

Autism Intervention Research Programs of the Maternal and Child Health Bureau

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KEY WORDS

autism, maternal and child health, research, Combating Autism Act, autism legislation

ABBREVIATIONS

ASD—autism spectrum disorder
 CAAI—Combating Autism Act Initiative
 DBP—Developmental Behavioral Pediatrics
 HRSA—Health Resources and Services Administration
 MCH—Maternal and Child Health
 MCHB—Maternal and Child Health Bureau
 SDAS—Secondary Data Analysis Studies

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Over the past 2 decades, autism has emerged as a major public health concern in the United States.¹ Since 1995, the US Department of Health and Human Services has sharpened its focus on autism spectrum disorders (ASDs) through development of new initiatives that are aimed at increasing our understanding of autism, its causes, and potential treatments.² However, families and young children with ASD and other related developmental disabilities continue to face many challenges in health care and educational service system access, ensuring optimal development through early intervention, a successful transition into adulthood, and fostering family well-being and positive family functioning in diverse racial and ethnic populations.

To further address autism as a critical and growing public health concern, Congress enacted the Combating Autism Act of 2006³ in December 2006, which authorized programs to combat autism through research, screening, intervention, and education. As stated in this legislation, the Secretary of Health and Human Services shall “establish and evaluate activities to:

- (1) provide information and education on autism spectrum disorder and other developmental disabilities to increase public awareness of developmental milestones;
- (2) promote research into the development and validation of reliable screening tools for autism spectrum disorder and other developmental disabilities and disseminate information regarding those screening tools;
- (3) promote early screening of individuals at higher risk for autism spectrum disorder and other developmental disabilities as early as practicable, given evidence-based screening techniques and interventions;
- (4) increase the number of individuals who are able to confirm or rule out a diagnosis of autism spectrum disorder and other developmental disabilities;
- (5) increase the number of individuals able to provide evidence-based interventions for individuals diagnosed with autism spectrum disorder or other developmental disabilities; and
- (6) promote the use of evidence-based interventions for individuals at higher risk for autism spectrum disorder and other developmental disabilities as early as practicable.”

Congressional appropriations included funding for the Health Resources and Services Administration (HRSA) to implement Section 399BB of the Combating Autism Act. HRSA’s Maternal and Child Health Bureau (MCHB) has a long and rich history of implementing programs that include but are not limited to services, research, training, and system infrastructure building for ensuring the delivery of health care and related services to

and promoting the well-being of all mothers, infants, children, adolescents, and children with special health care needs in the nation, including those with low incomes, from diverse ethnic or racial backgrounds, or isolated populations with limited access to care through Title V of the Social Security Act.⁴ Under the Combating Autism Act authority, HRSA's MCHB developed the Combating Autism Act Initiative (CAAI) to address ASDs and other developmental disabilities by: increasing awareness; reducing barriers to screening and diagnosis; supporting research on evidence-based interventions for children and adolescents with ASD and other developmental disabilities; promoting evidence-based guideline development for interventions; and training professionals to use valid and reliable screening tools to diagnose or rule out ASD and other developmental disabilities, and to provide evidence-based interventions.

Within the CAAI, the MCHB implemented programs in 4 domains in 2008: (1) Combating Autism Training Programs, including expansions to existing Leadership Education in Neurodevelopmental Disabilities training programs, as well as new Leadership Education in Neurodevelopmental Disabilities training programs; growth of current Developmental Behavioral Pediatrics (DBP) training programs; and development of a Maternal and Child Health (MCH) Training Autism Resource Center cooperative agreement; (2) 2 Autism Intervention Research Networks focused on intervention research, guideline development, and information dissemination (1 network that is focused on physical health interventions, and 1 on behavioral, mental, social, and/or cognitive health interventions); (3) Combating Autism State Demonstration and Policy Programs, which have included the following: (a) the founding of the State Autism Demonstration grants, which have

implemented comprehensive State autism plans to improve early screening, diagnosis, and access to comprehensive coordinated early intervention services and related health care for children and adolescents with ASD and other developmental disabilities; and (b) the

formation of a State Public Health Coordinating Center, which coordinates with the State Autism Demonstration grants and develops and implements strategies for defining, supporting, and monitoring the role of State public health agencies in assuring that children and

TABLE 1 HRSA/MCHB Autism Intervention Research Projects

Autism Intervention Research Networks				
Project Title	Organization	City	State	
Autism Intervention Research Network on Behavioral Health (AIR-B Network)	University of California, Los Angeles	Los Angeles	CA	
Autism Intervention Research Network on Physical Health (AIR-P Network)	Massachusetts General Hospital	Boston	MA	
R40 MCH Autism Intervention Research Projects				
Tele-health delivery of a family-focused intervention to reduce anxiety in youth with ASDs in rural Colorado	University of Colorado, Denver	Aurora	CO	
Parent-mediated versus center-based intervention for toddlers with ASD: a randomized controlled trial	Kennedy Krieger Institute, Inc	Baltimore	MD	
Supporting the well-being of families of young children with ASDs	Boston Medical Center	Boston	MA	
Family centered transition planning	University of New Hampshire	Concord	NH	
Assessing a participant directed service system for low income children with ASD	Brandeis University	Waltham	MA	
Predictors of effects of propranolol on language and connectivity in autism	University of Missouri	Columbia	MO	
Improved early identification of autism in Latino children	Georgetown University	Washington	DC	
Use of a family navigator in families with children newly diagnosed with ASD	Boston Medical Center	Boston	MA	
Transition to adult services for youth with ASD	Massachusetts General Hospital	Boston	MA	
A parent-to-parent model of support and service coordination for families of preschool-aged children with ASD	University of Connecticut Health Center	Farmington	CT	
Evaluating the impact of early intervention services on young children with ASD and their families: a state systems approach	Health Research, Inc/New York State Department of Health	Albany	NY	
Parent implemented training for autism through teleconsultation (PITA-T)	West Virginia University	Morgantown	WV	
R40 MCH Autism Intervention SDAS Projects				
Services and outcomes for transition age young adults with ASDs: secondary analysis of the NLTS2 and RSA 911	University of Massachusetts	Boston	MA	
The effectiveness of special education services for children with autism: a national longitudinal study	University of North Carolina at Chapel Hill	Chapel Hill	NC	
Medical service utilization by Medicaid-eligible children with autism in Georgia: an analysis of one year of claims and provider data	Georgia State University Research Foundation, Inc	Atlanta	GA	
Autism insurance policy and access to care for children with autism: a state-level analysis	University of North Carolina at Chapel Hill	Chapel Hill	NC	
Racial/ethnic disparities in family burden and health care of children with autism	Brandeis University	Waltham	MA	
DBP Research Network	DBP Research Network Children's Hospital of Philadelphia	Philadelphia	PA	

adolescents with ASD receive early and appropriate identification, diagnosis, and intervention; and (4) the Combating Autism National Evaluation, which will provide critical information on progress related to ASD and other developmental disabilities as required by the Combating Autism Act of 2006. Preliminary results from the national evaluation of HRSA's CAAI included in a report to Congress in December 2010 were positive, indicating that the CAAI investments had achieved the program purposes of (a) promoting early screening and treatment of those diagnosed with ASD, (b) increasing the number of individuals who are able to screen and provide evidence-based services to those with ASD, and (c) advancing research into the development and validation of reliable screening tools and interventions.

In 2009 and 2010, additional funding was authorized by the Act to further HRSA/MCHB's Combating Autism efforts in the areas of autism intervention research and training. With this additional funding for autism intervention research, the field-initiated R40 Autism Intervention Research, and Secondary Data Analysis Studies (SDAS) Programs were initiated in 2009, followed by the implementation of the DBP Research Network in 2010.

These Autism Intervention Research Programs, all components of HRSA/MCHB's CAAI, are administered by the MCH Research Program, located within MCHB's

Division of Research, Training and Education. Since its inception in 1963, the MCH Research Program has supported groundbreaking investigations that have significantly influenced clinical management, organization, and delivery of health care services, preventive care, and early intervention for the maternal and child health population, including children with special health care needs.

The portfolio of MCHB Autism Intervention Research Programs funded in 2008–2010 includes the following program activities:

- (1) Two Autism Intervention Research Networks that focus on (a) intervention research, (b) tool validation for interventions, (c) guideline development, and (d) information dissemination on research findings, guidelines, and tool validation activities to health professionals and the public, especially families impacted by ASDs and other developmental disabilities. One network focuses on physical health interventions (AIR-P), and 1 network focuses on behavioral, mental, social, and/or cognitive health interventions (AIR-B).
- (2) Twelve field-initiated R40 Autism Intervention Research grants on evidence-based practices for interventions to improve the health and

well-being of children and adolescents with ASD and other developmental disabilities, with a focus on addressing the unique and important needs of underserved populations.

- (3) Five field-initiated R40 SDAS grants on evidence-based practices for interventions to improve the health and well-being of children and adolescents with ASD and other developmental disabilities, utilizing exclusively the analysis of existing secondary data.
- (4) A DBP Research Network that focuses on the translation of multidisciplinary pediatric research to practice and fosters a new generation of developmental behavioral pediatric researchers.

A complete list of all HRSA/MCHB Autism Intervention Research Program projects awarded in 2008–2010 is included in Table 1. Information about all HRSA/MCHB CAAI programs can be found at <http://mchb.hrsa.gov/programs/autism/>. Subject to future amendment or reauthorization of Section 399BB, Public Health Service Act, Pub L No. 109-416, the Combating Autism Act of 2006 (42 USC 280i-1), it is expected that the MCH Research Program will continue and expand its autism intervention research programs. Manuscripts from select HRSA/MCHB Autism Intervention Research projects are included in this journal supplement.

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