

# Collaborative Efforts to Improve the Lives of Children and Families Affected by Autism Spectrum Disorders and Related Developmental Disabilities

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IACC Services Subcommittee  
June 16, 2009

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# Background

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- **In the past decade, the number of individuals with Autism Spectrum Disorder (ASD) has risen dramatically.**
- **This rapid growth is an urgent concern for affected families; ASD services providers; and Federal, State, and local service agencies.**

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# Background

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- **Children with ASD fare significantly less well in the system than other Children with Special Health Care Needs (CSHCN),**
- **Findings from the National Survey of Children with Special Health Care Needs (NS-CSHCN) indicate that among CSHCN, children with ASD:**
  - **Had less access to important components of access, particularly those associated with more comprehensive care such as difficulty receiving referrals, family support services, or delaying care.**

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# Background

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- **Were less likely to receive family-centered care.**
- **Their families were more impacted in terms of financial hardship, work and time spent coordinating care.**
- **Guidelines published by the American Academy of Pediatrics (AAP), recommended earlier and more frequent surveillance, and more aggressive management for ASD.**

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# Systems Challenges

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- **Challenges:**

- Ineffective integration of ASD services into broader system,
- Lack of inter-agency coordination,
- Ineffective transition planning, adult systems and services,
- Inadequate benefits in public and private insurance programs, financial planning.

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# Combating Autism Act (CAA)

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- **Enacted as Public Law 109-416 on December 19, 2006**
- **Amends the Public Health Service Act to “combat autism through research, screening, intervention and education”**

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# Combating Autism Act (CAA)

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- **NIH research into causes, diagnosis, early detection, intervention and treatment (\$114.5 million)**
- **CDC's Disabilities Surveillance and Research Program (\$16.5 million)**
- **HRSA to increase awareness, promote evidence based interventions, reduce barriers to screening & diagnosis, and train professionals to diagnose and provide evidence based interventions (\$37 million)**

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**Centers for Disease Control and Prevention  
National Center on Birth Defects and Developmental Disabilities**



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It's time to change how we view a  
child's growth



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# Components of Learn the Signs. Act Early.

- **Traditional Health Communication campaign**
- **Research and evaluation**
- **Stakeholder mobilization**

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# Campaign Objectives

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- Increase **AWARENESS** of developmental milestones and early warning signs
- Increase **KNOWLEDGE** in the benefits of early action and early intervention
- Increase parent-provider **DIALOGUE** on the topic of developmental milestones and disorders
- Increase **EARLY ACTION** on childhood developmental disorders

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# Target Audiences

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- **Health Care Professionals (HCPs)**
  - **Pediatricians, family physicians, physician assistants, nurse practitioners, nurses, and others**
- **Parents of Young Children**
  - **Ages 4 and younger**
- **Early Educators (EEs)**
  - **Preschool teachers, day care providers, and others**

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# Traditional Health Communication Learn the Signs.

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# Equipping HCPs

- **Resource Kit**
  - “How to Talk to Your Doctor” informational cards
  - Fact sheet series on milestones, developmental disorders and resources
  - Materials for waiting rooms and exam rooms
- **Website Resources**
  - CDC and AAP screening guidelines
  - Coding information
  - AAP Autism Toolkit



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# Educating Parents

- **Parent resource kit**
- **Website with information and interactive tools**
- **Spanish-language resources, including materials, call center and website ([www.cdc.gov/pronto](http://www.cdc.gov/pronto))**
- **Public Service Announcements for TV, radio, and print**



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# Equipping Early Educators

- **Resource Kit**
  - Growth chart, posters, flyers, and CD-ROM with fact sheets
  - Tips for talking with parents
- **Online Resources**
  - Information on child development
  - Interactive Milestones Checklist



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# Research and Evaluation

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# 2008 Research Topics of Interest (RTOI)

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- **Helping Family Practitioners Improve Developmental Services in Primary Care**
  - **Oklahoma**
- **Project 3D: Developmental Delays and Disabilities Screening and Referral Project**
  - **Wisconsin**

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# 2008 Collaborative Research Awards (CRA)

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- **Using Positive Parenting to Teach Child Development**



- **Involving Allied Health Care Professionals in Helping Parents to Navigate Systems for Autism Spectrum Disorder (ASD)**

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# 2009 RTOIs

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- **Adapting Learn the Signs. Act Early. to populations with health disparities**
- **Currently under peer review**
- **Will be awarded in Fall 2009**

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# Evaluability assessment

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- **Danya International engaged in a contract to do an evaluability assessment of the campaign**

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# **HRSA'S Combating Autism Act Initiative (CAAI)**

## **Goal:**

**Enable all infants, children, and adolescents who have, or are at risk for developing, autism spectrum disorders (ASD) and other developmental disabilities to reach their full potential.**

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# Strategy for Achieving CAAI

## **Develop a system of services including:**

- screening children early for possible ASD and other DD**
- conducting early, interdisciplinary, evaluations to confirm or rule out ASD and other DD and**
- if a diagnosis is confirmed, providing evidence-based early interventions**

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# CAAI Program Overview

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## **Address ASD and other developmental disabilities by:**

- Increasing awareness;**
- Reducing barriers to screening and diagnosis;**
- Supporting research on evidence-based interventions;**
- Promoting evidence-based guideline development;**
- Training professionals to utilize valid screening tools to diagnose and to provide evidence based interventions.**

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# CAAI Programs in 4 Areas

## **1. Training Programs**

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- 34 Expansions and 5 new LEND programs**
- Expansions to Developmental Behavioral Pediatrics training programs**
- National Interdisciplinary Training Resource Center (AUCD)**

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# Purpose of Training Programs

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- **Educate interdisciplinary health professionals**
- **Provide continuing education and technical assistance to other providers**
  - **Increase awareness, evidence based tools**
- **Contribute to building systems of care**

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# LEND Programs

Program	City	State
University of Alabama at Birmingham	Birmingham	AL
University of Arkansas for Medical Sciences*	Little Rock	AR
University of Southern California, Childrens Hospital of Los Angeles	Los Angeles	CA
University of Colorado*	Aurora	CO
University of Connecticut Health Center*	Farmington	CT
Children's Research Institute	Washington	DC
University of Illinois at Chicago*	Chicago	IL
Indiana University, School of Medicine	Kansas City	KS
Children's Hospital	Boston	MA

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# LEND Programs

Program	City	State
University of Nebraska	Omaha	NE
University of New Hampshire	Hanover	NH
Albert Einstein College of Medicine	Bronx	NY
University of Rochester	Rochester	NY
University of North Carolina at Chapel Hill	Chapel Hill	NC
The Children's Hospital of Philadelphia	Philadelphia	PA
University of Tennessee	Memphis	TN
Vanderbilt University Medical Center	Nashville	TN
University of Utah	Salt Lake City	UT

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# LEND Programs (\* = New)

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Program	City	State
University of Vermont	Burlington	VT
University of Washington	Seattle	WA
West Virginia University	Morgantown	WV

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# Developmental Behavioral Pediatrics

Program	City	State
Albert Einstein College of Medicine	New York	NY
Leland Stanford Junior University*	Palo Alto	CA
Boston University	Boston	MA
Children's Hospital Boston	Boston	MA
Case Western Reserve University	Cleveland	OH
Rhode Island Hospital*	Providence	RI
University of Arkansas for Med Sciences*	Little Rock	AR
University of Oklahoma Hlth Sci Center*	Oklahoma City	OK
University of Penn School of Medicine	Philadelphia	PA
Yale University	New Haven	CT

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# CAA Programs in 4 Areas

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## **2. Autism Intervention Research (AIR) Networks**

- Physical Health—The General Hospital Corporation of Boston**
- Behavioral Health—University of California at Los Angeles**

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# Purpose of AIR Networks

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**Improve the health of children and adolescents with ASD and other DD by:**

- **Establishing and maintaining a network infrastructure**
- **Utilizing the networks as platforms from which to conduct research on evidence based practice for interventions**

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# AIR Networks

- **Conduct research on evidence based practices;**
- **Develop evidenced based guidelines and validate tools for interventions to improve health; and**
- **Disseminate information on research, guidelines, and tools to health professionals and the public, especially families impacted by ASD and other DD.**

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# CAA Programs in 4 Areas

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## **3. State Demonstration and Policy Programs**

- Nine State Grants to implement state autism plans to improve systems of services for children with ASD and other DD**
- State Public Health Coordinating Center (AMCHP)**

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# Systems of Care

## Components

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- **Partnerships between professionals and families of children and youth with ASD**
- **Access to a culturally competent family-centered medical home which coordinates care with pediatric subspecialties and community-based services**
- **Access to adequate health insurance and financing of services**
- **Early and continuous screening of ASD and other developmental disabilities**
- **Community services organized for easy use by families**
- **Transition to adult health care**

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# State Demonstration Programs

Organization	City	State
Alaska Department of Health and Social Services	Anchorage	AK
The Hope School	Springfield	IL
The Curators of the University of Missouri/Thompson Center	Columbia	MO
Utah Department of Health	Salt Lake City	UT
Washington Department of Health	Olympia	WA
Wisconsin Department of Health and Family Services	Madison	WI
Rhode Island Department of Health	Providence	RI
University of New Mexico, Health Sciences Center	Albuquerque	NM
New York State Department of Health	Albany	NY

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# CAA Programs in 4 Areas

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## **4. National Evaluation**

- **Required by the “Combating Autism Act of 2006.”**
- **Logic Model and Research Questions for the entire Initiative**
- **Will be reported in HHS Secretary’s Report to Congress on progress related to ASD and other developmental disabilities**

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## Combating Autism

[www.mchb.hrsa.gov/autism](http://www.mchb.hrsa.gov/autism)

This \$37 million effort, HRSA's implementation of the Combating Autism Act of 2006, addresses some of the most urgent issues affecting people with autism and their families. A national evaluation also will be conducted to report to Congress on progress related to Autism Spectrum Disorders and other developmental disabilities.

The evaluation will contribute to the U.S. Department of Health and Human Services Secretary's Report to Congress on progress related to Autism Spectrum Disorders and other developmental disabilities as required by the Combating Autism Act of 2006.

### Funded Activities

- [Training for Professionals](#)
- [State Demonstrations and Policy](#)
- [Autism Intervention Research Networks](#)

- Increasing awareness;
- Reducing barriers to screening and diagnosis;
- Supporting research on evidence-based interventions for children and adolescents with Autism Spectrum Disorders or other developmental disabilities;
- Promoting evidence-based guideline development for interventions; and
- Training professionals to utilize valid screening tools to diagnose and to provide evidence based interventions.

### Goal

Enable all infants, children and adolescents who have, or are at risk for developing, autism spectrum disorders and other developmental disabilities to reach their full potential by

- **developing a system of services** that includes screening children early for possible Autism Spectrum Disorders and other developmental disorders;
- **conducting early, interdisciplinary, evaluations** to confirm or rule out Autism Spectrum Disorders and other developmental disorders; and,
- **providing evidence-based, early interventions** when a diagnosis is confirmed.



### About Autism

- [CDC: Autism Information Center](#)
- [NICHD: Autism Spectrum Disorders](#)

### Combating Autism Act

- [Combating Autism Act: Public Law 109-416](#) (PDF, 49 KB)
- [NIMH: Interagency Autism Coordinating Committee](#)
- [IACC: Strategic Plan for Autism Spectrum Disorder Research](#)

### Related Journal Articles

- [A National Profile of the Health Care Experiences and Family Impact of Autism Spectrum Disorder Among Children in the United States, 2005-2006](#)



# Mobilization and Partner Engagement Act Early

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# Act Early Regional Summits

Bringing together key stakeholders in states to improve early identification and early intervention.

- **2007**

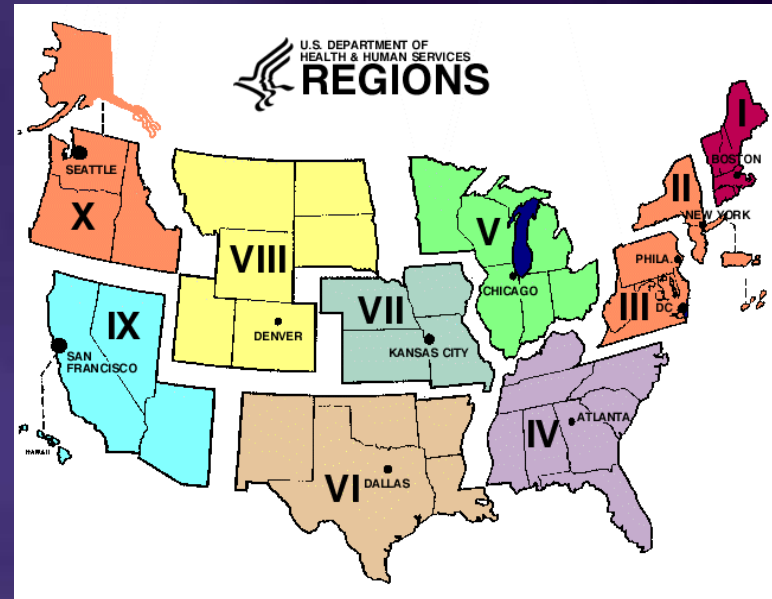
- Chicago, IL

- **2008**

- Kansas City, MO
  - Albuquerque, NM

- **2009**

- Nashville, TN
  - Salt Lake City, UT
  - The Bronx, NY
  - Sacramento, CA



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# Outcomes of the Regional Summits

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- **Increase awareness of Learn the Signs. Act Early, campaign and its impact in target regions**
- **Develop state teams to initiate and/or enhance state wide early identification, diagnosis and service provision and coordination for families with ASD**

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# Outcomes of Regional Summits

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- **Develop common understanding among stakeholders of opportunities, challenges and barriers to early identification and diagnosis**
- **Create national web-based forum to disseminate promising evidence-based practices for stakeholders to use to develop innovative approaches in their states**

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# State teams

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- **Continuing to meet**
- **Expanded membership of team**
- **Collaborating with others**



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# Systems change

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- **Legislative advocacy**
- **Raising awareness of policy makers about autism and Act Early messages**
- **Coordination across systems**
- **Activities focused on rural, underserved populations**



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# Minigrants

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- **Small seed grants**
- **Matching encouraged**



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# Act Early Minigrants

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- **Continue to enhance awareness and coordination of early identification and early intervention service systems for children with ASD and their families**
- **Provide catalyst to support ongoing collaboration of state team members**
- **Further activities developed in the state plan and initiated by State Teams as a result of the Regional Summits**

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# Together we can all help...

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## Every child reach his or her full potential.

Learn the Signs.  
Act Early.



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# Questions?

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*The findings and conclusions in this presentation are those of the author and should not be construed to represent any agency determination or policy*

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