Study on Home Visiting

- [Funding strategies](#): States made available \$1.36 billion to home visiting programs via two primary funding strategies: categorical funds for home visiting only; and broad-based prevention funds that could be used for home visiting (although most states could not verify whether or how much funding was directed for this purpose)
- [Sources of state support](#): State general funds were the largest source of support for home visiting programs
- [Investment in national home visiting models](#): 34 states invested \$277 million in national home visiting models

The Pew Home Visiting Inventory provides state leaders, agency administrators and program directors “a much-needed account of state and national home visiting investments and program strategies,” with a state-by-state and [national snapshot](#) of home visiting programs, models and funding.

According to Pew, the new resource “will help state and federal policy makers evaluate current home visiting approaches, compare systems across states, prepare for the upcoming infusion of [federal home visiting grant dollars](#) and make informed decisions to ensure the best results for families and strongest returns to taxpayers.”

Download a [complete list](#) of all state-administered programs, and find more information [here](#).

HHS Convenes Advisory Committee on the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program Evaluation

By Brent Ewig, MHS

Director of Policy & Government Affairs, AMCHP

Last March, HHS convened the Advisory Committee on the Maternal, Infant, and Early Childhood Home Visiting Program Evaluation for its first session. An archived webcast of the meeting is available [here](#). The purpose of the Committee is to advise the Secretary of Health

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HHS Convenes Advisory Committee

and Human Services on the design, plan, progress, and findings of the evaluation required for the home visiting program. The Committee is to review, and make recommendations on, the design and plan for this evaluation; maintain and advise the Secretary regarding the progress of the evaluation; and comment, if the Committee chooses, on the report to be submitted to Congress.

Study design options for a national evaluation were formally presented to the Committee for review. The Administration for Children and Families (ACF) has contracted with MDRC, formerly known as Manpower Demonstration Research Corporation, a nonprofit, nonpartisan education and social policy research organization, to develop the design options for the evaluation of the home visiting program.

As specified in the legislation, the evaluation will provide a state-by-state analysis of the needs assessments and the states' actions in response to the assessments. Additionally, the evaluation will provide an assessment of:

- The effect of early childhood home visiting programs on outcomes for parents, children and communities with respect to domains specified in the Affordable Care Act (such as maternal and child health status, school readiness and domestic violence, among others);
- the effectiveness of such programs on different populations, including the extent to which the ability to improve participant outcomes varies across programs and populations; and
- the potential for the activities conducted under such programs, if scaled broadly, to enhance health care practices, eliminate health disparities, improve health care system quality and reduce costs.

The Committee includes up to 25 members who are experts in program evaluation and research, education and early childhood development. The Committee includes ex-officio members representing HRSA and ACF.

Feature CONT.

The AMCHP Policy Framework: Roles for State Title V Programs in Building Systems of Care for Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities

By Treeby Brown

Senior Program Manager, Children & Youth with Special Health Care Needs

AMCHP's State Public Health Autism Resource Center (SPHARC) will soon be releasing a new report, "Roles for State Title V Programs in Building Systems of Care for Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities." The report addresses state Title V program efforts to address the increasing numbers of children identified and diagnosed with autism spectrum disorder and other developmental disabilities (ASD/DD) as they try to meet diverse and often complex needs of these children and their families across the six core outcomes for children and youth with special health care needs (CYSHCN).

The purpose of the AMCHP Policy Framework (Framework) is to help states, primarily Title V programs, determine appropriate roles and approaches to pursue in building systems of care for children and youth with ASD/DD. The Framework also provides examples from state programs to demonstrate the breadth and depth of involvement from state Title V programs and their partners. An overall theme of the state approaches is how Title V programs that initiate comprehensive efforts to meet the needs of children and youth with ASD/DD and their families can use ASD/DD as a mechanism to improve systems of care for all CYSHCN.

State examples of varied focus and innovative mechanisms are provided in the Framework, including:

- Overall Leadership in the Systems of Care
- Building Partnerships Across Public and Private Sectors
- Family Participation
- Quality Improvement
- Use of Available Resources
- Coordination of Service Delivery
- Data Infrastructure

Feature CONT. AMCHP Policy Framework

- Outreach and Awareness

The Framework outlines a range of roles for Title V as leader, partner and facilitator; provides state resources and examples to share with policy makers in leadership, outreach and awareness, and family participation; highlights ongoing challenges in data and financing, as well as opportunities for collaborative approaches; and provides opportunities for peer-to-peer technical assistance.

The Framework will be available on the AMCHP SPHARC [website](#) in the fall of 2011. For more information about the Framework, please contact [Treeby Brown](#).

Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Regional Consortia: Marching Forward Toward Better Systems of Care for Everyone

By **Stephen R. Hooper, Ph.D.**

Professor of Psychiatry, Psychology, Pediatrics, and Education

LEND Director

Director of Training and Education

Carolina Institute for Developmental Disabilities

University of North Carolina School of Medicine

Chapel Hill, North Carolina

The Maternal and Child Health Bureau (MCHB) has a long standing commitment to advancing the development of services for underserved populations, with a particular focus on linking various agencies, advocacy groups and personnel into more efficient and effective systems of care. These efforts are fueled, in part, by their emphasis on interdisciplinary involvement, cultural and linguistic diversity, and families. One of the major interdisciplinary investments by MCHB has been in the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) training program. The fundamental goal of the LEND training program is to improve the health of infants, children and adolescents with disabilities. This goal is accomplished by preparing trainees from diverse

Feature CONT. LEND Regional Consortia

professional disciplines to assume leadership roles in their respective fields. The LEND programs are funded under the Combating Autism Act of 2006 (Public Law 109-416) and managed under the auspices of the Health Resources and Service's Administration's (HRSA) MCHB. At present, there are 43 LEND programs scattered across 33 states. Consistent with the National Strategic Plan for MCH Training (MCH, 2010), each of the 43 LEND programs addresses the following objectives:

- Advancing the knowledge and skills of the full range of child health professionals to improve health care delivery systems for children (and adults) with Autism Spectrum Disorder (ASD) and related intellectual/developmental disabilities (I/DD)
- Providing high-quality interdisciplinary education to health professionals which emphasizes the integration of services supported by the state, local agencies, organizations, private providers and communities
- Providing a wide range of health professionals with the skills needed to foster a community-based partnership of health resources and community leadership
- Promoting innovative practice models that enhance cultural competency, partnerships among disciplines, and family-centered approaches to care
- Demonstrating that the proposed interdisciplinary training opportunities will increase diagnosis of, or rule out, individuals with ASD or other I/DD

While each LEND program is unique, shaped in large part by their state and regional needs, the LEND programs are in an important position to provide linkages not only within their respective states, but also to assert a positive impact within their national regions. These collaborative efforts within regions permit the examination of national issues of importance for children with special health care needs and their families, and allow for the sharing of innovative, evidence-based practices and products. Collectively, with technical assistance from HRSA and the [Association of University Centers on Disabilities](#) (AUCD), the LEND programs form a national network that shares information

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LEND Regional Consortia

and resources to maximize their impact, with much of the network being organized via regional consortiums.

LEND Regional Consortia

Within the LEND network, there are seven different groups that have organized to address key issues related to their region. Specific regional groups and their LEND (and University Centers for Excellence in Developmental Disabilities [UCEDD]) members include:

- PacWest (OR, CA, HI, UT, NM, CO, NV, AK, AZ)
- Southeast Region Consortium (NC, TN-Vanderbilt, TN-Boling, FL-Miami, VA, AL, MS, GA-CLDD, FL-CIC, SC, GA IHDD, KY, MS)
- Northeast New England (VT, NH, CT, MA-Shriver, MA-ICI, NY-Strong, NY-AECOM, NY-Westchester)
- Midwest (SD, NE, KS, MO, IA)
- Great Lakes (WI, MN, IL, IN)
- Mid-Atlantic (DC, MD, VA, WV, PA-CHOP)
- Central Conference Training Consortium (TN-Boling, TN-Vanderbilt, IN-Riley, OH-Cincinnati, OH-Nisonger, MO, IL, MN, WI, ND, IN-Institute of Disability & Community, KY, MI)

Given the overall mission of LEND, all of these regional groups have focused on training, professional development and infrastructure building. These activities have included collaborative webinars, regional conferences, workshops, and meetings with both faculty and trainees. One group, the Central Conference Training Consortium, even has their own [website](#) detailing their governance and ongoing collaborative activities. Taken together, these initiatives have contributed to ongoing infrastructure building and evolving systems of care for children with special health care needs and their families.

Southeast Region Consortium

The North Carolina LEND Program at the Carolina Institute for Developmental Disabilities at the University of North Carolina School of Medicine has been actively involved

in the Southeast Region Consortium. This group of LEND and UCEDD partners, largely encapsulating Region IV, has worked collectively over the past 10 years to develop training activities broadly addressing Title V needs. This group convenes via regular quarterly conference calls, and over the past year has inventoried each program to compile all of their respective training topics and modules. In this regard, the group has a library of over 125 prepared presentations in the areas of CSHCN, ASD and related I/DD, health care services, leadership training and cultural diversity to mention just a few. This library of topics has been cross-listed with the goals of each state Title V MCH Block Grant in the region to begin aligning potential presentations and modules for the Title V workforce in the southeast region. With the assistance of AMCHP, we also surveyed all of the Title V Directors in the southeast for their input. These initiatives have culminated in an annual training calendar that will showcase each LEND/UCEDD program in the region and, in partnership with AUCD, the training modules will be presented on a monthly basis to a national audience. The “Southeast Region Consortium and AUCD Presents!” program will begin in the fall of 2011 and will be available to both regional and national audiences.

Directions for the Future

The efforts of each of these seven regional consortiums are noteworthy, and their collective contribution to building the MCH workforce is impressive. These collaborative regional efforts address not only state-based needs, but national/regional challenges, and they undoubtedly permit ongoing infrastructure building. These innovative partnerships have contributed to training the MCH workforce, and will contribute to ongoing efforts to build more effective and efficient systems of care for children with special health care needs and their families. All Title V Directors and their personnel are highly encouraged to reach out to their respective LEND program and/or regional consortium in an effort to work collaboratively on these ongoing infrastructure building endeavors.

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Opportunities and Challenges in Building Systems for CYSHCN

By Judy Palfrey

Co-Principal Investigator, National Center for Ease of Use of Community Based Services (July 2010-August 2011)

Families of children with special health care needs (CYSHCN) turn to Maternal and Child Health programs for assistance with a wide variety of concerns. Like other children, CYSHCN require health, education and recreation services, but often their needs are more complex than those of other children. For CYSHCN, services are often not “easy to use” because of stringent eligibility criteria, distant access, limited time availability or lack of training of personnel about disability care. Title V agencies are charged with finding ways to organize health care, dental care, early intervention, therapies, mental health services, vocational and recreational interventions so that parents can readily take advantage of them. Instead of a maze, parents want a map. They have reasonable expectations that health, dental, education, nutrition, vocation and therapeutic professionals are working together to make a seamless whole of the various community-based offerings.

At the National Center for Ease of Use of Community-Based Services, our mission is “to advance policy and practice solutions that improve community-based services.” In taking a look at the current state of affairs for CYSHCN, we find that uninsured children, children from single family homes and children whose parents do not speak English as their first language report that services are not organized in a way that makes them easy to use. One major protective factor, though, is the presence of a Medical Home. CYSHCN without a Medical Home are six times more likely not to have services that are “easy to use” than children with a Medical Home.

As MCH professionals concerned with improving the ease of use of community-based services, a focus on the Medical Home allows emphasis on four important concepts: universality, access, value and affordability. MCH programs can and should be monitoring the child and adolescent population in the state to assure that all children (and especially all children with disabilities) actually have a Medical Home. The most recent [National Survey of CYSHCN](#) shows that only 47 percent of CYSHCN have a Medical Home. The universality principle will be achieved when 100 percent of CYSHCN have a Medical Home.

Accessibility to services is a function of both the physical accessibility and the availability of resources (including trained personnel). MCH professionals will improve the ease of use of services greatly by interventions such as the co-location of services, cross-training of providers and specific disability awareness training of community based professionals. The value of community-based services is enhanced whenever families find that the quality of their daily lives and that of their children is good. Not having to spend inordinate energy and time on overly bureaucratic procedures lessens stress and improves the quality of families’ lives. Finally, within the Medical Home, services are organized to be affordable, with reduction of unnecessary tests, and interventions and the provision of targeted, outcome-oriented, high quality services. At the National Center for Ease of Use of Community-Based Services, we are eager to learn more about how families and providers perceive community-based services. We are interested in learning both the challenges and the best practices that providers and families are aware of. To that end we have created a survey that will help us find out what is working and what is not. The survey is simple and quick. We would love to have as many Title V agencies, families and providers fill out the survey as possible. The [survey](#) will help us all as we work to ensure that families benefit from the best that is out there...the Medical Home.

Envision 2020

The Division of Services for Children with Special Healthcare Needs/Maternal and Child Health has been working on Envision 2020 – a strategic plan to guide the Division on improving the system of services for children, youth and adults with special healthcare needs. Last October, the Division brought together over 100 key partners, including Title V staff, providers and family leaders who provided a wealth of recommendations on improving the system. Following the meeting, participants were sent a survey to prioritize the strategies. For additional input, a series of expert panels have been held on three key emerging issues: life course, quality improvement and health information technology. The Division also held a one day meeting with its funded national resource centers. Division staff are now consolidating the input from its partners, and expects to release Envision 2020 by the end of the year. If you would like additional information, please contact Lynda Honberg at LHonberg@hrsa.gov.

Member to Member

We asked a couple of our members the following question:

What strategies are you using to address the measurement requirements of the federal home visiting program in your state?

Illinois

Ralph Schubert

Owner, Take It For Granted LLC, Retired Title V Director, and AMCHP member

Illinois is using multiple data collection methods for the constructs and benchmarks. Many maternal and newborn health items will be collected by self-report and replaced later with data extracted from vital records. Child maltreatment data will come from our child welfare agency. We are planning to use an external contractor to administer several questionnaires for child development and school readiness measures. The data for family economic self-sufficiency will be collected by self report. Indicators such as well child care, depression screening and developmental screening are consistent with established Medicaid HEDIS measures to enable comparison with other Medicaid-eligible children. Domestic violence and service coordination data will be collected by home visitors. Benchmark data and measures of model fidelity will be used for CQI and reported to MCHB.

Illinois has a data-sharing agreement between the Title V agency, the vital records registrar and Illinois' Medicaid and SCHIP agency which allows great information exchange among the three agencies. The Title V program worked with Illinois' child welfare agency to establish HealthWorks of Illinois, a partnership allowing the Title V program access to Medicaid eligibility and claims data about children in protective custody. A minor barrier is the need for a new interagency agreement to give the Title V program access to information about unsubstantiated maltreatment and founded maltreatment not in HealthWorks. A major barrier for all states is the negotiation of data exchange agreements between model developers and Title V programs to keep from driving local home visiting programs crazy with duplicate data entry.

Kansas

Debbie Richardson, Ph.D.

Manager, Home Visiting Program, Bureau of Family Health, Kansas Department of Health & Environment

In Kansas, we are focusing on community systems of existing Early Head Start, Healthy Families America, and Parents as Teachers programs. We will also incorporate a promising approach model. For the required benchmarks and constructs, our goal was to select common indicators and measures all programs will use without creating undue burden on any model or local program staff. We reviewed indicators, data and measures each program currently utilizes (i.e., a crosswalk). The programs use similar indicators or measures for a few constructs, yet for many they do not collect similar data or have not addressed at all. Ultimately, each program will have to incorporate some new measurement tools along with others they already use. Additionally, we will develop a comprehensive data management system. This will be accomplished using the Research Electronic Data Capture (REDCap) to create one database that integrates and stores linked client-level data across the program models' existing databases and other state databases. The database will allow us to collect, monitor, analyze, store and report on the required benchmarks and constructs as well as for Continuous Quality Improvement. We are excited about this opportunity to collect a similar set of data across all the program models.

Success Stories

Transformation in Primary Care: Indiana's Successes with Medical Home

By Mary Jo Paladino

IN CISS Project Facilitator at the Indiana University School of Medicine

As we quickly move past the first decade of the twenty-first century, health care reform and the need to transform primary care practice has never been more urgent. The health care reform bill contains Medical Home as the

Success Stories CONT. Transformation in Primary Care

model of primary care needed to improve patient care and stop spiraling costs. The Institute of Medicine and others have stated that system change is needed to make this transformation. System change within a practice is best done through quality improvement processes. Experiences by members of the American Academy of Pediatrics (AAP) have demonstrated that “learning collaboratives” help start and maintain this process.

Indiana’s Medical Home Learning Collaborative (MHLC) is a three-year joint project between the Indiana University School of Medicine and Indiana State Department of Health through a State Implementation Grant for Integrated Community Systems for CSHCN. The MHLC has been working to improve Medical Home concepts in primary care practices since the fall of 2009. The MHLC includes 18 primary care practices and run by a MHLC Resource Team. Our learning collaborative is unique in that it includes both pediatric and family medicine. The Collaborative meets biweekly on conference calls to share successes, challenges and updates regarding quality improvement projects and issues involving Medical Home. Two conferences are also held to present specific topics relating to Medical Home. The MHLC Resource Team makes site visits to the practices to provide consulting, support and community resources.

Practice QI teams include physicians, nursing staff, practice staff and family leaders, an important part of the practice QI teams. One of the accomplishments is the increase of family involvement in the MHLC. The family/parent partner is invited to these QI meeting to share their input and perspective. Feedback is given in less formal ways through the telephone or e-mail. Another success has been to explore different ways for family partners to engage in QI team activity. In an effort to sustain the child health improvement work of the MHLC our core partners have elected to adopt a child health improvement model. For more information, contact the MHLC Resource Team: mpaladin@indiana.edu or arpaxton@iupui.edu.

Success Stories CONT. Maryland’s Implementation Grant

By Josie Thomas

Director of the Parent’s Place of Maryland

The Parents’ Place of Maryland, in partnership with the Office for Genetics and Children with Special Health Care Needs (OGCSHCN, Maryland’s Title V program for CYSHCN at the Maryland Department of Health and Mental Hygiene) was awarded a State Implementation Grant for Integrated Community Systems for Children and Youth with Special Health Care Needs (CYSHCN) from the federal Maternal and Child Health Bureau in 2008. Other major collaborators included the Maryland AAP and the Johns Hopkins School of Public Health.

The backbone of the project is the development of the Maryland Community of Care Consortium for Children with Special Health Care Needs (COC) — a working group of diverse stakeholders, including families, providers, advocates, consumers, administrators, and professionals from the public and private service systems. The quarterly meetings brings together over 50 stakeholders and offers a forum for information exchange, problem solving, consensus building, and collaborative action to address gaps and barriers in services for CYSHCN and their families. During the past year, the accomplishments of the COC, including the provision of guidance and input on Maryland’s Title V Needs Assessment and the 2010 Maryland Parent Survey, were the driving force behind a restructuring of OGCSHCN, and a thriving mini-grant program. The COC serves as a model for developing respectful and respected family-professional partnerships at every level and as a model for an ongoing successful public, nonprofit, family and private collaborative.

Another key aspect of the project is the planned statewide implementation of a Baltimore City based developmental screening improvement pilot program at the pediatric practice level, conducted by project partners Dr. Tracy King (Johns Hopkins University), Baltimore City Reach Out and Read, and the Maryland AAP. In addition to large-group and on-site trainings, certain practices were offered multi-tiered, ongoing, in-office support. Dr. King published an article discussing her work in Pediatrics. Both the COC and the developmental screening implementation project will be sustained through Maryland’s Title V Block Grant.

View from Washington Out of Sync

By Brent Ewig, MHS

Director, Public Policy & Government Affairs, AMCHP

It should not come as a surprise to even the casual observer that the Congressional process has become rather dysfunctional lately. With the beginning of the 2012 fiscal year rapidly approaching we still have not seen a proposed funding level for the Title V MCH Block Grant or any other critical health program with the exception of WIC, which the House voted to cut by \$800 million. The recent debt limit deficit reduction agreement set a top line number of required cuts, but didn't identify a single specific program to be reduced. The bottom line is that we are beginning September at a place that the annual federal budgeting process is usually at in spring.

Meanwhile, the Affordable Care Act continues to wind its litigious path through the U.S. Court system, with Circuit Court of Appeals recently upholding a lower court's ruling that the individual mandate requirement in the health reform law is unconstitutional, but rejected the lower court's conclusion that the rest of the law should be invalidated as a result. This case with 26 states as plaintiffs is among a number of challenges to the Affordable Care Act, which have mixed results in the courts to date underscoring the obvious point that the Supreme Court will need to weigh in with a final decision, although timing on that too remains unknown.

A fair question to ask: How can state health program administrators be expected to plan amongst such uncertainty? To try to help, AMCHP convened a recent national teleconference to share with our members the details of the debt limit agreement, the potential impact on Title V and other critical MCH programs, and an outline of our advocacy strategies moving forward. A recording of the call will be posted to the AMCHP [website](#). In case you missed it, please also see our recent Action Alert [here](#) for more information on what you can do to help inform policymakers about the impact of current and expected cuts.

Looking forward to September it appears Congress will finally begin moving the annual appropriations bills that fund programs like Title V. It seems almost certain that they will not be completed by October 1 which means that a continuing resolution is highly likely once again. AMCHP will be working with elected officials in the coming weeks

to make sure they have information on the damage recent cuts at both the federal and state level have had on MCH populations. Our message is that further cuts will result in certain suffering, will endanger the capacity of states to provide the most basic MCH functions, and will do more harm than good. We will be keeping you informed as usual via our e-newsletters and Legislative Alerts, and will be asking again for your help to make the case for sustained funding.

Who's New

New MCH Leaders

NEW CYSHCN DIRECTORS

Ohio

Jessica Foster

Director, Children and Youth with Special Health Care Needs Program, Ohio Department of Health

NEW FEDERAL PARTNERS

Centers for Disease Control and Prevention (CDC)

David Goodman

*MCH Epidemiologist
National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention*

NEW ORGANIZATIONAL PARTNERS

American Academy of Pediatrics

Kristen Mizzi

*Associate Director, Department of Federal Affairs
American Academy of Pediatrics*

Get Involved

MCHB Call for Comments to Proposed Changes to the MCH Block Grant Application Annual Report

Please note that MCHB has published a notice in the Federal Register summarizing revisions and requesting comments on proposed changes to the Title V MCH Services Block Grant Application Annual Report guidance. AMCHP encourages Title V programs to review the Federal Register notice and provide feedback as appropriate. To learn more, visit [here](#).

RFA for Act Early State Systems Grants

Through funding from the Centers for Disease Control and Prevention (CDC)'s National Center for Birth Defects and Developmental Disabilities (NCBDDD), AMCHP will provide grants to state teams, led by either the Title V program or a member of the Association of University Centers on Disabilities (AUCD) network, to support the collaboration of Act Early Regional Summit Project teams and to further activities initiated by state teams during the Summits. These funds are designed to be a catalyst for collaboration with stakeholders, as well as for implementing specific activities outlined in Act Early State Plans. AMCHP will provide ongoing technical assistance, disseminate resource materials, and link grantees to other states and experts in autism spectrum disorders (ASD). Requirements: Approximately 10-15 state grants will be awarded in the amount of up to \$15,000 each. All states and territories who have participated in an Act Early Regional Summit except for those who currently have received a State Implementation Grant for Improving Services for Child and Youth with Autism Spectrum Disorder and other Developmental Disabilities are eligible to apply. The funding announcement will be released in mid-September 2011 and applications will be due in November 2011.

To access your Act Early State Plan or find information about the Act Early Regional Summit Project, visit the

AUCD [website](#) and click on the Learn the Signs. Act Early. icon.

The funding announcement will be posted on the AMCHP and AUCD websites and will be distributed through relevant listservs, or you can contact AMCHP directly for a copy. For more information, please contact [Treeby Brown](#) or [Melody Cherny](#).

Webinar on the Life Course Perspective

The webinar, "The Life Course Perspective in Promoting Health in Aging," will feature Diana Kuh, PhD, Director of the Unit for Lifelong Health and Ageing at the Medical Research Council (MRC), Director of the MRC National Survey of Health and Development, and Principal investigator for HALCyon, on October 10 from 1 to 2 p.m. EST. To register, visit [here](#).

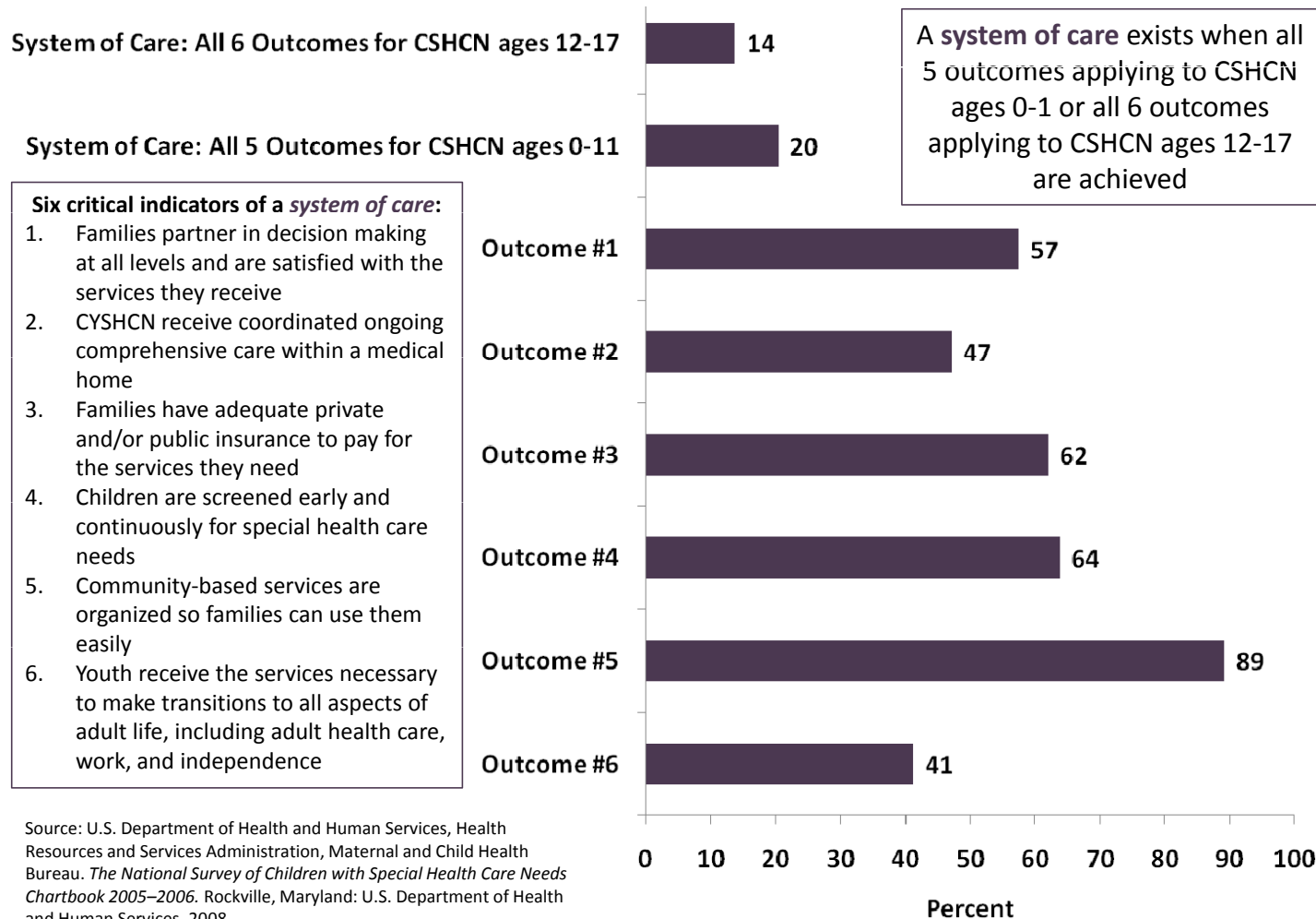
That National Center for Ease of Use of Community-Based Services

It takes a system of services to support a child with special health care needs and sometimes that system seems like a daunting, endless maze. [The National Center for Ease of Use of Community-Based Services](#) is trying to understand how they can improve their system by identifying which services are easy or not easy to use. The National Center wants to help make service systems more accessible, affordable, universal, and valuable to children with special health care needs and their families.

They are looking for input from a variety of stakeholders, including families and providers. Your response will help them identify what's working, what's not, and how they can make it easier for children to get the health care services they need. Please visit [here](#) to take the survey. For more information about the survey, please contact [Jacquelyn Bialo](#).

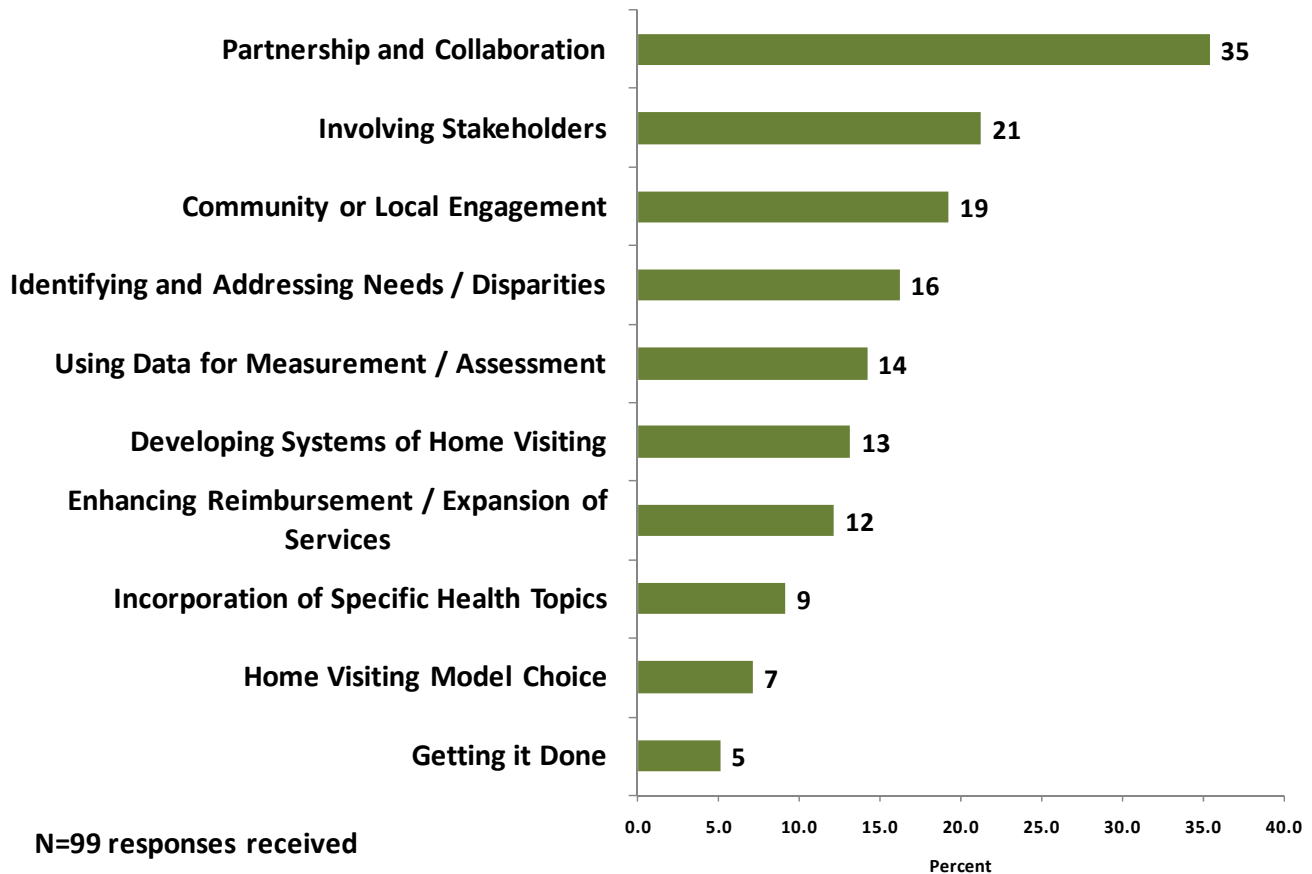
Data and Trends

Percent of CSHCN for whom the Core Outcome or System of Care was achieved



Data and Trends CONT.

Home Visiting: Successes in Designing the Updated State Plan



In response to the question, “What was the most significant success around designing the updated state plan for home visiting?” *Pulse* readers responded that **Partnership and Collaboration** was their most significant achievement. Respondents highlighted collaboration across agencies, across the maternal and early childhood system, in local communities and among state, federal and local stakeholders. They described partnership and collaboration as “building awareness, trust, and consensus with a diverse group of stakeholders,” “team work,” “networking” and as a “coordinated,” “inclusive,” “participatory” process. Many wrote that shared goals brought partners together, and they recognized that collaboration is valuable, if not always easy. “This collaboration was no small feat and the group can be jointly proud of the plan and equally accountable for its future success.”

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.

- [New Clinical Report on Supporting Health Care Transition from Adolescence to Adulthood in the Medical Home](#): This report appeared in the July issue of *Pediatrics*. The report is jointly authored by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians and provides practical, detailed guidance on how to plan and execute better health care transitions for all patients. The clinical report addresses health care transition for all youth but also provides a pathway for youth with chronic conditions. The approach to special health care needs in the report is not condition specific, but the algorithmic format can provide a template for enhancements pertinent to specific conditions. The report distinguishes between the transition to an adult model of care at age 18 and the transfer of care to an adult medical home that may occur at any time from age 18 to 23. For family physicians providing both pediatric and adult care, there may be no transfer of care, but the transition to an adult model of care should still involve preparation and planning. The clinical report coincides with the advent of [Got Transition](#) — the new National Health Care Transition Center — that works with pediatric and adult primary care practices in a learning collaborative model to develop a practical package of resources that align with the report's guidance. To learn more, e-mail transitions@aap.org.

[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

Resources CONT.

for families and health care/service providers, and timely announcements for state Title V programs on ASD/DD.

- [AMCHP Fact Sheet: State Birth Defects Performance Measures](#) [May 2011]: AMCHP reviewed the Title V Information System to identify states that have adopted performance measures related to birth defects surveillance. This fact sheet highlights innovative and effective ways that state Title V agencies utilize birth defects surveillance systems to improve maternal and child health.
- [AMCHP Fact Sheet: Health Care Reform: What's in it for Children and Youth with Special Health Care Needs?](#) [October 2010]: Developed by the National Center for Health Reform Implementation, this fact sheet outlines the sections of the Patient Protection and Affordable Care Act of 2010 that reference provisions affecting children and youth with special health care needs.
- [Models of Care for Children and Youth with Special Health Care Needs: Promising Models for Transforming California's System of Care](#) [November 2009]: The Lucile Packard Foundation for Children's Health commissioned AMCHP to produce this report, which identifies promising models implemented outside of California to support the system of care for children and youth with special health care needs.

[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 Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers](#) [January 2011]: A publication by the [National Academy for State Health Policy](#) (NASHP) for the Catalyst Center.
- [The Affordable Care Act: A Side-by-Side Comparison of Major Provisions and the Implications for Children and Youth with Special Health Care Needs](#) [February 2011]: A companion piece to the January 2011 NASHP publication.

[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 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

Resources CONT.

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 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.

[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 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.

[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.

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Calendar

MCH Events

[NASHP 24th Annual State Health Policy Conference](#)

October 3-5
Kansas City, MO

[American Public Health Association Annual Meeting](#)

October 29-November 2
Washington, DC

[Academy of Breastfeeding Medicine's 16th Annual International Meeting](#)

November 3-6
Miami, FL

[2011 AUCD Conference](#)

November 6-9
Crystal City, VA

[17th Annual MCH Epidemiology Conference](#)

December 14-16
New Orleans, LA



Do you have a successful program that has improved Child Health outcomes in areas such as injury and violence prevention, school readiness, mental health, oral health, and more?

Then consider sharing your program in [Innovation Station](#), AMCHP's searchable database of emerging, promising and best practices in maternal and child health. You'll have a chance to:

- 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. If you are looking for examples of successful child health programs, be sure to check out the Innovation Station profiles on the [Alaska Childhood Understanding Behaviors Survey \(CUBS\)](#) and [The Boys' Health Advocacy Program!](#)

For more information, contact [Kate Howe](#) at (202) 266-3056 or visit amchp.org/bestpractices.

Association of Maternal & Child Health Programs

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