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Intro

Developments is a newsletter for grantees of the Autism CARES legislation (Formerly 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

MCH Research Program Update

Through Title V of the Social Security Act, HRSA's Maternal and Child Health Bureau (MCHB) has a long and rich history of implementing programs that include but are not limited to services, research, training, and system infrastructure building for ensuring the delivery of health care and related services to and promoting the well-being of all mothers, infants, children, adolescents, and children with special health care needs. In 2008, with funding through the Combating Autism Act authority, HRSA's MCHB developed programs to address autism spectrum disorders (ASD) and other developmental disabilities by: increasing awareness; reducing barriers to screening and diagnosis; advancing the evidence base on effective interventions for children and adolescents with ASD and other developmental disabilities; promoting evidence-based guideline development for interventions; and training professionals to utilize valid and reliable screening tools to diagnose or rule out ASD and other developmental disabilities, and to provide evidence-based interventions.

The MCH Research Program plays a critical role in these efforts by supporting both research networks and investigator-initiated research projects to determine the evidence-based practices for interventions and to advance best practices for early identification. Consistent with HRSA's mission as the primary Federal agency for improving access to health care services and improving health equity, many of these MCH research projects focus on the unique and unaddressed needs of these vulnerable and underserved populations, by considering ethnic/racial, cultural, linguistic, socioeconomic, literacy and geographic (e.g., rural/urban) diversity of individuals for whom there is limited evidence of the effectiveness of interventions or for whom disparities in early identification of ASD and other developmental disabilities exist.

The portfolio of MCHB Autism Intervention Research Programs funded since 2008 includes the following projects:

• Five National Research Networks, which include: Autism Intervention Research Networks on Behavioral Health (AIR-B Network) and Physical Health (AIR-P Network) that focus on:
intervention research, tool validation for interventions, guideline development, dissemination of network findings and activities to the research community, health care professionals and service providers, communities, families of children and adolescents with ASD and other developmental disabilities and the public, and promote the transfer of findings on effective interventions into practice; Developmental Behavioral Pediatrics Research Network (DBPNet) to advance clinical practice, optimize health and functional status of children with developmental and behavioral concerns and disorders, including children with ASD and other developmental disabilities; MCH Research Network on Promoting Healthy Weight (HW-RN) to improve our understanding of factors contributing to the possible increased risk of overweight and obesity among children with ASD and other special health care needs; MCH Health Care Transitions Research Network for Youth and Young Adults with ASD (HCT-RN) to advance the field with research designed to improve health care transitions and promote an optimal transition to adulthood among youth and young adults with ASD, including optimal physical, psychosocial, educational, and vocational outcomes.

• Twenty eight field-initiated R40 Autism Intervention Research grants to determine the evidence-based practices for interventions and to advance best practices for the early identification of ASD and other developmental disabilities to improve the health and well-being of these children and adolescents.

• Seventeen field-initiated R40 Secondary Data Analysis Studies to determine the evidence-based practices for interventions and to advance best practices for the early identification of ASD and other developmental disabilities, utilizing exclusively the analysis of existing secondary data.

The research grantees have conducted studies addressing topics such as the efficacy of ASD interventions, early identification of ASD in minority populations, family well-being, and transition, have utilized innovative technology to address barriers in access to early intervention for rural, underserved children with ASD, and developed consensus-based guidelines and tools to support families and professionals in providing treatment for children with ASD. To date, over one hundred (100) peer-reviewed manuscripts have been published by the research grantees.

More information about all of these MCH research projects can be found at: http://mchb.hrsa.gov/programs/autism/interventionresearch.html.

With the recent passage of the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 (Autism CARES Act of 2014), the MCH Research Program plans to announce the availability of Fiscal Year 2015 funding for both the AIR-B and AIR-P Networks as well as the R40 Autism SDAS program. We encourage you to sign up for our listserv (www.mchb.hrsa.gov/research) to receive email alerts when these announcements are available, expected in early 2015!
Laura Kavanagh, Director of MCH Workforce Development on New Detail

Laura Kavanagh, Director of MCH Workforce Development, will be on a full time detail for 6 months as the Senior Advisor for Organizational Development, beginning December 1. She will be advising Dr. Lu and the MCHB leadership team. During this time, Lauren Raskin Ramos will be Acting Director of DMCHWD. Laura will still be involved in some of the Bureau's autism activities and will be at the Joint Training Meeting in January.

Training Topics

The Child Born Preterm Growing Up

Stanford University DBP Program has contributed several recent papers that contribute to understanding the neurocognitive outcomes of prematurity:


http://dbptraining.stanford.edu/

Missouri LEND Takes Training to the Cloud

TIPS for Kids (Missouri's LEND) is a partnership between UMKC's Institute for Human Development (IHD), Missouri's UCEDD, and the UMC's School of Medicine, Dept. of PM&R. The LEND is located in Columbia. The didactic classes specific to Autism Spectrum Disorders have been shared by UMC via video conference with professionals and family members who meet at the UCEDD. This year, the LEND decided to offer the presentations as videos in an online training for professionals, families, and graduate students across the state of Missouri.
The online training, offered free of charge, is designed so participants can go at their own pace. Each of 12 lessons consists of 2.5 hours of videos, broken into 20-minute segments, as well as handouts and resources provided during the presentation. Online trainees watch the videos and discuss their thoughts on a moderated discussion board. Thoughts and questions are shared back with the speakers through feedback forms. Each participant who completes the training can earn continuing education units in either social work or education. Currently 60 people are participating in the training from locations throughout the state, with additional people expressing interest in participating.

Here are some quotes from the discussion board where participants introduced themselves:

"I am excited about taking this training and very much appreciate that it is available on-line... a great way to reach a lot of people without requiring extensive time and travel."

"On a personal note, I have a 13 year old daughter who has an ASD diagnosis and am hopeful to learn some techniques in this program to help other families dealing with the spectrum diagnosis especially in the public school setting."

"I've worked for years as a therapist working with children and families. I'm looking forward to learning new and current information about Autism and other neurological disorders."

The videos are recorded using the videoconferencing equipment and posted on a server. IHD staff downloads the videos and edits them lightly. The edited video is transcribed and a film student intern captions each video. Approximately 2.5 hours of presentation are posted each week for the online trainees.

For the first year, Missouri LEND wanted to focus on delivering a training with useful information and learning how to offer an effective online professional development experience. Missouri LEND hopes to offer this again next fall with the goal of finding ways to increase interaction among the online trainees.

For more information on Missouri LEND, visit the TIPS for Kids website: [http://www.tips4kids.org/](http://www.tips4kids.org/)

To learn more about the Institute for Human Development located within the University of Missouri-Kansas City, visit the website: [http://www.ihd.umkc.edu/](http://www.ihd.umkc.edu/)

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**New Hampshire LEND Faculty and Trainees Collaborate with State Title V Program on an Autism State Planning Grant**

In 2013, the state of New Hampshire was awarded a two-year State Planning Grant for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities (the "ASD State Planning Grant") through the U.S. Department of Health and Human Services/Health Resources and Services Administration (HRSA) under the Autism CARES initiatives. In collaboration with the grantee - Special Medical Services (NH's Title V Program for Children with Special Health Care Needs), the NH Council on ASD, and NH Family Voices (NH's Family-to-Family Health Information and Education Center), NH LEND faculty and trainees are actively involved in a variety of activities to improve the system.
of care for children, youth, and young adults with ASD and other related developmental disabilities and their families.

LEND faculty and trainees participated in a needs assessment workgroup charged with the task of reviewing existing data sets and collecting additional information for a needs assessment. A number of data sets provided preliminary findings regarding the characteristics and needs of New Hampshire's children and youth with ASD and other developmental disabilities and their families. These data sets included: (a) NH Department of Education - Special Education Census Data, (b) NH Registry for ASD, (c) National Survey of Children with Special Health Care Needs, and (d) Needs Assessment Online Survey of Families and Young Adults with ASD completed by Special Medical Services in 2012. Based on the grant proposal a process was created for regional focus groups with targeted questions that would provide more in-depth understanding of families' experiences.

LEND faculty and trainees took the lead on hosting six parent focus groups held in different regions of the state to gather qualitative data regarding parents' perspectives on how the state's healthcare, human services, and related systems of care support children and youth with ASD including care coordination and gaps in available supports and services. Parents also discussed resiliency, commenting on what supports their families need to be strong and have hope for the future. The final needs assessment report will be available by the end of the year and will be used as the foundation for developing a comprehensive state plan to improve overall system of care. LEND trainees will be actively engaged in the development of the state plan.

To learn more about the NH LEND program, visit: http://mehlend.unh.edu/

The Center for START Services and the New Hampshire LEND Program Announce a New Partnership

The Institute on Disability (IOD) at the University of New Hampshire is excited to announce a unique graduate-level interdisciplinary partnership between the Center for START Services and the NH Leadership Education in Neurodevelopmental and Related Disabilities Program (NH LEND).

"This relationship allows future leaders to develop a broader understanding of what is needed to promote positive health and mental health practices. We're honored to be part of this important partnership," says Dr. Joan Beasley, Director of the Center for START Services, a program within the IOD.

NH LEND program is an intensive, nine-month graduate-level training program focusing on neurodevelopmental disabilities in children and youth. The Center for START Services’ New Hampshire program provides technical support and frameworks to help better meet the mental health needs of individual with intellectual/developmental disabilities.
This partnership will provide the opportunity for NH LEND trainees and fellows to conduct clinical rotations with the NH START project, and provide an important introduction to the mental health needs of individuals with disabilities. The trainees and fellows will work closely with the NH START coordinators to help prepare for Clinical Education Team trainings as well as with referrals to the NH interdisciplinary consult team/clinic at Dartmouth Hitchcock Medical Center in Hanover, NH.

"We are excited to be working with START this year," states Betsy Humphreys, Training Director for the NH LEND program at UNH. "We hope that our successful partnership with the NH START program will serve as an example for future LEND/START partnerships across the country."

http://iod.unh.edu/About/visionandvoice/Fall2014/NHLEND_START.aspx

Alaska LEND Meeting Training Needs for LCSWs in Rural Alaska

Spanning distances of over 800 miles, Alaska LEND without Walls is getting needed training out to Licensed Clinical Social Workers in rural Alaska who need specific training for licensure. In November 2014, AK LEND offered the training "Ethics in MCH Practice: Interdisciplinary Decision Making" which offered Ethics National Social Work Association CEUs to participants. The training used video conferencing to connect the interdisciplinary presenters and 35 Anchorage participants with 53 other Alaskans in Bethel, Homer, Seward, Juneau, and Fairbanks. Each training uses on-site moderators at each location and active learning activities to increase engagement and participation. This was the first of three planned for this year targeting the training needs of LCSWs.

WI MCH LEND Training Program Now Includes Milwaukee-Link

The "Milwaukee-Link" addition to the Madison-based Wisconsin LEND program provides opportunities for former MCHB-funded Pipeline undergraduate trainees and others who are in graduate school at UW-Milwaukee (UWM), to participate in the WI LEND program and receive leadership training to work with children with autism and other developmental disabilities, their families, and systems of care. A priority is placed on recruiting LEND trainees from under-represented groups who plan to live and practice in the city of Milwaukee. With a focus on serving children with autism in Milwaukee, this extension of the WI LEND program through a collaboration with UWM campus faculty and students is designed to 1) increase the number of professionals from under-represented groups trained to provide diagnostic and other services to children with autism and their families, and 2) increase access to diagnostic services for children in parts of the city of Milwaukee that are underserved and economically disadvantaged.

LEND faculty at UWM are Kris Barnekow, Occupational Therapy (LEND Milwaukee-Link Coordinator); Bonita Klein-Tasman, Psychologist (Coordinator for Clinical Training, Milwaukee); John Heilmann, Speech/Language Pathologist; and Kathy Sawin, Nursing. Up to five graduate students from the disciplines of psychology, occupational therapy, speech/language
pathology, nursing, and this year a family trainee, form the Milwaukee-Link "trainee team" that works together in a training clinic, and participates as a Life Course Story group, to learn how to provide diagnostic, family support and followup services. The LEND curriculum is the same for Madison and Milwaukee-based trainees, with those at UWM completing the didactic curriculum and policy group work by distance participation; traveling to Madison for intensive Leadership Development workshops, orientation and end-of-year activities; and completing other individual and group training activities in Milwaukee as determined in their Individualized Leadership Training Plans.

The Milwaukee-Link trainees engage in community service efforts aimed at positively impacting supports to families of children at risk for or diagnosed with autism. Milwaukee, like many urban areas, experiences significant health disparities in the early identification of children with autism and subsequent interventions. An autism diagnostic clinic staffed by the LEND interdisciplinary team at UWM provides training to LEND trainees and diagnostic evaluations for children in the central Milwaukee area. In the spring and summer of 2014, Milwaukee-Link LEND trainees were an integral part of planning and participating in the Urban Autism Summit held in June 2014, an event that hosted parents, consumers and professionals with the goal of improving autism services for individuals on the spectrum and their families in Milwaukee. LEND Milwaukee-Link trainees remain active in post-summit workgroups designed to address early identification of autism and family/community supports. Plans are underway for another Summit event.

In the pilot year for the Milwaukee Link program (2013-2014), 4 trainees were graduated from WI LEND; an ADOS training workshop was held in Milwaukee attended by LEND trainees and staff from both Madison and Milwaukee; trainees in Milwaukee conducted developmental screening in a preschool associated with UWM; and four families received services through the training clinic. The annual meeting of the Great Lakes LEND Collaborative, with a focus on "Regional Disparities in the Identification of Autism: Looking at Race, Ethnicity, Gender and Age" was held in Milwaukee Sept 26, 2013 and included Madison and Milwaukee WI LEND trainees, faculty and trainees from LEND programs in IL, MN and IN. In the current training year there are five first year trainees and one second-year trainee participating in WI LEND Milwaukee-Link, pictured here. Two of the Milwaukee-Link trainees were former MCH Pipeline trainees from UWM.

For more information about the WI LEND Milwaukee-Link program, please contact Anne Harris, WI LEND Director (harris@waisman.wisc.edu) or Kris Barnekow, LEND Milwaukee-Link Coordinator (krisb@uwm.edu).

South Carolina Presumptive Eligibility Policy Dramatically Increases Access to Early Intensive Behavioral Intervention for Young Children at Risk of Autism Spectrum Disorder
The South Carolina Act Early Team, co-chaired by the UCEDD Director/LEND Leadership Team member (David Rotholz, Center for Disability Resources) and the South Carolina LEND Assistant Training Director and Leadership Team member (Anne Kinsman, Greenville Health System Children's Hospital Pediatric Psychology) has, through its diverse membership of state agency and community organizational leaders, led the way with a policy of presumptive eligibility. This policy, developed through the collaborative effort of the team, provides for children under age 3 years to be eligible for Early Intensive Behavioral Intervention (EIBI) services through the Part C program (BabyNet) if they are found at risk of Autism Spectrum Disorder (ASD) based on a two-tiered screening system implemented by approved screeners. By using the Modified Checklist for Autism in Toddlers (MCHAT) along with the Screening Tool for Autism in Toddlers (STAT) to determine presumptive eligibility, the number of children receiving EIBI under Part C in South Carolina has increased from 86 in 2012 to 331 in 2014 (the policy was introduced in October, 2012). Along with this significant benefit to children under age three, is the seamless transition from Part C to state DD Agency funded EIBI at age three for children who receive a formal diagnosis of an Autism Spectrum Disorder. While there was initially some question about the potential for false positives from the two-tiered screening process (i.e., children being found at risk later being found not to have ASD), the screening process has been shown to be a highly reliable method for its intended purpose. Of the 376 children made eligible for (and receiving) EIBI all but 8 were later diagnosed with an ASD through a formal diagnostic process involving the Autism Diagnostic Observation Scale Second Edition (ADOS 2).

PCDA supports LEND fellows from the University of Washington LEND program and Children's Hospital Los Angeles UCEDD/LEND program

Interdisciplinary Feeding Therapy for Children with Autism and Other Developmental Challenges

Professional Child Development Associates (PCDA) is a non-profit agency in Pasadena, California that is recognized for expertise in the DIR/Floortime® Approach to interdisciplinary care for children with special health care needs and their families. This model takes into account the child's feelings, relationship with caregivers, developmental level, and individual differences in motor development, social-emotional development, cognitive function and a child's ability to process and respond to sensory information. Our unique approach to services includes training, individual and group therapy, and specialized feeding therapy for children with autism and other developmental challenges.

Eating challenges affect approximately 46-89% of children with autism.1, 2 When compared to typically developing peers, children with autism demonstrate greater selectivity, with approximately 60% eating less that 20 foods, and avoidance of novel foods.3, 4 Mealtime is often a stressful environment with greater disruption to family routines, different menus than others at the table, disruptive behaviors requiring frequent redirection, limited family interaction, and meals and snacks resembling or being used as "therapy sessions.2" The prevalence of obesity in children is rising and children with developmental disabilities are no exception.1, 5 Generally, children with autism tend to grow similar to their typical peers, however, the tendency to have fewer foods in a child's repertoire puts them at risk of nutrient deficiencies and exposure
to toxins.3, 6-7 Children with autism have also shown higher rates of gastrointestinal disturbances than their typically developing peers.8, 9

For over ten years, our feeding team has been successful in helping children to accomplish feeding goals, which make feeding safe, support growth and nutrition, and foster a positive experience with food and mealtime. Currently, LEND fellows are involved in our Food for Fit Families (F3), which is a 12 week weight management program for children with autism, and their families funded by The Doug Flutie, Jr. Foundation For Autism, Inc. F3 offers cooking activities, non-competitive sports to support motor skills, nutrition education games, strategies to address behavioral issues around eating, and parent-to-parent support. The fellows are also beginning to compile our feeding team data in order to share the effectiveness of the DIR/Floortime® Approach on feeding with other professionals. We hope to advance current knowledge around appropriate interventions for feeding difficulties seen in children with autism and other developmental challenges.

"The caring, devotion, knowledge and expertise of the staff at [PCDA] cannot be matched...they are the A-Team on all that is dietary and nutrition for special needs children." - Parent of child receiving feeding therapy at PCDA

http://www.pcdateam.org

References


VT-LEND Announces "Videos on Developmental Screening Practices and Autism Spectrum Disorders Diagnosis for Somali Bantu Families."

VT LEND Director, Dr. Contompasis and VT LEND Family Faculty, Ms. Fatuma Bulle collaborated with Vermont’s Title V Children with Special Health Care Needs Program to create educational fact sheets for parents of children recently diagnosed with autism spectrum disorder in Burlington’s growing refugee resettlement community.

These fact sheets were translated into the nine most common languages spoken in our refugee resettlement community: Arabic, Bosnian, Burmese, French, Nepali, Somali, Spanish, Swahili, and Vietnamese.

Dr. Contompasis and Mrs. Bulle also created two videos for Somali Bantu families, as Somali Mai Mai language spoken by the Somali Bantu has no written form.

• The first video describes the rationale for and the processes of developmental screening and referral for evaluation and intervention.
• Second video is based on the FAQ fact sheet for parents of children recently diagnosed with Autism Spectrum Disorder. Click Here for the fact sheets and videos.

Dr. Contompasis and Ms. Bulle presented the videos on November 10 at Association of University Centers on Disabilities (AUCD) 2014 conference.

For more information, please contact VT LEND program coordinator Naw Esther Doh.

Birmingham's "Autism Friendly" Baseball Game

Faculty and trainees from the UAB LEND participated in the planning and support of the Birmingham Barons' first "Autism Friendly" minor league baseball game in May. In collaboration with a number of local service providers and parent support networks, including the Autism Society of Alabama, the UAB LEND provided suggestions on adapting the gameday experience for children and adults with Autism Spectrum Disorder (ASD) and their families. Alterations to the game included reduced volume of music and announcements, placing the team mascot in a special location (instead of walking throughout the park) to reduce anxiety, changing a clapping activity to a jumping activity, and providing "cool down" areas for individuals with ASD and their families if they needed a break from the game.
In addition to volunteering at the event to distribute tickets and provide assistance in the play and "cool down" areas, faculty and trainees developed a social story for each attendee that described the events of the game and what is located throughout the park to prepare them for their experience as well as a brief informational pamphlet to educate the ballpark staff on ASD prior to the game. In addition, information regarding ASD was provided at tables in the park and by the announcer during breaks in the game.

Over 5000 fans were in attendance, including at least 350 individuals with ASD and their families. The first pitch was thrown out by several individuals with ASD ranging from children to adults, the seventh inning stretch song was performed by a young woman with ASD, and several adults with ASD were highlighted before the game. This collaborative community event not only educated others about ASD but also provided a supportive inclusion experience for individuals with ASD. Some parents reported that they never dreamed their child would last an inning at a baseball game, much less have a good time attending the entire game! It was such a good time that the Barons have promised to make this an annual event, with continued focus on increasing awareness and acceptance of individuals with ASD in the community.

More information on this game is available here: http://promo.milb.net/images/14/potm_birmingham_autism.pdf

**UW LEND: Innovative Systems Change for ASD Initiatives**


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 (CAAC) to guide effective systems change for ASD/DD initiatives in Washington State. The Council is in its sixth year and has been renamed the Washington Autism Advisory Council (WAAC). The UW LEND provides leadership and support in partnership with Washington State Title V and WA State Developmental Disabilities Council. Council membership is comprised of individuals and advocates from state and local agencies; diagnostic centers including the UW LEND's Child Development Clinic; UW LEND faculty and fellows; family members, self-advocates and other interested individuals. The WAAC enhances the visibility of the UW LEND training program and attracts potential fellows from nontraditional sources.

The following comment is from a former UW LEND Fellow who attended a meeting: "I attended this meeting not really knowing what to expect, nor who would be there. I was stunned by who was in attendance. Many heads of state departments (HCA, DDA, etc.) were there, as well as directors of clinics (SCH Autism Center, UW Adult Autism Center, UW LEND, etc.). Also many folks from resource agencies across the state were present. It seemed to me that the meeting was more like a State of the Union on what is currently happening on the autism front in Washington State. I appreciated seeing how many of the different parties were providing updates on legislation, Medicaid, insurance, etc in an effort to provide the most current information to those in positions that can make a difference in the delivery of care to those with ASD."
THE UW LEND faculty in partnership with WA State Title V currently collaborates with rural and under-served communities to increase community capacity and coordinated systems to screening, diagnostic, and intervention programs for children with ASDs and their families. The project is referred to as the Community Asset Mapping (CAM) Project. To date, nine CAM Communities across Washington State have improved early identification and diagnosis of children with ASD and other developmental concerns. UW LEND Fellows participate in CAM activities and have the opportunity to visit rural and underserved areas in Washington State.

UW LEND faculty were instrumental in helping to develop and support the Washington State Medicaid services for children with ASD program operated by the newly formed Health Care Authority (HCA). Because so few providers assess and treat children with public insurance, the Child Development Clinic supported by the UW LEND was designated as a Center of Excellence (COE) in the diagnostic assessment of ASD, ensuring improved access, assessment, and accuracy of autism specific diagnostic services for the entire state. Medicaid offers coverage for Applied Behavior Analysis (ABA) therapy for children who have a confirmed diagnosis of autism and treatment plans. ABA coverage was recently extended to children with developmental disabilities. UW LEND clinicians and fellows routinely perform interdisciplinary team evaluations; have experience in confirming autism diagnoses and make treatment plans for all children including children covered by Medicaid.

UW LEND faculty collaborated with Seattle Children's Autism Center to create a new ARNP fellowship utilizing UW LEND curriculum and MCH leadership competencies as part of a year long clinical, didactic and community training toward diagnosing and treating children with ASD and other neurodevelopmental disabilities. Two UW LEND fellows completed the program last year and two additional fellows are completing the program this year.

Mental Health Parity in Washington State was pursued through the legal system which has afforded the UW LEND to offer Continuing Education to primary care providers in rural and underserved areas. The Conference "Building a Medical Home for Children with ASD and Their Families" scheduled for October 2015 will offer a one day CME conference and corresponding online training modules addressing complementary and alternative medicine, transition, advocacy and appeals.

Research Roundup

AIR-P Updates

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

The Autism Intervention Research Network on Physical Health (AIR-P) conducts research on evidence-based interventions to improve the physical health and well-being of children and adolescents with autism spectrum disorders (ASD) and other developmental disabilities. The network also works to disseminate main findings to parent and professional communities. Network activities include developing evidence-based guidelines and tools; disseminating critical information on network research findings, guidelines developed, and tools to health
professionals and the public; and developing and mentoring new investigators in the field of ASD and other developmental disabilities. The AIR-P has been highly productive in all of these areas.

In 2014, with support from AIR-P, network members developed six ASD toolkits on the following topics: sleep in adolescents, pica, vision exams, delivering feedback to families, and feeding behavior. Two evidence-based guidelines on the topics of treating children with irritability and ASD and treating children with anxiety and ASD were also developed. The AIR-P Network published 9 manuscripts in peer-reviewed journals in 2014, adding to the 47 manuscripts published since the inception of the Network. Three additional papers have been submitted and are 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 (ATN). The main topics of our papers include co-morbidities for children with ASD, more specifically, nutrition and obesity, sleep problems, gastrointestinal concerns, anxiety, and quality of life. Currently, 16 of our 56 published manuscripts had junior faculty or fellows as lead authors, and 11 of our 25 research projects have/had junior faculty serving in the role of site Principal Investigator, demonstrating our progress in developing the next generation of autism researchers.

A key 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 Data (RFD), which allows individuals to submit a formal request to obtain summary data from the ATN Registry, which is supported in collaboration with AIR-P. Past analyses by external investigators have led to dissertations and manuscripts by trainees in pediatrics and psychology as well as other junior faculty members at various institutions. Individuals interested in learning more about the registry data should visit www.asatn.org.

AIR-P recently funded three new research projects, some from junior faculty, to conduct secondary analyses utilizing the existing ATN registry data: "Effectiveness of Early Intensive Behavioral Intervention Services for Children with Autism Spectrum Disorders" by Nalin Payakachat, PhD, University of Arkansas for Medical Sciences; "Communication Deficits and the Motor System in ASD: Dissecting Patterns of Association and Dissociation Between Them" by Maria Mody, PhD, Mass General Hospital for Children (MGHfC) Lurie Center for Autism; and "Relationship Between Subtypes of Restricted and Repetitive Behaviors and Sleep Disturbance in Autism Spectrum Disorder" by Rachel Hundley, PhD, Vanderbilt University Medical Center.

Similarly, AIR-P has recently supported three new innovative pilot proposals: "Bone Accrual Rates in Boys with Autism Spectrum Disorder" by Ann Neumeyer, MD, Lurie Center/MGH. This study proposes to re-examine boys with ASD and controls from an earlier AIR-P research study and evaluate changes in the bone mineral density (BMD) over time, and examine
volumetric BMD, micro-architecture and strength estimates. "Expanding Capacity of Primary Care to Care for Children with Autism Spectrum Disorder" by Jeanne Van Cleave, MD, MGHfC. This study proposes to develop a system to support primary care clinicians in caring for children with ASDs - to incorporate an evidence-supported toolkit and clinical pathway for identifying and managing associated physical problems. "Improving Hospitalizations for Children with ASD: Testing the Cost and Clinical Efficacy of Integrated Behavioral Intervention" by Kevin Sanders, MD, Vanderbilt University Medical Center. This study proposes to implement and test a specific brief Applied Behavior Analysis model for assessing and responding to severe challenging behavior during acute medical and behavioral hospitalization for children with ASD. All new AIR-P funded research projects are scheduled to be completed no later than August 31, 2015.

As part of our Network research planning, we've actively worked to engage our Family Advisory Committee (FAC) members in various research RFA discussions as sites worked to develop their research proposals. In August 2014, we held a series of three calls - mainly focused on emerging priorities reported by the FAC, including anxiety, sleep, and gastrointestinal issues. This series helped to bridge the gap between our Network researchers and our family partners across the sites. Similarly, as part of our anticipated AIR-P renewal submission in the spring 2015, we will engage our FAC members in the development of the Network's core signature research proposals, under the direction of Karen Kuhlthau, PhD. To do that, Dr. Kuhlthau and the Network Coordinating Center will work with interested members from the FAC to implement strategies for more effectively expanding and improving our model for family partnerships in our Network research program.

This year, AIR-P is coordinating a special supplement to Pediatrics with a timeline for publication in the Fall 2015. Dr. Marji Erickson Warfield, director of the Starr Center on Intellectual and Developmental Disabilities at the Heller School for Social Policy and Management at Brandeis University, and Dr. Lonnie Zwaigenbaum, Associate Professor and Director of Autism Research at University of Alberta, are co-editors for the supplement. The supplement will include: an overview of the AIR-P network, evidence-based guidelines, research studies arising from Registry analyses, reports from AIR-P clinical research studies, and reports from CAAI research grantees including R40s, Healthy Weight Research Network, and DBPNet. For more information, and a full listing of our published manuscripts, please visit our website: www.airpnetwork.org.

**Introducing the Healthy Weight Research Network for Children With Autism Spectrum Disorder & Developmental Disabilities**

The Healthy Weight Research Network for Children with ASD/DD (HWRN) was established in 2013 with funding from the Autism CARES Act via the Maternal Child Health Bureau and is coordinated by the Eunice Kennedy Shriver Center at UMass Medical School in collaboration with Tufts University School of Medicine.

**HWRN Mission**
The mission of the HWRN is to advance the understanding of obesity risk factors in children with autism spectrum disorder and other developmental disabilities, to promote the development of evidence-based solutions to achieve healthy weight in this population, and to disseminate research findings to broad and diverse audiences.

**HWRN Research Agenda**

The HWRN focuses on eating patterns, eating behaviors, family practices around food/mealtimes, as well as physical activity and sedentary behavior patterns and the relation of these to weight status. The HWRN also considers how school and community-based organizations exert influence on children's food intake and physical activity and how these environments may be modified to promote healthy weight in youth. Finally, the HWRN concerns itself with how prevention and intervention programs can be developed, adapted, and delivered in order to be responsive to the needs of youth with ASD/DD and yield the most positive outcomes possible.

The HWRN-ASD/DD fulfills its research agenda by:

- conducting research using existing datasets to improve knowledge about the prevalence of overweight/obesity, key risk factors, and obesity-related health conditions among children and youth with ASD/DD;
- engaging in formative work with the aim of understanding biopsychosocial barriers and facilitators to achieving healthy weight status;
- conducting pilot studies of interventions designed to prevent or reduce excess weight among children and youth with ASD/DD; and
- developing collaborative relationships to leverage extramural funding to conduct interdisciplinary research.

**Getting Involved with the HWRN**

**Subscribe to HWRN news.** Community members, families, self-advocates, clinicians, professionals, and others are invited to subscribe to receive HWRN news by going to: [http://hwrn.org/network-activities/join-the-network/](http://hwrn.org/network-activities/join-the-network/)

**Become an Associate Member.** Researchers, policy makers, or other stakeholders whose work is closely aligned with and relevant to the HWRN mission & research agenda may apply to become an Associate Members, who are eligible for applying for pilot funds in conjunction with Members, participating in ListServ discussions, attending educational offerings, and other relevant Network activities. Persons seeking to be an Associate Member are asked to submit a resume/CV and cover letter to HWRN@umassmed.edu

For more information, please see our website at: [www.HWRN.org](http://www.HWRN.org)

The HWRN is supported by grant UA3MC25735 Maternal and Child Health Research Program, Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.
The Developmental Behavioral Pediatrics Research Network (DBPNet) Expands

The Developmental Behavioral Pediatrics Research Network (DBPNet) is excited to announce the recent addition of two new associate member sites to the network. The network welcomed Doug Vanderbilt from Children's Hospital Los Angeles and Sandra Friedman from Children's Hospital Colorado. The DBPNet Steering Committee is very excited to have both sites in the network.

The DBPNet is developing a Parent Advisory Group, under the guidance of the Network Coordinating Center's Family Advisory Steering Committee Representative, Amy Kratchman from The Children's Hospital of Philadelphia. This group is being established to provide the network with a family centered perspective in the review and development of new protocols and other network activities. The network has accepted the first round of applications and will develop both a Parent Advisory Group and a "Friends of the Network" group. These groups will begin meeting in early 2015.

The Network is also proud to of the most recent acceptance to publication in Academic Pediatrics.
Feldman HM, Blum NJ, Gahman A, Shults J on behalf of the DBPNet Steering Committee. Diagnosis of Attention-Deficit/Hyperactivity Disorder by Developmental Pediatricians in DBPNet (Academic Pediatrics, 2014 accepted for publication).

To get more information on the Developmental Behavioral Pediatrics Research Network (DBPNet) and get updates on publications, research activities, additional site and Parent advisory news and expansions and award opportunities, please visit the website at www.dbpnet.org

State Stories

North Carolina State Implementation Grant Provides Intensive Autism Diagnostic Training to Part C Interdisciplinary Teams

The overarching goals of the North Carolina ASD State Implementation Grant (NC SIG) are to Increase the number of children with ASD who are identified by 24 months of age; increase the number of children with ASD who receive their first interdisciplinary diagnostic evaluation by 36 months of age; and increase the number of children identified with ASD who are enrolled in early intervention services by 48 months of age or younger. As such, the NC SIG, in partnership with the NC UCEDD/LEND Programs, sponsored two 2-day training workshops this year on autism assessment, specifically the clinical use of the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) for interdisciplinary early intervention teams in North Carolina and clinical fellows from the North Carolina Leadership Education in Neurodevelopmental and Related Disabilities (NC-LEND) program. The workshops were hosted by the Carolina Institute for Developmental Disabilities (CIDD) and taught by Pamela DiLavore, Ph.D., co-author of the
original ADOS, Assistant Director of the Chapel Hill TEACCH® Center, and collaborator on the NC SIG.

The ADOS-2 workshops were developed in collaboration with the NC Infant-Toddler Program (Part C) and targeted interdisciplinary personnel from the state-funded Children's Developmental Services Agencies (CDSA). Over 60 professionals and graduate student clinicians attended, including psychologists, nurses, speech-language pathologists, occupational therapists and early special educators. Prior to the workshop, the majority of participants reported that they had never been involved with ADOS-2 administration, nor did they feel entirely comfortable making autism diagnoses in very young children. As a group, however, they did express a desire to learn more about evidence-based assessment in children under 3 years of age and to begin to implement the ADOS-2 as part of their diagnostic practice. Following the workshop, nearly all participants stated that the information provided was pertinent to their day-to-day clinical practice and could be incorporated into their current assessment batteries. As a follow up, participants have reported increased use of and confidence with the ADOS-2 in their interdisciplinary diagnostic teamwork, and have noted a clear shift in their use of evidence-based tools for autism diagnosis. To further assist with implementation into practice, the NC SIG faculty and Dr. DiLavore will continue to provide technical assistance through email, video trainings, and phone conferencing over the next year.

In summary, as the CDSAs are the entry point for early intervention services in North Carolina and the primary agency serving children birth to three years, this training will increase the capacity of professionals available to conduct evidence-based interdisciplinary diagnostic evaluations of young children with or at-risk for autism spectrum disorder (ASD) across the state. In addition, the use of evidence-based assessments will provide opportunities for earlier diagnosis, earlier intervention, and improved developmental surveillance, particularly as children with or at-risk for ASD transition into the public school setting.

The NC SIG is a collaboration of the University of North Carolina at Chapel Hill Department of Allied Health Sciences (UNC DAHS), the CIDD (NC-LEND and UCEDD), and the Autism Alliance of North Carolina, in conjunction with university partners (Chapel Hill TEACCH® Center, Frank Porter Graham Child Development Institute, UNC CH Schools of Public Health and Social Work, the Sheps Center for Health Services Research) and state agencies (Autism Society of NC, NC Pediatrics Society, The NC Academy of Family Physicians, NC Department of Public Health Early Intervention Branch, NC Department of Public Health Women's and Children's Health Branch).

The NC SIG is funded by the Association of Maternal and Child Health Programs (H6MMC26248), and directed by Stephen Hooper, PhD, Associate Dean and Chair of the UNC DAHS, and Rebecca Edmondson Pretzel, PhD, Associate Director of the CIDD.


**Implementing a Statewide Autism Plan for Georgia**

The Center for Leadership in Disability at Georgia State University was awarded a two-year grant from MCHB in September 2014 to implement the Autism Plan for Georgia (APG). We
have worked diligently over the last several months with our Autism Advisory Council and other key stakeholders to implement targeted activities in ten areas that were designed during the 2011-2013 plan development phase.

These ten areas include:
• Early Identification & Screening
• Referral & Diagnosis
• Health, Behavioral Health, & Dental Services
• Family Support
• Early Intervention & Preschool Services
• Elementary & Secondary Education
• Community Services & Supports
• Transition from Youth to Adult Systems
• Adult Services & Supports
• Emergency Preparedness & First Responders

One activity that we expect to cut across many of the areas of the APG will be the Parent Partner Project. The Parent Partners serve as an office-based resource working toward the goal of providing "family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent" support to families of children with special health care needs. Parent Partners connect families to the resources and information they need, and are able to spend time the that is often difficult to provide in a primary care setting.

Georgia's Parent Partner program is a state/community agency collaboration being supported largely through funding from the Georgia Department of Public Health to Parent to Parent of Georgia. Modeled on demonstration projects in New Jersey and Rhode Island, parent partners will operate in four locations across the state. The APG implementation grant is providing partial funding for one Parent Partner to work with Dr. Leslie Rubin, developmental pediatrician, in his clinic in Children's Health Care of Atlanta at Hugh Spalding. Brenda Liz Munoz Williamson, who is a family trainee in the Georgia Leadership Education in Neurodevelopmental Disabilities (GaLEND) program and an Autism Advisory Council member, will serve in this role. The APG implementation grant will also support the evaluation of the impact this pilot project.

We look forward to continued collaboration with our Autism Advisory Council in accomplishing the goals of the APG to enhance access and coordination of services and support across the lifespan.

State Grantees Meet for Peer-to-Peer Exchange on Developmental Screening and Beyond

On August 5, AMCHP's State Public Health Autism Resource Center (SPHARC) held a Peer-to-Peer Exchange on "Screening and Beyond: Improving Systems for Developmental Screening and Early Identification" in Baltimore, Maryland. Hosted by the Maryland autism state implementation grantee team, a total of eight state autism grantees - AR, CO, CT, MD, MS, ND, OH and VA - met to share resources, challenges and successes related to improving developmental and ASD/DD screening, early identification and related systems of care.
The Maryland team shared information on their "Screening and Beyond" Quality Improvement (QI) Learning Collaborative for primary care practices across the state. The 12-month long project includes web-based learning conferences, chart audits to measure care and improvement, a patient roster tool to identify and track children with ASD/DD in participating practices, and hands-on QI coaching in practices and by phone. Additionally, the Learning Collaborative pairs each participating practice with a trained Parent Partner that provides follow-up and resources to families, collects and reports data and provides input as part of the quality improvement process. During the meeting, state and local partners involved in Maryland's efforts to improve screening, referral and diagnostic services also shared their roles and experiences. Participating states also shared updates and strategies with each other during roundtable sessions.

Resources from Peer-to-Peer, included state developmental screening profiles, can be online found here.

**Collaborators' Corner**

**Environmental Scan: State Strategies and Initiatives to Improve Developmental and Autism Screening and Early Identification Systems**

This report includes initial findings from an environmental scan of source documents in an effort to capture the range of developmental screening activities occurring within all U.S. states and territories. A companion fact sheet on state performance measures related to developmental screening and early identification is also available. [Funded by the U.S. Maternal and Child Health Bureau]


Readers: Over the coming year, the data will be further analyzed to develop resources to assist states, particularly Title V programs, in building and improving developmental screening and early identification systems. The tools and resources will be available in AMCHP's State Public Health Autism Resource Center at http://www.amchp.org/programsandtopics/CYSHCN/projects/SPHARC/Pages/default.aspx
AMCHP PULSE Newsletter on Early Childhood and Youth Development

AMCHP's bi-monthly, topic-specific e-magazine, AMCHP Pulse is shared with the entire AMCHP family, including members, partners and others interested in MCH issues. The November/December issue focused on various topics related to child and youth development. This includes features on developmental screening and early childhood systems. To download a PDF of the issue, click here.

www.amchp.org/AboutAMCHP/Newsletters/PULSE

Autism Speaks Early Access to Care Initiative

*Lowering the average age of diagnosis and increasing access to early intervention for all children*

Autism Speaks Early Access to Care initiative seeks to reduce the average age of diagnosis and increase access to high-quality early intervention for all children on the autism spectrum.

According to the CDC, the average age of diagnosis is 4-5 years, but a reliable autism diagnosis can be made as early as 18-24 months. While early detection is critical, research shows that many parents have very little knowledge about autism and its symptoms. Many studies have also documented that racial ethnic minority populations and those of lower socioeconomic status are diagnosed later. The earlier children are identified, the earlier they are able to receive early intervention services. Evidence-based early intervention services have been shown to reduce the core symptoms of autism, improve IQ and daily functioning.

Improving this unacceptable situation will take the combined efforts of families, healthcare professionals, educators and autism advocates in every community.

Resources of the initiative include:

- First Concern Action Tool Kit
- Resources for Parents
- Engaging Professionals
- Engaging Community Partners
- Research and Progress in Early Intervention

http://www.autismspeaks.org/early-access-care

The Autism NOW Answer Series

The Autism NOW Answers Series allows readers to ask experts a question. Two questions are selected each month to answer.
Center co-director Amy Goodman, an individual with autism, has filmed more than 30 short YouTube videos as part of the Autism NOW Answer series, answering individual's questions on topics ranging from "What is positive behavior support?, to "What is vocational rehabilitation?"

See more at: http://autismnow.org/2012/11/12/introducing-the-autism-now-answers-series/

These videos can be viewed on the Autism Now YouTube Channel: https://www.youtube.com/user/AutismNowCenter

**ITAC Items**

**AUCD Unleashed: The Power of Engagement**

The 2014 AUCD Conference theme reflects our goal of achieving an elevated level of engagement with our respective and collective communities, networks, and well beyond in order to better inform, enhance, and enrich the work we all do to improve the lives of people with disabilities and their families. View transcripts, photos, and other materials here.

**Act Early Update**

Thirty-one esteemed Act Early Ambassadors who serve as state liaisons to the "Learn the Signs. Act Early." (LTSAE) project have implemented several innovative and effective strategies to reach target audiences and improve early identification of Autism Spectrum Disorder and developmental delays. In six months, the Ambassadors have reached approximately 36,983 total target audience members. These target audience members include 18,873 parents of young children, 12,001 audience members through media outlets, 3,628 early care and education providers, 1,404 health care professionals, 846 family service providers, and 231 Act Early State Team members. A total of 39,984 LTSAE materials have been distributed to the target audience members. Ambassadors have distributed Milestone Moments booklets, brochures, and checklists, and Amazing Me: It's Busy Being 3! Materials, and integrated the Watch Me! online modules while delivering key LTSAE messaging to practitioners at UCEDDs, LENDs, health departments, home visiting programs, WIC, and public libraries.

In addition to delivering LTSAE key messaging to and collaborating with home visiting programs, public libraries, and museums, several Ambassadors are using media outlets to disseminate customized materials to primary and secondary target audiences. The Rhode Island Ambassador, Stacey Aguiar, is implementing a communication plan with the Communication Department at the Rhode Island Department of Health. The communication plan includes incorporating LTSAE web links onto www.health.ri.gov, showcasing LTSAE materials, web links, and videos on social media platforms, and having the DOH Director promote LTSAE messages on monthly Poder (Spanish language) radio appearances.

The 2013 Act Early State Systems Grantees aimed to improve their state and local systems for
early identification and early intervention services for children with signs of Autism Spectrum Disorder and developmental delays. The State Systems Grantees projects involved public awareness, education and training, and collaboration activities to improve early identification. The grantees have shared the most significant lessons that they learned throughout their program implementation. Several of the grantees discovered that many home visitor programs were not aware of the CDC Learn the Signs. Act Early. initiative. Grantees who worked with home visitor programs found that it is essential to emphasize the process of early identification including developing observation, then screening, and then referral and family support. The California Act Early State Systems Grantee project revealed that home visitors believed that they could positively impact a child's life course through observations using the LTSAE materials as a starting point. The grantees also found that they need to identify partners to distribute materials to, and partners who will continue to use the materials after the project has ended.

If you would like to receive the Act Early Network e-newsletter, please email your name and email address to Abigail Alberico at aalberico@aucd.org, and she will add you to the Act Early listserv.

**2014 CAAI Virtual Activities**

In 2014, ITAC and SPHARC hosted a series of virtual events for CAAI grantees (now Autism CARES grantees). This year, CAAI grantees had an opportunity to share their successes and discuss topics of mutual interest in a virtual environment. Activities began during Autism Awareness Month (April) and ended with an interactive poster symposium in July. The archived materials can be found [here](#).

**Sixby15 Campaign Early Childhood Initiatives**

Members of the AUCD network believe that early childhood intervention, and developmental screening is a priority for children. We hope that by the end of 2015, six states will have increased their current rate of developmental screening for children birth to three by 15 percent, and at least six states commit to improving cross-system information exchange that supports access to services for children identified by screening.

AUCD continues to support the Sixby15 campaign along with 5 other founding partners. The Early Childhood initiatives have now been officially endorsed by 153 state and national organizations.

Visit the Sixby15 campaign website to learn about how AUCD and its partners are moving forward on Early Childhood and other goals, endorse the campaign, and share what your state or program is doing.

[http://sixbyfifteen.org/](http://sixbyfifteen.org/)
[http://sixbyfifteen.org/endorsers/](http://sixbyfifteen.org/endorsers/)
About the Campaign
Senator Harkin officially announced the start of the "Sixby15" 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.

Meetings

2015 LEND Directors and LEND/DBP Directors Strategic Thinking Meetings

Friday, January 23, 2015
Washington Court Hotel
Washington, DC

AMCHP 2015: United to Build Healthier Communities

January 24-27, 2015
Hyatt Regency Washington
Washington, DC

Autism CARES Meeting

Save the Date!

July 16-17, 2015
Hyatt Regency Bethesda

More information about this meeting will be made available in the coming weeks.
Upcoming Webinars

The Commit to Inclusion Campaign and the Guidelines to Disability Inclusion in Physical Activity, Nutrition, and Obesity Programs and Policies

Tuesday, January 13, 2015
2:00 pm (ET)

CMS Guidance and Autism Spectrum Disorders

Thursday, January 22, 2015
2:30 pm (ET)

More information will be available in January

Positive Supports and Cross Systems Crisis Intervention Planning

Wednesday, January 21, 2015
3:00 pm (ET)

More information will be available in January

About

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