

Programs and Activities Funded through the Autism CARES Act – Listed by Agency

Department of Health and Human Services		
<ul style="list-style-type: none"> • National Autism Coordinator • Interagency Autism Coordinating Committee (IACC) 		
National Institutes of Health (NIH)	Centers for Disease Control and Prevention (CDC)	Health Resources and Services Administration (HRSA)
<ul style="list-style-type: none"> • Office of Autism Research Coordination (OARC) • Autism Centers of Excellence (ACEs) • ASD/DD investigator-initiated and targeted research, and NIH-wide research programs • Support for IACC publications and activities 	<ul style="list-style-type: none"> • The Autism and Developmental Disabilities Monitoring Network (ADDM) • Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) • The Study to Explore Early Development (SEED) • The National Health Interview Survey (NHIS) • Learn the Signs. Act Early. (LTSAE) 	<ul style="list-style-type: none"> • Autism Research Networks Program • Autism Single Investigator Innovation Program (Autism SIIP) • The R41 Autism Field–Initiated Intervention Research (Autism FIRST) • The R41 Autism Secondary Data Analysis Research (Autism SDAR) • Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Training Program • Developmental Behavioral Pediatrics (DBP) Training Program • Interdisciplinary Training Resource Center (ITAC) • State Systems Program • State Public Health Autism Resource Center (SPHARC)

**The above graphic outlines agencies that receive appropriations through the Autism CARES Act. The level of funding will vary by agency. For more information on funding levels, refer to the agency budget line items related to ASD/DD (i.e. [NIH – “Autism”](#); [CDC “Autism”](#) and [HRSA – “Autism and other Developmental Disabilities”](#)).*

***In [reports to Congress](#), the IACC reports on agencies and offices within HHS that are involved in ASD research, services and activities, including those that are not directly funded through the Autism CARES Act.*

Detailed Program List by Agency

Department of Health and Human Services

- The Autism CARES Act designates an existing official (**National Autism Coordinator**) within the U.S. Department of Health and Human Services to oversee, in consultation with the Secretaries of Defense and Education, national ASD research, services, and support activities. It also charges the IACC with monitoring federal activities related to ASD.
- The [Interagency Autism Coordinating Committee \(IACC\)](#) is charged with coordinating Federal activities concerning ASD and providing advice to the Secretary of Health and Human Services on issues related to ASD.
 - Committee membership includes representatives from a wide array of federal agencies involved in ASD research and services, as well as public stakeholders including but not limited to autistic adults, family members of children and adults with ASD, national organization staff, service providers, and researchers.
 - [Evaluation and Report to Congress](#): The law requires reporting to Congress on the progress and expenditures made in ASD research, services, and activities as well as implementing the provisions of the Act. The 2014 reauthorization required a specific report on young adults with ASD and the challenges related to the transition from existing pediatric and school-based services to services available during adulthood. [This report](#) summarized federal investments focused on this transition for individuals with ASD, and identified gaps in federal research, programs, and services that support youth with ASD during this critical time period.
 - [Strategic plan](#): The law requires the IACC to develop and annually update a strategic plan for ASD that includes information about available services and supports for individuals and families. Each edition of the plan is informed by researchers, autistic adults, family members, advocates, and the general public in order to reflect diverse perspectives from across the ASD/DD community. It provides guidance to federal agencies and private partner organizations regarding ASD research and services priorities, knowledge gaps, and goals.
 - [Strategic Plan for Research](#) –The IACC Strategic Plan provides a framework to guide the autism research efforts of federal and private funders.
 - [Develop and annually update a Summary of Advances in Autism Spectrum Disorder Research](#): The IACC is required to develop and annually update a Summary of Advances in ASD Research that highlights significant progress in the field. This document provides short, plain language summaries of the top research breakthroughs selected by the IACC from a pool of research articles nominated by its members.

National Institutes of Health (NIH)

The National Institute of Health (NIH) develops and promotes ASD/DD research initiatives related to causes; prevention; treatment; early screening; diagnosis or ruling out a diagnosis; interventions, including school and community-based interventions; and access to services and supports. NIH also contributes to research infrastructure to accelerate the pace of ASD research.

- The [Office of Autism Research Coordination \(OARC\)](#) at NIH coordinates and serves as a liaison between the IACC and participating agencies, Congress, and the public. The office also provides support for all IACC activities and publications.
- NIH encourages rigorous, evidenced-based research on ASD/DD through numerous investigator-initiated and targeted Funding Opportunity Announcements, as well as NIH-wide research programs.
 - [Autism Centers of Excellence \(ACEs\)](#): The ACE program supports large-scale multidisciplinary studies on ASD; the program’s goal is to determine the disorder’s causes and potential treatments. The ACE program is composed of individual research centers at a single institution and networks of research teams at different institutions working together on a common research problem.

Centers for Disease Control and Prevention (CDC)

The Centers for Disease Control and Prevention (CDC) conducts surveillance on prevalence, risk factors, and health status of children with ASD/DD. Main programs and activities include:

- [ADDM](#): The Autism and Developmental Disabilities Monitoring (ADDM) Network is a group of programs funded by CDC to estimate the number of children with ASD/DD living in different areas of the United States.
- [CADDRE](#) / [SEED](#): CDC established a network of regional Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE). The CADDRE Network is working on the Study to Explore Early Development (SEED). SEED is the largest study in the United States to help identify factors that may put children at risk for ASDs and other developmental disabilities.
- [NHIS](#): CDC conducts the National Health Interview Survey (NHIS), a nationally representative survey that provides data on the health of children in the United States, including information on developmental disabilities and delays.
- [“Learn the Signs. Act Early” \(LTSAE\)](#): CDC’s LTSAE program aims to improve early identification of children with ASD/DD, so children and families can get the services and support they need. In addition to a research and evaluation component (listed under the “Research” card), the program includes the following:
 - [Research and Evaluation](#): These research and evaluation projects advance our understanding of how to improve early identification of children with ASD/DD, especially among population groups that experience significant health disparities.
 - [Health education campaign](#): The LTSAE campaign materials and resources are available to help pediatric providers, families, state systems, and programs that serve parents of young children increase awareness of healthy developmental milestones during early

childhood; the importance of tracking each child's development; and the importance of acting early if there are concerns.

- [Act Early Initiative](#): The Act Early Initiative promotes collaboration among early childhood programs in states and territories so that children with ASD/DD can be identified early and get the services and support they and their families need. This initiative includes the (1) Act Early Ambassador program to expand the reach of the LTSAE program; and (2) Act Early State Systems grants to strengthen state and community systems for early identification and coordination of services for children with developmental disabilities.

Health Resources and Services Administration (HRSA)

To accomplish the goals of the Autism CARES Act, the Health Resources and Services Administration (HRSA), [supports three initiatives](#) to address ASD/DD through education, early detection, and intervention:

- **HRSA Autism Research Programs**: HRSA supports the establishment and maintenance of interdisciplinary, national, multisite, collaborative research to advance the evidence base on the effectiveness of interventions to improve the health and well-being of children and adolescents with ASD/DD and to advance best practices for early identification.
 - The Autism Research Networks support the creation of interdisciplinary, multicenter research and provide opportunities for scientific collaboration. These include:
 - [Autism Intervention Research Network on Physical Health \(AIR-P\)](#)
 - [Autism Intervention Research Network on Behavioral Health \(AIR-B\)](#)
 - [Developmental Behavioral Pediatrics Research Network \(DBPNet\)](#)
 - [Healthy Weight Research Network \(HWRN\)](#)
 - **Autism Single Investigator Innovation Program (Autism SIIP)** supports focused research on priority or emerging ASD research areas, and topics with limited research. These include:
 - [The Autism Longitudinal Data Project](#) examines risk factors for ASD/DD, the effects of various interventions, and trajectories of child development over the life course.
 - [The Autism Transitions Research Project](#) examines factors associated with healthy life transitions among adolescents and young adults with ASD.
 - **The R41 Autism Field-Initiated Intervention Research (Autism FIRST)** Program supports interventions designed to improve the health and well-being of children and adolescents with ASD and other developmental disabilities, with a particular focus on addressing barriers to identification, diagnosis, and services among underserved populations.
 - **The R41 Autism Secondary Data Analysis Research (Autism SDAR)** Program supports secondary data analysis of existing publicly available and accessible national databases and/or administrative records to review and evaluate the effectiveness of ASD and other developmental disabilities interventions and assess disparities in access to ASD and other developmental disabilities screening, diagnosis, and treatment.

- **HRSA Training Programs**
 - [Leadership Education in Neurodevelopmental and Related Disabilities \(LEND\) Training Program](#) – trains future leaders in an interdisciplinary context (through clinical, research, and community-based experiences) to improve the health of children who have autism or are at risk of developing autism and intellectual disabilities. Trainees are typically graduate students in a variety of professional fields, including audiology, genetic counseling, nursing, nutrition, occupational therapy, physical therapy, psychology, public health, social work, special education, speech/language pathology, and others. Individuals with disabilities and family members also fully participate as both trainees and faculty members.
 - [Developmental Behavioral Pediatrics \(DBP\) Training Program](#) – helps prepare post-residency fellows for leadership roles as teachers, researchers, and clinicians that work with other professionals in a family-centered manner to ensure positive outcomes for children with ASD/DD.
 - [The Autism CARES Act National Interdisciplinary Training Resource Center \(ITAC\)](#) – ITAC supports the LENDs and DBPs in their efforts to build program- and network-level capacity to provide impactful training experiences for pre-service and practicing professionals from across disciplines, in partnership with people with disabilities and family members.
- **[HRSA State Systems Program](#)**
 - State Implementation and Planning Grants aim to improve access to care through referrals, timely diagnosis and feedback, and entry into quality, coordinated care across systems for children with ASD/DD.
 - [State Public Health Coordinating Center for Autism/ State Public Health Autism Resource Center \(SPHARC\)](#)—is a comprehensive resource center that provides ongoing technical assistance, resource development, and peer-to-peer and cross-state learning. Its goal is to increase the capacity of states, particularly [Title V Maternal and Child Health Services](#) programs, in administering systems of care for children with ASD/DD. SPHARC serves as the technical assistance center to the state implementation grantees.