From the President

Looking Ahead in 2015

By Sam B. Cooper III, LMSW-IPR

Don't worry; I know where we are going!

OK, I admit it. Asking for directions? ...Just not a natural tendency in this former Boy Scout. We have so many more tools now to help us be “self-sufficient” – like that lady in my smartphone, or those fancy new Dick Tracy wristwatches from the famous fruit company. The thing is, even decked out with all the technology, the latest map and guidebook, finding one’s way in new territory is never easy. In this edition of Pulse, we have gathered great stories about children and youth with special health care needs (CYSHCN) programs and transition.

In one of my earliest social work adventures in the 90s, I was privileged to work with a family who had been dealing with the youngest child’s complex health conditions for several years. They had successfully navigated the specialists, the hospitals, the eligibility procedures for Medicaid; and their “Bud” was thriving. The new challenges arose at the time he was moving into high school; this was new territory. None of the family “maps” from the older siblings lined up with this experience. Building new relationships with school staff members and linking up the medical, educational, and social services to get the best fit for this kiddo was complicated.

At that time, “permanency planning,” was really the extent of any notion of transition related services, but that narrow definition was not the primary need in this case. Together though, the parents, the youngster, the essential players in all of the systems, and I worked through the details.
needed to make the passage from middle school to high school successful. We depended on one another when we got lost and kept the young man’s potential as our True North. In different ways, we all learned new ways to ask for directions, without fear of judgment and became even better prepared for the next transition.

As you read through the articles included within this edition, take time to think about how you might be able to share this exciting work – the tools, the new CYSHCN National Standards, the perspectives from our featured contributors – with your peers, families and AMCHP partners. So much progress has been made since the days of the Macarena, Furbies and mobile phones that were the size of a small child. Let’s all be brave and ask where WE are going next with Transition.

Slàinte,
Sam

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By Lori Tremmel Freeman,
BS, MBA
Chief Executive Officer, AMCHP

As you read this issue of Pulse focused on children and youth with special health care needs and transition, I’m going to ask you to take a few moments to imagine and to place yourself in a challenging situation.

Imagine you’re sick or injured in some way. You are a fully grown adult with special health care needs. When you logically seek care from your adult health care provider, who you want to trust, you are given the wrong advice or care. You sense this has occurred and may even continue to suffer further injury, but you aren’t sure what to do. You are living alone and are your only support system. Finally, as a last resort, you reach back across distance and time to consult with the pediatrician from your childhood to help. At least your childhood physician knows you well and understands your unique challenges. Through this process, you learn that what was originally a minor injury has become much more serious because of misunderstanding and incorrect diagnosis.

To overstate the obvious, CYSHCN grow up to be adults with special health care needs. And, there are all varieties of social, environmental, economic and other conditions that further complicate the transition and require real skills to address and navigate.

Unfortunately, the simple example provided here is a very real scenario that demonstrates a challenge faced by an adult with special health care needs that did not receive proper care within the health care system due to ignorance and lack of training. Sadly, it probably happens more often than not.

At the 2015 AMCHP Annual Conference, the organization had the pleasure of hearing from Ian Watlington, a disability advocate, who is all too familiar with this example. In fact, this example is based on one of Ian’s stories that he shared with us during his talk about a broken ankle. When Ian was transitioning in his adult life after growing up in Denver, Colorado surrounded by a solid family and health care systems support, he had some real challenges
in Washington, DC. He notes that the health care system “continues to be a maze” and that he has “yet to find the cheese.” Ian says, “Since the cheese remains allusive, I depend on telephonic support and consultations from physicians in Denver.”

I learned a lot from Ian in the short time that I’ve made his acquaintance. Here are some of my personal takeaways from chatting with Ian and getting to know him leading up to our conference.

We need to engage with and listen to the child, youth and adults with special health care needs directly. Although Ian is very vocal about having been raised by a tremendously supportive single mom and amazing grandparents, he often attributes self-reliance and self-advocacy among the greatest gifts they bestowed on him. Early on in his life, he learned how to effectively articulate and communicate his needs to adults. He was given permission to question authority, with respect, and taught that if something cannot be said directly to him then it probably shouldn’t be said at all.

If we are truly serving the population of CYSHCN, then we need to figure out who is best positioned and responsible for influencing the overall training of medical professionals so that they can treat CYSHCN after they transition to adulthood. With Ian’s example, we know that ignorance remains in the health care provider system with regard to the treatment of relatively basic injuries. There are still issues with adult coordinated care and unintended discrimination related to the treatment of injuries.

Lastly, Ian taught me about the value of respecting the person regardless of whether they are a child, an adolescent, a young adult or a grown adult with special health care needs. He spoke passionately of the “dignity of risk,” of the value of letting kids stumble. Overprotection by parents (which is natural of course) and even by systems (educational, health and other) does not really invite the kind of self-awareness and self-advocacy Ian so strongly believes in that shaped the adult he has become. He is stronger and more capable because of the risks he’s been permitted to take in his life.

I would be remiss if I didn’t mention some of the excellent work being done to help address some of these transition concerns. The AMCHP Standards of Systems of Care for Children and Youth with Special Health Care Needs represent a solid effort to document the recommended practices related to transition. Transition to adulthood is one of the core domains for the system standards. Within the overall recommended system outcomes, transition to adulthood is specifically addressed in order that “youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.” The recommended system standards address what should be occurring in the framework of both pediatric and adult settings. Additionally, the standards use existing national system definitions, principles and frameworks that might be helpful to reference including: a) a report from the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians on supporting the health care transition from adolescence to adulthood in the medical home (Pediatr. 2011;128:182); and b) the Six Core Elements of Health Care Transition 2.0 from Got Transition and the Center for Health Care Transition Improvement.

Feature
Measuring Transition Performance: Options for States to Consider

By Peggy McManus, MHS, Dan Beck, MA and Patience White, MD, MA
Got Transition

Health care transition is one of 15 national priority areas selected by the Maternal and Child Health Bureau (MCHB) as part of the MCH transformation. The performance measure calls for youth with and without special health care needs to receive services necessary to make the transition from pediatric to adult health care. Got Transition, the MCHB national resource center on transition, has been working with MCHB, AMCHP,
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Measuring Transition Performance

and five state Title V agencies (Maryland, Ohio, Oregon, Texas and Wisconsin) to develop a set of options for states planning to select and implement transition as one of their national performance measures. The intent of these combined efforts is to create a set of evidence-informed recommendations aligned with the 2011 Clinical Report on Health Care Transition from the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP); the Six Core Elements of Health Care Transition (a set of clinical tools based on the Clinical Report), and the National Standards for Systems of Care for Children and Youth with Special Health Care Needs.

This article describes transition needs assessment steps that state Title V agencies may want to consider as part of their Title V MCH Services Block Grant application due by July 2015.

- **Stakeholder Engagement:** To achieve transition progress, both pediatric and adult providers need to be involved at the outset. Examples of adult provider stakeholder groups that Title V agencies may want to reach out to include state chapters of the American College of Physicians, AAFP, Med-Peds Section of the AAP, and Adult Nurse Practitioners; leaders involved in adult medical home initiatives; health plan officials and payers involved in delivery system reforms; and/or state chronic disease programs. The intent of this outreach is to introduce the Clinical Report and the Six Core Elements and to begin to identify leaders interested in transition for future quality improvement and systems development efforts. See the Texas example in the Member to Member section.

- **Assessing Transition Needs among All Adolescents, Including Youth with Special Needs:** To obtain state-specific information on transition performance from the 2009-10 National Survey of Children with Special Health Care Needs, visit the research section on the Got Transition website. New state transition data for youth with and without special needs will not be available from MCHB until 2017. In the meantime, we recommend that states use the 2009-10 data and avoid conducting new studies on transition barriers since this type of research repeatedly shows a consistent set of problems – problems finding adult providers, time and reimbursement problems, difficulties ending longstanding pediatric relationships, lack of communication and coordination between pediatric and adult systems, lack of training in childhood-onset conditions among adult providers, lack of early and ongoing support in transition preparation for consumers, and lack of current medical information transferred to adult providers.

- **Examining Transition Strengths and Capacities:** Recognizing the many transition efforts that state Title V programs are involved in, we encourage states to determine the extent to which these initiatives include 1) youth with and without special needs and parents/caregivers, 2) both pediatric and adult health care providers, 3) a transition policy, 4) a method for tracking individual/provider transition progress, 5) a transition readiness/self-care assessment, 6) a plan of care with transition information, 7) a medical summary and emergency care plan, 8) a transfer checklist and 9) consumer feedback. See the Maryland example in the Member to Member section.

- **Selecting Transition Priority Areas:** States can elect to follow the Six Core Elements of Health Care Transition or the National Standards for Systems of Care for CYSHCN. It is important to note that while these two are very similar, they are not the same. The Six Core Elements offers more explicit detail. Importantly, Got Transition has been working with AMCHP to ensure a close crosswalk for implementing and measuring transition performance using the system standards. This crosswalk will be posted to the AMCHP website and shared with Title V CYSHCN programs in the coming month.

- **Setting Transition Performance Objectives:** We...
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Measuring Transition Performance

recommend that states establish a baseline for transition using the “Current Assessment of Health Care Transition Activities” that is part of the Got Transition Six Core Elements. This can be used with pediatric and adult practices starting a transition improvement project, as Wisconsin has done, or it can be used with Title V contracted programs or in a larger health plan or system. Once the baseline has been established, states can partner with these key stakeholder groups to select improvement goals and track progress. See the Wisconsin example in the Member to Member section.

• Developing a State Action Plan: Over the course of the next few months, Got Transition will continue working with AMCHP and state Title V CSHCN directors and adolescent health coordinators to develop options for transition strategies that states can use, again aligned with the Six Core Elements and the National Standards for Systems of Care for Children and Youth with Special Health Care Needs. This is a team effort and a work-in-progress.

For comments or suggestions, please contact Dan Beck at dbeck@thenationalalliance.org or Peggy McManus at mmcmanus@thenationalalliance.org.

Feature

Texas Children’s Hospital Innovates and Collaborates in Transition

By Albert Hergenroeder, MD
Professor of Pediatrics and Chief, Adolescent and Sports Medicine, Texas Children’s Hospital

Constance Weimann, PhD
Associate Professor, Pediatrics-Adolescent Medicine and Sports Medicine, Baylor College of Medicine

Currently, 90 percent of CYSHCN of primarily a physical nature in the United States will enter adulthood. Although CYSHCN are living longer, methods to improve survival have not been matched by methods to maintain their quality of life and/or medical care as they transition from pediatric to adult based health care. As a result, increased morbidity and mortality have been reported in this post transition period if the health care transition (HCT) is poorly managed. The need for improved HCT at the local, state and federal levels has been recognized for a generation, and call for action has gained momentum over the past decade.

Texas Children’s Hospital and the Department of Pediatrics, Baylor College of Medicine responded to this need with initiating two major initiatives that are discussed in this article: 1) establishing a HCT planning program around an electronic medical record-based transition planning tool; and 2) an annual, international HCT conference bringing together a unique collaboration of diverse stakeholders. These initiatives are discussed below.

Transition Planning Tool

Texas Children’s Hospital (TCH) has developed a Transition Planning Tool (TPT) that provides an infrastructure allowing youth and young adults with special health care needs (YYASHCN) and their families to plan their health care transition (HCT) from pediatric to adult based care. The TPT was designed as a ‘test of mastery’ to evaluate and remedy gaps in the patient’s condition-specific knowledge and skills needed for successful HCT. TCH integrated the TPT into Epic, its electronic medical record (EMR). The TPT directly or indirectly addresses five of the six core elements suggested for health care transition (Got Transition/Center for Health Care Transition, 2014).

The patient’s and/or family’s HCT knowledge and skills are assessed through dialogue initiated using 13 core questions, which were based on expert opinion and empirical literature. Content areas include knowing their illness and its manifestations, when an emergency is developing, how to refill prescriptions, and self-administer medications; treatment adherence; issues related to reproductive health, substance use, and insurance; and identifying an adult provider. The first question is “Can you tell me about your disease/disability?” If the patient does not provide a satisfactory explanation of their disease in the judgment of the clinician asking the question, then one or more of three education options is employed: an explanation of the disease is given by a care provider; a written fact sheet with an explanation of
TCH Initiatives

the disease is given; or a printed homework assignment is provided asking the patient to write the name of their disease/disability in the designated space and a short letter to a friend describing their disease/disability. At the next clinic visit, the homework assignment is reviewed. When the patient masters a question they are given a “successfully accomplished” designation in the Epic flow-sheet. Ideally, the patient will have successfully accomplished all 13 questions before leaving TCH. The TPT has a prepopulated portable medical summary that can be generated after any clinic visit and can be used in any inpatient or outpatient setting. A subset of questions is available to use with parents/caregivers whose children are developmentally unable to participate. More information on this TPT is available on request and the tool is available for Epic users to incorporate into their hospital/health systems: https://galaxy.epic.com/?#Browse/page=116816001733006.

Providers using the TPT have become more patient-centered, directing their discussions at the patient’s actual knowledge and skills, rather than assuming what the patient knows. After using the TPT, one provider realized how little her patients knew about their disease, despite considerable patient education efforts. She now starts with the first TPT question in all adolescent patients. Other providers have formalized HCT planning by focusing on the patient, whereas prior to using the TPT they thought they were reinforcing patients’ self-management knowledge and skills, when in fact much of the knowledge and skills was in the hands of the parents. Providers also have begun to appreciate the complexity of HCT planning and the need to start earlier: documentation of HCT planning is now occurring in 14-year-olds. The TPT has become an intervention that enables YYASHCN and their families to have conversations with their providers about the likelihood that they will survive into the third decade or beyond and the need to plan for independent living. Use of the TPT has expanded to 98 individual providers using the TPT with 498 individual patients in 25 clinics.

Transition Conference

The annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-based Care was founded in 2000. This meeting is sponsored by Baylor College of Medicine Office of Continuing Medical Education and Texas Children’s Hospital. The planning committee includes members from many professional disciplines, family members and advocates. It is designed to further attendee knowledge about and skills related to HCT and to provide an unusual platform for interaction among a broad spectrum of stakeholders at the clinical and public health level and from the community, state, and federal perspectives, including YYASHCN and families, state Title V CYSHCN programs led by the Texas Title V CYSHCN Program (provides funds for YYASHCN and their families to attend the conference and for live broadcast across Texas), the MCHB-funded Association of University Centers on Disabilities (AUCD; funds the...
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TCH Initiatives

live broadcast of the Conference to LEND and other training programs nationally), Baylor College of Medicine, Texas Children’s Hospital, and the Baylor University Robbins Institute for Health Policy and Leadership. The conference is attended by an interdisciplinary spectrum of health care professionals, including pediatrics, family medicine, internal medicine, combined medicine-pediatric physicians, psychiatrist as well as social workers, nurses and other health care coordinators/navigators; dieticians; psychologists; counselors; hospital and clinic administrators; public health officials; and community agency representatives (continuing education credits are offered). The 16th Annual Conference will be held Oct. 1-2, 2015 (see www.baylorcme.org for regularly updated information regarding the conference. For more information e-mail cme@bcm.edu) in the Texas Medical Center, Houston. Archived talks from the 2013 Transition Conference can be viewed at: http://texaschildrens.org/Transition-Talks.

The conference includes didactic presentations, parent and young adult panels, breakout sessions, and question and answer sessions. The topics include: HCT for specific diseases, yet the principles apply across all disease states; legal issues, health care reform, and guardianship (this has been the most highly rated topic consistently for 15 years); neurocognitive disabilities and HCT, models, systems and financing of HCT and youth and family perspectives, the latter being a tradition with one half day of the conference in which the youth, parents and family members are faculty. Since 2011, it has been held in conjunction with the annual meeting of the Health Care Transition Research Consortium (HCTRC), which added an important research complement to the conference. The 7th annual HCTRC annual meeting will be held in the same venue as the Transition Conference on Sept. 30, 2015. Conference attendance has grown from 52 participants in its inaugural year (2000) to an average of more than 400 participants annually, including those at broadcast sites, over the last five years. A rigorous evaluation has allowed the conference to improve to better meet the needs of attendees over the years. Evaluations from 2014 indicate that presentations consistently met or exceeded participant expectations. The majority (95 percent) of conference participants reported that the learning objectives were “very/mostly” met; 90 percent stated that content was “very/mostly” related to their practice; and 90 percent reported the syllabus/program handouts were “very/mostly” useful. An overall appraisal of the program was “excellent” (61 percent) or “good” (37 percent) and 99 percent said they would recommend the conference to others. Representative comments support these evaluations:

“Great program, I have never seen a conference address this topic so thoroughly.”

“Thanks you for providing the adolescent and family perspective; this was probably the most valuable perspective.”

“At the conference I learned how to get insurance for my son. That fundamentally changed our lives for the better.”

“Our transition program is just beginning. Much of the material provided here will be very helpful in getting our program off the ground.”

Feature

Advances in Autism Research and Care: The Autism Intervention Research Network on Physical Health

By Audrey Wolfe, MPH
Clinical Research Coordinator, Autism Intervention Research Network on Physical Health

The Autism Intervention Research Network on Physical Health (AIR-P) conducts research on evidence-based interventions to improve the physical health and well-being of children and adolescents with autism spectrum disorders (ASD) and other developmental disabilities. The network also works to disseminate main findings to parent and professional communities. Network activities include developing evidence-based guidelines and tools; disseminating critical information on network...
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AIR-P

research findings, guidelines developed, and tools to health professionals and the public; and developing and mentoring new investigators in the field of ASD and other developmental disabilities. The AIR-P has been highly productive in all of these areas.

As part of network activities, the AIR-P holds a monthly webinar series titled “Advances in Autism Research & Care” (AARC) that alternates autism research and care themes, and is available to all ATN/AIR-P network members, CAAI-sponsored programs, the entire LEND and DBP Fellowship networks, various other autism and pediatric organizations, collaborators, primary care providers, as well as autism advocates. Research webinars feature current AIR-P research study investigators, while care focused themes cover hot topics in the field of autism, and promote idea generation for future research.

During the network’s March AARC webinar, Julie Lounds Taylor, PhD, presented her research on the transition to adulthood and adult outcomes for individuals with autism spectrum disorder. Transition is an important topic that has been identified by the network Family Advisory Committee (FAC) as a priority area. Dr. Taylor focused on understanding the changes that are taking place for youth and adults during this time, as well as identifying those individuals who may be at higher risk. Dr. Taylor is an assistant professor in the Departments of Pediatrics and Special Education at Vanderbilt University, and a Vanderbilt Kennedy Center Investigator. Her research focuses on how the transition to adulthood impacts individuals with ASD and their families. Patience White, MD and Alice Kuo, MD, PhD also were discussants on the webinar. Dr. White is the co-director of Got Transition: The Center for Health Care Transition and Improvement and Dr. Kuo is the principal investigator of the MCHB Health Care Transitions Research Network for Youth and Young Adults with Autism Spectrum Disorder.

The April AARC webinar will be held on Thursday, Apr. 23 from 3-4 p.m. EST and will feature Amy Kratchman and Janet Seide, two members of the network Family Advisory Committee, presenting on the importance of family engagement in research and improvement activities.

All AARC webinars are recorded and available to the public. Please visit our YouTube site to view webinar recordings: www.youtube.com/asatnairpnetwork.

For registration links to these webinars and more information on the AIR-P, please visit our website: www.airpnetwork.org.

Feature

Improving Transitional Care for Children and Youth with Epilepsy

By Trisha Calabrese, MPH

Director, Division of Innovation, American Academy of Pediatrics

Although children and youth represent one of the fastest growing populations affected by epilepsy, many do not have access to pediatric neurologists and high-quality coordinated care provided in a medical home. In the fall 2013, the American Academy of Pediatrics (AAP) was proudly selected as the Coordinating Center for Children and Youth with Epilepsy under a Health Resources and Services Administration (HRSA) Maternal Child Health Bureau (MCHB) Cooperative Agreement. The overarching vision of the Center is to establish a multifaceted community-based system of care that ensures that children and youth with epilepsy (CYE) have access to the services required to achieve optimal health outcomes and an improved quality of life. The AAP is working with several state grantees to develop and implement a comprehensive evaluation methodology to support and monitor the various projects outcomes. A key component of this program is to ensure that grantees are also addressing transitional care for CYE. Grantees are creating epilepsy transition clinics, webinars, trainings for providers and families on beginning the transitional process, webinars, and more. For example, two of the grantees reported the following:

- During the summer of 2014, the Epilepsy Foundation of Texas offered a transition program to 147 campers during a weeklong summer camp. The program consisted of a series of four sessions to introduce concepts of self-advocacy in relationship to personal health management and transitioning in relationship to assuming greater responsibility for health care routines. Results of follow-up surveys from campers and parents reported improved medication adherence, an increase in self-advocacy skills and improved communication skills. Ninety-four percent of parents/caregivers agreed...
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Improving Transition for CYE

The transition programming was important information for their youth and reported observed improvements in personal appearance and hygiene, self-advocacy, knowledge about epilepsy, willingness to be around others, and remembering medication schedules. Parents/caregivers also reported CYEs were happier, had more positive attitudes and exhibited a greater willingness to help with household chores.

- The Maryland Team, through the Parents’ Place of Maryland and the Office for Genetics and People with Special Health Care Needs, is working on a learning collaborative with primary care pediatricians. This initiative focuses on improving access to comprehensive, coordinated health care and other services for CYEs, including youth transition to adult care within the medical home framework. Through the use of monthly quality improvement conference calls, webinar-based didactic sessions and in-practice team meetings, the practices will work toward developing and implementing a transition policy, establishing criteria for transitioning youth, and developing a plan for transition of care. Two key components of the learning collaborative include the training and placement of parent partners within each pediatric practice and the partnership with Epilepsy Foundation Chesapeake Region (EFCR). Through the partnership with the EFCR, the Teen Epilepsy Empowerment Now (TEEN) group established and supports. This social and educational group for teens with epilepsy combines learning sessions on topics such as common seizure triggers, seizure action plans, and transitioning to adult care with fun activities like bowling, movies, and an annual outdoor retreat.

In addition, transitions was included as a key educational component of the AAP CYE Project ECHO curriculum. The AAP partnered with the University of New Mexico Project Extension for Community Healthcare Outcomes (ECHO) to expand existing capacity to provide best practice care for CYE in rural and underserved areas. Finally, with help from its advisory committee, the Center also recently updated content to the HealthyChildren.org website and integrated content on transitions:

- Seizures and Epilepsy in Children (Spanish)
- Seizures (Spanish)

For additional information, please contact Trisha Calabrese, MPH, director of innovation at tcalabrese@aap.org.

Feature
AIM Access: A New Training Opportunity for Title V and Other State Officials

By Carolyn McCoy, MPH
Senior Policy Manager, Health Reform Implementation, AMCHP

The Alliance for Innovation on Maternal and Child Health: Expanding Access to Care for Maternal and Child Health Populations (AIM Access) project, funded through HRSA/MCHB, is an exciting grant opportunity for AMCHP and its members. The three-year (2015-2017) project is a collaborative effort of six national organizations committed to achieving significant impact in three focus areas: strengthening continuity of care and coverage and care for pregnant women and children, improving systems of care for CYSHCN, and promoting implementation of Bright Futures.

AMCHP, in partnership with the AIM collaborative (American Academy of Pediatrics (AAP), Association of State and Territorial Health Officials (ASTHO), National Academy of State Health Policy (NASHP), National Conference of State Legislatures (NCSL), National Governors Association (NGA), and Altarum Institute) will engage 20 states in an intensive process to expand access to care for MCH populations. Specifically, the national partners will work with state teams to develop state-level responses to the three focus areas. In addition, the national partner organizations will collect and disseminate best practices to health care leaders in the public and private sectors, raise awareness about insurance coverage options, support the implementation of evidence-based
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AIM Access

and best practices to expand access to care, promote cross-agency, state level, public-private collaboration, and respond to current needs of state programs. The AIM collaborative officially kicked off the project in March, with an "expert roundtable" discussion hosted by NGA. The roundtable was structured around the three focus areas, with each discussion featuring a presentation by a national subject matter expert, followed by two state-level reactors representing Title V, Medicaid, CHIP and state health departments. The discussions were rich and innovative, and the format lent itself to the collection of real-life examples and practices currently happening in the states.

The systems of care for CYSHCN presentation was led by Karen VanLandeghem from NASHP. Debra Waldron (IA) and Debra Garneau (RI) served as state reactors. Areas that were identified as highly relevant to states include creating a standard definition for the CYSHCN population; streamlining and organizing care coordination activities; understanding Marketplace health plan coverage for CYSHCN; operationalizing the ACA Medicaid health home option for pediatric populations; developing implementation models for the AMCHP Standards of Care for CYSHCN; and increasing pediatric specialty provider capacity, including behavioral health, at the state level.

As part of the project, AMCHP recently conducted an environmental scan of member best practices in the three focus areas. The results of the scan will be shared with the project collaborative to inform what best practices are most needed, where there are opportunities for engagement, and where there is a need for more focused energy. Many of the state reactors at the March roundtable also provided examples of success and opportunities in the three focus areas, which may be replicable in other states. The collaborative is excited to capture this information and help states with application.

A request for applications to participate in the AIM project first cohort of states will be sent to governors' offices in April. State teams may include the governor's health policy advisor, Medicaid and/or CHIP directors, state legislators, Title V directors and other state leaders involved in maternal and child health. States will be selected in June and the state engagement process will begin in the late summer or early fall of 2015. Please stay tuned to AMCHP newsletters for more information!

Feature

Evaluation of the CHIPRA Quality Demonstration Grant Program: Selected Findings about CYSHCN

By Ellen Albritton (AcademyHealth) and the national evaluation team from AcademyHealth, Mathematica Policy Research, The Urban Institute, and The Agency for Healthcare Research and Quality

The Children's Health Insurance Program Reauthorization Act (CHIPRA) Quality Demonstration Program funded grants that supported efforts in 18 states to identify effective, replicable strategies for enhancing quality of care for children. Together, the grant program and its evaluation are among the nation's largest and most important efforts to improve the quality of health care for children enrolled in Medicaid and CHIP. Several states in the demonstration have been implementing projects to improve care for CYSHCN, including supporting practices in enhancing care coordination and improving caregiver peer support programs.

Care coordination is a key component of high-quality care for CSHCN, but many practices struggle to find the resources to perform care coordination functions. Six CHIPRA quality demonstration states supported child-serving primary care practices in improving these functions, providing an opportunity to identify effective strategies for enhancing and sustaining care coordination.

These states took different approaches: Idaho, Utah and West Virginia used grant funds to hire care coordinators embedded in practices; Alaska and Oregon educated practices about the functions of care coordination; and Massachusetts deployed care coordinators from an existing state program to improve practice care coordination capacity. Practices reported that care coordinators improved the quality of care by improving patient centeredness, population management, provider efficiency and capacity, and caregiver satisfaction. These improvements led many practices to hire or commit to hiring care coordinators using practice resources.

States reported that effective strategies for supporting care coordination are tailored to the particular needs, circumstances, and readiness of practices, and practice
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Evaluating CHIPRA Grants

staff need to value and understand the contributions of care coordinators. To this end, states held learning sessions and shared information to help practices explore the functions, roles, and benefits of care coordinators. To learn more about these state efforts, see Evaluation Highlight # 9.

For caregivers of CYSHCN, receiving support from other caregivers of CYSHCN who have learned how to navigate health and social service systems can reduce their stress and improve their ability to care for their children. Four CHIPRA quality demonstration states are using grant funds to expand and improve caregiver peer support programs, and the lessons learned can be helpful to other states and practices looking to implement similar efforts.

In Maryland and Georgia the state recruited and trained caregivers of children with complex behavioral health care needs to work full time providing peer support through a variety of behavioral health organizations for children. These services are currently reimbursable through Medicaid in each state. In contrast, primary care practices in Idaho and Utah took the lead in partnering with parents of CYSHCN to provide peer support to other caregivers of CYSHCN in the practice and to advise the practice on quality improvement strategies. These “parent partners” worked part-time and received a small grant-supported stipend.

Because of concerns about privacy, liability, and the accuracy of information provided during peer support sessions, all four states worked closely with providers to ensure successful implementation of peer support programs. States addressed provider concerns by informing providers of caregiver training requirements, creating opportunities for practices to learn from other practices using peer support, and holding “get to know you” events for providers and peer support caregivers. States found that providing training and emotional support to caregivers who provide peer support also was key because these caregivers may experience medical emergencies or other stressors in their own family. To learn more, see Evaluation Highlight #7.

You can find descriptions of the demonstration projects, other findings, implementation guides, and state reports from the national evaluation website: http://www.ahrq.gov/chipra/demoeval/. To stay informed of future findings from the national evaluation, subscribe to e-mail updates. Contact CHIPRADemoEval@ahrw.hhs.gov with any questions.

Resources Available from the CHIPRA Quality Demonstration Grant Program

In February 2010, the Centers for Medicare & Medicaid Services (CMS) awarded 10 grants, funding 18 states, to improve health care quality and delivery systems for children enrolled in Medicaid and the Children’s Health Insurance Program (CHIP). Funded by the Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA), the five-year Quality Demonstration Grant Program aims to identify effective, replicable strategies for enhancing quality of care for children. Together, the grant program and its evaluation are among the nation’s largest and most important efforts to improve the quality of health care for children enrolled in Medicaid and CHIP.

As a group, the 18 demonstration states are implementing 52 projects in five general categories:

- Using quality measures to improve child health care
- Applying health information technology for quality improvement
- Implementing provider-based delivery models
- Investigating a model format for pediatric electronic health records (EHRs)
- Assessing the utility of other innovative approaches to enhance quality

Additional information about the national evaluation and the CHIPRA quality demonstration, issue briefs, how-to guides for specific projects, and other resources are available at ahrq.gov/policymakers/chipra/demoeval/index.html.
View from Washington
CHIP, CYSHCN, Transitions and Transformations

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

As this Pulse issue on CYSHCN and transitions goes to press, the future of the Children’s Health Insurance Program (CHIP) remains unresolved. While a two-year extension of CHIP – as well as Maternal, Infant and Early Childhood Home Visiting (MIECHV) program; the Personal Responsibility Education Program (PREP) and Family to Family Health Information Centers (F2Fs) – passed the House of Representative by a solid bipartisan vote of 392-37 on Mar. 26, the Senate put off its vote until the week of Apr. 13. Additional details are available in the most recent AMCHP Legislative Alert.

[Editors Note: On Apr. 15 the U.S. Senate gave final approval to this legislation with a vote of 92-8. Additional details are available here. It will now go to the president to be signed into law.]

The CHIP program plays a key role in reducing the number of uninsured children and, in fact, helped to cut the uninsured rate in half since its inception in 1997. Additionally, the protections CHIP provides both in benefits and cost sharing are two of the most important feature supporting children and youth with special health care needs.

Over the past year, congressional leaders sought input on the future of CHIP from a range of stakeholders, including all governors. A summary of this input by the United States Senate Finance and House Energy and Commerce Committees notes, “Governors reported that CHIP is more affordable to consumers than exchange or employer-sponsored coverage and generally has a richer benefit package. All 34 governors that mentioned the cost of care to consumers indicated that CHIP coverage is more affordable than private coverage, such as that offered on the exchanges or by employers.”

Perhaps one of the most important features CHIP offers in support of CYSHCN is the out of pocket cost protection provided to families. A study commissioned by colleagues at First Focus and conducted by Wakely Consulting included this key finding:

The financial impact of CHIP enrollees transitioning to QHPs [qualifying health plans] is especially pronounced for children with special health care needs (those with a large number of medical claims) who will likely reach the out of pocket maximum for cost sharing in a year. In some states, children with special health care needs could go from paying $0 in CHIP to over $5,000 in annual out of pocket expenditures in QHPs. All states included in the analysis had lower maximum out of pocket costs in CHIP compared to QHPs.

These tenets formed the central messages that AMCHP promoted in our advocacy for extending CHIP. Our hope is that the Senate will act quickly the week of Apr. 13 to provide at least two years of additional funding for CHIP.

AMCHP is collecting emerging, promising and best practices related to CYSHCN and/or Transition!

Does your program address an MCH best practice? If so, consider sharing your program through Innovation Station, the AMCHP 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 Ki’Yonna Jones at (202) 266-3056 or visit amchp.org/bestpractices.

You can also click here to refer an innovative MCH program that we should know about!
In the meantime, the transformation of the Title V Maternal and Child Health Services Block Grant is gaining momentum. The revised guidance released in January has galvanized state action to activate needs assessments and revise state plans, with applications reflecting the new framework due this July.

In particular, the new performance measurement framework confirms that CYSHCN remains a central focus of Title V services, with prominent measures on medical home, adequacy of insurance, and transition to adult care systems included - as well as stratification of other measures to help delineate potential disparities. More on the transformation is available from the Maternal and Child Health Bureau here.

As always, we value your feedback on AMCHP’s policy and advocacy activities. Please direct any comments or suggestions to Brent Ewig, Director of Policy, at bewig@amchp.org.

Real Life Story CONT.

I had dental/orthodontic procedures (pretty darn often), I had to take a large dose of antibiotics, a recommendation that has since changed. I don’t recall ever being told that I may someday require a valve replacement, but I know my parents were. In middle school, I experienced some palpitations and was fitted with a Holter monitor. Nothing specific was found, and this is the last time I recall having any contact with a cardiologist...until I was 24.

From what I gather, this is where my care dropped off. I should have been followed throughout childhood, adolescence and transitioned to an adult cardiologist. Instead, my mom happened to have a conversation while volunteering with a cardiologist at a free clinic. When she mentioned my BAV, he told her pretty clearly that I needed to get a baseline and be followed. In July 2013 I saw my adult cardiologist for the first time and was told my aorta, although slightly enlarged, seemed fine. Given we had no baseline measurement of my aorta or of the valve, we planned to follow-up a year later. In July 2014, I was diagnosed with a thoracic aortic aneurysm. My activity was restricted, as I had been training with a CrossFit gym, competing, and lifting heavy weights very often. However, I was told not to worry, we would follow-up in another six months.

When I want to know about something, I read. So, I began reading everything and anything I could find about thoracic aortic aneurysms, dissection, and at what point surgery is indicated. The biggest thing I kept taking away was that the condition was asymptomatic. I shouldn’t feel anything. So when I started to have chest pains six weeks later, I ignored them. When I finally went to the ER, my aorta had grown significantly and I was transported and admitted for surgery.

In the case of my cleft lip and palate, I had a clear transition plan from doctor to doctor, and procedure to procedure. My BAV was not monitored in the same fashion. What I can hope is, much of this would have been different if I was born later, given the increasing focus on care coordination and parent education in the health field. However, just because changes have been made, doesn’t mean there isn’t room for further improvements. Based on my own experience, while there may be one primary and more pressing diagnoses, we cannot forget the necessity of care coordination and transition as individuals deal with multiple and complicated health care needs that can span a lifetime.
Member to Member
State CYSHCN Highlights: Youth Transition to Adulthood

MARYLAND

By Donna Harris
Director, Office for Genetics & CYSHCN; Maryland Department of Health and Mental Hygiene

The Maryland Office of Genetics and People with Special Health Care Needs is planning on conducting a brief inventory of its programs and state disability organizations to identify the types of transition assistance offered and the populations served – youth and young adults with and/or without special needs, families, pediatric and adult clinicians. The inventory will ask respondents about whether they have a written transition policy, a method for tracking transitioning youth, a plan of care that incorporates health care transition, a portable medical summary and emergency care plan, referral assistance for supported decision making, a transfer checklist, a mechanisms to confirm transfer completion to adult providers, a process to obtain youth and family feedback on transition, and opportunities for youth to actively participate in transition improvements. In addition, the inventory will ask about respondent interest in learning more about health care transition quality improvements and, if interested, how respondents would prefer receiving assistance. Maryland also has formed a transition leadership team involving a pediatrician, adolescent health physician, internal medicine physician, local health department representative, insurance official, parent and teen experts, member of Governor’s Youth Council, individualized education program coordinator, and a Social Security Administration health policy expert.

TEXAS

By Manda Hall, MD
Director, CYSHCN, Texas Department of State Health Services; Purchased Health Services Unit

The Children with Special Health Care Needs (CSHCN) Services Program in Texas has identified multiple opportunities to integrate the Six Core Elements of Healthcare Transition into initiatives of the Texas Title V Transition and Medical Home Workgroups. This includes piloting the Six Core Elements with workgroup members and integration of these elements into strategic plans. The Six Core Elements will be featured as part of the 3rd Annual Texas Primary Care and Health Home Summit as a keynote and breakout session. This will provide pediatric, adult, and family medicine providers with tools for integrating transition into their practice.

WISCONSIN

By Sharon Fleischfresser, MD, MPH, FAAP
Medical Director, Wisconsin Children and Youth with Special Health Care Needs Program, Wisconsin Department of Health Services, Division of Public Health

Wisconsin Children with Special Needs, with the Waisman Center at the University of Wisconsin, is supporting transition quality improvement pilot projects involving pediatric and adult practices/health systems using the Six Core Elements of Health Care Transition. Two types of grants are available – planning grants ($2,000) and implementation grants ($20,000). Planning grants are for practices just beginning to focus on transition or for practices wanting to try small projects. Implementation grants are aimed at practices/systems that have already demonstrated transition work and are seeking to spread transition efforts throughout their practice/system. Senior leadership buy-in and in-kind match are required for implementation grants. Both types of grants call for teams that include personnel from pediatric and adult care, nursing, and youth and families. Grantees are required to complete pre and post assessments using the measurement tools in the Six Core Elements package. Technical assistance is provided by the Title V Youth Health Transition team and the Waisman Center, with periodic coaching support from Got Transition.
Get Involved

National MCH Workforce Development Center Coffee Talk Series – Check Out the Coffee Talk 2 Video!
This series will be hosted by the National MCH Workforce Development Center Change Management core on three pertinent topics benefiting the Title V workforce. The series will consist of three archived 20-minute videos for AMCHP members to access bi-monthly at their leisure. For the alternating months, AMCHP will host a Twitter chat on the content shared during the preceding month’s archived video. The topics and identified speakers for each video/Twitter chat are outlined below. Click here to learn more about each talk and to register!

Coffee Talk 1: Title V Transformation
Presenter: Lacy Fehrenbach, MPH, CPH, Director, Programs, AMCHP
Video Release: Mar. 2 – Click here to view the video

Coffee Talk 2: Getting to the Table
Presenter: Sharron Corle, MS, Associate Director, MCH Leadership Development & Capacity Building, AMCHP
Video Release: Apr. 1 – Click here to view the video
Twitter Chat: May 13 2-3 p.m. EST

Coffee Talk 3: Leading Change
Presenter: Karen Trierweiler, Director of Programs & Services, Prevention Services, Colorado Department of Public Health and Environment
Video Release: Jun. 1
Twitter Chat: Jul. 22 2-3 p.m. EST

Coffee Talk 4: Managing Change
Presenter: Brenda Jones, DHSc, RN, MSN, WHNP-BC, Deputy Director, Office of Women’s Health, Illinois Department of Public Health
Video Release: Aug. 1
Twitter Chat: Sept. 9 1-2 p.m. EST

Beyond Practice: Fostering Diverse Partnerships for Successful Care Coordination
The National Center for Medical Home Implementation (NCMHI) is hosting the second webinar in a three-part series focusing on implementation and evaluation of pediatric care coordination on Apr. 22 from 11 a.m. to noon CST. This webinar will showcase innovative models of cross-system care coordination through family engagement and partnership across clinical, public health, social service, and policy organizations. Faculty will provide real life examples of how successful cross-system care coordination positively influences outcomes for patients and families. To learn more, click here.

Upcoming Webinar on Comprehensive Care and Development for Children with ASD/DD
As part of its Autism Awareness Month activities, the State Public Health Autism Resource Center (SPHARC) will host a webinar that highlights programs to improve ASD/DD screening, early identification and evaluation services. The webinar will take place on Apr. 28 from 1-2 p.m. EST and presentations will include lessons learned from the Assuring Better Child Health and Development (ABCD) Initiative and Oregon’s state implementation grant project - ACCESS: Assuring Comprehensive Care through Enhanced Service Systems for Children with Autism Spectrum Disorders and other Developmental Disabilities. To register, click here.

PHIT 2015 Scholarships Now Available
The annual Public Health Improvement Training (PHIT) on Jun. 9-10, 2015 in New Orleans, Louisiana, will provide hands-on training workshops and networking opportunities for public health practitioners to be able to initiate and apply performance improvement skills. PHIT partial scholarship applications are now being accepted through Apr. 30 based on financial need. Seven partial scholarships are currently available to potential PHIT participants. To learn more, click here (under the "Fees" tab).

Does Your Hospital Need Help Improving Its Breastfeeding Rates?
The National Institute for Children’s Health Quality Improving Performance on Breastfeeding Measures group coaching program provides hospitals direction on how to hardwire change to improve perinatal care. Topics include breastfeeding & supplementation policies, measurement and using data to drive change. Although the Joint Commission revised its requirements, don’t lose momentum on how to improve & document breastfeeding measures. To learn more about the coaching program, click here.
Resources

Adolescent Health in Title V: Findings from an Environmental Scan
AMCHP completed an Environmental Scan of Adolescent Health activities in Title V programs. The full report is now available for download. The scan included an overview of key findings in adolescent health programs as reflected in activities reported by states in Title V MCH Services Block Grant narratives.

• Adolescent Health Activities in State Title V Programs Webinar
AMCHP recently completed an Environmental Scan of Adolescent Health activities in Title V programs and presented the findings in a webinar on Apr. 14, 2014. The scan included an overview of key findings in adolescent health programs as reflected in activities reported by states in Title V Block Grant narratives. In addition to the overview of findings, staff from the Iowa Department of Public Health and Ohio Department of Health shared presentations on how adolescent health programs are organized in their states. A recording of the webinar is available here.

Before and Beyond Pregnancy: The Preconception/Interconception Clinical Toolkit Webinar
The National Preconception/Interconception Clinical Toolkit, developed by the Preconception Health & Care Care Initiative, was designed to help primary care providers and their colleagues incorporate preconception/interconception health into the routine care of all women of childbearing age. The goal of this toolkit is to help clinicians reach every woman who might someday be pregnant every time she presents for routine primary care with efficient, evidence-based strategies and resources to help her achieve: healthier short and long term personal health outcomes; increased likelihood that any pregnancies in her future are by choice rather than chance; and decreased likelihood of complications if she does become pregnant in the future. This webinar included a presentation and step-by-step guidance of the use of the toolkit and information on who it can be used in every day practice. The creation of this toolkit was made possible by contributions from the W.K. Kellogg Foundation and the UNC Center for Maternal and Infant Health.

Building and Retaining a Resilient MCH Workforce for Tomorrow Webinar
Several forces, such as full implementation of the Affordable Care Act and enduring budget cuts, deficits and hiring freezes, are having a huge impact on the knowledge and skills needed for a competent public health workforce. To continue to effectively meet the needs of children, families and communities they serve, building and retaining a resilient MCH workforce has become especially critically important for state Title V programs. In order to support states’ efforts to maintain a talented workforce, AMCHP hosted the Building and Retaining a Resilient MCH Workforce for Tomorrow webinar on May 15, 2014. This webinar featured stories from two states, Michael Warren, MD, MPH, FAAP, Director of Maternal and Child Health for the Tennessee Department of Health and Meredith Pyle, Systems Development Chief in Maryland’s Office for Genetics and People with Special Health Care Needs, highlighting their successes in building a resilient workforce. The webinar also featured a brief overview from Mark Law, PhD, Director of Operations for CityMatCH, of two concepts, Positive Psychology and Emotional Intelligence, that have demonstrated effectiveness in building a resilient workforce. After viewing this event, you will be able to:

• Identify the challenges and barriers states may face in building and retaining talented staff
• Understand the importance of building and retaining a talented staff
• Identify strategies to building a “resilient” workforce

Part 1 and Part 2 of the webinar are available here.

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
Resources cont.

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.

- **National Standards for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs** are designed for use by a range of stakeholders including state Medicaid agencies and CHIP programs, state Title V programs, health plans, children's hospitals, families/consumers and provider groups. The standards address the core components of the structure and process of an effective system of care for CYSHCN. AMCHP recently developed a set of draft tools to aid states in using the standards. The tools are available here.

- **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.

**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.

**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.

**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.
Resources cont.

- **CDC 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.

- **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 plan.

**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.

**Genetic Alliance** is a nonprofit health advocacy organization committed to engaging individuals, families, and communities in transforming health. Genetic Alliance's network includes more than 1,200 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations.

**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. One of the newest resources from Got Transition is a practical set of steps and lessons learned for starting a Transition Improvement process in clinical practices and health systems – available here.

**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.

**Interagency Autism Coordinating Center (IACC)** is a federal advisory committee that coordinates all efforts within the U.S. 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.

**Lucile Packard Foundation for Children's Health** works to elevate the priority of children's health, and increase the quality and accessibility of children's health care through leadership and direct investment.

- **Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs**, and its accompanying implementation guide, recommend core content of a comprehensive and integrated plan, and outline the steps necessary to achieve it.

- **A Triple Aim Approach to Transition from Pediatric to Adult Health Care for Youth with Special Health Care Needs**, is an issue brief that describes key unmet needs regarding a) developing chronic disease self-management; b) enhancing capacity of the adult health care system to care for young adults with special health care needs; and c) reducing lapses in care during the transition period. Based on these unmet
needs, it make recommendations for improving health care during transition that incorporate relevant high-value strategies for health care delivery.

Maternal and Child Health Bureau (MCHB) is part of the Health Resources and Services Administration, 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.

MCH Navigator Training Spotlight on CYSHCN is a resource comprised of introductory trainings and other resources for professionals who work with CYSHCN, including trainings organized by the 10 core domains for system standards for CYSHCN. This page contains targeted learning opportunities and resources for professionals who work with CYSHCN and their families.

National Academy for State Health Policy (NASHP) is an independent academy of state health policymakers dedicated to helping states achieve excellence in health policy and practice. NASHP provides a forum for constructive work across branches and agencies of state government on critical health issues.

- Matching Patients with Their Providers: Lessons on Attribution and Enrollment from Four Multi-Payer Patient-Centered Medical Home Initiatives presents key considerations for states when developing assignment models: determining the degree of alignment across payers; establishing a means to collect and distribute patient assignment data; assessing the accuracy of the model; and ensuring sustainability.
- Identification and Assessment of Children and Youth with Special Health Care Needs in Medicaid Managed Care: Approaches from Three States looks at three states – California, Massachusetts and Michigan – and includes some promising practices states may consider in implementing Medicaid managed care for the CYSHCN population.

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.

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.

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 Collaborative on Workforce and Disability for Youth (NCWD/Youth) assists state and local workforce development systems to better serve all youth, including youth with disabilities and other disconnected youth. The NCWD/Youth, created in 2001, is composed of partners with expertise in education, youth development, disability, employment, workforce development and family issues.
Resources cont.

- **Guideposts for Success** is a publication to help steer families, institutions and youth themselves through the transition processes. The transition from youth to adulthood is challenging for almost every young person. This is particularly true for young people with disabilities. Yet, it is in those crucial transition-age years that a young person's future can be determined.

**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.

**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.

**Office of Disability Employment Policy (ODEP)** works in the youth arena and is based on the Guideposts for Success. The Guideposts represent what research and practice has identified as key educational and career development interventions that make a positive difference in the lives of all youth, including youth with disabilities. They were developed by ODEP in collaboration with one of its research and technical assistance centers, the National Collaborative on Workforce and Disability for Youth (NCWD/Youth), following an extensive review of more than 30 years of research and best practices in youth development, education, and workforce development. ODEP and NCWD/Youth identified five elements as essential for all youth, including youth with disabilities, to effectively transition into postsecondary education and employment.

- **The 2020 Federal Youth Transition Plan: A Federal Interagency Strategy** outlines how Federal Partners in Transition, a workgroup with representatives of several federal agencies, will enhance interagency coordination through the identification of compatible outcome goals and policy priorities, ultimately leading to improved outcomes for youth with disabilities by 2020.

**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.

**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.

**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.
Data and Trends
New Performance Measures with Special Importance for CYSHCN
By Reem M. Ghandour, DrPH, MPA and Ashley Hirai, PhD
Office of Epidemiology and Research, Maternal & Child Health Bureau/HRSA

As part of the recent transformation of the Title V MCH Services Block Grant, a new set of National Performance Measures (NPMs) were developed in partnership with states, families and other stakeholders. With their FY 2016 application due Jul. 15, 2015, grantees will develop annual performance objectives for eight of 15 NPMs to work toward over the next five years. In addition to the two health care quality measures specific to the CYSHCN population domain (medical home and transition), developmental screening and adequate insurance are of special importance in identifying and promoting appropriate health care access for CYSHCN (see table 1). All NPMs will be tracked by CYSHCN status, where possible.

The four NPMs with special relevance to CYSHCN, along with five other NPMs will be tracked using the redesigned National Survey of Children’s Health (NSCH). The new NSCH will reflect three fundamental changes: 1) annual administration, instead of every four years; 2) merged content from the previous NSCH and National Survey of Children with Special Health Care Needs (NS-CSHCN); and 3) a shift from a telephone survey to a mailed survey with an online response option. The change in survey mode was the primary driver for the redesign due to the increasing prevalence of households without landline phones and declining response rates.

### Table 1

<table>
<thead>
<tr>
<th>NPM #</th>
<th>Short Title</th>
<th>Description</th>
<th>Details</th>
<th>Changes in the Revised National Survey of Children’s Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Developmental Screening</td>
<td>Percent of children, ages 10 through 71 months, receiving a developmental screening using a parent-completed screening tool</td>
<td>Screening must include questions regarding child’s language and social development</td>
<td>Data will now be collected for children aged 9-71 months to be consistent with AAP guidelines</td>
</tr>
<tr>
<td>11</td>
<td>Medical Home</td>
<td>Percent of children with and without special health care needs having a medical home</td>
<td>Medical home includes 19 different items within 5 subcomponents (personal doctor/nurse, usual source of sick and well care, getting needed referrals, family-centered care, care coordination when needed)</td>
<td>No change</td>
</tr>
<tr>
<td>12</td>
<td>Transition</td>
<td>Percent of adolescents with and without special health care needs who received services necessary to make transitions to adult health care</td>
<td>Necessary services include discussion of shift to adult provider, future health care needs, and future insurance needs if necessary, and age-appropriate self-care</td>
<td>Newly captured for non-CYSHCN. Content has been significantly revised and expanded to capture information on: planning for future; making positive health choices; managing health and health care; understanding changes when transitioning from pediatric to adult care; and development of a transition plan.</td>
</tr>
<tr>
<td>15</td>
<td>Adequate Insurance</td>
<td>Percent of children ages 0 through 17 who are adequately insured</td>
<td>Adequate insurance includes coverage that usually/always meets child’s health needs, allows the child to see needed providers, and has reasonable out-of-pocket costs</td>
<td>No change to overall insurance adequacy measures. A new item on adequacy of coverage specifically for mental or behavioral health services has been added.</td>
</tr>
</tbody>
</table>

Baseline Data from NSCH 2011-2012 and NS-CSHCN 2009-2010

A pretest of the redesigned NSCH will be conducted summer 2015 to test opportunities to maximize participant response. The survey will then be fielded in 2016, yielding both national and state-level estimates in late spring 2017. National estimates will be produced annually with new state-level estimates produced annually as two-three year rolling estimates beginning in 2018 or 2019. The NSCH will continue to serve as a critical data source for the nation and states in monitoring and identifying opportunities for improving the health of all children, including those with special health care needs. With more timely data, the NSCH will become an even stronger resource to inform and evaluate state action to improve children’s health.
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Kris-Tena Albers, CMN, MN
Florida

Jessica Foster, MD, MPH, FAAP
Ohio

Region VI (2013-2016)
Susan Chacon, MSW, LISW
New Mexico

Heather Smith, MPH
Kansas

Region VIII (2012-2015)
Linda McElwain, RN
Wyoming

Region IX (2013-2016)
Mary Ellen Cunningham, MPA, RN
Arizona

Board of Directors CONT.

Region X (2013-2016)
Marilyn Hartzell, MEd
Oregon

Director-At-Large I (2015-2018)
Rodney E Farley
Arkansas

Director-At-Large I (2014-2016)
Michael D. Warren
Tennessee

Family Representative I (2015-2018)
Donna Yadrich
Kansas

Family Representative (2014-2017)
Susan Colburn
Alabama

AMCHP Staff

Matt Algee, Senior Accountant

Brittany Argotsinger, MPH, Program Manager, Women’s & Infant Health and CDC Public Health Prevention Service Fellow

Julio Arguello, Jr., Digital Communications Manager

Erin Bonzon, MSPH/MSW, Associate Director, Women’s and Infant Health

Treeby Brown, MPP, Associate Director, Child and Adolescent Health

Atyya Chaudhry, MPP, Policy Analyst, Health Reform Implementation

Stacy Collins, MSW, Associate Director, Health Reform Implementation

Sharron Corle, MS, Associate Director, MCH Leadership Development and Capacity Building

Andria Cornell, MPH, Senior Program Manager, Women’s and Infant Health

Kidist Endale, Bookkeeper/Human Resources Assistant

Brent Ewig, MHS, Director of Public Policy and Government Affairs

Jennifer Farfalla, MPH, Analyst, Quality Improvement and Life Course

Lacy Fehrenbach, MPH, CPH, Director of Programs

Lori Tremmel Freeman, MBA, Chief Executive Officer

Laura Goodwin, Publications and Member Services Manager
AMCHP Staff CONT.

Krista Granger, MPH, Program Manager, Data and Assessment
Amy Haddad, Associate Director; Government Affairs
Piia Hanson, MSPH, Senior Program Manager, Women’s and Infant Health
Michelle Jarvis, Program Manager, Family Involvement
Ki’Yonna Jones, Program Manager, Workforce and Leadership Development
Nora Lam, Senior Executive Assistant and Board Administrator
Tania Majors, Office Assistant
Carolyn McCoy, MPH, Senior Policy Manager, Health Reform Implementation
Maria Murillo, Administrative Assistant, Programs and Policy
Megan Phillippi, Program Analyst, Women’s & Infant Health
Meredith Pyle, Senior Program Manager, CYSHCN
Caroline Stampfel, MPH, Associate Director, Epidemiology and Evaluation
Kate Taft, MPH, Senior Program Manager, Child Health
Jessica Teel, MS, CHES, Program Manager, Workforce & Leadership Development

Calendar CONT.

31st Pacific Rim International Conference on Disability and Diversity
May 18-19
Honolulu, HI

2015 Association of Public Health Laboratories Annual Conference
May 18-21
Indianapolis, IN

CSTE Annual Conference
Jun. 14-18
Boston, MA

8th Biennial Childhood Obesity Conference
Jun. 29-Jul. 2
San Diego, CA

NACCHO Annual 2015
Jul. 7-9
Kansas City, MO

2015 CityMatCH Annual Urban MCH Leadership Conference
Sept. 27-30
Salt Lake City, UT

2015 ASTHO Annual Meeting
Sept. 29-Oct. 1
Salt Lake City, UT

AAP National Conference and Exhibition
Oct. 24-27
Washington, DC

2015 APHA Annual Meeting & Exposition
Oct. 31-Nov. 4
Chicago, IL

Want your event listed on the AMCHP MCH Events Calendar? It’s easy! Just complete our online submission form.