
Act Early Forum Webinar Series



Part II: Stories from State Systems Grantees

What works, what doesn't and why

May 15, 2014

Webinar Overview

- Webinar Recording
 - Visit www.aucd.org/webinars
- Q & A
 - Please submit your questions throughout the webinar via the “question box” on your webinar dashboard. Questions will be answered following the presentation.
- Survey
 - Please complete the short survey at the end of the webinar!

Introductions

Moderator:

Camille Smith, MS, EdS: Educational Psychologist, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Centers for Disease Control and Prevention

Introductions



Debra Vigil, PhD: Associate Professor, University of Nevada Reno; Director, University Center for Autism and Neurodevelopment (UCAN); Co-Director, Nevada Leadership Education in Autism and Related Disabilities (NvLEND) Program



Peggy Schaefer Whitby, PhD: Associate Professor and Program Coordinator for the graduate certificate in Autism Spectrum Disorders, University of Arkansas



Kate Taft, MPH: Senior Program Manager for Children and Youth with Special Health Care Needs, Association of Maternal & Child Health Programs (AMCHP)

Nevada

Learn the Signs Act Early

Debra C. Vigil, Ph.D., CCC-SLP

Associate Professor

Dept of Speech Pathology & Audiology

University of Nevada Reno

Co-Director NvLEND

Projects

- **48,000 Milestone Booklets**
- **Annual summit**
- **Training of childcare workers**
 - **AMCHP Grant: Onsite**
 - **Video training modules**
- **Ages & Stages Pilot**
- **ADOS training**
- **Nevada MCH Program Grant**

First Year

- **Summit: Jennifer Bogin & Cheryl Rhodes**
- **Mission statement & Impact Statements**
 - **Educate & bring awareness to parents, healthcare professionals, & educators in all communities across Nevada about early warning signs of autism & other neurodevelopmental disorders**
 - **Children are identified earlier to reduce the time between first concern & diagnosis**
 - **Individuals of all geographical locations have access to evidence-based, culturally competent, family-centered services & care that assures optimal outcomes**
 - **Professionals and families collaborate across disciplines, agencies, and a statewide system of care**
- **Presentations across the state**
- **Personalize Milestone Booklets & print 48,000**
- **Steering Committee**

Second Year

- **Summit: Amy McDaniel, Ph.D. from Autism Speaks**
- **AMCHP State Systems Grant**
- **Nevada MCHP Grant**
- **Planning for projects**

Third year

- **Summit: Andy Imparato, Executive Director of AUCD**
- **Positive outcomes:**
 - **Brings together stakeholders**
 - **LEND trainees**
 - **Collaborations with other state agencies**

ADOS Training

- **50 professionals & 11 multidisciplinary teams**
- **Continuing education through Project Echo**
 - **Cultural considerations**
 - **Co-morbidities**
 - **Reliability**
 - **Toddler Modules**

Ages & Stages Online Pilot

- **3 childcare facilities**
- **ASQ-3 & Social-emotional**
- **ASQ Training Institute**
- **Early Childhood Care Systems Committee**

AMCHP State Systems Grant

- **12 childcare sites across the state**
- **Childcare directors: Pathway to referral**
- **Onsite training for childcare workers**
 - **ASQ & Milestone Moment Booklets**
- **Training parents**

NvLTSAE Website

- **NvLEND Trainees**
- **Launching soon**
- **Milestones**
- **Reference & referral**

Online Video Training Modules

- **Working with Nevada Registry for CEU**
- **Videos**
 - **What is autism**
 - **Developmental screening**
 - **Referral & diagnostic process**
 - **Strategies for inclusion**
 - **IFSP-IEP process**
 - **Other neurodevelopmental disorders**
 - **Challenging behaviors**

Challenges

- **Number of projects**
- **Frontier aspect of the state**
 - **Travel**

Successes

- **Number of projects!**
- **Staying focused on Mission & Impact statement**
- **Collaboration and support**
 - **Nevada MCH**
 - **NvLEND**
 - **Nevada Center for Excellence in Disabilities**
- **Education of both parents and professionals**

Finally!!

**Nevada Act Early State Ambassador
Mario Gaspar de Alba, M.D.
Developmental Behavioral Pediatrician**

Arkansas

Learn the Signs. Act Early State System Grant

Peggy J. Schaefer Whitby, Ph.D.,
BCBA-D



Arkansas Learn the Signs. Act Early State Planning Meeting

To provide outreach to minority and rural communities in Arkansas on early childhood screenings for developmental disabilities.

Services include development of:

- Re-establish the Arkansas Team
- Identify materials for distribution
- Customize materials for Distribution
- Translation into Spanish and Marshallese
- Identification of Distribution sites to reach rural and Minority communities

Re-Establish State Team

Progress:

- Met four times
- Worked together to identify materials and target areas for mass distribution
- Work teams completed projects at each meeting

Lessons Learned:

- Action plans between meetings
- Check on the progress between meetings

Materials and Customization

- Progress

- Identified points of contact for the state
- Customized the materials with these points of contact
- Distributed over 30,000 LTSAE Materials across the state.
- Card Rack Brochures, Milestone Moments booklet, and posters for Dr.'s accepting Medicaid in high need areas, i.e. The Delta.

- Lessons learned

- Begin early in the year
- Group process
- Identify PARTNERS to distribute and who can continue to use the materials after you are gone.

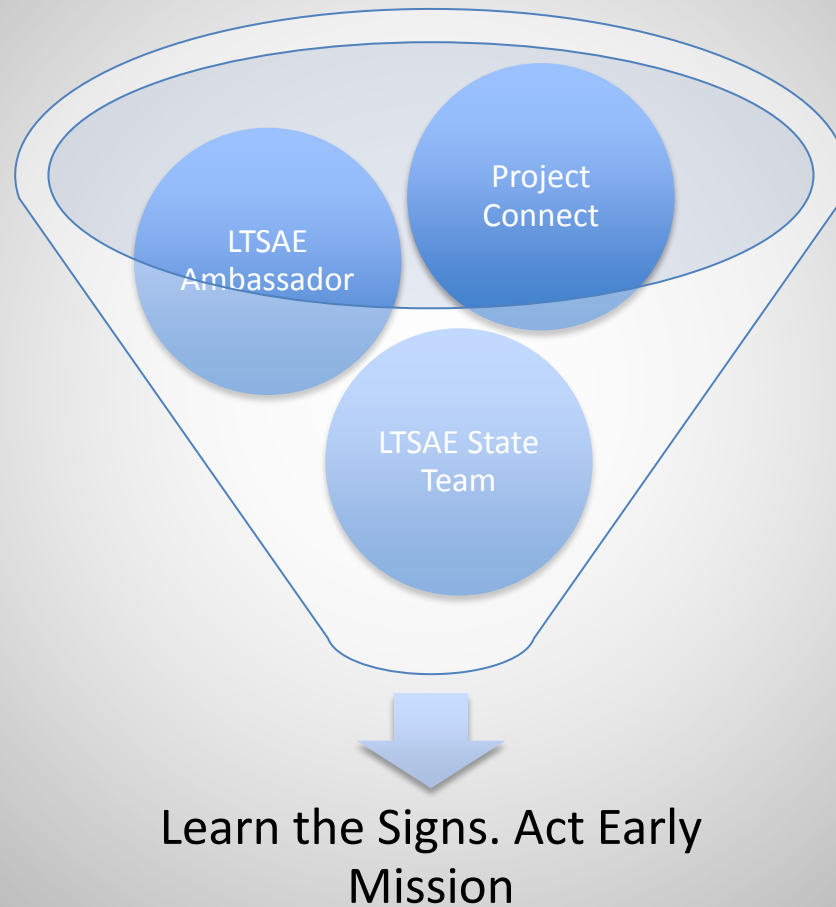
Outreach to Rural Minority Communities

- Progress
 - Added families from different cultural backgrounds to our team.
 - Distributed materials in both English and Spanish across the state
 - Focused on public funded early childhood centers
 - Distributed materials to church groups in the Black and Hispanic communities
 - Radio PSAs to culturally diverse areas in English and Spanish
- Lessons Learned
 - These materials already exist. Do not try to recreate.
 - Discuss as a team, how the state systems will handle the increase of calls.

Exposure = Opportunities= Responsibility

- LTSAE gave me a platform and an outlet to organize like minded people
- When you organize state stakeholders great ideas come to life.
- Have a team focus versus an individual focus or you will get overwhelmed.
- Choose projects wisely- whatever the team chooses to do you must lead to completion.

Projects Merge with Mission



Other Projects Based Upon Exposure

- UA ASD Symposium
 - Increased outreach
 - 250 in attendance for PRT training
- Camp Connect
 - Inclusive camp for children with autism
 - Peer mentors
 - Infused with behavior technician training
 - Parent Education and Resource Session

Other Projects Based Upon Project Connect Exposure

- Statewide Proposal for Rural Centers for Autism and Related Disabilities
 - Presented to the Governors Taskforce on Autism
 - Legislative support for funding
 - Hoping for appropriations in the next legislative session
 - Expansion and long term funding for Project Connect!

KEEPING OUR FINGERS CROSSED!

Next Year

- Continue
 - Quarterly meetings
 - Focus on establishing a partnership with WIC and Head Start to distribute materials and conduct screenings
- Expand
 - Regional teams?
 - Distribute more materials
- Evaluate
 - Number of children identified with ASD
 - Age of diagnosis decreasing in the state?
 - Are children receiving services?

Struggles and Insight

- Staffing the first semester of grant work
 - People work for free once they find out what you are doing- don't ask, just pay!
 - SPEND THE MONEY! Don't wait.
 - Use the money to customize your materials and mail the materials
 - Talk to other state teams and collaborate!
 - Get started early as the year will fly by!

Questions?

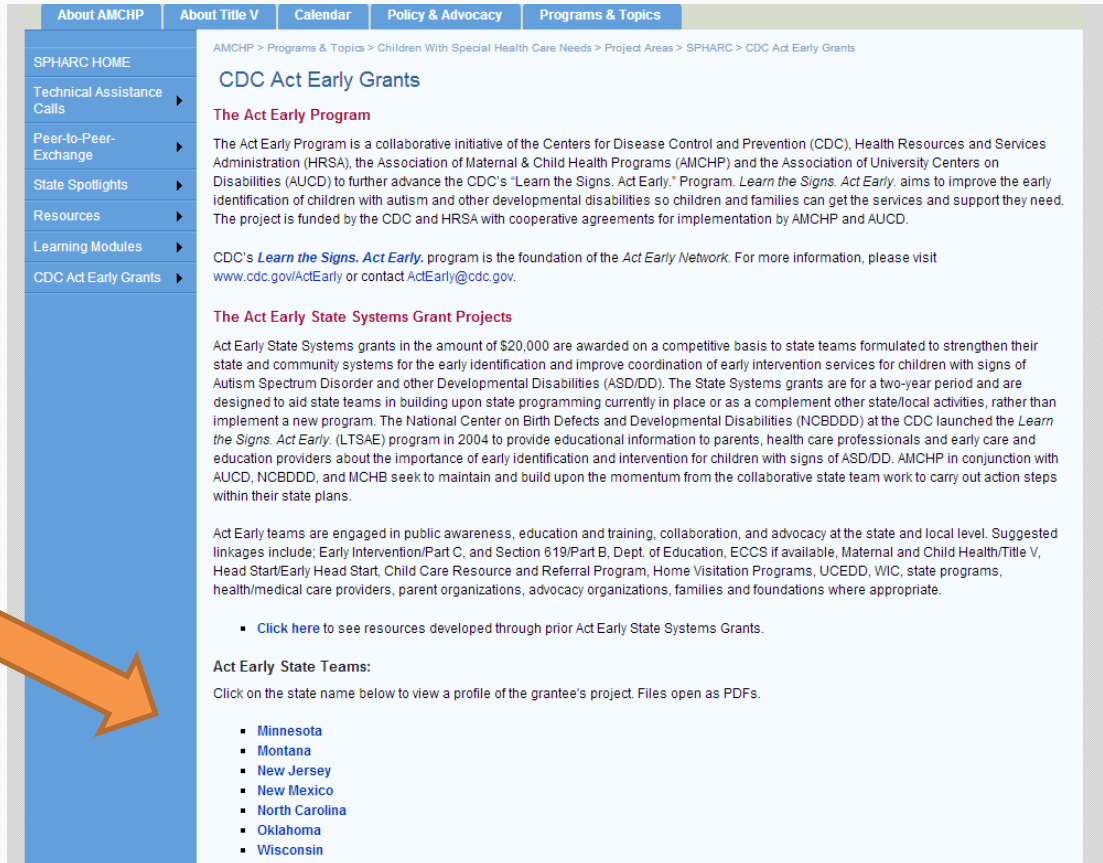
Peggy J. Schaefer Whitby, Ph.D., BCBA-D

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Act Early Systems Grants - Resources

On the AMCHP website,
you can find:

- Information about the Act Early State Systems Grant program
- Overview of current grantee projects & contact information
- Resources developed by former grantees



AMCHP > Programs & Topics > Children With Special Health Care Needs > Project Areas > SPHARC > CDC Act Early Grants

CDC Act Early Grants

The Act Early Program

The Act Early Program is a collaborative initiative of the Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), the Association of Maternal & Child Health Programs (AMCHP) and the Association of University Centers on Disabilities (AUUCD) to further advance the CDC's "Learn the Signs. Act Early." Program. *Learn the Signs. Act Early.* aims to improve the early identification of children with autism and other developmental disabilities so children and families can get the services and support they need. The project is funded by the CDC and HRSA with cooperative agreements for implementation by AMCHP and AUUCD.

CDC's *Learn the Signs. Act Early.* program is the foundation of the *Act Early Network*. For more information, please visit www.cdc.gov/ActEarly or contact ActEarly@cdc.gov.

The Act Early State Systems Grant Projects

Act Early State Systems grants in the amount of \$20,000 are awarded on a competitive basis to state teams formulated to strengthen their state and community systems for the early identification and improve coordination of early intervention services for children with signs of Autism Spectrum Disorder and other Developmental Disabilities (ASD/DD). The State Systems grants are for a two-year period and are designed to aid state teams in building upon state programming currently in place or as a complement other state/local activities, rather than implement a new program. The National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the CDC launched the *Learn the Signs. Act Early.* (LTSAE) program in 2004 to provide educational information to parents, health care professionals and early care and education providers about the importance of early identification and intervention for children with signs of ASD/DD. AMCHP in conjunction with AUUCD, NCBDDD, and MCHB seek to maintain and build upon the momentum from the collaborative state team work to carry out action steps within their state plans.

Act Early teams are engaged in public awareness, education and training, collaboration, and advocacy at the state and local level. Suggested linkages include; Early Intervention/Part C, and Section 619/Part B, Dept. of Education, ECCS if available, Maternal and Child Health/Title V, Head Start/Early Head Start, Child Care Resource and Referral Program, Home Visitation Programs, UCEDD, WIC, state programs, health/medical care providers, parent organizations, advocacy organizations, families and foundations where appropriate.

- [Click here](#) to see resources developed through prior Act Early State Systems Grants.

Act Early State Teams:

Click on the state name below to view a profile of the grantee's project. Files open as PDFs.

- Minnesota
- Montana
- New Jersey
- New Mexico
- North Carolina
- Oklahoma
- Wisconsin

www.amchp.org/SPHARC >> "CDC Act Early Grants" tab

Q & A

- Ask a question!
 - Type your question in the “question box” on your webinar dashboard.
 - The moderator will read the question.

Thank You!

- Learn more about Act Early!
 - www.cdc.gov/actearly
 - www.aucd.org/actearly
- Questions about the webinar?
 - Email Tory Christensen (tchristensen@aucd.org)

Please take a few minutes to complete the survey!