

Developments, December 2012

Issue 1, Volume 1

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Intro

Developments is a quarterly newsletter for grantees of the Combating Autism Act Initiative (CAAI). Published by AUCD's Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities ([ITAC](#)) and AMCHP's State Public Health Autism Resource Center ([SPHARC](#)), this newsletter allows grantees and partners to share current news, activities, events, research, and accomplishments in autism and related developmental disabilities with program faculty, students, and supporters. Sections of the newsletter are regularly devoted to each of the grantee groups (research, states, LEND training and DBP training), as well as MCHB and our collaborating partners.

MCHB Minute

http://www.aucd.org/template/news.cfm?news_id=8320&id=17

Laura Kavanagh, MPP

Director, Division of MCH Workforce Development and Autism Team Lead

Welcome to this inaugural issue of *Developments*, the CAAI newsletter, and greetings from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA)!

Exchanging information between CAAI grantees has been a priority of the CAAI program since it's outset in 2008, and I am very pleased about this new newsletter. We're using a variety of methods to ensure that you are aware of the lessons learned through CAAI investments, the two funded resource centers ([ITAC](#) and [SPHARC](#)), various grantee meetings, numerous webinars, toolboxes and other tools, and more. We want to be sure that you have access to the latest research findings, training approaches, and state program priorities in the area of autism spectrum disorders and other developmental disabilities. All current investments are also highlighted on our web site, www.mchb.hrsa.gov/autism.

We at MCHB have several news items to share with you. First, the Developmental-Behavioral Pediatrics Training Program competition recently concluded, and results will be announced later this fiscal year. Second, in the Spring of 2013 we also plan to compete two other CAAI programs, autism research and state demonstration grants, and these program announcements will appear on Grants.gov, <http://grants.gov>. Lastly, we were pleased to see research findings from multiple HRSA-supported autism research grants recently published in a Pediatrics Supplement, http://pediatrics.aappublications.org/content/130/Supplement_2.toc (*Pediatrics*, November 2012, VOLUME 130, Issue Supplement 2).

Please let us know if you find this new newsletter helpful in communicating and sharing information, and provide feedback as to how we can improve it over time. I hope to see you soon.

Training Topics

University of Arizona LEND Trainees Reach Out

http://www.aucd.org/template/news.cfm?news_id=8343&id=17

Trainees at the University of Arizona LEND are participating in a research project focused on increasing the systematic developmental screening in early childhood, consistent with AAP surveillance and screening guidelines.[1] The project will implement a general pediatric screening tool at 9, 18, 24 months and an autism-specific screening tool at 18 and 24 months. Some of the goals of the project include:

1. Increase the number of timely developmental screenings conducted on children age birth to 24 months in Arizona in communities with underserved populations.
2. Decrease time to diagnosis for children birth to 36 months at high risk for ASDs by providing an intermediate referral physician source in communities with underserved populations.
3. Increase the number of appropriate referrals for full autism screening and early intervention services in communities with underserved populations.

Fourteen LEND trainees are grouped into teams and each team is working with a rural community health center to implement developmental screening process in each clinic site. As part of the project, the teams have reviewed clinical processes, made suggestions for how the program might be implemented and have trained staff and providers on developmental screening tools. In the spring, they will return to each clinic and will abstract medical records to assess the effectiveness of the intervention.

The teams are working with three community health centers in communities on the Arizona-Mexico border (west to east on map: San Luis, Nogales, Douglas). Each team has visited the clinic sites and has been welcomed by staff members in the clinics. Clinic staff have shared the challenges of working on the border and have discussed with the LEND trainees and faculty how they are able to function successfully as a community health center. Each of the sites faces challenges of poverty, a migrant population and limited healthcare resources. The teams were able to discuss these issues with clinicians and administrators to appreciate each health center's mission, priorities, resources and community.

[1] American Academy of Pediatrics, Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening, Pediatrics, 2006; 118; 405

LEND Leadership Project Provides Summer Camp Experience to Children with High Functioning Autism

http://www.aucd.org/template/news.cfm?news_id=8338&id=17

When Misti Moxley realized that her son's high functioning autism diagnosis might keep him from having an overnight summer camp experience, she saw an opportunity, not a barrier. She and her husband founded ASD Oregon, a non-profit organization that hosts the only summer camp specifically for children with high functioning autism spectrum disorders in the Pacific Northwest. While planning the inaugural session of camp, Misti was a family consultant trainee in the LEND program at Oregon

Health and Science University's Institute on Development and Disability. Her LEND cohort and the faculty of OHSU's IDD helped to transform Misti's dream into an unforgettable camp experience for over forty children, including Misti's son.

The mission of Camp Quest is to facilitate the kind of summer camp experience that most children enjoy with added support, encouragement, and expertise specifically designed for children with these special needs. Camp activities are designed according to the interests of campers and have included computer programming, science club, and arts and crafts. Though Camp Quest has twice the operating cost of a traditional overnight camp, ASD Oregon keeps it accessible by charging families just half of what it takes to run the camp.

The additional funds are raised through generous sponsors and fundraising events like The Camp Quest 5k Run, which started last Spring as another LEND trainee project supervised by Misti.

Now preparing for its fourth summer, Camp Quest has grown to serve even more families and continues to be a popular leadership experience for LEND trainees. As a LEND alumni, Misti understands the importance of giving trainees a leadership opportunity that not only suits their individual interests but develops their unique leadership skills. Trainees are involved in planning camp activities, coordinating logistics for the 5k run, and serving as camp counselors. The collaboration between current LEND trainees and LEND alumni from OHSU's IDD represents the long-term impact of interdisciplinary training on individual trainees and their communities.

LEND Great Lakes Collaboration Holds Regional Forum on Autism

http://www.aucd.org/template/news.cfm?news_id=8339&id=17

The Riley Child Development Center (Indiana LEND) hosted the 2012 LEND Great Lakes Collaboration annual regional meeting in Indianapolis. The 2012 Forum was follow-up from the 2010 *Learn the Signs. Act Early.* regional summit also held in Indianapolis. The goal of the 2012 Forum was to bring together trainees, community partners and faculty to share ideas to influence practice, policy, intervention, and advocacy in the area of autism identification, screening/assessment, and intervention/services. In addition to the four Great Lakes LEND programs, representatives from the UCEDD programs at the University of Puerto Rico and Wayne State University participated in the day long forum. These programs are actively preparing to establish LEND training activities in their states.

The Great Lakes Collaboration annually plans an onsite, regional learning opportunity with the goal of bringing faculty and trainees together on a selected topic. These participants have a unique opportunity to share ideas and resources around a particular topic. Trainees report the experience enhances their understanding and appreciation of the AUCD network as well as their knowledge of autism and other developmental disorders. In an effort to expand the regional forum impact, the morning session is broadcast electronically to all participating sites with local facilitators. The afternoon session is designed to build on the issues identified in the morning. Groups at each site take advantage of this time with LEND faculty, trainees and community partners.

For the 2012 Forum, each state partnered with their state autism planning groups to prepare a brief presentation to share about their progress since the 2010 *Learn the Signs. Act Early.* Summit. Presentations provided highlights of each state's demographics, their state plan for autism, the partners involved in implementation, what has worked (lessons learned) and what challenges remain. Participants were provided a handout with reflective questions to help focus their thinking in preparation for the afternoon breakout sessions to focus on sharing and solving challenges. Reflective questions included:

- What ideas did you hear that you might further explore in our state?
- Who else might be invited to the table in our state?
- What are the gaps or missing pieces in our state plan?
- What additional outcomes should be added to our plan? Which outcomes should be modified?
- What are the priorities in our state from each constituent's perspective?
- How can we measure our success?

Stephan Viehweg of the Indiana LEND opened the 2012 Forum with a review of goals and outcomes from the 2010 Summit held in Indianapolis. Participants were reminded of the materials available from the CDC and updated on new materials and programs. States were recently encouraged to use the self-assessment rubric to review progress of goals and activities at the state level. Viehweg explained the process for sharing states' progress and challenges. Each of the six participating states shared a presentation highlighting their progress. Presentations were made by both faculty and trainees, including Act Early Ambassadors Gail Chodron (Wisconsin) and Nicole Quintero (Illinois). After the state presentations, Scott Badesch from the Autism Society of America addressed the audience, sharing updates and challenges from a national perspective.

Four main themes or topical areas emerged from the presentations as discovered by LEND faculty Amy Hewitt (Minnesota), Ann Cutler (Illinois), and Anne Harris (Wisconsin) who observed the session. The main themes as well as highlights of group discussions recorded by Amy Hewitt included:

1. Research and Data – *Discussion highlights:* Data collection must be meaningful and relevant. We must demonstrate how our results can be translated into practice and used by families and the community. Research efforts should focus on outcomes. A unified database (across programs) could be extremely useful. A future goal is to discover possible research activities that collaborate across the programs in the network.
2. Transition to Adulthood – *Discussion highlights:* Programs are exploring how to support transition from childhood to adulthood. Some are focusing on partnerships with vocational rehabilitation and employment programs. Some programs are devising specialty clinics to focus on transition. Some wonder if adult self-advocates should be considered as core faculty in LEND programs. Programs noted challenges for people with autism in accessing appropriate supports and evidence based treatment and services. Individuals with dual diagnosis present particular challenges. A goal is to encourage self-advocates to participate in policy and program development. Participants agreed to continue sharing ideas and program developments.

3. Access to Screening and Diagnostic Services (including pre-service training) – Discussion highlights: All states shared frustration and concerns with challenges to service delivery to access screening, assessment, diagnosis and treatment. This results in waiting lists and frustrated parents. With the increase in prevalence, there is a shortage of personnel to address the increased need. The group discussed striving for a parallel process in training families and providers, improving diagnostic practices and availability, collaborating with insurance providers about supporting evidence based procedures and interventions, and increasing knowledge of providers and community partners about autism and related developmental disorders.
4. Outreach to Rural and Minority/Underserved Populations – Discussion highlights: Technology advances could enhance service delivery to rural areas however challenges include security and access. Some states are promoting collaborative efforts between programs currently serving rural areas such as Title V clinics, neighborhood and community organizations, as well as exploring innovative interactive information and materials to use with families and their children.

Participants made a commitment to continue sharing ideas and strategies across programs and states. There was a sense of possibility to positively impact screening, diagnosis, and services for individuals with autism and other developmental disorders as a direct result of collaboration across states and programs. From a LEND program perspective, these annual regional meetings that focus on specific topics such as autism have been found to exceed expectations for their outcomes and value.

To review each state's presentation of their current information as well as a summary of this forum, please visit <http://www.aucd.org/template/page.cfm?id=777>. The Great Lakes Collaboration is already planning for next year's meeting and will build on the successes of the 2012 Forum as we strive to improve our training and service outcomes.

University of Pittsburgh LEND and Autism Treatment Network of Pittsburgh Awarded Autism Intervention Research Network on Physical Health Funding
http://www.aucd.org/template/news.cfm?news_id=8332&id=17

This year long project is being conducted in conjunction with ACHIEVA (Arc of Greater Pittsburgh). Parent-focused topics include "Navigating the Medical System" and continuing education topics include "Autism and Epilepsy" and "Autism and Genetics and Autism." The medical topics are aimed at addressing the need for...

Autism Center of Excellence Network Grant: Newly Established Collaboration of LEND Programs and Tuberous Sclerosis Clinics
http://www.aucd.org/template/news.cfm?news_id=8322&id=17

A consortium of five pediatric hospitals that are geographically-distributed throughout the US have been awarded a five-year project, funded by the National Institutes of Neurological Disorders and Stroke (NINDS). The project, **TSC Autism Center of Excellence Research Network (TACERN)**, is aimed at elucidating biomarkers of autism...

Act Early Alabama Team Reaches Across the State

http://www.aucd.org/template/news.cfm?news_id=8328&id=17

The UAB LEND continues their work in supporting the "Learn the Signs, Act Early" campaign in the state of Alabama. Dr. Sarah O'Kelley, clinical psychologist and LEND interdisciplinary training coordinator, helps lead a statewide work group focused on early recognition and referral of individuals at risk for ASD/DD.

Brief Video on Using Autism Case Training (ACT) for Residency Training

http://www.aucd.org/template/news.cfm?news_id=8330&id=17

A new instructional video produced by the [University of Cincinnati UCEDD/LEND](#) illustrates how to use the Autism Case Training (ACT) Modules created by the Centers for Disease Control and Prevention (CDC) in training pediatric and Family Medicine residents. The ACT Modules are available at the [Centers for Disease Control and Prevention website](#) and the video link is available on [Vimeo](#) or [YouTube](#).

The *Autism Case Training* (ACT) case-based curriculum is designed for use in training on screening, diagnosing and treatment for autism spectrum disorders and other developmental disabilities. ACT is a component of the "Learn the Signs. Act Early" Program of the Centers for Disease Control and Prevention. The purpose of "Act Early" is to improve early identification of autism and other developmental disabilities so children and their families can get the services and support they need.

Research Roundup

Improved Early Identification of Autism in Latino Children

http://www.aucd.org/template/news.cfm?news_id=8321&id=17

Despite evidence that formal Autism screening tools improve identification, the use of these tools in primary care settings tends to be low (Dosreis, Weiner, Johnson, & Newschaffer, 2006). In addition, although the prevalence of Autism has increased (CDC, 2012), there continues to be strong evidence of disparities in identification and service utilization for Latino children as compared to non-Latino white children (Mandell, et. al., 2009).

Georgetown's project, "Improved Early Identification of Autism in Latino Children," funded by the Maternal and Child Health Bureau (MCHB) at the Health Resources and Services Administration (HRSA), grew out of disquiet about disparities in access to developmental services in Washington among D.C. delegates to the Act Early Region III Summit in 2010. One of the goals that emerged from the summit was to increase screening for Autism Spectrum Disorders (ASD) among Washington's largely Central American immigrant families.

Screening in pediatric primary care was recognized as a key step in identifying young children with ASD in order to expedite early behavioral and educational interventions that can improve outcomes. In order to develop an effective approach, Georgetown partnered with Unity Health Care, a large provider of medical care, whose Upper Cardozo Clinic is the largest primary care center in D.C. serving a primarily Latino population. Through a community participatory process, which included preparatory research with families, primary care providers and medical staff, the "Supported Screening" model was created to enhance identification of ASD and successful referral and timely evaluations for Latino children.

The formative phase of the program included community research. Focus groups with Latino parents explored their beliefs and attitudes about Autism, knowledge of developmental milestones and comfort using a developmental screening questionnaire. Focus groups with medical providers surveyed their beliefs and practices related to Autism screening. Several potential barriers to successful intervention were identified. Families reported limited knowledge of developmental milestones or Autism. They also indicated that when there was a concern, they would more likely approach a community or family member rather than a medical provider, partly because this was not viewed as a topic that one would raise with a doctor. Primary care personnel were concerned that low literacy rates among Latino families would limit parents' ability to independently complete the screening tool, the Modified Checklist for Autism in Toddlers (M-CHAT, Robins, Fein, & Barton, 2001), conducted at 18- and 24-month well-child visits. Providers were also apprehensive about the time needed to administer the M-CHAT and follow-up interview and reported that families only infrequently raised developmental concerns. Additionally, cognitive interviews with parents about the 23 M-CHAT questions suggested that some wording in the translated tool was not culturally relevant. For example, the majority of Central American parents did not understand a question about the game "peek-a-boo," even when explicitly described, because there is no equivalent game in their native countries. As a result, it was

necessary to adapt the M-CHAT wording slightly and modify the administration to meet the cultural and linguistic needs of participating families.

The resulting Supported Screening Program consists of three main components: (1) outreach activities for families around developmental milestones; (2) hands-on training for primary care providers, involving five 75-minute sessions covering diagnosis of ASDs, screening with the adapted M-CHAT, interpretation and referral, engaging and activating families as well as addressing barriers identified in formative research; and (3) ongoing care coordination and support for families by bilingual and bicultural family navigators with relevant professional and personal experience. Family navigators complete the M-CHAT in Spanish or English in a face-to-face interview with parents or over the phone. Screens and referrals are tracked for 18-60 month children who receive care at the Upper Cardozo clinic. Efforts continue to develop and strengthen relationships in the community serving Latino children and families, including the school and early intervention systems, providers, and advocacy organizations.

Results in the second year of the project are promising. Pre-post training and follow-up evaluations with providers showed an increase in their knowledge of Autism. They also demonstrated increased understanding of the rationale and skills for evidence based screening as well as methods to encourage disclosure of developmental concerns by families. The rate of M-CHATs completed for eligible children at 18 and 24 months has shown rapid growth, increasing from less than 5% prior to the onset of Supported Screening to approximately 60% after three months of implementation to almost 100% six months into the intervention. Only modest changes have been seen in other Unity Care sites that did not receive the training. Referrals to Early Intervention have increased after positive screens. Patients report satisfaction with family navigation services. The family navigators have also noted anecdotally that parents of children in the targeted age range as well as older children show increased interest and awareness of developmental milestones.

Lessons learned thus far suggest that universal screening for ASDs and developmental delays in primary care is facilitated by preparatory research on community and provider needs. This assessment informs outreach, family engagement, screening instruments, procedures and staff training. Attention to these issues can influence engagement and disclosure of developmental concerns by Latino families and facilitate the adoption of a formal screening program focused on reducing disparities in rates of diagnosis and treatment.

About the Center and Program

The Improved Early Identification of Autism in Latino Children's program is a collaborative partnership between the Georgetown University Center for Child and Human Development (GUCCHD), the Department of Psychiatry at MedStar Georgetown University Hospital, and Unity Health Care, Upper Cardozo (UHC):

The GUCCHD is a division of Georgetown University's Department of Pediatrics. The Center's mission is to improve the quality of life for all children and youth, children with special needs, adults with developmental and other disabilities, and their families. The Center both directly serves vulnerable

children and their families, as well as influences local, state, national and international programs and policy through three resource centers: *Georgetown University Center for Excellence in Developmental Disabilities*; *The National Technical Assistance Center for Children's Mental Health* and the *National Center for Cultural Competence*.

The Department of Psychiatry at MedStar Georgetown University Hospital offers comprehensive mental health care and outreach to children, adolescents and adults as well as education and training. It is also houses the Autism and Communications Disorders Clinic, which conducts multidisciplinary diagnostic evaluations, and provides recommendations with service coordination.

UHC operates 12 health centers in all eight wards of the District and is the largest provider of outpatient medical services to DC. The Upper Cardozo clinic located in Columbia Heights serves primarily Latino families and is the largest in terms of patient volume and clinical staff.

The study (project) is funded by grant, R40 MC 20171, through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program.

Autism Intervention Research Network on Physical Health: Progress and Update

http://www.aucd.org/itac/detail/news.cfm?news_id=8289&parent=646&parent_title=News&url=/itac/template/page.cfm?id%3D646

The Autism Intervention Research Network on Physical Health (AIR-P), a collaboration of 14 academic health centers in the US and Canada, recently published a major supplement to the journal, *Pediatrics*, entitled "Improving Health Care for Children and Youth with Autism and Other Neurodevelopmental Disorders." This supplement provides information on recent research carried out by the network, as well as guidelines and other guidance regarding sleep, gastrointestinal, and hyperactive-impulsive behaviors among children and adolescents with autism and related conditions. Other papers reflect analyses of the network registry, now including over 5,000 children and adolescents. Additional papers reflect the work of other projects supported by the CAAI in other institutions. (Find the supplement at http://pediatrics.aappublications.org/content/130/Supplement_2.toc.)

We expect this supplement will help both families and clinicians to recognize the growing literature that provides clear guidance on how to provide better health care for children with neurodevelopmental disabilities.

The AIR-P is directed by James M. Perrin, MD, Harvard professor of pediatrics at the MassGeneral Hospital for Children in Boston. Built on core funding from Autism Speaks to support its Autism Treatment Network (ATN), the AIR-P has also produced a number of professional and parent toolkits to improve health care for children with autism and related conditions. A major activity of the AIR-P has been dissemination of these toolkits, guidelines, and other findings to parent and professional communities. Autism Speaks sponsored its first parent-oriented national conference in August 2012 as one part of the effort to bring the findings of the network to larger audiences. Network clinicians have

been involved in many continuing medical education conferences and national research meetings to broaden the reach of the network.

With its renewal in 2011, the AIRP expanded the work of both its family advisory committee (FAC) and its steering committee. The FAC works at both site and systemwide levels. Members have taken major lead in network oversight and in review of network research and improvement projects. The Steering Committee, led by Drs. Patty Manning (Cincinnati) and Lonnie Zwaigenbaum (Edmonton), has led efforts to strengthen understanding of the network clinical care model and to enhance its spread to other communities across North America. Working closely with the National Initiative for Children's Healthcare Quality, the committee has guided the application of improvement methodology to the several efforts of the network to improve care for children with autism spectrum disorders. The recent fall program meeting for the ATN and AIR-P focused on ensuring consistent application of the network care model, new efforts in initial triage, staff assignment, and follow up in centers, and ways to increase primary care involvement across the sites.

With support through the AIR-P funding, the network has now initiated over 16 clinical research projects across the sites. Many of these have completed their data collection and are busy in preparing manuscripts for publication. The recent Pediatrics supplement included initial results from some of these projects. We expect a steady stream of publications from these research activities over the next year, as well as initiating additional projects.

Supporting Families and their Toddlers on the Autism Spectrum

http://www.aucd.org/template/news.cfm?news_id=8326&id=17

The Family Implemented TEACCH for Toddlers study (FITT, renamed from Home TEACCHing Program to emphasize the project's relationship with families) recently finished its first of three funded years and the team has many accomplishments to celebrate. Based on structured teaching and naturalistic strategies, this family-implemented approach provides coaching and support for families to increase interaction and engagement with their young children with ASD across daily routines. Interventionists provide 24 weekly sessions held across a 6-month intervention time period, which include four clinic-based parent group sessions (3 families per group) plus 20 in-home intervention sessions. FITT introduces families to the concepts of structured teaching, and provides families a set of strategies for working, playing, and communicating with their toddler.

Currently 22 of the projected 60 families have enrolled in the study, with 13 randomly assigned to the intervention condition. The study team has developed a comprehensive manual that provides guidance for interventionists, activity ideas, parent handouts and homework, and a comprehensive photo library of materials to share with families.

Early data around feasibility and acceptability of the intervention are promising, with high rates of intervention fidelity, strong parent adherence to intervention strategies, and social validity data that indicates that families strongly endorse both the intervention strategies as well as the impact of the intervention on their child's skills.

Next Steps for Project

The FITT team is committed to recruiting and retaining families from rural communities. We have recently increased recruitment efforts in rural areas through collaboration with local TEACCH centers and early intervention agencies to support efforts around early identification, and to connect with already identified families who have limited access and opportunity to receive services for their toddlers on the autism spectrum.

Project Team

FITT is an inter-disciplinary project, led by Co-PIs Dr. Lauren Turner-Brown, clinical psychologist, and Dr. Kara Hume, special educator, housed at the Carolina Institute for Developmental Disabilities at University of North Carolina at Chapel Hill (<http://www.cidd.unc.edu>). Project staff includes social workers, allied health professionals, and a number of student and community volunteers. For more information about the project, please contact Project Coordinator Laurie Moses, Laurie.moses@cidd.unc.edu

Program Reference: HRSA MCHB grant R40 MC 22648-01, *Efficacy of the Home TEACCHing Program for Toddlers with Autism*

Predicting Obstructive Sleep Apnea in Down Syndrome

http://www.aucd.org/template/news.cfm?news_id=8329&id=17

Obstructive sleep apnea (OSA) in individuals with Down syndrome is associated with multiple morbidities: systemic and pulmonary hypertension, glucose intolerance, cardiovascular and cerebrovascular disease, and behavioral problems. The prevalence of OSA in this population is very high, with estimates ranging between 55-97%. Currently, an overnight polysomnogram (sleep study) is the gold-standard diagnostic test for patients with Down syndrome. Yet, this testing is cumbersome, poorly tolerated by these children, costly, and not widely available around the country. In the first year of this study, we propose to identify predictive factors for OSA in persons with Down syndrome. By doing so, we will provide the foundation for establishing an effective, reliable, and user-friendly tool to screen for OSA in individuals with Down syndrome without needing a polysomnogram. We will enroll 100 subjects, ages 3-18 years, who already participate in the Down syndrome Program at Massachusetts General Hospital.

For each patient, we will collect subjective and objective measurements using validated parental survey instruments, standardized physical exams, lateral cephalograms, 3Ddigital photogrammetry, and urine samples. Afterwards, all participants will undergo standardized polysomnography at the Massachusetts General Hospital Sleep Laboratory where objective measurements will be collected on OSA. We will analyze which combination of our assessment methods predicts OSA as ultimately determined by polysomnography. During years two and three of our study, we will validate our model with 100 new participants. Our final screening tool will thereby allow physicians to avoid ordering polysomnograms for those individuals with Down syndrome at lowest risk of OSA. Further, those patients with Down syndrome and clear predictors for OSA can proceed directly toward adenotonsillectomy, the current treatment.

State Stories

Another Key Piece to the Overall Strategy for Cross Systems Data Collection and Integration in Colorado

http://www.aucd.org/template/news.cfm?news_id=8323&id=17

The Colorado Department of Public Health and Environment (CDPHE) is a partner in Project CASCADE (Collaborative Addressing System Change in ASD and other DEvelopmental disabilities). Project CASCADE proposes to build upon the state's infrastructure for sharing electronic screening records. This involves CDPHE's Integrated Data System (IDS) to maintain client records. IDS includes electronic birth records, newborn screening results, and Colorado Responds to Children with Special Needs (CRCSN) data. Each program has its own IDS application (e.g., Early Hearing Detection and Intervention (EHDI) IDS). The Colorado Immunization Information System (CIIS - immunization registry) is in the process of adding the newborn screening and newborn hearing screening results to the platform to allow primary care providers to see the screening results in a timely manner to support the medical home approach. IDS applications have been created for children followed by specialty clinics (e.g. Sickle Cell, Inherited Metabolic Disease, Cystic Fibrosis). The database can also facilitate long-term management and tracking of these children. Dates of clinical evaluations, secondary diagnoses, complications, hospitalizations, surgeries, and subspecialty evaluations can be entered and diagnostic and monitoring laboratory studies and dietary therapy can be tracked.

Maine Works to Make System Navigation Easier for Children with ASD/DD and their Families

<http://www.amchp.org/AboutAMCHP/Newsletters/Pulse/NovDec2012/Pages/SuccessStories.aspx#ME>

In 2008, Maine began an ASD Systems Change Initiative sponsored by the Commissioners of Education, Labor and Health and Human Services. The ASD initiative was charged with analyzing the multiple systems of care that individuals with ASD and their families had to navigate. The work began by analyzing the early identification and early intervention systems, which revealed that it took an average of 32 months from parent concern to actual diagnosis of ASD. Stakeholder recommendations include lowering barriers to reduce the overall time between concern and diagnosis.

Utilizing the HRSA State Implementation Grant for Children and Youth with ASD allowed Maine to improve identification rates of children with ASD by encouraging early childhood professionals, such as Part C IDEA staff, head start staff, public health nurses and physicians, to screen all children at 18 months for an ASD. This initiative also is linked with the state CMS grant, Improving Health Outcomes for Children, which includes routine developmental screening in all well-child visits using the ASQ-SE and ASQ-3 as one of their pediatric quality-improvement projects with follow up with the MCHAD when indicated. Through the HRSA grant, Maine produced a training DVD and curriculum on the administration and scoring of autism screening tools. Hundreds of professionals have received the training and materials. In addition, Maine implemented monetary incentives to encourage professionals to screen for autism. Results have shown steady improvement, with a 98 percent increase in ASD screening at well-child visits over a one-year period.

A second issue is the long wait time to receive a diagnosis due to diagnostician wait-lists. Maine piloted new processes between early education professionals (Part C and Section 619B IDEA) diagnosticians to

expedite the time between referral and diagnosis for those suspected of having an ASD. Preliminary results show a 54 percent reduction in time has been achieved. The change is a result of early childhood professionals assisting families with necessary paperwork needed for the first visit. In total, the multiple improved processes have shown a decrease between referral to diagnosis from 11 weeks to nine (19 percent) for children aged three to five years.

Mississippi MACSS Project: Changing Systems within a Community Health System of Care

<http://www.amchp.org/AboutAMCHP/Newsletters/Pulse/NovDec2012/Pages/SuccessStories.aspx#ME>

There are 21 Community Health Centers in Mississippi serving the health care needs of medically underserved and indigent populations, including those living in rural areas. The mission of the Mississippi Community Health Centers is to ensure equal access to quality, comprehensive health care services and the elimination of health disparities in the state. Community health centers play a critical role in the health care of Mississippi children and youth because of the rural nature of the state, the high rates of poverty, and the fact that Mississippi has the highest rate of disability per population in the nation. All 21 Community Health Centers provide developmental screening for young children, but none screen specifically for autism.

Through the HRSA State Implementation Grant for Children and Youth with ASD, the Mississippi Access to Coordinated Systems of Services (MACSS) project has teamed with the Southeast Mississippi Rural Health Initiative (SeMRHI) to develop and implement a screening protocol and algorithm for autism that includes both primary and secondary screens. The screening protocols and algorithm will be replicated at each of the 14 community clinics associated with SeMRHI. A Web portal has been developed for each of the 14 community clinics to report data on the numbers of children screened, the numbers of children who fail a secondary screen, the numbers referred for a full diagnostic assessment, the number of children diagnosed with autism, and information obtained during periodic follow-up.

During the final year of the project, replication information and technical assistance will be available to all 21 community health centers for use in their community clinics. Finally, a special health care clinic for children on the spectrum and those with other disabilities has been established to serve as a medical home at one of the primary SeMRHI clinics that is housed on the campus of a public school.

Housing a community health clinic on the campus of a public school increases access to a medical home for the large numbers of indigent and uninsured families residing in rural areas of Mississippi. Housing a specialty clinic in collaboration with the community health clinic provides family support and coordination of care that is not readily available with other health care providers. Replication of this specialty clinic across other Community Health Care Centers will ensure that children on the spectrum and those with other disabilities and their families have access to a system of community care that is coordinated across a network of providers.

Vermont Medical Home and Community-Based Teams Collaborate to Improve Services

<http://www.amchp.org/AboutAMCHP/Newsletters/Pulse/NovDec2012/Pages/SuccessStories.aspx#ME>

The goals of the Vermont State Implementation Grant for Improving Services to Children and Youth with ASD/DD include increasing collaboration between the Medical Home and community-based teams. An exciting accomplishment this year is the piloting of care coordination by placing medical social workers, from the Vermont Title V CYSHCN program, in Medical Homes. The mutual experience has produced a practical description of the scope of collaboration needed between Medical Homes and communities, as well as strategies that work to increase understanding of the pediatric system of care and access to community resources. This activity is coordinated with the Vermont Blueprint for Health expansion to pediatric populations, Children's Integrated Services Early Intervention (Part C), and the medical home training projects of the Leadership Education in Neurodevelopmental Disabilities (LEND) program at the University of Vermont (VT-ILEHP).

Since the inception of Part C, CYSHCN medical social workers in Vermont have an integrated role in order to ensure streamlined navigation and care coordination for families; they work directly in Child Development Clinics in the evaluation of children with ASD/DD; they provide regionally based care coordination to families of children with a wide range of special health needs; and they also are core members of Part C Early Intervention teams. Participating in care conferences in the Medical Home has further integrated these roles and reduced categorical/ programmatic silos and fragmentation.

These care conferences are family-centered meetings, led by the primary care provider (typically lasting one hour), that may include any specialty care providers, community providers, schools, the family and their formal and informal supports (i.e., personal care attendants or grandparents). The purpose is to organize and streamline care for families by facilitating effective communication about strengths, challenges, current services, needs and gaps in services. A coordinated plan of care is developed with goals, resources and action steps. These regular care conferences are an efficient and effective strategy of health care reform, utilizing the expertise of all providers and facilitating creative problem solving that supports the both child and family health. Family success stories to date include: 1) preventing out of home institutional placement of a child with a neurodegenerative syndrome and ASD through creative, multi-agency funding and wrap-around home based services, 2) providing in-home anticipatory bereavement counseling and increased nurse case-management as part of a new pediatric palliative care program, and 3) the recent expansion of the role of CYSHCN Title V care coordination to include not only social workers but psychiatric consultation as well (our Child Development Clinic psychiatrist also is assisting in the Medical Home with medication management, links to community mental health resources, etc.).

Key outcomes that emerged from this pilot include:

1. Increased understanding by physicians, families and community providers of the health care delivery system
2. Appropriate referrals and increased access to community-based resources, including psychiatric consultation
3. Identifying systems issues and barriers (insurance issues, poverty, lack of psychiatric and mental health services, etc.)
4. Increased ease of use and coordination of community-based services for families

5. Prevention of duplication of services

This Vermont medical home pilot recently was selected as a case study for research by the National Center for Ease of Use of Community-Based Services, one of six national centers addressing the core outcomes measures for success in serving children with special health care needs.

Collaborators Corner

SPHARC Announces New Senior Program Manager for Children and Youth with Special Health Care Needs

http://www.aucd.org/template/news.cfm?news_id=8362&id=17

AMCHP's State Public Health Autism Resource Center (SPHARC) is pleased to announce that Jennifer Bolden Pitre, currently Senior Program Manager for Children and Youth with Special Health Care Needs for New Jersey's Statewide Parent Advocacy Network, will join the association as Senior Program Manager for CYSHCN. Jennifer Bolden Pitre, MA, JD is an attorney, Parent Leader, and the Mother of CYSHCN. Jennifer previously worked as Director of the Statewide Parent Advocacy Network's (SPAN) State Implementation Grant for CYSCHN (D70) from 2009-2012 and Director of the State Implementation ASD/DD grant from 2010-2012. From 2008-2011, Jennifer worked as a SPAN Family Resource Specialist providing information and support to parents and professionals regarding education and family-centered care.

After law school, Jennifer worked as an Assistant Attorney General for Louisiana. In 2000, she served as Assistant Director of the NJ Division on Civil Rights, Bureau of Prevention and moved from there to litigation as a Deputy Attorney General, representing the NJ Department of Labor until 2007, where she received a Notable Commendation for Outstanding Representation of the Department of Labor, Division of Vocational Rehabilitation.

Jennifer was an AMCHP Family Scholar in 2010-2011, selected as a Children's Hospital of Philadelphia CHOP LEND Fellow in 2011, earned a certificate in Public Health Leadership from the MCH Public Health Leadership Institute in 2012, and currently serves on the Board of Family Voices and as an AMCHP Family Scholar Mentor. At AMCHP, Jennifer will oversee the work of SPHARC, Act Early Activities, and overall programming for CYSHCN. Jennifer's predecessor, Treeby Brown, will continue to stay involved with CAAL activities through her new role as Associate Director for Child and Adolescent Health at AMCHP.

SPHARC Planning Peer to Peer Exchange on Role of Data in Building, and Evaluating Systems of Care for Children and Youth with ASD/DD with New Approaches in Screening, Financing, and Transition

http://www.aucd.org/template/news.cfm?news_id=8361&id=17

AMCHP's State Public Health Autism Resource Center (SPHARC) is tentatively planning to continue its highly successful series of state peer exchange programs in Spring 2013 with a new exchange addressing data and evaluation issues. This peer to peer exchange would provide State Autism Grantee, LEND programs, and research projects the opportunity to talk about how their grants have used to data to plan and build systems of care, implement activities and/or evaluate the impact of their implementation strategies. If your state or grant has an interesting experience to share about data/evaluation in any stage of the process and you would be interested in sharing your experiences, challenges and lessons learned, we would welcome ideas and proposals (including from former grantees). We are looking for both Peer Leaders as well as state teams (must include representative from State Planning or

Implementation Grant). For more information, please contact Treeby Brown at AMCHP (tbrown@amchp.org).

Autism NOW Answer Series #1: What is Autism NOW?

<http://autismnow.org/2012/11/26/autism-now-answer-series-1-what-is-autism-now/>

Autism NOW has recently released its first video in its Autism NOW Answers Series. Each month experts will answer questions about autism and developmental disabilities that viewers have submitted. The first video in the series has been uploaded to Autism NOW's You Tube channel. Watch the video and think of what questions about autism and other developmental disabilities you want answered.

Easter Seals Siblings Study

http://www.easterseals.com/site/PageServer?pagename=ntl_siblings_study_home

Sibling relationships are our longest-lasting relationships in life. Twenty-three percent of adults are already the primary caregiver for their adult brother or sister with a disability. The new Easter Seals Siblings Study calls attention to the experiences of siblings as caregivers, and the services and supports families need. The Study, conducted by Ipsos and made possible by MassMutual Financial Group, aims to better understand the implications of adults who have siblings with developmental disabilities.

NYLN's Reap What You Sow: Harvesting Support Systems Curriculum

http://www.aucd.org/template/news.cfm?news_id=8325&id=17

The National Youth Leadership Network is excited to promote our new curriculum - *Reap What You Sow: Harvesting Support Systems*. Our curriculum was created by disability rights activities, family members, and community allies. The curriculum teaches participants how to set goals, build support system (a network of people in your life that support you), and find power among an inclusive community.

If youth with disabilities and their families come together, we can all learn how to build great, interdependent support systems. Our definition of "family" and "support system" includes people we're related to and people we choose. Many of us learn to follow our desires by building a support system that works to help us have a voice and make our own choices. We want to teach other young people how to create these support systems, too.

IMPORTANT DETAILS:

- Youth, family members, and adult allies learn together.
- It is 100% hands-on learning!
- It looks at the "big picture" by talking about ableism, power, and community.
- Reap What You Sow can be led in many different ways - short sessions or three-day trainings.
- Organizations can host trainings and become certified leaders themselves.

For more information, e-mail Betsy Valnes, NYLN Executive Director, at betsy@nyln.org.

ITAC Items

Tory Christensen, MSW, BCBA joined the ITAC staff in November

https://www.aucd.org/template/person.cfm?person_id=431&parent=13

Tory previously worked on the CDC Cooperative Agreement and brings her experience to the ITAC team, providing technical assistance to LEND and other MCH grantees on topics in autism and developmental disabilities, including the "Learn the Signs. Act Early." Campaign and Ambassadors.

ITAC's New Training Toolbox

http://www.aucd.org/itac/template/training_toolbox.cfm

The Training Toolbox makes it easy for program staff to browse and share innovative and time-tested training strategies on a variety of topics relevant to leadership and Maternal and Child Health. In the Toolbox, training strategies are categorized by topic, making it easy for you to browse different methods by which others teach important concepts to their trainees. Along with strategies neatly organized into topics and a user-friendly interface, the Training Toolbox can be completely personalized. While you're browsing, create a "My FAVORITES" account by simply entering your email. Add any of the strategies to your personal Favorites account and save them for the next time you're planning the school year or are in need of a new idea or inspiration. Add notes to the strategies in your Favorites account to remind you of how you might incorporate that strategy into your program, and email the strategy to another faculty member for their inspiration

"Learn the Signs. Act Early." Ambassador Project

http://www.aucd.org/template/news.cfm?news_id=8364&id=17

The "[Learn the Signs. Act Early.](#)" Ambassador project is a collaborative effort between the Center for Disease Control's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD), the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB), the Association of University Centers on Disabilities (AUCD), and the Association of Maternal & Child Health Programs (AMCHP). It was launched in 2011 to establish a network of national, state, and local experts to support state awareness activities, improve early identification practices, and advance CDC's "[Learn the Signs. Act Early.](#)" program.

Through this project, Act Early Ambassadors have focused on conducting activities that aim to reduce disparities in early screening, diagnosis, and referrals to services, including screenings with at-risk English language learner groups, outreach to rural areas, trainings for culturally and economically diverse populations, translation of materials, and training native speakers to conduct developmental screening assessments. In addition, Ambassadors have partnered and collaborated with programs that serve young children and their parents, such as Head Start and Early Head Start, WIC, and home visiting; health care and child care professionals; and their Act Early state teams. Ambassadors have also promoted the [Autism Case Training \(ACT\): A Developmental Behavioral Pediatrics Curriculum](#), which is a case-based, facilitated curriculum designed to teach pediatric residents and other trainees about autism identification, diagnosis, and treatment.

Currently, there are 25 Ambassadors serving 24 states and the Autism and Developmental Disabilities Monitoring (ADDM) Network. They will continue their assignment through December 2012.

Events

2012 AUCD Conference A Success

<http://www.aucd.org/conference/>

Nearly 700 individuals participated in the 2012 AUCD Conference! We had a great time learning and sharing the newest in promising practices and innovations that shape the lives of people with disabilities and their families through research, policy, education, and service. We continue to post additional session materials, photos, and wrap up items on the conference website and in the app, so check back often, and save the date for Nov 16-20, 2013.

2013 HRSA/MCHB's Combating Autism Act Initiative

http://www.aucd.org/template/event.cfm?event_id=3550

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

2013 AMCHP Conference

<http://www.amchp.org/Calendar/Conferences/amchp-conference/Pages/default.aspx>

Join hundreds of Maternal and Child Health (MCH) leaders at the 2013 AMCHP Annual Conference to discover cutting-edge MCH programs, methods, and policies from across the country; network with other MCH professionals, researchers, and government leaders to share ideas, information and experiences; develop practices and policies that strengthen partnerships between local and state MCH programs and families; and build on existing competencies and learn new skills that enhance your abilities or those of your workforce.

2013 LEND Directors Meeting

http://www.aucd.org/template/event.cfm?event_id=3550

Thursday, May 30, 1-6pmET

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

2013 SPHARC/State Autism Grantees Meeting

http://www.aucd.org/template/event.cfm?event_id=3550

Thursday, May 30, 1-6pmET

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

Upcoming Webinars

Be Early/Act Early: Your Role in Identifying Young Children with Disabilities including Autism

December, 14, 2012

http://www.aucd.org/template/event.cfm?event_id=3555

This webinar is a collaborative effort between AUCD and the North Carolina Autism Alliance. It is targeted to statewide Local Interagency Council (LICC) members and others involved with services to young children and their families. The presenters will provide information on the importance of child find and early identification of at-risk children birth to five; behaviors that place a child at-risk for

Emergency Preparedness-What Does That Mean For People With I/DD, Their Families, And Their Communities?

Tuesday, January 22, 2013

http://aaid.org/content_9982.cfm

This webinar will cover the current state of disaster preparedness for individuals with I/DD; identify gaps in preparedness plans; and discuss future research in this area particularly in linking community resources/supports/services with individual, family, and agency disaster planning and how social connectedness and resources might be leveraged to provide such support.

About

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