



# PULSE

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

## CYSHCN

### May/June 2014

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## From the President

### Upward Shifting Baselines



By Millie Jones, MPH

Recently I read about the concept of **“shifting baseline”** as a type of change to how a system is measured. The term comes out of the ocean/environmental world and the article went on to describe that a decline occurs in a way that is almost too slow for one to notice and that what we think of as normal is really reflective of a diminished reality (concept was coined by Daniel Pauly in 1995 and discussed in a recent *Time* magazine article).

I can’t seem to stop thinking of this concept, shifting baseline, as it relates to our work in public health and particularly, maternal and child health (MCH). While so many wonderful health improvements have occurred over the past decades, I feel we must constantly reevaluate to prevent and not accept a diminished reality. The realization that we are seeing a generation of individuals likely to under-live their parents certainly seems like a diminished reality.

We in the MCH world must evaluate our history, measure our progress and incorporate the life course –future generations – in all we do. Title V services must respect and include the reality of our families – all families, including those with children with special needs. In order to reflect these realities we need to have an expanded scope to include social determinants of health across the life course. As we transform Title V, let’s do so in a way that clearly says we are focused on shifting to improved baselines and prevention of any decline in the health and well-being of all families.



ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

## From the President CONT.

I have edited the following highlights from a December 2002 article by Randy Olson, a marine biologist, from [actionbioscience.org](http://actionbioscience.org) in terms of our MCH focus (*amazing how transferrable the concepts are*):

- Shifting baselines result from chronic, slow and hard to notice changes
- Baselines document how things used to be and are used to evaluate change
- A baseline that shifted before it was charted can cause a degraded state to be accepted as normal
- **Maternal and Child Health** groups are calling attention to the **family's** problems
- Making the **family/community** healthy is everyone's responsibility
- **Conclusion: we cannot afford to lower our standards for the family/community**

## From the CEO

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



What a pleasure it is to finally have arrived at AMCHP in mid-March! Departing from one extraordinary organization (NACCHO) with its critical focus on local governmental public health and getting orienting to another vibrant, thriving organization (AMCHP) with its focus on a target population has truly been a transition within a transition. And, although the evolution will continue for me for some time, the work of AMCHP forges ahead.

It's been a busy and productive spring as our leadership, members, partners, staff and others provide initial finishing touches to the MCH 3.0 Transformation. In a short time, I have witnessed the incredible passion and involvement of maternal and child health leaders, including active participation from families and parents of children and youth with special health care needs (CYSHCN), as we shape our future through the Title V transformation. It bears repeating that the essential inputs that you – the very champions of moms, kids, and families of CYSHCN – have provided would not have been possible without the openness and willingness of Dr. Lu and the Maternal and Child Health Bureau (MCHB) to commit to a repeated process of engagement with AMCHP. Please join me in acknowledging and thanking them for that ongoing commitment. The work is not done and we should remain diligent in our efforts to continue to ensure the transformation's success. We are moving now into new phases of MCH 3.0 Transformation and your careful review of the upcoming guidance due out in June, your thoughtful and constructive suggestions during the public comment period, and further consideration of what kinds of technical and other assistance will benefit you as we move toward implementation, will be crucial still. We will all need to be poised to move on quickly after the public comment period and prepare ourselves for the implementation phases and, ultimately, for success.

It's very fortuitous that this issue of *Pulse* should focus on children and youth with special health care needs. One of the many new joys that I've experienced in my first three months with AMCHP has been learning more about how

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this organization partners with families, including those families with children and youth with special health care needs. I'm fascinated by the partnership. Having been involved with a variety of health-related nonprofits for 25 years, I can honestly say that the incorporation of families, who are the true consumers and ultimate navigators of health care systems and understand much more about it than perhaps anyone, unfortunately is not very common at all. AMCHP, may in fact, be one of the only national organizations in our field that also dedicates a full-time staff member to family engagement alone. It's been extremely gratifying to know that AMCHP was (and still is) truly on the forefront of this partnership that speaks so clearly to our vision of healthy children and healthy families living in healthy communities.

There are certain things that you should know about how families of children and youth with special health care needs have enriched this organization over time.

- Since 1996, the Family and Youth Leadership Committee, including families of CYSHCN, has been providing leadership, advice, expert guidance, and information to AMCHP to advance partnership opportunities for families and to develop and implement effective programs, strategies and policies at local, state, and national levels. Take time to understand the importance of their efforts by visiting [amchp.org/programsandtopics/family-engagement/Pages/default.aspx](http://amchp.org/programsandtopics/family-engagement/Pages/default.aspx).
- Pursuant to my earlier comments about MCH 3.0, a special Family/Consumer Engagement Work Group was formed earlier this year to provide specific recommendations regarding strengthening family/consumer partnerships and to ensure that this partnership is intentional, collaborative and respectful in the new Title V MCH Services Block Grant. I commend the work group on its final recommendations to the Bureau that include concepts of broadened family and consumer partnerships, prioritizing the partnership in Title V programs and using it to strategically inform national performance measures, structure and process measures; and improved reporting of partnerships. This informed response is invaluable to the feedback and to improving Dr. Lu's work around the final draft guidance.
- Family Delegates are voting members of AMCHP for a good reason. We recognize the value their input and unique perspective provides in guiding

the current activities and future of this organization. Family Delegates are one of five of the designated representatives from each member state and bring the family voice to AMCHP and its programs.

- At least one family member sits on each AMCHP committee, providing active participation and feedback, sharing in the work of the committee and bringing the voice and perspective of the family across the full spectrum of AMCHP work including best practices, emerging issues, legislative & health care finance, and workforce issues.
- There are two family representatives on the AMCHP Board of Directors. Including representation at the highest level of governance was purposeful and intentional, bringing much desired perspective to the overall leadership of the organization. The inclusion of board roles for families also is designed to provide leadership development to family representatives and exposure for them among other leaders in the organization.

If you would like more information about any of these initiatives, please contact me at [lfreeman@amchp.org](mailto:lfreeman@amchp.org) or our program manager for family engagement and leadership development, Michelle Jarvis, at [mjarvis@amchp.org](mailto:mjarvis@amchp.org). If you are a family member, please consider getting involved in this work by responding to the call for committee members later this year. Enjoy this issue of *Pulse*!

## Feature

### National Standards Designed to Help States Build Quality Systems of Care for Children and Youth with Special Health Care Needs

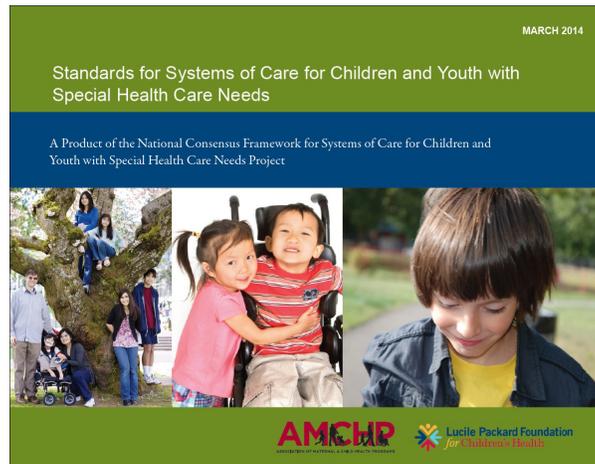
**By Karen VanLandeghem, MPH**  
*Senior Advisor, AMCHP*

In March of 2014, AMCHP, with support from the Lucile Packard Foundation for Children's Health, released a groundbreaking [set of standards and companion background white paper](#) designed to help communities, states, and the



## Feature CONT. National CYSHCN Standards

nation build and improve systems of care for CYSHCN. “This set of standards, built around a framework and the guidance of a diverse set of stakeholders, represents one of the first efforts of its kind to comprehensively and systematically collect and categorize system standards that affect CYSHCN and their families,” said AMCHP President Millie Jones in a press release about the work.



The standards address the core components of the structure and process of an effective system of care for CYSHCN. They were derived from a comprehensive review of the literature, early project guidance from more than 30 key informants, case studies of standards currently in use within selected sites, and input and guidance from a national work group comprised of national and state leaders representing state Title V CYSHCN programs, state Medicaid agencies, pediatric providers, health plans, children’s hospitals, families/consumers, health services researchers, and others. They were developed for use or adaptation by a wide range of stakeholders at the national, state and local levels.

“All of us working with special needs children and their families know how important it is to have a high-quality, coordinated system of care designed to meet their needs. Until now, we have found it easy to identify what is lacking, but much more difficult to describe what a comprehensive health care system would look like. We believe that this report and its accompanying guide should serve as a benchmark for those responsible for designing and operating health care systems for these especially vulnerable children.” said Ed Schor, senior vice president at the Lucile Packard Foundation for Children’s Health, in announcing the availability of the standards.

Creating a comprehensive, quality system of care for CYSHCN has been one of the most challenging areas for state health leaders. The Affordable Care Act is extending coverage to millions of uninsured children and adults, designing essential health benefits, and implementing new provisions to achieve the ‘Triple Aim’ of improving the patient experience of care, improving the health of populations, and reducing health care costs. These

changes are heightening the need for system standards.

Since their release, the standards have been met with wide support and interest by state and national leaders. For example, the Maternal and Child Health Bureau, Health Resources and Services Administration referenced the standards in a recent grant announcement and the Centers for Medicare and Medicaid Services is promoting them with

state Medicaid agencies. AMCHP will be leading several activities to further promote use of the standards in states. These activities include: development of an interactive, online tool kit that will house the standards and additional products – existing and to be developed – related to their use, technical assistance to selected states that are interested in using the standards to improve their system of care for CYSHCN, and further national dissemination. Additionally, AMCHP plans to seek support for work to develop metrics that would align with the standards. These metrics could be used by states, particularly state Title V MCH programs in development of national performance measurement activities for the Title V block grant program.

For more information about this project, please contact: Karen VanLandeghem, senior advisor, at [kvan@amchp.org](mailto:kvan@amchp.org).

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## Feature

# Transitioning CYSHCN into Medicaid Managed Care: An Emerging Issue for Title V Programs

By **Veronica Helms**

*Program Manager, Child and Adolescent Health, AMCHP*



Creating a comprehensive, quality system of care for CYSHCN has been one of the most challenging priorities for state Title V programs and key stakeholders such as Medicaid, health plans, provider groups, and families. As states undergo health reform, many struggle to provide high-needs populations with quality, cost-effective care. Recent state successes in managed care has led to increased reliance on managed care to improve access, improve program quality, and reduce program costs for such populations. When coupled with ongoing budgetary pressures, Medicaid managed care is increasingly looked upon by states as a vehicle to promote healthier outcomes for high-needs, high-risk populations such as CYSHCN.

### The Managed Care Environment

Historically, most CYSHCN were enrolled in fee-for service (FFS) commercial or Medicaid insurance coverage plans in the 1990s. During this time, conversations regarding managed care as an emerging model sparked discussion among state public health officials. Title V CYSHCN programs and advocates for CYSHCN were concerned about whether managed care systems would meet the complex health care needs of children generally and CYSHCN in particular. During this time, shifts to managed care first began to occur for CYSHCN, but these experimental shifts did not result in nationwide momentum.

Although FFS commercial models historically dominated the health care market, this trend has changed as most of today's commercial insurance is managed care (75 percent). Moreover, two-thirds of states (32 states) have mandated the enrollment of at least some CYSHCN into managed care arrangements with the trend continuing. Under federal law, states are required to identify individuals with special health care needs to managed care organizations (MCOs). Medicaid MCOs are then required

to assess enrollees with special health care needs and identify any ongoing conditions that require treatment or monitoring. Additionally, state Title V CYSHCN programs have a statutory requirement to serve CYSHCN in their state. Altogether, health reforms, federal requirements and the changing roles of state Title V CYSHCN programs pose important opportunities and unique challenges for states which choose to transition CYSYHCN into managed care arrangements.

### AMCHP Action Learning Collaborative (ALC) for States Transitioning CYSHCN into Medicaid Managed Care

Recognizing the needs of state Title V programs related to the transition of CYSHCN into Medicaid managed care arrangements, AMCHP received funding from the Maternal and Child Health Bureau (MCHB) to further explore this emerging need. In April 2014, AMCHP convened seven state teams in Washington, DC for a day-long meeting to discuss strategies, opportunities, and challenges in this area. State teams were multidisciplinary and comprised of representatives from Title V, Medicaid, health plans, families/consumers, and pediatricians. This multisector approach allowed teams to collaboratively discuss the needs of CYSHCN in their states. Seven states participated in the ALC: Alabama, Colorado, Kentucky, Louisiana, Michigan, New Mexico and Washington.

### Key Themes

As state Title V CYSHCN programs and their key partners face strategic decisions about their roles and responsibilities in the context of health reform and CYSHCN transitions to Medicaid managed care, many states consistently cited many key themes and challenges. Below are just a few of the challenges described by states:

- **Provider Network Adequacy:** Many states expressed difficulties recruiting and retaining both primary care physicians and specialty care providers for health plans serving CYSHCN. Since many CYSHCN require consistent, ongoing primary and/or specialty care, this was a major area of concern for state teams seeking to promote a quality system of care for CYSHCN in their state. This issue represents a crucial access issue.
- **Care Coordination:** Many states struggled to clearly define and demarcate statewide responsibilities and expectations regarding care coordination. In many states, multiple systems serve CYSHCN, providing care coordination services which differ in definition and

## Feature CONT.

### Transitioning into Medicaid MCOs

scope across sectors. Many of the multidisciplinary state teams decided to focus on utilizing Title V expertise in care coordination and further clarify care coordination roles and responsibilities across sectors.

- **Provider Education:** Due to the ever-evolving nature of health reform, many states struggled to provide providers with up-to-date information regarding the transition of CYSHCN in Medicaid managed care. The need to provide education and outreach to providers varied by state with some states citing the need to educate providers on the managed care process overall and others citing the need to educate providers on more specific components of the managed care system, such as service changes and billing procedures.
- **Patient Education:** Similar to states' need to educate providers about the Medicaid managed care system, many states also described the need to educate families of CYSHCN about the managed care system overall (including enrollment), the benefits of competing plans (if the consumer has the choice), and how their child's health care service system could change in a managed care environment. Many states described planned efforts to work collaboratively with Medicaid and health plans to provide such education.
- **Collaboration and Communication with Key Partners:** There is a pressing need for state Title V CYSHCN programs to strengthen their knowledge, understanding and engagement with public and private health insurance coverage systems to effectively communicate the needs of CYSHCN. Many Title V representatives described the ongoing need to communicate the statewide role of Title V in an effective, efficient, and comprehensive manner to key partners such as Medicaid and health plans. This was particularly important for state teams when considering potential service replication across systems.

#### Upcoming Issue Brief

For more information, AMCHP will release a follow-up issue brief in early fall 2014. The issue brief will feature detailed information regarding the historic and recent context of managed care for CYSHCN and will also feature current state efforts in transitioning CYSHCN into Medicaid managed care arrangements. It highlights seven states – Alabama, Colorado, Kentucky, Louisiana, Michigan, New Mexico and Washington – and describes emerging trends, challenges, and successes in this area.

## Feature

### AMCHP Supports Oregon's Work on Preconception Health for Young Adults with Disabilities

By Julie M. McFarlane, MPH

*Women's Health Operations & Policy Analyst, Center for Prevention and Health Promotion, Oregon Public Health Division*



Carolyn McCoy, MPH

*Senior Policy Analyst, AMCHP*



As part of an ALC supported by AMCHP, Oregon created a team that consisted of members from Oregon Public Health Division offices (Women's Health and Adolescent Health); Oregon Health & Science University, Office of Women's Health; Women with Disabilities Health Equity Coalition (WowDHEC); National Youth Leadership Network; GimpGirl Community; and youth with disabilities, with the goal of developing and implementing action plans, sharing strategies and problem solving across communities around preconception health. The Oregon team set the goal of creating a set of [Preconception Health Recommendations for Young Adults with Disabilities](#) to build on its Preconception Health Action Plan, which was created in 2008. The action plan focuses on four main recommendations: 1) increase public awareness of the importance of preconception health behaviors and preconception care services by using information and tools appropriate across various ages; literacy, including health literacy; and cultural/linguistic contexts. 2) As a part of primary care visits, provide risk assessment and educational and health promotion counseling to all women of childbearing age to reduce reproductive risks and improve pregnancy outcomes. 3) Integrate components of preconception health into existing local public health and related programs, including emphasis on interconception interventions for women with previous adverse outcomes. 4) Maximize public health surveillance and related research mechanisms to monitor preconception health.

The team working on the Preconception Health Recommendations for Young Adults with Disabilities performed a literature review, data analysis, and online survey of youth with disabilities to inform the recommendations. The recommendations were developed

## Feature

### Oregon Preconception Health

as a starting point for a national discussion to further expand on the work by continuing the dialogue and test their viability.

1. Using the Socio-Ecological Model of Health (SeMH) as a framework, the ALC made recommendations organized by individual-level, relationship-level, community-level, and societal-level. Within each level, a variety of recommendations were made. Recommendations included: individual-level: preconception health care for young adults with disabilities (YAWD) should be supported by encouraging access, information, health equality and physical safety.
2. Relationship-level: Family members, caseworkers, and teachers should work to support and encourage environments that allow for access of reproductive and preconception health information and services.
3. Community-level: Community-based programs, social service providers, and health systems play an important role in creating a community that is supportive, ensuring that YAWD are included in program and services design and implementation and recognized for their strengths and contributions to the community.
4. Societal-level: Preconception health policies, marketing and health messages, data collection, and research should reflect the inclusion and support of young adults with disabilities.

Suggestions for further work regarding preconception health and disability include developing recommendations and suggestions for alcohol, tobacco and other drug use, obesity and physical activity, folic acid, diabetes, and special challenges that YAWD may face, such as physical barriers in receiving clinical care (as in a mammogram or PAP smear). The ALC team recommends that YAWD, stakeholders, public health entities, and the medical community continue this work, and contribute to the dialogue to improve on these recommendations and test their viability. Oregon is continuing its preconception health care work in focusing on well-women visits and health equity issues.

## Feature

### New Health Care Transition Efforts: Clinical Resources, Interactive Website and State Title V Partnership

**By Daniel Beck and Margaret McManus**

*Got Transition/Center for Health Care Transition Improvement, The National Alliance to Advance Adolescent Health*

Got Transition, the federally funded Center for Health Care Transition Improvement, is the new national resource center dedicated to expanding the availability of effective health care transition supports. Funded by the Maternal and Child Health Bureau, this new center began its first year's activities by updating the Six Core Elements of Health Care Transition (Version 2.0) and launching a new website.

The Six Core Elements are a set of clinical resources that define the basic components of transition support and are based on the 2011 Clinical Report on Health Care Transition, jointly developed by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians. Three Six Core Elements packages are available in English and Spanish for 1) practices serving youth who will transition out of pediatric care into adult care, 2) practices serving youth who will remain with the same provider but need to transition to adult-focused care, and 3) practices accepting new young adults into adult care.

Each package includes sample tools that are customizable and available for download. They include a sample transition policy, a tracking mechanism, a readiness/self-care assessment tool, a plan of care template, medical summary, emergency care plan, transfer checklist, and a transfer letter. Each package also includes consumer feedback surveys and two new measurement tools to assess progress in transition quality improvement. According to Dr. Patience White, the codirector of Got Transition, "We are pleased to make available these new resources to stimulate new quality improvement efforts aimed at ensuring that all youth effectively transition from pediatric to adult-focused care."

Got Transition is also launching its newly redesigned website, [GotTransition.org](http://GotTransition.org). The site includes an interactive health provider section that corresponds to the Six Core

## Feature CONT. New Health Care Transition Efforts

Elements packages. It also includes a set of frequently asked questions developed by and for youth, young adults, and families, as well as new information for researchers and policymakers and a robust listing of transition resources.

To build state Title V leadership in transition, Got Transition has started to work with six states – Maryland, Ohio, Oregon, Rhode Island, Texas and Wisconsin – to promote more widespread use of the Six Core Elements using quality improvement strategies. Future plans are to develop a set of webinars and slide decks that all Title V agency staff can use as they further their important efforts at achieving transition improvements.

For more information on Got Transition, please visit [GotTransition.org](http://GotTransition.org).

## Feature Moving Toward Health Equity: Reducing Disparities for People with Autism Spectrum Disorder

**Kate Taft, MPH**  
*Senior Program Manager, CYSHCN,  
AMCHP*



Reducing health disparities is an important focus in public health and a critical strategy in moving toward health equity. In May, the Health Resources and Services Administration (HRSA) Combating Autism Act Initiative (CAAI) grantees from Iowa, Minnesota and Ohio presented on their efforts to address health disparities for people with autism spectrum disorder and other developmental disabilities (ASD/DD). For individuals on the autism spectrum, disparities can exist in accessing diagnostic and treatment services, access to care based on location, and racial and cultural differences.

Grantees shared their efforts to better understand disparities in their states and communities, and initiatives to address those disparities. For example, the Minneapolis Somali Autism Spectrum Disorder Prevalence Project

## Feature CONT. Moving Toward Health Equity

aimed to determine the prevalence of ASD in Minneapolis and assess if there was a difference in prevalence among Somali vs. non-Somali children. The study found that Somali and White children were more likely to be identified with ASD than Black and Hispanic children in Minneapolis, and Somali children with ASD were more likely to also have an intellectual disability than children with ASD in all other racial and ethnic groups. The results have implications to help family members better understand ASD and talk to community leaders about the need for increased awareness; for providers to identify where services are needed and where outreach should be targeted; and for policymakers and advocates to develop and refine policies to promote early identification and equity in access so that all children have access to evaluation and treatment.

Similarly, grantees in Ohio have been working to ensure all families have equitable access to needed services and are able to navigate the system of care. Collaboration with families and state and community partners is a key strategy to this work. This includes outreach to families in minority populations, such as Somali, African-American and Latino communities, as well as the community and provider agencies that work with families. By developing and engaging new networks of partners, Ohio grantees have been able to increase dissemination of information and resources to families throughout the state. Partnerships have led to the development of joint projects, such as training webinars, families with autism medial lecture series, social media toolkits, public service announcements and the translation of materials into Spanish and Somali.

In Iowa, grantees at the University of Iowa Children's Hospital are addressing disparities in access to health care for people living in rural and other underserved areas. For children with ASD, many access to urgently needed behavioral services, especially those in small towns and rural areas. This project examined telehealth as a strategy to increase the availability of evidence-based Applied Behavior Analysis (ABA) practices to all geographic areas. The study results indicated that ABA and behavioral consultation delivered through telehealth can help parents significantly reduce challenging behavior and improve social communication in children with ASD. It also can be a more cost-effective option for delivering those services to families living in rural areas when compared to costs of behavioral consultants having to travel onsite or to the home.

## Feature CONT.

### Moving Toward Health Equity

The [CAAI Virtual Activity series](#) provides a way for grantees to share their successes and lessons learned with fellow grantees and others in the field of ASD/DD, and facilitate discussion on topics of mutual interest. To find out more information about efforts to reduce health disparities, access the webinar recording and presenter slides and materials on the AMCHP website at: [amchp.org/programsandtopics/CYSHCN/projects/spharc/technical-assistance-calls/CurrentWebinars/Pages/default.aspx](http://amchp.org/programsandtopics/CYSHCN/projects/spharc/technical-assistance-calls/CurrentWebinars/Pages/default.aspx).

For more information about the CAAI, visit [mchb.hrsa.gov/programs/autism/](http://mchb.hrsa.gov/programs/autism/).

## Feature

### The National MCH Workforce Development Center: Focusing on Services for CYSHCN

**By Dorothy Cilenti, Principal Investigator and Director**  
*National MCH Workforce Development Center, UNC Gillings School of Public Health*



**Amy Mullenix, Senior Collaboration Manager**  
*National MCH Workforce Development Center*



The National MCH Workforce Development Center (Center) aims to strengthen the capacity of Title V agencies to be the “go to” leaders in their states and territories for the maternal and child health population in an era of health transformation. The Center provides an integrated set of training, coaching and consultative resources to support states and territories in implementing and sustaining effective change in the context of health reform. The Center’s work focuses on four core areas: access to care, change management, systems integration and quality improvement.

In April 2014, the Center launched its first cohort of eight states to engage intensively with the Center around a wide

## Feature CONT.

### Focusing on Services for CYSHCN

range of projects addressing one or more of the Center’s core areas. Two of the states demonstrated a clear need or opportunity related to advancing health reform implementation to improve services for CYSHCN. Their proposed scopes of work are described here.

Colorado has engaged the Center to assist in mapping care coordination activities across multiple systems, primarily the Title V Health Care Program for Children with Special Needs (HCP), Healthy Communities (EPSDT outreach) and the Medicaid Regional Care Collaborative Organizations (RCCOs) in order to maximize existing resources and identify duplications and gaps in care coordination services. There are a significant number of Colorado children and youth with special health care needs who are eligible for all three programs. The overall goal is to make policy changes that result in a system of care coordination with clear roles and processes for state and local partners who play a role in implementing the identified programs. Colorado’s partners in this effort include: Colorado Department of Health and Environment, Health Care Policy and Financing, Children’s Hospital Colorado, local public health agencies, and RCCOs (Medicaid ACO collaborative).

The Minnesota project goal is to improve access to and quality of care for CYSHCN through the implementation of a comprehensive strategic plan focused on the six national core outcomes for CYSHCN. The state team has requested assistance from the Center in developing collaborative action steps to implement five of the 80 identified activities included in the strategic plan, particularly through the use of systems mapping, appropriate quality improvement tools, and change management approaches. Minnesota’s partners include: Minnesota Department of Health, Family Voices of Minnesota, Minnesota Department of Education, Minnesota Department of Human Services, and Parent Advocacy Coalition for Educational Rights Center.

As participants in the first intensive cohort of the Center, Colorado, Minnesota and other state teams have met in Chapel Hill in mid-June to learn within a collaborative environment how systems integration, quality improvement and personal leadership development may help them achieve their health transformation goals and sustain long-term improvements in service delivery and outcomes for CYSHCN.

## Feature CONT. Focusing on Services for CYSHCN

A second cohort of states will be selected to engage intensively with the Center in late summer 2014. The Center is particularly interested in working with and learning from states and territories where Title V leadership seeks to be successfully engaged in health care reform efforts and supports workforce development activities to improve health outcomes for women, children and families. More information about this opportunity will be available in July 2014.

To learn more about the Center, visit [amchp.org/Transformation-Station/Pages/Home.aspx](http://amchp.org/Transformation-Station/Pages/Home.aspx).

## View from Washington Raising the Flag for Collective Impact in MCH

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

Each year around this time I start thinking about the upcoming Fourth of July holiday. The parades, cook outs, fireworks and flags will all be on display soon. And when I think about these patriotic celebrations, I'm reminded that nothing is more American than baseball, motherhood and apple pie. Here at AMCHP, we see our job as raising the flag for all moms (and we like our Washington Nationals baseball team and a good slice of pie too – but I digress).

Recently I was raising this flag at a meeting of public health advocates and federal officials who oversee the entire budget of the U.S. Department of Health and Human Services. The meeting was following the predictable script with advocates highlighting the relentless onslaught of budget cuts, sequestration, and job loss. Our partners were confirming that the uncertainty is likely to continue for the foreseeable future.



## View from Washington CONT.

So it was a bit jolting to many in the room when I spoke up to say that despite this gloomy situation, the Centers for Disease Control and Prevention (CDC) had recently released [data](#) showing that the U.S. infant mortality rate declined 12 percent from 2005 to 2011. This, I said, translates into thousands of saved lives, and is a substantial public health victory that deserves to be celebrated.

I thought I was taking the high road when I went on to say that while we think the Title V MCH Services Block Grant has contributed to this success, we recognize that other critical programs have contributed to this success, including Medicaid, the Children's Health Insurance Program, WIC, Healthy Start, Home Visiting, the Personal Responsibility Education Program and evidence-based Teen Pregnancy Prevention Grants, Community Health Centers, Title X Family Planning and critical efforts of the CDC and the National Institutes of Health.

Around the room there were nods of agreement and a general sense of pride that this example indeed illustrated that public health is best when working as a system, and not a series of siloed categorical grants. The bubble burst, however, when one of the budgeteers indicated that while they get systems thinking, they still are charged with asking the tough questions about what each program specifically contributed to this progress so they can increase funding for evidence-based programs and end funding for what's not.

In that moment, it became clear to me that the theory of collective impact, which intuitively appeals to so many of us in public health because it recognizes there is no silver bullet solution to complex problems, will run into considerable interference as long as our budgeting process is premised on an isolated impact model that holds out for scaling up single programmatic solutions.

So, here's where we need your help. How are you educating your budget officials on collective impact? What's working, and what should be avoided? Let me know what you are thinking ([bewig@amchp.org](mailto:bewig@amchp.org)), and we'll share the best ideas in a future column.

## Real Life Story

### It's Time to Apply Workforce Development to Family Leaders

By Donna Yadrich

*Kansas Department of Health and Environment Family Delegate*

In April 2010, my daughter, Audrey, was planning the transition from middle school to high school. She would only attend high school for less than one day.



Audrey was diagnosed as a toddler with a very rare autoimmune syndrome that caused unpredictable, chronic and acute life-threatening diseases. She had been in the gifted and talented program since kindergarten and managed to earn straight As. However, her ability to physically function had been greatly impaired by medical fragility. We looked but never found support groups or organizations that were applicable to our experience. We had been led to believe that a very limited set of diagnoses qualifying for state or federal program services were considered 'special needs/disability' by providers unfamiliar with the diverse reach of Title V.

Audrey was a bright star whose primary loves were animals, learning, friendships, reading, music, community service and dance. We were able to "hide" her functional disabilities for many years although her physical appearance did show signs of disease. Seventh grade was the most difficult year of her academic career: she nearly died several times during an 89-day hospitalization and was extremely fragile when released.

Audrey expressed her concerns about "missing high school" to her nurse practitioner who then consulted a social worker. The social worker for medically complex children suggested we seek the guidance of Families Together, Inc., the Kansas Family to Family (F2F) organization. The social worker forwarded me a newsletter from the F2F announcing the recruitment of Youth Advisory Council members in Kansas for youth with special needs funded by a D70 award.

Audrey was immediately interested in the position but we didn't know if she qualified. Indeed she did! Audrey's

application was accepted, and she officially joined the Youth Advisory Council in Topeka, Kansas, July 2010 at the age of 14.

I became involved with the Family Advisory Council (FAC) along with Audrey. We participated via phone conferences from Audrey's hospital room – where she celebrated her 15th birthday and passed away in January 2011. Briefly, she had been empowered as an advocate for those with disabilities.

It no longer seemed suitable for me to attend FAC meetings following Audrey's death, so I intended to resign. However, something compelled me to attend and I will always be grateful to my FAC peers and leadership for encouraging my continued participation. In 2012, my Title V program supported my AMCHP Family Scholar application. I attended my first AMCHP annual conference in 2013 where I met a University of Minnesota LEND fellow and coproduced a fact sheet on Family Caregivers of CYSHCN. That fall, I was appointed to the Family and Youth Leadership Committee and also as the Kansas Family Delegate (FD). As the FD, I am serving in a greater capacity for the Block Grant preparation and onsite Region VII review as well as developing a family caregiver assessment. Recently I accepted an invitation to serve within the Kansas MCH- American Academy of Pediatrics (AAP) Partnership as a member of the Kansas Maternal and Child Health Council and in Missouri, I serve as a stakeholder for the Missouri Life Course Network. I have been working to strengthen family engagement in MCH workforce development and accepted a three-year term as a Title V Family Representative to the National MCH Workforce Development Center.

I am so excited about MCH 3.0 – a new way of integrating existing resources! My hope is to install windows and bridges within silos between academic institutions/affairs and family-to-family endeavors.

For example, after my first AMCHP conference I learned only 37 percent of CYSHCN family leaders had pre-AMCHP awareness of LEND. That tells me we've got lots of MCH workforce development work to do!

## Success Story

### Addressing Health Disparities for CYSHCN in New Mexico

**By Susan Chacon, MSW, LISW**  
*New Mexico CYSHCN Director*

In New Mexico approximately 80,000 children and youth meet the MCH definition of having a special health care needs. The percent who identify their race/ethnicity other than white alone is 74 percent. Many families live in rural/frontier areas and have high rates of poverty. Many are immigrant families of mixed status with limited options for health care.



The mission of the CYSHCN program Children's Medical Services (CMS) is to ensure coordinated, compassionate, culturally competent care for CYSHCN in NM, and increase access to specialty medical care for CYSHCN in rural NM. How does CMS close the gap in health care disparities? The provision of care coordination for CYSHCN by professional licensed medical public health social workers evens the playing field by providing access to care and alleviating the fragmented care that CYSHCN may be receiving. This care coordination is provided in local public health offices in every county of the state. The CMS social workers live where they work and are based in the culture of the community. The public health offices are trusted community resources where clients can receive health care services such as WIC, Family Planning, immunizations and can be assessed for eligibility for Medicaid and Insurance Exchange options.

Research has shown that CYSHCN are more likely to have multiple health needs and to see multiple providers who fail to provide a full range of services. A study by Antonelli et al (Pediatrics 2004) noted that "more than half of care coordination encounters with CYSHCN were attributable to issues not considered typically medical." CMS social workers assess family needs and strengths, assist families in understanding diagnosis and its implications, assist with accessing medical information and make appropriate referrals to community services, and ensure linkages exist between families, the Medical

Home and specialty providers. In addition, they develop individual care plans, and empower families as decision makers and self-advocates with providers and community system. They honor cultural diversity, plan long term care for CYSHCN and their families through the life span, share legal safeguards, provide social and emotional support, and assist youth with special health care needs to make appropriate transitions to adult health care, work and self-sufficiency. The CMS social workers strengthen support networks and systems of care including assurance that the cultural and linguistic needs of the clients are addressed during medical appointments. Most importantly, they guide families through multiple health care agencies and insurances that make up a complex and fragmented medical system.

The Public Health offices also serve as an access point for multidisciplinary pediatric specialty clinics facilitated by CMS social workers and staffed by specialists from the University of New Mexico Health Sciences Center and Presbyterian Hospital. These community-based pediatric specialty outreach clinics provide multidisciplinary, coordinated diagnostic and/or ongoing medical care to children and youth with pulmonary, endocrine, cleft palate, neurological, nephrology, metabolic and genetic conditions in rural areas that experience a dearth of specialty providers. This service is available to all CYSHCN who have diagnoses addressed by these clinics. There were 130 clinics held in 16 towns and cities throughout the state in 2013. CMS social workers ensure that recommendations and follow-up care is linked back to the Medical Home for each client seen at clinic and provide ongoing care coordination.

CMS staff are dedicated to the clients in their communities and work on many levels to promote human rights and the principles of social justice and the empowerment of families, reduce disparities in health care access due to issues of poverty, racism and inadequate health care resources, advocate for health improvement policies, and increased funding through leadership around community and public health issues.

## Who's New

### NEW HRSA STAFF

#### Dr. Reem Ghandour

Dr. Reem Ghandour has been selected as the Director for the Division of Epidemiology, within the Office of Epidemiology and Research (OER). Reem served in the Office of Women's Health at MCHB from 2003-2008, while working with our office on data publications. She has been with OER since 2008. At various points in her tenure In OER, she has served as the managing editor for the bi-annual Child Health USA databook, Women's Health USA, the MCHB-lead for Healthy People 2020, the MCHB-lead for the Interagency Forum on Child and Family Statistics, and the colead for the redesign of the National Survey of Children's Health. She was also the initial manager for the COIIN on Infant Mortality. Reem holds a Masters of Public Administration from Syracuse University and a Doctorate in Public Health from the Johns Hopkins Bloomberg School of Public Health.

### NEW AMCHP STAFF

#### Leah Broadhurst

Leah Broadhurst joined AMCHP as a summer intern with the Women's and Infant Health (WIH) team. She is a rising second year medical student at Georgetown University School of Medicine who plans to train in medicine-pediatrics and then specialize in infectious diseases. Leah received her Bachelor of Science degree in biology from the University of North Carolina-Chapel Hill and completed a Master of Science in Public Health at the University of North Carolina-Charlotte before matriculating into medical school. She will be working on various projects with the WIH team throughout the summer.



## Get Involved

### July ColIN Infant Mortality Summits

AMCHP is proud to partner with MCHB and NICHQ to organize sessions at the 2014 Collaborative Improvement and Innovation and Network (ColIN) Infant Mortality Summits. The Infant Mortality Summits will convene states from Regions I-III and VII-X to prepare them for the rollout of the ColIN initiative in their state. Regions VII-X will meet Jul. 21-22, and Regions I-III will meet Jul. 24-25. Both summits will take place in the Washington, DC, area. A third summit for the Pacific Basin jurisdictions will be held Aug. 24-26 in Honolulu, HI. For more information on the summits, please visit the ColIN website [here](#) or contact our partners at NICHQ at [coiin@nichq.org](mailto:coiin@nichq.org).



**AMCHP is collecting emerging, promising and best practices related to children and youth with special health care needs!**

Does your program address a best practice related to CYSHCN? 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 [Kate Howe](#) at (202) 266-3056 or visit [amchp.org/bestpractices](http://amchp.org/bestpractices).

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

## Get Involved CONT.

### Building, Implementing, and Sustaining Teen Pregnancy Prevention Efforts

Please join us on Thursday, Jun. 26 from 2-3 p.m. EST for a timely discussion of state examples of teen pregnancy prevention programming through the lenses of positive youth development, the program implementation life cycle, and disparity reduction. In recent weeks and coinciding with Teen Pregnancy Prevention Month in May, numerous federal partners and their grantees participated in webinars on teen pregnancy prevention activities, including on the topics of engaging males and prevention of subsequent teen pregnancies. As MCH programs consider their own efforts designing, coordinating, and evaluating teen pregnancy prevention programs within their state, this AMCHP webinar will highlight three state teen pregnancy initiatives at different stages of implementation, and will focus on their efforts to reduce disparities (by race/ethnicity and urban versus rural) in teen pregnancy and childbearing, leveraging novel partnerships and outreach methods. This webinar is part of the AMCHP Women's Health Info Series, funded by the Centers for Disease Control and Prevention (CDC) Division of Reproductive Health.

Featured speakers:

- Gabriel McNeal - PREP Coordinator, Adolescent & Youth Development Specialist, Minnesota Department of Health
- Benita Decker – State Adolescent Health Coordinator, Kentucky Department of Public Health
- Tiffane Raulerson – Teen Pregnancy Prevention Project Coordinator, Florida Department of Health

Please [register here](#) for the webinar. Web access and call-in information will be e-mailed to registrants in the week prior to the event.



## Resources

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

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

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

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

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

## Resources CONT.

[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.
- [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.

- [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's 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.

## Resources CONT.

[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.

[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 makes 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. Topics include cultural competence, leadership and using data. Contents include archived webinars, narrated slide presentations, an online course, and videos. Funded by the MCHB and produced by the Health Information Group at Georgetown University.

- [The MCH Navigator Training Brief on Diversity and Health Equity](#), is designed to help the Title V work force identify and address disparities in MCH populations. Contents include archived conferences and webinars, lectures, and videos. Links to the MCH Navigator Training Brief on Cultural and Linguistic Competency, the MCH Library's Racial and Ethnic Disparities in Health Knowledge Path, and other online resources are included.

[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

## Resources CONT.

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.

- [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.

[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

### Health Equity for CYSHCN: Do CYSHCN Face Higher Rates of Disparities when Compared to Non-CYSHCN?



**% of Children with All Criteria Met for Medical Home**

**CYSHCN: 50.9%**  
**Non-CYSHCN: 63.2%**



**% of Children with Condition of Teeth Described as Excellent, Very Good, or Good**

**CYSHCN: 89.6%**  
**Non-CYSHCN: 93.1%**

Data indicates that Children and Youth with Special Health Care Needs (CYSHCN) often face higher rates of disparity when compared to non-CYSHCN. The 2011-2012 National Survey of Children's Health provides comprehensive data regarding such health inequities. To further explore available data, visit the [Data Resource Center for Child & Adolescent Health](#).

**Approximately 19.8%** children in the United States have a special health care need.



In the national survey, CSHCN Status is determined using a validated instrument for identification of CSHCN as defined by the Maternal and Child Health Bureau.



**% of Children Consistently Engaged in School**

**CYSHCN: 66.8%**  
**Non-CYSHCN: 84.7%**



**% of Children Who Live In Supportive Neighborhoods**

**CYSHCN: 79.6%**  
**Non-CYSHCN: 82.7%**



**% of Children with Healthy Weight**

**CYSHCN: 59.2%**  
**Non-CYSHCN: 64.2%**

\*Data collected from the [Data Resource Center for Child & Adolescent Health](#)

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

## Calendar

### AMCHP Events

AMCHP 2015 Annual Conference  
Jan. 24-27  
Washington, DC

[Supporting Children Affected by Parental Co-Occurring Disorders: Substance Abuse, Mental Illness, HIV](#)

Jun. 30-Jul. 2  
Seattle, WA

## Calendar CONT.

[NACCHO Annual Conference](#)

Jul. 8-10  
Atlanta, GA

[Regions VII-X Infant Mortality ColIN](#)

Jul. 21-22  
Washington, DC

[45th Annual Autism Society National Conference](#)

Jul. 23-26  
Indianapolis, IN

[Regions I-III Infant Mortality ColIN](#)

Jul. 24-25  
Washington, DC

[Pacific Basin Infant Mortality ColIN](#)

Aug. 24-26  
Honolulu, HI

[ASTHO Annual Meeting and Policy Summit](#)

Sept. 9-11  
Albuquerque, NM

[CityMatCH Leadership & MCH Epidemiology Conference](#)

Sept. 17-19  
Phoenix, AZ

[APHA 2014 Annual Meeting and Exposition](#)

Nov. 15-19  
New Orleans, LA

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

### Association of Maternal & Child Health Programs

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