

Welcome to the 2019 Autism CARES Meeting:

Ten Years of Autism CARES Act Programs *Improving the Lives of People with ASD/DD, their Families, and Communities*

JULY 18-19, 2019



Welcome

LISA HUND AND MONICA LATHAN-DYE
2M RESEARCH





Evaluation of the HRSA Autism CARES Act Initiative

2019 Autism CARES Grantee Meeting
Washington, D.C.
July 19, 2019

Lisa Hund, MPH

Monica Lathan-Dye, DrPH

2M Research

Vision: Healthy Communities, Healthy People



Agenda

- The 2M Research Team
- Goals of the Analysis
- Autism CARES Grantee Survey and Interviews
- Pilot Study

The 2M Research Team



Regina James, MD
Project Director



Lisa Hund, MPH
Project Manager



Monica Lathan-Dye, DrPH
Evaluation Team Lead



Amy Windham, PhD, MPH
Evaluation Expert



Daniel Chow, MS
Senior Analyst



Molly Matthews-Ewald, PhD
Evaluation Team



Holly Heisler, MPH, MBA
Evaluation Team



Goals of the Analysis

- ✓ Address program priorities
- ✓ Reduce reporting burden
- ✓ Ensure accurate and valid data
- ✓ Demonstrate progress and impact
- ✓ Identify opportunities
- ✓ Provide program and policy recommendations

Annual Grantee Survey



The survey questions will examine *what* activities you are engaged in.

Purpose: To inform the key evaluation questions and semi-structured interviews

- Online survey
- Approximate time to complete: 30 minutes
- Starting Summer 2020

Semi-Structured Interviews

Purpose: To obtain descriptive information on grant efforts

- Telephone interviews
- Primarily open-ended questions
- Approximate time to complete: 45 minutes
- Starting Summer 2020



The interviews will explore *how* you are implementing activities.

Pilot Study

Purpose: To assess feasibility of administration and effectiveness of the survey and interview tools

- Nine pilot participants
 - Identify **five** training, **three** research, and **one** state systems grantee
- Test both the survey and interview tools
- Starting August 2019



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Policy Update

RYLIN RODGERS
DIRECTOR OF PUBLIC POLICY, AUCD



History

Combating Autism Act of
2006.

Combating Autism
Reauthorization Act 2011

The Autism Collaboration,
Accountability, Research,
Education and Supports
(CARES) Act 2014

- President George W. Bush signed the original law in 2006



National Institutes of Health (NIH)

- Office of Autism Research Coordination (OARC)
- Autism Centers of Excellence (ACEs)
- ASD investigator-initiated and targeted research
- Support for IACC publications and activities

Centers for Disease Control and Prevention (CDC)

- 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)

Health Resources and Services Administration (HRSA)

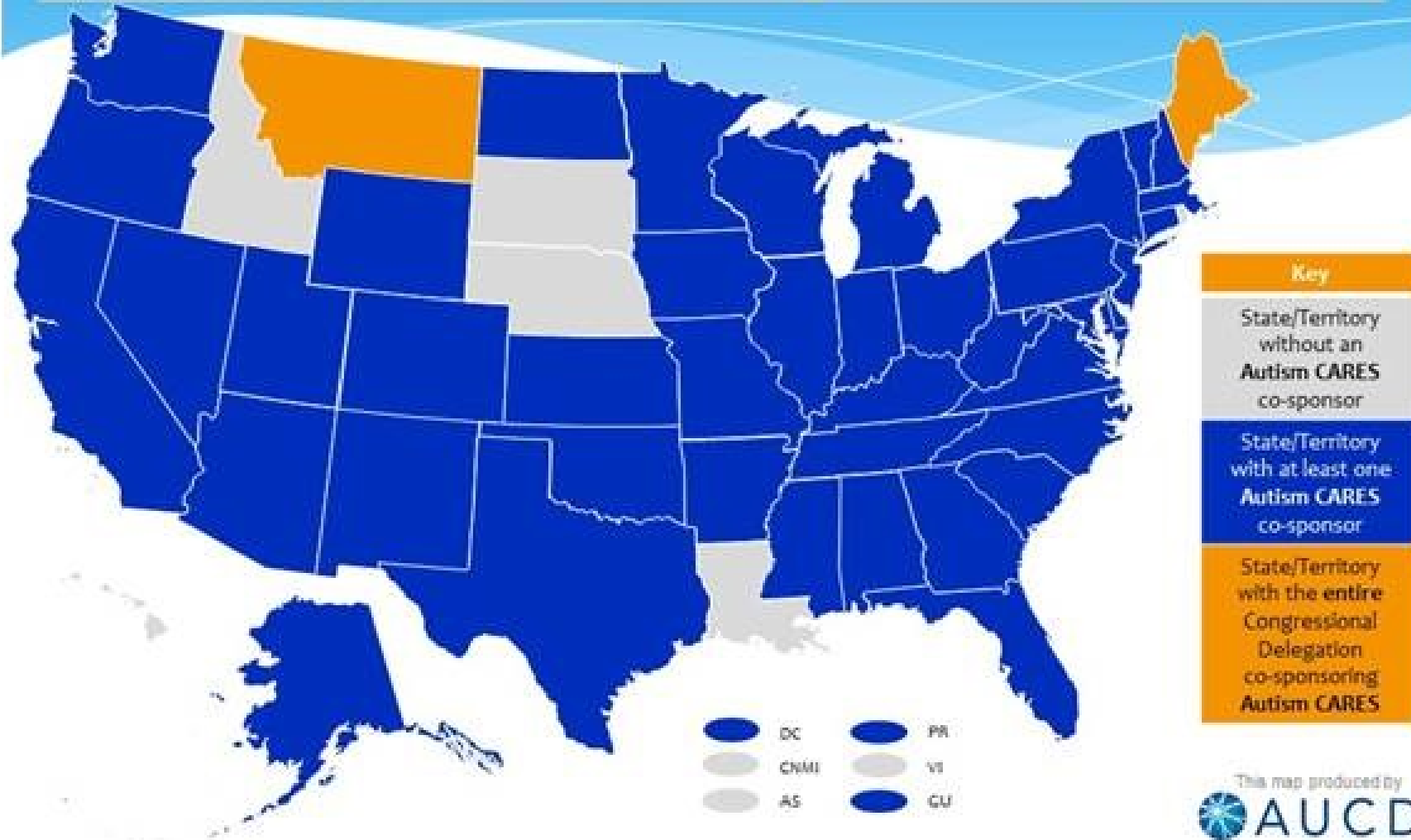
- Autism Research Networks Program
- Autism Single Investigator Innovation Program (Autism SIIP)
- The R41 Autism Field–Initiated Intervention Research (Autism FIRST)
- The R41 Autism Secondary Data Analysis Research (Autism SDAR)
- Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Training Program
- Developmental Behavioral Pediatrics (DBP) Training Program
- Interdisciplinary Training Resource Center (ITAC)
- State Systems Program
- State Public Health Autism Resource Center (SPHARC)
- Department of Health and Human Services
- National Autism Coordinator
- Interagency Autism Coordinating Committee (IACC)

Autism CARES 2019

- Bills to reauthorize the Act were introduced on February 7th (HR. 1058, S. 427).
 - Must be reauthorized or sunsets September 30, 2019
- Notable changes include
 - Increased appropriations to FY19 level
 - Requires report to Congress on the health and well-being of individuals on the autism spectrum.
 - Directs NIH to conduct research targeted at improving outcomes and detection for persons with autism of all ages.
 - Directs HRSA to prioritize grants for developmental-behavioral pediatricians in medically-underserved areas.
 - Amends sections of the Public Health Service Act (PHSA) to reflect the need for research, surveillance, education, detection, and intervention for individuals with autism spectrum disorder of all ages, not just children.
- Currently seeking co-sponsors in House and Senate
- House Energy and Commerce Subcommittee on Health Hearing June 25, 2019



States with Co-Sponsors of Autism CARES Legislation (06-19-19)



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Model Roundtable: “Partnerships and Collaboration with Community-Based Organizations”

GAIL CHODRON, UNIVERSITY OF WISCONSIN-MADISON
REBECCA DOSCH-BROWN, UNIVERSITY OF MINNESOTA
HYON SOO LEE, UNIVERSITY OF CALIFORNIA, LOS ANGELES
PAUL SHATTUCK, AJ DREXEL AUTISM INSTITUTE
FACILITATED BY TONI WHITAKER

