

Results of the Autism  
Collaboration, Accountability, Research, Education  
and Support (CARES) Act of 2014:

HRSA's Efforts to Improve ASD/DD Service Delivery  
Through Research, Training, and State  
Implementation Grants

July 16, 2015

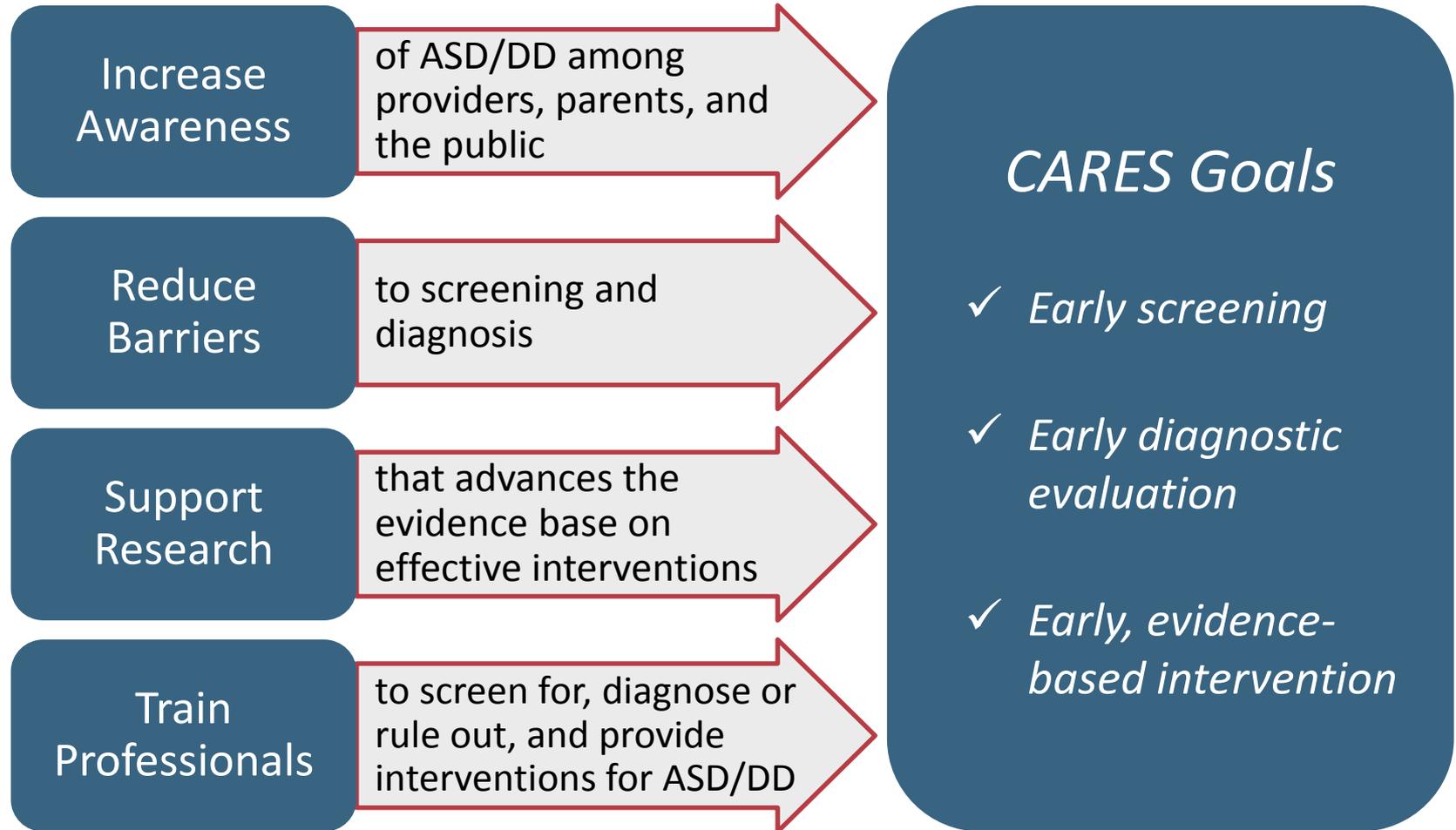
# Presentation Overview

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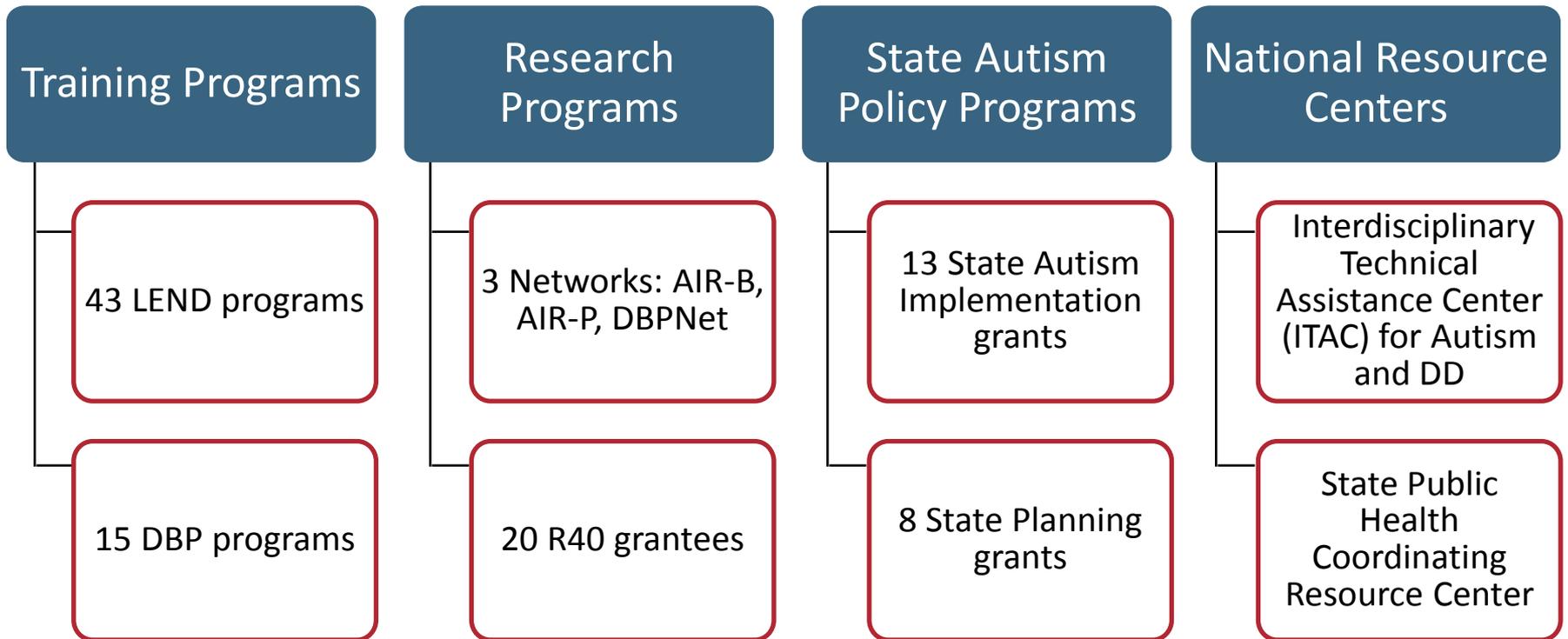
1. Introduction
2. MCH Autism Intervention Research Program
3. Leadership Education in Developmental-Behavioral Pediatrics (DBP)
4. Leadership Education in Neurodevelopmental Disabilities (LEND)
5. State Implementation Grants
6. Conclusion

# CARES Objectives

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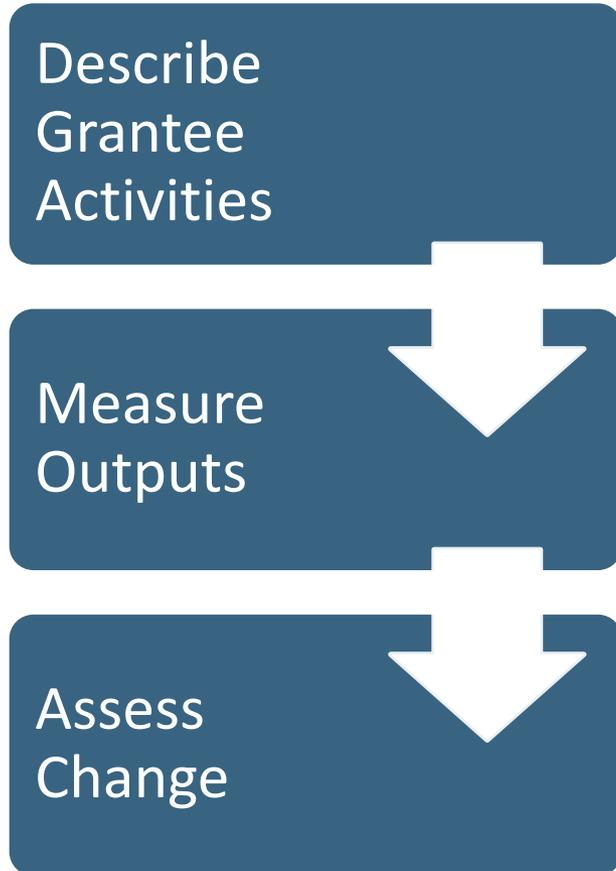
# Scope of Evaluation



Evaluation covers all active grants between FY2011–FY2013, with the exception of new Research grants that were first funded in FY2013.

# Evaluation Approach

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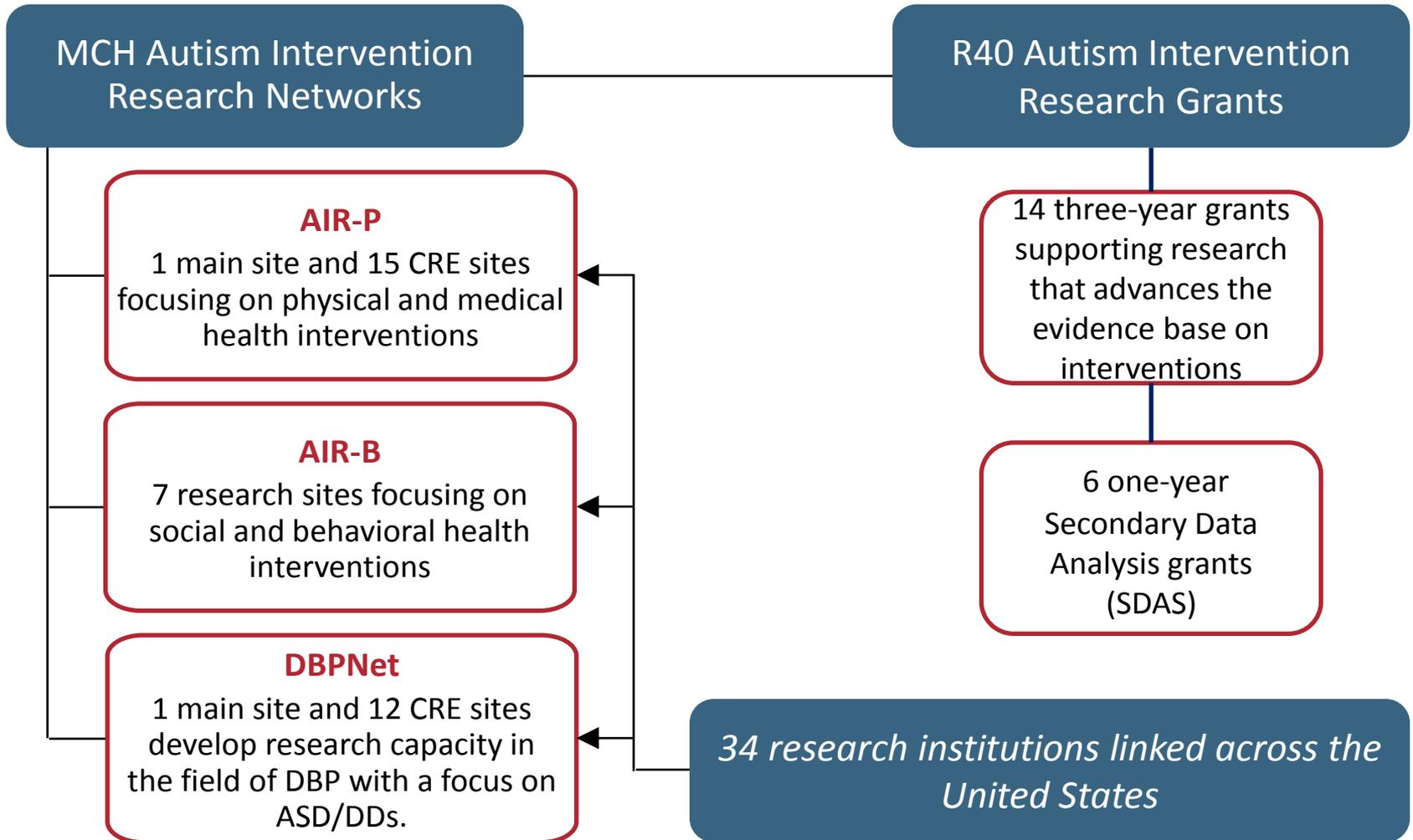


- ▶ Qualitative Data Sources
  - Grantee Applications and noncompeting continuation applications
  - Semi-structured interviews
  
- ▶ Quantitative Data Sources
  - Surveys
    - NIRS
    - Research Network questionnaire
    - State Implementation survey
  - DGIS items

# MCH Autism Intervention Research Program

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# MCH Autism Intervention Research Program

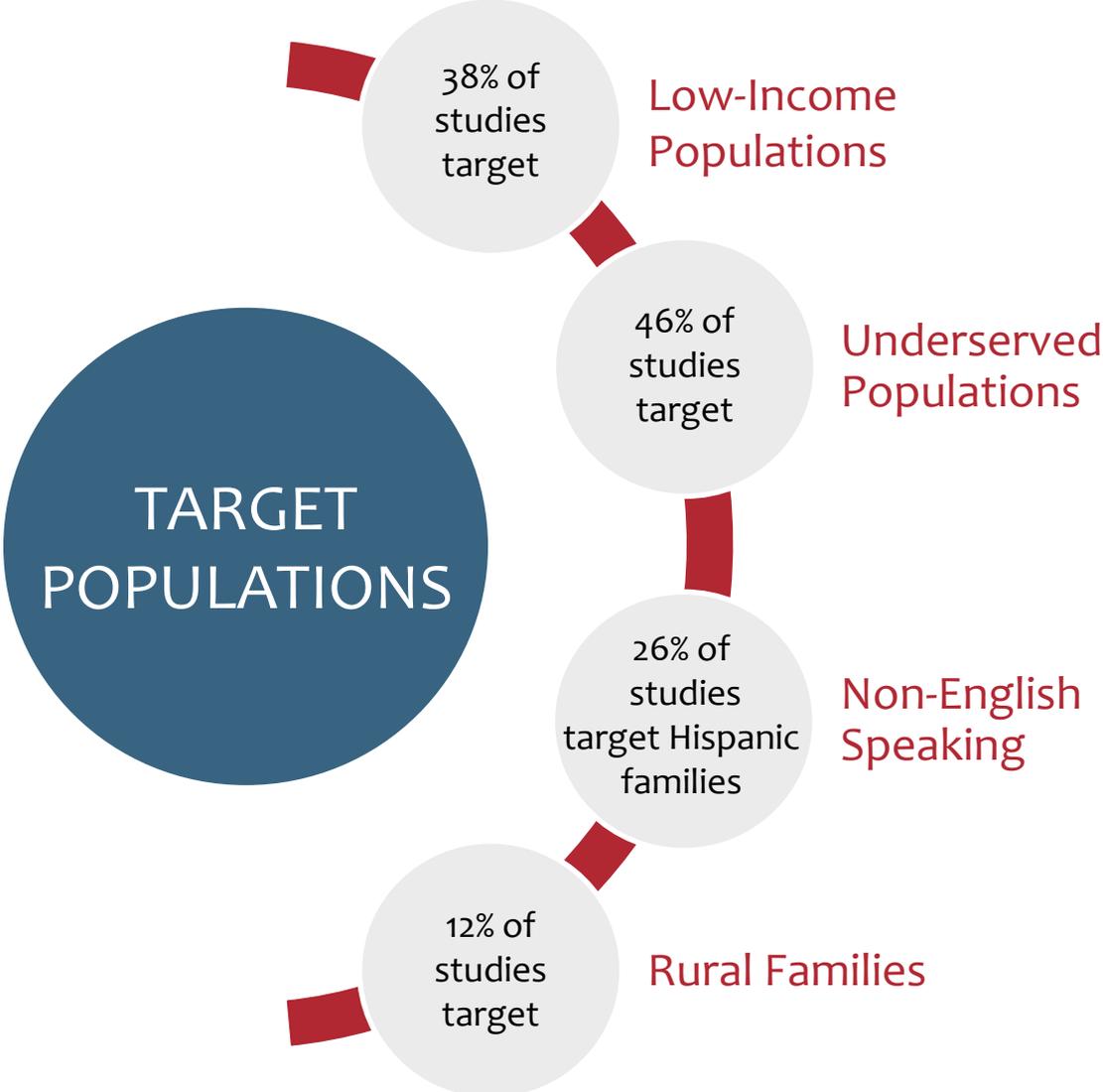


# Supporting Research: AIR Program Studies and Topic Areas

## Key Topic Areas

AIR-P	AIR-B	DBPNet	R40
<ul style="list-style-type: none"><li>▶ Sleep disturbances</li><li>▶ Gastrointestinal issues</li><li>▶ Diet and nutrition</li><li>▶ Medication choice and monitoring</li><li>▶ Genetic variability</li><li>▶ Immunity and hormones</li></ul>	<ul style="list-style-type: none"><li>▶ Social skills/connections including joint attention/engagement</li><li>▶ Peer relationships and friendships</li><li>▶ Language and social communication skills</li><li>▶ Underserved populations</li></ul>	<ul style="list-style-type: none"><li>▶ Practice variations of developmental behavioral pediatricians</li><li>▶ Screening and diagnostic measures</li><li>▶ Referral programs to reduce barriers to early diagnosis and intervention</li></ul>	<ul style="list-style-type: none"><li>▶ Special-education services</li><li>▶ Transition to adulthood</li><li>▶ Early intervention</li><li>▶ Child and parental mental health</li><li>▶ Participant-directed services</li></ul>

# Supporting Research: Target Populations for Research Network Program Studies



# Research Network Accomplishments

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## AIR-B, AIR-P and DBPNet

- ▶ AIR-B published a guideline report in the 2012 supplement to Pediatrics on the strength of evidence for effective behavioral treatments for children with ASD.
- ▶ AIR-B developed 6 assessment tools for school settings, 2 for any setting, and 1 for a home-based environment.
- ▶ AIR-P published 3 guideline statements in the 2012 supplement to Pediatrics, and two new guidelines were developed, which will be published in the November 2015 supplement to Pediatrics.
- ▶ The 20 AIR-P toolkits for parents and caregivers have been downloaded an average of 7,900 times (range: 1,000 – 26,000 downloads)
- ▶ DBPNet was awarded additional funds to build upon successful pilot research on family navigation.
- ▶ DBPNet is validating 3 PROMIS measures (Stress Experiences, Family Involvement, and Peer Relationship) in children with ASD.

# R40 Accomplishments

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## 14 Three-year Studies and 6 One-year SDAS

- ▶ Development of an effective research-based program to prepare ASD/DD youth for school.
- ▶ Identification of specific challenges to transition, emphasizing the need for continued high quality care of youth with ASD/DD.
- ▶ Reduction in problem behavior through a parent-implemented, in-home, telehealth intervention; results similar to traditional ABA treatment.
- ▶ Dissemination of the Parent-to-Parent intervention to parents of children with ASD in Colorado. The intervention was successful in increasing parent satisfaction with care in the first year after diagnosis.
- ▶ Reduction in stress experienced by parents of toddlers with ASD was achieved through a group-based parent education and in-home coaching intervention.
- ▶ Success of a pilot study of family navigation with low-income populations led to a multi-site R01 study, which is currently being tested.

# MCH Autism Research Program Final Products

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MCH Autism Intervention Research products include:



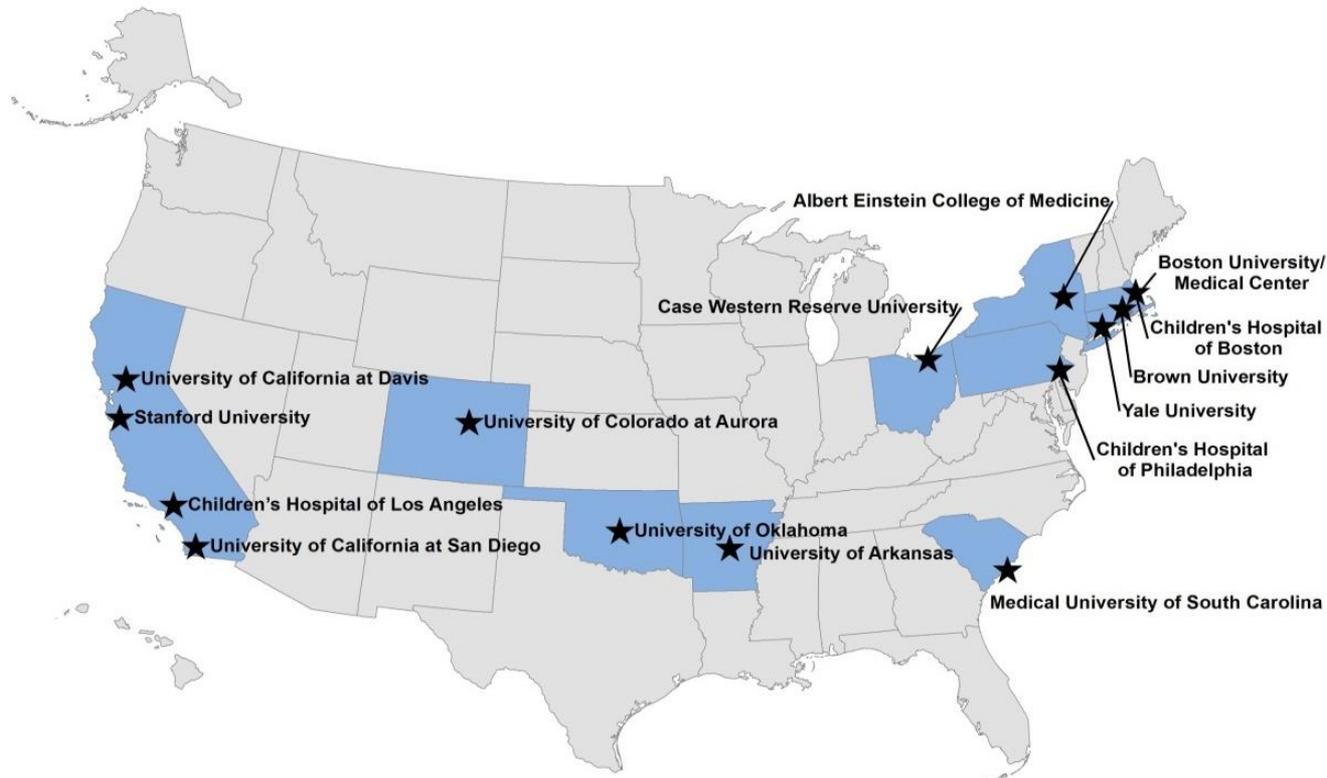
# Leadership Education in Developmental-Behavioral Pediatrics Training Programs

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# Training/Workforce Development

DBP programs are increasing the number of professionals with advanced skills in ASD/DD diagnosis and intervention. Between FY2011-FY2014, the CARES funded DBP programs enrolled:

- ▶ Nearly 50 long term fellows
- ▶ More than 1,300 medium term trainees



# Training/Workforce Development

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## Enhancing Knowledge and Skills Among Practicing Healthcare Professionals Through Continuing Education

DBP programs hosted 322 continuing education events between FY2011 and FY2014, reaching 31,106 professionals.

## Building community capacity and awareness

DBP grantees held 688 informational and training events for members of the community, reaching close to 15,000 families, educators, allied health professionals, self-advocates and others over the three year evaluation period.

Source: NIRS

Notes: For each year, N = 10. However, institutions that received grants in 2011–2012 and 2012–2013 were different from those receiving grants in 2013–2014.

# Leadership Training

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Leadership projects explore innovative strategies for improving the system of care for ASD/DD:

- ▶ One project helped researchers identify barriers to care using GeoMapping, which pinpointed areas in a metropolitan city with the highest number of missed appointments.
- ▶ Fellows from one DBP program participated in a community-based program that teaches resident physicians how to identify community assets and resources, build partnerships with community organizations, and enhance the community's capacity to improve local health. New fellows work with the general pediatrics faculty to select a community partner, develop materials, and help train residents.

# DBP Areas of Impact

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- ▶ Training more diagnostic specialists (fellows)
  - Most significant contribution of the CARES grants
  - Expands workforce capacity for providing diagnostic assessments and managing care of children with ASD/DDs.
  
- ▶ Developing future DBP leaders
  - Programs' rich leadership training builds research, teaching, and advocacy/systems-building skills
  - Fellows equipped to transform the field

# DBP Areas of Impact (continued)

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- ▶ Supporting training for current and future physicians
  - Grantees work closely with medical residents, medical students, and practicing physicians to promote screening and early identification
- ▶ Reducing Barriers to Screening and diagnosis.
  - Examples include piloting a triage clinic in a FQHC, developing an electronic database to track statewide service needs and collaborating with community-based clinics to increase screening capacity.

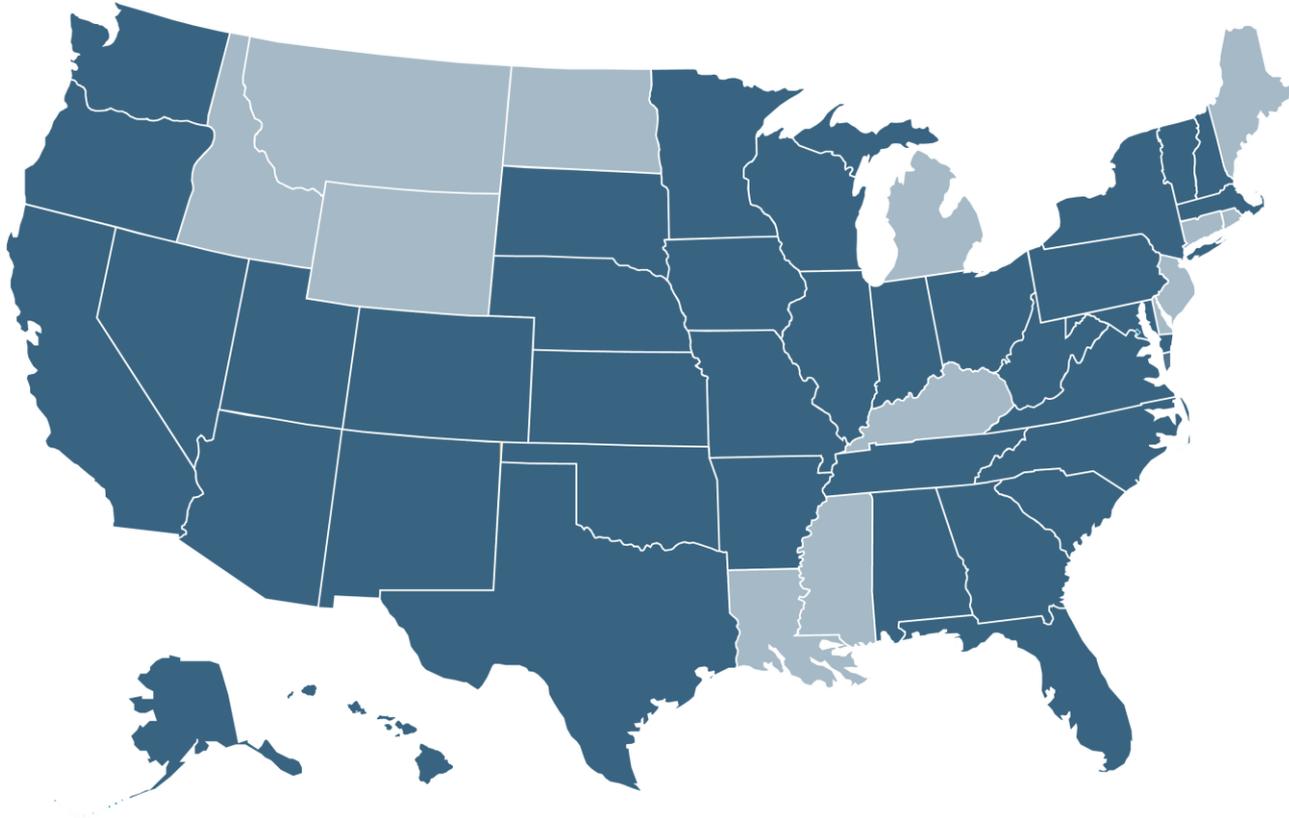
# Leadership Education in Neurodevelopmental and Related Disabilities Training Programs

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# Training/Workforce Development

LEND programs are expanding the supply of professionals trained to provide ASD /DD screening and referrals and to participate in interdisciplinary, diagnostic evaluations. Between FY2011–FY2014 the 43 CARES funded LEND programs enrolled:

- ▶ More than 1,300 long term trainees
- ▶ Close to 10,000 medium term trainees



# LEND Training/Workforce Development

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## Enhancing Knowledge and Skills Among Practicing Healthcare Professionals Through Continuing Education

Between FY2011 and FY2014, LEND programs hosted more than 2,700 continuing education events between FY2011 and FY2014, reaching more than 183,000 professionals

## Outreach Training for Community Providers

Between FY2011 and FY 2014, LEND programs provided more than 5,000 outreach trainings, reaching more than 161,000 educators, early intervention specialists, childcare providers, and child/family advocates

# Leadership Training

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LEND Leadership projects meet community needs:

- ▶ A long term LEND trainee developed an educational series for families with a newly diagnosed child called the ABCs of Autism. With additional Title V funding, the series has expanded to a new program, “ABCs of Special Needs.”
- ▶ Long term trainees from a LEND program are providing training and technical assistance to six community based agencies in underserved communities to increase ASD screening. Associated leadership projects are planned to collect data that will assess post-training outcomes.

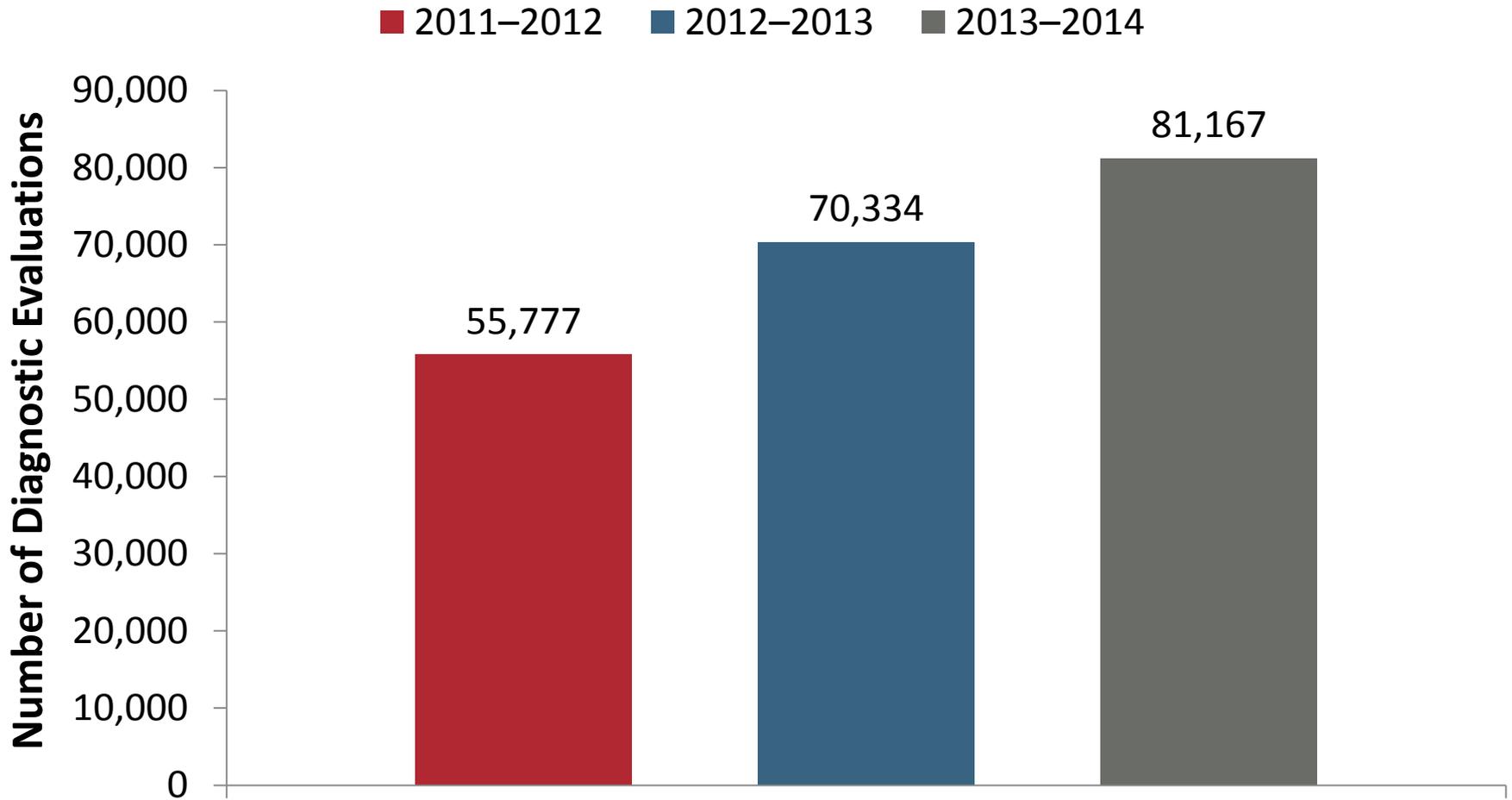
# Reaching Underserved Populations

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LEND programs are improving access to services among minority and rural populations by:

- ▶ Providing clinician consultation and ASD screening for underserved low-income Latino and African American families.
- ▶ Working with rural clinics to promote early identification and connect families with resources.
- ▶ Building connections with native and immigrant populations to increase awareness about ASD and the importance of early identification.

# Evidence of Progress: Increased Number of Diagnostic Evaluations



Data source: NIRS CARES module

# State Implementation Grants

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# Building Family Awareness

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## Development of Resource Information

Grantees develop and distribute resource guides



Families use guides to navigate the service system



## Grantee Highlights

Colorado	North Dakota	Hawaii
Colorado developed and distributed a one-page algorithm with information about resources and referral procedures	North Dakota developed a roadmap to diagnostic evaluation training, screening, early intervention, resources	Hawaii developed the Rainbow Book – a resource directory, with a special section on ASD services, supports and referral procedures

# Family Engagement Efforts

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## Parents

Parents		
Family Resource Specialists	Members of Statewide Advisory Councils	
Connecticut	Ohio	New Jersey
Connecticut has trained Parent Listeners to become leaders in the State and support other parents of CSHCN	In Ohio, multiple family members participate on its advisory board to help shape ASD-related policy	New Jersey invited parents to participate in quarterly meetings for the Community of Care Consortium

# Promoting Access to Family Centered Medical Homes

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- ▶ Colorado's partner, ABCD, trained more than 100 pediatric and family practices in local communities to increase early identification and timely referral within the MH.
- ▶ CT implemented a CQI plan to promote screening, identification and referral within pediatric medical home practices. Five of 17 practices that had not been conducting routine screening received training and follow-up support to ensure adherence to the screening guidelines.
- ▶ Maine's grantee developed a curriculum on medical homes for families of children with ASD/DD and delivered 17 face-to-face trainings to 130 families over the course of the grant. Training is also available via Webinar for families unable to attend in person.
- ▶ Vermont's grantee developed a medical home algorithm to train family and pediatric medical homes to improve screening at all 18- and 24-month well-child visits , to increase timely referrals, and manage chronic care. 89 of 103 practices received training. Screening increased from 41% in 2009 to 79% in 2013

# Training Efforts: M-CHAT Screening

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State	Number Trained
Hawaii	173 Medical providers
Maine	170 Early childhood professionals
North Dakota	514 Medical professionals
North Carolina	120 Pediatricians and other medical professionals
Vermont	89 Pediatric practices
Colorado	10 Pediatric practices
Virginia	17 Pediatric practices

# Promoting Early Identification Through Community Providers

State	Trained (#)	Audience	Activity
Maine	43	WIC staff	WIC held in-person trainings about basic recognition of the first signs of ASD/DD and what to do if ASD/DD is suspected.
North Dakota	231	Childcare professionals	Held 17 training sessions for childcare professionals
Ohio	23 teams	School district personnel	Provided a 5 day educational identification training series school district assessment teams.
North Carolina	120	Managed care organization and FQHC staff	Held in-person and webinars focused on early warning signs and symptoms of ASD/DD.
Virginia	82	Early interventionists, home visitors, and childcare providers	Held in-person training for providers on signs and symptoms of ASD/DD and appropriate next steps for children showing signs of developmental delays

# Quality Improvement Efforts: Using Learning Collaboratives to Promote Screening

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New Jersey	Maryland
<ul style="list-style-type: none"><li>▶ Goal of the collaborative was to improve medical home access and implement strategies to increase the rate at which children are screened early and continuously</li><li>▶ Training was provided to primary care providers participating in the medical home learning collaborative</li><li>▶ M-CHAT screening rates increased by 10% (62% to 72%) at 9 months and 3% (90% to 93%) at 24 months among participating pediatricians</li></ul>	<ul style="list-style-type: none"><li>▶ A major goal is to increase early and continuous screening</li><li>▶ M-CHAT training was provided for 10 primary care practices as part of a statewide learning collaborative</li><li>▶ M-CHAT use has increased from 75% to 94% since September 2014</li></ul>

# Additional Evidence of Improved Screening Rates

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State	Reported Outcomes
Colorado	18% increase in pediatric practices conducting screenings, as well as a 50% increase in M-CHAT use at 18 and 24 month appointments.
Connecticut	Between 2011 and 2012, the number of HUSKY enrollees (State's Medicaid program) receiving a developmental screen between the ages of 0-6 increased by 29%.
Oregon	Seven community-based ASD Identification teams have evaluated 51 children. (37 confirmed with ASD, 10 ruled out, 3 referred for further evaluation.)
Vermont	Results from the VCHIP Developmental Screening in Primary Care Survey showed a significant increase in practices performing autism screening since 2009 (baseline) when 58.5% answered yes, to almost 90% in 2013.
Virginia	MCHAT and ASQ screenings for children seen by 30 months at the 17 practices that received training increased from 50% to 73% from August 2014- January 2015

# Transition Services

- ▶ Transition-related training and resources to help parents and providers ensure a smooth transition from childhood to adolescence to adulthood

Grantee Highlights		
Hawaii	Vermont	Colorado
Conducted in-service trainings with special education teachers and supported the development of in-service trainings on transition for all middle school teachers	Developed three transition guides for young adults, parents, and professionals. Each guide contains best practices, resources, and tools to help individuals transition to adulthood.	Developed a transition-focused training for the State's Medical Home Community Forum and hosted a conference, <i>Supporting Youth with Autism Spectrum Disorders as They Transition From Adolescence to Adulthood</i> , for clinicians, school personnel, community providers, and parents of children with ASD/DD.

# Community Services Organized For Easy Use

