

Combating Autism Act

AUCD Webinar for LEND Directors

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RESEARCH, EDUCATION, SERVICE

Disclaimer

- Other than what is in the law, appropriations report language or budget all comments are unofficial and are suppositions of what it likely to be
- Purpose is to help LEND programs and other network members prepare
- Specific questions should be directed to MCHB
- Many answers may not be possible until RFP is released

Background

- Initially wanted to develop a comprehensive Autism Bill – Research, services, resources
- Proved to be too difficult because of costs, controversies, community fragmentation
- Decided to take it one piece at a time
 - Research first; then Services
- AUCD developed professional preparation component
- Started with LEND survey in 2004

Combating Autism Act History

- S. 843 introduced April 19, 2005 by Sens. Santorum (R-PA) and Dodd (D-CT)
- H.R. 2421 introduced in House by Mary Bono (R-CA) May 18, 2005
- Passed Senate Aug. 3; then again on Dec. 7, 2006
- Passed House Dec. 6, 2006
- Signed into law PL 109-416 Dec. 19, 2006
- Amends the Public Health Service Act to “combat autism through research, screening, intervention and education.”

Combating Autism Act History

- Major players:
 - Autism Speaks
 - Autism Society of America
 - Cure Autism Now (now part of Autism Speaks)
 - AUCD
 - Easter Seals
 - Several smaller “mercury mom groups” advocating for cures

Background and Purpose

- 1 in 150 children being diagnosed with autism
- need to know more about ASD
- Need more services
- Part of the reauthorization of Title 1 of the Children's Health Act of 2000 (P.L. 106-310)
- Purpose of S. 843, the Combating Autism Act of 2006, "to improve upon our previous activities with respect to autism" by:
 - expanding research and coordination at the National Institutes of Health (NIH);
 - increasing awareness through the Centers of Disease Control and Prevention (CDC);
 - integrating health, education, and disability programs;

Combating Autism Act

- Authorized \$168 million in FY08 (received **\$162M**), \$20 million more than FY07 for:
- **114.5** for **NIH** research into causes, diagnosis, early detection, intervention, and treatment (received **\$108.5 million**)
- **\$16.5 million** for the **CDC's** Disabilities Surveillance and Research Program (received **\$16.212 million**)
- **\$37 million** to **HRSA** to increase awareness, reduce barriers to screening and diagnosis, promote evidence-based interventions for individuals with autism, and train professionals to utilize valid and reliable screening tools to diagnose autism and provide evidence-based interventions (received **\$36,354,000**)

Sections



- NIH: Section 2 - Activities to improve Autism research at NIH
- CDC: Sec. 399AA - Developmental Disabilities Surveillance and Research Programs
- HRSA: Provide information through Federal programs to individuals and families (such as Head Start, Early Start, Healthy Start and Medicaid and SCHIP)
 - Designation of Lead state agency with expertise in autism

Sec. 399BB Autism Education, Early Detection, and Intervention

- (c) Information and Education
 - (d) Tools
 - (e) Diagnosis
 - (f) Intervention
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- Authorizes \$42 million for FY 09 to HRSA for all of these activities

(d) Tools

- (1) promote valid and reliable screening tools, develop curriculum for continuing ed
- (2) provide for collection and storage of these tools used by federal programs under (c) including DD Act, Part C and Title V programs
- (3) Ensure sharing of tools among entities

(f) Intervention

- Grants for research for evidence-based interventions for ASD and other DD, develop tools and guidelines, and disseminate results



(e) Diagnosis – LENDs!

- (1) Training – Secretary (subject to appropriations) shall expand existing interdisciplinary training opportunities or opportunities to increase number of sites able to diagnose or rule out ASD or other DD and ensure:



(e) Diagnosis – LENDs!

- (A) competitive grants or cooperative agreements are awarded to expand existing or develop new maternal and child health interdisciplinary LEND programs in States that do not have such a program.

Next Steps



- HRSA has discretion, up to a point, on how to spend the \$37 million appropriated in FY 08
 - Needs to balance what was authorized with what was appropriated
 - To the extent possible will likely want to work within existing systems
 - Has sought input from groups who have worked with Congress on the bill

FY 08 Appropriations Report

- \$37 million for separate program for “autism and other related developmental disorders”
- An increase of no less than \$6 million is provided to continue and expand the Leadership Education in Neurodevelopmental and Related Disabilities programs
- In addition, an increase of no less than \$6 million is provided for research on evidence-based practices for interventions for individuals with autism and other DD, for development of guidelines for those interventions and info dissemination

General Structure

- For LENDS Monies AUCD has suggested:
 - Supplemental increase for up to $\frac{1}{2}$ of the 34 LENDS (\$200,000 to \$250,000 each), and
 - For the duration of current grant
 - If funds available – renewable at time of new cycle- if performance is as proposed
 - Internal competition open to entire network- RFP
 - Development of 3-4 new programs in states that do not have one

Grant Considerations

- Criteria questions for selection:
 - Geographic representation
 - Size and capacity – only those who currently have or to also recognize need and lack of resources
 - Ability to impact on overall goals
 - Accountability needs – report to Congress
- Emphasis on Autism but meant to include other DD

Likely Goal Aspects

- Increase number of students trained with specialized knowledge to identify, assess and intervene
- Development of curriculum & modules for training
- Pre-professional as well as continuing education
- University based as well as outreach to community

Consistent with MCH Values

- Interdisciplinary –especially those who can diagnose, assess and provide services
- Family Centered
- Culturally Competent
- Community based – at least outreach & clinical experience
- Evidence Based – practices taught

What's Expected

Trainees under such training programs:

- receive an appropriate balance of academic, clinical, and community opportunities;
- are culturally competent;
- are ethnically diverse;
- demonstrate a capacity to evaluate, diagnose or rule out, develop, and provide evidence-based interventions to individuals w/ASD & other dd;
- demonstrate an ability to use a family-centered approach; and
- program sites provide culturally competent services

Accountability

- Impact of additional dollars on:
 - Students and their competencies
 - Where they go and what they do – longer term
 - Modules and curricula that can be disseminated
 - On professionals currently in field
 - ?Children assessed, diagnosed and served?
- Baseline – do we have a way of estimating impact of additional dollars

To Prepare

- Think through how an autism concentration would fit within your current program
- Identify the didactics, experiences and competencies,
- Consider how you will recruit the necessary students interested in Autism and related DD
- Identify internal & external partners
- Identify materials, modules, training modes, etc
- Show how you will benefit larger community
- Show how you will measure your impact

For New LENDs

- Show need in your state
- Demonstrated capacity to have the necessary faculty and clinical experiences
- Should fit in within an overall LEND structure
- Identify a focus or emphasis on Autism without neglecting other DD
- Identify partners and liaison with key players in university, community & state
- Be sure to be clear about parent participation and roles
- Demonstrate understanding of interdisciplinary, family centered, cultural competence and community-based

Other provisions

- (2) Secretary may award 1 or more contracts for Technical Assistance
- (3) Secretary shall promote research into additional valid and reliable tools for shortening the time required to confirm or rule out a diagnosis of ASD or other DD and detecting ASD and other DD.

Timeline

- Would like to get the money out this cycle
- RFAs – no date set but hopefully soon – next month or two
- Likely to have 45 to 60 days to submit
- Will be tough to get awards out by July 1

Questions



Comments or Suggestions

Expanding the Promise to Individuals with Autism Act

- Sens. Hillary **Clinton** (D-NY) and Wayne **Allard** (R-CO) introduced S. 937
- Reps. Mike **Doyle** (D-PA) and Chris **Smith** (R-NJ) introduced H.R. 1881
- EPIAA all about **SERVICES**, not research

Expanding the Promise Act

- authorizes funding for demonstration and planning projects to expand services and supports for children and adults
- grants to expand access to post-diagnosis care and to reduce delays in getting services
- GAO report on improving financing structure
- **interdisciplinary training of professionals who diagnose and treat individuals (UCEDDs)**
- other provisions to improve access to services for individuals with ASD and their families

Expanding the Promise - UCEDDs

- authorizes **\$13.4 million** in FY 08 to award supplemental grants to University Centers for Excellence in Developmental Disabilities (UCEDD)
 - **\$200,000** for Centers to provide training, TA, dissemination, and services, and address the unmet needs of individuals with autism and their families

Expanding the Promise - UCEDDs

- authorizes **\$5 million** to establish up to four new UCEDD with a primary focus on providing interdisciplinary training and services for individuals with autism and related developmental disabilities.
 - Priority must be given to Centers in minority-serving institutions or states with underserved populations.

Resources

- AUCD website www.aucd.org:
 - Public policy section on autism for legislative activity
 - Issues section on autism for news articles, reports, fact sheets etc.
- AUCD's Action Center
 - Action alerts and sample letters
 - Contact info on congressional delegation
 - Read full text of legislation
- Read *In Brief* for legislative updates:
<http://www.aucd.org/template/page.cfm?id=164>

