Autism CARES Evaluation Update: Results and Next Steps

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Presented at the July 2017 Autism CARES Annual Grantee Meeting
Overview

- Introduction to Autism CARES evaluation
- Key results from FY 2011 to FY 2014
- Current evaluation activities
- Next steps
Introduction to Autism CARES Evaluation
Insight Policy Research has conducted three evaluations for the Maternal and Child Health Bureau (MCHB)

Purpose: Obtain descriptive data about grantees’ efforts to meet legislative objectives
MCHB Autism CARES Grant Programs

**Training Programs**
- LEND
- DBP

**Research Programs**
- Research Networks
- R40s

**State Programs**
- State Implementation
- State Innovation in Care Integration

**National Resource Centers**
- Interdisciplinary Technical Assistance Center on Autism and DDs
- State Public Health Autism Resource Center

LEND = MCH Leadership Education in Neurodevelopmental and Related Disabilities Program
DBP = MCH Leadership Education in Developmental-Behavioral Pediatrics Program
R40 = R40 Maternal and Child Health (MCH) Research Multiyear Grant Program and R40 MCH Research Secondary Data Analysis Studies (SDAS)
DD = developmental disability
Key Results From Prior Evaluation

(FY 2011 to FY 2014)
Research Program Grantees

MCH Autism Intervention Research Networks

AIR-P
Fifteen research sites focusing on physical and medical health interventions

AIR-B
Seven research sites focusing on social and behavioral health interventions

DBPNet
Twelve research sites focusing on developmental-behavioral pediatrics and ASD/DDs

R40 Autism Intervention Research Grants

Fourteen 3-year grants

Six 1-year Secondary Data Analysis Studies (SDAS)

Thirty-four research institutions linked across the United States
Research Program Final Products

- **Research**
  - 58 autism intervention research studies
  - 27 studies reaching underserved populations

- **Translation and Dissemination**
  - 105 published manuscripts
  - 300,000+ website hits among Research Network grantees
  - 1,614 parents trained in ASD interventions
  - 3,746 health or school professionals trained

300,000+ parents trained in ASD interventions

1,614 health or school professionals trained
Supporting Research: Target Populations for Research Network Program Studies

TARGET POPULATIONS

- Underserved Populations: 46% of studies targeted
- Low-Income Populations: 38% of studies targeted
- Non-English-Speaking Populations: 26% of studies targeted
- Rural Families: 12% of studies targeted

46% of studies targeted

26% of studies targeted

12% of studies targeted
DBP Grantees

- Fifteen DBP programs received 5-year grants
- Ten programs received grants in 2008
- Ten programs received grants in 2013 (5 new grantees, 5 continuing grantees)

Funded July 2008–June 2013
- Albert Einstein College of Medicine*
- Boston University School of Medicine/Boston Medical Center*
- Case Western Reserve University*
- Yale University*
- University of Arkansas for Medical Sciences

Funded July 2008–June 2018
- Stanford University
- Brown University
- University of Oklahoma
- Boston Children’s Hospital*
- The Children’s Hospital of Philadelphia*

Funded July 2013–June 2018
- Medical University of South Carolina
- University of California, Davis
- University of California, San Diego
- University of Colorado
- Children’s Hospital Los Angeles

*DBP grantee also included in 2011 evaluation
### DBP Training Key Contributions

**Increased Number of Professionals With Advanced Skills in ASD/DD Diagnosis and Intervention**

Between 2011 and 2014, DBP grantees trained—
- Nearly 50 long-term fellows each year
- At least 350 medium-term trainees each year

**Supported Additional Fellow(s)**

- Reported by 7 out of 10 grantees interviewed
- The program supported additional fellows to expand the capacity to provide ASD services, particularly in underserved communities
## Enhanced Training on ASD/DDs

- Expanded training on ASD diagnostic tools
- Provided more faculty/fellow time for teaching and mentoring in clinical settings
- Expanded community- and family-based experiences

## Enhanced Leadership Training

- Enhanced focus on training fellows to be leaders in field of DBP (to improve systems of care at the micro and macro levels; advance the evidence base for ASD through research; and promote patient-centered, coordinated care for children with ASD/DDs and their families)
LEND Grantees

- Offered graduate-level, interdisciplinary training
- 5-year grants awarded in 2011
- Forty-three grantees
  - Thirty-seven States with LEND training programs
  - Five grantees with interstate collaborations
  - Eight States/territories with collaborating institutions

- Trained 1,325 long-term, 3,196 medium-term, and 10,993 short-term trainees per year
Evidence of Progress: Increased Number of Diagnostic Evaluations by LENDs

Diagnostic Evaluations per year

Data source: NIRS
LEND Activities To Improve Systems

Efforts To Ensure Access to Care for Underserved Populations

- Had 2,054 faculty members working in clinics with underserved populations each year
- Expansions of telehealth services to reduce barriers for rural populations
- Clinical outreach to rural areas

Expert Guidance to Providers and Families

- Technical assistance to help providers appropriately incorporate screening services into routine practice
State Implementation Grants

- **Purpose:** Improve access to healthcare and related services for children and youth with ASD/DDs

- **Objectives:** Increase awareness; promote comprehensive, coordinated, community-based and family-centered services that include early screening, evaluation and referral, and support for transitions

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<tr>
<th>Year</th>
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## State Grantee Highlights

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<th>Building Awareness</th>
<th>Ohio’s grantee collaborated on a PSA targeting African-American and Hispanic families on the importance of early screening</th>
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<td>Promoting Medical Homes</td>
<td>Connecticut implemented a continuous quality improvement 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 screening guidelines</td>
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<td>M-CHAT Screening</td>
<td>Grantees trained hundreds of individuals and practices on the Modified Checklist for Autism in Toddlers</td>
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<td>Working With Providers</td>
<td>North Dakota provided 17 training sessions for childcare professionals and taught 231 people about early signs of autism</td>
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<td>Engaging Families</td>
<td>Maryland’s grantee trained 25 families to participate in the statewide Community of Care Consortium</td>
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Current Evaluation Activities
Study Objectives

Assess grantees’ efforts to—

1. Train professionals

2. Increase awareness and disseminate information

3. Contribute to research and develop evidence-based and/or consensus-based guidelines and screening tools

4. Reduce barriers to screening and diagnosis, and improve systems of care

5. Identify needs and develop services for youth transitioning to adulthood
Evaluation Approach

- **Qualitative Data Sources**
  - Grantee applications and noncompeting continuation applications
  - Semistructured interviews

- **Quantitative Data Sources**
  - NIRS
  - DGIS
  - Research program questionnaire
Next Steps
Where Have We Been and Where Are We Now?

- **2016**: Designing and Planning
- **2017**: Data Collection
- **2018**: Analysis and Reporting
- **Grantee Interviews**
Interviews: What To Expect

- Anticipated data collection in fall 2017
  - Flexible scheduling
  - Exact timing depends on approval from Office of Management and Budget
- Email outreach from Insight Policy Research
  - Questionnaire, if applicable
  - Overview of interview topics
- Approximately 60 minutes via phone; recorded
You Will Be Talking With …

Rachel Gaddes
Rachel Holzwart
Carla Bozzolo
Denise Bellows
Rikki Welch
Whitney Schott
Claire Wilson
Debra Wright
Allyson Corbo
Elaine Wilcox-Cook
Questions?

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