

Developments, December 2016

Issue IV, Volume 5
Table of Contents

Developments, Dec. 2016

Introduction

MCHB Minute

Training Topics

Research Roundup

State Stories

Collaborators Corner

ITAC Items

Upcoming Meetings

Submit Articles

Introduction

Developments is a newsletter for Autism CARES legislation grantees, published by AUCD's Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities (ITAC) in partnership with AMCHP's State Public Health Autism Resource Center (SPHARC). Its purpose is to share news, activities, events, research, and accomplishments across grantee areas - research, training, and state implementation

MCHB Minute

MCHB Update – DMCHWD

As we near the end of 2016, I want to acknowledge the ongoing accomplishments of the Autism CARES grantees. Your dedication to supporting children and youth with autism spectrum disorder (ASD) and developmental disabilities (DD) and their families is making an impact. Collectively, you are improving access to screening and diagnostic services for children with ASD, training the pipeline of future leaders in neurodevelopmental disabilities, advancing the evidence base around the effectiveness of autism interventions, reducing barriers to care for underserved populations, and pursuing new, innovative models of care and training to extend your reach.

Recently we shared findings from the latest Autism CARES evaluation from 2011-2014. While there are many achievements and innovations from across the grant programs, I wanted to highlight a few of the impressive results with you:

- LEND and DBP programs expanded the pipeline of future leaders in neurodevelopmental disabilities and developmental behavioral pediatrics by training over 4,000 long-term trainees and more than 10,000 medium term trainees, and reaching over 210,000 individuals through continuing education on topics such as using valid, reliable screening and diagnostic tools, and evidence-based interventions for ASD/DD tools;
- LEND and DBP programs continued to increase the number of children receiving diagnostic evaluations in each year of the evaluation, providing over 81,000 diagnostic evaluations in 2013-2014;

- The Autism CARES Research Program grantees developed 42 toolkits and measures, and 6 clinical guidelines, and prepared over 200 manuscripts for publication in peer-reviewed journals;
- State implementation grantees demonstrated improvements in both early and continuous screening, and increasing community capacity for timely identification and evaluation of children with ASD/DDs; and
- The national resource centers, ITAC and SPHARC, continued to provide solid support and technical assistance to all grantees, including promoting collaboration and coordination, and facilitating the exchange of resources and best practices across grantees.

I'd also like to welcome the new Autism CARES grantees from across the autism grant programs. We look forward to working with you and engaging you in the CARES network!

On behalf of the MCHB [Division of MCH Workforce Development](#), I wish you a happy holiday season and best wishes for the new year. Thank you for all that you do children, youth and their families.

Lauren Raskin Ramos, MPH

Director, Division of MCH Workforce Development

Maternal and Child Health Bureau Autism Team Lead

Training Topics

Teaching Disability Awareness to Fourth Graders (Boston Children's Hospital)

This article was written by Carol Wilkinson, MD PhD, DBP Fellow at Boston Children's Hospital.

Every fall, the Boston Children's Hospital Division of Developmental Medicine fellows in Developmental Behavioral Pediatrics and Pediatric Psychology partner with the Brookline Public Schools (MA) to teach fourth graders about various disabilities. Fellows are trained in a hands-on curriculum and then spend several mornings implementing the curriculum to educate children about people with physical, sensory, or developmental disabilities. [Understanding Our Differences](#) is an interactive disability awareness curriculum that teaches children to "see the person and not the disability." Taught over several weeks, the activities harness a

child's innate curiosity and desire to understand differences, coupled with lessons of how to engage with and respect peers with disabilities, the program focuses on acceptance in an inclusive world.

During the Deaf and Hard of Hearing week, students practiced signing with each other, learned the sign language alphabet, and tried communicating through lip reading. When learning about physical disabilities, we think about how environmental modifications make the world accessible and safe for everyone. The curriculum includes directions and materials to facilitate the sessions. After the end of a busy morning, moving from one activity to the next, students regroup to hear first hand from a guest speaker experiencing the disability focus of that day. This year, a local high school student came educate us about being deaf and hard of hearing. The students listened, they used signs to show respect - shaking their hands for applause, and they asked questions - "Do you like music?", "How do you know what your teacher is saying?", and of course "Who is your favorite player on the Patriots?" The day when we learned about the Spectrum of Vision, Haben Girma (<https://habengirma.com>) joined the classes to inform and inspire us. As the first deaf blind graduate of Harvard Medical School, Ms. Girma, with her assistive technology and guide dog, mesmerized the students, teachers, fellows, vice principal, principal, and school superintendent!

Over the course of the last three years, the Understanding Our Differences curriculum has become a highlight of the fourth graders' year - often talked about with anticipation during the weeks preceding. For Boston Children's Hospital Fellows, it is also a highlight - providing opportunity to teach within our community, and learn hands-on the rewards and challenges of teaching in the classroom setting.

CT LEND: An authentic interdisciplinary experience

The CT LEND has had an exciting new start this fall. Nine UCONN graduate students from various disciplines, two Yale Developmental-Behavioral Pediatric fellows, four community trainees, and four Human Services/Family Studies students from Goodwin College fill our conference room at UCONN Health each Friday. We welcome family faculty and several UCEDD staff members to each weekly seminar as well. Our true interdisciplinary cohort includes participants

from an AUCD Auditory supplement and also a Diversity grant, several of whom are first generation college students.

In addition to the weekly didactic sessions, students have visited the Hospital For Special Care, University of Hartford Magnet School, and Yale Child Study Center, as well as participated in local events like the Fragile X Conference, a Medical Management series at the school of Social Work, an Autism Workshop sponsored by the Institute for System Genomics, and guest lectures from Dr. Carl Dunst, Dr. William McGaughey, and Dr. Allan Bergman. Students successfully completed group research projects on topics including post-hospitalization supports for children with ABIs, ASD prevalence in the Connecticut foster system, and prematurity and ASD. Students look forward to Spring clinical placements, independent research projects, and participation with CT KASA for the authentic opportunity to experience advocacy from the perspective of local children with disabilities.

If other state LEND trainees are travelling through Connecticut this year, please feel free to join us at a Friday seminar, or simply to visit the CT UCEDD!

Oklahoma's New Portal Seeks to Help Thousands on Medicaid Waiver Waiting List (OK UCEDD/LEND)

Following the recommendation of a Blue Ribbon Panel and an Executive Order from Gov. Mary Fallin, Oklahoma officials are developing a Web portal that could speed up service delivery for thousands who may have waited years to learn whether they qualify for a medical waiver. One of many issues addressed in April 2015 by the Governor's Blue Ribbon Panel for Developmental Disabilities was how to better serve thousands of Oklahomans seeking community services from the state Developmental Disabilities Services Division (DDSD) of the Oklahoma Department of Human Services. [Read More...](#)

LEND Project Looks at Developmental Surveillance and Screening in Early Childcare settings (OH-Nisonger Center UCEDD/LEND)

Nisonger LEND trainees and faculty Andrea Witwer, PhD and Jennifer Walton, MD, MPH, are involved in a multi-year project examining developmental screening and surveillance of Ohio children in early childhood settings. The goal of the project is to improve early identification of children with developmental delays. As more very young children spend time in childcare, providing training on

evidence based screening to childcare providers can potentially provide an additional safety net to help identify children with delays early. Now in its third year this leadership project has completed a needs assessment of childcare providers and childcare center directors with regard to developmental surveillance and screening of children with developmental delays. [Read More...](#)

Linking Latino Parents to Autism Resources (IL UCEDD/LEND)

For parents who have a child with autism, navigating the service system to find ways to help their child can be overwhelming. Within the Latino community, promotoras - community health workers who are indigenous to the community - help educate parents on autism and appropriate services. Two UIC researchers are going global by expanding a parent educational intervention designed for Latino parents in the U.S. to Colombia. [Read More...](#)

Research Roundup

AIR-P Network Activities

The Autism Intervention Research Network on Physical Health (AIR-P), led by Karen Kuhlthau, PhD, 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, with an emphasis on underserved communities. Two key goals of the AIR-P network are to provide opportunities to develop collaborations and partnerships with clinicians and researchers and to support junior investigators in developing their research efforts to improve medical care of children with autism.

The AIR-P provides opportunities for researchers from across the network to collaborate with each other as well as other CAAI sponsored programs such as LEND and Developmental-Behavioral Pediatrics Training Programs. Successful partnerships with these programs have increased AIR-P presence at various scientific meetings, including abstracts at IMFAR and PAS, and papers submitted for publication. So far for 2017, AIR-P network members have submitted 8 abstracts for consideration at IMFAR.

The network provides ongoing opportunities to support investigators through a Request for Applications (RFA) mechanism, which has supported more than 25 research projects at more than \$10M throughout the past 7 years. AIR-P recently funded three new research projects under RFA ATN-AIR-16-09: “Pilot to Proposal”. This mechanism provides 15 months of support for the development and implementation of a study to show overall feasibility of the proposal and to provide adequate data demonstrating that expansion to a multi-center study will provide a clinically important effect. The pilot studies include: “Two-Phase Study of Probiotics for Quality of Life through GI and Emotional Stability in Youth with ASD and Anxiety: Single-Site Pilot Trial Followed by 3-Site RCT” by L. Eugene Arnold, MD at The Ohio State University; “Physical Exercise to Reduce Anxiety in Underserved Children with ASD” by Jean Gehricke, PhD at the University of California, Irvine; and “Clonidine and Trazodone for Sleep Disturbance in Children with ASD” by Jill Hollway, PhD at the Ohio State University.

Additionally, the network provides support to investigators interested in mining data from the Autism Treatment Network (ATN) Registry. We have developed a Request for Data (RFD), which allows individuals to submit a formal request to obtain summary data from the ATN Registry, which is supported in collaboration with AIR-P. Past analyses by external investigators have led to dissertations and manuscripts by trainees in pediatrics and psychology as well as other junior faculty members at various institutions. Individuals interested in learning more about the registry data should visit <http://asatn.org/request/data>.

The AIR-P continues to hold its monthly webinar series titled “Advances in Autism Research & Care (AARC)” which alternates autism research and care themes, and is available to all AIR-P/ATN 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 AIR-P investigators, often junior investigators, presenting their work in various stages of development while care focused themes cover hot topics in the field of autism and promote idea generation for future research. If you’re interested in being added to the distribution list for information on these webinars, please email Audrey Wolfe, Research Coordinator, at awolfe2@mgh.harvard.edu. Archived webinars can be viewed by visiting the network’s YouTube page:

<http://www.youtube.com/asatnairpnetwork> or by clicking the “Tools” link on the AIR-P website.

For more information on the AIR-P, please visit our public website:

<http://www.airpnetwork.org>.

What’s New in AIR-B3?

The AIR-B3 network consists of 5 sites--- UCLA, UC Davis, University of Pennsylvania, Drexel University and University of Rochester. We have been actively preparing for the intervention studies we proposed, Mind the Gap and Building Better Bridges. Both of these intervention teams have been collecting pilot data, and refining the interventions which focus on the gap between diagnosis and services for many low-resourced families (Mind the Gap), and in maintaining continuity between major schooling transitions, such as between preschool and Kindergarten, elementary to secondary school (Building Better Bridges).

A major activity of the network this past year has been to expand our community partnerships. Our overall Network community partner, Healthy African American Families (HAAF) has continued to help us develop our expertise in Community Partnered Participatory Research (CPPR) while we have expanded our partnerships in each community. These partnerships consist of local school districts, community health centers, and community parent groups, among others. In conjunction with our community partners, we held our AIR-B Network conference in October in Philadelphia. This free conference, “Strengthening the Bond: Families Living with Autism in our Community” was at capacity, and held in the Free Library in downtown Philadelphia. All four sites were represented as speakers where the audience was largely parents of children with autism and community service providers.

AIR-B investigators have also been active in participation of their local community conferences and meetings. For example, in Los Angeles, community partner Fiesta Educativa held a parent conference in October that featured our local AIR-B team as speakers, and community partner, South Central Los Angeles Regional Center (SLARC) launched a “Lunch and Learn” meeting on transitions for youth in collaboration with our AIR-B team.

We have recently published several new papers using our AIR-B data, and are continuing to focus our efforts on low resourced families of children with ASD, and under-researched topics, such as girls with ASD.

Dean, M, Harwood, R., & Kasari, C. (2016). The art of camouflage: Gender differences in the social behaviors of girls and boys with ASD. *Autism*.

Locke, J, Williams, J, Shih, W, & Kasari, C (2016). Characteristics of socially successful elementary school-aged children with autism. *Journal of Child Psychology and Psychiatry*.

Azad, G., Locke, J., Kasari, C., and Mandell, D. (2016). Ethnicity, disability, and grade: Social relationships in children with autism spectrum disorders in elementary school. *Autism*. 1362361315627792.

Iadarola, S., Oakes, L. A., Shih, W., Dean, M., Smith, T., & Orlich, F. (2016). Relationship Among Anxiety, Depression, and Family Impact in Adolescents With Autism Spectrum Disorder and Average-Range IQ. *Focus on Autism and Other Developmental Disabilities*, 1088357616672416.

Developmental-Behavioral Pediatrics Research Network Update

The Developmental-Behavioral Pediatrics Research Network (DBPNet) is a 14 site Network whose mission is “to conduct collaborative, interdisciplinary research in developmental and behavioral pediatrics that advances clinical practice, supports research training, and optimizes the health and functional status of children with developmental and behavioral concerns and disorders, including children with autism spectrum disorders and other developmental disabilities”. The Network had a successful competitive renewal in the past year and is now funded from 9/16 through 8/21.

Current studies within DBPNet include a study to validate outcome measures developed by the NIH Patient Reported Outcome Measurement Information System (PROMIS) initiative in adolescents with ASD and a NIMH-funded multi-site randomized clinical trial of a family navigator intervention to improve access to

care and reduce health disparities among vulnerable low-income families with children with an autism spectrum disorder.

Over the past year the network presented 10 scientific presentations at national meetings and had 3 peer reviewed publications in scientific journals.

Hansen RL, Blum NJ, Gahman A, Shults J, on behalf of the DBPNet Steering Committee. Diagnosis of Autism Spectrum Disorder by Developmental Behavioral Pediatricians in Academic Centers: A DBPNet Study. *Pediatrics* 2016;137(s2):s79-89.

Harstad EB, Blum NJ, Gahman A, Shults J Chan E, Barbaresi W for the DBPNet Steering Committee. Management of Attention Deficit Hyperactivity Disorder by Developmental-Behavioral Pediatricians: A DBPNet Study. *Journal of Developmental and Behavioral Pediatrics* 2016;37(7):541-547.

Toomey M, Schwartz J, Laverdiere M, Tucker C, Bevans K, Forrest CB, Blum NJ. Preliminary Validation of the PROMIS Pediatric Parent-Proxy Peer Relationships Measure in Children with Autism Spectrum Disorder: A DBPNet Study. *Journal of Developmental and Behavioral Pediatrics* 2016;37:724-729

News from the Healthy Weight Research Network (HWRN)

(1) The Healthy Weight Research Network (HWRN), coordinated by the E.K. Shriver Center at UMass Medical School and Tufts University School of Medicine, was refunded for the next 5 years from the Maternal Child Health Bureau. The mission of the HWRN is to advance the understanding of obesity risk factors in children with ASD and other developmental disabilities, to promote the development of evidence-based solutions to achieve healthy weight in this population, and to disseminate research findings to broad and diverse audiences.

(2) The HWRN held its first symposium on May 11, 2016 in Baltimore, MD. The symposium, entitled *Promoting Healthy Weight In Children and Youth With Autism Spectrum Disorder and Developmental Disabilities: Current Research and Future Directions*, featured presentations by HWRN Core and Associate Members

on the following topics: (1) The prevalence and risk factors for obesity in children with Autism Spectrum Disorder and developmental disabilities; (2) Eating behaviors and parent feeding practices in children with ASD; (3) Physical activity participation among youth with ASD; Interventions promoting physical activity and weight loss in adolescents with developmental disabilities; and (4) Supporting physical activity and recreation in the community: a community-based participatory research feasibility study for increasing physical activity with adolescents with ASD.

(3) The HWRN's Secondary Data Analysis Core recently completed and published the results of two analyses using data from the National Survey of Children's Health documenting the elevated prevalence of obesity in children and youth with intellectual disabilities and also autism. The citations and links to these papers are listed below.

- Segal, M., Eliasziw, M., Phillips, S., Bandini, L., Curtin, C., Kral, T. V., ... & Must, A. (2016). Intellectual disability is associated with increased risk for obesity in a nationally representative sample of US children. *Disability and health journal*, 9(3), 392-398.

See: [http://www.disabilityandhealthjnl.com/article/S1936-6574\(15\)00208-3/abstract](http://www.disabilityandhealthjnl.com/article/S1936-6574(15)00208-3/abstract)

- Must, A., Eliasziw, M., Phillips, S. M., Curtin, C., Kral, T. V., Segal, M., ... & Bandini, L. G. (2016). The effect of age on the prevalence of obesity among us youth with autism spectrum disorder. *Childhood Obesity*.

See: <http://online.liebertpub.com/doi/abs/10.1089/chi.2016.0079>

Please visit www.HWRN.org for more information and please consider becoming an Associate Member or Subscriber. Any inquiries about the HWRN can be directed to HWRN@umassmed.edu

Like us on Facebook! <http://tinyurl.com/HWRN-Facebook>

Health Care Transitions Research Network (HCT-RN) Updates

The Health Care Transitions Research Network (HCT-RN) for Autism Spectrum Disorder (ASD) and Other Developmental Disabilities was funded to support the creation of an interdisciplinary, multicenter research forum for scientific collaboration and infrastructure-building with a focus on research designed to improve health care transitions and promote an optimal transition to adulthood (including physical, psychosocial, educational, and vocational outcomes) among youth and young adults with autism spectrum disorder (ASD). Since April 2016, our network has been actively engaged in the following research and practice improvement efforts related to the transition to adulthood of youth with ASD.

Building on the first edition of the National Autism Indicators Report (<https://shar.es/1DW8Pg>) which found that a third of young adults never got work or continued education between high school and their early 20s, Dr. Paul Shattuck and his partners at the A.J. Drexel Autism Institute published the second National Autism Indicators Report (<https://shar.es/1DWDnd>) exploring the use of vocational rehabilitation (VR) services by individuals on the autism spectrum. This second edition of the National Autism Indicators Report details the characteristics of individuals with autism who used VR services, how VR services were used, employment indicators of individuals with autism who utilized VR services, as well as compared services and outcomes across states and disability type. Dr. Shattuck and several HCT-RN members also attended the 2016 International Meeting for Autism Research (IMFAR) in Baltimore, MD, where they presented in multiple poster and panel sessions and Dr. Shattuck provided a keynote address (<http://bit.ly/2h7DpBq>) on “moving the needle” to improve outcomes for adults on the autism spectrum by conducting research using a life course perspective.

To promote best practices in health care transitions in national physician professional organizations, Dr. Kuo developed an official positions/statement manuscript on best practices for health care transition for the Society for Adolescent Health and Medicine (SAHM), co-authored a manuscript with learning objectives and curriculum content for medical residents developed by members of the Health Care Transitions Research Consortium, the Transition Committee of the Medicine-Pediatrics Program Directors Association, and the Society for General Internal Medicine’s (SGIM) Task Force on Adults with Chronic Conditions Originating in Childhood, and worked with Dr. Debra Lotstein at Children’s Hospital Los Angeles to develop a national residency curriculum designed to improve health care transitions among youth and emerging adults with special

health care needs (including those with ASD). Dr. Kuo also led the development of standardized forms (available for download and use at <http://bit.ly/1XdapaB>) to improve transitions for youth with intellectual and developmental disabilities (including ASD) with input from staff at Got Transition and members of an American College of Physicians (ACP) work group and co-authoring and editing a textbook entitled Care of Adults with Chronic Childhood Conditions for primary care physicians, which includes a chapter on care of young adults with ASD which was written by members of the HCT-RN Advisory Board.

Finally, in April 2016, the HCT-RN built upon a scan of the existing literature and the ideas that were discussed during our 2015 launch meeting to launch a two-stage survey of our network members with the goal of identifying research priorities that have the greatest potential to improve the transition experiences and outcomes of individuals on the autism spectrum. Results from this literature scan and network survey were analyzed and will be reported in an official national agenda setting article by the HCT-RN, which we are working to publish together with a series of related papers by HCT-RN network members focused on transitions over the life course of individuals on the autism spectrum. After many months of collaboration and coordination with the members from the HCT-RN, Life Course Research Network (LCRN), and the A.J. Drexel Autism Institute, these articles – including three opinion pieces by self-advocates – are now in the final stages of preparation for review as a packaged journal supplement in *Pediatrics*. We are hoping to publish this journal supplement in April 2017, to coincide with Autism Awareness month, but short layperson-friendly versions of these articles will be published on the HCT-RN website (<http://www.autismtransition.net>), beginning in mid-January 2017, in anticipation of the supplement's official publication date. Please stay tuned to our website for further updates.

Paul Shattuck, co-director of HCT-RN, keynotes the International Meeting for Autism Research.

State Stories

Updates from the State Public Health Autism Resource Center

AMCHP's State Public Health Autism Resource Center (SPHARC) has released several new resources and technical assistance opportunities designed to aid and assist ASD/DD grantees.

New SPHARC Webinar and Infographic Resources

AMCHP celebrated Autism Awareness Month this past April by sharing news via AMCHP's [Facebook](#) and [Twitter](#) pages, conducting an autism awareness [webinar](#): "Telehealth and Autism Treatment, Training and Systems Building", and releasing a new [infographic](#) on autism awareness and the role of Title V and state grantees.

In addition, AMCHP hosted an August [webinar](#): "Early Childhood Data Systems Integration" and developed another [infographic](#) highlighting three key features of SPHARC: Resource Development, Technical Assistance (TA) and Peer Learning that can help improve and support any state ASD/DD program.

Addressing Gaps in ASD/DD Diagnosis: Peer to Peer Exchange

In June 2016, Virginia's HRSA Autism state team hosted this year's Peer-to-Peer Exchange. Five other grantees (Georgia, Iowa, Maryland, Michigan and Minnesota) learned about VA's model related to collective impact, strategies such as streamlining language between medical and school mental health professionals, and lessons learned during their project period. The attending grantees were also able to present on their work around family engagement, shared resource/outreach or Telepractice. To see an overview of each state's work, check out AMCHP's poster presentation at the 2016 AUCD conference [here](#).

ASD/DD at the 2017 AMCHP Annual Conference

AMCHP's 2017 Annual Conference will take place March 4-7 at the Kansas City Marriot Downtown in Kansas City, Missouri. This year's theme: *Engagement with Intention: Inclusivity, Diversity & Non-Traditional Partnerships* will showcase a myriad of exciting skills building sessions, workshops, and poster sessions related to ASD/DD and featuring state grantees' work. Resources on these sessions will also be available soon via the SPHARC and [AMCHP conference website](#).

For more information about SPHARC, visit www.amchp.org/SPHARC.

New State Grantee Community of Learners Kicks-Off!

SPHARC, in partnership with HRSA, recently held an October in-person kick-off meeting in Washington, DC for the new Autism Community of Learners state grantee cohort. Grantees include:

- Delaware
- Rhode Island
- Washington
- Wisconsin

This meeting helped lay the ground work for national partner and peer-to-peer support around grantee activities for the project period, which focus on implementation three key evidence-based/informed strategies: Shared Resource, Family Navigator and Telemedicine/Telehealth. The community currently has access to their new team SharePoint site to facilitate resource sharing and peer learning. They will also be participating in monthly technical assistance calls that cater to grantee needs by providing access to experts and national partners, as well as a forum to discuss successes and best practices with one another.

To learn more about each grantee's work, check out a new article: *Implementing Evidence-Based/Informed Practices: Snapshots from the New Autism Community of Learners* that will be published in AMCHP's upcoming November/December 2016 issue of [PULSE](#): Evidence-Based/Informed Practice.

Collaborators' Corner

New Resource from "Learn the Signs. Act Early." Milestones in Action Photo and Video Library

[Milestones in Action](#) is a **FREE** image library that features photos and videos of children demonstrating developmental milestones from 2 months to 5 years of age. This tool was created to help parents, early care and education providers, and healthcare providers identify developmental milestones in children and know if there is cause for concern.

Benefits:

- Free!
- Shows parents what each milestone looks like
- Appeals to caregivers with limited literacy skills
- Great for showing complex milestones

- No permissions needed to use the photos and images in this library for educational or awareness-building purposes

WAYS TO USE:

Parents and Caregivers

Use this library as an aid in completing the milestones checklist for your child's age. To see these photos and videos with milestones checklists, go to www.cdc.gov/Milestones.

Professionals

- Embed and share photos and videos on your website and within presentations
- Share photos and videos to support information given during trainings
- Use Milestones in Action to support observations and conversations with parents on age-appropriate milestones
- Share photos and videos on social media to build community awareness of developmental milestones.

Please explore the Milestones in Action library at www.cdc.gov/MilestonesInAction.

UC Davis CEDD awarded LTSAE grant

The Center for Excellence in Developmental Disabilities (CEDD) at the UC Davis MIND Institute was awarded a Learn the Signs / Act Early (LTSAE) grant from the Association of Maternal and Child Health Programs (AMCHP) for 2016-2018 to support the dissemination of LTSAE resources designed to increase parent-engaged developmental monitoring. CEDD is partnering with the California Autism Professional Training and Information Network (CAPTAIN), the State LTSAE Ambassadors, the LEND at UC Davis and the LEND at USC in this effort.

Over the last several years CEDD has facilitated the development of the California Autism Professional Training and Information Network (CAPTAIN), a statewide initiative to develop the infrastructure and interagency collaborations to implement a statewide plan for improving services to children and youth with ASD. CEDD staff member Patty Schetter, who is involved in the DBP fellowship and LEND training programs at UC Davis, is the coordinator of the CAPTAIN project, with key support from Patrice Yasuda, the training director of the USC LEND. They work with state agencies to develop strategic plans for

implementation of evidence-based practices and various policy and initiatives related to serving individuals with ASD.

Using a training-of-trainers model in up-to-date evidence-based practices, with ongoing support for implementation, CAPTAIN consists of over 400 members who have been nominated by their respective agencies to bring the training back to the staffs of their agencies. The agencies that have nominated trainers include the Department of Developmental Disabilities, Regional Centers, the Special Education Local Plan Areas (SELPAs), the Family Resource Center Network, and two of the California UCEDDs (USC and UC Davis). For more information, see www.CAPTAIN.ca.gov.

The LTSAE grant is funding the development of regional resource and referral brochures as well as the training of CAPTAIN members and LEND trainees on the LTSAE campaign. LEND trainees will be monitoring the use and impact of the LTSAE resources by CAPTAIN members. Designated CAPTAIN members will continue to work with the LTSAE Ambassadors to become trainer of trainers so that they can further support the campaign across California.

Sibling Leadership Network Update

The Sibling Leadership Network (SLN) receives lots of questions about the Family and Medical Leave Act (FMLA) as it applies to siblings of people with disabilities. To assist siblings in understanding more about FMLA, we compiled responses to some of the most commonly asked questions as a reference.

Click here to view our latest resource –

[Siblings and the Family and Medical Leave Act \(FMLA\): Common Questions](#)

Additionally, the Sibling Leadership Conference has been announced for June 24 - 25, 2017 in Hartford, Connecticut

Who should attend the conference?

- ***Siblings of people with disabilities.*** *The conference is for adults and is welcome to siblings who have a brother or sister with any type of disability.*
- ***People with disabilities.*** *Self-advocates are important to the sibling movement and we encourage people with disabilities to come and share your sibling perspective.*

- **Parents and family members.** Families can learn a lot at this conference and share their perspectives.
- **Professionals.** Professionals, including researchers, can gain a stronger understanding of the sibling relationship and ways to support siblings throughout the lifespan.
- **Sibling supporters.** Anyone who is a friend or colleague to siblings and their families is welcome.

[Click here to download a printer-friendly save-the-date flyer.](#)

Got Transition Releases MOC Module, Announces CME Course, and Launches Advisory Group

Free Pediatric Maintenance of Certification Transition Module Available

The University of California San Diego/Rady Children's Hospital with the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) partnered with Got Transition to develop a new pediatric Maintenance of Certification (MOC) Part 4 Module on transition. The web-based activity – "Transitioning Youth from Pediatric to Adult-Centered Care – will evaluate adequacy of participant documentation of patients' transition from pediatric to adult centered care within the 6 Core Element framework developed by Got Transition: Center for Health Care Transition Improvement. Eligible participants include clinicians who actively evaluate pediatric patients with chronic diseases on a frequent enough basis to report data on 30 patient visits over a year period. This activity will provide MOC Part IV credits to participants who successfully meet completion criteria. To learn more about completion criteria and to register for FREE, email Kim Rose (KRose@naspghan.org) by March 31, 2017 and mention "GotTransition.org/UC San Diego/Rady Children's Hospital."

Earn CME Credits in Transition

Health Services for Children with Special Needs (HSCSN) is offering a [free online one-hour CME course](#) on health care transition. The one-hour CME features the experiences of physicians in busy pediatric, family medicine, and internal medicine practices in the District of Columbia who successfully implemented the Six Core Elements using quality improvement methodologies. The course was developed in collaboration with The National Alliance to Advance Adolescent Health/Got Transition, HSCSN, and the DC Department of Health.

New National Young Adult Transition Advisory Group Formed

Got Transition has created a new National Young Adult Transition Advisory Group to advise the organization on young adult perspectives on health care transition. The advisory group consists of young adults with and without disabilities between the ages of 18-25 that come from diverse geographic locations and ethnic backgrounds. They all represent various state and national health-related organizations around the country. The Young Adult Transition Advisory Group will ensure that young adult consumer perspectives are included in Got Transition's plans moving forward. They will help review tools designed to educate and inform young adults on the importance of health care transition, guide Got Transition's social media platforms to relay important health care transition-related messages and resources to youth and young adults, and bolster Got Transition's partnerships with their organizational affiliates.

Content originally posted in the Got Transition News and Announcements section:
<http://www.gottransition.org/news/index.cfm>

ITAC Items

Autism CARES Grantees Share Resources, Best Practices for Transition

ITAC, in collaboration with [SPHARC](#) and [HRSA-MCHB](#), hosted the Autism CARES (Collaboration, Accountability, Research, Education, and Support) Grantee Virtual Meeting on July 21, 2016. This bi-annual meeting was an opportunity for over 200 MCHB-funded Autism CARES legislation grantees – representing research, training, and state implementation stakeholders – to share information about activities within their respective network, discuss emerging trends, and facilitate meaningful collaboration. This year's theme was "Integrated, Person-Centered Approaches to Transition."

The meeting kicked off with an informative [keynote](#) by Anne Roux, a research scientist at the A.J. Drexel Autism Institute's Life Course Outcomes Research Program and lead author of the award-winning [National Autism Indicators Report series](#). Anne shared data about the transition landscape as we are currently able to quantify across a variety of life domains including connection to others and to services, independent living and employment. She concluded with

a challenge to the present grantees to invest in “building the gauges” that are needed to determine when and how autism interventions “move the needle” on transition outcomes. This presentation was followed by time for participants to view selections from a variety of pre-recorded 5-10 minute grantee presentations showcasing innovative practices in transition services and research. Participants then joined small group discussions facilitated by the grantee presenters to dig deeper into one of eight available topics. The virtual meeting wrapped up with a panel discussion of self-advocates and family members reflecting on the topics discussed.

To capture this information and encourage ongoing collaboration, ITAC created an [online archive](#) of meeting materials including recordings of the presentations (with slides when possible) and an Autism CARES policy update.

ITAC is already working with SPHARC, HRSA-MCHB, and grantee representatives to plan an in-person CARES meeting July 10-11, 2017. Please mark your calendars and contact Sarah DeMaio (sdemaio@aucd.org) for more information. Visit www.aucd.org/itac for updates in the coming months.

Resources for Zika and Developmental Monitoring Available in Public Health is for Everyone

There is an urgent need to educate public health practitioners on developmental monitoring, screening, and early identification of the health complications for infants and children affected by Zika. Babies affected by Zika may experience a spectrum of needs from the most severe cases of microcephaly, to vision problems, hearing loss, seizures, intellectual disabilities, reduced speech and language abilities, and other long-term developmental disabilities. Even though babies affected by Zika may look typical at birth, subtle changes that turn into serious health problems could occur as they become older.

Ongoing developmental monitoring and screenings are necessary to be able to detect these changes. Sensitive language that supports these children and their families is essential. To address this urgent need, AUCD has added a [Zika section to Public Health is for Everyone](#) with resources on supporting families and infants affected by Zika, developmental monitoring, and how to speak sensitively with families about their concerns.

"Learn the Signs. Act Early." Resources Now Available in Vietnamese

The "Learn the Signs. Act Early." Team is pleased to announce the completion of its project to translate and adapt the Milestone checklists, Milestones brochure, and tip sheets (How to Help Your Child & How to Talk to the Doctor) into Vietnamese. These materials were professionally translated and adapted in consultation with a small group of Vietnamese parents of young children and a group of Vietnamese subject matter experts. To access these files for local customization and/or printing, send your request to ActEarly@cdc.gov.

Meetings

2017 AUCD for All Gala: Celebrating Leadership in Employment

March 22, 2017

2017 Disability Policy Seminar

March 20 - 22, 2017

The Renaissance Washington, DC Downtown Hotel

2017 Autism CARES Grantee Meeting

July 10-11, 2017

Bethesda, MD

Article Submissions

To have an item considered for publication in Developments, submit your article and photo using [this online form](#).

The next edition of Developments will be published in April 2017