
Act Early Forum Webinar Series



The Act Early Network and You: Autism CARES Act

July 24, 2014

Webinar Overview

- Webinar Recording
 - Visit www.aucd.org/webinars
- Q & A
 - Please submit your questions throughout the webinar via the “question box” on your webinar dashboard. Questions will be answered following the presentation.
- Survey
 - Please complete the short survey at the end of the webinar!

Introductions



Kim Musheno: Director of Public Policy, Association of University Centers on Disabilities (AUCD)



CARES Act Summary and Update

Kim Musheno, Director of Public Policy

Brief History

- Prevalence growing= 1 in 150; 1 in 110; 1 in 68
- Consensus about the need to act; consensus about need for early diagnosis and intervention
- No consensus about causes; lots of questions about vaccines
- Parents groups pushed for legislation in 2005
- AUCD and Easter Seals main DD groups involved; pushed to include wider focus

Combating Autism Act

Signed into law in 2006 (PL 109-416)

- Unique: wide-reaching by targeting and coordinating every available system in order to efficiently and effectively address ASD
- Focused on expanding research and coordination at the **National Institutes of Health (NIH)**, increasing awareness and surveillance at the **Center for Disease Control (CDC)**, and expanding the **interdisciplinary training** of health professionals to identify and support children with ASD and their families within **HRSA**
- Existing LEND programs expanded and number of sites increased from 34 to 43
- Interagency Autism Coordinating Committee

Combating Autism Reauthorization Act of 2011

\$22 m for surveillance and awareness activities at CDC

\$48 m for early detection, professional training and development of interventions through HRSA

Extended Combating Autism Act of 2006 for three years at current (FY 2011) funding levels

\$161 m for autism research at NIH

Reauthorizes Interagency Autism Coordinating Committee

CARES Act

- Autism Collaboration, Accountability, Research, Education, and Support Act of 2014
- H.R. 4631 introduced on May 9, 2014 by Chris Smith (R-NJ) and Mike Doyle (D-PA)
 - Now has 86 bipartisan co-sponsors
- S. 2449 introduced on June 9 by Bob Menendez (D-NJ) and Mike Enzi (R-WY)
 - 15 bipartisan co-sponsors

CARES Act Changes

- Reauthorizes the law for five (5) years (not 3)
 - Extends through FY2019: (1) CDC developmental disabilities surveillance and research program; (2) HRSA autism education, early detection, and intervention program; and (3) Interagency Autism Coordinating Committee.
- Changes the name! Autism CARES; not “combat”
- Sec. 2 creates National Autism Spectrum Disorder Initiative
 - Designates an existing HHS official to oversee implementation; ensure activities not “unnecessarily duplicative”
- Sec. 3 CDC report on State epidemiological data must include “children and adults”

Changes to IACC

Sec. 5 Revises responsibilities of the Interagency Committee concerning:

- inclusion of school- and community-based interventions in the Committee summary of advances
- monitoring of ASD research and federal services and support activities (“as practicable”)
- recommendations to the Director of the National Institutes of Health regarding the strategic plan
- recommendations regarding the process by which public feedback can be better integrated into ASD decisions
- strategic plan updates to include annual summary and recommendations to minimize duplication, and
- reports to the President and Congress

Changes to IACC

- Revises Interagency Committee membership requirements to specify additional federal agencies that might be represented
 - E.g. ACL, CMS, FDA HRSA, DOD and ED
- Requires additional non-federal members:
 - at least two individuals on the autism spectrum,
 - at least two parents or legal guardians of individuals on the autism spectrum, and
 - at least two representatives of leading research, service, and advocacy organizations

CARES Act Changes

- Allows HRSA training programs (like LEND) to collaborate with research centers or networks (such as UCEDDs) to provide training of respite care (Sen. Franken)
- Respite care defined as planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.

HHS Report

- Sec. 6. Adds a requirement to report from HHS Secretary on ASD activities to Congress to include recommendations concerning young adults with ASD and the challenges related to the transition from existing school-based services to those available during adulthood

Next steps

- House passed bill on June 24 under “suspension of the rules”
- Senate HELP Committee approved the bill by voice vote on June 25
- Sent straight to the floor under a “unanimous consent agreement” (UC)
- Process delayed when one or two Senators asked for time to review the bill
- AUCD is hopeful that the Senate will consider the bill before their August recess

Resources

- Congressional report: <http://iacc.hhs.gov/reports/reports-to-congress/FY2010-2012/index.shtml>
- GAO Report of November 2013:
<http://www.gao.gov/products/GAO-14-16>
- AO Report: Oversight of CAA Grantees
<http://www.gao.gov/assets/660/652356.pdf>
- AUCD CAAI-ITAC: TA resources
<http://www.aucd.org/itac/template/index.cfm>
- AUCD/Policy/Autism – text of law, summary
<http://www.aucd.org/template/page.cfm?id=311>
 - [Law text](#)
- AUCD Action Center: congress directory
<http://cqrcengage.com/aucd/home>
- HRSA Maternal & Child Health:
<http://mchb.hrsa.gov/programs/autism/>

Q & A

- Ask a question!
 - Type your question in the “question box” on your webinar dashboard.
 - The moderator will read the question.

Thank You!

- Learn more about Act Early!
 - www.cdc.gov/actearly
 - www.aucd.org/actearly
- Questions about the webinar?
 - Email Tory Christensen (tchristensen@aucd.org)

Please take a few minutes to complete the survey!