

# Developments, April 2013

Issue 1, Volume 2

## Contents

Intro.....	3
MCHB Minute.....	3
Training Topics .....	5
Iowa and South Dakota LEND Trainees Participate in ADOS-2 and ADOS-Toddler Workshop .....	5
Act Early New Hampshire! .....	5
The Amazing Brain: Select Topics in Neuroscience and Child Development for the Clinician .....	7
Research Roundup .....	8
The Autism Intervention Research on Behavioral Health (AIR-B 2): Deploying Evidence Based Strategies to the School Setting .....	8
Developmental-Behavioral Pediatrics Research Network Update .....	10
University of Colorado/JFK Partners R40 Grantee Studies Support Program for Families of Children with Autism Spectrum Disorder.....	11
State Stories .....	12
New Jersey's State Autism Implementation Grantee receives Two (2) Awards! .....	12
Collaborators Corner.....	13
Focus on Data: The State Public Health Autism Resource Center .....	13
Easter Seals' Make the First Five Campaign Provides Free On-Line Access to the Ages and Stages Questionnaire .....	14
Collaborating Partners Address Issues Related to Early Hearing Detection and Intervention.....	14
ITAC Items .....	15
AUCD Celebrates April as Autism Awareness Month .....	15
Collaboration.....	15
Training .....	16
Information Dissemination .....	17
Webinars.....	17
Postsecondary Options for Students with ASD: Three Programs and a Parent Perspective .....	17
Targeted Treatments for Autism: From Genes to Pharmacology.....	17
Publications.....	18

Developments Newsletter .....	18
CAAI Infographic .....	18
Additional Resources .....	18
About Autism Spectrum Disorder .....	19
25 Act Early Ambassadors Selected for 2013 .....	19
2013 Ambassadors.....	19
Support Autism Awareness Month by Submitting a Training Strategy to the Training Toolbox.....	20
LEND Accomplishments Under CAAI, 2008-2012 (infographic).....	20
Events.....	20
2013 HRSA/MCHB’s Combating Autism Act Initiative Meeting.....	20
2013 LEND/DBP Directors Meeting .....	20
2013 SPHARC/State Autism Grantees Meeting .....	21
Upcoming Webinars.....	21
Postsecondary Options for Students with ASD: Three Programs and a Parent Perspective .....	21
MCHB/HRSA Autism Awareness Month Activities.....	21
Webinar: Autism Spectrum Disorders: Family Support and Involvement.....	21
Webinar: Expediting Detection of Autism Risk and Intervention Access .....	22
Webinar: Screening, Early Diagnosis, and Early Intervention.....	22
HRSA/MCHB Autism Awareness Booth .....	23
Targeted Treatments for Autism: From Genes to Pharmacology.....	23
About.....	23

## Intro

Developments is a quarterly newsletter for grantees of the Combating Autism Act Initiative (CAAI). 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](#)), this newsletter allows grantees and partners to share current news, activities, events, research, and accomplishments in autism and related developmental disabilities with program faculty, students, and supporters. Sections of the newsletter are regularly devoted to each of the grantee groups (research, states, LEND training and DBP training), as well as MCHB and our collaborating partners.

## MCHB Minute

[http://www.aucd.org/template/news.cfm?news\\_id=8698&id=17](http://www.aucd.org/template/news.cfm?news_id=8698&id=17)

Greetings from MCHB! I hope that Spring has finally arrived where you are.

I have several items I'd like to share with you for this issue of the newsletter, including the release of a HRSA/CDC Report on estimated autism spectrum disorder prevalence, and planned Autism Awareness Month Activities for April.

1. On March 20, 2013, the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC), agencies within the Department of Health and Human Services (HHS), released a report which estimated autism spectrum disorder (ASD) prevalence based on parental reporting using the National Survey of Children's Health (NSCH), a national sample of families across the country. The report, "Changes in Prevalence of Parent-Reported Autism Spectrum Disorder in School-Aged Children: 2007 to 2011-2012" is available at [www.cdc.gov/nchs](http://www.cdc.gov/nchs).

The survey was funded by HRSA and the data collection was conducted by the National Center for Health Statistics (NCHS) of CDC. The data come from the National Survey of Children's Health, a nationally-representative phone survey of households with children. This survey is conducted every four years. This new report from a survey of parents helps us understand what parents are experiencing.

Main findings of the report:

- The prevalence of parent-reported ASD among children aged 6-17 years was 2 percent in 2011-2012 compared to 1.2 percent in 2007.
- The change in prevalence estimates was greatest for boys and for adolescents aged 14 to 17 years.
- Much of the increase in the prevalence estimates from 2007 to 2011-2012 for school-aged children was the result of diagnoses of children with previously unrecognized ASD.

2. Thank you to our grantees and also to Dr. Robin Harwood and Deidre Washington-Jones for their efforts to organize three engaging webinars for Autism Awareness Month. Please be sure to tune in for the live events or archived webinars if you are not available at the scheduled times. [HRSA/MCHB](#) will be hosting the webinars on April 4th, 8th, and 24th. The webinars feature the work of MCH CAAI State, Training and Research Grantees.

Mark your calendars for the events! You can register for the webinars using the links below.

- Webinar: **Autism Spectrum Disorders: Family Support and Involvement**  
When: Thurs, April 4, 12:30-1:30 EDT  
[Register](#)
- Webinar: **Expediting Detection of Autism Risk and Intervention Access**  
When: Mon, April 8, 1-2 pm EDT  
[Register](#)
- Webinar: **Screening, Early Diagnosis, and Early Intervention**  
When: Wed, April 24, 2-3 pm EDT  
[Register](#)

I look forward to seeing the Developmental-Behavioral Pediatrics grantees this week in Connecticut and all CAAI grantees in May.

**Laura**

**Director, MCH Workforce Development**

**Maternal and Child Health Bureau**

## Training Topics

### Iowa and South Dakota LEND Trainees Participate in ADOS-2 and ADOS-Toddler Workshop

[http://www.aucd.org/template/news.cfm?news\\_id=8686&id=17](http://www.aucd.org/template/news.cfm?news_id=8686&id=17)

Dire weather predictions and five inches of snow in mid-February proved to be no match for a group of hardy professionals and students from Iowa, South Dakota, and Minnesota.

[Dr. Amy Esler](#), Assistant Professor of Pediatrics from the University of Minnesota, conducted an ADOS-2 and ADOS-Toddler workshop on February 21-23, 2013 for approximately 38 individuals including University of Iowa faculty/staff and graduate students, professionals from the community and LEND faculty/staff and trainees from Iowa and South Dakota. The three-day workshop was held at the UI Center for Disabilities and Development (CDD), and was a collaborative effort between the Iowa LEND program and the CDD.

The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) improves an instrument already viewed as "the gold standard" for observational assessment of autism spectrum disorders (ASD). The Autism Diagnostic Observation Schedule, Second Edition, Toddler Module (ADOS-T) is a new module of the ADOS-2 for use with children between the ages of 12 and 30 months who have minimal spoken language.

Dr. Esler provided descriptions of the test instruments and demonstrated administration, scoring, and operationalizing diagnostic criteria for ASD. Participants had numerous opportunities to practice scoring while watching Dr. Esler administer the ADOS-2 to two children with autism, and while watching video footage of several children who participated in testing. During group discussions, attendees shared their observations of behavior and language and received feedback from Dr. Esler on interpretations and coding.

### Act Early New Hampshire!

[http://www.aucd.org/template/news.cfm?news\\_id=8690&id=17](http://www.aucd.org/template/news.cfm?news_id=8690&id=17)

The New Hampshire LEND faculty and former trainees have provided ongoing leadership to coordinate a number of Act Early initiatives within the state in collaboration with NH's Title V program for CSHCN (Special Medical Services), the Association of Maternal and Child Health Professionals (AMCHP), the NH Council on Autism Spectrum Disorders, and other key stakeholders.

NH LEND had a key role in organizing NH's Act Early Team beginning in 2010. Initial activities included statewide distribution of Act Early materials, the development of a "road map" to guide families in the next steps following a developmental screening, and collaboration with Watch Me Grow, NH's statewide system for early developmental screening. The Act Early Team's activities were directly aligned with the work of the NH Council on ASD's Screening and Diagnosis workgroup. In December 2011, this workgroup assumed the responsibilities of the Act Early Team under the leadership of Director of Special Medical Services for CSHCN, Elizabeth Collins, RN-BC, MS, (LEND 2005).

Based on the identified need for more collaboration among providers, Collins spearheaded an AMCHP Act Early State Systems Grant in 2012. Act Early Ambassador and NH LEND Faculty, Rae Sonnenmeier,

Ph.D. (LEND 1997), NH LEND Training Director, Betsy Humphreys, Ph.D. (LEND 1995), and the Act Early Team collaborated to host two Open Forums on the topic of early developmental screening with primary care providers, early childhood programs, and families. Approximately 75 participants learned about early developmental screening efforts in the state, including the use of the *Ages and Stages Questionnaires* (ASQ-3, ASQ-SE) and the M-CHAT in primary care settings. Additionally, the AMCHP grant supported integration of information about early development as part of the NH Council on ASD's "virtual resource center" (<http://www.nhvirtualautismcenter.info/>) coordinated by Kirsten Murphy, Administrative Director of the NH Council on ASD (LEND 2010).

A second AMCHP Act Early State Systems Grant was recently awarded for 2013. LEND Faculty, Rae Sonnenmeier, Ph.D. and Jenn Pineo (LEND 2012) are collaborating with New Hampshire's Women Infants and Children (WIC), Food and Nutrition Services program to integrate Act Early messaging into one regional WIC office and coordinate with the local Watch Me Grow site to support a seamless point of contact within the region. This effort will support educating families about early developmental screening, based on the work of Janet Farmer and colleagues who partnered with WIC in St. Louis.

Jen Doris, M.Ed. (LEND 2010) was recently named as the second NH Act Early Ambassador (2013-2014), taking the reins from Rae Sonnenmeier, who served in this role in 2012. To date, Act Early Ambassador activities in New Hampshire have included coordinated efforts to integrate Act Early messaging into NH's statewide developmental screening system, known as Watch Me Grow. Efforts are underway to blend Act Early graphics into the Watch Me Grow brochure and website. Collaboration and communication strategies with primary care providers, including family medicine, will be a focus in the coming year.

To learn more about New Hampshire's collaborating partners please visit:

New Hampshire Title V Program for Children with Special Health Care Needs  
at <http://www.dhhs.nh.gov/dcbcs/bds/sms/>

The New Hampshire LEND Program at <http://www.mchlend.unh.edu/>

The New Hampshire Council on Autism Spectrum Disorders at <http://www.nhcouncilonasd.org/>

### **Systems Change for ASD/DD Initiatives in Washington State**

[http://www.aucd.org/template/news.cfm?news\\_id=8715&id=17](http://www.aucd.org/template/news.cfm?news_id=8715&id=17)

In 2008, Washington State DOH/CSHCN and UW LEND received one of the first rounds of grants under the Combating Autism Act 2006 and formed the Combating Autism Advisory Council to guide effective systems change for ASD/DD initiatives in Washington State. The Council is in its fourth year and has been renamed the Washington Autism Advisory Council (WAAC). Council membership is comprised of individuals and advocates from state and local agencies, diagnostic centers including UW LEND, family members, and self-advocates and other interested individuals.

WAAC members collaborated with the newly formed Washington State Health Care Authority (HCA) to develop and launch new Medicaid benefits for children with autism. Medicaid began offering coverage for Applied Behavior Analysis (ABA) therapy in January 2013 for children who had a confirmed diagnosis of autism and a treatment plan. HCA designated The UW LEND program as one of the regional Centers of Excellence for the diagnosis and to establish the need for ABA therapy. The UW LEND clinicians and trainees routinely perform interdisciplinary team evaluations, have experience in confirming autism diagnoses, and make treatment plans for all children including children covered by Medicaid. The initial collaborations between WA State Department Of Health/Children with Special Health Care Needs and UW LEND culminated in systems change for children with ASD/DD.

**The Amazing Brain: Select Topics in Neuroscience and Child Development for the Clinician**  
[http://www.aucd.org/template/event.cfm?event\\_id=3732](http://www.aucd.org/template/event.cfm?event_id=3732)

*This webinar series is being jointly sponsored with the [Yale School of Medicine, Section of Developmental-Behavioral Pediatrics](#).*

**About the webinar series:**

The purpose of this webinar series is to introduce clinicians to exciting developments in neuroscience that provides complex and new understanding of developmental and behavioral disorders in children. Participants will gain a greater understanding of the structure and functioning of areas of the brain, novel ways to study the brain and emerging treatments. Renowned speakers from Yale School of Medicine who are conducting innovative neuroscience and translational research will lead these discussions. All clinicians who care for children with developmental and behavioral disorders will benefit from participating in this exciting series, "The Amazing Brain."

CME/CEUs will be available. [Click here](#) to learn more.

**Part I - Targeted Treatments for Autism: From Genes to Pharmacology**

April 23, 12-1 pm ET

Speaker: Paul Wang, MD

*To learn more and register, [click here!](#)*

**Part II - The Neurobiology of ADHD and Related Disorders**

April 30, 12-1 pm ET

Speaker: Amy F.T. Arnsten, MD

*To learn more and register, [click here!](#)*

**Part III - Shedding Light on the Brain: Optical Tools for Studying Synaptic Transmission**

May 7, 12-1 pm ET

Speaker: Michael J. Higley, MD

*To learn more and register, [click here!](#)*

## Part IV - Nicotine and Cortical Development

May 14, 12-1 pm ET

Speaker: Marina Picciotto, MD

To learn more and register, [click here!](#)

Want to attend the entire "Amazing Brain" series? [Click here](#) to register for all four webinars!

## Research Roundup

### The Autism Intervention Research on Behavioral Health (AIR-B 2): Deploying Evidence Based Strategies to the School Setting

[http://www.aucd.org/template/news.cfm?news\\_id=8691&id=17](http://www.aucd.org/template/news.cfm?news_id=8691&id=17)

The Autism Intervention Research on Behavioral Health (AIR-B 2) designed a three-year study to examine the implementation of proven-efficacious interventions for students with ASD in under-resourced schools. The AIR-B 2 team of principal investigators includes Connie Kasari, Ph.D., at the University of California, Los Angeles, David Mandell, Sc.D., at the University of Pennsylvania, and Tristram Smith, Ph.D., at the University of Rochester. The first study year was devoted to improving our understanding of how public schools currently serve students with autism and to developing community partnerships with the school districts and community stakeholders at each of the three sites. The second and third year of the study evaluate the deployment of evidence-based practices into schools.

In order to elucidate the strengths and challenges that school personnel and parents of students with ASD face, the AIR-B 2 team conducted focus groups with parents, paraprofessionals, and general and special education teachers of students with ASD. We also interviewed related service providers and school and district administrators about their experiences. Based on preliminary analysis of these findings and discussions with stakeholders during community partnership meetings, the AIR-B 2 team identified two priorities for intervention: (1) increasing social engagement among students with ASD who are included in general education settings for most of the school day and (2) improving behavior during transitions among students with ASD in special education classrooms.

To address these priorities, we adapted and are implementing two interventions: Remaking Recess, which teaches school staff specific strategies to increase the quality and quantity of peer engagement during social times for children with ASD, and Schedules, Tools, and Activities for Transitions (STAT), which teaches classroom staff how to facilitate efficient, successful transitions between activities throughout the daily routine.

In Remaking Recess, coaches collaborate with playground assistants on strategies to engage children during recess in 14-16 sessions over 8 weeks. The strategies in the intervention are designed to be helpful not only for children with ASD but also for their peers. For example, one key strategy is providing developmentally and school appropriate conversational supports in the cafeteria in the form of fun "social menus" made available to all students by the lunchroom staff. Another important element

is teaching staff how to interpret a child's level of peer engagement and then empowering them to provide individualized and group level support as needed. Primary outcome measures in this arm of the study include direct observations of peer engagement using the Playground Observation of Peer Engagement (POPE) and a classroom survey of friendships from which a social network can be calculated and friendship reciprocity can be examined. Both measures have captured positive change in playground peer engagement and social network status in previous intervention studies, particularly Kasari, et al. (2012).

In STAT, coaches work with classroom staff during ongoing school activities for 30-45 minutes at a time, with 12-16 visits over a 6-10 week period. Coaches and staff collaboratively identify which transitions (and which steps within a transition) are most challenging for the students with ASD in the classroom, and they select strategies to overcome these challenges. For example, they might determine that students have particular difficulty going from their primary classroom to specials (music, art, and physical education) and that the beginning of the transition (putting away materials and lining up) is especially time-consuming and stressful. Potential solutions may include providing a clear and consistent warning that the transition is about to occur, choosing a signal that reliably gains the students' attention, and presenting a visual schedule that shows what the students are expected to do during the transition. Primary outcomes for this intervention include direct observations of engagement in classroom-based activities and rating scales of school-related adaptive functioning.

Our deployment strategy relies on a coaching and consultation model to train school personnel working with children with ASD during the school day. We are measuring student outcomes (social and classroom engagement), as well as school personnel implementation and uptake of evidence-based strategies learned during intervention. The overall goal is to determine the feasibility and sustainability of the practices in underserved and under resourced school settings.

Using a randomized wait-list control trial design, schools and classrooms were assigned to immediate treatment or waitlist conditions. We now are training teachers in the treatment arm. Ultimately, our goal is to learn not just whether these interventions are effective in public schools, but the best ways to work with classroom staff to ensure their effectiveness and sustainability once the research study ends.

## Reference

Kasari, C., Rotheram-Fuller, E., Locke, J., & Gulsrud, A. (2012). Making the connection: Randomized controlled trial of social skills at school for children with autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, 53(4), 431-439. doi:<http://dx.doi.org/10.1111/j.1469-7610.2011.02493.x>

AIR-B team includes Connie Kasari, Nancy Huynh, Mark Kretzmann, and Michelle Dean at UCLA; David Mandell, Jill Locke, and Erica Reisinger at University of Pennsylvania; Tristram Smith, Christopher Clinton, Susan A. Hetherington, Suzannah Iadarola, and José Pérez-Ramos at the University of Rochester

and the Partnership of Stakeholders in the Los Angeles Unified School District, Rochester City School District and School District of Philadelphia.

### **Developmental-Behavioral Pediatrics Research Network Update**

[http://www.aucd.org/template/news.cfm?news\\_id=8702&id=17](http://www.aucd.org/template/news.cfm?news_id=8702&id=17)

The Developmental-Behavioral Pediatrics Research Network (DBPNet) was formed in September 2010 when initial infrastructure funding was obtained from the Maternal Child Health Bureau. DBPNet is a collaboration between 12 academic developmental-behavioral pediatrics programs and the Society for Developmental-Behavioral Pediatrics (SDBP). The mission of DBPNet is, "to conduct collaborative, interdisciplinary research in developmental-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 first study conducted by DBPNet surveyed a sample of developmental-behavioral pediatricians, psychologists, and parents of children with disabilities utilizing the Delphi procedure to identify important clinical research questions for the field of developmental-behavioral pediatrics. This study, published in the July/August 2012 issue of the Journal of Developmental-Behavioral Pediatrics (JDBP) identified 39 consensus important questions including research questions related to risk factors, assessment of DBP conditions, practice variation, outcome assessment, and efficacy or effectiveness research.

A second DBPNet study identified components of research training in developmental-behavioral pediatrics fellowship programs and some outcomes of this research training. This study was presented at the 2012 SDBP Annual Meeting and found that the scholarly work of DBP fellows focuses primarily on observational/epidemiological research, secondary data analysis, community-based research, and survey design. The study highlighted barriers to research training including faculty time and expertise for research mentoring as well as inadequate funding in programs that have high clinical demands and little resources for research efforts. Ongoing DBPNet studies include a study of practice variation in the assessment and treatment of ADHD and autism by developmental-behavioral pediatricians, a study of referral concerns addressed by developmental-behavioral pediatricians, and a study of the use of psychotropic medications using data captured from electronic health records.

During the past year DBPNet has also offered two awards. The DBPNet Young Investigator Award was received by Kathleen Angkustsiri, M.D. from the University of California at Davis M.I.N.D. Institute for her study, ***Maternal Immune Status and Autism Severity***, which will be conducted at 3 DBPNet sites. In addition the Network provided an Experienced Investigator Award to Emily Feinberg, ScD CPNP at Boston University for her proposal to develop a grant application for her study, ***Family Navigation to Reduce Disparities in Timely Autism Diagnosis and Access to Early Intervention***.

Individuals interested in learning more about DBPNet can visit the website at [www.DBPNet.org](http://www.DBPNet.org) or contact Nathan Blum, M.D. ([blum@email.chop.edu](mailto:blum@email.chop.edu)) or Amy Gahman, B.A. ([gahmana@email.chop.edu](mailto:gahmana@email.chop.edu)) at the Network Coordinating Center at The Children's Hospital of Philadelphia.

### **University of Colorado/JFK Partners R40 Grantee Studies Support Program for Families of Children with Autism Spectrum Disorder**

[http://www.aucd.org/template/news.cfm?news\\_id=8704&id=17](http://www.aucd.org/template/news.cfm?news_id=8704&id=17)

The growing prevalence of autism spectrum disorders (ASD; Centers for Disease Control and Prevention) has left many families in a position where they must decide how best to support their child's needs. Unfortunately, clinicians are rarely available to support families in acting on recommendations from diagnostic reports ([Banach, Iudice, Conway, & Couse, 2010](#)). As a result, most families are left to coordinate services for their children on their own (Autism Treatment Network, 2009). This, combined with the other barriers to treatment ([Minnes & Steiner, 2009](#); [Summers et al., 2007](#)) may put all family members at risk for mental health problems ([Estes et al., 2009](#); [Gabriels, Hill, Pierce, Rogers, & Wehner, 2001](#)). This has led to a tremendous need for interventions that will help families understand and access the existing systems of care. Parent-to-Parent (P2P) mentoring programs ([Santelli, Turnbull, Marquis, & Lerner, 1995](#)) are one strategy for accomplishing this; however, few programs have developed systematic curricula and rigorously evaluated their effects. University of Colorado/JFK Partners (Colorado LEND/UCEDD) funded by the Maternal and Child Health Bureau (MCHB) at the Health Resources and Services Administration has developed a support program for families that have recently received a diagnosis of autism spectrum disorder for their child.

The Colorado Parent Mentoring Program (CPM) provides two sources of support: 1) parent training and education, and 2) a parent-to-parent mentoring program. These two sources of support are focused on the first year immediately after diagnosis. Parent mentors are trained in a two-day program and paired with mentees. For mentees, study staff provide individualized education and assistance in thinking critically about intervention and support, access to care, and develop individualized *Action Plans*, a comprehensive strategy for determining the child's treatment-needs, plan to access care, strategies for school collaboration and family care. Following the initial meeting, Mentors continue to support the family for 6 months.

Currently in year two of the three-year grant cycle, the program is being evaluated with a randomized clinical trial. Quality of life, sense of competence, parenting stress, and time to treatment are measured pre and post intervention. Preliminary results show mentors report greater confidence and competence as a result of the training. All mentees reported feeling more prepared to manage their child's condition as a result of the navigation training and action planning. Data on the mentoring experience is still being collected but initial feedback is promising. Preliminary reports suggest an increased sense of empowerment, decreased isolation and better quality of life. The study team plans to manualize the program and work with rural community partners locally and nationally to implement sustainable

aspects of the model in the final year of the grant. The use of videoconferencing technology and on-line education and training are planned to support families in areas of the country that are underserved and in need of effective and economic ways to connect with resources and support.

## State Stories

### New Jersey's State Autism Implementation Grantee Receives Two (2) Awards!

[http://www.aucd.org/template/news.cfm?news\\_id=8688&id=17](http://www.aucd.org/template/news.cfm?news_id=8688&id=17)

The Statewide Parent Advocacy Network (SPAN) which is based in New Jersey has been named as the recipient of a ***Project Oasis Neighborhood Development Corporation 2013 Community Outreach Award***. SPAN was selected based upon a record of providing local support to parents/families, in recognition of its statewide contributions and due to accomplishments which have made a difference and impacted the lives of the community served by the *Montclair* Neighborhood Development Corporation.

The award will be presented on June 9, 2013 at the 17<sup>th</sup> Annual Project OASIS Dinner in New Jersey.

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New Jersey was also selected to receive: ***The Council on Developmental Disabilities Distinguished DD Systems Change Community Building Award***

The Statewide Parent Advocacy Network's (SPAN) Military Family 360 Support Project has been selected to receive the ***NJ Council on Developmental Disabilities' 2013 Distinguished DD Systems Change Community Building Award***. The Military Family 360 Support Project, initially funded by the US Department of Health and Human Services Administration on Intellectual and Developmental Disabilities and now supported by SPAN's Parent Training and Information Center project, provides intensive, one-on-one wrap-around, cross-systems advocacy and support for military families of children and youth with Autism Spectrum Disorders and other Developmental Disorders.

The Military Family 360 Support Project which is housed on the Joint Base in central New Jersey, trained parent navigators and provided leadership development for military families. The Distinguished DD Systems Change Award honors an individual or organization that has made outstanding contributions toward real systems change and positive outcomes for individuals with DD and their families.

The award will be presented on April 24, 2013 at the NJ Council on Developmental Disabilities' Annual Awards Luncheon.

## Collaborators Corner

### Focus on Data: The State Public Health Autism Resource Center

[http://www.aucd.org/template/news.cfm?news\\_id=8695&id=17](http://www.aucd.org/template/news.cfm?news_id=8695&id=17)

AMCHP's mission is to support state maternal and child health programs by providing national leadership on issues affecting woman and children. In support of this mission, the State Public Health Autism Resource Center (SPHARC) ushered in 2013 with a vast array of presentations, webinars and technical assistance programs designed to aid and assist ASD/DD grantees.

#### **Preparing ASD/DD Grantees to Address Emerging MCH Data Issues:**

On January 16, 2013, SPHARC sponsored a teleconference entitled: "Let's talk about Data!" The teleconference was designed to engage ASD/DD Grantees in a collaborative learning exploration session examining data and its use in grantee programs. Grantees discussed financing program evaluators, grant funding streams, whether their grant program was connected with a LEND program, state affiliate and /or a private consultant. ASD/DD Grantees also explored the type of data they were collecting, various methodologies of collection and the use of practice level data from state programs. The "Let's talk about Data" teleconference aligned with one of SPHARC's technical assistance goals, which is to aid, assist and inform grantees in identifying, collecting and evaluating data, so that ASD/DD grantees may increase their capacity to assess the impact of their pilots, programs and projects on systems of care for children with ASD/DD.

#### **Building Capacity through Information Dissemination & Leadership Development:**

AMCHP's State Public Health Autism Resource Center (SPHARC) featured a lively presentation at the 2013 AMCHP Annual Conference. On February 11, 2013, Three Autism Grantees presented: The Role of Data in Building, Implementing and Evaluating Systems of Care for Children and Youth with ASD/DD; State Autism grantees who have used data in the planning, implementation, and evaluation of systems of care. The 75 minute session was moderated by HRSA's Deidre Washington-Jones and featured the states of Maryland, Maine and Utah. Meredith Pyle discussed Maryland's "needs assessment process" as a model of how to use data early in the process. Nancy Cronin discussed how the state of Maine has utilized data in building systems of care, and Judith Holt from Utah, discussed the use of data in program evaluation.

#### **Enhancing MCH Skill/Competency Development: Engaging Audiences through Social Media:**

In response to growing demand for information, on March 27, 2013, SPHARC sponsored a webinar

entitled: "Social Media 101." The webinar was taught by an interdisciplinary team consisting of an On-line Media & Information Technology Manager, an Associate Director of a UCEDD, an ASD Grantee Co-Director/ Parent of a CYSHCN and an AMCHP Family Scholar. Julio Arguello, Jr., AMCHP's Online Media & Information Technology Program Manager began the interactive webinar by defining Social Media for participants and reviewing basic Facebook and Twitter terminology. Arguello then provided a virtual "hands on" opportunity for participants to learn (1) how to create profiles on Facebook, (2) how to create profiles on Twitter and (3) how to post content to Facebook and Twitter. Other featured presenters included: SPHARC ASD Grantee from Connecticut; Ann Gionet and Tierney Giannotti, who shared their Facebook page and discussed how their program has used social media to reach the local and worldwide community on ASD/DD issues, and AMCHP Family Scholar, Randi Cites, who discussed using Twitter to communicate.

### **Easter Seals' Make the First Five Count Campaign Provides Free On-Line Access to the Ages and Stages Questionnaire (ASQ)®**

[http://www.aucd.org/template/news.cfm?news\\_id=8692&id=17](http://www.aucd.org/template/news.cfm?news_id=8692&id=17)

[Easter Seals](#), through the generous support of the [CVS Caremark Charitable Trust](#), is now making it possible for parents and caregivers to track their children's development through age 5 through on-line completion of the Ages and Stages Questionnaire (ASQ)®. Traditionally used by clinicians, therapists, professionals, and educators, Brookes Publishing's ASQ® is now available to parents and caregivers on Easter Seals' *Make the First Five Count* [website](#). The ASQ® helps monitor child development and identify potential issues so that any concerns can be readily addressed to make sure children are on track and ready to enter school. To learn more about *Make the First Five Count*, click [here](#).

### **Collaborating Partners Address Issues Related to Early Hearing Detection and Intervention**

[http://www.aucd.org/template/news.cfm?news\\_id=8703&id=17](http://www.aucd.org/template/news.cfm?news_id=8703&id=17)

Universal newborn hearing screen and technological advances have provided children with hearing loss with the opportunity to achieve outcomes comparable to their typically developing peers. Unfortunately, children with hearing loss born into poverty do not always have access to these opportunities and therefore do not always experience the same level of success. This is just one of the many critical issues to be addressed during the 2013 Early Hearing Detection and Intervention (EHDI) Annual Meeting in Glendale, Arizona (April 14-16, 2013) co-sponsored by the National Center for Hearing Association & Management at Utah State University (NCHAM), HRSA, CDC and AAP. Additional topics for this year's meeting include: early intervention; medical home; follow-up, tracking and data management; workforce issues and program evaluation /quality improvement.

As in past years, the 2013 EHDI conference will provide a unique forum for families and the audiology and speech language community to identify areas of concern, to promote collaboration and to share best practices. To complement these goals, AUCD has partnered with the Maternal and Child Health Bureau (MCHB) to organize a pre-EHDI LEND workshop. This two-hour workshop will engage over 40 LEND faculty and students in a team-based learning format which will include pre-workshop reading materials, a readiness assurance test and small group, case-based discussions. Through this active

learning strategy, participants will partner with other LEND students and faculty to apply key concepts in pediatric audiology to scenarios of early hearing detection and intervention. Organization of this workshop would not have been possible without the generous support of AUCD's collaborating partner, NCHAM and a small group of dedicated planning committee members: Irene Forsman (MCHB); Robyn Schulhof (MCHB); Lisa Mancl (LEND-WA); Robert Fifer (LEND-FL); Diane Sabo (LEND-PA), Anne Harris (LEND-WI) and Jackson Roush (LEND-NC). For more information on the LEND pre-EHDI workshop program or for information on any LEND pediatric audiology activity, please contact Meaghan McHugh at AUCD ([mmchugh@aucd.org](mailto:mmchugh@aucd.org)).

## ITAC Items

### AUCD Celebrates April as Autism Awareness Month

[http://www.aucd.org/template/news.cfm?news\\_id=8665&id=17](http://www.aucd.org/template/news.cfm?news_id=8665&id=17)

On December 18, 2007, the UN General Assembly designated April 2 as World Autism Awareness Day, which was first observed in 2008. This UN resolution is one of only three official disease-specific United Nations Days that brings world attention to autism spectrum disorder, a developmental disorder that affects as many as 1 in 50 children, according to new estimates from the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA). In this spirit, the entire month of April is recognized as National Autism Awareness Month<sup>1</sup>.

AUCD joins the autism community in celebrating this month focused on raising awareness of the needs of families and individuals affected by autism and the research and training that is underway to address those needs. Although significant progress has been made over the past few years, a great deal more needs to be done in developing appropriate services and supports for children, adolescents and adults on the autism spectrum and their families.

AUCD and our national networks are taking action by providing cutting edge information, news, events and resources. AUCD's network of nonprofit university-based interdisciplinary centers which include 67 UCEDDs, 43 LENDs and 15 IDDRCs, work in every state and territory to advance policy and practice for people living with disabilities and their families. Below, are just a few highlights from AUCD's current autism-related activities in diagnosis, treatment, supports, professional training, research and education.

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## Collaboration

AUCD collaborates with federal and state agencies, university centers, and other nonprofit organizations to promote the health, education and well-being of individuals with autism and other developmental

disabilities, their families and their communities. These collaborations help advance policies and practices at the local, state and national level.

### ***"Learn the Signs. Act Early."***

AUCD collaborates with the Centers for Disease Control and Prevention ([CDC](#)), the Health Resources and Services Administration ([HRSA](#)) and the Association of Maternal and Child Health Programs ([AMCHP](#)) on the "[Learn the Signs. Act Early.](#)" program. The program aims to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need. The "Learn the Signs. Act Early." program also serves as the foundation for the *Act Early Network*, a collaborative initiative that supports work being done across the country to improve early identification. The *Act Early Network* is comprised of three parts: 1) Act Early Forum, an email discussion forum and webinar series; 2) Act Early Ambassadors, early identification champions in 25 states; and 3) Act Early State Systems Projects, 10 funded projects for improving early identification. Visit [www.aucd.org/actearly](http://www.aucd.org/actearly) to learn more.

### ***SPHARC***

AUCD works closely with the Association of Maternal and Child Health Programs' ([AMCHP](#)) State Public Health Autism Resource Center ([SPHARC](#)). The purpose of this center is to develop a strategy for defining, supporting, and monitoring the role of state Public Health agencies in assuring that children and youth with ASD and other developmental disabilities receive early and timely identification, diagnosis, and intervention.

### ***CAAI Network***

AUCD partners with HRSA to help support three sets of grantees funded under the [MCHB Combating Autism Act Initiative \(CAAI\)](#): training grantees including Leadership Education in Neurodevelopmental Disabilities (LEND) programs and Leadership Education in Developmental-Behavioral Pediatrics (DBP) programs; research grantees and state implementation grantees. These programs help achieve the CAAI goal of enabling all infants, children and adolescents who have or are at risk for developing autism spectrum disorder (ASD) and other developmental disabilities (DD) to reach their full potential by: 1) developing a system of services that includes screening children for early possible ASD and other DD; 2) conducting early, interdisciplinary evaluations to confirm or rule out ASD and other DD; and 3) providing evidence-based, early interventions when a diagnosis is confirmed.

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## **Training**

The purpose of the [Interdisciplinary Technical Assistance Center \(ITAC\)](#) on Autism and Developmental Disabilities at AUCD is to improve the health of infants, children, and adolescents who have, or are at risk for developing, ASDs and other developmental disabilities. ITAC provides technical assistance to LENDs and Developmental-Behavioral Pediatrics (DBP) training programs funded by the Maternal and Child Health Bureau 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.

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## Information Dissemination

AUCD and its network of nonprofit university-based interdisciplinary centers work in every state and territory to advance policy and practice for people living with disabilities and their families. AUCD, our national networks and partners regularly collaborate to disseminate cutting edge news, materials and publications, events and resources.

## Webinars

### Postsecondary Options for Students with ASD: Three Programs and a Parent Perspective

- April 15, 2:30-3:30 pm ET

Presentations will include an overview of three programs and a parent perspective. Cathryn Weir, M.Ed., will discuss how Think College works with programs for students with autism who are not likely to matriculate, how they work with programs around the country, and resources they have available. Barbara Becker-Cottrill, Ed.D., and Marc Ellision, Ed.D., will provide details on how The College Program for Students with Asperger's Syndrome at Marshall University supports students in the program, including strategies for working with professors, residence advisors and others involved in the life of the student; details will also be provided about a summer college experience for high school students. Cathy Pratt, Ph.D., BCBA-D, will share information about Students on the Spectrum at Indiana University, a student-directed club facilitated by the Indiana Resource Center for Autism. The club provides social, support and informational opportunities and has covered topics such as effective self-advocacy, dealing with anxiety, communication and social skills, and finding supports and activities on campus and in the community. Scott Badesch, M.A., will discuss what a parent needs to know and do to help their child succeed when they are living with autism.

### Targeted Treatments for Autism: From Genes to Pharmacology

This webinar is part of [The Amazing Brain webinar series](#).

April 23, from 12-1 pm ET

The presenter will discuss translational research related to targeted drug development for core symptoms of autism based on the emerging understanding of autism neuroscience, explain the "targeted treatment" approach to drug development for autism, discuss the synapse as a convergence

point for multiple genes associated with autism, and describe the challenges to demonstrating treatment efficacy on the core symptoms of autism.

*Upcoming and past webinars on autism spectrum disorders and other topics are housed in the [AUCD Webinar Library](#). All of our archived webinars are free and open to the general public.*

## Publications

### Developments Newsletter

[Developments](#) is a quarterly newsletter for grantees of the Combating Autism Act Initiative (CAAI). 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), this newsletter allows grantees and partners to share current news, activities, events, research, and accomplishments in autism and related developmental disabilities with program faculty, students, and supporters. Sections of the newsletter are regularly devoted to each of the grantee groups (research, states, LEND training and DBP training), as well as MCHB and our collaborating partners.

### CAAI Infographic

The Combating Autism Act Initiative (CAAI) was created by the Maternal Child Health Bureau in 2008 to promote early screening, diagnostic evaluation, and intervention for children with autism spectrum disorders and other developmental disabilities through training, awareness building, research, and systems development. This [infographic](#) shows data highlighting some of the accomplishments from LEND Programs under CAAI since 2008.

## Additional Resources

- [CDC's Autism Resource Center](#)
  - [CDC's "Learn the Signs. Act Early." program](#)
  - [CDC's Autism Case Training: A Developmental-Behavioral Pediatrics Curriculum](#)
  - [HRSA's Maternal and Child Health Training Program](#)
  - [Combating Autism and Other Developmental Disabilities \(HRSA\)](#)
  - [Eunice Kennedy Shiver National Institute of Child Health and Human Development](#)
  - [Interagency Autism Coordinating Committee](#)
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## About Autism Spectrum Disorder

Autism is a complex developmental disability that typically appears during the first three years of life and affects a person's ability to communicate and interact with others. Autism is defined by a certain set of behaviors and is a "spectrum disorder" that affects individuals differently and to varying degrees. There is no known single cause for autism, but increased awareness and funding can help families today. For more information about autism and early warning signs, see [CDC's Autism Information Center](#) and "[Learn the Signs. Act Early.](#)" program.

## 25 Act Early Ambassadors Selected for 2013

[http://www.aucd.org/template/news.cfm?news\\_id=8643&parent=16&parent\\_title=Home&url=/template/index.cfm?](http://www.aucd.org/template/news.cfm?news_id=8643&parent=16&parent_title=Home&url=/template/index.cfm?)

The [National Center on Birth Defects and Developmental Disabilities](#) at the [Centers for Disease Control and Prevention](#), the [Maternal and Child Health Bureau](#) at the [Health Resources and Services Administration](#), the [Association of University Centers on Disabilities](#), and the [Association of Maternal and Child Health Programs](#) have announced that 25 new Act Early Ambassadors have been selected as liaisons to the "Learn the Signs. Act Early." program.

Act Early Ambassadors will work as community champions with programs that serve young children and their parents, such as Head Start and Early Head Start, WIC, home visiting, and others, and health care and child care professionals to improve early identification of developmental delay and collaborate with state agencies and campaign partners to improve policy and programs for early identification. Twelve of the Ambassadors are also actively involved with a [MCHB/HRSA-funded LEND program](#).

Learn more about the Act Early Ambassadors project and read biographies of each Ambassador [here](#).

## 2013 Ambassadors

- Alabama: Anna McConnell
- Arizona: Ann Mastergeorge
- Arkansas: Peggy Shaefer Whitby
- Colorado: Debra Efird
- Connecticut: Tierney Giannotti
- Hawaii: JoAnn Yuen
- Illinois: Tracy McKinney
- Indiana: Stephan Viehweg
- Kansas: Louann Rinner
- Kentucky: Scott Tomchek
- Louisiana: Maria Blanco
- Maine: Nancy Cronin
- Massachusetts: Elaine Gabovitch
- Montana: Ann Garfinkle
- New Hampshire: Jennifer Doris
- North Carolina: Rebecca Edmondson Pretzel

- Ohio: Shana Kralovic
- Oklahoma: Bonnie McBride
- South Carolina: Jane Witowski
- Tennessee: Toni Whitaker
- Texas: Pauline Filipek
- Utah: Tracy Golden
- Vermont: Janet Kilburn
- Virginia: Deana McGuire Buck
- Wisconsin: Gail Chodron

### **Support Autism Awareness Month by Submitting a Training Strategy to the Training Toolbox**

[http://www.aucd.org/template/news.cfm?news\\_id=8689&id=17](http://www.aucd.org/template/news.cfm?news_id=8689&id=17)

With estimates of 1 in 50 children identified as being on the autism spectrum, now is a perfect time to submit an innovative training strategy to help those working with individuals with autism spectrum disorders reach their full potential. Take a moment to think about what you do in your program that may be new or time-tested that helps individuals with autism spectrum disorders. [Browse](#) what others have submitted to the toolbox and [submit](#) your center's training strategy.

### **LEND Accomplishments Under CAAI, 2008-2012 (infographic)**

[http://www.aucd.org/template/news.cfm?news\\_id=8700&id=17](http://www.aucd.org/template/news.cfm?news_id=8700&id=17)

The nation's 43 LEND programs, part of MCHB's Combating Autism Act Initiative (CAAI), are tasked with improving the lives of children who have or are at risk for autism and other developmental disabilities in part by promoting early screening, diagnostic evaluations, and interventions. For this infographic, AUCD examined data from the past four years of LEND CAAI activities in training the next generation of providers, training current professionals, screening and diagnosis of children, and disseminating publications and products.

## **Events**

### **2013 HRSA/MCHB's Combating Autism Act Initiative (CAAI) Meeting**

[http://www.aucd.org/template/event.cfm?event\\_id=3550](http://www.aucd.org/template/event.cfm?event_id=3550)

The 2013 CAAI Meeting, scheduled for May 30-June 1, 2013, will bring together individuals from the training, research, and state programs funded by HRSA/MCHB's Combating Autism Act Initiative. The 2013 CAAI Meeting will be held at the Crystal Gateway Marriott in Arlington, Virginia. More details will be available soon.

### **2013 LEND/DBP Directors Meeting**

[http://www.aucd.org/template/event.cfm?event\\_id=3550](http://www.aucd.org/template/event.cfm?event_id=3550)

Thursday, May 30, 1-6pmET

A LEND/DBP Directors meeting will be held in conjunction with the 2013 CAAI Meeting. More information will be released as it becomes available on the meeting webpage.

### **2013 SPHARC/State Autism Grantees Meeting**

[http://www.aucd.org/template/event.cfm?event\\_id=3550](http://www.aucd.org/template/event.cfm?event_id=3550)

Thursday, May 30, 1-6pmET

A SPHARC/State Autism Grantees meeting will be held in conjunction with the 2013 CAAI Meeting. More information will be released as it becomes available on the meeting webpage.

## **Upcoming Webinars**

### **Postsecondary Options for Students with ASD: Three Programs and a Parent Perspective**

Monday, April 15, 2013

[http://www.aucd.org/template/event.cfm?event\\_id=3771](http://www.aucd.org/template/event.cfm?event_id=3771)

Presentations will include an overview of three programs and a parent perspective. Cathryn Weir, M.Ed., will discuss how **Think College** works with programs for students with autism who are not likely to matriculate, how they work with programs around the country, and resources they have available. Barbara Becker-Cottrill, Ed.D., and Marc Ellision, Ed.D., will provide details on how **The College Program for Students with Asperger's Syndrome** at Marshall University supports students in the program, including strategies for working with professors, residence advisors and others involved in the life of the student; details will also be provided about a summer college experience for high school students. Cathy Pratt, Ph.D., BCBA-D, will share information about **Students on the Spectrum** at Indiana University, a student-directed club facilitated by the Indiana Resource Center for Autism. The club provides social, support and informational opportunities and has covered topics such as effective self-advocacy, dealing with anxiety, communication and social skills, and finding supports and activities on campus and in the community. Scott Badesch, M.A., will discuss what a parent needs to know and do to help their child succeed when they are living with autism. There will be time reserved for questions. Please join us!

### **MCHB/HRSA Autism Awareness Month Activities**

April 4, 8, 24, 2013

[http://www.aucd.org/template/news.cfm?news\\_id=8696&id=17](http://www.aucd.org/template/news.cfm?news_id=8696&id=17)

***April is Autism Awareness Month***

### **Webinar: Autism Spectrum Disorders: Family Support and Involvement**

**When:** Thurs, April 4, 12:30-1:30 EDT (Next Week!!)

**Webinar Registration:** <https://www.etches.com/mchresearch042013>

**Presentation 1: The Colorado Parent Mentoring Program: Comprehensive Support for Families Newly Diagnosed with Autism**

The Colorado Parent Mentoring Program is an innovative approach to providing families with greater support following the diagnosis of their child's autism. It includes individualized parent action planning and education and ongoing parent-to-parent mentoring. This webinar will describe the need for such programs, the program itself, and preliminary results.

**Presenters:** *Cordelia Robinson Rosenberg, PhD, RN, & Eric Moody, PhD, University of Colorado Denver*

### **Presentation 2: The Power of Family Voices in Creating and Sustaining Systems Change**

This presentation will discuss strategies and lessons learned for improving state systems through the incorporation of diverse family involvement, support, and empowerment at multiple levels. The Community of Care Consortium has integrated family engagement and leadership throughout its infrastructure, work groups, and activities.

**Presenter:** *Diana MTK Autin, Esq., Statewide Parent Advocacy Network*

### **Webinar: Expediting Detection of Autism Risk and Intervention Access**

**When:** Mon, April 8, 1-2 pm EDT

**Webinar Registration:** <http://learning.mchb.hrsa.gov/LiveWebcastDetail.asp?leid=323>

This webinar will define numerous barriers to the early detection of ASD and describe a variety of tools and procedures developed at the Kennedy Krieger Center for Autism and Related Disorders to address these barriers. Also, resources developed for families and children showing early signs of ASD, or with recent ASD diagnosis, will be described.

**Presenters:** *Rebecca Landa, PhD, & Jennifer Sharpless, CCC-SLP, Kennedy Krieger Institute*

### **Webinar: Screening, Early Diagnosis, and Early Intervention**

**When:** Wed, April 24, 2-3 pm EDT

**Webinar Registration:** <http://learning.mchb.hrsa.gov/LiveWebcastDetail.asp?leid=324>

### **Presentation 1: Coordination of Evaluation and Early Intervention among Early Childhood Professionals and Diagnosticians**

This presentation describes quality improvement activities undertaken in Maine to improve early identification and intervention by increasing coordination and communication between medical diagnosticians and early childhood providers.

**Presenter:** *Nancy Cronin, MA, Maine Developmental Disabilities Council*

### **Presentation 2: Collaborative Efforts to Improve Access and Care for Children at Risk for Autism Spectrum Disorders**

This presentation focuses on three efforts in Massachusetts designed to improve access and care: (a) approval for reimbursement for developmental screening through insurance companies; (b) a new triage mechanism which has led to decreased wait times for specialty evaluations; and (c) development of an email messaging service for families in the first year following diagnosis.

**Presenter:** Leonard Rappaport, MD, MS, Boston Children's Hospital

### **HRSA/MCHB Autism Awareness Booth**

When: Tues, April 2, 8:30-2pm, 5th floor lobby area, Parklawn Building

### **Targeted Treatments for Autism: From Genes to Pharmacology**

[http://www.aucd.org/template/event.cfm?event\\_id=3850](http://www.aucd.org/template/event.cfm?event_id=3850)

This webinar is Part I of *The Amazing Brain Webinar Series: Select Topics in Neuroscience and Child Development for the Clinician*. It is being jointly sponsored with the [Yale School of Medicine, Section of Developmental-Behavioral Pediatrics](#). For more information about the webinar series, [click here](#).

### **About**

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