



ESSO WEEKLY MEMO – JANUARY 13, 2011

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ACTION NEEDED

CAPTA Agreements Request for Information

If your agency has signed or updated a local interagency agreement related to CAPTA in the past 2 months, please email Dawn Lynch at dawn_lynch@doh.state.fl.us to provide information about the agreement and a copy (if possible). At the Early Steps State Office, we are routinely asked about our CAPTA agreements from various parties, and it is important that our CAPTA information be current.

Florida Outreach Project for Children & Young Adults Who Are Deaf-Blind

The Florida Outreach Project for Children & Young Adults Who Are Deaf-Blind is currently conducting its annual [deaf-blind census](#). Please consider youth within your constituencies who are affected by multiple disabilities that include sensory loss. These individuals and families may benefit from inclusion in the [Florida deaf-blind registry](#) and access to Florida Outreach Project (FOP) training and services.

Each year, FOP is required by federal and state law to identify and document the profiles of children aged 0-21 with concurrent hearing and vision losses (deaf-blindness), with or without other disabilities, in the state of Florida. **Please assist us in identifying and serving the youth and families who should be included in our constituency.**

Please see information on [HIPAA-compliant procedures and forms](#) for reporting de-identified profiles of children and youth with deaf-blindness to the Florida Outreach Project (FOP). When we receive these de-identified profiles of youth with deaf-blindness, we are able to include them in the mandatory [National Child Count](#).

When collecting data for the National Child Count of Children and Youth Who Are Deaf-Blind (aka "census"), the Florida Outreach Project (FOP) functions as a HIPAA *covered entity* that transforms *nonstandard* information on children and youth with deaf-blindness into standard format for the annual census (<https://www.cms.gov/HIPAAgenInfo/Downloads/CoveredEntitycharts.pdf>). Under HIPAA, healthcare providers may disclose de-identified information to the Florida registry of children and youth who are deaf-blind without authorization. In compliance with HIPAA, FOP transmits only de-identified information about the health and disability profiles of children and youth with deaf-

blindness to the National Consortium on Deaf-Blindness for the annual census (http://privacyruleandresearch.nih.gov/pr_08.asp).

Help the Florida Outreach Project (FOP) to help children and youth with deaf-blindness and their families!

Please encourage identified families to complete a [Consent for the Exchange of Information & Records](#), so that we can provide information and offer services to children with deaf-blindness, their families, and their educational teams. Once a family has provided consent, any family member or team member may make a [request for Technical Assistance](#) from FOP.

INFORMATION AND RESOURCES

Nominations for the Antonia Brancia Maxon Award for EHDI Excellence (With 2 Attachments)

Nominations are being accepted until January 15, 2011 for the Antonia Brancia Maxon Award for EHDI Excellence to be presented at the 2011 National EHDI Conference in Atlanta, Georgia. This award honors the work of Dr. Antonia Brancia Maxon to promote effective Early Hearing Detection and Intervention (EHDI) programs for all newborns, infants, and young children. Dr. Maxon was a pioneer in EHDI programs, beginning with her leadership in the Rhode Island Hearing Assessment Project in the late 1980's. She was one of the first to recognize the feasibility and value of universal newborn hearing screening and was a tireless advocate for connecting screening programs with timely and appropriate diagnosis and early intervention.

Her extensive contributions to creating excellent EHDI programs were abruptly ended by a tragic automobile accident in May of 2007. In memory of her contributions, an Award for EHDI Excellence is presented each year at the National EHDI Conference to honor an individual or group of people who have made a noteworthy accomplishment in achieving excellence in EHDI programs nationally or in a particular state or region of the country. Activities such as the following might be considered:

- Completion and publication of a noteworthy research project that contributes to improved EHDI programs
- Implementation of a program, set of procedures, or guidelines that significantly improved the effectiveness of EHDI programs in a state or region.
- Development and dissemination of a training curriculum, instructional package, or educational materials that significantly improved EHDI programs in a state or region.
- Development and dissemination of a public awareness campaign.

- Creation of an effective family-to-family support program.

Nominations for the **Antonia Brancia Maxon Award for EHDl Excellence** should be made in the form of a letter or email and sent to Karl White at karl.white@usu.edu or mailed to:

National Center for Hearing Assessment and Management

Utah State University

26150 Old Main Hill

Logan, Utah 84322-2880

Attention: Antonia Brancia Maxon Award for EHDl Excellence

Nominations must be received by **January 15, 2011** and should be limited to no more than 500 words. The nomination should describe:

- The noteworthy accomplishment that led to the improvement of EHDl programs in a particular state or region.
- How this accomplishment demonstrates significant creativity or initiative.
- The specific ways in which the activity contributed to EHDl excellence.

Presentation of the 2011 Antonia Brancia Maxon Award for EHDl Excellence will be made at the National EHDl Conference in Atlanta Georgia on February 21, 2011. More about the conference, including past nominees and recipients can be found at www.ehdconference.org.

The Advocacy Center for Persons with Disabilities, Inc. is now

Disability Rights Florida

- Designated protection and advocacy system for individuals with disabilities in the State of Florida.
- Authority and responsibility under eight federal programs.
- Statewide not-for-profit corporation.
- Provides information & referral, self-advocacy support, advocacy services, dispute resolution representation, systemic advocacy, facility and program monitoring, community education and outreach.
- Educates policy makers about the needs of people with disabilities in areas such as abuse/neglect, health care, community resources, education, employment, housing,

transportation and access to voting.

MEMBER NATIONAL DISABILITY RIGHTS NETWORK

www.DisabilityRightsFlorida.org · Find us on [Facebook](#) · Follow us on [Twitter](#)

Combating Autism Act Report Shows Significant Progress

Kim Musheno, Director of Legislative Affairs

301-588-8252 ext. 222

kmusheno@aucd.org

SILVER SPRING, MD (January 12, 2011) — A new congressionally-mandated report, released by U.S. Representatives Mike Doyle (D-PA) and Chris Smith (R-NJ) and prepared by the Office of Autism Research Coordination at the National Institutes of Health, shows that the Combating Autism Act (CAA) of 2006 (Public Law 106-416) has expanded research and surveillance and addresses the growing need for appropriately trained professionals able to assess, diagnose, treat and support individuals with Autism Spectrum Disorders (ASD).

“One of the greatest needs identified during the development of the legislation is the lack of trained professionals to provide diagnostic and clinical services for children with ASD,” says George Jesien, PhD, Executive Director of the Association of University Centers on Disabilities, a nonprofit network of university-based interdisciplinary centers and programs working to advance policy and practice for people living with disabilities and their families. “The law provided for the expansion of the existing members of the AUCD network such as the Leadership Education and Neurodevelopmental Disabilities (LEND) programs and related Developmental Behavioral Pediatrics (DBP) interdisciplinary training programs to focus on training health professionals in the use of valid, reliable screening and diagnostic tools and in the provision of evidence-based interventions for children with ASD. These training efforts are effectively reducing barriers to screening and diagnosis by increasing health professional capacity and awareness about ASD among parents and early childhood providers.”

The CAA funding allowed the LEND training program to dramatically improve the ability of health professionals to conduct screenings and assessments, and enhance the capability of the workforce to screen and treat those with ASD. In 2009, the 22 LEND programs that received funding collectively screened 12,751 infants or children and provided diagnostic evaluation services to 12,390. In FY 2010, the 39 LENDs collectively screened more than 46,000 infants and children and provided diagnostic evaluation services for more than 35,000 infants and children.

CAA funding enabled the CDC “Learn the Signs. Act Early” campaign not only to provide over 11 million health care professionals, parents, partners, and child care providers with educational resources, but also to collaborate with the Health Resources and Services Administration (HRSA) and AUCD to convene 11 Regional “Act Early” Summits with over 900 participants from all 50 states and trust territories. Each summit brought together families, professionals, providers, and state leaders from various sectors to increase collaboration and coordination of programs and services for children with ASD and other developmental disabilities. State teams developed Summit action plans to address challenges and gaps, and they continue to update their plans and expand focus to increasing coordination and interagency collaboration and awareness efforts, as well as creating a more seamless system of care.

Though the report documents significant progress, CDC data indicate a critical need for improved access to early evaluation and diagnostic services. The typical time gap from developmental concern to diagnosis is over 2 years. “With a continued focus on ASD awareness and training, within both the public and healthcare spheres, this critical time gap can and should be reduced. Increased attention is being given to pinpointing underserved communities where diagnostic and intervention support are in the greatest need,” says Jesien. Through CAA funding, the Federal coordination provided by the Interagency Autism Coordinating Committee (IACC), will continue to identify key research and service priorities and foster communication and collaboration between Federal agencies, private foundation partners and the public.

The CAA is up for reauthorization this year. AUCD will be working with Congress to ensure that gaps in the research and service system are filled during this review and that the law is reauthorized in a timely way.

AUCD is a national network of 67 University Centers for Excellence (UCEDD); 39 Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs; and 15 Intellectual and Developmental Disabilities Research Centers (IDDRC). As the prevalence of autism has risen, University Centers have initiated many activities to help meet the growing need for children, adults, and families. Together, these programs provide a direct national impact through direct services, the development of new professionals, and the application of new knowledge generated from research. For more information and a national directory of Centers, see AUCD's website at www.aucd.org.

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For more information and the full text of the report: "Report to Congress on Activities Related to Autism Spectrum Disorders and Other Developmental Disabilities Under the Combating Autism Act of 2006 (FY 2006-FY 2009)," please visit [Representative Doyle's website](#)

Vacant Position in ESSO Performance Improvement Unit

Requisition ID: 64005403-51370114-20101104144503

Agency: DOH - Health

Working Title: OPERATIONS REVIEW SPECIALIST Closing Date: 1/21/2011

Location: TALLAHASSEE Annual Salary Range: \$41,106-\$45,652

Technical Assistance position in the Performance Improvement Section in Bureau of Early Steps.

This is a highly responsible position in the Bureau of Early Steps, Children's Medical Services. Job responsibilities include quality assurance and compliance monitoring and provision of technical assistance to local service providers.

Preferred Qualifications:

Extensive knowledge of federal, state and local programs and policies that impact families with young children with disabilities, particularly the requirements of Part C, IDEA.

Expertise in quality assurance monitoring and performance improvement planning.

Ability to coordinate interagency collaborations and negotiate roles and responsibilities.

Knowledge and experience in applied research and training delivery.

Requisition ID: 64801123-51371327-20101230161502

Agency: DOH - Health

Working Title: OPS OPERATIONS REVIEW SPECIALIST Closing Date: 1/21/2011

Position Number: 64801123

Location: TALLAHASSEE Annual Salary Range: \$25 per hour

Temporary position to take the lead in organizing the Early Steps Sustainability Strategic Plan Implementation Committee and assist in preparing new contracts for 2011-12.

Preferred Qualifications:

Bachelors degree or higher, 1 -3 years experience with contracting, state agency contract manager certification preferred, and experience with leading a complex group project.

To apply, go to <https://peoplefirst.myflorida.com/logon.htm>.

NECTAC NEWS

For the current issue of NECTAC eNotes go to <http://www.nectac.org/enotes/enotes.asp>

UPCOMING TRAININGS, MEETINGS, CONFERENCES AND OTHER OPPORTUNITIES

10th International CHARGE Syndrome Conference

July 28 - 31, 2011

Orlando, Florida

We are pleased to announce that a limited number of scholarships are available for our 10th Annual CHARGE Syndrome Foundation conference. The Lee E. Norbury Memorial Scholarship for first-time conference attendees and the Charge It for CHARGE Scholarship applications are available [here](#).

A CHARGE Syndrome Foundation conference is a truly magical, life-changing experience. Families gather together to share experiences with each other and learn from the experts. Everyone has an opportunity to meet with professionals and ask questions. With 60+ sessions and presentations, the knowledge gained helps us all to cope with the challenges we face. However, it's more than a conference with breakout sessions. It's an educational experience in a nurturing environment. It's a celebration of life. It's a place where we establish life-long relationships. We are truly one big CHARGE family.

Everyone must be a member of the CHARGE Syndrome Foundation to apply for a scholarship. [Join Now](#). Please make sure that you explore all funding possibilities before you apply to the Foundation for a scholarship as funds are limited. ([Read more about finding funds here](#).) The application deadline is April 1, 2011.

Assistive Technology Industry Association (ATIA) Orlando Conference

The ATIA Orlando Conference will be held on January 26-29 and is an excellent professional development opportunity. The 200+ educational sessions are organized within the following strands; Augmentative and Alternative Communication, Education/Learning, Everyday Technologies, Physical Access/Mobility, Policy to Practice, Research & Professional Development, Sensory Impairment, and Services for Adults.

- o Online Registration: https://www.goeshow.com/atia/orlando/2011/attendee_registration.cfm
- o Download Registration Form: <http://www.atia.org/i4a/pages/index.cfm?pageid=3816>
- o Download a FREE Exhibit Hall Pass: <http://www.atia.org/i4a/pages/index.cfm?pageid=3822>
- o You can obtain more information on ATIA Orlando at:
<http://www.atia.org/i4a/pages/index.cfm?pageid=3733>
- Link: https://www.goeshow.com/atia/orlando/2011/attendee_registration.cfm
- Link: <http://www.atia.org/i4a/pages/index.cfm?pageid=3816>
- Link: <http://www.atia.org/i4a/pages/index.cfm?pageid=3822>
- Link: <http://www.atia.org/i4a/pages/index.cfm?pageid=3733>

Evidence-based Intervention for Toddlers with Autism Spectrum Disorders

A Webinar from AUCD's Early Intervention/ Early Childhood Special Interest Group

About the Webinar

This presentation will provide an overview of the Early Achievements model of early intervention for Autism Spectrum Disorders. Important ingredients of very early intervention for ASD will be discussed. Following the presentation there will be time for questions and answers.

Speaker

Rebecca Landa, PhD

Director

Center for Autism and Related Disorders, Kennedy Krieger Institute

Associate Professor, Psychiatry and Behavioral Sciences, The Johns Hopkins University School of Medicine

This Webinar will take place on Tuesday, January 25th from 4:00PM to 5:00PM Eastern Standard Time. The visual portion of the webinar will be conducted via GoToMeeting and the audio portion via telephone or VoIP (requires microphone and speakers). After registration you will be given a unique web address for viewing the webinar and audio information.

For more information please see the [EVENT WEBSITE](#) or contact [Jennifer Bogin](#), Project Manager at AUCD

The Early Intervention/ Early Childhood Special Interest Group (EIEC SIG) at AUCD provides information to Network members on critical issues related to early childhood. The EIEC SIG Website can be accessed at www.aucd.org/eiec

Save the Dates!

Future webinars coming to you from The Early Intervention/Early Childhood SIG:

February 22, 2011

March 23, 2011

April 26, 2011

May 23, 2011

June 28, 2011

Please Note- All webinars are from 4:00PM-5:00PM Eastern Standard Time