

Developments, April 2014

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Intro

Developments is a 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

Division of MCH Workforce Development New Resources Related to Autism and Other Developmental Disabilities

In keeping with our [calendar of monthly topics](#), the Division of MCH Workforce Development is excited to share new resources related to this month's focus - **Autism and Other Developmental Disabilities**.

Three Recently Added *In Trainees' Words*, including:

- *DeWayne Lazenby*, DBP Fellow at Boston Children's Hospital
- *Tia Nelis*, Self-Advocate LEND Trainee at Illinois LEND
- *Anson Koshy*, DBP Fellow, Children's Hospital of Philadelphia

April Autism Highlights from Around the Network

Information on the new *Birth to 5: Watch Me Thrive!* initiative

New Resources Focused on Autism Spectrum Disorder from the MCH Library

Updated Fact Sheets for our training programs, including:

[Developmental Behavioral Pediatrics \(DBP\)](#)

[Leadership Education in Neurodevelopmental and Related Disabilities \(LEND\)](#)

To learn more about HRSA's efforts, including training for professional, state demonstration & policy grants, and the research program please visit HRSA's [Combating Autism and Other Developmental Disabilities](#) page.

As always, if you would like to contribute to a Grantee Spotlight, Trainee Story, news item, or other accomplishments and innovations, please contact your Project Officer. We would love to highlight and promote your work and practices with the field!

New Resources Focus on Autism Spectrum Disorder

The MCH Library at Georgetown University, with support from the Health Resources and Services Administration's Maternal and Child Health Bureau, released a new knowledge path and set of resource briefs about autism spectrum disorder. Released in time for Autism Awareness Month in April, the knowledge path directs readers to a selection of resources about ASD screening, diagnosis, treatment, care, and impact on family life. The knowledge path includes tools for health care practices; training; improving state systems and services; research; and finding data and statistics, journal articles, reports, and other materials. The knowledge path aims to help health professionals, program administrators, policymakers, and researchers learn more about ASD; to integrate what they know into their work in new ways to improve screening, diagnosis, treatment, and care; for program development; and to locate information to answer specific questions. The knowledge path is available at http://www.mchlibrary.org/KnowledgePaths/kp_autism.html.

Companion resource briefs include:

Autism Spectrum Disorder: Resources for Families http://www.mchlibrary.org/families/frb_autism.html

Autism Spectrum Disorder: Resources for Schools http://www.mchlibrary.org/schools/srb_autism.html

Screening: Resource Brief <http://www.mchlibrary.org/guides/screening.html>

Training Topics

Boston Children's Hospital Autism Spectrum Center's Autism Friendly Hospital Initiative

Mission: To provide excellent, timely, culturally competent, multi-disciplinary care for all children with ASD and their families.

Providers in the Autism Spectrum Center at Boston Children's Hospital have been working on several projects as part of a larger Autism Friendly Hospital initiative to improve care of children with autism spectrum disorder (ASD) and related conditions. The Autism Spectrum Center is a multidisciplinary effort which brings together clinicians from a multitude of disciplines - neurology, developmental behavioral pediatrics, psychiatry and psychology, genetics and genomics, communication enhancement, child life, social work, OT, gastroenterology, nursing and the Center for Families. The Center offers diagnostic and ongoing care services to children from birth to 21 years who have or are suspected to have ASD. In addition, clinicians in the Center provide education and consultation to colleagues throughout the hospital with the goal to improve awareness of the unique care needs of children with ASD, remove barriers to care and improve the patient and family experience.

One challenge for our group was maintaining the hospital's mission of providing care to children and families in the communities where they live. Rather than having a single co-located clinic, the Autism Spectrum Center offers diagnostic and management services in multiple departments throughout the main hospital and our many community satellite facilities. An initial key effort to standardizing care across diverse departments was establishing a multidisciplinary clinical practice guideline (CPG) for diagnosis and management of ASD at Boston Children's Hospital. The multidisciplinary focus of our guideline is unique and reflects the expertise of many specialties. Part of this process involved creating an online tutorial required of all clinicians who diagnose ASD, ensuring that all clinicians use the same standards for diagnosis and treatment, regardless of the department in which they are working.

Our Clinical Outcomes Workgroup leads innovative efforts to improve care through smaller task-focused workgroups that include members from a variety of disciplines and clinical departments. One important effort has involved writing a set of preparatory stories related to specific procedures and clinical areas. "My Hospital Stories" was created to assist patients with ASD and their caregivers as they prepare for procedures in the hospital, to increase their knowledge of what to expect, and to decrease anxiety about upcoming visits. Over 50 "My Hospital Stories" have been written using language, pictures, and formatting familiar to children with ASD and are available electronically for families to access. In addition, our innovative team has just launched the "My Hospital Stories" interactive app that includes photographs to accompany the stories and allows for customization by the end user. The app can be downloaded to smartphones and tablets.

We offer ongoing supports to families in between visits through our parent email messaging service and our Parent Forums. The email messaging provides educational material in weekly/then biweekly emails to families for the first year after diagnosis; quarterly updates on timely health information, research and educational opportunities to all families. We also provide a series of evening forums for families and providers. These presentations are practical state of the art updates on topics of key importance to families such as management of anxiety, seizures toileting, feeding and sleep problems, keeping up to date on various technologies that support children's communication and navigating the early intervention and special education systems. The forums are presented and broadcast live but also archived so participants can view them at any time. You can view any of the past presentations at

<http://authoring.chboston.org/centers-and-services/departments-and-divisions/division-of-developmental-medicine/events/archived-events>

Another key component of the Autism Friendly Hospital initiative involves the education and training of hospital personnel to improve care for children with ASD. We provide training to specific, high-priority departments in the hospital in a systematic, tiered, and multidisciplinary fashion. We tailor the training to the department and individualize trainings to the personnel involved. There are many points at which care for children with ASD may be impacted, from individuals speaking with parents on the phone, to those greeting them at the front desk, to personnel involved directly in invasive procedures.

To assess the impact of these initiatives and ensure we are improving quality of care, we developed an electronic caregiver survey (ASD Assessment of Barriers to Care, ASD-ABC) that will be periodically administered to families in order to determine the scope of the problem and to inform ongoing efforts to improve outcomes for children with ASD. This survey asks parents specifically about barriers to following through on medical recommendations and what support services might be helpful to improve access. The survey will be administered through our Integrated Clinical Information Sharing System (ICISS) system, a secure web portal that allows caregivers to provide information directly to clinicians prior to or following clinical visits. In addition, we have developed a Comprehensive Accommodation Plan (CAP). The CAP is designed to be completed/updated electronically by parents prior to visits to ensure that a proactive behavior plan exists in the electronic medical record that any provider can access.

We are currently developing a parent survey to monitor progress and identify areas of concern for families prior to clinical visits. The Autism Spectrum Disorder Parental Response Outcome Measure (ASD-PROM) was developed to accompany follow-up visits to track behavioral concerns and progress specific to children with ASD. The survey will be administered through ICISS and will allow for graphical representation of results and formatting that allows for incorporation into clinical notes. We will monitor the impact of the survey on clinical care and anticipate that it will streamline visits and allow clinicians to provide more family-centered care.

Finally, all of our initiatives receive guidance from our Autism Spectrum Center Family Advisory Council (FAC). This group was formed in September of 2013, meets quarterly, and is comprised of approximately 10 to 12 parents of children with ASD who are seen by specialists throughout the BCH system. We are fortunate to have such committed parent partners working alongside us to accomplish all of our autism friendly initiatives.

Our Clinical Outcomes Workgroup includes several current HRSA MCHB DBP and LEND trainees. Sabrina Sargado is a DBP fellow and Niki Baumer and Karen Spencer are LEND fellows. Many of our faculty are also former trainees: Carolyn Bridgemohan (Center Co-director), Eugenia Chan (Quality Management Director), Laura Weissman and Alison Schonwald are former DBP trainees and Leah Welchons is a former LEND trainee.

Minnesota LEND Trainees Participate in Important Autism Prevalence Project

The Minneapolis Somali Autism Spectrum Disorder Prevalence Project was developed to answer the question, "Is there a higher prevalence of ASD in Somali children who live in Minneapolis versus non-Somali children?" The project looked at information on children who were between the ages of 7 to 9 during the year 2010. At least one parent was required to have been a resident of Minneapolis in 2010. MN LEND faculty, staff and, trainees played a significant role in this research serving in various capacities from Principle investigator to Community Liaisons. Project activities included: Review of school and medical records; Review of the child's records by a clinician reviewer (such as a clinical psychologist) to determine if the child meets the ASD definition used in this project; Community collaboration regarding the project and its importance. This project was funded by the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and Autism Speaks, and it was managed through the Association of University Centers on Disability (AUCD). The project began in July 2011, and was completed in December 2013.

[MN Somali ASD Prevalence Project – Community Report 2013](#)

LEND Workshop: Autism Spectrum Disorder and Hearing Loss

On Sunday April 13, 2014, over 60 LEND faculty and students participated in an interactive workshop using active learning strategies and case-based discussions about issues and challenges surrounding hearing loss and autism spectrum disorder (ASD). During the workshop, participants were placed in large and small group settings and encouraged to share personal examples while learning best practices used by LEND faculty and staff. The workshop, funded by MCHB and organized by the Association of University Centers on Disabilities (AUCD), was a pre-conference activity held in conjunction with the Early Hearing Detection and Intervention (EHDI) conference in Jacksonville, Florida in partnership with NCHAM. All participants were asked to review a related webinar prior to participation in the workshop titled, **Autism Spectrum Disorder and Children Who are Deaf or Hard of Hearing**. This MCHB/AUCD webinar is currently archived at www.aucd.org/webinars and features presentations by Susan Wiley, MD and Michael Scott, AuD of the LEND program at the Children's Hospital in Cincinnati. For more information, please contact Meaghan McHugh at AUCD (mmchugh@aucd.org)

Project DOCC is a Major Component of the Nebraska LEND Program's Family-Centered Curriculum

The Nebraska LEND (NE-LEND) Program has been using Project DOCC (Delivery of Chronic Care) in their training program since 2003. Project DOCC is a national curriculum founded in 1994 by three mothers of children with disabilities utilizing parents as teachers. The program includes a structured home visit and a one-on-one training session on history-taking and interview skills. These activities offer a perspective to students that faculty usually do not have; promote provider/patient partnerships; and empower families. Project DOCC is a recommended training activity by the National Medical Home Autism Initiative.

Project DOCC was initially used in the NE-LEND program to train Pediatric and Family Medicine residents and students to incorporate family-centered care principles into their care of children with chronic illness and neurodevelopmental and related disabilities. With Combating Autism Act funding and the development of the NE-LEND Autism Leadership Academy in 2008, LEND faculty collaborated with the national Project DOCC organization to adapt this family-centered training program for use with allied health, education, and family trainees. Since that time, over 25 parents have participated in the program, training 77 medical students and residents and 81 interdisciplinary students (including psychology, speech/language pathology, nursing, social work, nutrition, education/special education, physical therapy, health administration and family trainees).

"The experience will help me become a more compassionate, family-centered physician. Observing the sacrifices parents make while caring for children with developmental disabilities was transformative in my thought process towards family oriented medicine. This program helped me understand what these families deal with on a daily basis," said Matthew Freeman, LEND trainee. Project DOCC focuses on these issues and, by using parents as the teachers and the home as the classroom, broadens the faculty and clinical settings in which these important concepts can be taught.

Telemedicine Clinic for Early Detection of Neurodevelopmental Disabilities

Kennedy Krieger Institute launched a Telemedicine clinic in partnership with Atlantic General Hospital, Berlin, MD which is on the Eastern Shore of Maryland, in Dec 2013. The aim of the Clinic is to serve a rural and underserved population who have concerns about their child's development. Dr. Paul Lipkin and Dr. Deepa Menon from Kennedy Krieger Institute have twice monthly clinics and have been able to conduct neurodevelopmental initial evaluation and testing on the children. They have been able to connect patients and families to resources in their local area, as well as provide referrals for further evaluations at KKI. To read more about the program, click [here](#).

Research on Head Circumference in Young Children with Autism

Dr. Pasquale Accardo, James H. Franklin Professor of Developmental Pediatrics at and Interim Director of Virginia LEND at Virginia Commonwealth University (VCU), working with colleagues from Children's Hospital of Richmond, VCU, and Penn State University have been investigating the head circumference in young children with autism and the impact of different head circumference charts. The recently published article in the *Journal of Child Neurology* (<http://jcn.sagepub.com/content/29/3/412.long>) reports on their research.

Abstract: The hypothesis that the presence of macrocephaly might vary with the specific growth chart used was tested by using the Nellahus, CDC, and recent Rollins et al revision head circumference charts to plot the head circumferences of 253 children with neurodevelopmental disorders and with ages between 12 to 36 months; of these children, 59 had a diagnosis of autism spectrum disorder. The CDC and Rollins et al head circumference charts identified more cases of macrocephaly and fewer cases of microcephaly than did the older Nellhaus chart but did not significantly differ in their identification of macrocephaly in children with autism.

Jackson Roush, PhD Named the Director of CIDD NC LEND

The Carolina Institute for Developmental Disabilities (CIDD) is pleased to announce that **Jackson Roush, PhD** has been named the Director of the NC Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. LEND is one of the CIDD's three federally funded core grants (along with the UCEDD and IDDRC) and is funded through HRSA's Maternal Child Health Bureau. The LEND grant provides core support for in-depth graduate level interdisciplinary training as well as interdisciplinary services and care. Dr. Roush has been the Audiology Section Head at the CIDD for many years and is Professor and Director of the Division of Speech and Hearing Sciences, University of North Carolina School of Medicine. He has many years of teaching and clinical experience, and has directed national training and leadership grants funded by MCHB and OSEP.

Dr. Roush will be assisted in the LEND leadership effort by **Dr. Rob Christian**, Psychiatrist/Pediatrician, the new LEND Associate Director and **Dr. Jean Mankowski**, Psychologist, the new LEND Training Director. Dr. Roush takes over the LEND Director position from Dr. Stephen Hooper who directed the LEND program for over a decade and was recently named Chair of the Department of Allied Health Sciences. In addition, the LEND program was co-directed by Dr. Angela Rosenberg who also served as the program's Training Director. Dr. Rosenberg will be retiring from UNC March 1, 2014.

AUCD joins CIDD in thanking Drs. Hooper and Rosenberg for their years of excellent service and dedication to the LEND program and welcome Drs. Roush, Christian and Mankowski.

LEND Directors Meeting: April 2014

The Spring 2014 LEND Directors meeting was held in Washington, DC, in conjunction with the Disability Policy Seminar. Significant time was spent on discussing the following topics: training opportunities in transition, trainee long-term follow up surveys, increased participation of self-advocacy trainees, trainee diversity efforts, examining LEND programs, the new MCH Workforce Development Center, LEND leadership training, AUCD Network Strategic Planning, the need to reauthorize the Combating Autism Act, and regional group work. Select meeting materials are now [posted](#).

LEND Trainees Attend Disability Policy Seminar

Rachel Nash, LEND Trainee: Center for Disabilities and Development, University of Iowa
Caitlin Owens, LEND Trainee: Center for Disabilities and Development, University of Iowa

Engage.

AUCD Trainees and disability advocates from across the country came together last week for the annual Disability Policy Seminar held in Washington, D.C. At the Disability Policy Seminar, attendees were armed with the information

needed to help educate our Members of Congress and their staff on the priorities of the ID/DD community. One of the most important lessons that we as young professionals learned from the Seminar and Hill Visits was the importance of engaging with the legislative process in order to create change for individuals with disabilities. As a current LEND trainee in the field of public health, I was impressed with the collaboration between the multiple sponsor organizations (American Association on Intellectual and Developmental Disabilities, The Arc, Association of University Centers of Disabilities, National Associations of Councils on Developmental Disabilities, Self-Advocates Becoming Empowered, and United Cerebral Palsy). It is rare to see so many groups with differing missions come together to work towards a common goal and bring a united front when working on key policy issues.

The opening presentation entitled *Forging a Path Toward Bipartisanship* featured such notable panelists as former U.S. Senator Pete Domenici, Former U.S. Representative Tony Coelho, and several staff members from the Bipartisan Policy Center. This session highlighted the importance of using commonalities and personal stories to get things done in Congress. The panelists stressed how vital it is to identify new disability champions in both parties, especially with all the new faces in Congress. With several important pieces of legislation coming down the pipeline, such as the ABLE Act and Combating Autism Reauthorization Act, it has never been more important to advocate in a bipartisan manner. In addition, we learned that future legislation which hopes to garner bipartisan support should be developed in a bipartisan manner.

Another highlight of the conference was hearing from the speakers with disabilities who represent the disability community. In particular, Claudia Gordon, who served as the liaison between the disability community and the Obama Administration last year through her post at the White House, delivered an inspiring speech (through sign language) that made each person in the audience feel like they could make a difference as an advocate. A special appearance by Senator Harkin on Monday evening energized the entire audience. He delivered a passionate speech about his steadfast commitment to the disability community and how, even after his retirement from the Senate, he would continue to advocate for things like the Convention on the Rights of Persons with Disabilities. Hearing Senator Harkin's feeling of responsibility to advocate regardless of his position reinforced to trainees that we could and should do the same.

The seminar and a preparatory session on Sunday evening from AUCD where we got to practice our legislative visits on AUCD staff both left our trainees feeling prepared and energized for the Capitol Hill Visits on Wednesday. For many of us, this was our first time advocating for something we each care deeply about – the Combating Autism Act. After meeting with the staff of Senators Harkin and Grassley, we were surprised by how accessible the whole process was and encouraged by the fact that each of our voices were heard and taken seriously. LEND is all about becoming leaders, not only in our disciplines, but also in the communities that we serve. The Disability Policy Seminar empowered each of us to take on this role as future leaders in healthcare.

Disability Policy Seminar 2014: My Experience

Ashley Coates, MS, Trainee: Children's Hospital Boston LEND

The Grand Hyatt in Washington, D.C., was the perfect setting for a seminar where thoughtful content and committed colleagues mirrored the impressive accommodations. Self-advocates, families, trainees and dedicated professionals came together to share personal experiences, learn new strategies and promote change for the community of persons with disabilities across the country. Throughout the halls, in elevators, and in conference rooms, people from across the country found a common voice and shared passion. I arrived at the Seminar as part of my group of colleagues and LEND Trainees from Boston Children's Hospital, but left as a member of a much larger community of Disability Advocates.

Seminar sessions covered current and upcoming legislative priorities that seek to ensure individuals with disabilities have their personal, financial, and educational needs met. From Sunday night's Trainee Symposium featuring mock meetings with AUCD staff (including an un-canny role play as Senator Elizabeth Warren, D-MA, by AUCD Executive Director Andy Imparato) until our group crossed the threshold leaving House and Senate offices on Wednesday, the contagious passion of my fellow attendees rivaled the spectacular sight of cherry blossoms on Capitol Hill.

I am definitely marking my calendar for next year's seminar and have already taken to social media to share a smiling photo of Senator Warren and myself. As I return to my office this week back in Massachusetts, I'll do so with a renewed passion for equality for persons with disabilities and a little tan from the Washington D.C. sun.

Research Roundup

Update on the MCHB Autism Intervention Research Network on Behavioral Health

The Autism Intervention Research Network on Behavioral Health consists of a group of senior researchers, junior faculty and trainees at seven different research centers who are focused on delivering behavioral interventions to under-resourced, under-served and under-represented children with autism spectrum disorder (ASD). Supported by the Maternal and Child Health Bureau, the goal of both AIR-B I (2008-2011) and AIR-B II (2011-2014) has been to develop novel, evidence-based interventions for children from low-resource community settings.

Research Studies of the Network:

We have implemented five large cross-site randomized controlled trials (RCTs), all in low resource community settings, as well as several descriptive and smaller scale intervention studies. **In AIR-B I we completed three RCTs.** One study compared two parent-mediated interventions targeting core deficits in preschoolers in under-resourced homes. A second study compared two different social skills programs for children in under resourced schools. A third study, leveraged with additional funding, implemented two peer-mediated social inclusion interventions in secondary schools. Smaller projects included a pilot study of an intervention for teaching assistants to foster inclusion during recess and another pilot study focusing on enhancing the peer relationships of girls with ASD. Papers are currently published, in press or under review, with most still embargoed.

Our experience from AIR-B I galvanized us to move even further into the community. **In AIR-B II we proposed a community-partnered participatory research approach** to delivering interventions in low-resourced school districts, in order to reach the most under-served children with ASD and to test the exportability of our interventions. Together with our community partners we chose and are currently implementing two interventions in urban schools that serve students from economically disadvantaged households. One intervention is based in special education classrooms and focuses on helping students make transitions between activities throughout their daily routine. The second intervention focuses on the recess inclusion intervention pilot-tested in AIR-B I. A theme that cuts across all AIR-B II projects is tailoring interventions that address community needs and are accessible to school staff and parents alike.

Highlights:

Caregiver-Mediated Intervention for Low-Resourced Preschoolers with Autism: A RCT

Young children with autism spectrum disorder (ASD) have core deficits in engaging in play with others, and initiating effective social communication gestures. These skills are important to children's later development of social and language skills. In this cross-site study of 112 low-resourced preschoolers and their parents, families were randomized to receive active parent coaching on teaching social communication skills, particularly targeting joint attention with their children in the home or to a parent education group format in which parents received instruction on the same social communication goals but no active coaching. Both intervention groups received two hours of intervention weekly for twelve weeks with one twelve-week follow up. This study was unique in its focus on parents of under-resourced children, with intervention delivered in their homes or neighborhoods, and emphasis on the core developmental impairments of young children with ASD. *Pediatrics, accepted for publication.*

Social experiences of girls with ASD at school

ASD affects more boys than girls, and we have little information on the social functioning of girls with ASD in school. AIR-B researchers have published two studies that explored the social experiences of girls with ASD at school. The first study was a qualitative, in depth analysis of girls interacting with each other over several weeks. This discourse analysis was based on 12 hours of video footage collected during 16 'lunch club' sessions among four girls, one with ASD. Of interest in this study was how girls may sanction relationships that exclude others based on subtle nuanced interactions. Results found that the persistence in topic by the girl with ASD and her limited attention to subtle conversational cues resulted in greater exclusion within the group over time. In contrast to boys who often

engage with each other in structured, physical games, girls with ASD may require specialized interventions to guide their inclusion within girl groups. Full study details are available in *Discourse Studies*, 2013, 15 (2), 147-166.

The second study examined the social networks of 100 girls and boys with and without ASD, closely matched on IQ, gender, and classroom placement. Children completed a friendship survey about their friends in the class and groups that played together at recess. From this survey we obtained information about social preferences and acceptance, social connections, reciprocal friendships, and rejection experiences. The study is the first study to examine gender in children with ASD's social relationships, and results yielded some unique considerations for girls at school. *Journal of Child Psychology and Psychiatry*, accepted for publication.

Remaking Recess: Targeting paraprofessionals on the school playground

This small, randomized trial yielded important pilot and feasibility data that guided the development of the cross-site intervention study we are currently implementing in urban schools. Children in four schools were randomized to receive immediate intervention or later (wait-listed) intervention. Paraprofessionals on the playground were taught to intervene with target children and to engage all children in games or activities with the goal of improving peer engagement on the playground. The results of this study will appear in *Behavior Therapy*.

School interventions: Perceptions of teachers, parents and administrators

In preparation for implementation of interventions in schools, focus groups were conducted across three urban school districts. Altogether 35 parents and 89 educators participated in these focus groups. Three themes emerged from the groups and were remarkably consistent across the large and diverse urban school districts: tension among stakeholders, need for improved staff training, and acceptance of differences. The study results have been submitted for publication. Results also led to the selection and implementation of two school-based interventions across the three districts. These interventions center on peer engagement on the playground and management of classroom behaviors and transitions. Teachers and paraprofessionals have been taught interventions with support from AIR-B researchers; completion of these studies is scheduled for 2014.

GUIDELINES and TOOLS

A systematic review of behavioral interventions focused on the core deficits of ASD was published in *Pediatrics* supplement, November 2012. This guideline provides information on evidence-based behavioral interventions for parents and professionals. Full details can be found in *Pediatrics* 2012; 130:S169-S178

Several tools also have been produced by the network, and these can be found on our website, www.airbnetwork.org. Tools include our remaking recess materials for paraprofessionals, social menus for lunchtime conversation building, and the Playground Observation of Peer Engagement (POPE) measure.

AIR-B participating sites: UCLA (lead site; Connie Kasari, PhD), Cornell-Weill Medical Center (Catherine Lord, PhD), Florida State University (Amy Wetherby, PhD), Kennedy Krieger Institute (Rebecca Landa, PhD), University of Pennsylvania (David Mandell, ScD), University of Rochester (Tristram Smith, PhD), University of Washington (Bryan King, MD).

Autism Intervention Research Network on Physical Health (AIR-P) Activities

The Autism Intervention Research Network on Physical Health (AIR-P) conducts research on evidence-based interventions to improve the physical health and well-being of children and adolescents with autism spectrum disorders (ASD) and other developmental disabilities. The network also works to disseminate main findings to parent and professional communities. Activities include developing and/or updating evidence-based guidelines and validating tools for interventions; disseminating critical information on network research findings, guidelines developed, and validated tools to health professionals and the public; and developing and mentoring new investigators in the field of ASD and other developmental disabilities. The AIR-P has been highly productive in all of these areas. In 2013, the AIR-P Network published 15 manuscripts in peer-reviewed journals, adding to the 32 manuscripts previously published since the inception of the Network. Three papers have already been accepted for publication in 2014, with seven more submitted and under review. Many manuscripts are also in process using data from two signature AIR-P research projects, various other AIR-P research projects, as well as from secondary data

analysis of the patient registry, built as part of the Autism Speaks Autism Treatment Network (AS ATN). The main topics of our papers include co-morbidities for children with ASD, and more specifically, nutrition and obesity, sleep problems, gastrointestinal concerns, anxiety as well as quality of life.

The AS ATN/AIR-P Network has also developed evidence-based guidelines and validated tools for interventions as well as mentoring new investigators in the field. One area in need of better instruments is a good measure of function in individuals with autism, as current functional measures tend to focus on conditions with physical disabilities. Demonstration of treatment effects has been limited by a lack of psychometrically sound measurement tools that are sensitive to change in core symptoms of ASD. Under AIR-P RFA-11-03 a pilot study of the Autism Impact Measure (AIM) was conducted by Drs. Micah Mazurek, a young investigator, and Steve Kanne of the Thompson Center at the University of Missouri. The AIM uses a novel approach designed to be sensitive to incremental changes in ASD symptoms. Results of their project were published in *Journal of Autism and Developmental Disorders*, titled "The Autism Impact Measure (AIM): Initial Development of a New Tool for Treatment Outcome Measurement" (2014 Jan; 44(1):168-79. doi: 10.1007/s10803-013-1862-3). Dr. Mazurek, an assistant professor at University of Missouri, has received an NIH grant that will further examine construct validity and examine the measure's sensitivity to change following treatment. A major goal across federal health agencies is to improve the lives of children with ASD by developing interventions that target core symptoms of the disorder, and the development of a reliable and valid treatment-outcome measure has the potential to enhance the pace of treatment-outcome research.

Another goal of the AIR-P Network is to provide opportunities to develop collaborations and partnerships with clinicians and researchers who are external to the current AIR-P centers. The Network provides a variety of mechanisms to encourage involvement in AIR-P activities and has demonstrated particular interest in supporting junior investigators in developing their research efforts to improve the medical care of children with autism. One of these mechanisms provides support to investigators interested in mining existing Network Registry data. We have developed a Request for Analysis (RFA), which allows an individual to submit a formal request to obtain summary data from the AS ATN Registry which is conducted in collaboration with AIR-P. The online RFA submission is electronically routed to the MGH Clinical Coordinating Center (CCC) for review and approval. Upon approval, the MGH Data Coordinating Center (DCC) - the MGH Biostatistics Center - supports necessary follow-up and analysis. Past analyses by external investigators has led to dissertations and manuscripts by trainees in pediatrics and psychology as well as other junior faculty members at various institutions.

For more information, and a full listing of our published manuscripts, please visit our public website: www.autisminterventionresearch.net.

Beta Blocker May Ease Social Problems in Autism

The beta blocker propranolol may help teenagers and young adults with autism spectrum disorder (ASD) improve their social interaction and problem-solving skills, new research suggests.

The double-blinded, placebo-controlled study showed that 20 patients scored significantly higher ($P = .03$) on a performance-based measure of social competence after a single 40-mg dose of propranolol than after placebo in a separate test session.

This result is important because it suggests that a widely available, inexpensive generic medication used to treat hypertension and anxiety can alleviate at least 1 of the core symptoms of ASD, David Beversdorf, MD, the principal investigator and a neurologist at the University of Missouri, Columbia, told *Medscape Medical News*.

"We have drugs to treat anxiety and irritability in individuals with ASD, but not for the core symptom of impaired social communication," Dr. Beversdorf said.

The findings will be reported in May at the [International Meeting for Autism Research \(IMFAR\) Annual Meeting](#) in Atlanta, Georgia, but have not yet been published.

Improved Communication

The investigators studied 1 female and 19 male patients with high-functioning ASD (IQ above 85) who ranged in age from 15 to 31 years. Ten of the patients received propranolol first and placebo the next day, and the other half received the agents in reverse order. The patients underwent sociability and cognitive testing 1 hour after drug administration.

The sociability task, the General Social Outcome Measure, involved a conversation between a researcher and a patient about a topic the patient selected. (The topic changed at the second study session.) This previously validated measure tests for 6 domains:

- staying on topic
- sharing information
- reciprocity-providing or eliciting information beyond simple or vague comments
- transitions/interruptions
- nonverbal communication
- eye contact

For assessment of verbal problem-solving ability and word memorization, the patients performed anagrams and the Hopkins Verbal Learning Test.

When participants received propranolol, they solved the anagrams significantly faster and had a mean sociability score that was nearly 1 point higher compared with placebo, according to data the authors supplied:

Table. Effect of Propranolol on Social and Cognitive Abilities in Patients With Autism Spectrum Disorder (N = 20; mean ± SEM)

Outcome	Propranolol	Placebo	P-value ^a
Sociability (General Social Outcome Measure, total score)	9.40 ± 0.35	8.65 ± 0.47	.03
Verbal problem solving (anagrams test latency, number of seconds to correct response) ^b	17.33 ± 2.21	21.52 ± 2.50	.045
Verbal memory (Hopkins Verbal Learning Test discrimination index)	11.75 ± 0.09	11.35 ± 0.20	.09 (NS)

^aPaired-samples *t* test ($P < .05$). ^bN = 18 owing to missing data. Abbreviations: NS, not significant; SEM, standard error of the mean (rounded).

Additionally, patients receiving propranolol showed a significant improvement in score for 1 of the sociability test domains, specifically, appropriate nonverbal communication, such as body posture and nodding. The mean (± SEM) score in propranolol recipients was 1.7 ± 0.47 vs 1.5 ± 0.69 for placebo ($P = .04$).

Predicting Response

The researchers had predicted that patients with high levels of stress and anxiety would respond to propranolol better than other patients would because of the drug's known anxiolytic effects, Dr. Beversdorf said. Yet he noted that they found no relationship between self-reported anxiety and the drug's effects on cognitive and social function.

They did, however, report a significant positive linear relationship ($P = .03$; $R^2 = 0.23$) between drug response and baseline heart rate variability, measured with electrocardiography.

Participants with greater heart rate variability before receiving propranolol demonstrated greater response to this drug related to the total score on the General Social Outcome Measure, according to the study data.

Dr. Beversdorf said there was not enough data to determine a minimum cutoff at which heart rate variability would predict treatment response.

"Propranolol is worth further exploration in individuals with ASD," he stated. "Perhaps at a sustained, serial dosage, we'd see a more robust effect of the drug. We also don't know if it works for lower-functioning individuals or younger children [with ASD]."

Patients with asthma or depression would not be good candidates for propranolol treatment because the medication can worsen these conditions, he said.

Possible Adjunctive Treatment?

Asked by *Medscape Medical News* to comment on the research, Daniel Coury, MD, medical director of the Autism Speaks Autism Treatment Network in New York City, said the study raises all sorts of questions and opportunities.

"With such small numbers of patients, it's hard to say how big an impact this drug will have, but it's exciting anytime we see a benefit for children with ASD."

Dr. Coury, a developmental and behavioral pediatrician from Nationwide Children's Hospital, Columbus, Ohio, was not involved with the study. He added that this research is one of the few studies showing changes in sociability resulting from pharmacologic intervention in autistic individuals.

Should future research find that propranolol has similar or better effects in greater numbers of patients and in younger children, he speculated that the drug could be useful as an adjunct to first-line behavioral therapy.

"If propranolol can help the child focus and be more attentive, it has the potential to make behavioral treatment more effective," Dr. Coury said.

The study received grant funding from the Health Resources and Services Administration, Rockville, Maryland. The University of Missouri Center for Autism Spectrum Disorders is one of the sites in the Autism Speaks Autism Treatment Network, but Autism Speaks did not fund this study, according to the organization. Dr. Beversdorf and Dr. Coury have disclosed no relevant financial relationships.

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State Stories

Increasing Early Identification and Access to Services for Young Children with ASDs and other Developmental Disabilities - A Community Team Approach

In November, 2013, the Oregon Center for Children and Youth with Special Health Needs (Title V) was awarded a state implementation grant for children with autism spectrum disorders (ASD) and other developmental disabilities (DD). The grant is through the Maternal Child Health Bureau. The goal of the grant project is to improve the care of children with ASD and other developmental disabilities in rural or semi-rural communities throughout Oregon, including communities with Latino and/or Native American populations. The project is aimed at implementing the recommendations of the Oregon Commission on Autism Spectrum Disorders (OCASD), Screening, Identification and Assessment Committee.

Components of the project include: 1) Early identification of ASD/DD and entry into services. The objective is to develop local teams that bring together education and medicine, including mental health, to make an ASD identification jointly and to jointly share results with families. Parent partners sit on the local teams to support families receiving an ASD/DD identification and to provide resources. Currently, there are four existing ASD ID teams with plans to expand to eight. 2) Strengthen overall healthcare by working with practices to improve medical home for children with ASD/DD. Parents of children with ASD sit on practice quality improvement teams addressing medical home strategies.

To increase local capacity for Medical-Education team identification, the following OCASD State Plan recommendations are being addressed:

- Identification of co-occurring conditions will be improved
- Partnerships between local primary care providers and education programs will be strengthened
- DSM-5 criteria will be used for all identifications
- The identification of children with ASD will be made through an interdisciplinary team evaluation
- The standard evaluation for the identification of ASD will include:
 - A. Diagnostic interview, including family history, with pertinent people such as child/person, parent/caregiver, and education staff.
 - B. Standardized observation using research-based, autism-specific instrument(s).
 - C. C. Observation of the individual in unstructured activity, to include at least one observation outside of the team evaluation setting
 - D. D. A developmental assessment, using the best available standardized tools, appropriate to the age and developmental level of the individual.
 - E. E. A formal hearing test for those up to age 5, for the first evaluation, if none has been done in the previous 6-12 months AND one or more of the following is true:
 - F. F. Vision screening, if indicated.
 - G. G. Once identification has been made, reports will be made available to caregivers in accessible language and format, with specified content areas included regarding the findings.
- Specialty consultations will be available to health care professionals regarding the care of individuals with ASD

In year three, the project will develop a care coordination curriculum to support practices in improving their medical home activities for children with ASDs and other developmental disabilities.

Project staff will work with community partners and the project advisory committee members to develop a plan for sustaining community infrastructure and identifying financing strategies.

State Grantees' Activities Around Autism Awareness

Read the activities current and former State grantees are doing for Autism Awareness Month. Click [HERE](#).

Collaborators' Corner

Celebrating Autism Awareness: The State Public Health Autism Resource Center

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) has several new activities planned, along with presentations, webinars and technical assistance opportunities designed to aid and assist ASD/DD grantees.

Celebrating Autism Awareness Month

National Autism Awareness Month provides a special opportunity to increase public awareness of autism spectrum disorders (ASD), which are estimated to affect 1 in 68 children in the U.S. AMCHP will be celebrating by sharing news, resources and information through the SPHARC website, social media and listservs. The SPHARC website has a calendar of events from current and former state grantees, which will be updated throughout the month. Check out AMCHP's [Facebook](#) and [Twitter](#) pages for regular social media posts all about autism spectrum disorder and other developmental disabilities. For more information, [click here](#).

ASD/DD at the 2014 AMCHP Annual Conference - Resources Posted

AMCHP's 2014 Annual Conference was held January 25-28, 2014 at the Hyatt Regency Washington in Washington, DC. There were several exciting sessions and events related to ASD/DD and that featured state grantees. Resources from these sessions have been posted to the SPHARC website and are available [here](#).

Encouraging Mentorship and Replication of Effective Practices

SPHARC recently launched a new technical assistance activity that provides funds for current state planning and implementation grantees to receive mentorship from another state on replicating or adapting an effective practice to improve systems of care for children, youth and families with ASD/DD. This is an exciting opportunity to offer an individualized form of technical assistance to help states work towards their goals. AMCHP has had success with this model in the past - if you'd like to read about how states used a similar opportunity to advance implementation on parent-provider partnerships and youth transition, [click here](#). Stay tuned for updates!

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

The ARC Working to Empower People with Autism Spectrum Disorder

April is national Autism Awareness Month and [The Arc](#) and The [Autism NOW](#) National Autism Resource & Information Center are working to empower people with autism spectrum disorders (ASD) with the information and resources they need to live their lives to the fullest potential. We are also working to help others become more accepting of people with ASDs.

With the CDC now declaring that 1 in 68 children may be impacted by autism spectrum disorders (a jump of 30% from earlier figures), it's a fair bet that each one of us knows someone with autism or someone who has a family member or friend with autism. Since this disorder is a spectrum and not everyone with a diagnosis of ASD "appears" to have autism, you may know someone on the spectrum and not even realize it.

That's why it's important to dispel all of the myths and misinformation to understand and accept what having an ASD really means. And that's why [The Autism NOW Center](#) exists, to weed through the volumes of information out there and provide high-quality, vetted resources and information to people with autism and other developmental disabilities, their family, friends, colleagues, teachers, employers and others.

To promote awareness and acceptance, we invite you to [view and share a new video about Autism NOW](#) and learn more. Also, we encourage you to join in the conversation! Follow us online and on [Autism NOW's blog](#) and read the personal stories of people with autism in a series of guest posts during April. And use the hashtag #AutismAware to generate discussion about autism awareness and acceptance.

Act Early Update

The [CDC's National Center on Birth Defects and Developmental Disabilities](#) and [AUCD](#), with support from [MCHB](#), are currently reviewing applications for a funding opportunity for Act Early Ambassadors to work with CDC's "[Learn the Signs. Act Early.](#)" (LTSAE) program to improve early identification of developmental delays and disabilities, including autism. This will be the forth cohort of Act Early Ambassadors who will continue work of serving as a state, territory or organizational point-of-contact for the national LTSAE program and support of the work of Act Early Teams and other state or national initiatives to improve early identification of developmental delay and disability. Ambassadors also work to promote adoption and integration of [LTSAE resources](#), including materials to support developmental monitoring (milestone checklists, Milestone Moments booklet) and professional education tools ("[Autism Case Training: A Developmental Behavioral Pediatrics Curriculum](#)", "[Autism Case Training: Web-based CE Course](#)") for primary care health professionals. Announcements of this forth cohort of Act Early Ambassadors will be made in early May. Please check out www.aucd.org/actearly for more details.

ITAC Items

AUCD Celebrates April as Autism Awareness Month

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 68 children**, according to new estimates from the [Centers for Disease Control and Prevention \(CDC\)](#). The new rate of 1 in 68 reflects a 30% increase from two years ago when the CDC released data that 1 in 88 children has autism.

These new numbers confirm that this developmental disability continues to be on the rise, which is why AUCD strongly supports a swift reauthorization of the Combating Autism Act (CAA). The CAA targets every federal department, agency, and office that addresses Autism Spectrum Disorder (ASD) research, surveillance, and the development of evidence-based interventions in order to accelerate the pace of scientific discovery and translation to services. The law has helped to expand research and coordination at the National Institutes of Health (NIH), increased public awareness and surveillance at the Centers for Disease Control (CDC), and expanded the interdisciplinary training of health professionals to identify and support children and youth with ASD and their families through programs of the Health Resources and Services Administration (HRSA). The law was reauthorized in 2011 (P.L.112-32) and is scheduled for reauthorization this year. If no action is taken, the activities authorized under the law will expire on September 30, 2014. For more information, visit AUCD's [Public Policy Page](#).

Supporting Autism Awareness

During the month of April, AUCD joins the autism community in supporting increased 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, family support, professional training, research and education.

- [Partnerships](#)
- [Training Materials and Workshops](#)
- [Public Policy](#)
- [Sharing Current Autism Related Information](#)
 - [Webinars](#)
 - [Publications](#)
 - [Additional Online Resources](#)

PARTNERSHIPS

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."

The [Centers for Disease Control and Prevention \(CDC\) National Center on Birth Defects and Developmental Disabilities](#) and the [Association of University Centers on Disabilities \(AUCD\)](#), with support from the [Health Resources and Services Administration \(HRSA\)](#), [Maternal and Child Health Bureau \(MCHB\)](#), are currently reviewing applications

for a funding opportunity for Act Early Ambassadors to work with CDC's "[Learn the Signs. Act Early.](#)" (L TSAE) program to improve early identification of developmental delays and disabilities, including autism. This will be the fourth cohort of Act Early Ambassadors who will continue work of serving as a state, territory or organizational point-of-contact for the national L TSAE program and support of the work of Act Early Teams and other state or national initiatives to improve early identification of developmental delay and disability. Ambassadors also work to promote adoption and integration of [L TSAE resources](#), including materials to support developmental monitoring (milestone checklists, Milestone Moments booklet) and professional education tools ("[Autism Case Training: A Developmental Behavioral Pediatrics Curriculum](#)", "[Autism Case Training: Web-based CE Course](#)") for primary care health professionals. Announcements of this fourth cohort of Act Early Ambassadors will be made in early May. Please check out www.aucd.org/actearly for more details.

SPHARC

AUCD works closely with the Association of Maternal and Child Health Programs' (AMCHP) State Public Health Autism Resource Center (SPHARC). The goal 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 types 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.

TRAINING MATERIALS and WORKSHOPS

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.

DSM-5 Resources

Under the new DSM-5 criteria, clinicians will diagnosis individuals with a single umbrella diagnosis of ASD, rather than the four separate disorders that could be diagnosed under the DSM-IV: autistic disorder, Asperger's disorder, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified. This page includes select resources that AUCD network members have found to be helpful in understanding the changes to the new criteria. Questions? contact tchristensen@aucd.org.

Workshop: LEND Workshop: Autism Spectrum Disorder and Hearing Loss: On Sunday April 13, 2014, over 50 LEND students and faculty will participate in an interactive workshop using active learning strategies and case-based discussions to review issues and challenges surrounding hearing loss and autism spectrum disorder (ASD). During the workshop, participants will be placed in large and small group settings and will be encouraged to share personal examples while learning best practices used by LEND faculty and staff. The workshop, funded by MCHB and organized by the Association of University Centers on Disabilities (AUCD), is a pre-conference activity held in conjunction with the Early Hearing Detection and Intervention (EHDI) conference in Jacksonville, Florida in partnership with NCHAM. For more information, please contact Meaghan McHugh at AUCD (mmchugh@aucd.org)

PUBLIC POLICY

The new numbers released in March by the CDC that 1 in 68 children are now estimated to be on the Autism Spectrum confirm that this developmental disability continues to be on the rise, which is why AUCD strongly supports a swift reauthorization of the Combating Autism Act (CAA). The CAA targets every federal department, agency, and office that addresses Autism Spectrum Disorder (ASD) research, surveillance, and the development of evidence-based interventions in order to accelerate the pace of scientific discovery and translation to services. The law has helped to expand research and coordination at the National Institutes of Health (NIH), increased public awareness and surveillance at the Centers for Disease Control (CDC), and expanded the interdisciplinary training of health professionals to identify and support children and youth with ASD and their families through programs of the Health Resources and Services Administration (HRSA). The law was reauthorized in 2011 (P.L.112-32) and is scheduled for reauthorization this year. If no action is taken, the activities authorized under the law will expire on September 30, 2014.

AUCD member programs include 67 UCEDDs, 43 LENDs, and 15 IDDRCs, and we support the 7 DBP programs as well as the agendas of many other disability and training programs around the nation. AUCD members are located across the United States and its territories and are all part of universities or medical centers. Our networks, individually and together, have participated in the conduct of research, education, and training and technical assistance related to the Combating Autism Act.

AUCD urges Congress to quickly reauthorize the Combating Autism Act before it expires. Continued collaborative efforts between the public and private sectors are essential to drive the innovations that will lead to improved identification, interventions, and services for people with ASD and their families. Without reauthorization of the CAA, HRSA would have to terminate grants for training programs, intervention research, and State demonstration grants. With the increasing prevalence of ASD, we cannot scale back our national effort by letting provisions of the Combating Autism Act sunset.

AUCD stands ready to assist Congress to introduce and pass a bill to reauthorize this important legislation as soon as possible. If you have any questions or need more information, please contact me or AUCD's Director of Public Policy, Kim Musheno (kmusheno@aucd.org).

For more information on Autism, the Combating Autism Act, or other Policy issues supported by AUCD, visit our [Public Policy](#) page.

SHARING CURRENT AUTISM RELATED INFORMATION

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

Thursday, April 24, 2014 (3-4pm ET)

Applied Behavior Analysis: Statewide Issues and Solutions

In this webinar, issues around the implementation of Applied Behavior Analysis (ABA) programs will be discussed including licensure, funding, diversity of practices and quality, understanding of ABA and collaboration between ABA providers and other organizations. Both Tennessee and Indiana have addressed these issues and in different ways. This webinar will highlight the processes both states have followed in trying to reach some consensus and to promote legislation in this area. Contact Rebecca Carman at rcarman@aucd.org for more information.

Wednesday, April 30, 2014

Autism Spectrum Disorder and Transition

This webinar will begin with a presentation from Got Transition staff who will speak broadly about transition and an upcoming Federal transition plan. This presentation will be followed by CAAI grantee presentations on research, training, state-specific successes and best practices for advancing transition for individuals on the autism spectrum. For more information, contact Rebecca Carman at rcarman@aucd.org

May 2014 (TBD)

Reducing Disparities for People with Autism Spectrum Disorder (May, TBD)

Disparities in accessing diagnostic and treatment services, access to care based on location, and racial and cultural differences in outcomes exist in our health care service systems. This webinar will focus on CAAI grantees work in reducing some of these disparities for individuals on the autism spectrum. Date and presenters are being confirmed and will be announced soon. For more information, contact Rebecca Carman at rcarman@aucd.org

*AUCD ARCHIVED Webinar: **Autism Spectrum Disorder and Children Who are Deaf or Hard of Hearing** (also found at: www.aucd.org/webinars)*

This webinar used a combination of information from the literature, retrospective chart review of children with a dual diagnosis and feedback from family and professional focus groups to assist participants in understanding the unique needs of children who are deaf/hard of hearing (hoh) with an autism spectrum disorder. Red Flags for atypical communication were presented as well as information about the needs related to communication, functional skills, and integrated care models. (Speakers: Susan Wiley, MD and Michael Scott, AuD of the LEND program at the Cincinnati Children's Hospital and Medical Center.)

*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 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 Online 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](#)

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 [Centers for Disease Control and Prevention \(CDC\)](#).

New Transition Training Strategies Posted to ITAC Training Toolbox

5 new transition training strategies are now available in ITAC's Training Toolbox. The Toolbox is an easy way to browse and share innovative and time-tested training strategies on a variety of topics relevant to leadership and the Maternal and Child Health.

Senator Harkin Introduces Six By '15 Campaign

During an evening reception at the Disability Policy Seminar, Senator Harkin officially announced the start of the "6 By '15" campaign - an national effort to work on six national goals by the end of 2015, the year that marks the 25th anniversary of the Americans with Disabilities Act (ADA) and 40th anniversary of the Individuals with Disabilities Education Act (IDEA). The campaign builds on Senator Harkin's goal to have 6 million working-age adults with disabilities participating in the workforce by 2015 and adds goals on community living, education, transition, healthy living, and early childhood. More information is available at <http://sixbyfifteen.org> and you can join the conversation on twitter using #6by15. AUCD is a founding partner of the campaign, along with the National Association of Councils on Developmental Disabilities, National Disability Rights Network, US Business Leadership Network, Special Olympics, and National Council on Independent Living.

CAAI Meetings

[CAAI Virtual Poster Symposium](#)

July 28, 2014

A virtual poster symposium focuses on bringing the concept of a poster presentation beyond the walls of a conference hall. The virtual poster symposium will share a wide variety of successes CAAI grantees have had in the identification, assessment, diagnosis, and services to children with autism spectrum disorders and other developmental disabilities and their families.

[2014 CAAI Virtual Activities Series](#)

Upcoming Webinars

Autism Spectrum Disorder: From Numbers to Know-How

April 22, 2014

Join us to discuss the challenges of understanding and diagnosing this complex disorder and the opportunities for early identification and screening. [Read more...](#)

Applied Behavior Analysis: Statewide Issues and Solutions

April 24, 2014

This webinar will highlight the processes Tennessee and Indiana have followed in trying to reach some consensus and to promote legislation around the implementation of ABA programs, including licensure, funding, and more. [Read more...](#)

AS ATN/AIR-P AARC Webinar Series: Topic AIR-P Research - Functional GI

April 28, 2014

[Register here](#)

Autism Spectrum Disorder and Transition

April 30, 2014

This webinar look broadly at transition and an upcoming Federal Transition Plan, followed by CAAI grantee presentations on research, training, state-specific successes and best practices for advancing transition for individuals on the autism spectrum. [Read more...](#)

Reducing Disparities for People with Autism Spectrum Disorder

Disparities in accessing diagnostic and treatment services, access to care based on location, and racial and cultural differences in outcomes exist in our health care service systems. This webinar will focus on CAAI grantees' work in reducing some of these disparities for individuals on the autism spectrum.

The date and presenters will be announced soon [here](#).

About

Developments is a newsletter for CAAI programs funded under MCHB. The content of this newsletter has been generated by program staff and trainees, and does not necessarily reflect the views and policies of HRSA-MCHB. No official support or endorsement by HRSA-MCHB is intended or should be inferred. This publication is funded in part by cooperative agreement #UA5MC11068.