

Autism and Other Developmental Disabilities Research Programs of the Maternal and Child Health Bureau

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In the United States, it is estimated that 1 in 68 children have autism spectrum disorder (ASD) according to data from the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network.¹ Based on data from the 2011–2012 National Survey of Children's Health, a recent report suggests an even higher prevalence estimate of 1 in 50 children with ASD.² These increasing prevalence data indicate that ASD continues to be a major public health concern in the United States requiring coordinated and collaborative efforts at the national, state, and community levels.

Since 1995, the US Department of Health and Human Services has supported initiatives aimed at increasing our understanding of ASD, its causes, and potential treatments.³ These initiatives have paved the way to a more coordinated federal effort to address ASD and other developmental disabilities with the enactment of the Combating Autism Act of 2006 (CAA). This act authorized programs to address ASD and other developmental disabilities through research, screening, intervention, and education. Congressional appropriations included funding for the Health Resources and Services Administration (HRSA) to implement section 399BB of the CAA⁴ to address the following:

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Ms Park contributed to the conception and design of the study as well as drafting and revising the manuscript and agrees to be accountable for all aspects of the work; Drs Harwood and Yu contributed to drafting, reviewing, and revising the manuscript and agree to be accountable for all aspects of the work; Dr Lu and Ms Kavanagh contributed to revising the manuscript, provided final review and approval of the version to be published, and agree to be accountable for all aspects of the work; and all authors approved the final version as submitted.

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1. increase awareness of ASD and other developmental disabilities;
2. reduce barriers to screening and diagnosis;
3. support research to advance the evidence base on interventions;
4. promote the development of guidelines for evidence-based practices; and
5. train health care professionals to use valid, reliable screening tools to confirm or rule out an ASD diagnosis and, if diagnosis is confirmed, to provide evidence-based, early intervention.

Under this authority, in 2008 the HRSA's Maternal and Child Health Bureau (MCHB) developed and implemented the CAA Initiative, a coordinated portfolio of programs in 4 domains:

1. training programs, including new Leadership Education in Neurodevelopmental Disabilities training programs as well as expansions to existing Leadership Education in Neurodevelopmental Disabilities programs, and enhancements to existing Developmental Behavioral Pediatrics training programs, with the goal of addressing the shortage of health care professionals who are qualified to provide screening and diagnostic evaluation for ASD and other developmental disabilities;
2. a new Autism Intervention Research Program to advance the evidence base on the effectiveness of interventions, promote guideline development, and facilitate the translation of research findings into practice;
3. state autism programs to improve access to comprehensive, coordinated health care and related services for children and youth with ASD and other developmental disabilities and to help state systems of services strengthen early and continuous

- screening, coordination of family-centered services through a medical home, and increased awareness of ASD and other developmental disabilities among parents and professionals; and
4. a national evaluation, as required by the CAA, which provided key information on progress and outcomes related to ASD and other developmental disabilities.

Findings from the evaluation were included in the "Report to Congress on Activities Related To Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006 (FY 2006–2009)," submitted to Congress in 2010 by the Secretary of the US Department of Health and Human Services. Findings from the evaluation indicated that HRSA's MCHB program investments made significant progress toward meeting the program purposes of (1) promoting early screening and treatment of those diagnosed with ASD, (2) increasing the number of practitioners who are able to screen and provide evidence-based services to those with ASD, and (3) advancing the evidence base on intervention effectiveness and early identification.⁵

Reauthorization of the CAA through the Combating Autism Reauthorization Act of 2011 and the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 has enabled the HRSA's MCHB to continue to promote the health and well-being of children and adolescents with ASD and other developmental disabilities through its coordinated programs in research, training, and service systems. Through these programs, the HRSA's MCHB is building our nation's capacity to provide comprehensive, coordinated services for the growing population of individuals diagnosed with ASD.⁶ A subsequent "Report to Congress on Activities Related

To Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006 and the Combating Autism Reauthorization Act of 2011 (FY 2010–FY 2012)" provided further findings indicating the significant achievements made by federal agencies, in partnership with communities, in addressing many of the pressing needs of individuals and families affected by ASD. Among the achievements cited included those of the HRSA's research, training, and state programs in the following: rapidly assembling guidelines to help individuals with ASD, families, and practitioners address these needs in the context of daily living; identifying and evaluating best practices among services and supports across the states; raising awareness and reducing barriers to early identification and access to services; and advancing the evidence base on the effectiveness and outcomes of interventions for individuals with ASD and other developmental disabilities, including underserved populations.⁷

Reauthorization has enabled support of new research investments that address urgent needs of the field and are aligned with HRSA/MCHB goals as well as the Interagency Autism Coordinating Committee Strategic Plan for ASD Research. In particular, consistent with HRSA's mission as the primary federal agency for improving access to health care services and health equity, many of these projects have focused on the needs of vulnerable and underserved populations by considering ethnic/racial, cultural, linguistic, socioeconomic, and geographic (eg, rural/urban) diversity of individuals; this focus addresses the need for more research with regard to the effectiveness of interventions among these underserved populations, for whom disparities in the identification of ASD and other developmental disabilities currently exist.

The portfolio of HRSA's MCHB autism and other developmental disabilities research programs includes both national research networks and field-initiated research projects, which include the following:

5 national research networks, which include

Autism Intervention Research

Networks on Behavioral Health (AIR-B) and Physical Health (AIR-P); first funded in 2008, these 2 research networks provide national leadership in research designed to improve the behavioral and physical health and well-being of children and adolescents with ASD and other developmental disabilities through multisite research that focuses on developing, testing, and improving treatments and interventions; validating new tools for interventions; developing practice guidelines; and promoting the transfer of findings into practice through the dissemination of network findings and activities to researchers, practitioners, communities, and families of children and adolescents with ASD and other developmental disabilities;

Developmental-Behavioral

Pediatrics Research Network (DBPNet); first funded in 2010, DBPNet provides national leadership in research to improve clinical services provided by developmental and behavioral pediatricians and the health outcomes for children with the most prevalent and serious developmental and behavioral conditions including ASD;

MCH Research Network on

Promoting Healthy Weight; first funded in 2013, the MCH Research Network on Promoting Healthy Weight promotes coordinated research activities

related to promoting healthy weight among children and youth with ASD and other developmental disabilities, to increase the knowledge base regarding factors that may contribute to increased risk of overweight and obesity and to advance the evidence base on the efficacy of interventions designed to help prevent and reduce overweight and obesity among this population; and

MCH Health Care Transitions

Research Network for Youth and Young Adults with ASD; first funded in 2014, the MCH Health Care Transitions Research Network for Youth and Young Adults with ASD focuses on identifying research needed to improve health care transitions and promote an optimal transition to adulthood among youth and young adults with ASD, including physical, psychosocial, educational, and vocational outcomes.

In addition to the research networks, the field-initiated R40 Autism Intervention Research and Secondary Data Analysis Studies programs were developed in 2009. Since 2009, these 2 programs have funded the following:

30 field-initiated R40 Autism

Intervention research grants designed to advance the evidence base on the effectiveness of interventions and expand the research base that will lead to best practices for the early identification of ASD and/or its treatment, with a particular focus on advancing health equity for underserved populations; and

17 field-initiated R40 Secondary

Data Analysis Studies that add to the evidence base regarding the health and well-being of children and adolescents with ASD through the secondary analysis

of existing national data sets and/or administrative records.

In sum, the HRSA's MCHB has played a pivotal role in providing national leadership in research to improve early identification, effective treatments, and access to a continuum of quality care and services. Through its research networks and investigator-initiated research programs, the MCHB has conducted studies on a range of topics; developed and tested the efficacy of new and newly adapted interventions; promoted early identification, family well-being, improved health care delivery services, and optimal transitions to adulthood; and developed guidelines and tools to support families and professionals in providing treatment and care for children with ASD and other developmental disabilities. A complete list of all HRSA MCHB-supported autism and other developmental disabilities research projects awarded from 2008 to 2014 is included in Table 1. In the area of early detection and access to care, these research investments have addressed disparities in early identification and access to treatment experienced by children in minority and underserved communities, including the development of culturally appropriate autism screening programs and the use of telehealth to overcome the geographic barriers to treatment of rural populations. Advances have been made in the provision of services and supports for those with ASD. The work of the AIR-P is improving the clinical care of children suffering from significant comorbidities associated with ASD, including constipation and insomnia, 2 key areas of concern for parents and families. The AIR-P has developed practice guidelines on the treatment of both insomnia and constipation as well as a guideline on medication choice to improve the clinical care provided to these

TABLE 1 HRSA/MCHB's Autism and Other Developmental Disabilities Research Projects

Project Title	Organization	City	State
Research networks			
AIR-B	University of California, Los Angeles	Los Angeles	CA
AIR-P	Massachusetts General Hospital	Boston	MA
DBPNet	Children's Hospital of Philadelphia	Philadelphia	PA
HW-RN	University of Massachusetts	Waltham	MA
HCT-RN	University of California, Los Angeles	Los Angeles	CA
R40 MCH autism intervention research projects			
Telehealth 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: an RCT	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 ASDs and their families: a state systems approach	Health Research, Inc/New York State Department of Health	Albany	NY
PITA-T	West Virginia University	Morgantown	WV
Controlled trial of sertraline in young children with fragile X syndrome	University of California, Davis	Sacramento	CA
Behavioral treatment through in-home telehealth for young children with autism	University of Iowa	Iowa City	IA
Efficacy of the home TEACCHing program for toddlers with autism	University of North Carolina at Chapel Hill	Chapel Hill	NC
Comprehensive support for families with autism: a parent-based mentoring approach	University of Colorado	Aurora	CO
Studying the impact of service-learning on career development, self-determination, and social skill building for youth with ASDs	University of Massachusetts	Boston	MA
Predicting obstructive sleep apnea in Down syndrome	Massachusetts General Hospital	Boston	MA
Efficacy of a Qigong massage methodology for children with ASD aged 3 to 11 years	Western Oregon University	Monmouth	OR
Addressing health disparities in ASD diagnosis, services, and school engagement	University of Massachusetts	Boston	MA
Improving part C services and outcomes for underserved children with ASD	Kennedy Krieger Institute, Inc	Baltimore	MD
Toddlers and families together: addressing early core features of autism	University of North Carolina at Chapel Hill	Chapel Hill	NC
Parent-mediated interventions in autism: the search for meaningful outcomes	University of Colorado	Aurora	CO
Investigation of teacher-mediated toilet training using a manualized moisture alarm intervention	University of Rochester	Rochester	NY
Comparative efficacy of a self-directed and therapist-assisted telehealth parent training intervention for children with ASD	Michigan State University	East Lansing	MI
SaLSA	University of Colorado	Aurora	CO
Does mindfulness training enhance early evidence-based parent-coaching interventions?	Vanderbilt University	Nashville	TN
A controlled trial of sertraline in young children with ASD	University of California, Davis	Sacramento	CA
Comprehensive communication intervention for minimally verbal children with autism	Vanderbilt University	Nashville	TN
A prospective birth cohort study on pre- and perinatal determinants of ASDs and developmental disabilities	Johns Hopkins University	Baltimore	MD
R40 MCH autism intervention SDAS projects			
Services and outcomes for transition-age young adults with ASDs: secondary analysis of the NLTSS2 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 1 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
Transition-age young adults with autism: the role of self-determination, social skills, job search, transportation, and rehabilitation services in employment outcomes	University of Massachusetts	Boston	MA
Access, quality, and financial implications of the transitions of children with autism	University of North Carolina at Chapel Hill	Chapel Hill	NC
Autism intervention challenges for low-income children	University of California, Los Angeles	Los Angeles	CA
Access to therapy for children with autism: a population-based analysis	Thomas Jefferson University	Philadelphia	PA

TABLE 1 Continued

Project Title	Organization	City	State
Trends in racial and ethnic health care disparities for children with autism and other developmental disabilities	Brandeis University	Waltham	MA
Dental homes for Medicaid-enrolled children with ASDs in the Iowa I-Smile Program	University of Washington	Seattle	WA
Adequate health insurance for children with autism: evidence and implications for defining essential benefits	University of North Carolina at Chapel Hill	Chapel Hill	NC
Racial and ethnic disparities in children's early diagnostic and health services	Brandeis University	Waltham	MA
Making a more effective and efficient SCQ	Texas Tech University	Lubbock	TX
Tough choices: autism, private health insurance, and family out-of-pocket	University of North Carolina at Chapel Hill	Chapel Hill	NC
Peer-victimization of adolescents with ASD: filling the knowledge gaps to create antibullying interventions	University of California, San Francisco	San Francisco	CA
Patterns and variations in emergency department visits for US children with autism: a rural-urban comparison	University of North Carolina at Chapel Hill	Chapel Hill	NC

AIR-B network, Autism Intervention Research Network on Behavioral Health; HCT-RN, Health Care Transitions Research Network for Youth and Young Adults with ASD; HW-RN, Healthy Weight Research Network for Children with ASD and Developmental Disabilities; NLTS2, ; PITA-T, Parent-Implemented Training for Autism through Teleconsultation; RCT, randomized controlled trial; RSA 911, ; SaLSA, Screening and Linkage to Services for Autism; SCQ, ; SDAS, Secondary Data Analysis Studies; TEACCHing, .

children. Research conducted by the AIR-B has resulted in interventions that have been shown to improve the core deficits and the social and developmental outcomes of children with ASD from underresourced and minority backgrounds; these interventions have been made available to parents, professionals, educators, and community members.

The increasing prevalence of ASD suggests that more children may be receiving screening and diagnosis of ASD, but disparities still exist in early identification, effective treatment, and access to services for underserved populations, including minority and rural communities. The HRSA's MCHB will continue to play a critical role in addressing these disparities and ensuring health equity through comprehensive and innovative programs that will ensure a qualified health workforce that can provide screening and diagnostic evaluation for ASD and other developmental disabilities, conduct research to advance the evidence base on early identification and effective interventions, and improve access to comprehensive, coordinated health care and related services for children and adolescents with ASD and other developmental disabilities.

To date, >100 peer-reviewed articles have been published by HRSA MCHB's autism and other developmental disabilities research grantees (<http://www.mchb.hrsa.gov/research/autism-publications.asp>). Information on the HRSA MCHB's autism and other developmental disabilities research, training, and state grant programs can be found at <http://mchb.hrsa.gov/programs/autism/>. Articles related to select HRSA MCHB research project findings are included in this supplement issue.

ABBREVIATIONS

- AIR-P: Autism Intervention Research Network on Physical Health
- ASD: autism spectrum disorder
- CAA: Combating Autism Act
- DBPNet: Developmental-Behavioral Pediatrics Research Network
- HRSA: Health Resources and Services Administration
- MCHB: Maternal and Child Health Bureau

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