

What is the Act Early Network?

The **Act Early Network** supports you and the work in your state to improve early identification of developmental delays or concerns in young children, utilizing CDC's Learn the Signs. Act Early. Program. (<http://www.cdc.gov/ncbddd/actearly/index.html>)

The **Act Early Network** is a collaborative initiative comprised of three parts:

- 1) **Act Early Forum** – email discussion forum and Act Early webinars
- 2) **Act Early Ambassadors** – early identification champions
- 3) **Act Early State Systems Projects** – state projects for improving early identification

The **Act Early Network** is a collaborative effort of the Centers for Disease Control and Prevention (**CDC**), Health Resources and Services Administration (**HRSA**), the Association of Maternal and Child Health Programs (**AMCHP**) and the Association of University Centers on Disabilities (**AUCD**) and you.

Act Early Forum

Already signed up for the Act Early Forum email?

You can send an email to the national Act Early Forum! Please address your email to:

act_early_summit@lyrisvs.aucd.org

Share your resources and announcements about early identification with colleagues around the country. (Note that as a group email all members receive both original and replies to this address.)

Act Early Forum Webinar Series

Save the date for the next webinar, "Stories from Act Early State Systems Grantees-What works, what doesn't, and why" on Thursday, February 13, 2:00-3:30 pm ET

Don't reinvent the wheel! Join this webinar to hear more about success stories and lessons learned from the 2013 Act Early State Systems Grantees from Maryland, Wyoming, California, and New Jersey. The Act Early State Systems Grants support the collaboration of the Act Early State Teams and work to further the activities initiated by state teams during the Act Early Summits. There will be ample time for you to ask questions on what works, what doesn't, and why. We hope you will be able to join us!

Register: Go to <https://www1.gotomeeting.com/register/855487713>

Missed the last webinar?

View the archived webinar, Creative Ways to Reach Hard to Reach Populations- Part 2 of 2: Addressing Disparities in "Learn the Signs. Act Early." at

http://www.aucd.org/template/event.cfm?event_id=4355&id=740&parent=740

Are you listed in the AEN Directory?

Ok – that's a trick question because we have not published the directory yet. But we hope to do so in February and need just a few minutes of your time to make that happen. Please go to <https://www.surveymonkey.com/s/AENDirectory> and complete a few short questions to be listed on the directory, even if you think we already have your information. We want to be sure to have everyone's most current contact information so you are all getting the Act Early announcements. Many thanks for your help!

New Project Findings: Autism Spectrum Disorder Among Somali and Non-Somali Children in Minneapolis

NCBDDD, in partnership with the National Institutes of Health and Autism Speaks, supported the University of Minnesota (UMN) through a cooperative agreement with the Association of University Centers on Disabilities, to conduct the largest project to date looking at the number and characteristics of Somali children with autism spectrum disorder (ASD) in any US community. NCBDDD also provided technical support to help the UMN implement CDC's rigorous method for tracking autism, modeled after the Autism and Developmental Disabilities Monitoring Network. Below is a summary of the key findings:

Based on children who were 7-9 years old and living in Minneapolis in 2010:

- About 1 in 32 Somali children in Minneapolis was identified as having autism spectrum disorder. This estimate of the number of Somali children with autism spectrum disorder is about the same as White children but higher than Black and Hispanic children in Minneapolis.
- Somali children with autism spectrum disorder were more likely to have intellectual disability than children with autism spectrum disorder in all other racial and ethnic groups in Minneapolis.
- The average age of first autism spectrum disorder diagnosis among Somali children was the same as White, Black, and Hispanic children---about 5 years old. This means that many children in Minneapolis are not being diagnosed as early as they could be.

These new data can be used to understand how ASD affects children differently, and where improvements can be made so that all children in Minneapolis are identified and connected to services and supports as soon as possible. Go to <http://www.cdc.gov/ncbddd/autism/features/keyfinding-somali.html> to learn more about this project.

Potential impact of DSM-5 criteria on autism spectrum disorder (ASD) prevalence estimates

JAMA Psychiatry has published a new NCBDDD study: "Potential impact of DSM-5 criteria on autism spectrum disorder (ASD) prevalence estimates."

(<http://archpsyc.jamanetwork.com/article.aspx?articleid=1814891>) Researchers found that estimates of the number of children with ASD might be lower using the current Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria than using the previous Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) criteria.

This study looked at information collected by CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. (<http://www.cdc.gov/ncbddd/autism/addm.html>) This is the first population-based study in the United States to look at what effect the updated ASD criteria in the DSM-5 might have on estimates of the number of children with ASD. One of the advantages of the ADDM Network method is that it does not rely solely on the presence of an ASD diagnosis, but also includes review of records for children who have behaviors consistent with ASDs, even if they do not have a diagnosis. Because of the way the ADDM Network collects data, in the future CDC will be able to use both the previous DSM-IV-TR and the current DSM-5 criteria to estimate the number of children with ASD. CDC will also continue to evaluate the

effect of using the DSM-5 on trends in how doctors and other health professionals diagnose ASD and how service providers evaluate and document symptoms as they transition to using the new criteria. Below is a summary of the key findings:

- Over 80% of children who met the Autism and Developmental Disabilities Monitoring (ADDM) Network (<http://www.cdc.gov/ncbddd/autism/addm.html>) classification for ASD, which is based on DSM-IV-TR criteria, also had documented symptoms that met the DSM-5 criteria (which were published in May 2013).
 - The remaining 20% met the ADDM Network classification for ASD, but did not meet the DSM-5 criteria.
 - However, many of those children were very close to meeting DSM-5 criteria and were missing only one of the necessary symptoms.
 - Children who met the ADDM Network classification for ASD were more likely to meet DSM-5 criteria if:
 - They had a history of developmental regression;
 - They had intellectual disability; or
 - They had been diagnosed with ASD by a community provider or were receiving special education services under an autism exceptionality, or both.
 - There were no differences between boys and girls or between White and Black children in their likelihood of meeting both the DSM-5 criteria and the ADDM Network classification for ASD.
- The findings suggested that estimates of the number of children with ASD might be lower using the current DSM-5 criteria than using the previous DSM-IV-TR criteria.
- As doctors and other clinicians start using the DSM-5 criteria, they might diagnose ASD using new or revised tools or they might document symptoms differently. These changes in everyday community practice could offset the DSM-5's effect on estimates of the number of children with ASD.

Please visit NCBDDD's homepage to read a summary of the key findings from this study: www.cdc.gov/ncbddd/autism/features/impact-dsm5.html

LTSAE Funding Opportunity

The Centers for Disease Control and Prevention is announcing a funding opportunity to evaluate developmental monitoring using "Learn the Signs. Act Early." materials in child care settings.

The link to the announcement is: <http://www.disabilityresearchcenter.com/research/ltsae-monitoring/>

Other CDC RFAs are below:

RFA-NR14-01 EHDI Quality Measures <http://www.disabilityresearchcenter.com/research/ehdi-quality-measures/> – Development of Quality Measures to Facilitate Reporting of Newborn Hearing Screening and Follow-Up Data by Providers to Jurisdictional EHDI Programs

RFA-R14-001 EHDI C-Section <http://www.disabilityresearchcenter.com/research/ehdi-c-section/> – Birth by Cesarean Delivery and Failure on First Otoacoustic Emissions Hearing

RFA-R14-002 EMR Rare Conditions <http://www.disabilityresearchcenter.com/research/emr-rare-conditions/> – Linkage of Electronic Medical Records and Administrative Databases: A Novel Tool for Surveillance and Health Services Research for Rare Conditions

RFA-R14-003 Healthy Weight <http://www.disabilityresearchcenter.com/research/healthy-weight/> - Validating and/or Modifying Mainstream Health Weight Interventions for People with Disabilities

RFA-R14-004 PLAY-MH <http://www.disabilityresearchcenter.com/research/play-mh-2014/> – Project to Learn About Youth – Mental Health (PLAY – MH)

All applications are due February 28!

Make the First Five Count – Online Access to the ASQ for Families

Developmental screening is important for every young child. To address the need for greater access to developmental screening Easter Seals created Make The First Five Count®, a nationwide advocacy and awareness campaign that provides direct access to The Ages and Stages Questionnaires (ASQ™). The ASQ is available online in English and Spanish. Access to the ASQ is provided at no cost to parents/care providers at www.easterseals.com. Easter Seals scores the screening and provides the results to parents as well as follow-up information if the child has been identified to be in-need of further evaluation. Please share information about Make The First Five Count® with your personal and professional networks to ensure access to developmental screening for every child. The earlier a child receives support, the better the chance he or she will be successful in school, and in life.

Submit your updates for the next Act Early Network News (Spring 2014) by emailing Adriane Griffen at agriffen@aucd.org.

Want to send updates sooner? You can send an email send to the national Act Early Forum at any time by emailing: act_early_summit@lyrisvs.aucd.org.